The Caregiver Framework for Seniors: Achieving a Supported Self-Directed Care Model

National Healthcare Leadership Conference
Niagara Falls, Ontario, June 2013
## Outline

**Objective**
- Introduce a “supported” self-directed model

**Agenda**
- Applying the model in practice:
  - Changing the conversation
  - Prioritizing needs
  - Implementing the plan
- Results to date
- Lessons learned
TC LHIN Stakeholders Say...

I need help caring for my mother at home.

I want to live at home for as long as possible.
“Patient education and health promotion are helpful, but even more powerful are patient self-management skills.”

Health Quality Ontario, 2011
What is the Goal of the Project?

To pilot a demonstration project that aims to improve the resiliency of at risk caregivers, using a model designed to meet their needs as they define them.
Strategically Align Decisions with Vision, Values, and Evidence

- Funder: the Aging at Home Strategy via the TC-LHIN
- Lead: Alzheimer Society of Toronto
- Charter: April 2011
- Preliminary findings: January 2012
- Phase 1 completion: March 31, 2012
- Phase 2 completion: March 31, 2013
What is the Project?

Caregivers choose how, when and where to receive goods and services.

Funding for services, equipment, bill payments, respite.

Focus on a “supported” self-directed care model.

An approach that maximizes caregiver autonomy, capacity and resiliency.

A TC LHIN funded project designed to support “at risk” caregivers.

In-Kind Services

Problem Solving Therapy

Direct Financial Support
Who provides referrals?
Enhanced Self-Efficacy

Who is Eligible?

Eligibility

- Care recipient is a senior living in TC LHIN
- Care recipient or caregiver identified as at risk in RAI-HC, or on Caregiver Distress Scale
- Caregiver provides ten or more hours of direct care per week
- Caregiver agrees to participate and provide feedback

Defining Risk

Caregivers

- Physical, emotional, social or financial risks (singly or in combination) that could lead to burn-out
- Too high caregiving demands, possibly leading to burn-out and/or elder abuse
- Disclosed feelings of poor health, high stress or burden, anger or conflict because of caring role

Care Recipients

- Frailty, medical complexity and/or medical instability
- Frequent self-reported emergency room visits and hospital readmissions
- Intensity of formal and informal supports and/or the financial strain relating to these supports
- New long term care home applications or crisis application in processing

*Seniors are defined as persons age 55 and older. Exceptions were permitted where someone has prematurely aged or where an age related diagnosis (i.e. Parkinsonism, early onset dementia) was present.*
Project Boundaries

The Local Health Integration Networks (LHINs) that make up the City of Toronto

Source: 2001 Census, Statistics Canada, Health System Intelligence Project, Toronto Community Health Partnership Profiles
Prepared by Toronto Central Local Health Integration Network
Process mapping: Implementation

**Phase 1 and 2**

**Caregiver Project for Seniors**

- **Coordinator identifies potential caregivers**
- **Assessment, eligibility and consent process**
- **Caregiver info captured from RAI**
- **Coordinator works with caregiver to develop care plan**
- **Coordinator follows up with caregiver**

**AST**

- **Caregiver Approved?**
  - Yes
  - No
    - **Caregiver notified. Referral made to other partner agencies.**

**External Service Provider**

- **Caregiver identifies needs and prepares budget**
- **Self Managed?**
  - Yes
    - **Caregiver arranges services**
  - No
    - **Bill generated**
      - **Bill allocated**

**LHIN**

- **Funding**
- **Framework approved**

**Financial reporting to LHIN**

**Approval of plan and budget**

**Financial reporting to management team**
## Evaluation Strategy

<table>
<thead>
<tr>
<th>Stakeholder Engagement</th>
<th>About the Care Recipient and Caregiver</th>
<th>About the Care Coordinator and System</th>
<th>Mix of Formal and Informal Supports</th>
<th>Self-Directed Caregiver Supports</th>
<th>Outcomes and Outputs</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Seniors, caregivers and advocacy groups were consulted on the framework development</td>
<td>• Key demographic data</td>
<td>• Debriefing sessions with coordinators</td>
<td>• Total service utilization hours</td>
<td>• Care plans: What was selected, by whom?</td>
<td>• Satisfaction</td>
</tr>
<tr>
<td>• Advisory board provided feedback on framework and project design</td>
<td>• Caregiver status</td>
<td>• Pre-Post: ED, LTC, services, stress rating</td>
<td>• Type and extent of supports</td>
<td>• PST process and project implementation</td>
<td>• Impact on system, senior, and caregiver</td>
</tr>
<tr>
<td></td>
<td>• IADL/ADL scale score, CPS</td>
<td>• How well has the project responded to caregiver’s needs?</td>
<td>• What types of care do caregivers provide?</td>
<td>• What help is needed to assist caregivers?</td>
<td>• Compare project clients to SEC clients</td>
</tr>
<tr>
<td></td>
<td>• Stress rating</td>
<td>• Survey</td>
<td>• What would they change?</td>
<td>• #coordinators trained in PST</td>
<td>• #participating agencies</td>
</tr>
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</table>
Setting the Direction: PDSA

What are we trying to accomplish?

How will we know that a change is an improvement?

What changes can result in improvement?

Act

Plan

Study

Do

Health Quality Ontario (2012)
1. Developed a person-centred Framework for delivery of individualized care

2. Built alliances across sectors and enhanced system navigation for clients

3. Founded upon best practices and evidence informed
   - U.S. Cash and Counselling Program
   - SE LHIN/VON Seniors Managing Independent Living Easily (SMILE)
   - Choice in Supports for Independent Living (CSIL)

4. Recognized and included vulnerable and marginalized groups

6. Focused on sustaining caregivers for as long as they deem possible

7. Dedicated staff and resources were made available to sustaining care in the community through the development of innovative strategies for the delivery of caregiver supports

www.alzheimertoronto.org
Caregiver Demographics

Caregivers – average age 66
Caregivers – range of age Youngest 24 Oldest 95
Caregivers – sex Female 77% Male 23%
Caregivers – financial need (observed by care coordinators) 97%

Self-reported Ethnic Group

Language

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## Services Selected by Caregivers

<table>
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<tr>
<th>Interventions in Care Plans (n = 263)</th>
<th>%*</th>
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<tr>
<td>Informal respite care (relative, friend, neighbour, etc.)</td>
<td>31%</td>
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<tr>
<td>Health care supplies</td>
<td>25%</td>
</tr>
<tr>
<td>Personal Support Worker</td>
<td>23%</td>
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<tr>
<td>Social activity / self-care</td>
<td>20%</td>
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<tr>
<td>Equipment</td>
<td>19%</td>
</tr>
<tr>
<td>Physiotherapy/acupuncture / gym</td>
<td>16%</td>
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<tr>
<td>Bill payment</td>
<td>15%</td>
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<tr>
<td>Transportation</td>
<td>15%</td>
</tr>
<tr>
<td>Home help (Meals on Wheels, cleaning services)</td>
<td>11%</td>
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<tr>
<td>Adult day program</td>
<td>9%</td>
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<tr>
<td>Short-stay respite in a residential facility</td>
<td>7%</td>
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Examples of “Care Plans”
Achieving Results through a Supported Self-Directed Care Model

- Most receiving home support receive services like this:

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<th>CCAC</th>
<th>Home Care Agency</th>
<th>Care Recipient</th>
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<tr>
<td>Assesses eligibility for home support, used to determine an approved number of hours based and set services.</td>
<td>Funding for these hours goes to an agency that delivers supports in home.</td>
<td>Receives services provided by a personal support worker employed by the agency.</td>
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- In the Caregiver Project there may be one fewer step:

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<th>CCAC &amp; referral agency</th>
<th>Direct payment</th>
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<tr>
<td>Assesses eligibility for home support, then Caregiver project, and hours</td>
<td>Funding goes directly to caregiver to purchase services and supplies, or directly to vendor.</td>
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Managing the Budget

**Notes**

1. To manage funds as a group it may be necessary to set up a legal trust fund.
2. An independent organisation that manages a personal budget is sometimes called a 'broker'.
3. A personal budget managed by a service provider is sometimes called an Individual Service Fund.
4. In social care, the lead professional is often a social worker but other professionals can also manage budgets.
Assess and Evaluate

• Family caregivers without training/support are at higher risk of developing health issues (Mittelman, et al. 2008; Mausbach et al. 2007).

• Results after the project intervention:
  – People have more control over their lives and feel valued for the role they perform.
  – The system saves over the long run because resources are appropriately allocated, as the caregiver determines what is needed.
Baseline: As compared to peers, participant's scored higher on indices of stress and distress and are more likely to state they are unable to continue caring (29% vs. 16%) and to express feelings of distress, anger or depression (65% vs. 35%).

Post-Questionnaires were mailed directly to caregivers 1 month and 6 months after care plans were implemented with respective return rates of 81% (N=214) and 69%(N=184). Over this time frame caregiver satisfaction remained very high (9.1 of 10); stress remained relatively stable at 4.26 of 10.
Limitations

• Multiple simultaneous interventions.
  – Caregivers were selected from diverse communities and were enrolled on a continuous basis by providers representing multiple sectors.

• Follow up has its time constraints, however this was proven to be a crucial element of the supported self-directed model.

• At-risk caregivers, who are not accessing any support services whatsoever, remain to be targeted.
Achieving Results through a Supported Self-Directed Care Model

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Key Lessons

• Focus on the “triad” – caregivers, care recipients and the health professional
• Be flexible and responsive to caregivers expressed needs for support
• Streamline assessment procedures
• Establish a clear implementation plan
• Revisit the plan and revise as circumstances change
“I don’t know how I coped for all these years. Homecare is a big help. Respite for myself I can't run on empty.”

“My husband goes to adult day program twice a week, this break allows me to rest so I can manage taking care of my husband at night.”
Questions?

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