Strengthening and Supporting Family Caregivers: The UJC Family Caregiver Access Network (FCAN) Project

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Definition

• Family caregivers are individuals who provide care to family members and friends with physical, mental, and/or emotional impairments
Facts

- Family caregivers provide about 80% of the community care in the U.S.¹
- 30% of family caregivers caring for an older adult are themselves 65 or over²
- 60% of family caregivers are women³

Facts

- The value of the services family caregivers provide for ‘free’ is estimated to be $306 billion a year – almost twice as much as is spent on homecare and nursing home services combined\(^1\)

Health Consequences

- Family caregivers suffer from chronic conditions at more than twice the rate of non-family caregivers\(^1\)

- Family caregivers are vulnerable to infection and increased risk of cancers\(^2\)


Health Consequences

• Declining health in family caregivers poses the greatest risk for the institutionalization of care recipients¹

Mental Health Consequences

• Half of all family caregivers suffer from feelings of isolation\(^1\)
• Half report that the burden of family caregiving is too much for them to handle\(^2\)


Mental Health Consequences

- 40-70% of family caregivers have clinically significant symptoms of depression\(^1\)
- Family caregivers are at risk for increased alcohol and substance use as a response to the stress of caregiving\(^2\)


Consequences at Work

- 40% of family caregivers report that caregiving has affected their ability to advance in their jobs\(^1\)
- Family caregivers each lose an average of $659,000 over a lifetime in lost wages and benefits\(^2\)


Family Caregiver Support Programs

• Family caregiver support services can diminish caregiver burden, allow caregivers to remain in the workforce, and prevent or delay out-of-home placement for care recipients\(^1\)

Family Caregiver Support Programs: Targets of Intervention (Gutheil and Chernesky, 1999)

- Caregivers
- Care recipients
- Social service delivery systems
Family Caregiver Support Programs

The National Family Caregiver Support Program:

- Created by Congress in 2000
- Calls for states, working with area agencies on aging and local community providers, to provide caregiver support services including information, counseling, support groups, training, respite, and supplemental services
Family Caregiver Support Programs

Federation Services:

- Information and referral
- Respite
- Support groups and counseling
- Case management
- Education and training
- Other support services
The UJC Family Caregiver Access Network (FCAN) Model

Theoretical Framework: The ‘caregiver career:’ (Montgomery & Kosloski, 1999):
1. Performance of initial caregiving tasks
2. Self-identification as a caregiver
3. Provision of personal care
4. Seeking out and using formal caregiver support services
The UJC Family Caregiver Access Network (FCAN) Model

Theoretical Framework: The ‘caregiver career:’ (Montgomery & Kosloski, 1999):
5. Consideration of institutionalization of the care recipient
6. Nursing home placement
7. Termination of the caregiving role
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Literature review:

- Family caregivers often do not use existing support services, for three primary reasons:
  - Lack of self-identification
  - Inadequate assessment
  - Poor service coordination
The UJC Family Caregiver Access Network (FCAN) Model

- Family Caregiver Access Networks (FCANs) are family caregiver resource centers designed to enable family caregivers to access and use the services that can help them maintain their health, well-being, and ability to continue in the caregiving role
The UJC Family Caregiver Access Network (FCAN) Model

Core Activities:

1) Outreach/education/awareness: Interventions designed to promote self-identification among family caregivers and mobilize them to seek out family caregiver support services
The UJC Family Caregiver Access Network (FCAN) Model

Core Activities:

2) **Assessment**: Interventions designed to ensure that the needs, strengths, preferences, etc., of family caregivers are assessed and understood, and that referrals to support services are made based on those needs and preferences.
The UJC Family Caregiver Access Network (FCAN) Model

Core Activities:

3) *Service coordination*: Interventions designed to eliminate gaps and duplications in service, and to promote the ability of family caregivers to access services in an efficient and effective manner.
# The UJC Family Caregiver Access Network (FCAN) Model

<table>
<thead>
<tr>
<th>ISSUE</th>
<th>ACTIVITY</th>
<th>SHORT-TERM GOAL</th>
<th>INTERMEDIATE GOAL</th>
<th>LONG-TERM GOAL</th>
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</thead>
<tbody>
<tr>
<td>Non self-identification as a caregiver</td>
<td>Outreach Awareness Education</td>
<td>Caregiver self-identification</td>
<td>Increased service utilization</td>
<td>Improved health and well-being of family caregivers and increased ability to sustain their caregiving in a positive way</td>
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<tr>
<td>Lack of referral to appropriate services</td>
<td>Caregiver Assessment</td>
<td>Referral to appropriate services</td>
<td>Increased service utilization</td>
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<tr>
<td>Fragmented service delivery</td>
<td>Service Coordination</td>
<td>Seamless service delivery</td>
<td>Increased service utilization</td>
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The UJC Family Caregiver Access Network (FCAN) Model

The ‘caregiver career’ model, revisited:

Stage: *Initiation of Caregiving*
- Performance of initial caregiving tasks
- Self-identification as a caregiver
- Provision of personal care

*FCAN Intervention:*
- Outreach
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The ‘caregiver career’ model, revisited:

**Stage: Exploration of Caregiver Services**

- Thinking about using formal caregiver support services
- Deciding which support services to use

**FCAN Intervention:**

- Caregiver Assessment
The UJC Family Caregiver Access Network (FCAN) Model

The ‘caregiver career’ model, revisited:

**Stage: Formal Service Use**
- Use of caregiver support services
- Consideration of nursing home placement
- Nursing home placement
- Termination of the caregiving role and use of support services for as long as necessary

**FCAN Intervention**
- Service Coordination
The UJC Family Caregiver Access Network Pilot Project

3-year pilot project in which UJC and a small group of federations will test the ability of FCANs to:

- Increase caregiver self-identification
- Improve caregiver assessment
- Improve service coordination
- Improve the health and well-being of family caregivers
The UJC Family Caregiver Access Network Pilot Project

Timeline: Pre-planning stage
• UJC recruits communities for the pilot, creates planning and evaluation materials, convenes conference calls
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Planning stage: Year 1

- Communities identify gaps in services, create mission statements, establish community partnerships, etc.
- UJC creates and disseminates planning materials, convenes conference calls, and creates a national evaluation strategy
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Implementation Stage : Years 1 – 3

- Communities implement and monitor the three core components of the model (outreach, assessment, service coordination)
- UJC creates implementation materials, convenes conference calls, conducts a national process evaluation
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Evaluation stage: Years 1 – 3

- Communities assess the impact of their FCAN activities on the community and on family caregivers who use FCAN services
- UJC creates national evaluation materials, convenes conference calls, and conducts a national outcomes evaluation of the FCAN model
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Dissemination/Sustainability stage:
Years 1 – 3

• Communities sustain their local FCAN projects and work with UJC to disseminate results of the pilot
• UJC convenes conference calls and works with communities on national and international dissemination of the pilot
The UJC Family Caregiver Access Network Pilot Project

Materials:

1) *The FCAN Demonstration Project: A Planning and Resource Guide:*
   - Theoretical framework and model
   - Family caregiver outreach strategies
   - Family caregiver assessment tool
   - Service coordination strategies
The UJC Family Caregiver Access Network Pilot Project

Materials:

2) *The FCAN Demonstration Project: A Project Toolbox:*

- Service mapping instruments
- Process evaluation tools
- Outcomes evaluation tool (family caregiver survey)
- Planning instruments and logs
The UJC Family Caregiver Access Network Pilot Project: Next Steps

Funding efforts:

1) Federal Demonstration Initiative – Project initiated to help 5 communities (Baltimore, Chicago, Durham-Chapel Hill, New York, and New Haven) apply for federal demonstration dollars to develop and test the FCAN model
The UJC Family Caregiver Access Network Pilot Project: Next Steps

Funding efforts:

2) Foundation Initiative – Project initiated to seek foundation dollars to develop and test the FCAN model in 5-7 communities across the country
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