APPENDIX H

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Family Caregiver Supports and Services Study

May 10, 2016

STUDENT FOCUSED • LAND GRANT • RESEARCH UNIVERSITY

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Research Team

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Project Overview

Aim 1. Identify current public and private resources, services, and supports for family caregivers, by region and/or county.
Aim 2. Identify barriers and challenges family caregivers experience
Aim 3. Identify best practice models for family caregiver support programs from other states.
Aim 4. Identify emerging practices and technology that can enhance caregiver and patient home supports.
Aim 5. Provide recommendations to the interim committee

Family Caregiver Study Objectives

Aim 1: **Identify current public and private resources, services, and supports for family caregivers, by region and/or county.**

- Create database of:
  - a) informal community supports
  - b) private community supports
  - c) governmental supports

Aim 1: Methods

19 categories of services/supports were determined

Managing the Logistics of Caregiving	Direct Support in Providing Care	Improving Caregivers' Ability to Provide Care	Fostering Caregivers' Well-being
Advocacy Services	Adult Day Care	Meal Services	Emotional Support
Assistive Technology & Equipment	Dementia Care	Training and Education	Respite
Care Management	Home Health Care	Transportation	
Information and Referral	Homemaker/Chore	Volunteer Services	
	Hospice		
	Personal Care		
	Parish Nurses		
	Public Nurses		
	Qualified Service Providers		

Aim 1: Methods

- Services/supports were identified by region
- Qualtrics online regional surveys developed
- Survey links emailed to County Social Service Directors for all 53 counties
- Mapping procedure
- Regional databases created

Map of Assistive Technology/Equipment

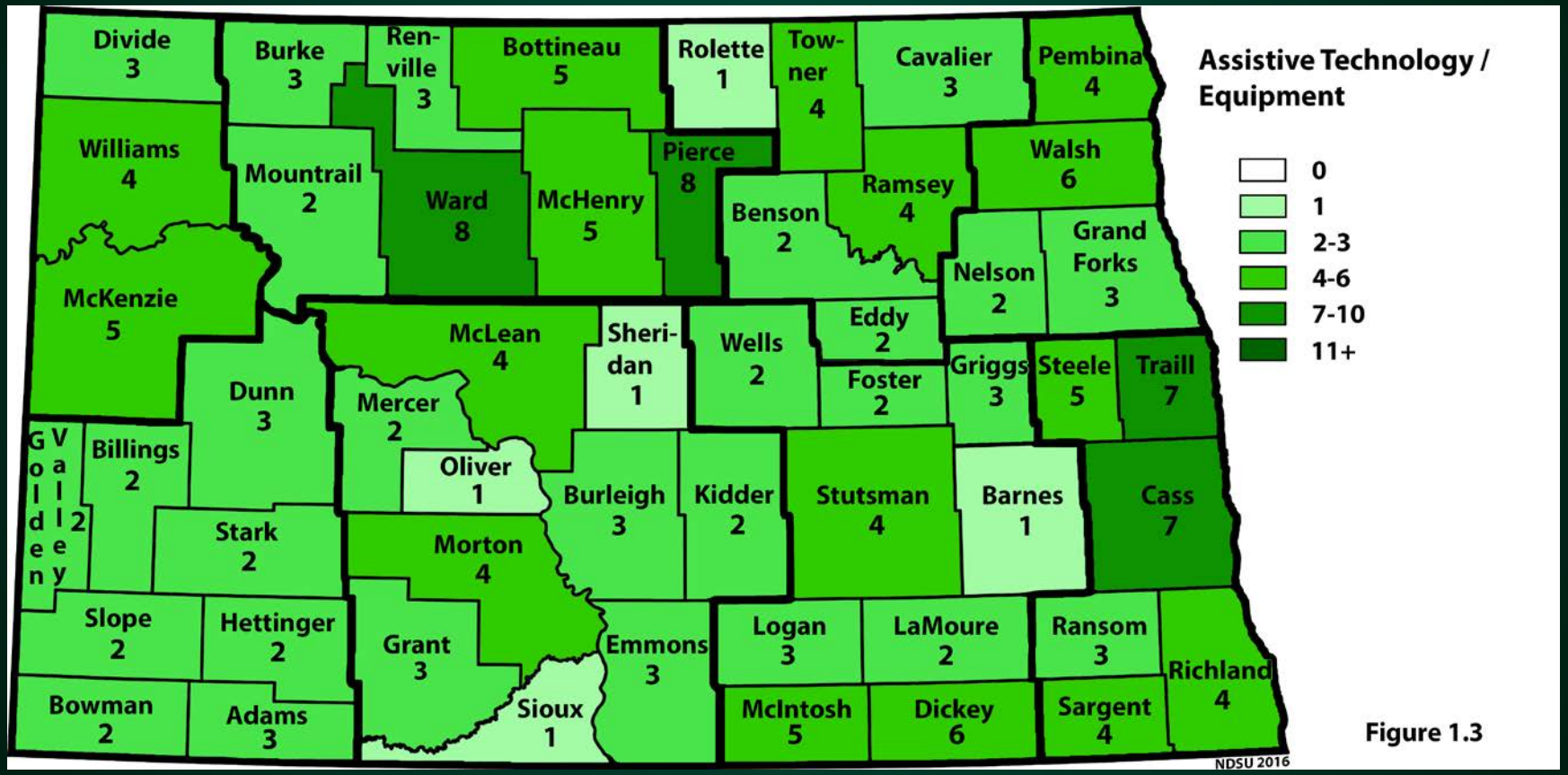

Figure 1.3

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Map of Adult Day Care

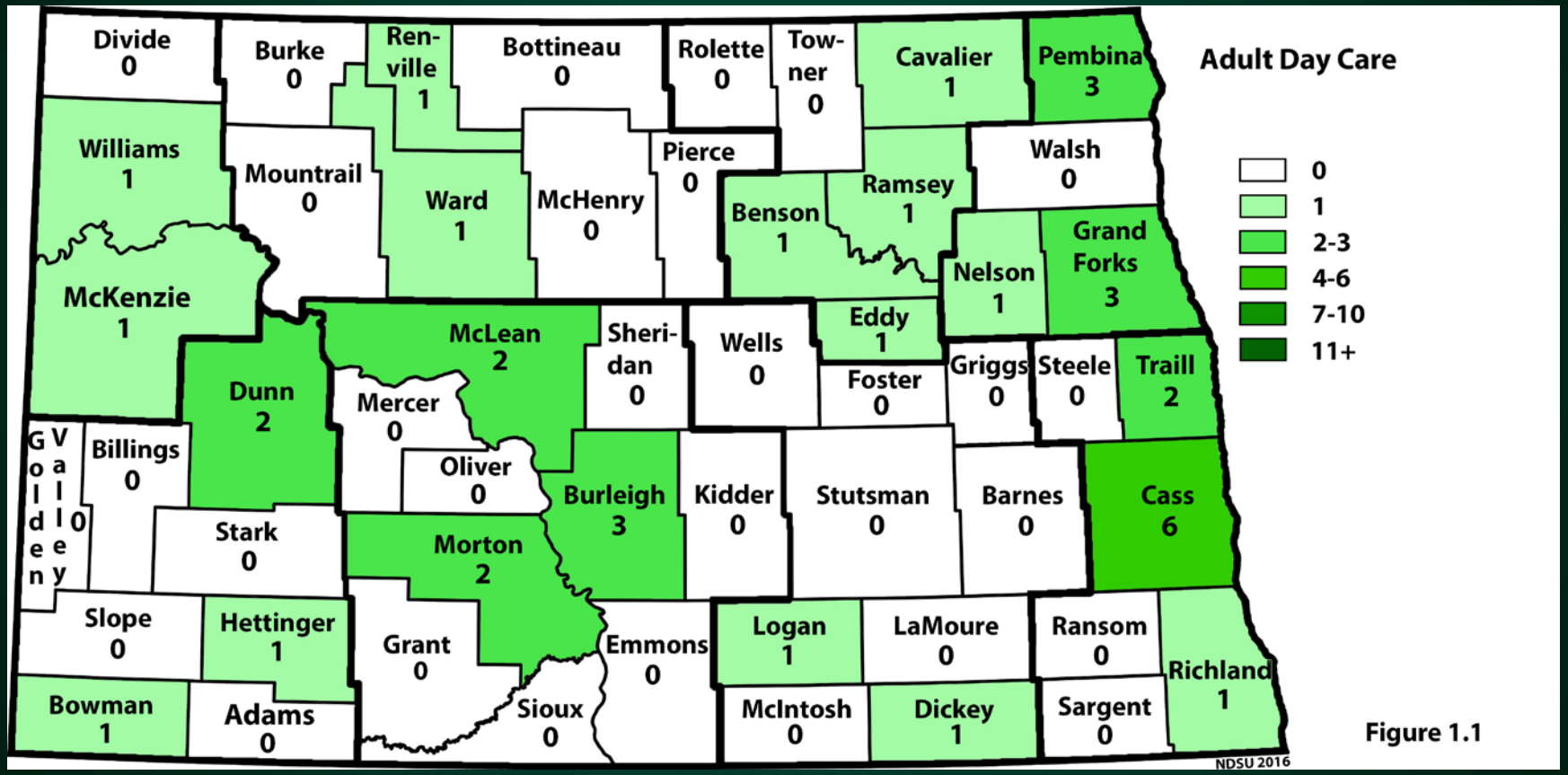

Figure 1.1

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Aim 1: Results

- **Services related to managing caregiving are more developed than many other caregiving services across ND:**
  - Information and referral, assistive technology and equipment, and advocacy services seem to be evenly represented across the state
  - Care management is one area that would support managing the logistics of caregiving that seems to be lacking across the state

Aim 1: Results

- **There is a clear rural/urban divide in resources that provide direct eldercare support:**
  - In urban areas we find a strong representation of direct care services (such as adult day care, dementia care, hospice, home health care, homemaker and personal care)
  - However, these direct care services seem to be lacking in rural areas across the state

Aim 1: Results

- **Some services (such as training and education, transportation, meal services, and volunteer services) indirectly help caregivers by improving the caregiver's ability to provide care him or herself.**
  - Of these, training and education, transportation, and volunteer services seem to be lacking across the state

Aim 1: Results

- **Respite care and emotional support have a primary aim of helping to foster well-being of the caregiver.**
  - These services are under represented across North Dakota, which is concerning because if the well-being of the caregiver is not a priority, seniors and their families may be put at risk.

Aim 1: Keep in mind…

- **Availability** (Are services available across the designated region / county?)
- **Accessibility** (Does the travel distance to the service create a barrier?)
- **Appropriateness** (Do services address actual needs?)
- **Affordability** (Can families afford to pay for available services?)
- **Awareness** (Do families and communities know about these services?)

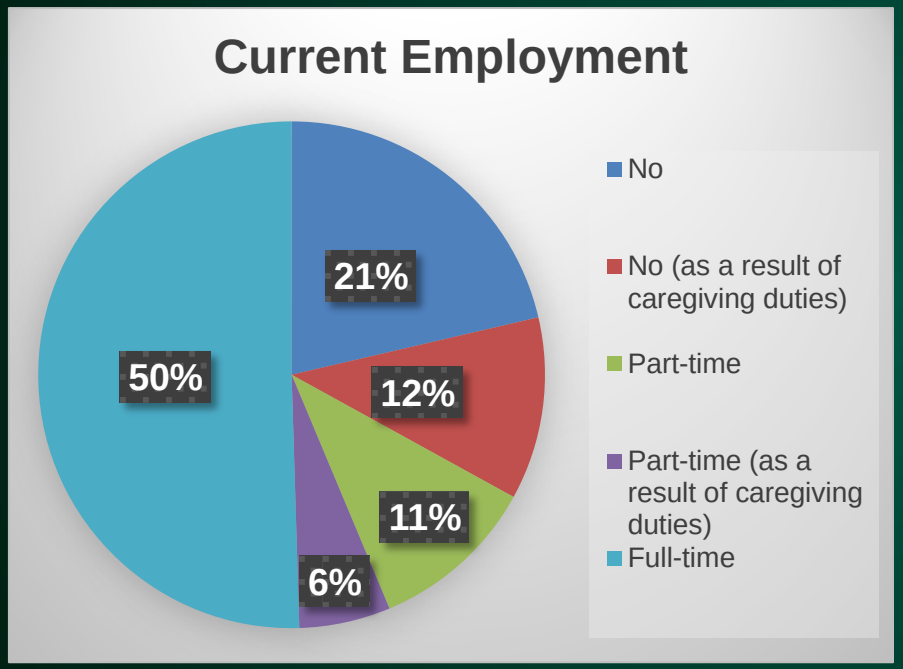
Family Caregiver Study Objectives

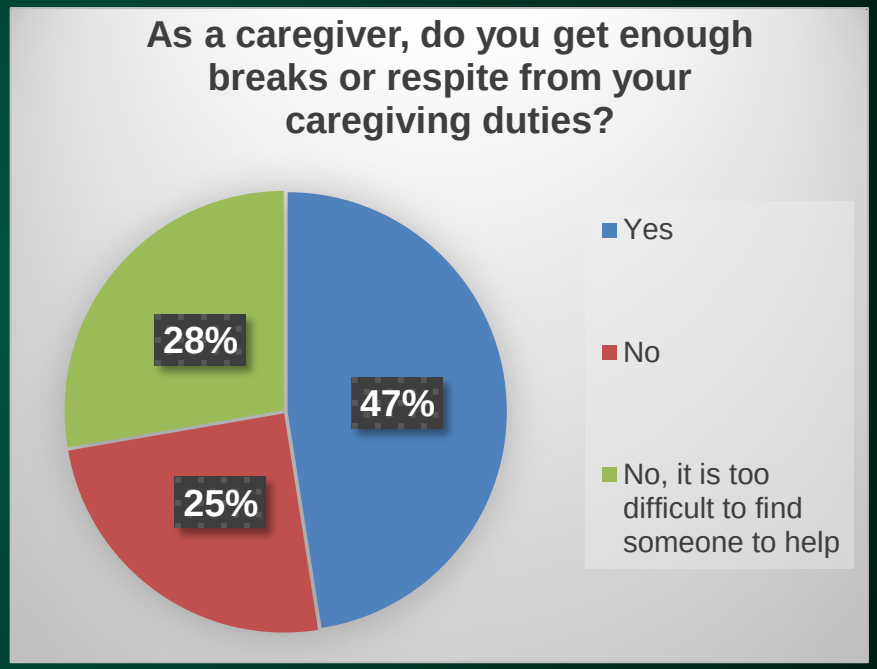
Aim 2: **Identify barriers and challenges family caregivers experience, which includes the need for training, respite care services, medical leave policies, and delegation of tasks to family members and nonmedical aides.**

- Phase A. Family caregivers
  - AARP-ND, survey of caregivers (2015-16)
  - Family Caregiver Support Program (2014, 2015)

Aim 2: Caregiver's Perspective

Data from AARP Caregiver Survey analyzed (2015) – 110 Caregivers across ND





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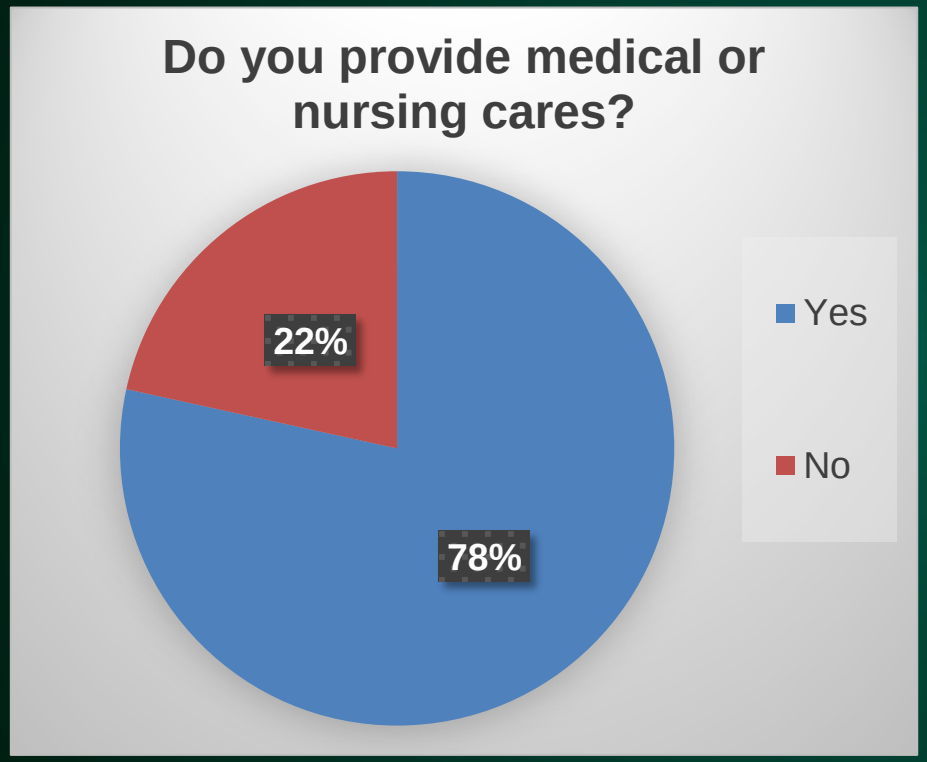
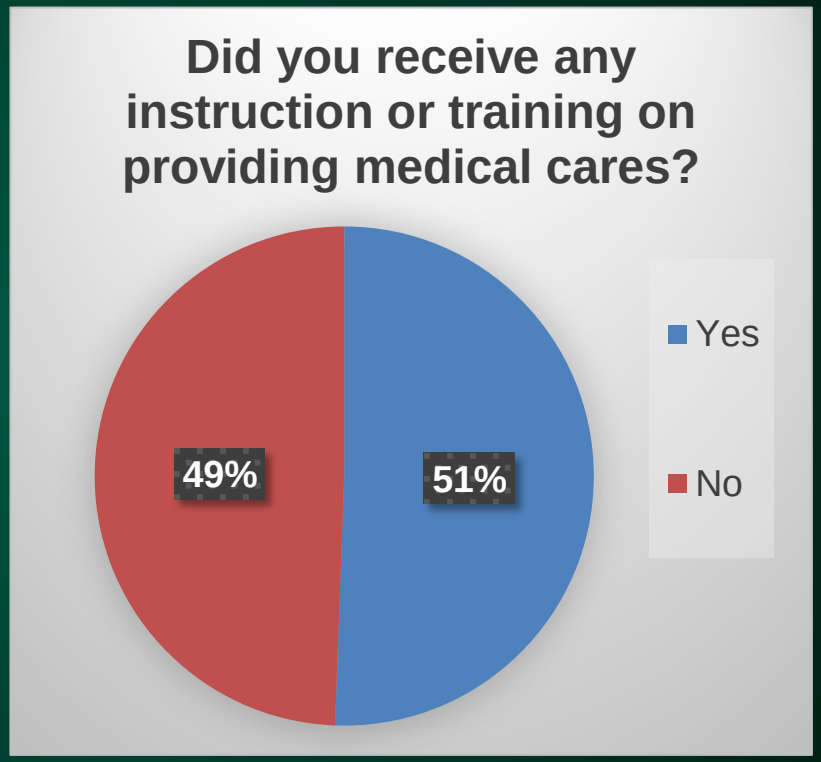
Aim 2: Caregiver's Perspective

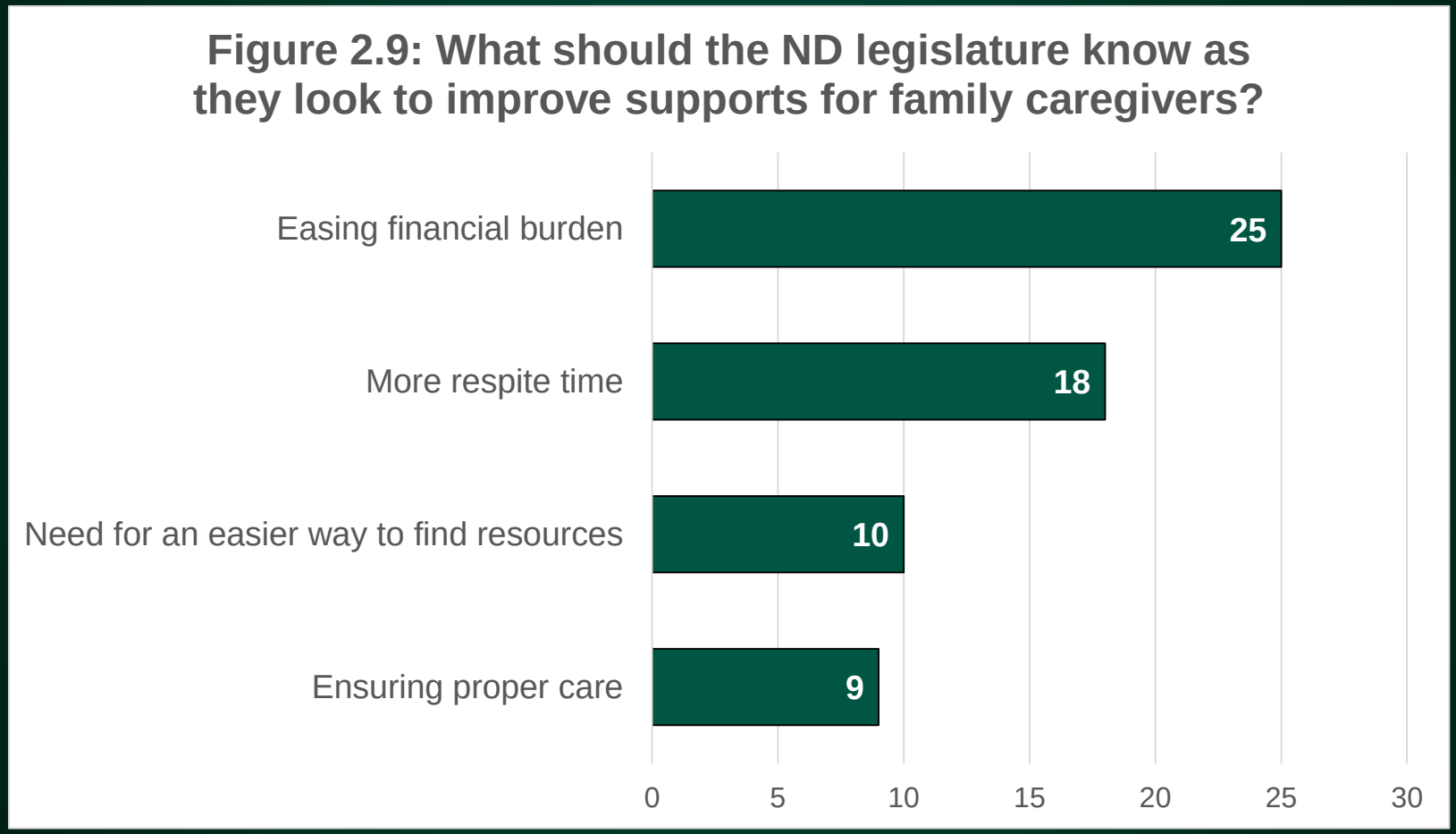
AARP Caregiver Survey (2015)





Aim 2: Caregiver's Perspective

AARP Caregiver Survey Data



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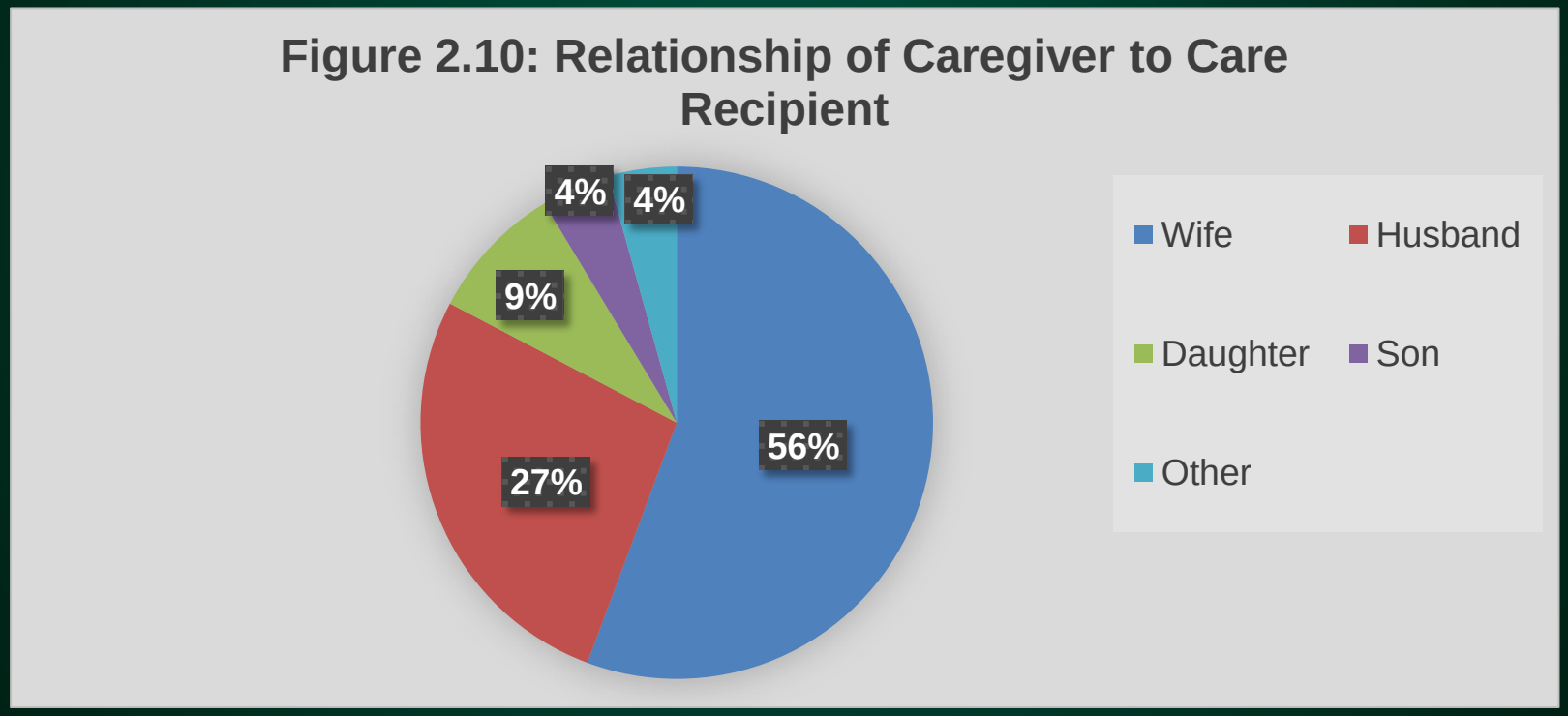
Aim 2: Caregiver's Perspective

Data from ND Family Caregiver Support Program – Caregivers' Survey (2014)

- 196 Caregivers across ND



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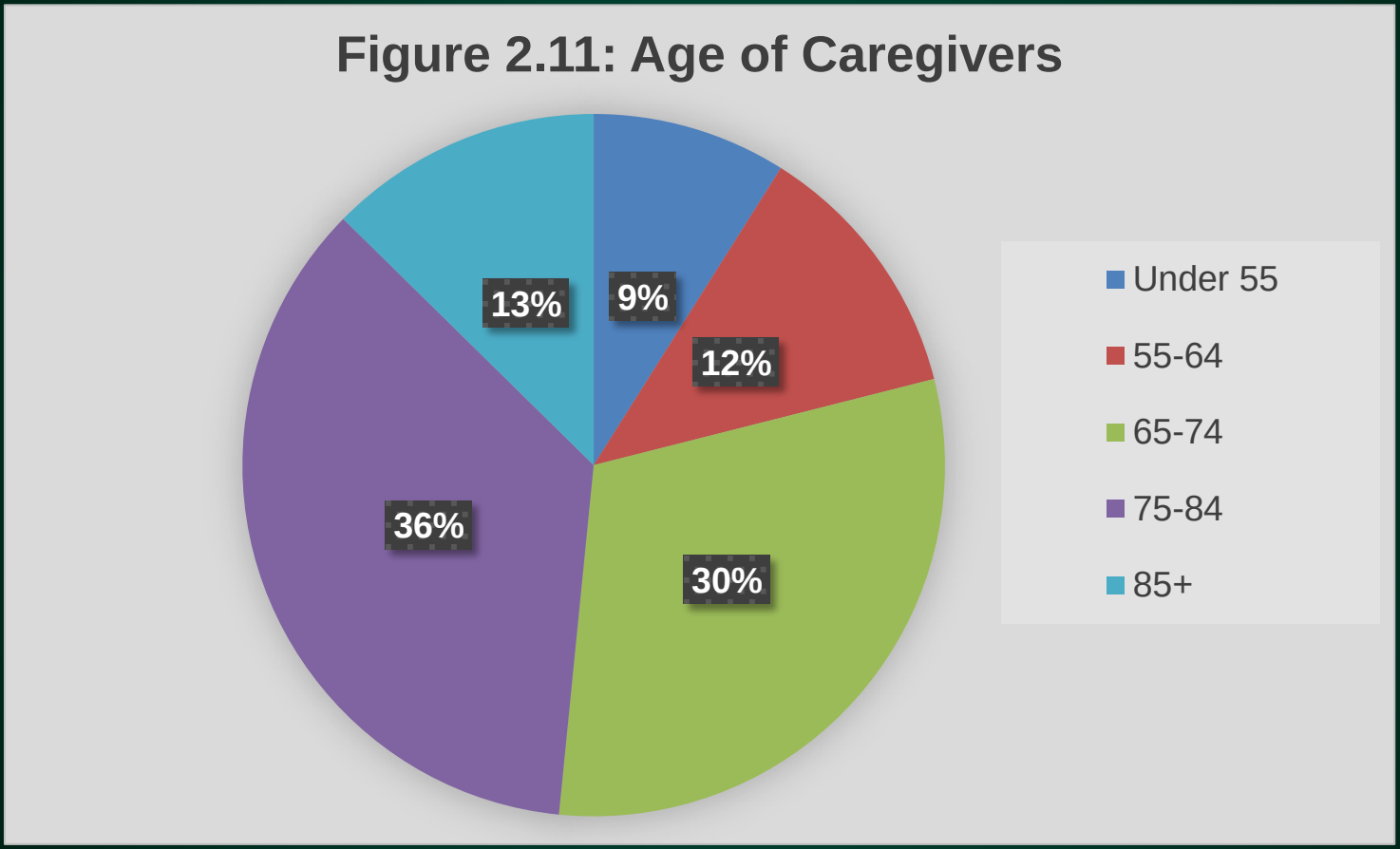
Aim 2: Caregiver's Perspective

ND Family Caregiver Support Program (2014)



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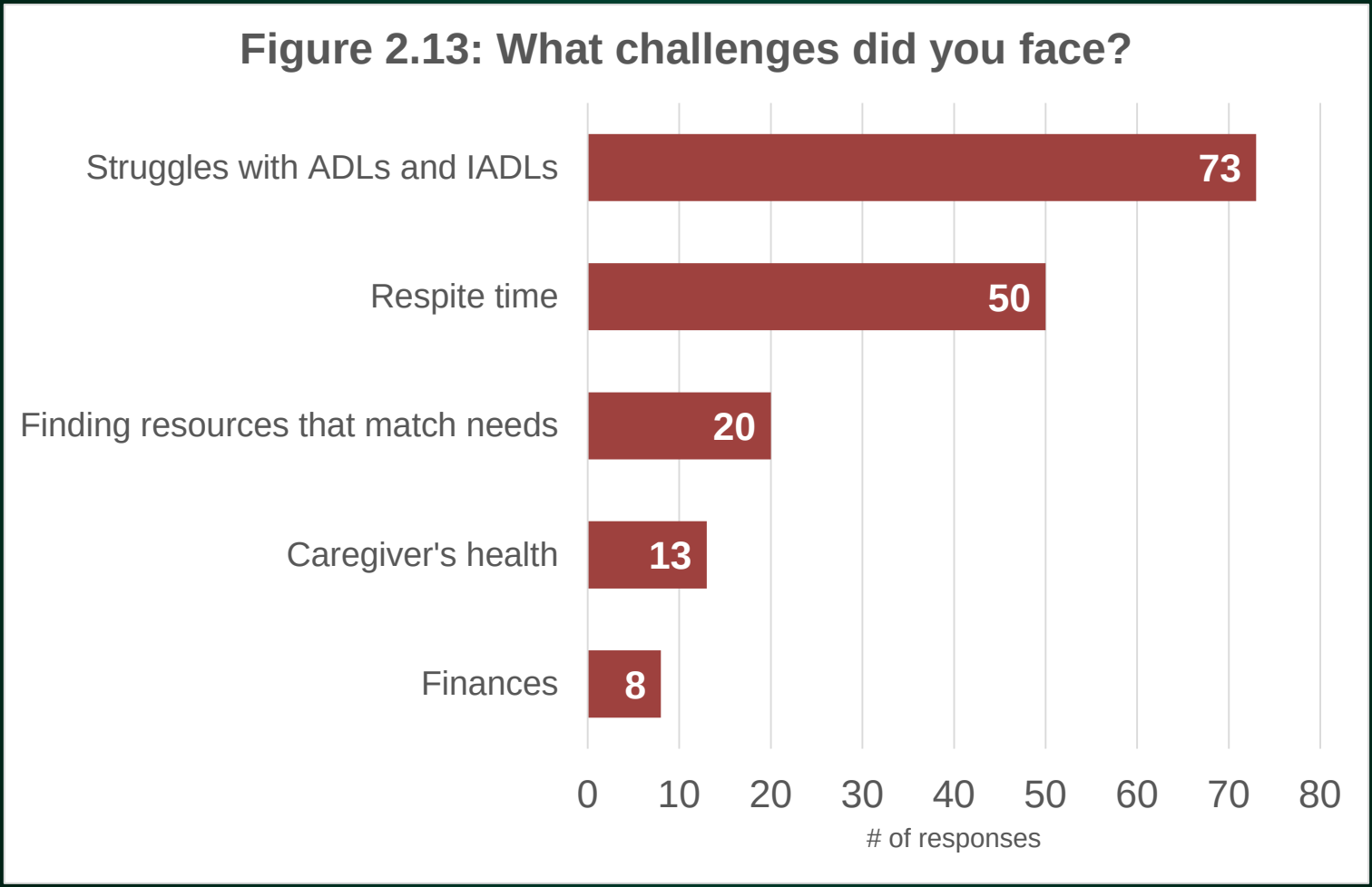
Aim 2: Caregiver's Perspective

ND Family Caregiver Support Program (2014)



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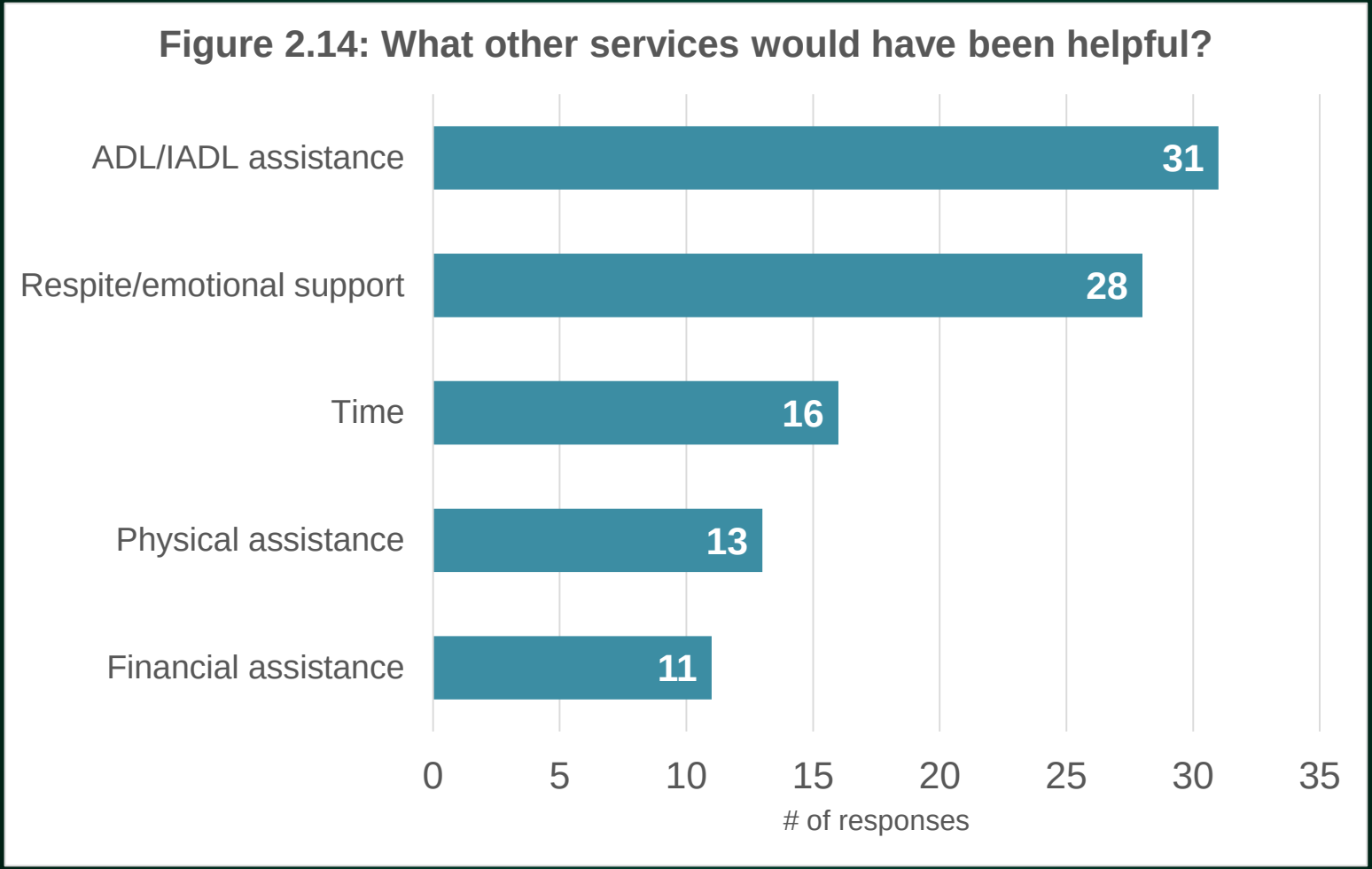
Aim 2: Caregiver's Perspective

ND Family Caregiver Support Program (2014)



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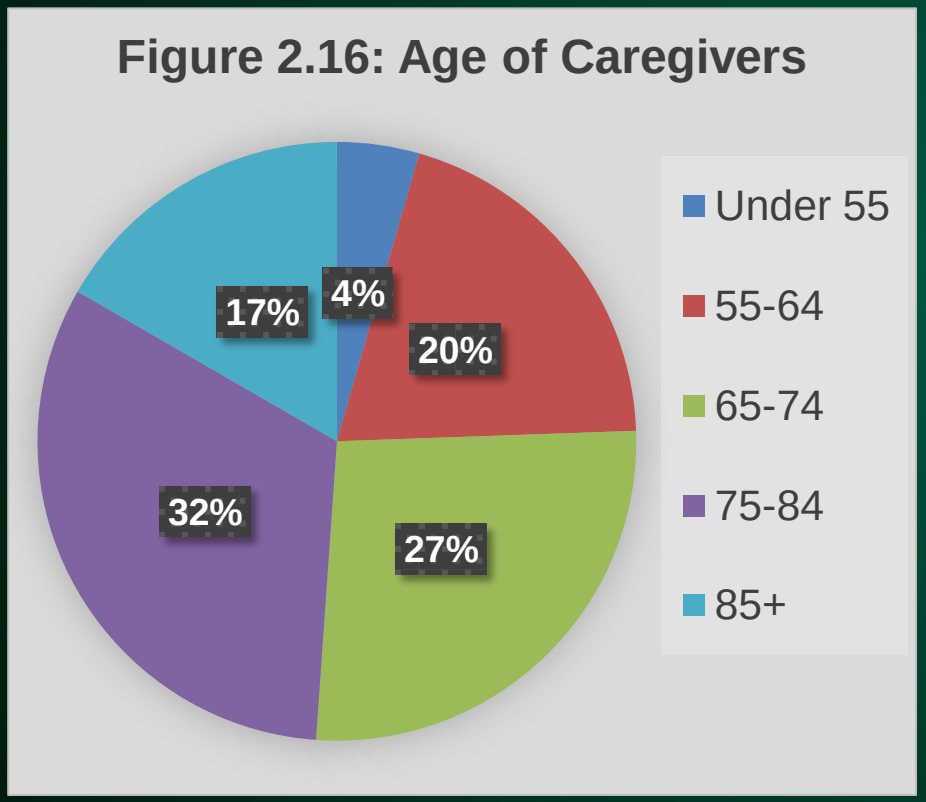
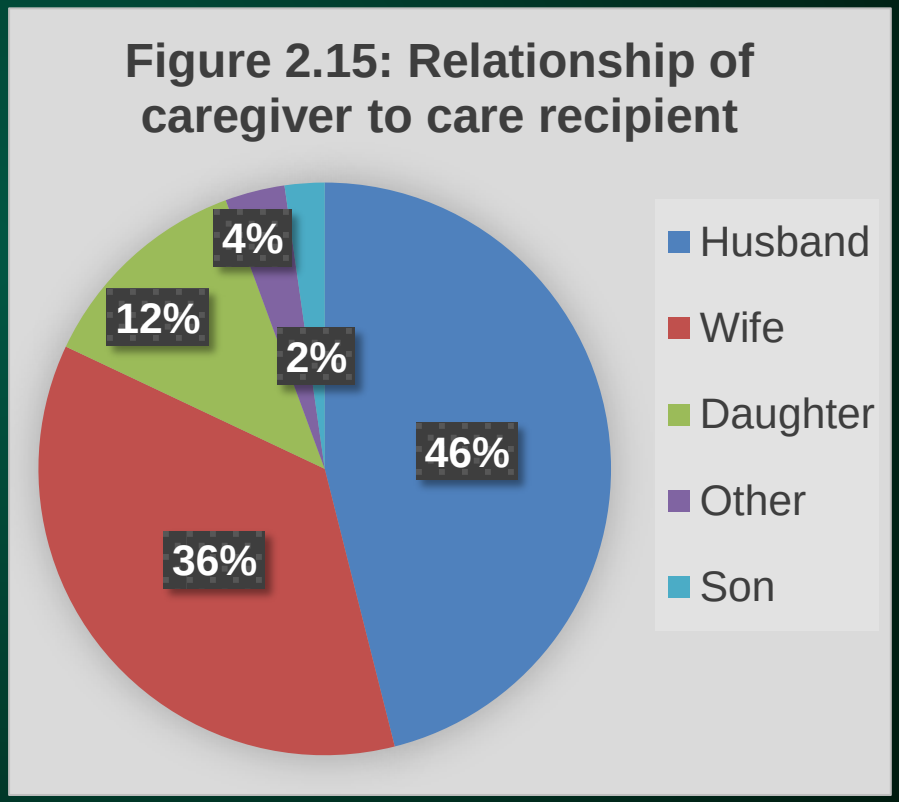
Aim 2: Caregiver's Perspective

- Data from ND Family Caregiver Support Program – Caregivers' Survey (2015)
- 92 Caregivers across ND





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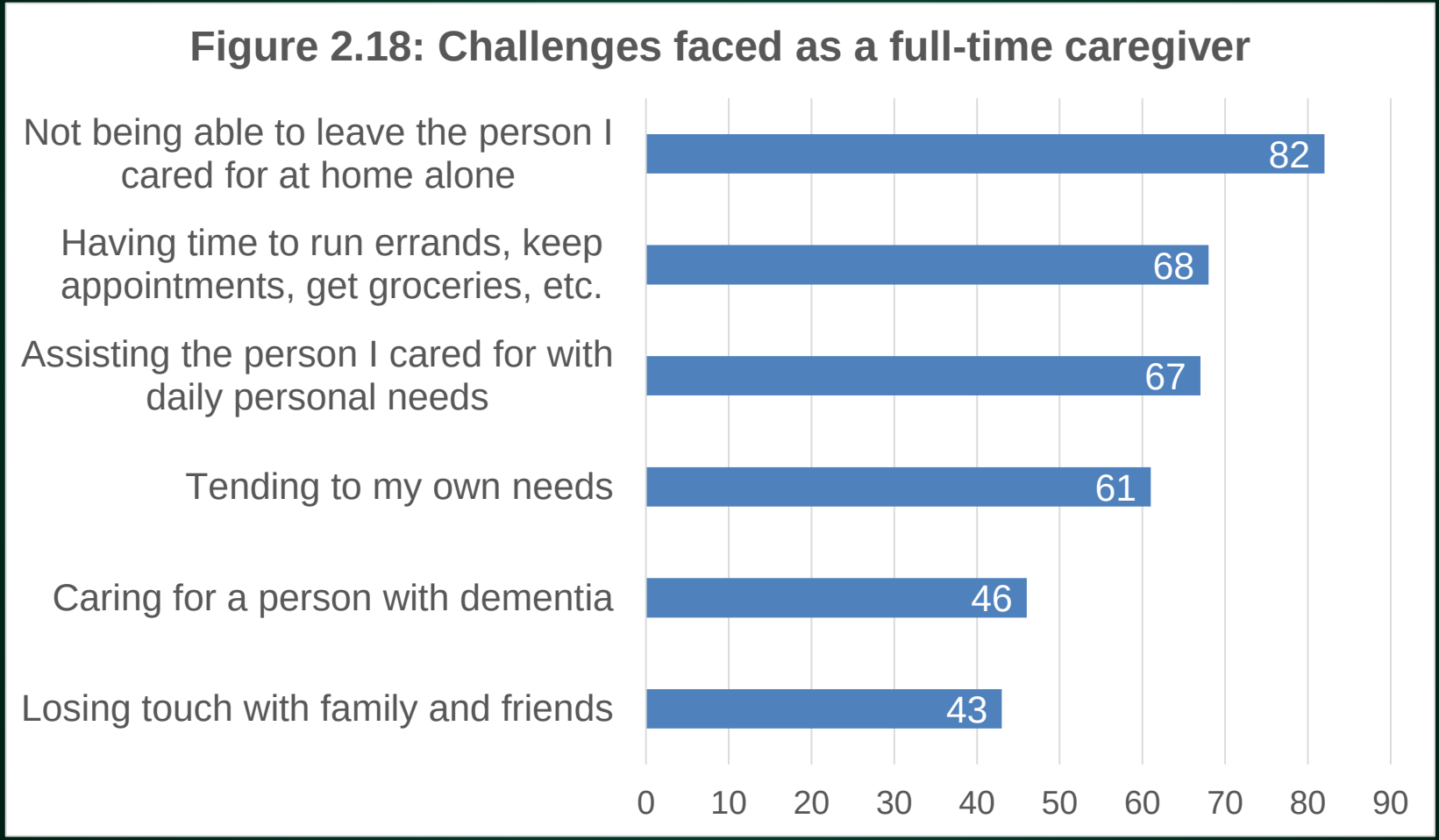
Aim 2: Caregiver's Perspective

ND Family Caregiver Support Program (2015)



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A few quotes from caregivers…

- *"It is exhausting to be a caregiver 7 days a week 24 hours a day. It is expensive to hire help and there is no time for yourself. You feel like you have no life."*

- *"The variety of care options and funding is confusing to anyone not educated in the "system". Even though social workers do a good job of providing information, it is still an overwhelming tasks to make decisions and find financial resources to deal with someone needing care."*

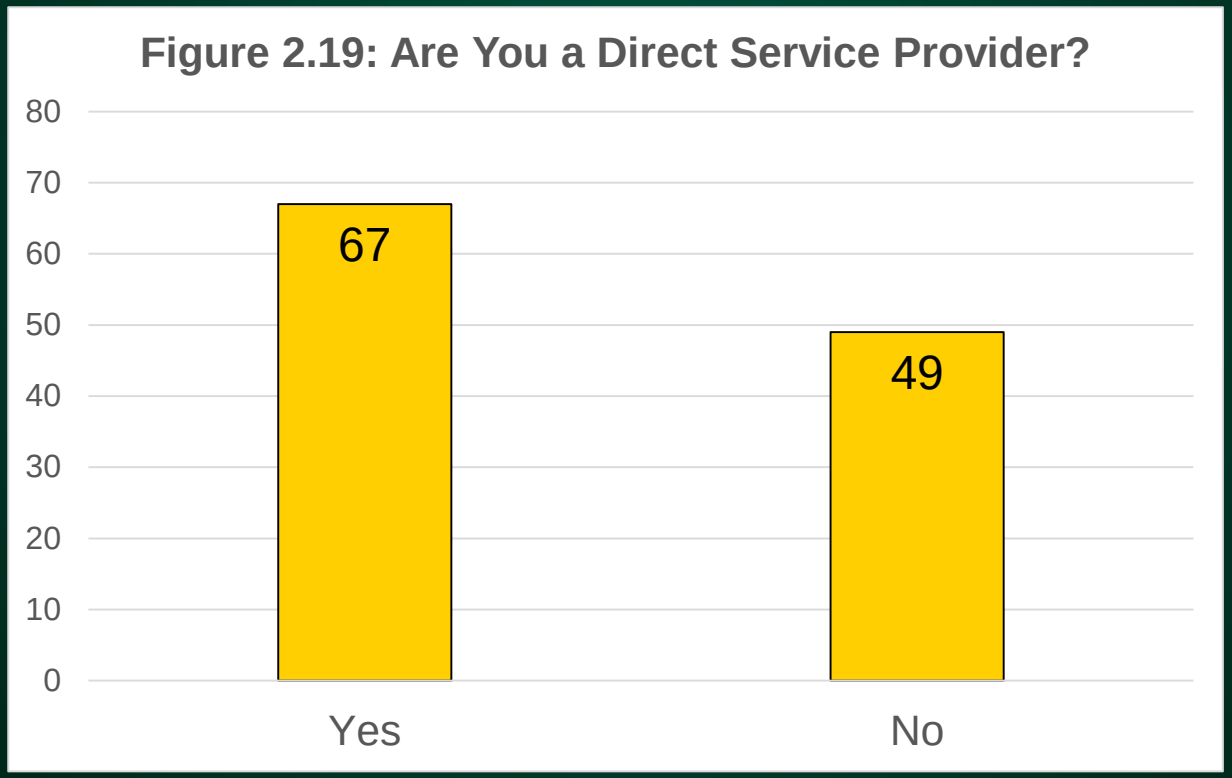
- *"The shortage of short-term medical care and home health nurses led my family member to an expensive facility rather than allowing him to remain in his apartment."*

Aim 2: Stakeholder's Perspective

- Phase B. Stakeholders Survey (NDSU, 2016)
  - Survey stakeholders across ND (online and interview)
  - Types of questions asked:
    - Challenges faced by caregivers and organizations providing services & supports
    - Barriers to using caregiver services & supports
    - Ways to improve services & supports for family caregivers
    - Initiatives or policies to improve experiences of family caregivers

Aim 2: Stakeholder's Perspective

- Stakeholders Survey (NDSU, 2016)
- 116 respondents



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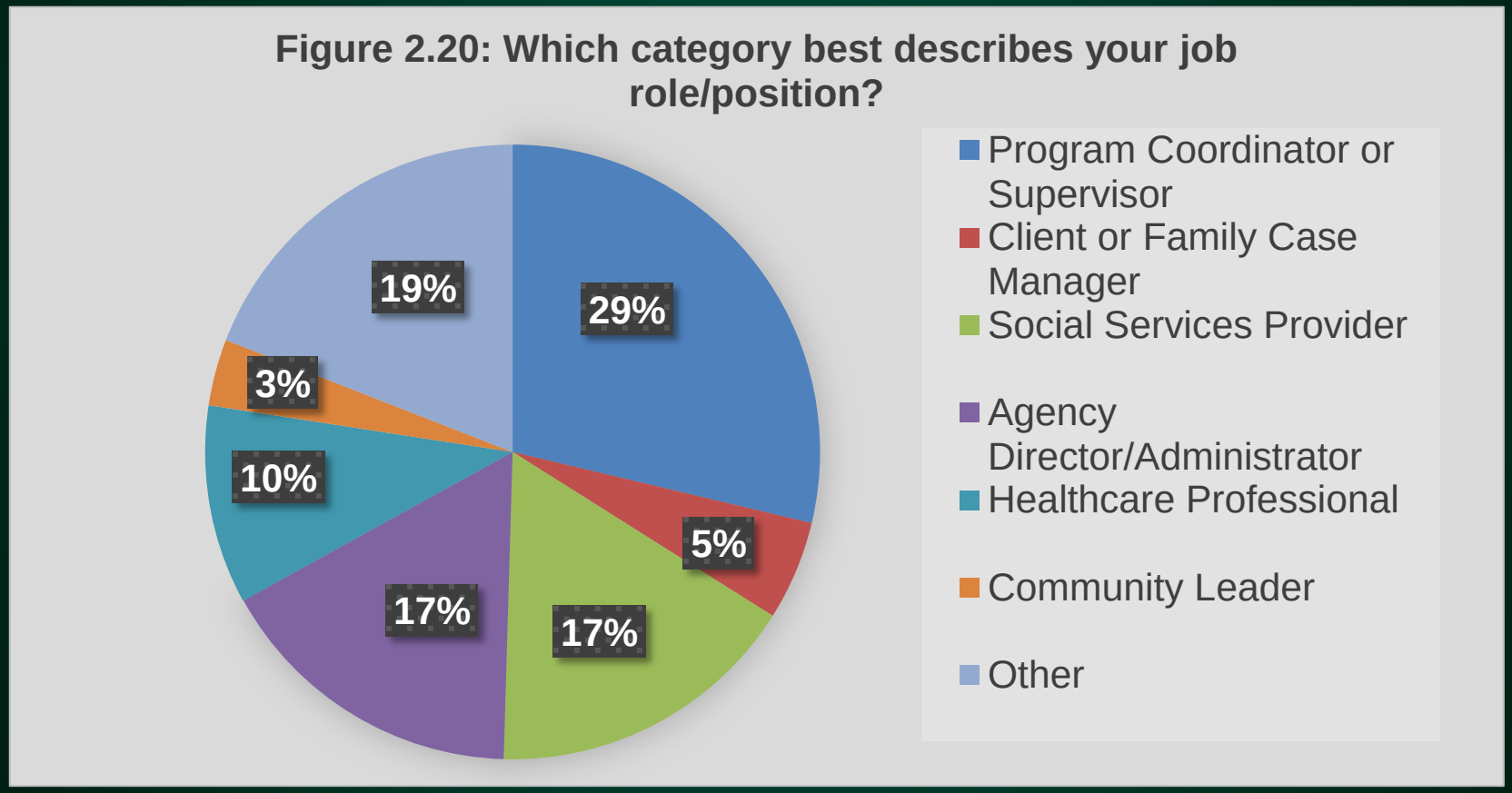
Aim 2: Stakeholder's Perspective

Stakeholders Survey (NDSU, 2016)



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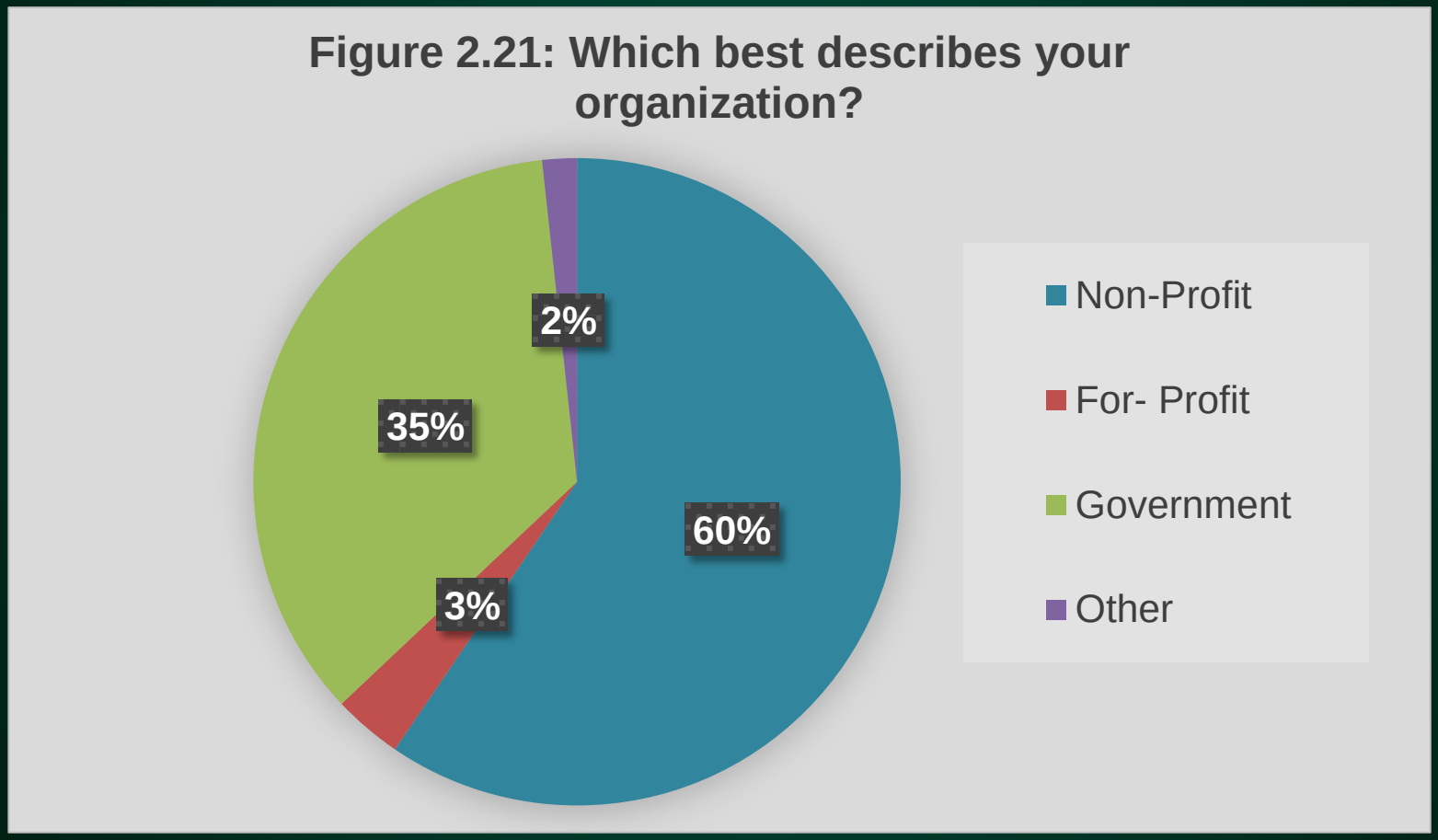
Aim 2: Stakeholder's Perspective

Stakeholders Survey (NDSU, 2016)



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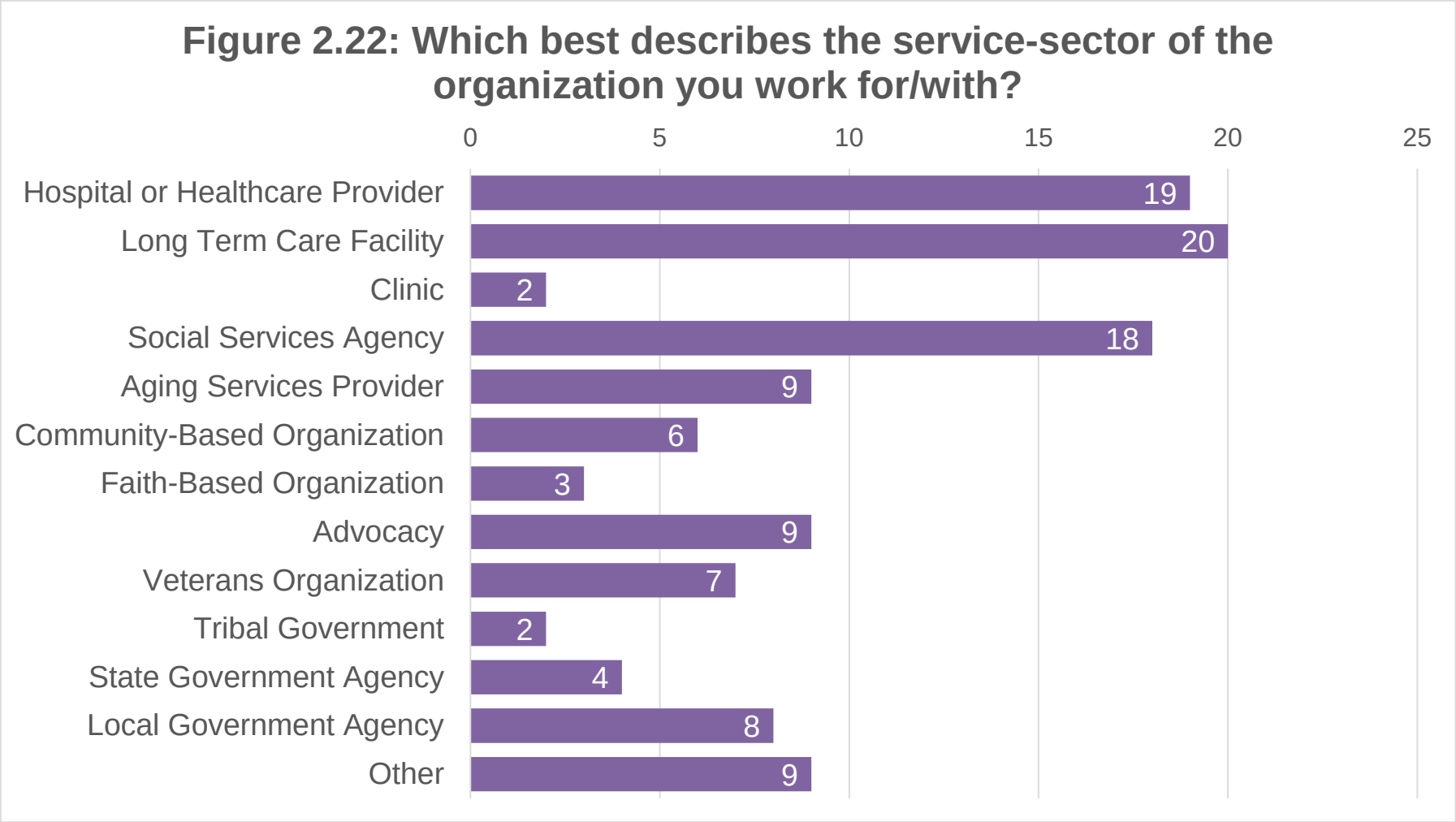
Aim 2: Stakeholder's Perspective

Stakeholders Survey (NDSU, 2016)



Aim 2: Stakeholder's Perspective

Challenges that family caregivers face

	Percent Agree or Strongly Agree
Insufficient income/funds	88%
Needed services not offered	71%
Lack of knowledge / training	73%
Unsupportive workplace policies	65%
Lack of help from family/friends	74%
Poor work/life balance	92%
Lack of community awareness / support	86%

Aim 2: Stakeholder's Perspective

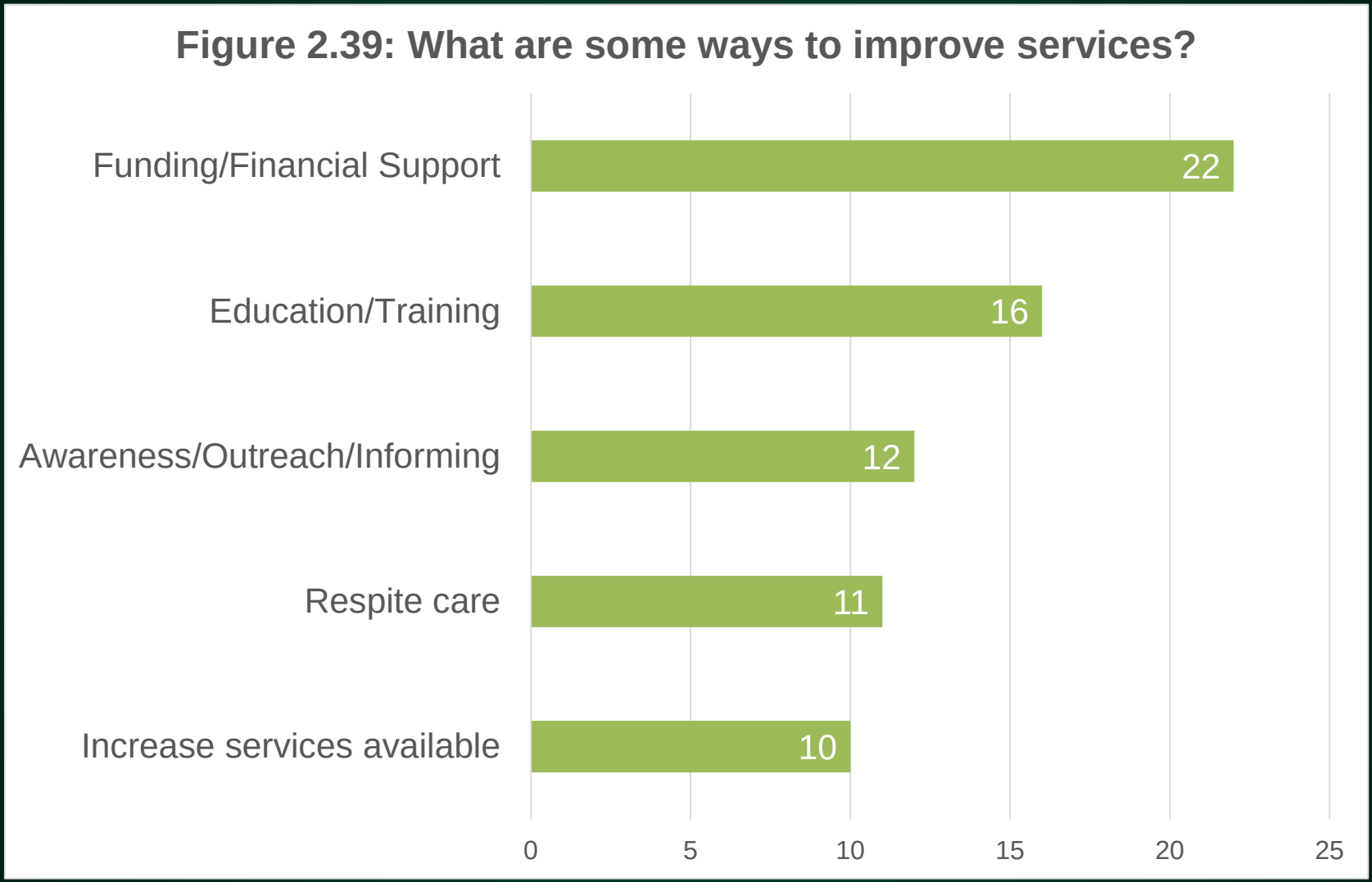
Barriers to the use of Family Caregiver Services

	Percent Agree or Strongly Agree
Caregivers reluctant to accept help	62%
Caregivers not interested in services	22%
Caregivers unaware of services	90%
Schedules of services	85%
Locations of services	87%
Workforce shortage	95%
Restrictive eligibility criteria	79%
Agencies lack funding	90%

Aim 2: Stakeholder's Perspective

Challenges faced by family caregivers		Unmet needs of family caregivers		Challenges facing organizations	
Financial costs of care	50	Lack of Support	44	Lack of available / compatible services	85
Difficulty connecting to / navigating services	49	Respite	38	Financial costs of programming	62
Lack of compatible services	41	Financial costs of care	38	Connecting to services	34
Respite	30	Education and training	31	Issues with policies and regulations	22
Work/life balance	24	Transportation	18	Location	15
Lack of Support	24	Difficulty connecting to / navigating services	14	Time	4
Location (rurality)	20	Location (rurality)	7		
Education and Training	16	Safety	3		
Caregiver's Well-being	11	Work/life balance	2		
Time	5				
Safety	3				

Aim 2: Stakeholder's Perspective



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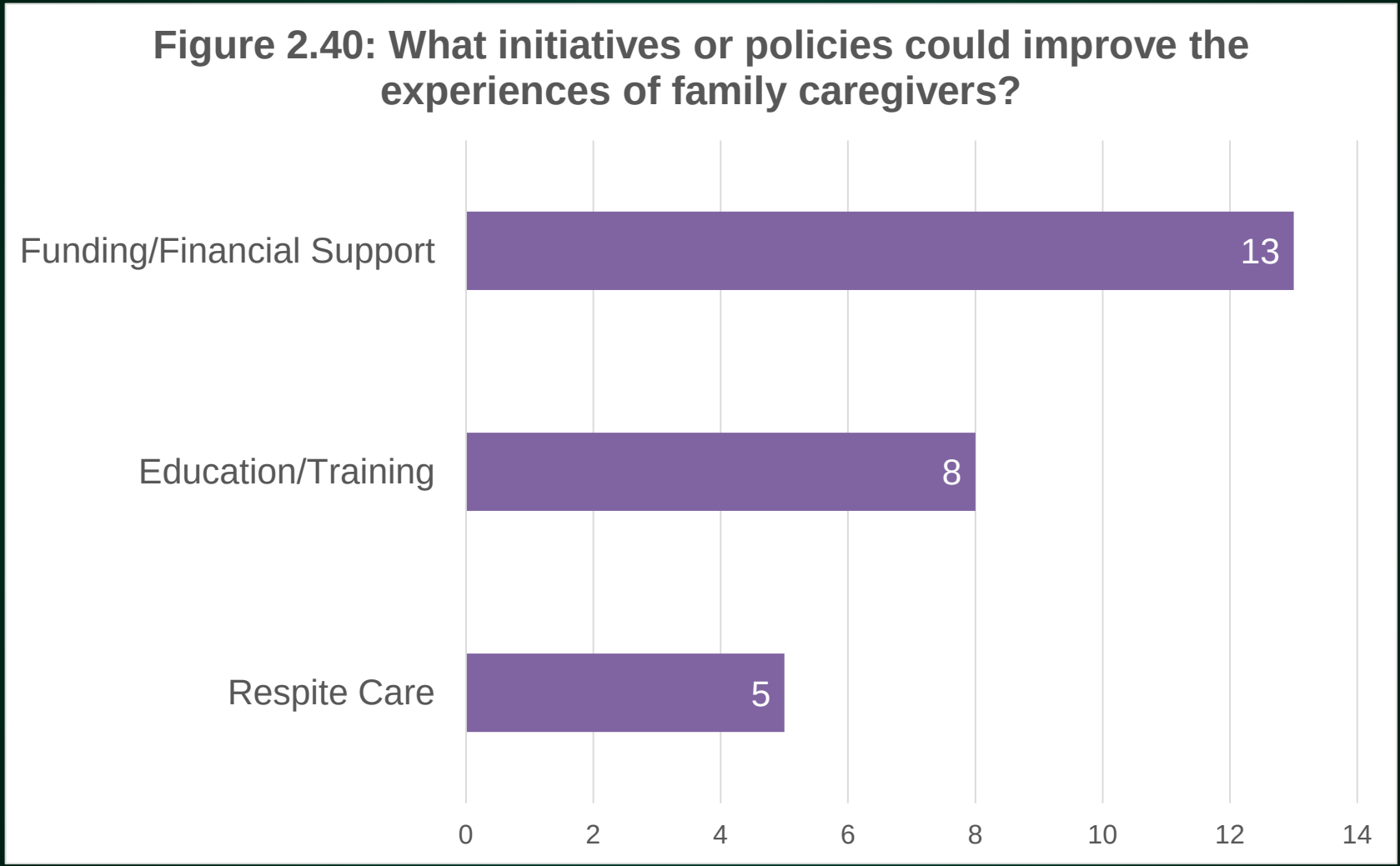
Aim 2: Stakeholder's Perspective



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A few quotes from stakeholders…

- *"People don't know about services that are available until they need them and then they feel overwhelmed and don't know where to start."*

- *"Policies written too restrictively to provide adequate and realistic needed services to people in a variety of communities, sizes, and settings"*

- *"Education to family members before they need help—I am not sure how this would occur but I often hear from family members that they were unprepared for this role or never expected it to be so difficult. Many also do not realize that they are not alone—so many family members are experiencing the same thing."*

Aim 2: Stakeholder's Perspective

Unique needs of Veterans and American Indians:

- **Veterans' groups:** have special needs related to coordinated services with the VA, particularly challenging in rural North Dakota.

- **American Indian Tribes:** coordinating services between Tribal and state programs is a challenge. Special consideration needs to be made to support family caregivers in a culturally sensitive way.

Family Caregiver Study Objectives

- Aim 3. **Identify best practice models for family caregiver support programs from other states.**
  - Extensive review of research literature and practice sites

Aim 3 : Availability of Help

- Telephone-based psycho-educational interventions
- Virtual care
- Community nurses

Telephone-based psycho-educational interventions have been proven to provide relief from caregiver burden, distress, and depression while allowing caregivers to remain in their homes. (Davis, Burgio, Buckwalter, et al., 2004).

Aim 3: Cost / Finances

- Sliding scales and vouchers
- Increasing access to paid family medical leave
- Long-term care planning

Coleman (2000) recommended using sliding scales for services for those whose income exceeds Medicaid or state-funded income eligibility criteria instead of eliminating those individuals from the program. Cash allowances or vouchers could be used to purchase the type of services or supplies unique to the caregivers needs.

Aim 3 : Knowledge and Ability to Provide Needed Cares

- Interactive training (e.g. role playing)
- Comprehensive discharge planning
- Long-term education programming
- Preventative care

Using skills training, role-playing, and interactive practice were the most successful training methods in reducing caregiver burden (Lykens, Moayad, Biswas, Reyes-Ortiz, & Singh, 2014).

Aim 3: Respite / Well-being of Caregiver

- In-home care
- Health education programs

Oregon provides start-up and ongoing funds to build community networks to help families access respite care and find payment options. (Silberberg, 2001)

Family Caregiver Study Objectives

- Aim 4. **Identify emerging practices and technology that can enhance caregiver and patient home supports.**
  - Extensive review of research literature and practice sites

Aim 4: Availability of Help

- Person-centered care (i.e., Money Follows the Person)
- Mobile adult day care (i.e., especially in rural areas)
- Working with college students
- Technology (i.e., smart-homes, robotic applications, etc.)
- Socially Assistive Robots
- Smart Wear

Aim 4: Cost / Finances

- Telemedicine reduced hospitalization
- Co-op models
- Tax credits for caregiving

A study conducted in MA showed promise in reducing re-hospitalization when a telemedicine service was used in place of a traditional on-call medical professional (Grabowski and O' Malley, 2014).

Aim 4: Knowledge and Ability to Provide Needed Cares

- Home visits upon discharge
- Virtual learning modules in hospital waiting rooms
- Use social media to increase awareness
- Trainings for employers about eldercare
- Mobile apps for long distance care

Aim 4: Respite / Well-being of Caregiver

- Respite provided by volunteers
- Online emotional support groups
- Employ Behavioral Risk Factor Surveillance System's Caregiver module to detect caregiver burden

Aims 3 & 4: Challenges

Challenges	
Logistics and Implementation	Limitations and Caveats
• Balancing the needs of care recipient and caregiver • Increasing costs • Staffing shortage • Rurality	• Budget Cuts • Lack of flexibility in federal programs (i.e. Medicare) • Lack time to learn and implement technologies

Aims 3 & 4: Caregiver Best and Emerging Practices Conclusions

- **Service coordination and collaboration is key**

- **Technology offers opportunities**

Autonomous vehicles may be used to deliver caregivers to appointments without the need of volunteer or caregiver drivers (Delaware Family Caregiving Taskforce, 2015).

- **Training is critical**

Doody et al (2001) --short-term education programs have little impact. Longer-term, intensive education improved caregiver health ratings and delayed nursing home placement of the elder by a year or more.

Family Caregiver Study Objectives

Aim 5: **Provide recommendations.**

- Synthesize information gathered in Aims 1-4
- Provide recommendations for best practices for community and technology supports, policy needs, and top priorities for family caregiver supports and services.

Aim 5

- **Improve avenues for sustainable funding for family caregivers and programs that support them.**
  - **To help working caregivers:**
    - tax credits for private sector employers who offer a 12-week paid family medical leave.
    - requirements of Family & Medical Leave Act (FMLA)
  - **To improve funding for programs and caregivers:**
    - proposed budget cuts to Homemaker Services
    - sliding fee scale for Service Payments for the Elderly & Disabled (SPED)
  - **To encourage private financial responsibility:**
    - long-term care education and tax credit expansion

Aim 5

- **Increase access to respite care across the state.**
  - **By fostering collaborative statewide efforts:**
    - federal grant from the Lifespan Respite Care Program
  - **By increasing availability:**
    - training college students (i.e., nursing, social work students) and volunteers to give family caregivers a break
  - **By increasing awareness:**
    - fully utilizing Family Caregiver Support Program (FCSP)
    - directory of local respite care available to family caregivers

Aim 5

- **Improve outreach (i.e., marketing) and resources (i.e., technology) to help family caregivers find, connect to, and navigate available services.**
  - **By promoting existing services:**
    - the Aging & Disability Resource LINK and state-wide options counseling system
  - **By creating user-friendly, easy-to-access tools:**
    - Caregiver Resource Center
    - comprehensive guide to caregiving
  - By targeting public awareness:
    - understanding of family caregiving issues by public at large

Aim 5

- **Create programs and policies to foster an increase in the training and education of both informal and professional caregivers.**
  - **By providing in-person instruction:**
    - about medical/nursing tasks that the caregiver will need to provide at home
  - **By ensuring training is available in-person and online:**
    - to meet the variety of family caregiver training needs
  - **By supporting the unique needs of caregivers:**
    - in-person and online support groups specifically for caregivers of older family members

Aim 5

- **Close the gaps in caregiver support services in rural areas.**
  - **By addressing workforce shortage:**
    - support statewide direct care workforce initiatives to increase the number of individuals interested in caregiving professions, particularly in rural areas
  - **By supporting existing services:**
    - assist county social services in rural areas to continue to provide services to eligible clients and to expand services, if possible, to private pay clients
  - **By making funding available for:**
    - pilot best practices, especially in rural areas (e.g. mobile adult day care, volunteer respite & innovative technologies)

Overarching Recommendations

- Develop family caregiving taskforce consisting of caregivers, service providers, and community leaders

- Explore ways to lift restrictive eligibility criteria and cut the red tape, or expand funding opportunities to include those not currently financially eligible

Overarching Recommendations

- Increase availability of respite care, care management, training and education, emotional support, volunteer programs and a range of direct care supports (adult day care, homemaker/chore, and personal care)

- Improve resources to address caregiver well-being (including preventative, screening, and intervention care)

Questions?

Thank you!