Family and Friend Caregivers: Profile of Program Participants and Needs

FY 2017-18

Presentation to the Dignity Fund Oversight and Advisory Committee

January 28, 2019
Agenda

• Background

• FY 2017-18 Program Participants

• Caregiver Needs

• Findings
Background
Background and Data Sources

• Dignity Fund Community Needs Assessment
  • Findings highlighted the need for additional support for caregivers
  • Particular reference to;
    • Accessibility of services for caregivers with limited English proficiency
    • Utility of respite care and in-home

• Data sources:
  • DAAS Program Enrollment – CA GetCare database – FY 2017-18
  • Family Caregiver Alliance – FY 2017-18
  • DFCNA 2017 Consumer Survey
### Definitions

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>API</td>
<td>Asian/Pacific Islander</td>
</tr>
<tr>
<td>Informal caregivers</td>
<td>Family or friends caring for an older adult or person with disability, typically without financial compensation</td>
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<tr>
<td></td>
<td>Also referred to as “unpaid caregivers” and “non-professional caregivers”</td>
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<tr>
<td>LGBTQ</td>
<td>An acronym/term used to refer to persons who self-identify as non-heterosexual and/or whose gender identity does not correspond to their birth sex. This includes, but is not limited to, lesbian, gay, bisexual, transgender, genderqueer, and gender non-binary.</td>
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</tbody>
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FY 2017-18 Program Participants
Age of OOA Caregivers
Total: 552

- 16% 18 to 44
- 17% 45 to 54
- 13% 55 to 59
- 13% 60 to 64
- 22% 65 to 74
- 15% 75 and older
- 4% Unknown

Source: Office on the Aging, FY 2017-2018
Race/Ethnicity of OOA Caregivers
Total: 552

- White: 26%
- Chinese: 25%
- Japanese: 15%
- Other API: 8%
- Latino: 8%
- Black or African American: 5%
- Other: 4%
- Unknown: 9%

Source: Office on Aging, FY 2017-18
Language of OOA Caregivers
Total: 552

- English, 43%
- Chinese, 19%
- Unknown, 25%
- Spanish, 4%
- Other, 10%

Source: Office on the Aging, FY 2017-18
**Office on the Aging FY 2017-18: Caregiver Sexual Orientation**

<table>
<thead>
<tr>
<th>Gay/Lesbian/Same-Gender Loving</th>
<th>Bisexual</th>
<th>Not listed/All other</th>
<th>Straight/Heterosexual</th>
<th>Declined to answer</th>
<th>Incomplete/Missing</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>101</td>
<td>7</td>
<td>3</td>
<td>282</td>
<td>17</td>
<td>161</td>
<td>571</td>
</tr>
<tr>
<td>18%</td>
<td>1%</td>
<td>1%</td>
<td>51%</td>
<td>3%</td>
<td>26%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Source: Office on the Aging, FY 2017-18

- 66% are female
- 1.4% identify as gender queer/gender non-binary
Home Supervisorial Districts of OOA Caregivers
Total: 552

Source: Office on the Aging, FY 2017-2018
Employment Status of Caregivers

Total: 552

- Working Full-Time: 32%
- Working Part-Time: 14%
- Unemployed: 9%
- Retired: 27%
- Other: 5%
- Incomplete/Missing: 12%

Source: Office on the Aging, FY 2017-2018
Unduplicated Program Enrollment by Caregivers
Total: 552

- FCSP Caregiver: 537
- Caregiver Respite (DF): 92
- Community Service Centers: 77
- Congregate Meals: 44
- Home-Delivered Meals: 17
- Short-Term Home Care: 11
- Case Management: 8

Source: Office on the Aging, FY 2017-2018

Chart displays top accessed services
Unduplicated Enrollment in Caregiver Support Programs
Total: 552

- Counseling: 445
- Assessment: 219
- Caregiver Training: 165
- Respite: 156
- Support Group: 145
- Case Mgmt: 118
- Caregiver Registry: 71
- Other: 40

Source: Office on the Aging, FY 2017-18
Caregiver Needs
Caregiver Demographics

- **Ethnicity**: The largest racial/ethnic group of FCA caregiver respondents was Chinese (49%), followed by White (20%).

- **Language (English Proficiency)**: Most FCA respondents speak English (62%). At least 34% speak Chinese and have limited English proficiency. About two percent speak Spanish (2%).

- **Gender**: Most FCA respondents are female (76%).

- **Age**: Over half of FCA caregiver respondents are under age 60 (54%). They are mostly middle aged (28% are between ages 45 and 52, and 17% are between age 55 and 59).
Primary Diagnosis of Care Recipients

Total: 189

- Dementia: 64%
- Alzheimer's: 29%
- Other: 6%
- Stroke: 8%
- Cardiovascular: 7%
- Cancer: 6%
- Diabetes: 4%
- Blood, Liver or Kidney: 3%
- Other: 8%

Source: 2017-18 Family Caregiver Alliance
FCA Time Spent Caregiving
Total: 242

Source: 2017-18 Family Caregiver Alliance Assessment
FCA Type of Help Received
Total: 241

- No help: 14%
- Unpaid help only: 28%
- Paid and unpaid help: 44%
- Paid help only: 14%

Source: 2017-18 Family Caregiver Alliance Assessment
FCA Degree of Help Needed
Total: 241

- Don’t need help: 1%
- Amount of help needed: 17%
- Less than needed: 66%
- No help: 16%

Source: 2017-18 Family Caregiver Alliance Assessment
FCA No Time for Self and Stress Between Caregiving and Other Responsibilities

Total: 218

- Nearly Always: 30% (No Time for Self), 31% (Feel Stressed)
- Frequently: 29% (No Time for Self), 31% (Feel Stressed)
- Sometimes: 28% (No Time for Self), 27% (Feel Stressed)
- Rarely: 6% (No Time for Self), 7% (Feel Stressed)
- Never: 6% (No Time for Self), 4% (Feel Stressed)

Source: 2017-18 Family Caregiver Alliance Assessment
I Know Where to Go to Get Support as a Caregiver

Total: 31

- Not at all true: 13%
- A little bit true: 48%
- Mostly true: 26%
- Very true: 10%
- Not applicable: 3%

Dignity Fund Consumer Needs Assessment Survey 2018
Findings
Findings

• Latino caregivers represent a small portion of OOA caregiver participants and may be underrepresented in DAAS Office on Aging services.

• Caregivers seeking support are most commonly caring for a person with a primary diagnosis of dementia.

• Caregiving is a fulltime commitment for caregivers and many indicate they receive little or no help.

• Caregivers reported high levels of stress and indicated they have little time to care for themselves.

• Caregivers expressed limited knowledge of caregiver support services and where they can access services.
Discussion