Idaho Family Caregiver Survey Report, 2025

Prepared for the
Idaho Department of Health and Welfare

July 2025

Prepared by:
Jennifer Nguyen, Hanna Scheuffele, Dr. Sarah Toevs
Idaho Caregiver Alliance
School of Public and Population Health
Boise State University

Partial funding was provided from the state of Idaho and the Administration for Community Living (ACL) of the U.S. Department of Health and Human Services (HHS); as part of a financial assistance award (No. 90LRLI0058) totaling four hundred thousand dollars ($400,000) with seventy percent (70%) funded by the ACL/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government, or the state of Idaho. 7/31/2025

Idaho Caregiver Alliance

BOISE STATE UNIVERSITY
COLLEGE OF HEALTH SCIENCES
School of Public and Population Health

2025

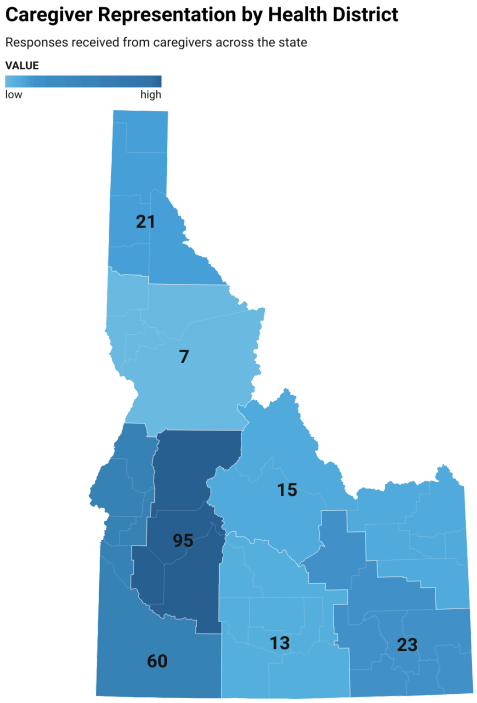
IDAHO FAMILY CAREGIVER SURVEY REPORT

Overview

At the heart of every care system are unpaid family caregivers—relatives and loved ones quietly managing the day-to-day needs that keep others safe and supported. Family caregivers play an essential role in Idaho's healthcare system, providing unpaid care to loved ones with disabilities, chronic illnesses, or age-related conditions. Caregivers also have a profound impact on Medicaid expenditures by delaying the need for institutional care. In Idaho, Medicaid covers 65% of nursing home residents at a cost of approximately $100,000 per person per year. Every day family caregivers help an individual remain in the community and they reduce reliance on state-funded assistance. Caregivers complete critical work and this role often places significant emotional, financial, and physical burdens on caregivers.

In 2014 an evaluation of caregiver needs in Idaho was completed. Findings from this survey were used by the Idaho Caregiver Alliance (ICA) and partners to build awareness and enhance services for caregivers. In 2025 a similar survey was conducted to gain understanding of the demographics, challenges, and support systems available to family caregivers across the state (see Appendix A for the full survey).

The survey was conducted by the ICA and funded by the Idaho Department of Health and Welfare (IDHW) from the Administration on Community Living (ACL) Lifespan Respite Grant. All data collection tools and procedures were approved by the Institutional Review Board at Boise State University. Analysis of the survey was initiated in February of 2025 using Statistical Package for the Social Sciences (SPSS).

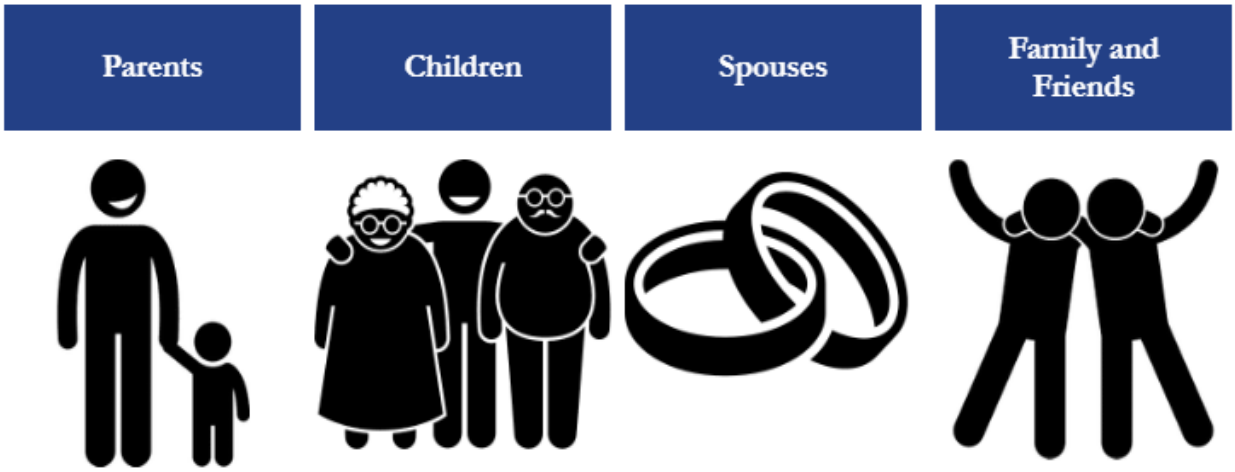


A total of 280 responses were captured representing caregivers from every health district in Idaho. See district map for distribution and Appendix B for zip code groupings.

Putting a face to care.

Family caregivers provide essential support to individuals with chronic illnesses, disabilities, or aging-related conditions. They often serve as the primary source of assistance, managing medical tasks, providing emotional support, and ensuring their care recipients' daily needs are met.

Who are Idaho Family Caregivers?



Caregiving in Idaho is predominantly undertaken by women with approximately half of respondents (52.1%) older than 55 years of age, but anyone can be a caregiver. Respondents ranged in age from 23 to 91 and represented a variety of identities and income levels.

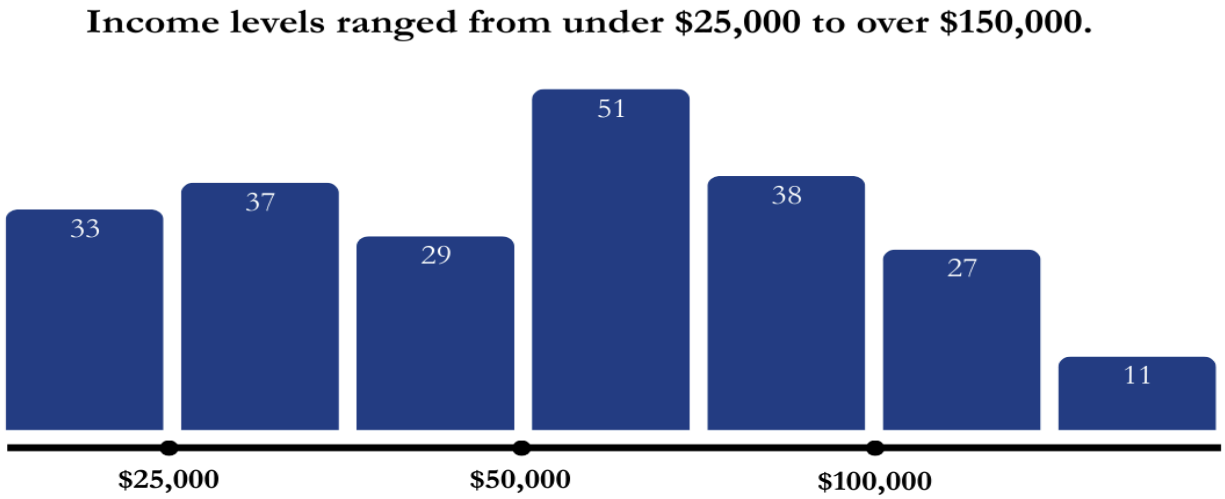
88.8% women

52.1% 55 years or older.

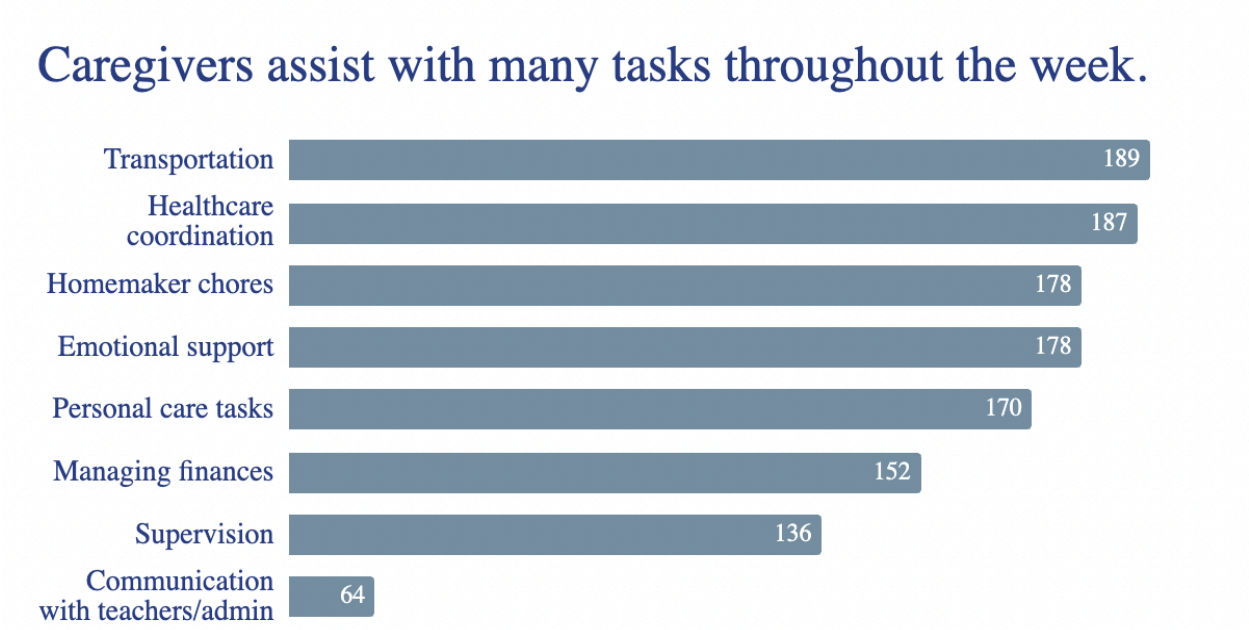
5% identified as a part of the LGBTQ+ community

Over half (60.1%) of caregivers are employed full time, part time, self-employed, or working seasonal or gig jobs. Less than 50% of respondents reported having employer-sponsored benefits and only

35.7% reporting also having employer-sponsored retirement benefits. Income level information was gathered in ranges with a reported median range of $50,001 to $75,000.



The majority of caregivers have been providing care for 4 or more years (65.9%) for just one recipient (64.2%) and assisting with tasks related to caregiving for at least 22 hours per week (64.2%).



The caregiving experience.

A family caregiver is an adult family member or another individual with a close relationship who provides support to a person with a chronic illness, disability, or functional limitation. Having so much to juggle can take a toll on the health and wellbeing of the caregiver.

More than half of caregivers reported noticing a decline in their own health.

- Over 70% said they have felt left out or isolated.
- 56.9% said they are frequently or nearly always feeling stressed.
- 45.6% said they are frequently or nearly always lacking time to care for themselves.

Caregivers who had been providing care for longer periods were more likely to report:

> **"I have cancelled events to care for my dad. I don't get my work done... As a person working as a professional artist it is very hard to be creative after caregiving all day."**

Most respondents experienced career impacts due to caregiving.

The majority of respondents (75.1%) say caregiving had an impact on their employment or career. From juggling schedules to dropping out of school or quitting jobs, caregiving has had an impact on caregiver's career and employment in many ways. Employed caregivers reported using sick leave, reducing hours, or declining promotions to manage care responsibilities.

"I quit my job and I'm living off of my retirement in order to provide care for my loved one."

"Had to stop going to nursing school because of the demands of caregiving."

"I remain in a position that doesn't pay a fair wage due to not having the time available to look for or begin a new career path."

Work Flexibility=Supporting Caregivers

48.5% arranged for flexible work hours
40.0% arrived late or left work early
36.8% used sick time or annual leave to provide care
Providing caregivers flexible options helps keep workers in the workforce.

Challenges are faced by caregivers with minimal training and assistance.

Training

When provided with a list of 16 options, caregivers indicated that training in many areas would be helpful, including: Powerful Tools for Caregivers Training (40.4%), navigating Idaho's Medicaid training (38.8%), and respite care training (28.4%). Caregivers also expressed additional training needs (see all responses in Appendix C):

- "Basic CNA type training: physically handling my spouse when he needs help moving around, proper way to provide hygiene when patient unable to assist, choking prevention & Heimlich, CPR, wound care, how to feed someone, how to safely pick someone up after they fall, bedpan use, proper transfer from bed to bedside commode, etc", and
- "Training on proper nutrition planning tailored to the specific dietary needs of the care recipient."

Most caregivers had received CPR training (58.6%) and basic first aid training (53.8), approximately 34.8% of respondents received some form of Alzheimer's and/or dementia training, and very few had received respite care training (7.6%) or charting the life course skill building (5.2 %), see the word cloud below for additional training received by caregivers; larger fonts indicate more responses to that option.

Training and education caregivers have received:

The range of health challenges experienced by care recipients highlights the need for specialized training and/or support tailored to different conditions. The most commonly reported ailment was Alzheimer's disease and/or other forms of dementia (36.2%).

Assistance

Caregivers were asked to select what assistance they received from a list of 14 options, the most frequent response was "Medicaid assistance" (33.5%) followed by "I do not receive any assistance" (33%). When asked, "What assistance would help you feel more capable of providing the necessary care to your care recipient(s)?"caregivers expressed a need for financial support, respite, personal support, and training. See all responses in Appendix C.

What assistance would help you feel more capable of providing the necessary care to your care recipient(s)?

- "Compensation instead of having to spend my life savings to care for my father."
- "Finding someone to give good alternative care so I could have time off."
- "Support Group where you could talk about the stress of making all the decisions, not having siblings help, seeing your loved one change and suffer, etc."
- "More knowledge on my parent's medical conditions. How to get my mother to eat more and how to manage my father's anger and anxiety."

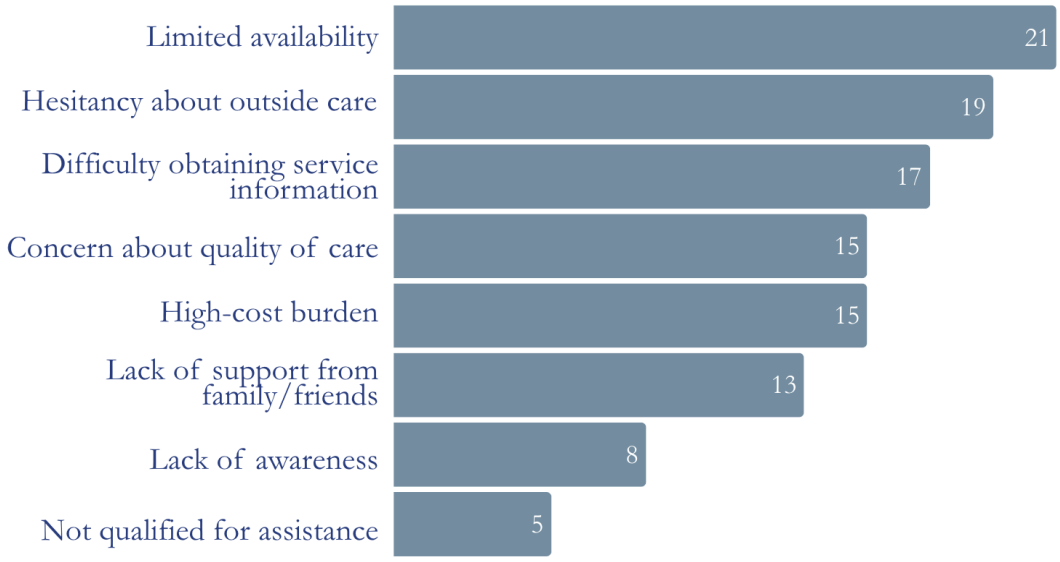
Top 3 types of assistance caregivers receive:

Respite is the opportunity for a caregiver to have a break from providing care while someone else helps the care recipient. Although respite care can be a vital source of relief, 77.2% of caregivers reported they have never accessed it.

> **... I can appreciate an extra set of eyes and ears and even a hand to assist with equipment, therapies, and in worst case of emergencies.**

The primary reasons for not obtaining respite services differed based on the type of care recipient. Caregivers of children most often expressed concern about having outsiders care for their loved ones. Spousal caregivers were primarily worried about the quality of available respite services. Meanwhile, those caring for a parent frequently cited challenges in accessing respite care.

Barriers prevent many caregivers from utilizing respite services.



What caregivers need now.

Idaho's caregivers need clear and compassionate support systems. When asked what would help caregivers provide the necessary care to their care recipients, they emphasized the importance of having someone to guide them through and to available resources, and having access to respite, financial support, and mental health resources.

Navigation assistance

What assistance would help you feel more capable of providing the necessary care to your care recipient(s)?

- "Navigating Idaho Medicaid long term care."
- "How to navigate Dementia/Alzheimer's going forward."
- "I would like assistance to help with all of the paperwork and also assistance on knowing what will happen to him when I die."
- "A social worker to help me plan for future costs and decisions."
- "Clear & prominent links to Case Management & health navigation services. Payors, health systems, government, and some CBOs employee CM, Care Coordinators & Navigators. The avalanche of available resources can be overwhelming, but helpful when a trained professional provides personal assistance to evaluate all of the options."

Respite care access

What assistance would help you feel more capable of providing the necessary care to your care recipient(s)?

- "A break with a competent provider in my place."
- "Some time when I can get a break from caregiving and household chores."
- "Access to reliable respite for my spouse and I since we are the only ones supporting our neurodivergent children."

Many caregivers expressed a need for respite services. Barriers to utilizing respite most frequently included the limited availability of the service, concerns about others caring for the care recipient, and difficulty obtaining information about the service. Caregivers reported they primarily needed respite so they have time to step out and rest, manage stress, and find some peace of mind.

Financial Support

What assistance would help you feel more capable of providing the necessary care to your care recipient(s)?

- "Compensation for providing care."
- "After becoming a single income household the financial strain and mental stress of having to find ways to create funds without neglecting the needs of the care receiver is without a doubt the biggest challenge."

- "State and federal commitment to funding programs needed to maintain home and community-based services."
- "Help with the costs of medical care, equipment, or home modifications."
- "Housing financial assistance."

Caregiving responsibilities significantly impact employment, with 75.1% of respondents reporting employment impacts.

Caregiver mental health support

What assistance would help you feel more capable of providing the necessary care to your care recipient(s)?

- "Access to therapy, counseling, or stress management tools."
- "Support groups."
- "Knowing I'm making the best decision for them."
- "Stress management."

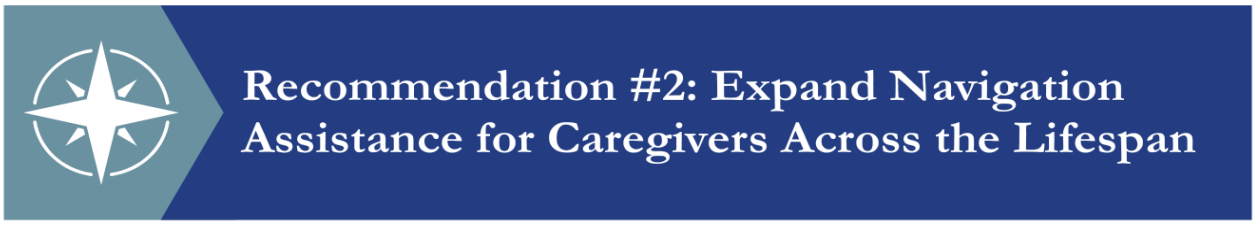
Responses highlight the emotional and physical health impacts of caregiving with 80.4% reporting a noticeable deterioration of physical and/or mental health and 75.4% listing emotional strain and/or burnout among their common challenges.

Conclusion

The Idaho Family Caregiver Survey provides a snapshot of the experiences of caregivers across the lifespan in Idaho. This invisible workforce assumes many critical, ongoing care responsibilities of their loved ones. While this care is often more than a full-time job, these caregivers do it out of love, respect, and necessity.

Strengthening systems that offer a helping hand to caregivers reflects Idaho values of independence, respect for the family, and fiscal responsibility. The following recommendations are based on findings from the survey and the knowledge that support for caregivers strengthens the family unit, the community, and reduces health care and Medicaid spending.

Caregivers express frustration with finding help and navigating systems as their care recipients age into programs with different guidelines and/or as caregivers find themselves caring for multiple recipients across the age spectrum, e.g. a grandchild and a grandparent or spouse. Idaho has the opportunity to capitalize on the system-building work conducted by ICA in partnership with the Idaho Commission on Aging (ICOA) and the Idaho Department of Health and Welfare. The statewide coalition of over 1,000 caregivers, organizations, and agencies working under the umbrella of ICA has a history of action and impact. ICA provides a platform for cross-sector partners to work together to capitalize on innovations driven by community-, local-, and state-based entities, healthcare systems, and philanthropy. Establishing a public-private partnership with base funding from the State will expand the capacity of the ICA and strengthen the network of organizations who engage with caregivers across the lifespan.



Family caregivers need help navigating complex programs and systems. Enhanced navigation services equipped to address the range of caregiver experiences is needed. Partners must include community organizations, primary and secondary schools, healthcare providers/systems, and public health and social services in order to provide clearer pathways for caregivers to access support. Actions could include expanding:

- The network of individuals equipped to help caregivers map their caregiving journey regardless of age, income, or needs of the care recipient.
- Promotion of informal and formal supports available to caregivers.
- Access to resources and services through online tools and use of technology.
- The capacity of the Aged and Disability Resource Centers (ADRCs) located in the regional Area Agencies on Aging and resources available to Foster Families.

The majority of caregivers identified the need for financial support and respite (a break from caregiving responsibilities). Comments provided by caregivers highlighted the impact of caregiving on financial stability, employment and their health and well-being, and the need for respite tailored for the needs of the care recipient

To address these challenges, Idaho must rebalance the level of support available to family caregivers to reflect their value and the critical nature of the care they provide. As identified by Idaho's Office of Performance Evaluations (OPE), the state lost 2,642 direct care workers between 2020 and 2021 with Idaho now facing the worst caregiver shortage in the nation, as confirmed during the January 21, 2025 Joint Legislative Oversight Committee (JLOC) hearing. This growing dependency on family caregivers is further compounded in rural areas and the projected population growth of those over the age of 65.

Increasing recognition of family caregivers in the work environment can help provide the flexibility needed to continue employment and provide care. Providing targeted financial relief and workplace accommodations can help caregivers maintain economic stability while fulfilling their caregiving duties.

Actions to address this recommendation could include:

- Establish a collaborative process with the IDHW, legislators, stakeholders, agencies, and participants that allows legally responsible individuals (biological parents, adoptive parents, and spouses) to serve as paid caregivers. Programming would incorporate safeguards and assure fiscal responsibility and transparency.
- Explore other options to compensate caregivers for the care they provide.
- Increase recognition of the family caregivers and how to support them in the workplace
- Expansion of existing infrastructure for consumer directed respite care to caregivers across the lifespan.
- Increased monetary support for respite for caregivers providing care for an individual of any age who is ill, frail, has disabilities, or whose parent is no longer able to fill that role. Expand access to training for respite providers statewide.

The majority of employed caregivers indicated that they did not receive health insurance from their employer. Of those who did not have employer-sponsored health benefits, or were not employed, less than half reported having access to another form of insurance or Medicare. This puts them at increased risk of health challenges and financial insecurity.

Caregivers also expressed the need for support groups and access to mental health services equipped to offer emotional relief and promote wellness. Wellness programs tailored to caregivers, including stress management training and respite care integration, should be promoted to help caregivers maintain their health while continuing their caregiving responsibilities.

Actions to address this recommendation could include:

- Develop an Idaho model of a Paid Family Caregiver Program that ensures sustainability and efficiency.
- Ensure equitable access to respite, training, and navigation services in rural and remote regions where access is limited.
- Develop telehealth-based caregiver supports and virtual navigation assistance to bridge the gap.
- Establish caregiver support groups and caregiver-specific mental health understanding and services statewide.
- Promote wellness programs tailored to the needs of caregivers addressing areas such as stress management and education on emotional well-being.

Additional recommendations:

- Training and education for family caregivers (survey respondents requested hands-on, condition-specific training)
    - Promote the development and accessibility of condition-specific and practical training programs for family caregivers.
    - Encourage partnerships with health systems to integrate caregiver education into discharge planning and home health visits.
- Ensure equitable access to resources in rural areas.

Addressing these challenges requires a coordinated effort from community organizations. Expanding respite care availability, increasing financial support, and improving access to caregiver resources through streamlined navigation services are crucial steps in strengthening Idaho's caregiving infrastructure. By implementing these changes, Idaho can better support its family caregivers, ensuring they receive the resources and relief they need to continue providing essential care for their loved ones.

References

No outside references were used in this report; all included quotes and data were obtained directly from the collected survey data.

Appendices

Appendix A

2025 Idaho Family Caregiver Survey Informed Consent

Study Title: Study Title: Idaho Family Caregiver Needs Assessment
Principal Investigator: Sarah Toevs

If you are an informal caregiver or care partner you are invited to complete this survey. This consent form will provide you with the information you need to understand why this study is being done and why you are being asked to participate. It will also describe what will be expected of you as a participant, as well as any known risks, inconveniences or discomforts that you may have while participating. We encourage you to ask questions at any time.

Purpose and Background
The information you provide will be used to guide the actions of the Idaho Caregiver Alliance as it works to enhance the network of support available to people who care for others. Procedures You will be asked to complete an online survey that will take approximately 10 minutes to complete. Please read each question carefully and only complete the survey once.

- You are not required to complete this survey and you do not need to answer any questions you don't want to answer.
- Your responses are anonymous and will not affect any services or benefits you receive.
- Responses will only be reported after they are combined with the responses from everyone who took the survey.

Benefits
Once you have completed the survey you will be eligible to participate in a raffle for two, $50.00 Amazon gift cards. The findings will be used by the Idaho Caregiver Alliance to plan and implement caregiver services and supports. The results will also be shared with community partners, policy makers and others who can assist in addressing the needs of informal caregivers.

Risks
The risk to you of completing this survey is minimal. Responses are anonymous and will only be reported after they are combined with the responses from everyone who took the survey. The personal information (name, phone number, and/or email address) needed for the raffle will be collected in a separate survey and destroyed after the gift cards have been distributed.

Extent of Confidentiality
All reasonable efforts will be made to keep the personal information in our research records private and confidential. Any identifiable information obtained in connection with this study will remain confidential and will be disclosed only with your permission or as required by law. The members of the research team and the Boise State University Office of Research Compliance (ORC) may access

the data. The ORC monitors research studies to protect the rights and welfare of research participants. Data will be kept for at least 3 years (per federal regulations) after the study is complete and then destroyed.

Compensation
You will not be paid for your participation in this research study. Once you have completed the survey you will have the option of entering a raffle for a $50.00 Amazon gift card.

Participation is Voluntary
Your decision to take part in this research study is entirely voluntary. You may withdraw from this research study at any time without penalty or loss of benefits to which you are entitled.

Questions
If you have any questions or concerns about your participation in this survey, you may contact the Principal Investigator, Dr Sarah Toevs with the Idaho Caregiver Alliance at 208-426-5899, stoevs@boisestate.edu.

This study has been reviewed and approved by the Boise State University IRB (IRB). If you have questions about your rights as a research participant, you may contact the IRB, which is concerned with the protection of volunteers in research projects. You may reach the board through the Office of Research Compliance by calling (208) 426-5401 or emailing humansubjects@boisestate.edu.

If you know of other informal caregivers we encourage you to share the link to this survey with them. Thank you.

1. Do you consent to participate in this survey?

☐ Yes
☐ No
<Respondents who select "No" will skip to the end of the survey>

2. Do you currently live in Idaho?

☐ Yes
☐ No
<Respondents who select "No" will skip to the end of the survey>

3. How long have you lived in Idaho?

☐ Less than one year
☐ 1-5 years
☐ More than 5 years

4. Do you provide care to one or more family members and/or a friend?

☐ Yes, currently provide care as an unpaid caregiver
☐ Yes, currently provide care as an Idaho Certified Family Home provider

☐ Yes, other provider type, please describe _____
☐ No, formerly provided care but do not anymore
☐ No
<Respondents who select "No" will skip to the end of the survey>

5. What is your zip code? _____

6. What year were you born? _____

7. How would you describe your racial background?
☐ White
☐ Black
☐ Hispanic or Latino
☐ American Indian or Alaska Native
☐ Asian or Pacific Islander
☐ Other (please specify) _____
☐ Prefer not to say

8. Which gender do you identify with?
☐ Male
☐ Female
☐ Other
☐ Prefer not to say

9. Do you identify as part of the LGBTQ+ community?
☐ Yes
☐ No
☐ Prefer not to say

10. What is your marital status?
☐ Single (Never Married)
☐ Married
☐ Living with Partner
☐ Divorced
☐ Widowed

11. Which of the following best describes your annual household income before taxes?
☐ Under $25,000
☐ $25,001 to $40,000
☐ $40,001 to $50,000
☐ $50,001 to $75,000
☐ $75,001 to $100,000
☐ $100,001 to $150,000

☐ Over $150,000
☐ Prefer not to say

12. I am currently:

☐ Employed full time
☐ Employed part time
☐ Self-employed
☐ Employed as seasonal or gig worker
☐ Not employed, but seeking work
☐ Retired and not seeking work

13. As part of your employment, do you receive health insurance and retirement benefits?

☐ Yes, I receive health insurance and retirement benefits
☐ Yes, but I only receive health insurance
☐ No, I do not receive health insurance or retirement benefits
<Respondents who select "No" will skip to # 15>

14. Does your coverage extend to family members in your household?

☐ Yes
☐ No

15. Has caregiving had an impact on your employment or career?

☐ Yes
☐ No
<Respondents who select "No" will skip to # 17>

16. Please select all that apply:

☐ I arrived late or left work early
☐ I used sick leave to provide care
☐ I used vacation time to provide care
☐ I used Family and Medical Leave to provide care
☐ I arranged for flexible work hours
☐ I changed from full-time to part-time work or reduced my work hours
☐ I took a leave of absence to provide care
☐ I took a less demanding job
☐ I declined a promotion
☐ I experienced a loss in wages and/or benefits
☐ I considered taking early retirement or leaving the labor force
☐ I'm stressed at work, worrying that I'll not appear to be focused on or dedicated to my job responsibilities
☐ Other, please describe _____

17.

	Never	Rarely	Sometimes	Frequently	Nearly always
Do you feel that because of your care receiver that you don't have enough time to take care of your own health?					
Do you feel stressed between caring for your care receiver and trying to meet other responsibilities (work, home)?					
Do you feel strained when you are around your care receiver?					
Do you feel uncertain about what to do about your care receiver?					
How often do you feel that you lack companionship?					
How often do you feel left out?					
How often do you feel isolated from others?					

18. Since you became a caregiver, have you noticed a decline in your own health?

- ☐ Yes, in my physical and mental health
- ☐ Yes, in my physical health only
- ☐ Yes, in my mental health only
- ☐ No

19. How many care recipients are you currently providing care for? (If you formerly provided care, how many care recipients did you provide care for?)

- ☐ 1 care recipient
- ☐ 2 care recipients
- ☐ 3 or more care recipients

20. How long have you been providing care?

- ☐ Less than 1 year
- ☐ 1-3 years
- ☐ 4-6 years
- ☐ More than 6 years

21. Do your children or other individuals younger than 18 help care for your care recipient(s)?

☐ Yes
☐ No

22. Who is your care recipient? Please select all that apply.

	How many?	Age of Recipient, select all that apply.			
	Answer 1	Younger than 6	6-21	22-64	65 and Older
Child					
Grandchildren, Nieces, or Nephews					
Siblings					
Spouse					
Parent (including in-laws)					
Grandparent (including in-laws)					
Friend					
Neighbor					
Other, please describe _____					

23. Thinking of all the care you provide to the family members or friends you identified, how many hours of care do you provide overall in a typical week?

☐ 0-7 hours per week
☐ 8-14 hours per week
☐ 15-21 hours per week
☐ 22 hours or more per week

24. What ailments or disabilities have your care recipient(s) suffered from? Please select all that apply.

☐ Alzheimer's Disease/Other forms of Dementia

☐ AIDS
☐ Autism
☐ Behavioral Disorder
☐ Blindness or Vision Loss
☐ Cancer
☐ Chronic Disease (Heart Disease, Lung Disease, Arthritis, Diabetes, Multiple Sclerosis)
☐ Deafness or Hearing Loss
☐ Developmental Disability
☐ Mental Illness/Emotional Disturbance (Anxiety, Depression, Bipolar Disorder)
☐ Mobility Challenges (walking, transferring from position, holding position)
☐ Physical Disability/Limitations
☐ Short-term health/medical conditions
☐ Stroke
☐ Traumatic Brain Injury
☐ Other, please describe _____

25. What tasks or activities do you assist the care recipient with? Please select all that apply.

☐ Personal care tasks
☐ Homemaker chores
☐ Transportation
☐ Managing finances
☐ Communications with teachers and school administrators
☐ Health care coordination (doctor visits, medication monitoring)
☐ Supervision
☐ Emotional support
☐ Other, please describe _____

26. Where do you provide care to your care recipient?

☐ I provide care in my primary residence
☐ I provide care in my care recipient's primary residence
☐ Other, please describe _____

27. How far must you travel in order to provide care?

☐ Less than 5 miles
☐ 5 to 20 miles
☐ 21 to 50 miles
☐ More than 50 miles

28. Are there challenges that prevent you (the care provider) from providing care to your care recipient(s) regularly?

☐ Yes
☐ No
<Respondents who select "No" will skip to # 30>

29. What kinds of challenges do you face? Please select all that apply.

- ☐ Financial challenges
- ☐ Transportation challenges
- ☐ Difficult interactions with care recipient's teachers, employers, others
- ☐ Conflicts with school or work
- ☐ Time constraints
- ☐ Family conflict
- ☐ Emotional strain and/or burnout
- ☐ Depression and isolation
- ☐ Lack of cooperation and/or aggression from care recipient
- ☐ Health/medical issues
- ☐ Being afraid to ask for help
- ☐ Language barriers
- ☐ Other, please describe _____

30. What training or education have you received? Please select all that apply.

- ☐ Alzheimer's Disease and Dementia Training
- ☐ Dementia Friends Training
- ☐ Autism Training
- ☐ Babysitting Training
- ☐ Basic First Aid Training
- ☐ CPR Training
- ☐ Powerful Tools for Caregivers Training
- ☐ Respite Care Training
- ☐ Foster Parent Training
- ☐ Charting the Life Course Skill Building Training
- ☐ Person-centered Thinking Training
- ☐ Navigating Idaho's Medicaid Training
- ☐ Understanding Special Education Training
- ☐ Behavior Management with Children Training (e.g., positive approaches at home)
- ☐ Advocacy Training
- ☐ Formal Training/Education (e.g., degree in social work, nursing)
- ☐ Other, please describe _____
- ☐ I have not received any training for my caregiving responsibilities

31. What type of training or education would help you as a caregiver? Please select all that apply.

- ☐ Alzheimer's Disease and Dementia Training
- ☐ Dementia Friends Training
- ☐ Autism Training
- ☐ Babysitting Training
- ☐ Basic First Aid Training

☐ CPR Training
☐ Powerful Tools for Caregivers Training
☐ Respite Care Training
☐ Foster Parent Training
☐ Charting the Life Course Skill Building Training
☐ Person-centered Thinking Training
☐ Navigating Idaho's Medicaid Training
☐ Understanding Special Education Training
☐ Behavior Management with Children Training (e.g., positive approaches at home)
☐ Advocacy Training
☐ Formal Training/Education (e.g., degree in social work, nursing)
☐ Other, please describe _____
☐ I have not received any training for my caregiving responsibilities

32. If you receive any assistance for your caregiving role, what types of assistance do you receive for the services you provide to the care recipient(s)? Please select all that apply.

☐ Donations
☐ Help from friends/family/neighbors/church
☐ Medicaid assistance
☐ Assistance from Area Agencies on Aging
☐ Assistance from Idaho Parents Unlimited (IPUL)
☐ Assistance from Idaho Centers for Independent Living (Disability Action Center Northwest [DAC], LIFE A Center for Independent Living, Living Independence Network [LINC]
☐ Assistance from Las Senoras
☐ Assistance from the Idaho Commission on Aging
☐ Assistance from the Idaho Council on Developmental Disabilities
☐ Assistance from Aging Strong a program by Jannus
☐ Assistance from Veterans Services
☐ Family health insurance
☐ Coverage from care recipient's insurance
☐ Voucher
☐ Other, please describe _____
☐ I do not receive any assistance

33. Do you feel capable of providing the necessary care to your care recipient(s)?

☐ Yes
☐ Somewhat
☐ Not Sure
☐ No

34. What assistance would help you feel more capable of providing the necessary care to your care recipient(s)? Please describe _____

Respite

Respite is the opportunity for you to have a break from providing care while someone else helps the person you care for.

35. What do you need most from any respite care services? Please select all that apply.

☐ Time for yourself to step out and rest
☐ Balancing responsibilities better
☐ Time to handle personal business
☐ Attending to job responsibilities
☐ Social engagement
☐ Peace of mind
☐ Managing stress
☐ Other, please describe _____
☐ I am not in need of respite services
<Respondents who select "I am not in need of respite services" will skip to # 37>

36. How often do you need respite care per year?

☐ 1-3 times per year
☐ 4-6 times per year
☐ 7-9 times per year
☐ 10 or more times per year

37. Have you utilized respite care services in the past?

☐ Yes
☐ No
<Respondents who select "I am not in need of respite services" will skip to # 41>

38. What services have you utilized? Please select all that apply.

☐ In-home respite care (home/personal/medical assistance/hospice)
☐ Consumer-directed respite
☐ Respite available through the Idaho Community Care Program (for caregivers caring for an individual with memory concerns, dementia, or Alzheimer's)
☐ Assisted living facility
☐ Nursing home
☐ Day activity programs
☐ Adult day care centers
☐ Specialized camps
☐ Financial assistance

☐ Respite provided through trade or barter with other caregivers
☐ Other, please describe _____

39. How often have you utilized these services?

☐ 1 time per year
☐ 2-3 times per year
☐ 4-5 times per year
☐ 6 or more times per year
☐ Never

40. Why haven't you utilized respite services? Please select all that apply.

☐ Did not know what respite was or that it may be available to me
☐ High-cost burden
☐ Difficulty obtaining respite services information
☐ Concern for the quality of available respite services
☐ Limited availability of respite services in my community
☐ Lack of support from family/friends
☐ Concern about outsiders caring for my loved one(s)
☐ Do not qualify for respite or financial assistance
☐ I have enough resources and do not need respite services
☐ Feel friends and family might judge me
☐ Other, please describe

41. What respite care services are you aware of? Please select all that apply.

☐ In-home respite care (home/personal/medical assistance/hospice)
☐ Consumer-directed respite
☐ Idaho Community Care Program (respite available to caregivers caring for an individual with memory concerns, dementia, or Alzheimer's)
☐ Assisted living facility
☐ Nursing home
☐ Day activity programs
☐ Adult day care centers
☐ Specialized camps
☐ Respite provided through trade or barter with other caregivers
☐ I don't know what types of respite care programs are available in my area

Thank you for taking the time to complete this survey. Your response has been recorded.

If you would like to be entered into a raffle for a $50 gift card for completing the survey please use this link to access and complete the entry form.

Note, the entry form is not connected to your survey response. Your response to the survey will remain anonymous if you choose to participate in the drawing.

Appendix B

Health District Zip Codes Groupings

Survey respondents were asked to provide their zip codes, which were first grouped by health districts and then further consolidated for analysis.

District 1 (Panhandle)	83801, 83864, 83854, 83835, 83814, 83815, 83869, 83867, 83858, 83843
District 2 (North Central)	83501, 83857, 83499, 83522, 83533,
District 3 (Southwest)	83641, 83605, 83628, 83651, 83686, 83615, 83687, 83639, 83616, 83607, 83661, 83644, 83655, 83606, 83643, 83632
District 4 (Central)	83704, 83638, 83703, 83716, 83646, 83642, 83634, 83706, 83702, 83622, 83705, 83714, 83669, 83713, 83799, 83633
District 5 (South Central)	83341, 83352, 83316, 83301, 83355, 83333, 83353
District 6 (Southeast)	83234, 83201, 83203, 83245, 83204, 83211, 83202, 83254, 83221
District 7 (East)	83401, 83440, 83406, 83404, 83442, 83402
Outside of TN	84705, 19019, 83734, 15615, 87304, 23185

Appendix C

Full categorized responses to the question: "What assistance would help you feel more capable of providing the necessary care to your care recipient(s)?"

Respite	• "Access to reliable respite for my spouse and I since we are the only ones supporting our neurodivergent children." • "Respite care." • "Respite caregiving." • "In home caregiver, respite, activity ADL assistance." • "A volunteer respite option for our local caregivers." • "A break with a competent provider in my place." • "Respite Care." • "Respite." • "Respite." • "When I was caring for my mother I had respite care and something similar would be nice while being temporary guardian to my granddaughter." • "More respite." • "Someone who can come help a couple times per week and be paid by insurance. If" • "Getting a break from caregiving sometimes." • "Having a break." • "Finding someone to give good alternative care so I could have time off." • "Respite Care & Support Networks: Temporary relief options, support groups, or community programs to prevent burnout." • "Temporary relief regular break from caregiving duties." • "Available Respite care." • "Respite care." • "Respite care." • "Respite." • "Some time when I can get a break from caregiving and household chores. I guess this would be Respite Care." • "I will feel better when I get B's DD Waiver finalized, and our CFH up and running. I am learning about what Idaho has to offer, and so, other than the occasional respite break, I can't think of anything right now. It just is, what it is." • "Respite Care." • "If I could get some help in completing all of the household chores so that the time we do spend together when I'm not working is quality time, rather than me running about doing things like cleaning, laundry, etc. and him feeling like I don't have time for him."
Training	• "In-Person Guardianship training. Understanding various Idaho assistance programs." • "Training." • "More knowledge on my parent's medical conditions. How to get my mother to eat more and how to manage my father's anger and anxiety." • "Trainings." • "Basic CNA type training: physically handling my spouse when he needs help moving

	around, proper way to provide hygiene when patient unable to assist, choking prevention & Heimlich, CPR, wound care, how to feed someone, how to safely pick someone up after they fall, bedpan use, proper transfer from bed to bedside commode, etc." ● "If I'm able to get free trainings on how to better be a caregiver." ● "Actually being trained to care for my dad by the doctors or social workers we have contact with. Instead of just getting nothing." ● "Training on proper nutrition planning tailored to the specific dietary needs of the care recipient." ● "Proper training." ● "Education."
Navigation	● "Assistance in working with various agencies and systems that are supposed to help adults with a life plan and employment. The systems don't work together." ● "I wish I could coordinate the VA services and the skilled nursing facility services that he receives here at our retirement community more easily." ● "Financial, Medicaid and insurance guidance." ● "navigating Idaho Medicaid long term care." ● "Navigating services in the form of a case manager." ● "We need assistance on who will take care of him since we are elderly and will eventually not be here to help." ● "a social worker to help me plan for futUre costs and decisions." ● "Help with the IEP, - I really need that! help finding supports for my mom." ● "How to navigate Dementia/Alzheimer's going forward... how to get legal help with steps like POA, FPOA, and what signs to watch for, regarding safety (when to take the car away), memory issues (when to look for assisted living), financial help (how to plan for paying for help when it gets beyond me." ● "Medicaid navigation--simply the process from childhood to adult services." ● "education on the programs that are available." ● "Directory of Assistance available in my area Wood River Valley." ● "I would like assistance to help with all of the paperwork and also assistance on knowing what will happen to him when I die. He needs supported living." ● "Social worker, funeral planner, instructional coach, respite." ● "Clear & prominent links to Case Management & health navigation services. Payors, health systems, government, and some CBOs employee CM, Care Coordinators & Navigators. These key support people need to be the primary point of entry for caregivers. Once they connect with a professional, they are no longer alone and have help creating a sustainable plan including self-care strategies. The avalanche of available resources can be overwhelming, but helpful when a trained professional provides personal assistance to evaluate all of the options." ● "If I knew who was going to take care of him when I die."
Finances	● "Compensation instead of having to spend my life savings to care for my father." ● "Time. This is typically provided in financial compensation." ● "Possible compensation." ● "Higher income ranges for funding! No one can live on 2000 a month! Higher wages

	for CSW and respite." ● "It's essential that family caregivers that are hired under agencies get a competitive wage. I am doing this and could go and make a TON more money elsewhere and feel like if the state had to pick up the bill for another caregiver coming in, it FAR EXCEEDS me taking care of my loved one." ● "financial encouragements from the family of the person I care for too." ● "After becoming a single income household the financial strain and mental stress of having to find ways to create funds without neglecting the needs of care reciever is without a doubt the biggest challenge." ● "Financial assistance with making our home ADA accessible." ● "A paid wage so i can help support my sons needs while im caring for him." ● "Financial support." ● "Housing financial assistance." ● "State and federal commitment to funding programs needed to maintain home and community-based services." ● "To keep getting paid." ● "Fuel mileage reimbursement for travels." ● "Financial assistance. Do not require medicaid recipients to live below the poverty line in order to receive health benefits--instead allow them to live lives to their fullest potential without having to sacrifice their health coverage." ● "Income for the care given." ● "Paid support from trained caregivers." ● "Financial help, food security." ● "I'd like to be paid for my help I offer to her." ● "A paycheck." ● "Financial assistance." ● "Financial Assistance: Help with the costs of medical care, equipment, or home modifications." ● "Financial support." ● "Higher pay." ● "As of January 31 I will no longer be paid to give care for my wife and there isn't anyone that is available to care for her. So I am stuck at home with no way to pay bills. And food assistance is at $65 per month. How do I feed her with that?" ● "Financial help and education would be very helpful. I'd like to become a Certified Family Home for my mother but I don't have the finances to pay for the inspections, medication class and background check."
Personal Support	● "Support groups." ● "Support and communication with others in my situation." ● "Mental health care." ● "Knowing I'm making the best decision for them." ● "Counseling for all the mental stress." ● "Ongoing support group." ● "Stress management." ● "Support Group where you could talk about the stress of making all the decisions, not having siblings help, seeing your loved one change and suffer, etc." ● "Talking with others who are caregivers."

	• "Support group for my own stress." • "Emotional & Mental Health Support: Access to therapy, counseling, or stress management tools." • "Mental health assistance." • "Provision of emotional support." • "I need help for myself!" • "More ideas on how to handle family/sibling conflict." • "Being able to work and give care without burning out."
Child Care	• "Part time child care availability." • "Having childcare that is affordable, dependable, safe, fun, and geared towards children with special needs. Childcare that pays the provider well to keep them there. I would like to work more to afford the cost of living, but not having childcare prevents me from doing so."
Caregivers/trained support personnel	• "Caregivers, nurses, and PCS workers to help. There are almost no people in the pool of workers available for this job to help." • "More trained direct care workforce that can come into my home and be a community support worker for my child." • "Appropriate Behavior Interventionists (that can be paid a living wage)." • "Outside caregiver for medications." • "If someone could share the work load with me would be so beneficial."
Transportation	• "Increased transportation resources for rural populations.". • "Transportation available for support groups." • "Help with transportation to my dads many doctors appointments, he has balance/mobility issues." • "Providing me with a better means of Transport." • "Transportation to community activities."
Communication	• "Communication assistant." • "Information on my first language. Spanish." • "Signing. He has hearing loss but doesn't sign - so communication is a challenge. Maybe some help teaching him signs." • "More involvement and clear communication with her family."
System change	• "Less state rules/paperwork for Certified Family Homes." • "The systems involved to really understand our needs and help us, and not to fight against us." • "Not having to jump through hoops to get the assistance that is available so we can focus on the important part which is caring for the individual." • "It would be really helpful if the doctors would talk with each other; if his medications were reviewed quarterly and updated as necessary."
Other	• "Housing security." • "A new back." • "If they were easier to work with."

	• "House more handicap acceptable." • "flexible employment options for my son." • "I live 90 miles away from elderly parents who live in a rural part of Idaho and apparently can not get any kind of help with anything." • "Family help." • "Keeping fpcs open for us, my kids don't do well with strangers. And strangers don't have back ground that I do with them how to handle them." • "Peer Support if my recipient would accept it again." • "Having a more inclusive community that will step up and support our family and our care recipients without the stigma and fear associated with it." • "More time in my day." • "If I had time off work to be able to attend his doctor's appointments (sick time, comp time, etc.)"
General help/unknown	• "Still figuring it out." • "Not sure." • "None." • "Unknown." • "Assistance." • "?" • "More help, especially through the hospice days." • "Help dealing with Alzheimers." • "Having more resources for parents." • "Dementia caregiving specifically. Hands on caregiving in general."
Comments	• "Well, I finally got assistance 5 weeks ago when I moved her to Memory Care. Most of my answers were from before the move, but some of it I'm still doing." • "Placement was very helpful. I was at three end of my rope. Getting sick, trouble sleeping. Much better now." • "Please don't get rid of the ability for parents to be caregivers to their children." • "If Health and Welfare wasn't so anti-disability and more inclined to help instead of making things absolutely difficult for people who need services." • "Many of the asssistance options listed above could possibly be helpful. I've never heard of several of them. However, I have reached out to IPUL, Area Agencies on Aging, RISE, and LINC in Boise and Twin Falls, but they were unable to either answer my questions, provide any assistance, or offer support resources for my elderly adult sister who is on the Medicaid DD Waiver. What I've experienced as my sister's Caregiver (sole CSW on the Self Direction Program) is that there seems to be very limited services and supports for older Adult DD participants. Instead, most services and supports are focused/geared for children and young DD adults. This has been extremely frustrating because my Sister's needs have continued to increase and evolve as she ages, and I can't find the resources, services, supports, additional CSW's to provide her needed care, or even any Respite for myself as I care for her. Over the past decade we've tried several Res. Hab. Agency placements and Certified Family Homes who were unable to meet her basic needs let alone provide her the required care for her safety and well-being. In these environments she was neglected, taken advantage of,

	abused, assaulted, not provided the Dr. prescribed medical and health care and therapies that she required, she was stolen from, and even abandoned at the last DD Res. Hab. Agency she tried. After all those horrible experiences where her health, safety, and well-being were consistently compromised, she went on the DD Waiver Self Direction Program, but I can't even find other qualified CSW's who are willing to work for $16/hour (program limited wage with no benefits, vacation, sick leave, family leave, etc.). They tell me $16/per hour is not a living wage, and they are unwilling to work for $16/hour at the level of care my sister requires. Furthermore, my sister's Self Direction budget only allows for 16 hours/day of paid coverage, so the remaining 8 hours per day is simply volunteer time. With her Intellectual Disabilities, Autism, Medical, Mental Health, and Behavioral challenges, mobility issues, incontinence, and inability to sleep through the night, she requires 24/7 supervision and assistance for her health and safety, so my Guardian role and Caregiving experience has been extremely difficult." ● "Idaho needs required respite like CA and basic insurance because most parents have to leave there jobs to provide care uninsured or cannot hire higher trained staff due to low wages and no insurance." ● "I wish I had sooner contact with caregiver's support groups, local and online. A problem with having outside help come in was our house being so filled with stuff." ● "Instead of PCS where there are no providers to hire, money we could use on housekeeping.. This would be a gamechanger/ stress reducer and in the long run be cheaper for tax payers and help with caregiver burnout." ● "I would like to qualify for PCS hours through the state. Then I would like to apply as the familial caregiver for my underage child. Until I know that the bill is renewed in 2025, I can't quit my current job. Everything I do is a full-time job."

Appendix D

Idaho Family Caregiver Survey Technical Report

Consent to participate in the survey was required in order to proceed. All participants reflected below consented to participation.

Table 1. General Caregiver Demographics

Caregiver Demographics		
Characteristics	***n***	***%***
Gender	**242**	
Male	25	10.3
Female	215	88.8
Other	1	0.4
Prefer not to say	1	0.4
Do you identify as part of the LGBTQ+ community?	**240**	
Yes	12	5.0
No	220	91.7
Prefer not to say	8	3.3
Age	**236**	
18-24	2	0.8
25-34	21	8.9
35-44	43	18.2
45-54	47	19.9
55-64	60	25.4
65+	63	26.7
Marital Status	**242**	
Single (never married)	29	12
Married	157	64.9
Living with a partner	12	5
Divorced	34	14.1
Widowed	10	14.1
Currently live in Idaho	**280**	
Yes	279	99.6
No*	1	0.4

*If a participant answered "no", they were not prompted to answer any further questions.

Length of time living in Idaho	**268**	
Less than 1 year	5	1.8
1-5 years	30	11.2
More than 5 years	233	87.0
In what health district do you reside*	**240**	
District 1 (Panhandle)	21	8.8
District 2 (North Central)	7	2.9
District 3 (Southwest)	60	25.0
District 4 (Central)	95	39.6
District 5 (South Central)	13	5.4
District 6 (South east)	23	9.6
District 7 (East)	15	6.3
Not in Idaho	6	2.5

*This question was modified based on zip code data collected. Zip codes were grouped into health districts as outlined in appendix B.

Annual household income before taxes	**241**	
Under $25,000	33	13.7
$25,001 to $40,000	37	15.3
$40,001 to $50,000	29	12.0
$50,001 to $75,000	51	21.2
$75,001 to $100,000	38	15.8
$100,001 to $150,000	27	11.2
Over $150,000	11	4.6
Prefer not to say	15	6.2
Racial background	**242**	
White	193	79.8
Black	6	2.5
Hispanic or Latino	27	11.2
American Indian or Alaska Native	4	1.7
Asian or Pacific Islander	1	0.4
Other	3	1.2
Prefer not to say	8	3.3

Caregiver Responsibilities

A substantial number of caregivers in Idaho have been providing care for extended periods, with 65.9% engaged in caregiving for more than four years. The time commitment of caregiving is also notable, as 64.2% of respondents provide over 22 hours of care per week. The most common tasks caregivers provided assistance for included transportation, healthcare coordination such as doctor visits and medication monitoring, emotional support, and homemaker chores.

Table 2. General Caregiver Responsibilities

Caregiver Responsibilities

Characteristics	*n*	*%*
Provides care to one or more family members	**266**	
Yes, currently provide care as an unpaid caregiver	159	59.8
Yes, currently provide care as an Idaho Certified Family Home provider	44	16.5
Yes, other provider type*	24	9.0
No, formerly provided care but do not anymore	27	10.2
No*	12	4.5
*If a participant answered "no", they were not prompted to answer any further questions.		
Duration of caregiving	**216**	
Less than 1 year	13	6.0
1-3 years	61	28.2
4-6 years	44	20.4
More than 6 years	98	45.5
Number of care recipients	**215**	
1 care recipient	133	61.9
2 care recipients	57	26.5
3 or more care recipients	25	11.6
The person I care for is a (select all that apply)	**185**	
Child	86	46.5
Grandchildren, Nieces, or Nephews	13	7.0
Siblings	14	5.6
Spouse	37	20.0
Parent (including in-laws)	66	35.7
Grandparent (including in-laws)	9	4.8
Friend	15	8.1
Neighbor	7	3.8
Other, please describe	7	3.8

- Other, please describe categories:
    - Paid caregiver
    - Patient
    - Client
    - Emergency placement
    - Uncle/aunt

How many hours of care provided in a typical week	**215**	
0-7 hours per week	22	10.2
8-14 hours per week	29	13.5
15-21 hours per week	26	12.1
22 hours or more per week	138	64.2
Children/other individuals under 18 help you to provide care	**212**	
Yes	42	19.8
No	170	80.2
Where care is provided	**216**	
I provide care in my primary residence	132	61.1
I provide care in my care recipient's primary residence	58	26.9
Other	26	12.0

- Other, please describe categories:
  - Both my home and theirs
  - In another facility

Travel distance to provide care	**196**	
Less than 5 miles	123	62.8
5 to 20 miles	47	24.0
21 to 50 miles	14	7.1
More than 50 miles	12	6.1
Tasks or activities assistance is provided for (select all that apply)	**222**	
Personal care tasks	170	76.6
Homemaker chores	178	80.2
Transportation	189	85.1
Managing finances	152	68.5
Communications with teachers and school administrators	64	28.8
Health care coordination (doctor visits, medication monitoring)	187	84.2
Supervision	136	61.3
Emotional support	178	80.2
Other, please describe	44	19.8

- Other, please describe response categories:
  - Full-time and general Caregiving responsibilities
  - Medical and health-related care
  - Paperwork, advocacy, and coordination
  - Education and skill development
  - Social and community engagement
  - Housing and living arrangements
  - Behavioral and emotional support
  - Household and daily living support

Caregiver Experiences

Caregivers frequently reported that their responsibilities affected their personal health with 80.4% of respondents indicating a decline in physical and/or mental health. Most respondents indicated that they regularly do not have time to take care of themselves and experience stress from trying to juggle caregiving and other duties. Caregivers also indicated that they, at least sometimes, feeled strained, isolated, and/or left out.

Table 3. General Caregiver Experiences

Caregiver Experiences		
Characteristics	***n***	***%***
Don't have enough time to take care of your own health	**217**	
Never	8	3.7
Rarely	23	10.6
Sometimes	87	40.1
Frequently	68	31.3
Nearly always	31	14.3
Feelings of stress between caring for your care receiver and trying to meet other responsibilities (work/home)	**218**	
Never	9	4.1
Rarely	14	6.4
Sometimes	71	32.6
Frequently	75	34.4
Nearly always	49	22.5
Feelings of strain when you are around your care receiver	**216**	
Never	22	10.2
Rarely	45	20.8
Sometimes	91	42.1
Frequently	46	21.3
Nearly always	12	5.6
Feelings of uncertainty about what to do about your care receiver	**216**	
Never	34	15.7
Rarely	36	16.7
Sometimes	87	40.3
Frequently	42	19.4
Nearly always	17	7.9
Feelings of lacking companionship	**217**	

Never	27	12.4
Rarely	42	19.4
Sometimes	72	33.2
Frequently	57	26.3
Nearly always	19	8.8
Frequency of feeling left out	**218**	
Never	27	12.4
Rarely	32	14.7
Sometimes	74	33.9
Frequently	62	28.4
Nearly always	23	10.6
Frequency of feeling isolated from others	**218**	
Never	21	9.6
Rarely	30	13.8
Sometimes	75	34.4
Frequently	58	26.6
Nearly always	34	15.6
Decline in health since becoming a caregiver	**215**	
Yes, in my physical and mental health	123	57.2
Yes, in my physical health only	19	8.8
Yes, in my mental health only	31	14.4
No	42	19.5
Feelings of being capable of providing the necessary care to care recipient	**208**	
Yes	124	59.6
Somewhat	70	33.7
Not sure	7	3.4
No	7	3.4

Ailments or Disabilities of Care Recipients

Care recipients in Idaho present a diverse range of conditions, highlighting the complexity of caregiving responsibilities. Mobility challenges were the most frequently reported category, affecting 38.9% of those receiving care. The most common ailment reported was Alzheimer's Disease/Other forms of Dementia affecting 36.2% of care recipients. Additionally, 35.3% of care recipients had mental health conditions such as anxiety, depression, or bipolar disorder while 34.4% were reported to have developmental disabilities. Other notable conditions include Chronic Diseases such as Heart Disease, Lung Disease, Arthritis, Diabetes, and Multiple Sclerosis. The range of health challenges highlights the need for specialized support services tailored to different conditions.

Table 4. Ailments or Disabilities of Care Recipients

Ailments or Disabilities of Care Recipients		
Characteristics	***n***	***%***
Ailments or disabilities among care recipients (select all that apply)	**221**	
Alzheimer's Disease/Other forms of Dementia	80	36.2
AIDS	2	0.9
Autism	61	27.6
Behavioral Disorder	64	29.0
Blindness or Vision Loss	26	11.8
Cancer	23	10.4
Chronic Disease (Heart Disease, Lung Disease, Arthritis, Diabetes, Multiple Sclerosis)	72	32.6
Deafness or Hearing Loss	43	19.5
Developmental Disability	76	34.4
Mental Illness/Emotional Disturbance (Anxiety, Depression, Bipolar Disorder)	78	35.3
Mobility Challenges (walking, transferring from position, holding position)	86	38.9
Physical Disability/Limitations	64	29.0
Short-term health/medical conditions	34	15.4
Stroke	17	7.7
Traumatic Brain Injury	11	5.0
Other	42	19.0
● Other, please describe response categories:		
○ Neurological disorders and developmental disabilities		
○ Physical disabilities and mobility Issues		
○ Chronic illnesses and medical conditions		
○ Post-surgical and long-term Recovery		
○ Behavioral and mental health issues		
○ Caregiving for multiple generations		
○ Therapy and rehabilitation needs		

Employment Status and Financial Impact

Employment and financial stability are significantly impacted by caregiving duties with 75.1% stating that their employment has been impacted 20.5% reporting they have considered early retirement due

to their caregiving obligations.. Among caregivers, 34.7% are employed full-time, while 29.7% are retired.

Table 5. Employment Status and Financial Impact

Employment Status and Financial Impact		
Characteristics	***n***	***%***
Employment status	**236**	
Employed full time	82	34.7
Employed part time	33	14.0
Self-employed	21	8.9
Employed as seasonal or gig worker	6	2.5
Not employed, but seeking work	24	10.2
Retired and not seeking work	70	29.7
Employment benefits	**224**	
Yes, I receive health insurance and retirement benefits	84	37.5
Yes, but I only receive health insurance	21	9.4
No, I do not receive health insurance or retirement benefits	119	53.1
Benefits Coverage Extend to Household Family Members	**109**	
Yes	58	53.2
No	51	46.8
Caregiving Impact on Employment/Career	**237**	
Yes	178	75.1
No	59	24.9
Employment impacts due to caregiving (select all that apply)	**190**	
I arrived late or left work early	76	40.0
I used sick leave to provide care	70	36.8
I used vacation time to provide care	70	36.8
I used Family and Medical Leave to provide care	30	15.8
I arranged for flexible work hours	92	48.4
I changed from full-time to part-time work or reduced my work hours	52	27.4
I took a leave of absence to provide care	32	16.8
I took a less demanding job	44	23.2
I declined a promotion	29	15.3
I experienced a loss in wages and/or benefits	56	29.5
I considered taking early retirement or leaving the labor force	39	20.5
I'm stressed at work, worrying that I'll not appear to be focused on or dedicated to my job responsibilities	73	38.4

Other	77	40.5

- Other, please describe response categories:
  - Left work and/or reduced hours
  - Was already retired
  - Deferred education or left school
  - Physical and mental health challenges
  - Impacts on lifestyle/personal plans

Caregiver Challenges and Support Needs

Caregivers in Idaho face numerous challenges that impact their ability to provide consistent and effective care. The most commonly reported barriers to caregiving include emotional strain and/or burnout, time constraints, and financial challenges. Challenges were evaluated in relation to income. Financial challenges were more frequently reported by caregivers with an annual household income of 50,000 or less. Time constraints were listed more frequently by those with an annual household income of more than 50,000. All income levels showed emotional strain and/or burnout among their most reported challenges.

Table 6. General Caregiver Challenges and Support Needs

Caregiver Challenges and Support Needs		
Characteristics	***n***	***%***
Are there challenges that prevent you from providing care to your care recipient regularly?	**213**	
Yes	88	41.3
No	125	58.7
Common challenges faced (select all that apply)	**207**	
Financial challenges	107	51.7
Transportation challenges	57	27.5
Difficult interactions with care recipient's teachers, employers, others	30	14.5
Conflicts with school or work	59	28.5
Time constraints	112	54.1
Family conflict	60	29.0
Emotional strain and/or burnout	156	75.4
Depression and isolation	88	42.5
Lack of cooperation and/or aggression from care recipient	75	36.2
Health/medical issues	80	38.6
Being afraid to ask for help	39	18.8
Language barriers	8	3.9
Other	28	3.5

- No description option provided on the survey.

What assistance would help you feel more capable of providing the necessary care (n=125)

This question was open ended and was analyzed using thematic analysis. Responses have been categorized with some specific responses included in the listings below. See full responses in Appendix C. Most frequently responses fell into three primary categories:

Respite Care

- "A break with a competent provider in my place".
- "Some time when I can get a break from caregiving and household chores".

Financial support

- "Compensation for providing care".
- "After becoming a single income household the financial strain and mental stress of having to find ways to create funds without neglecting the needs of care reciever is without a doubt the biggest challenge".
- "Help with the costs of medical care, equipment, or home modifications".
- "Housing financial assistance".

Navigation services

- "Navigating Idaho Medicaid long term care".
- "How to navigate Dementia/Alzheimer's going forward".
- "I would like assistance to help with all of the paperwork and also assistance on knowing what will happen to him when I die".
- "A social worker to help me plan for futUre costs and decisions".
- "Clear & prominent links to Case Management & health navigation services. Payors, health systems, government, and some CBOs employee CM, Care Coordinators & Navigators. The avalanche of available resources can be overwhelming, but helpful when a trained professional provides personal assistance to evaluate all of the options".

Caregiver training or education received (select all that apply)	**210**	
Alzheimer's Disease and Dementia Training	55	26.2
Dementia Friends Training	18	8.6
Autism Training	39	18.6
Babysitting Training	16	7.6
Basic First Aid Training	113	53.8
CPR Training	123	58.6
Powerful Tools for Caregivers Training	43	20.5
Respite Care Training	16	7.6
Foster Parent Training	15	7.1
Charting the Life Course Skill Building Training	11	5.2

Person-centered Thinking Training	32	15.2
Navigating Idaho's Medicaid Training	17	8.1
Understanding Special Education Training	17	8.1
Behavior Management with Children Training (e.g., positive approaches at home)	20	9.5
Advocacy Training	22	10.5
Formal Training/Education (e.g., degree in social work, nursing)	51	24.3
Other	34	16.4

- Other, please describe response categories:
  - Formal healthcare and medical training
  - Caregiving-specific training and experience
  - Self-taught and informal learning
  - Continuing education and professional development
  - Expired or unspecified training
  - No formal training

Caregiver training or education that would help (select all that apply)	**183**	
Alzheimer's Disease and Dementia Training	48	26.2
Dementia Friends Training	31	16.9
Autism Training	32	17.5
Babysitting Training	10	5.5
Basic First Aid Training	33	18.0
CPR Training	29	15.8
Powerful Tools for Caregivers Training	74	40.4
Respite Care Training	52	28.4
Foster Parent Training	4	2.2
Charting the Life Course Skill Building Training	48	26.2
Person-centered Thinking Training	50	27.3
Navigating Idaho's Medicaid Training	71	38.8
Understanding Special Education Training	21	11.5
Behavior Management with Children Training (e.g., positive approaches at home)	28	15.3
Advocacy Training	57	31.1
Formal Training/Education (e.g., degree in social work, nursing)	25	13.7
Other	19	10.4

- Other, please describe response categories:
  - Practical caregiving skills and medical training
  - Financial, legal, and bureaucratic navigation

- End-of-life and healthcare system navigation
- Mental and emotional support for caregivers
- General uncertainty or lack of training
- Alleviation of access and administrative burdens

Types of assistance received for caregiving (select all that apply)	**200**	
Donations	14	7.0
Help from friends/family/neighbors/church	64	32.0
Medicaid assistance	67	33.5
Assistance from Area Agencies on Aging	18	9.0
Assistance from Idaho Parents Unlimited (IPUL)	9	4.5
Assistance from Idaho Centers for Independent Living (Disability Action Center Northwest [DAC], LIFE A Center for Independent Living, Living Independence Network [LINC]	7	3.5
Assistance from Las Senoras	4	2.0
Assistance from the Idaho Commission on Aging	7	3.5
Assistance from the Idaho Council on Developmental Disabilities	9	4.5
Assistance from Aging Strong a program by Jannus	8	4.0
Assistance from Veterans Services	11	5.5
Family health insurance	22	11.0
Coverage from care recipient's insurance	33	16.5
Voucher	4	2.0
Other	15	7.5

- Other, please describe response categories:
  - Financial assistance
  - Medical and healthcare support
  - Community and government aid
  - Lack of assistance or unclear support
  - Care placement and specialized services
  - Private or alternative assistance programs

I do not receive any assistance	66	33.0
Insurance Summary:	**224**	
Caregivers reporting having employer-sponsored benefits	105	46.9
Caregivers reporting only having insurance from family/care recipient	24	10.7
Caregivers reporting utilizing medicare as their only form of insurance	29	12.9

Use of Respite Care Services

Despite the known benefits of respite care, 77.2% of caregivers reported never having accessed these services. The primary barriers to respite utilization included limited availability of respite

services, concern about outsiders caring for the care recipient, and difficulty obtaining respite service information. Among those who expressed a need for respite, the most desired benefits include time to step out and rest, peace of mind, and time for personal activities.

Table 7. General Use of Respite Care Services

Use of Respite Care Services		
Characteristics	***n***	***%***
What do you need most from respite services (select all that apply)	**200**	
	128	64.0
Time for yourself to step out and rest	72	36.0
Balancing responsibilities better	90	45.0
Time to handle personal business	48	24.0
Attending to job responsibilities	86	43.0
Social engagement	94	47.0
Peace of mind	114	57.0
Managing stress	24	12.0
Other		
● Other, please describe response categories:		
○ Respite for personal well-being and self-care		
○ Respite for family and relationship needs		
○ Flexibility and availability of respite services		
○ Financial stability and employment needs		
○ Specialized and trained respite support		
○ Long-term planning and stability		
○ Travel and social participation		
○ Caregiving for others		
How often do you need respite care per year	**158**	
1-3 times per year	47	29.7
4-6 times per year	45	28.5
7-9 times per year	14	8.9
10 or more times per year	52	32.9
Have you utilized respite care services in the past	**206**	
Yes	47	22.8
No	159	77.2
What respite services have you utilized (select all that apply)	**48**	
In-home respite care (home/personal/medical assistance/hospice)	33	68.8
Consumer-directed respite	10	20.8
Respite available through the Idaho Community Care Program	5	10.4

(for caregivers caring for an individual with memory concerns, dementia, or Alzheimer's)		
Assisted living facility	4	8.3
Nursing home	3	6.3
Day activity programs	4	8.3
Adult day care centers	2	4.2
Specialized camps	3	6.3
Financial assistance	5	10.4
Respite provided through trade or barter with other caregivers	5	10.4
Other	13	27.1

- Other, please describe response categories:
  - Family support
  - Formal respite services
  - Financial and grant assistance
  - Paid and professional caregiving services
  - Issues expressed with service availability and quality

How often have you utilized these respite services	**47**	
1 time per year	7	14.9
2-3 times per year	13	27.7
4-5 times per year	5	10.6
6 or more times per year	19	40.4
Never	3	6.4
Barriers to utilizing respite services (select all that apply)	**41**	
Did not know what respite was or that it may be available to me	8	19.5
High-cost burden	15	36.6
Difficulty obtaining respite services information	17	41.5
Concern for the quality of available respite services	15	36.6
Limited availability of respite services in my community	21	51.2
Lack of support from family/friends	13	31.7
Concern about outsiders caring for my loved one(s)	19	46.3
Do not qualify for respite or financial assistance	5	12.2
I have enough resources and do not need respite services	2	4.9
Feel friends and family might judge me	1	2.4
Other	6	14.6

- No description option provided on the survey.

What respite care services are you aware of (select all that apply)	**206**	
In-home respite care (home/personal/medical assistance/hospice)	82	39.8
Consumer-directed respite	39	18.9

Idaho Community Care Program (respite available to caregivers caring for an individual with memory concerns, dementia, or Alzheimer's)	19	9.2
Assisted living facility	55	26.7
Nursing home	44	21.4
Day activity programs	46	22.3
Adult day care centers	40	19.4
Specialized camps	16	7.8
Respite provided through trade or barter with other caregivers	19	9.2
I don't know what types of respite care programs are available in my area	95	46.1

The primary reasons for not obtaining respite services differed based on the type of care recipient. Caregivers of children most often expressed concern about having outsiders care for their loved ones. Spousal caregivers were primarily worried about the quality of available respite services. Meanwhile, those caring for a parent frequently cited challenges in accessing respite care.