Caregiver Support Service Assessment:  
Documenting Existing Support Services for Caregivers in the 9 County Metropolitan Area

FINAL RESULTS  
Funding provided by the Greater Twin Cities United Way

Acknowledgements

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We would also like to thank the following individuals who contributed to the development of the assessment and this report:

Steering Committee:  
Lynn Cibuzar – DARTS  
Leah Driscoll – Wilder Foundation  
Emily Farah-Miller – MAAA  
Cindy Guddal – Courage Center  
Mike Reckard – Veterans Administration

Project Team:  
Kirsten Johnson – Project Manager  
Abdiwahab Ali – Intern  
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Leanna Smith – MAAA  
Tabatha Barrett

Caregiver Service Providers

- **67 organizations** completed the full survey

Geographic Area Served

Geographic Area Served: Select the county or counties in which your organization provides services.
Caregiver Populations Served

- The majority of organizations surveyed served both **Older Adults and Adults** with a chronic illness or disability.

Number of Caregivers Served

- **63 organizations** provided varying levels of service to an estimated **45,150 caregivers**.

Culturally Specific Caregiver Services

- **21 organizations**, 31% of those surveyed, provide culturally specific services:

<table>
<thead>
<tr>
<th>Population</th>
<th># of Organizations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Latino/Hispanic</td>
<td>9</td>
</tr>
<tr>
<td>African American</td>
<td>5</td>
</tr>
<tr>
<td>African Immigrant</td>
<td>3</td>
</tr>
<tr>
<td>Russian</td>
<td>2</td>
</tr>
<tr>
<td>Southeast Asian</td>
<td>4</td>
</tr>
<tr>
<td>LGBT</td>
<td>3</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>1</td>
</tr>
<tr>
<td>Karen</td>
<td>1</td>
</tr>
<tr>
<td>Korean</td>
<td>1</td>
</tr>
</tbody>
</table>
Caregiver Assessment Usage

- **36 organizations**, approximately **53%** utilize a formal caregiver needs assessment

<table>
<thead>
<tr>
<th>Does your organization provide a formal assessment of caregiver needs?</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>47</td>
</tr>
<tr>
<td>No</td>
<td>37</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>14</td>
</tr>
<tr>
<td>Cannot answer question</td>
<td>12</td>
</tr>
<tr>
<td>Skipped question</td>
<td>9</td>
</tr>
</tbody>
</table>

Caregiver Services Provided

- **75%** of organizations provide services to caregivers whether or not the care receiver is served
- **25%** of organizations serve caregivers only if the care receiver is served
- **100%** of organizations serve all caregivers

Caregiver Support Groups

<table>
<thead>
<tr>
<th>Number of Support Groups Offered</th>
<th>Number of Organizations</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>10</td>
</tr>
<tr>
<td>5-9</td>
<td>10</td>
</tr>
<tr>
<td>10 or more</td>
<td>0</td>
</tr>
</tbody>
</table>

- **Number of Support Groups Offered**
- **Number of Organizations**
Caregiver Support Groups

- 36 organizations of the 41 who provide support groups offer them to caregivers only

Respite Services

- Types of Respite Provided:
  - Overnight, weekend or extended
  - Emergency or crisis respite
  - In-home
  - Adult Day Services
  - Out-of-home

- Length of Respite Provided:
  - 1 or more days
  - 3 days
  - 1 day
  - Less than 1 day

Note: Adult Day Health programs were included in 3 or more days.
**Respite Services**

- **36% of organizations** who provide respite felt that the length offered was **not sufficient**

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
<th>Percent</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the average length of time of your organization’s respite services sufficient for most family/friend caregivers?</td>
<td>Yes</td>
<td>51%</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>44%</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>5%</td>
<td>0</td>
</tr>
</tbody>
</table>

**Services Across the Lifespan**

If your organization serves multiple populations of caregivers, how integrated would you say these various caregiver support services are? *Integrated could mean services to different populations are provided by the same staff, department or unit OR it could mean that different staff, departments or units work together across your organization to provide service.*

<table>
<thead>
<tr>
<th>Response</th>
<th>Percent</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>62%</td>
<td>18</td>
</tr>
<tr>
<td>No at all integrated</td>
<td>35%</td>
<td>18</td>
</tr>
<tr>
<td>Somewhat integrated</td>
<td>2%</td>
<td>0</td>
</tr>
<tr>
<td>Mostly integrated</td>
<td>1%</td>
<td>0</td>
</tr>
<tr>
<td>Completely integrated</td>
<td>1%</td>
<td>0</td>
</tr>
</tbody>
</table>

**Service Availability**

- **52% of organizations** receive requests for support services they do not provide

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
<th>Percent</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often have caregivers requested caregiver support services that are not provided by your organization?</td>
<td>More than once per month</td>
<td>40%</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>At least once per month</td>
<td>20%</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>At least once per week</td>
<td>10%</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Daily</td>
<td>10%</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>10%</td>
<td>3</td>
</tr>
</tbody>
</table>

**Service Availability**

- **34% of organizations** receive requests for support services not available in their community

<table>
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**Service Availability**

- **Affordability** was often an issue in addition to availability of services
- **Long-term respite** for vacations, or **free respite** were the types most often requested

**Requested Services**

![Chart showing requested services]

**Service Payment Options**

- **Over 90% of organizations** provide Caregiver Education, Support Groups, Health & Wellness Programming, and Information & Assistance **free of charge**

**Number of Organizations**

- Professional Counseling/Therapy
- Respite
- Family Meeting Facilitation
- Care Management
- Coaching/Consultation

**Service Expansion**

- If you were able to expand your organization’s services to offer more support to caregivers, what services would you add?

**Funding Sources**

- What sources of funding does your organization receive to provide caregiver support services? Please check all that apply.
Benefits of MCSC Membership

Key Findings

• Services are available in all 9 counties with level of service being correlated with population
• Majority of organizations serve either Adults & Older Adults or Children; integration across the lifespan is still uncommon
• Relatively few Culturally Specific services are available
• The majority of organizations serve 500 or fewer caregivers each year
• More than half of organizations utilize a caregiver assessment

Key Findings

• Affordability is a key barrier to access – in particular with respite
• Areas in which organizations want to expand services may not be correlated to areas of need
• Majority of organizations are providing a selection of services free of charge
• Networking is the number one reason new organizations would be interested in joining the Metropolitan Caregiver Services Collaborative

Insights & Next Steps

• Map Caregiver Services Provided
  — Service provision by county
• Conduct follow-up survey in 2013
  — Clarify questions by adding definitions of types of respite, duration of support groups, culturally specific services, payment types, etc.
  — Ask additional questions about affordability and other barriers to access, referral practices
• Explore opportunities for innovations in respite
  — Learn more about which types are most utilized; common barriers to accessing existing services
  — Think outside the box about new ways of providing respite
Insights & Next Steps

• Caregiver Assessments
  – Gather information from active MCSC members about assessment usage
  – Provide feedback to funders on efficacy of assessment tools; promote use of certain assessment tools

• MCSC Expansion Strategies
  – Invite non-profit and for-profit partners to twice annual networking events
  – Continue to target engagement of providers serving caregivers across the lifespan

Appendix A

Caregiver Support Service Assessment Survey Respondents, page 1 of 2:
- 180 Degrees
- Alzheimer’s Association MN-ND
- Anaphylaxis & Food Allergy Association of MN (AFARA)
- Anoka County Family Caregiver Connection
- Apparent Plan/Normandale United Methodist Church
- CAP
- CLUES
- Catholic Charities Caregiver Support Program
- Como Park/Falcon Heights Living at Home Block Nurse Program
- Consewa-Battle Creek LAY/BNP
- Courage Center
- DARTS
- Elder Mediation MN, LLC
- Encore Carver County Adult Day Services Program
- Family Adolescents & Children Therapy Services Inc (FACTS)
- FamilyMeans
- Family Pathways
- Friendship Center Adult Day, East Side Neighborhood Services, Inc.
- Guardian In Home Health & Security, LLC
- HCMC
- Hamline Midway Elders
- Highland Block Nurse Program
- International Dyslexia Association Upper Midwest Branch
- Jewish Family Services - St Paul
- Jewish Family and Children’s Service of Minneapolis
- Keystone Community Services
- Korean Service Center
- Lakes Area Youth Service Bureau
- Lakewinter Homes
- Longfellow/Seward Healthy Seniors
- Lutheran Social Service of Minnesota
- LyndaleCare
- Macalester-Summit Hill Living At Home Program
- Meridian Services
- Minneapolis VA Medical Center
- Minnesota Community Services
- Minnesota DeafBlind Project
- Minnesota Governor’s Council on Developmental Disabilities
- Minnesota Kinship Caregivers Association
- Minnesota Organisation on Fetal Alcohol Syndrome
- NAMI Minnesota
- National Multiple Sclerosis Society, Upper Midwest Chapter
- Normandale Hylands United Methodist Church
- Normandale Center for Healing and Wholeness,
  North East Neighborhoods Living At Home
  Block Nurse Program (St. Paul)
- Pathfinder Care Management
- People Serving People
- RM Medical
- Roseville Area Senior Program
- Riverdale Church, Andover, MN
- Senior Community Services
- SouthEastSeniors
- StruthersParkinson’s Center
- TWIN CITIES SENIOR HOUSING GUIDE
- The ALS Association, MN, ND, SD Chapter
- The Arc Greater Twin Cities
- The Leukemia & Lymphoma Society
- Tubman Elder Care & Rights Center
- University of Minnesota: UMP/Fairview Memory Clinic
- University of Minnesota Extension
- Upper Midwest American Indian Center
- Vietnamese Social Services
- Volunteers of America MN
- West 7th Senior Services
- Westwood Lutheran Church
- Wilder Foundation

Caregiver Support Service Assessment Survey Respondents, page 2 of 2: