



National Family Caregiver Support Program (NFCSP) Process Evaluation

Aging Network Webinar



#### Agenda

- NFCSP (Title III-E) Background
- NFCSP Evaluation Goals and Survey Topics
- NFCSP Evaluation Methodology
- State Unit on Aging (SUA), Area Agency on Aging (AAA) and Local Service Provider (LSP) Survey Highlights
  - Development and Administration
  - Targeting of Special Populations, Prioritization and Wait Listing
  - Assessments
  - Respite and Supplemental Services
  - Program Challenges
- Next Steps





#### NFCSP (Title III-E) Background

- Founded in 2000 as part of the Older Americans Act reauthorization
- Federal investment in supporting caregivers who provide care and assistance to aging adults and grandparents raising grandchildren
- Leveraging resources to support individuals who prefer to age in their own homes and communities – as opposed to institutional settings – through lower-cost, non-medical services and supports





#### NFCSP Evaluation Objectives

- Provide information to support program planning, including an analysis of program operations;
- 2. Develop information about program efficiency; and,
- 3. Assess program effectiveness in determining community and client needs, targeting and prioritizing, and providing services to family caregivers.

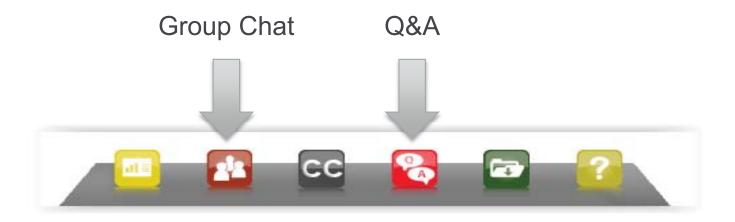
Final process evaluation report is expected to be released in Summer 2016.





#### NFCSP Webinar Housekeeping Items

- All attendees are in "listen only" mode
- Please input questions into the chat box or the Q&A
- We will compile your questions after the webinar and send responses to all attendees







#### **NFCSP Process Evaluation Team**



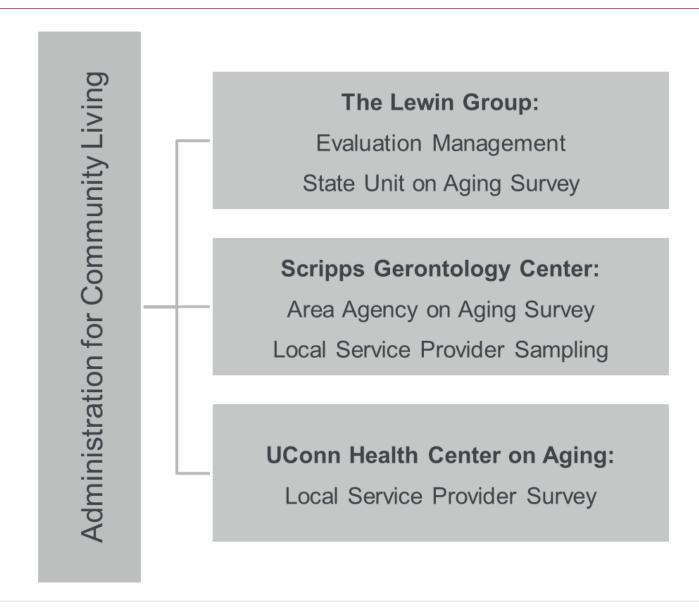








#### **NFCSP Process Evaluation Roles**







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### Methodology





#### Survey Methodology

- Survey Development and Outreach:
  - Developed a comprehensive internet survey to address ACL needs
  - Covered a range of topics

Survey	Sampled	Dates	Response rate
SUA	All 54	Jan-May 2015	100%
AAA	All 619	Jan-July 2015	73%
LSP	579 sampled from all responding AAAs	Aug-Dec 2015	68%





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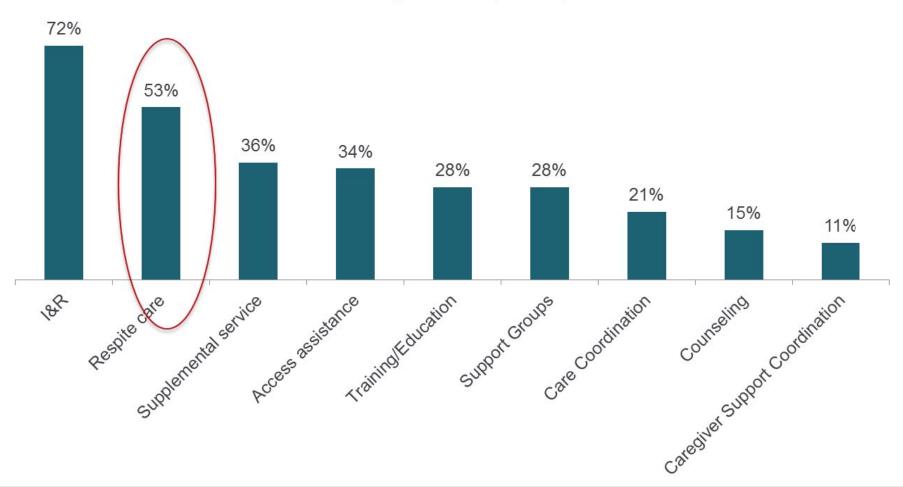
### Remarkable Findings





#### Remarkable Findings: SUA Survey

# Prior to the establishment of NFCSP in your SUA, which of the following services did your SUA offer to caregivers? (n=53)

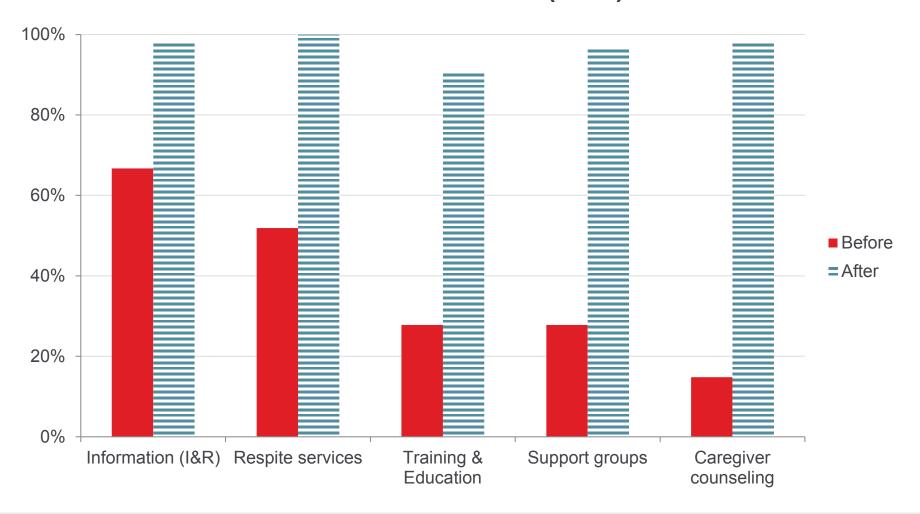






#### Remarkable Findings: SUA Survey

# SUA Changes in Service Offerings Before and After Enactment of the OAA NFCSP in 2000 (n=54)







#### Remarkable Findings: SUA Survey

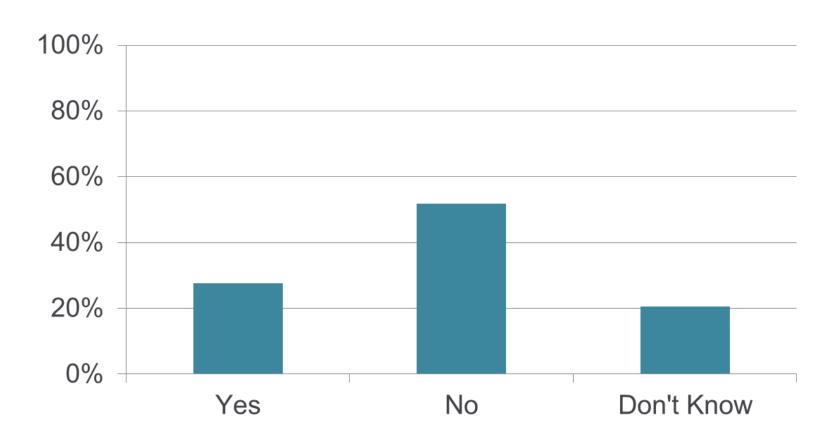
 Over two-thirds (68%) of SUA respondents reported that the NFCSP resulted in the creation of standardized eligibility criteria for caregiver services





#### Remarkable Findings: AAA Survey

# Did your AAA have a caregiver program (a set of services specifically for caregivers) prior to the enactment of the OAA NFCSP in 2000? (n=446)

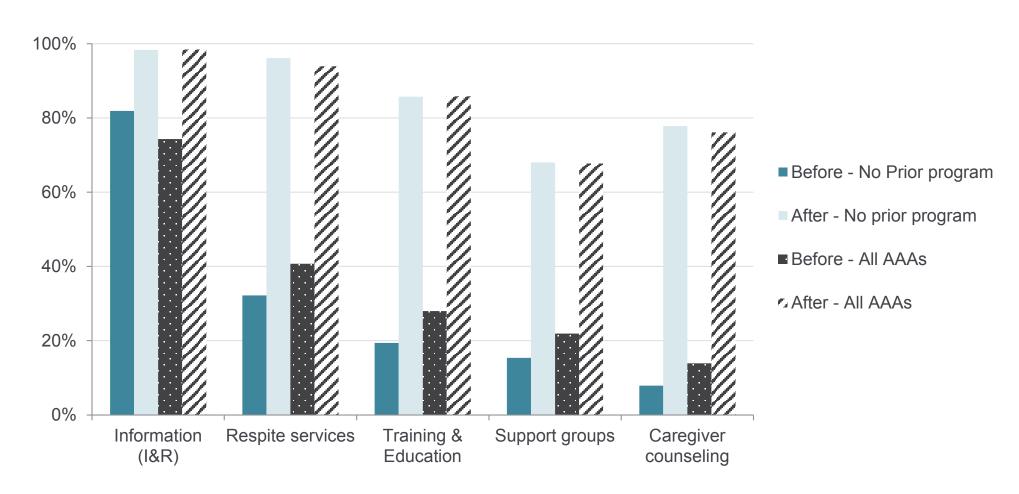






#### Remarkable Findings: AAA Survey

## Changes in Service Offerings Before and After Enactment of the OAA NFCSP in 2000 for AAAs (n=446)

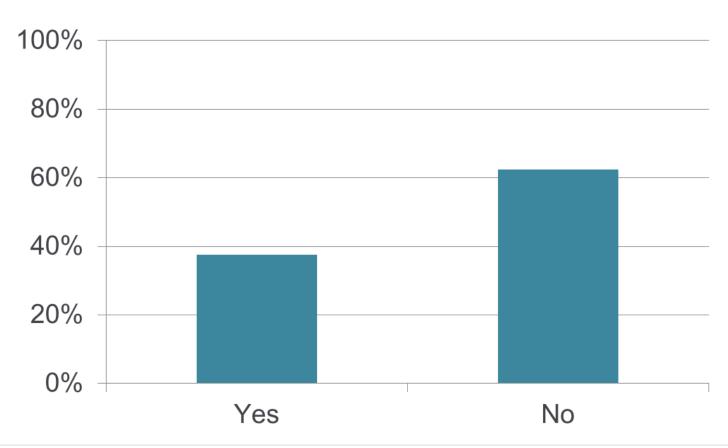






#### Remarkable Findings: AAA Survey

Are you aware of organizations or individuals in your PSA that provide caregiver services such as respite, counseling and support, information and assistance or supplemental services with funds other than the OAA/NFCSP? (n=408)







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### State Unit on Aging (SUA) Survey





#### SUA Survey: Partnerships

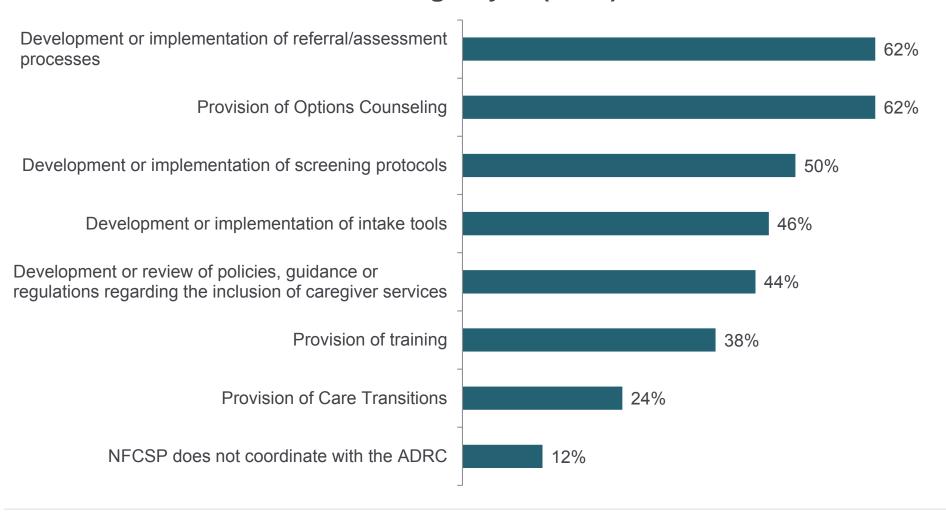
- Nine are working with other State agencies to implement NFCSP
  - Four are working with departments of health services
  - Three are working with departments of social services
  - Three are working with Medicaid departments
  - Two are coordinating and collaborating with departments of family services, especially for services to grandparents caring for grandchildren
- Other partners include Lifespan Respite, State Councils on Developmental Disabilities, university extension services, Veterans Affairs, mental health departments, and Centers for Independent Living





#### SUA Survey: Aging and Disability Resource Center (ADRC) Coordination

### Has the NFCSP coordinated with ADRCs in any of the following ways? (n=50)



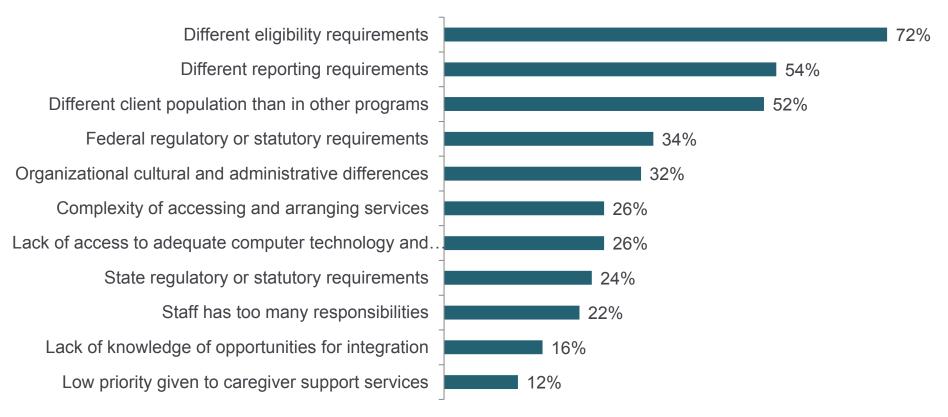




# SUA Survey: Barriers limiting integration of NFCSP with other HCBS programs

 31% of responding SUAs said there has been an effort at the state level to use the same caregiver and care recipient assessment tools across all HCBS programs

What are the major barriers limiting/preventing integration of NFCSP with other home and community-based programs in your state? (n=50)







#### SUA Survey: Selection of Special Training Topics

- 52% of SUAs reported specific training about program data collection and reporting
- 44% reported training on Alzheimer's disease or a related disorder
- 43% reported training focused on caregiver assessment
- 30% of SUAs reported training about grandparents raising grandchildren
- 26% reported this focused on caregiver health and well-being





#### SUA Survey: NFCSP Target Populations

Since program implementation, which special populations of caregivers, if any, has your program made a specific effort to serve? (n=54)

Caregivers of persons with Alzheimer's disease or a related 84% disorder with neurological and organic brain dysfunction Grandparents raising grandchildren and other relative 82% caregivers Rural caregivers 67% Racially and ethnically diverse caregivers 63% Caregivers, Older (age 70+) 49% Employed family caregivers 31% Caregivers of veterans 31% Caregivers, Younger (age 18-25) 14%





#### SUA Survey: NFCSP Targeting Activities

# Since program implementation began, which of the following activities has your program undertaken to address those special populations of caregivers? (n=46)

Targeted marketing and outreach campaigns

Translated or adapted materials in languages other than English

Hired staff or obtained volunteers with specialized knowledge of or skills working with special populations of caregivers

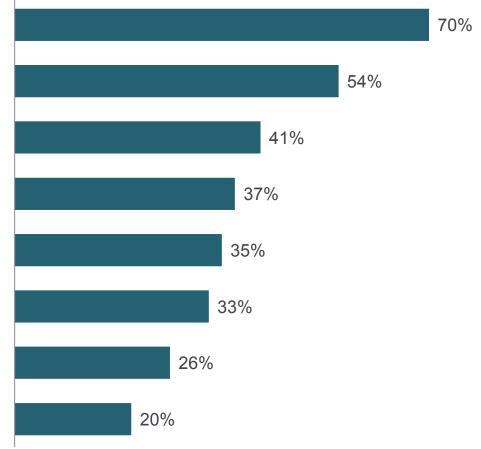
Developed partnerships with VA systems

Developed services to meet specialized needs (e.g., mobile adult day services and mobile I&R units for rural caregivers)

Produced culturally specific and appropriate materials

Developed partnerships with schools

Developed partnerships with employers







#### SUA Survey: Criteria for Determining NFCSP Service Priority

44 SUAs reported using criteria for service prioritization

- 68% indicated a diagnosis of Alzheimer's disease or a related disorder with neurological and organic brain dysfunction
- 57% indicated an ADL or IADL impairment minimum or both
- 50% indicated low income level





#### SUA Survey: Standardized Processes for Caregiver Assessments

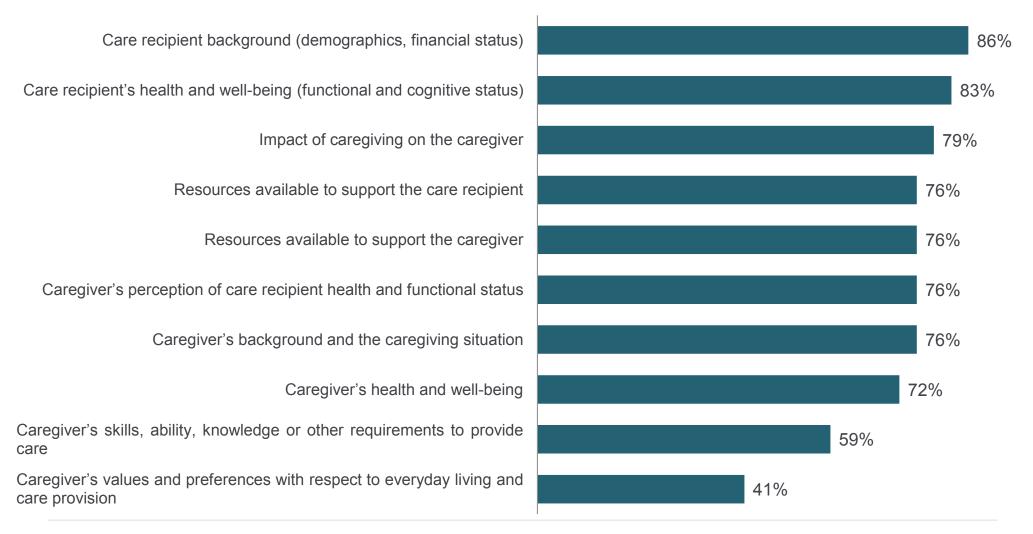
- Most SUAs (59%) reported a standardized process for assessing caregiver needs
  - 70% of these SUAs reported using this process for all family caregiver program clients, and the remaining 30% reported only using the process for specific services
- 41% of SUAs reported not having a standardized process for assessing caregivers





#### SUA Survey: NFCSP Caregiver Assessment Domains

### Which of the following domains are included in your standardized caregiver assessment? (n=29)

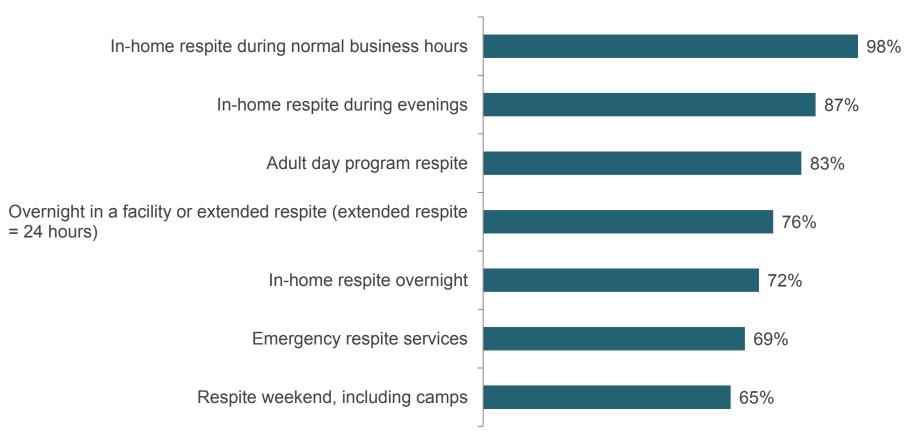






#### SUA Survey: Respite Services

Please check all of the following services that your family caregiver support program provides specifically to family caregivers (directly through the AAA or local service providers) regarding respite services. (n=54)

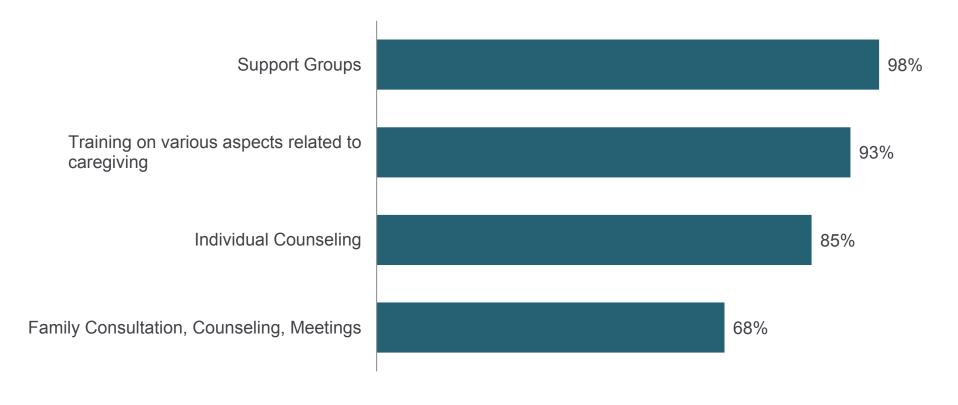






#### SUA Survey: Counseling, Training & Education Services

Please check all of the following services that your family caregiver support program provides specifically to family caregivers (directly through the AAA or local service providers) regarding counseling, education and training. (n=53)

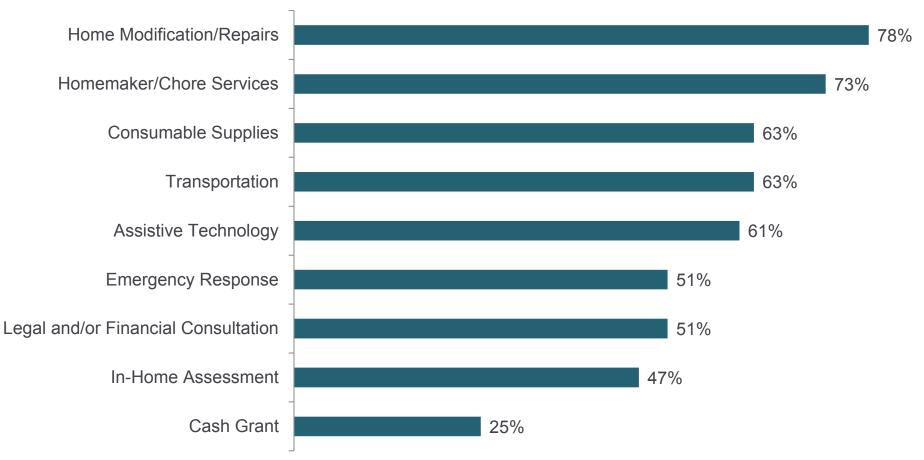






#### SUA Survey: Supplemental Services

Please check all of the following services that your family caregiver support program provides specifically to family caregivers (directly through the AAA or local service providers) regarding supplemental services. (n=51)







## SUA Survey: Supplemental Services for Grandparents Raising Grandchildren

Responses were more diverse than those for caregivers of older adults but covered many of the same responses

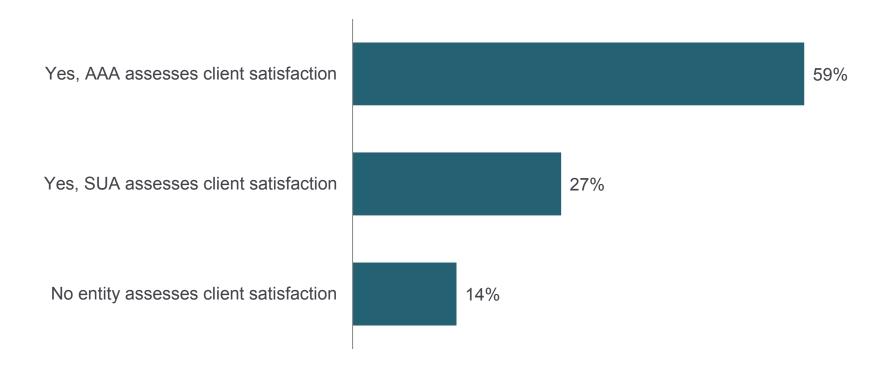
- Material supplies were the most common responses including: school supplies (8) and children's clothing (5)
- Home modifications (3) and material aid (7) were also common responses
- Respite (6) was the most common non-goods based services





#### SUA Survey: Monitoring Program Performance

#### Does your SUA assess client satisfaction? (n=44)







#### SUA Survey: Family Caregiver Program Challenges

- Significant issues over the next year
  - Increasing demand from a growing population
  - Limited or decreased funding
  - Provider availability in rural areas
- Significant issues over the next three to five years
  - Same as above
  - Shortage of caregivers
  - Increasing costs of providing services
  - Increasing complexity of care needs for an aging population
  - AAA staffing shortages





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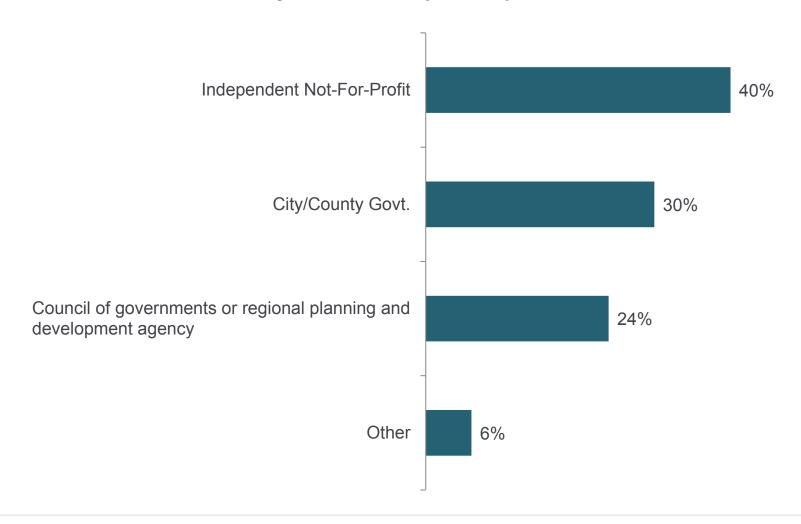
### Area Agency on Aging (AAA) Survey





#### AAA Survey: Governance

# Which of the following best describes the governance of your AAA? (n=453)

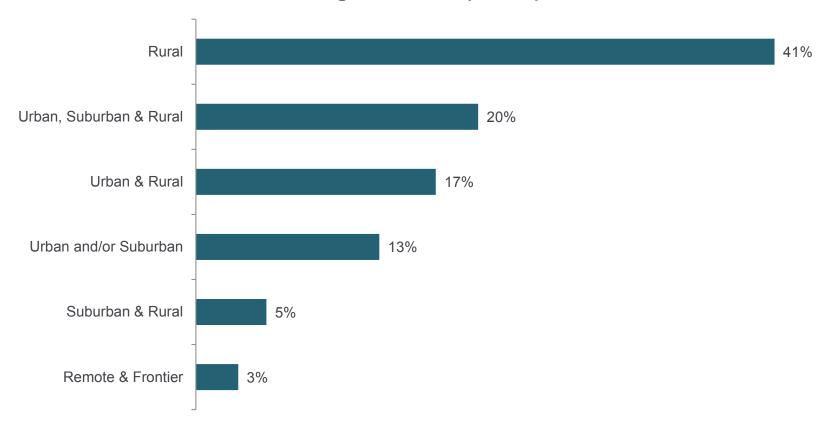






#### AAA Survey: Areas Served

### Which of the following best describes the area served by your organization? (n=457)

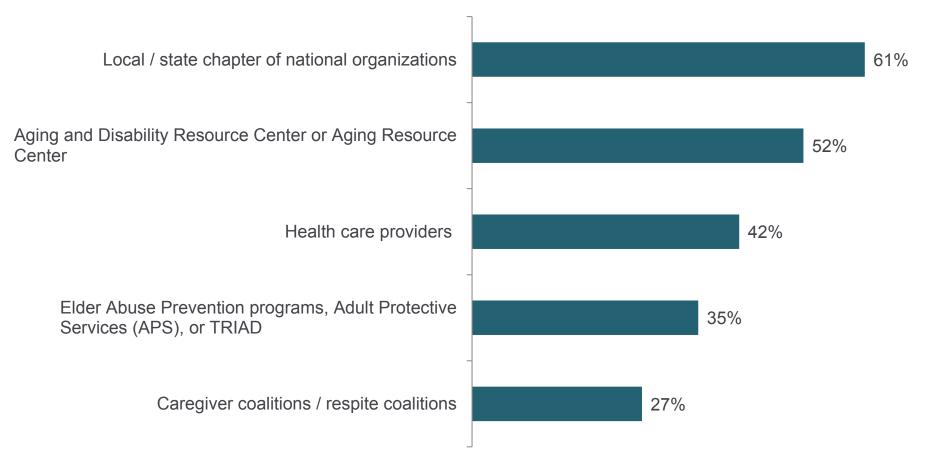






#### AAA Survey: Important Partners in Caregiving

# Please mark up to three of your most important partners specifically for administering program (n=409)







### AAA Survey: Caregiver Program Employees

- Most (82.7%) have a dedicated caregiver program manager
- Most (85.4%) say that position includes other duties or focus areas

### FTEs by AAA Budget Size

AAA Size	Mean	Range
> \$5.7 million	4.3	.05-60
\$2.2-5.7 million	1.9	.04-13
< \$2.2 million	1.7	.1-9.3



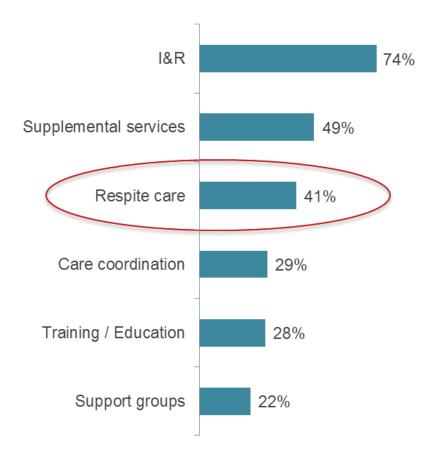


### AAA Survey: Prior to NFCSP

### Prior to NFCSP:

- 28% had caregiver programs
- 20% with paid program manager established position 2000 or earlier
- 51% didn't have policy for caregivers as clients

### Top Services Prior to NFCSP (n=438)

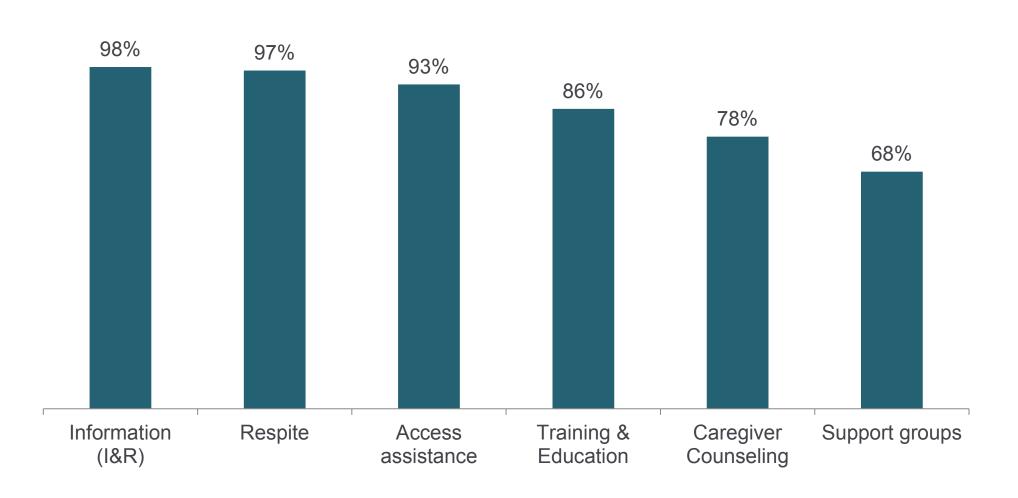






### AAA Survey: NFCSP Services in AAAs

### NFCSP Services Offered by AAAs (n=448)







### AAA Survey: NFCSP Implementation

- 88% of AAAs have policies or standardized eligibility criteria that defines caregivers as clients
- 71% of caregivers being served by AAA NFCSPs are also eligible to receive caregiver support from other state- and locally-funded programs, such as state respite programs





### AAA Survey: Targeted Populations

### Since program implementation, which special populations of caregivers, if any, has your program made a specific effort to serve? (n=443)

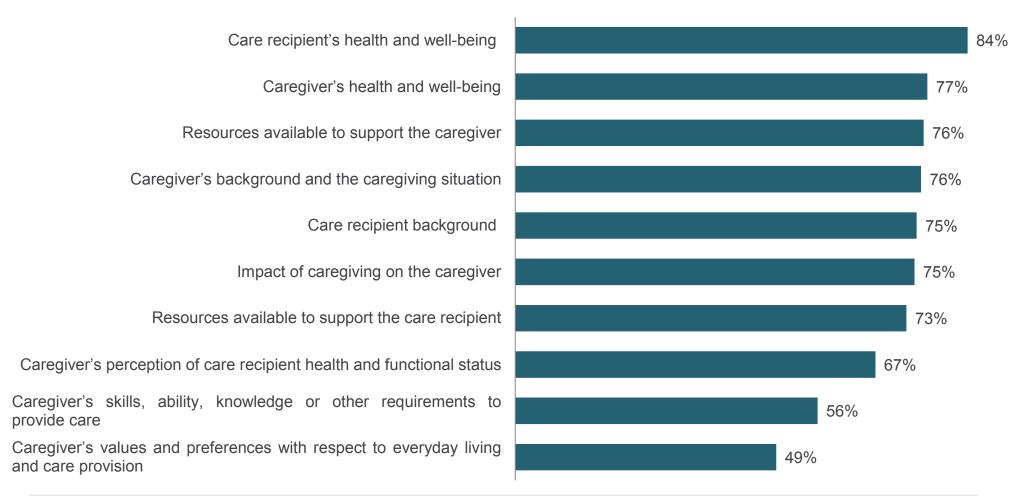
Caregivers of persons with Alzheimer's disease or a related 63% disorder Grandparents raising grandchildren and other relative 49% caregivers Rural caregivers 46% Older Caregivers (age 70+) 43% Racially and ethnically diverse caregivers 35% Caregivers of veterans 29% Employed family caregivers 28% Younger Caregivers (under age 25) 7%





### AAA Survey: Domains of Standardized Assessment

# Which of the following areas are included in your AAA's individual-level needs assessment? (n=411)

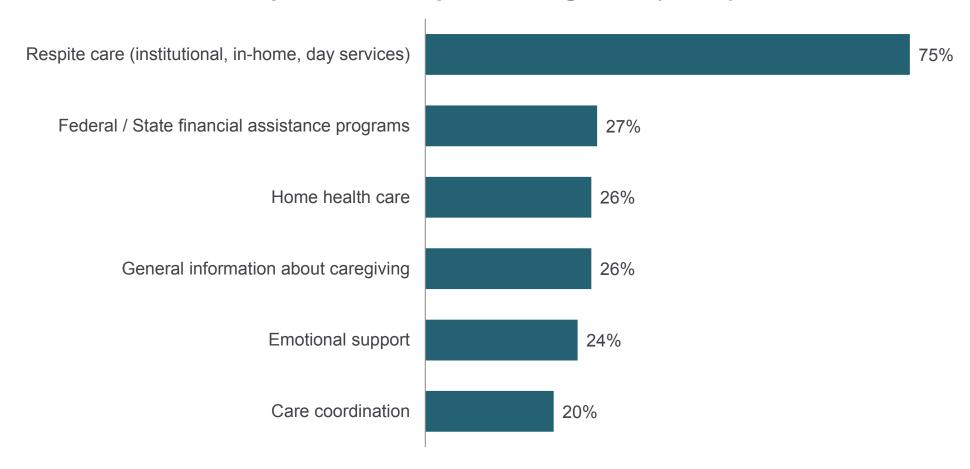






### AAA Survey: Caregiver Service Requests

### What are the types of services or information most frequently requested on the part of caregivers? (n=434)

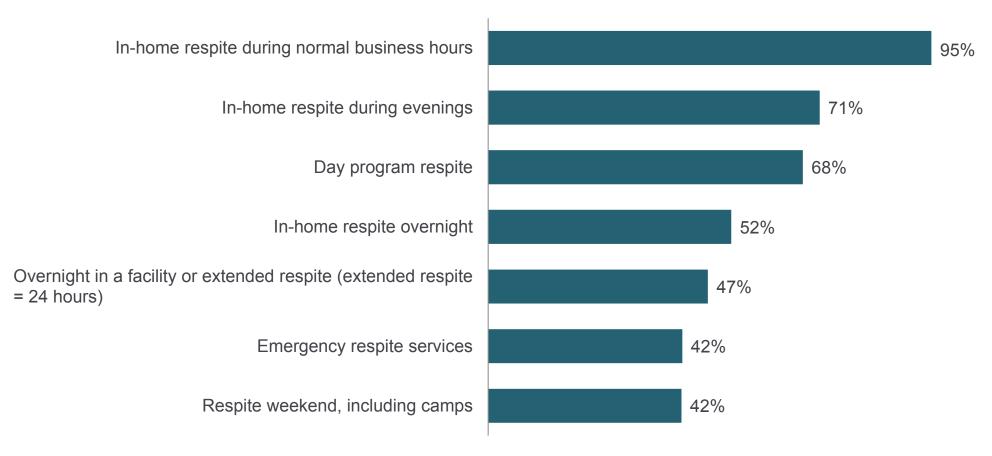






### AAA Survey: Type of Respite Services Provided

# What respite services are provided to support caregivers, either directly by your AAA or contracted by a grant or contract with a provider? (n=441)



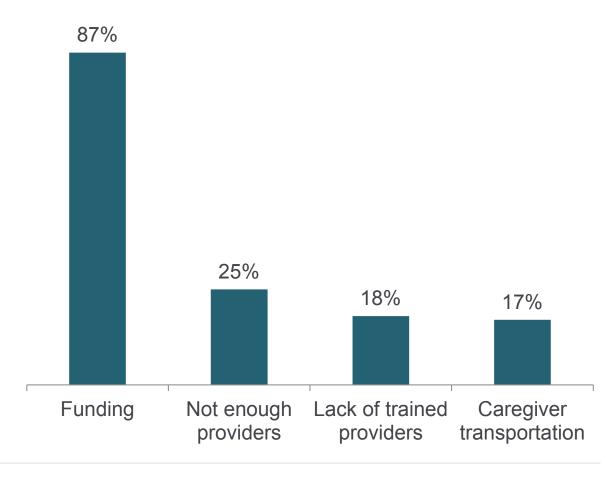




### AAA Survey: Unmet Respite Needs

- Half (52%) of AAAs meet respite needs "sometimes"
- Four in ten (41%)
  meet "all" or "'most of
  the time"

# Which of the following are common reasons caregiver respite needs are unmet? (n=42)

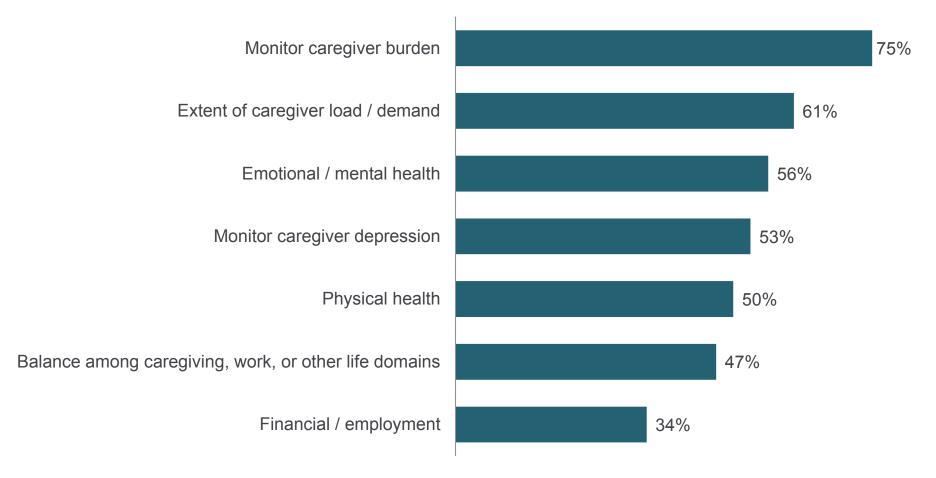






### AAA Survey: Quality of Programs - Caregiver Outcomes Measured

# You indicated that you measure caregiver program outcomes. Which of the following outcomes do you measure? (n=64)

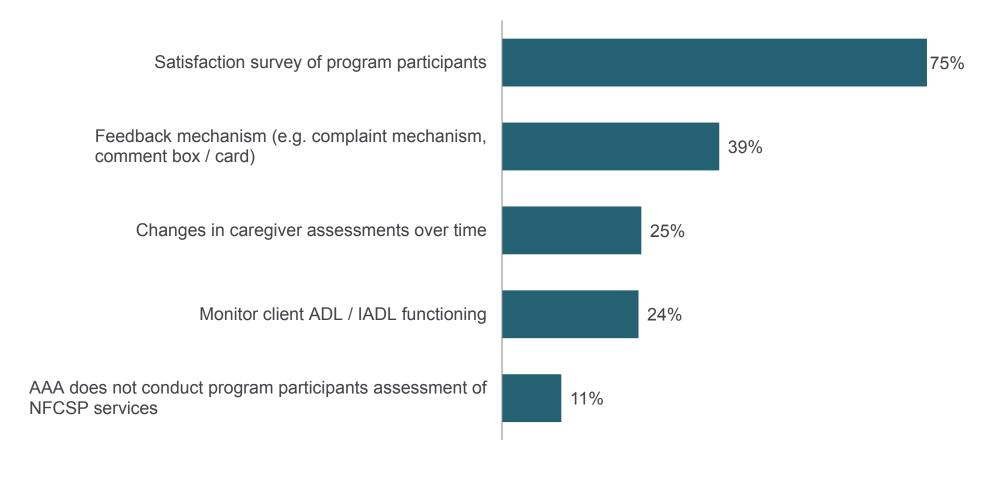






### AAA Survey: Quality of Programs – Assessing Program Outcomes

## Does your AAA use any of the following strategies to assess program outcomes related to NFCSP service receipt? (n=429)







### AAA Survey: Service Caps

- Three-quarters of AAAs (74.4%) have service caps
  - 37% of AAAs apply service caps to all NFCSP services
- 37% of all AAAs use yearly caps for at least some services
- 36% of all AAAs vary the limit depending on service
- 61% of AAAs that have a policy for service caps indicate that they set that policy





### AAA Survey: Criteria used for Service Priority

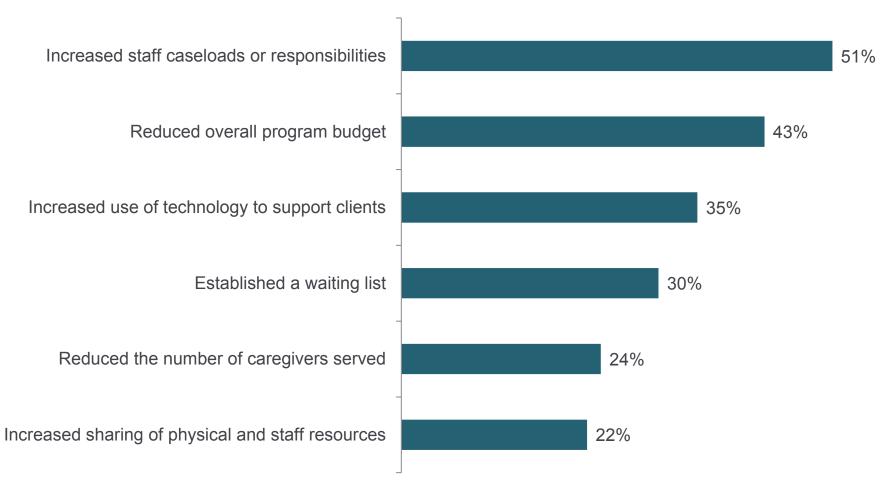
Top 3 Service Priority Criteria for Caregivers	Top 3 Service Priority Criteria for Care Recipients
Lack of informal/family support	ADL/IADL impairment minimum
Low income	Alzheimer's diagnosis
Mental Health / Emotional Status	Low income





### AAA Survey: NFCSP Changes in the last 3 years

# In the last 3 years, has your AAA experienced any of the following changes to the NFCSP? (n=440)







### AAA Survey: Areas for Improvement

- Increased direction & standardization on:
  - Forms, assessments, service definitions
- Increased flexibility on:
  - Designating funds and services
  - Hours of service or types of service
  - Eligibility
- Coordination/communication within state
- Streamlining reporting and administration
- Development of outreach materials
- Other: sliding scale fees, coordination with state HCBS, unnecessary intrusive questions, and incentivizing providers to recommend NFCSP





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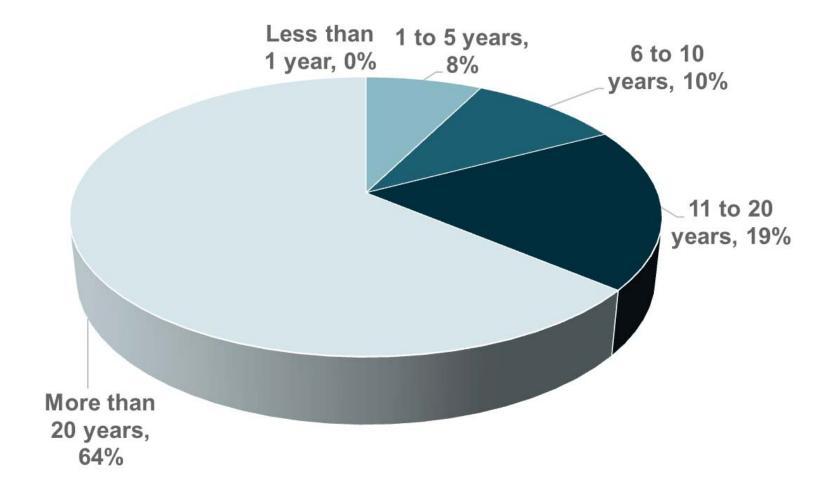
### Local Service Provider (LSP) Survey





### LSP Survey Findings

### How long has your organization been in operation? (n=389)

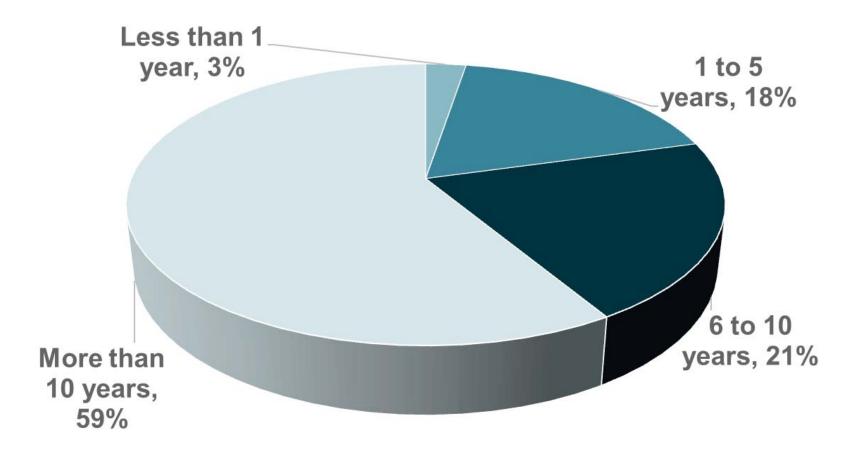






### LSP Survey: Serving Caregiver Clients

# How long has your organization been serving NFCSP caregiver clients? (n=387)

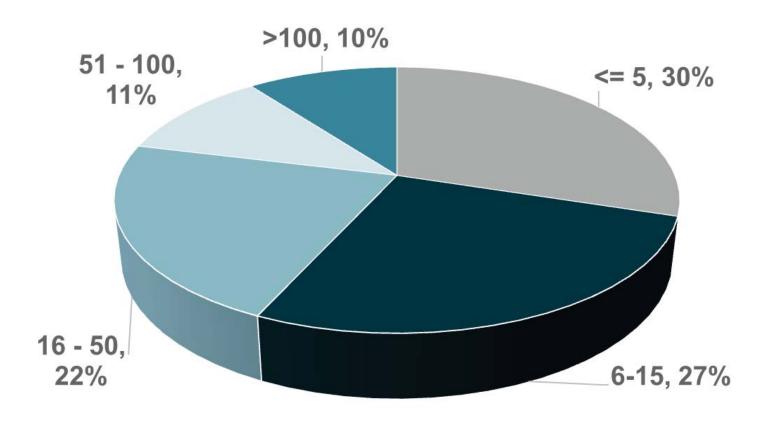






### LSP Survey: Employees

### How many full time equivalent employees? (n=341)

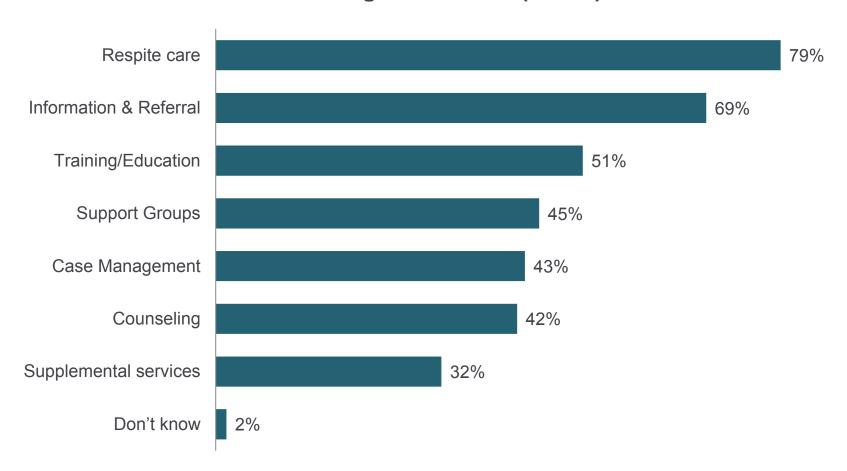






### LSP Survey: NFCSP services provided

# Which of the following services do you provide to NFCSP caregiver clients? (n=393)

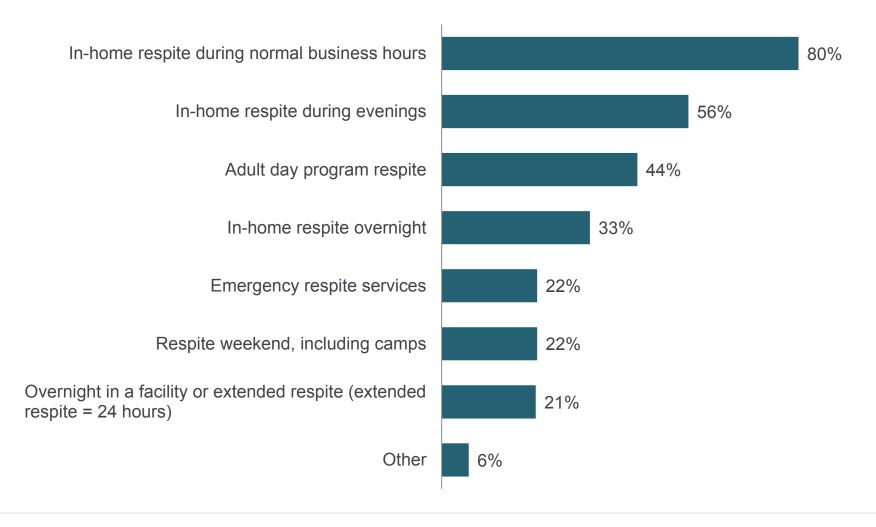






### LSP Survey: NFCSP respite care provided

### What kind of respite care does your organization provide? (n=311)

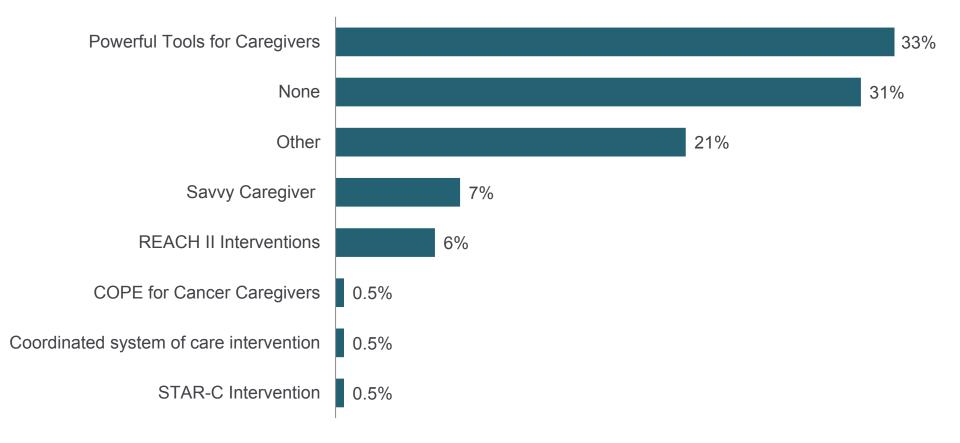






### LSP Survey: Use of evidence-based caregiver programs

# Which of the following evidence-based caregiving training/education interventions does your organization provide to NFCSP caregiver clients? (n=202)

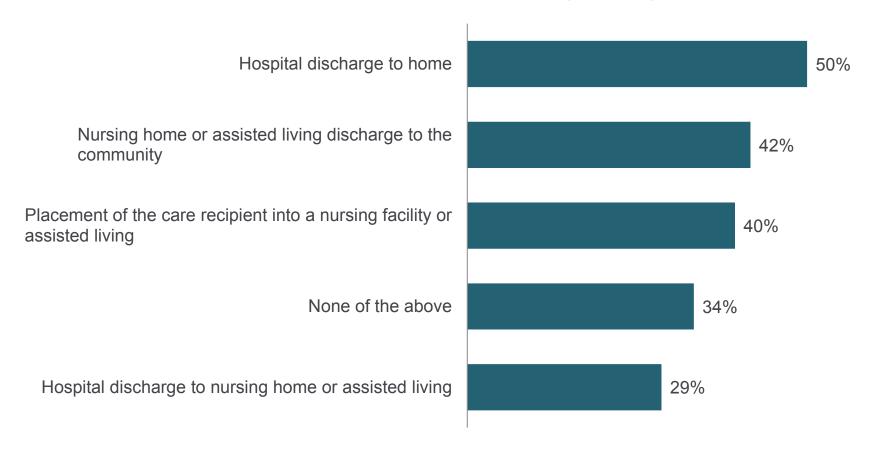






### LSP Survey: Assist with transitions of care

# Does your program support caregivers with care transitions of their loved ones between any of the following settings? (n=393)

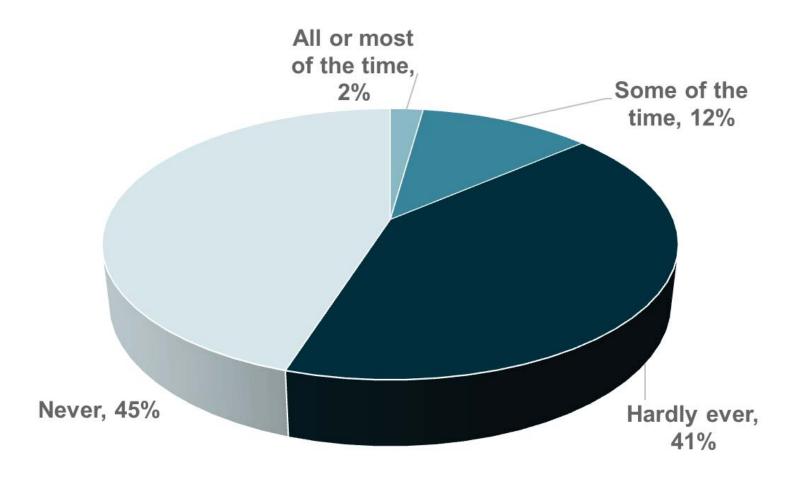






### LSP Survey: Accepting Caregiver Clients

# How often does your organization NOT accept an NFCSP caregiver client? (n=366)

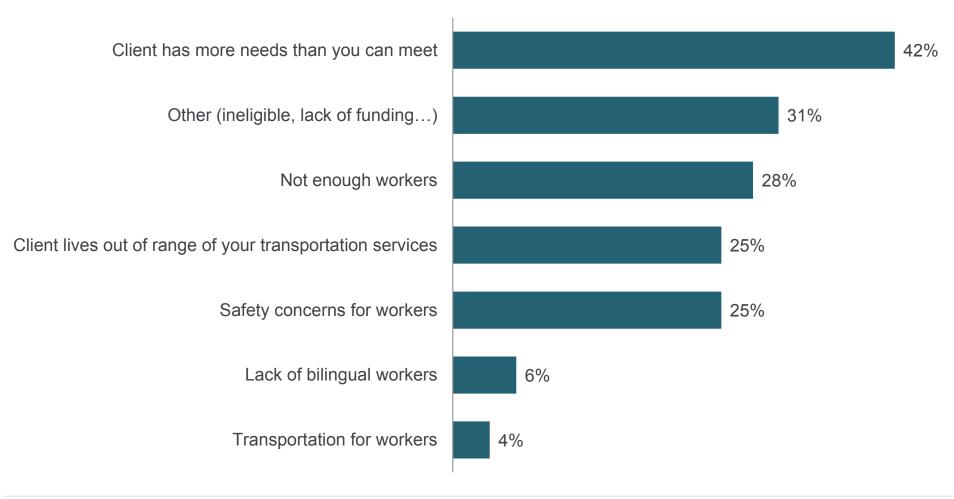






### LSP Survey: Reasons for not accepting a client

# Which of the following are common reasons your organization ever cannot accept a client? (n=201)







### LSP Survey: Challenges

- LSP recruitment slow: required substantial personal follow-up
- Many LSPs don't know their contract money is from the NFCSP (in contrast with nutrition program)
- Many LSPs do not consider themselves to be providing caregiver services: believe they serve only care recipients
  - Confusion with other evaluations or surveys
  - Don't want to share or cannot access financial information
  - Cannot produce information
- Don't have staff or time to complete
  - Reduction in funds → fewer personnel
  - Busy schedules
  - Other evaluations take precedence, e.g. state or AAA





National Family Caregiver Support Program – Process Evaluation

### Discussion





#### NFCSP Process Evaluation Results Discussion

- NFCSP was a catalyst for supports and services designed specifically for caregivers.
- The Aging Network deploys NFCSP staff to properly serve caregivers through hiring managers devoted to this program and routinely training staff on caregiver topics.
- Special caregiver populations are being targeted to address their needs.
- AAAs are engaging in critical partnerships to implement their NFCSP.





#### NFCSP Process Evaluation Results Discussion

- The Aging Network is moving toward standardized caregiver assessment; however, there is room for growth.
- Wait lists data was not widely reported by SUAs and AAAs. At the local level, LSPs report low rates of inability to accept NFCSP clients.
- Respite is a critical caregiver service.
- The Aging Network is engaged in regular program monitoring.
- There are opportunities to integrate the NFCSP with other HCBS programs.





### NFCSP Process Evaluation Recommendations

- Ongoing NFCSP Communications Across the Aging Network
- Suggestions for Further Research
- Caregiver Assessment and Outcomes
- Funding for the NFCSP





### **NFCSP Process Evaluation: Poll**

- How do you think the evaluation results present the NFCSP (Title III-E) program?
  - Very Positively
  - Positively
  - Neither positively or negatively
  - Negatively
  - Very negatively





### NFCSP Process Evaluation Research Team

This research team below completed the work under contract HHSP23320095639WC HHSP23337031T.

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