National Family Caregiver Support Program (NFCSP) Process Evaluation

2015 HCBS Conference
Agenda

• NFCSP (Title III-E) Background

• NFCSP Evaluation Goals and Survey Topics

• NFCSP Evaluation Methodology

• State Unit on Aging (SUA) and Area Agency on Aging (AAA) Survey Highlights – Preliminary Results
  – Development and Administration
  – Targeting of Special Populations, Prioritization and Wait Listing
  – Assessments
  – Respite and Supplemental Services
  – Program Challenges

• Next Steps

Preliminary NFCSP Survey Results
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

1. Provide information to support program planning, including an analysis of program operations;

2. Develop information about program efficiency and costs; and,

3. Gauge program effectiveness in assessing community and client needs, targeting and prioritizing, and providing services to family caregivers.
Wide Range of Survey Topics

- Staff and volunteer training
- Caregiver intake, screening and assessments*
- Referrals
- Additional service information (e.g., training/education, access assistance)
- Self-directed care / consumer direction
- Caregiver outcome measurement*
- Program quality assurance
- Program partnerships
- Detailed information on non-OAA caregiver programs
- Funding Sources
- Community Needs Assessments*
- Monitoring and Evaluation*

* Examples of state documents & tools gathered & available from ACL
## NFCSP Process Evaluation Team

<table>
<thead>
<tr>
<th>Contractor</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Lewin Group</td>
<td>The Lewin Group is a premier national health and human services consulting firm with more than 40 years of experience in delivering objective analyses and strategic counsel. Lewin was awarded both process evaluation contracts for the NFCSP (Title III-E) evaluation. Lewin has experience conducting large-scale program evaluations and disseminating best practices, and understands the diversity within the caregiver population (e.g., low-income older relatives caring for children with developmental delays), the complexity of their needs, and the variation in how supports are delivered.</td>
</tr>
<tr>
<td>Scripps Gerontology Center</td>
<td>Scripps Gerontology Center supports the interests of older adults, families and an aging society and serves students, faculty, professionals, agencies, and professional organizations in the field of aging. Research efforts include generating, organizing, and disseminating high quality multidisciplinary aging related knowledge that will make a difference in the lives of older adults. Service activities include, but are not limited to, leadership in the profession, technical assistance and service to the community, planners, providers, policy makers, and other professionals. Scripps regularly fields surveys of AAAs through a contract with n4a funded by ACL.</td>
</tr>
<tr>
<td>UConn Health Center on Aging</td>
<td>UConn Health Center on Aging is dedicated to improving the lives of older adults through clinical care, teaching, and research. Their multidisciplinary faculty includes social and behavioral scientists conducting community- and population-based health outcome studies, all committed to increasing our knowledge of the aging process and to the discovery of strategies for the promotion of quality of life in older adults. UConn Health Center on Aging staff conduct research to determine the effectiveness of policies and programs involving older adults, people with disabilities, their families, and their service providers at the state and national level.</td>
</tr>
</tbody>
</table>

*Preliminary NFCSP Survey Results*
NFCSP Process Evaluation Roles

**Administration for Community Living**

- **The Lewin Group:**
  - Evaluation Management
  - State Unit on Aging Survey

- **Scripps Gerontology Center:**
  - Area Agency on Aging Survey
  - Local Service Provider Sampling

- **UConn Health Center on Aging:**
  - Local Service Provider Survey

*Preliminary NFCSP Survey Results*
National Family Caregiver Support Program – Process Evaluation

METHODOLOGY
SUA Survey: Methodology

• Survey Development and Outreach:
  – Developed a comprehensive internet survey to address ACL needs
  – Covered a range of topics
  – Tested by SUA volunteers

• Data Collection:
  – Census of 54 SUAs that operate an NFCSP
  – Fielded from January 22 – May 30 2015
  – Achieved 100% response rate – Thank You!!
AAA Survey Methodology

• Survey Development and Outreach:
  – Comprehensive internet survey developed to address ACL needs
  – Covered similarly wide range of topics

• Data Collection
  – Census of AAAs
  – Survey fielded January 22-July 2 2015
  – Achieved 71% response rate!
Local Service Provider (LSP Survey)

• Survey Development and Outreach:
  – Comprehensive internet survey developed to address ACL needs
  – Covers similarly wide range of topics
  – Conducting outreach through email and phone calls

• Sampling and Data Collection:
  – Sample of 275 AAAs + 10 single-PSA states that completed AAA survey
  – Stratified by budget and geographic area served
  – AAAs provide list of all LSPs providing training or respite
  – 1125 LSPs randomly selected from the lists
National Family Caregiver Support Program – Process Evaluation

State Unit on Aging (SUA) Survey
Prior to the establishment of NFCSP in your SUA, which of the following services did your SUA offer to caregivers? (n=53)

- I&R: 72%
- Respite care: 53%
- Supplemental service: 36%
- Access assistance: 34%
- Training/Education: 28%
- Support Groups: 28%
- Care Coordination: 21%
- Counseling: 15%
- Caregiver Support Coordination: 11%
SUA Survey: NFCSP Development

• Over two-thirds (n=34; 68%) of respondents reported that the NFCSP resulted in the creation of standardized eligibility criteria for caregiver services
SUA Survey:
Aging and Disability Resource Center (ADRC) Coordination

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

- Development or implementation of referral/assessment processes: 62%
- Provision of Options Counseling: 62%
- Development or implementation of screening protocols: 50%
- Development or implementation of intake tools: 46%
- Development or review of policies, guidance or regulations regarding the inclusion of caregiver services: 44%
- Provision of training: 38%
- Provision of Care Transitions: 24%
- NFCSP does not coordinate with the ADRC: 12%

Preliminary NFCSP Survey Results
SUA Survey: Caregiver Programs and HCBS Integration

- 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 (n=16)
What are the major barriers limiting/preventing integration of NFCSP with other home and community-based programs in your state? (n=50)

- Different eligibility requirements: 72%
- Different reporting requirements: 54%
- Different client population than in other programs: 52%
- Federal regulatory or statutory requirements: 34%
- Organizational cultural and administrative differences: 32%
- Complexity of accessing and arranging services: 26%
- Lack of access to adequate computer technology and...: 26%
- State regulatory or statutory requirements: 24%
- Staff has too many responsibilities: 22%
- Lack of knowledge of opportunities for integration: 16%
- Low priority given to caregiver support services: 12%
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)

- In-home respite during normal business hours: 98%
- In-home respite during evenings: 87%
- Adult day program respite: 83%
- Overnight in a facility or extended respite (extended respite = 24 hours): 76%
- In-home respite overnight: 72%
- Emergency respite services: 69%
- Respite weekend, including camps: 65%
### 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)

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Modification/Repairs</td>
<td>78%</td>
</tr>
<tr>
<td>Homemaker/Chore Services</td>
<td>73%</td>
</tr>
<tr>
<td>Consumable Supplies</td>
<td>63%</td>
</tr>
<tr>
<td>Transportation</td>
<td>63%</td>
</tr>
<tr>
<td>Assistive Technology</td>
<td>61%</td>
</tr>
<tr>
<td>Emergency Response</td>
<td>51%</td>
</tr>
<tr>
<td>Legal and/or Financial Consultation</td>
<td>51%</td>
</tr>
<tr>
<td>In-Home Assessment</td>
<td>47%</td>
</tr>
<tr>
<td>Cash Grant</td>
<td>25%</td>
</tr>
</tbody>
</table>
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
National Family Caregiver Support Program – Process Evaluation

State Unit on Aging (SUA) and Area Agency on Aging (AAA) Surveys
Since program implementation, which special populations of caregivers, if any, has your program made a specific effort to serve?

<table>
<thead>
<tr>
<th>Special Population</th>
<th>SUA (n=54)</th>
<th>AAA (n=441)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer's</td>
<td>76%</td>
<td>63%</td>
</tr>
<tr>
<td>Grandparents</td>
<td>74%</td>
<td>48%</td>
</tr>
<tr>
<td>Rural</td>
<td>61%</td>
<td>57%</td>
</tr>
<tr>
<td>Racially and ethnically diverse</td>
<td>46%</td>
<td>35%</td>
</tr>
<tr>
<td>Age 70+</td>
<td>44%</td>
<td>42%</td>
</tr>
<tr>
<td>Veterans</td>
<td>28%</td>
<td>30%</td>
</tr>
<tr>
<td>Employed</td>
<td>28%</td>
<td>28%</td>
</tr>
</tbody>
</table>

Preliminary NFCSP Survey Results
## SUA and AAA Surveys: Caregiver Assessment

### In your caregiver support program, who is assessed?

<table>
<thead>
<tr>
<th>Category</th>
<th>SUA (n=53)</th>
<th>AAA (n=434)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Both</td>
<td>81%</td>
<td>70%</td>
</tr>
<tr>
<td>Care Recipient</td>
<td>8%</td>
<td>15%</td>
</tr>
<tr>
<td>Family caregiver</td>
<td>8%</td>
<td>12%</td>
</tr>
<tr>
<td>No assessment is conducted</td>
<td>4%</td>
<td>3%</td>
</tr>
</tbody>
</table>

**Preliminary NFCSP Survey Results**
SUA and AAA Surveys: Caregiver Assessment

• 57% of SUAs reported having a statewide standardized caregiver assessment (n=29)

• 71% of AAAs use a standardized assessment tool (n=298)
SUA Survey: Caregiver Assessment Domains

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

- Care recipient background (demographics, financial status): 86%
- Care recipient’s health and wellbeing: 83%
- Impact of caregiving on the caregiver: 79%
- Caregiver’s background and the caregiving situation: 76%
- Caregiver’s perception of care recipient health and functional status: 76%
- Resources available to support the caregiver: 76%
- Resources available to support the care recipient: 76%
- Caregiver’s health and wellbeing: 72%
- Caregiver’s skills, ability, knowledge or other requirements to provide care: 59%
- Caregiver’s values and preferences with respect to everyday living and care provision: 41%
### AAA Survey: Caregiver Assessment Domains

<table>
<thead>
<tr>
<th>Area</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care recipient’s health and well-being</td>
<td>84%</td>
</tr>
<tr>
<td>Caregiver’s health and well-being</td>
<td>77%</td>
</tr>
<tr>
<td>Resources available to support the caregiver</td>
<td>76%</td>
</tr>
<tr>
<td>Caregiver’s background and the caregiving situation</td>
<td>76%</td>
</tr>
<tr>
<td>Care recipient background (demographics, financial status)</td>
<td>75%</td>
</tr>
<tr>
<td>Impact of caregiving on the caregiver</td>
<td>74%</td>
</tr>
<tr>
<td>Resources available to support the care recipient</td>
<td>73%</td>
</tr>
<tr>
<td>Caregiver’s perception of care recipient health and functional status</td>
<td>67%</td>
</tr>
<tr>
<td>Caregiver’s skills, ability, knowledge or other requirements to provide care</td>
<td>57%</td>
</tr>
<tr>
<td>Caregiver’s values and preferences with respect to everyday living and care provision</td>
<td>49%</td>
</tr>
</tbody>
</table>
What is your [SUA’s/AAA's] policy on the frequency of conducting family caregiver reassessments for services?

- **Annually**: SUA 83%, AAA 50%
- **Change in caregiver status**: SUA 76%, AAA 38%
- **Change in care recipient status**: SUA 72%, AAA 36%
- **No policy**: SUA 35%, AAA 13%
- **Left up to the AAA**: SUA 28%, AAA n/a
- **Semi-annually**: SUA 24%, AAA 24%
What is the policy for how the caregiver assessments and reassessments are used?

- Care plan development for the caregiver
  - SUA: 63%
  - AAA: 78%

- To prioritize who receives services
  - SUA: 45%
  - AAA: 46%

- Decided at the AAA level
  - n/a

- Strategic planning/forecasting and/or program development
  - SUA: 22%
  - AAA: 24%

- Measuring caregiver program outcomes
  - SUA: 18%
  - AAA: 15%
National Family Caregiver Support Program – Process Evaluation

Area Agency on Aging (AAA) Survey
Prior to NFCSP:

- 27% had caregiver programs (n=120)
- 20% with paid program manager established position 2000 or earlier (n=72)
- 51% didn’t have policy for caregivers as clients (n=226)

Top Services Prior to NFCSP (n=438)

- I&R: 74%
- Supplemental services: 48%
- Respite care: 40%
- Care coordination: 28%
- Training / Education: 27%
- Support groups: 21%
AAA Survey: NFCSP Implementation

- The NFCSP impacted caregiver services provided by AAAs.
  - 80% provided new services (n=351)
  - 75% increased numbers served (n=330)
  - 68% increased amount of service (n=297)
AAA Survey: NFCSP Implementation

• 88% of AAAs have policies or standardized eligibility criteria that defines caregivers as clients (n=392)

• 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 (n=312)
AAA Survey: Important Partners in Caregiving

Please mark up to three of your most important partners specifically for administering program (n=408)

- Local / state chapter of national organizations: 61%
- Aging and Disability Resource Center or Aging Resource Center: 52%
- Health care providers: 42%
- Elder Abuse Prevention programs, Adult Protective Services (APS), or TRIAD: 35%
- Caregiver coalitions / respite coalitions: 27%

Preliminary NFCSP Survey Results
AAA Survey: Waiting Lists

- 40% of AAAs currently have waiting lists for NFCSP services (n=174)
- 84% reported about waiting list policies and practices (n=364)
- Many AAAs are unfamiliar with the waiting times

How are waiting lists organized?

- Single NFCSP list: 56%
- No list or 0 on it: 37%
- Respite Service Wait: 19%
AAA Survey: Service Caps

• Three-quarters of AAAs (74%) have service caps (n=318)
  – 37% of these AAAs apply service caps to all NFCSP services (n=113)

• 37% of all AAAs use yearly caps for at least some services (n=160)

• 36% of all AAAs vary the limit depending on service (n=155)

• 61% of AAAs that have a policy for service caps indicate that they set that policy (n=190)
AAA Survey: Establishing Service Priority

Who established this [NFCSP service] prioritization mechanism? (n=362)

- AAA: 59%
- SUA: 37%
- Other State-level entity: 14%
- Local Service Provider: 9%

Preliminary NFCSP Survey Results
### AAA Survey: Criteria used for Service Priority

<table>
<thead>
<tr>
<th>Top 3 Service Priority Criteria for Caregivers</th>
<th>Top 3 Service Priority Criteria for Care Recipients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of informal/family support</td>
<td>ADL/IADL impairment minimum</td>
</tr>
<tr>
<td>Low income</td>
<td>Alzheimer’s diagnosis</td>
</tr>
<tr>
<td>Mental Health / Emotional Status</td>
<td>Low income</td>
</tr>
</tbody>
</table>

*Preliminary NFCSP Survey Results*
How is the type and amount of caregiver service determined? (n=433)

- Availability of program resources: 74%
- Caregiver needs assessment: 59%
- Availability of services: 50%
- Program participant / family request: 46%
- Standardized service amount: 35%
- Prioritization criteria other than caregiver needs (e.g., targeted group, care recipient diagnosis, etc.): 24%
In the last 3 years, has your AAA experienced any of the following changes to the NFCSP? (n=439)

- Increased staff caseloads or responsibilities: 51%
- Reduced overall program budget: 43%
- Increased use of technology to support clients: 35%
- Established a waiting list: 30%
- Reduced the number of caregivers served: 24%
- Increased sharing of physical and staff resources: 22%
NFCSP (Title III-E) Process Evaluation Highlights

• NFCSP was a catalyst for focusing resources on caregiver support

• Movement toward standardized assessment tools

• Respite is a key NFCSP service
Next Steps
Participate in the LSP Survey!

- If you’re a AAA, please respond to the request for lists.
- If you’re a AAA who provided lists, please endorse with LSPs.
- If you’re an LSP and were contacted, please reply to the survey!
- For more information, please contact:
  - Julie Robison
    - jrobison@uchc.edu
    - 860-679-4278
Next Steps

• Conduct Local Service Provider (LSP) Survey

• Data Cleaning and Analysis

• Final Report
  – Background
  – Methodology
  – Results
    • SUA results
    • AAA results
    • LSP results
    • Combined survey results
Questions and Contact Information

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