



Institute of Health Policy, Management & Evaluation  
UNIVERSITY OF TORONTO

# *Caring for Caregivers: Challenging the Assumptions*

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*Caring for Caregivers Symposium  
Ryerson University  
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IHPME

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*Thinking About Caregivers:  
Key Themes*

# Caregivers: Who They Are, What They Do

Catalogue no. 89-652-X — No. 001  
ISBN 978-1-100-22502-9

## Analytical paper

Spotlight on Canadians: Results from the General Social Survey

## Portrait of caregivers, 2012

by Maire Sinha

Social and Aboriginal Statistics Division



September 2013



Statistics  
Canada

Statistique  
Canada

Canada

# Caregivers: A Crucial and Growing Role

## Living Longer, Living Well

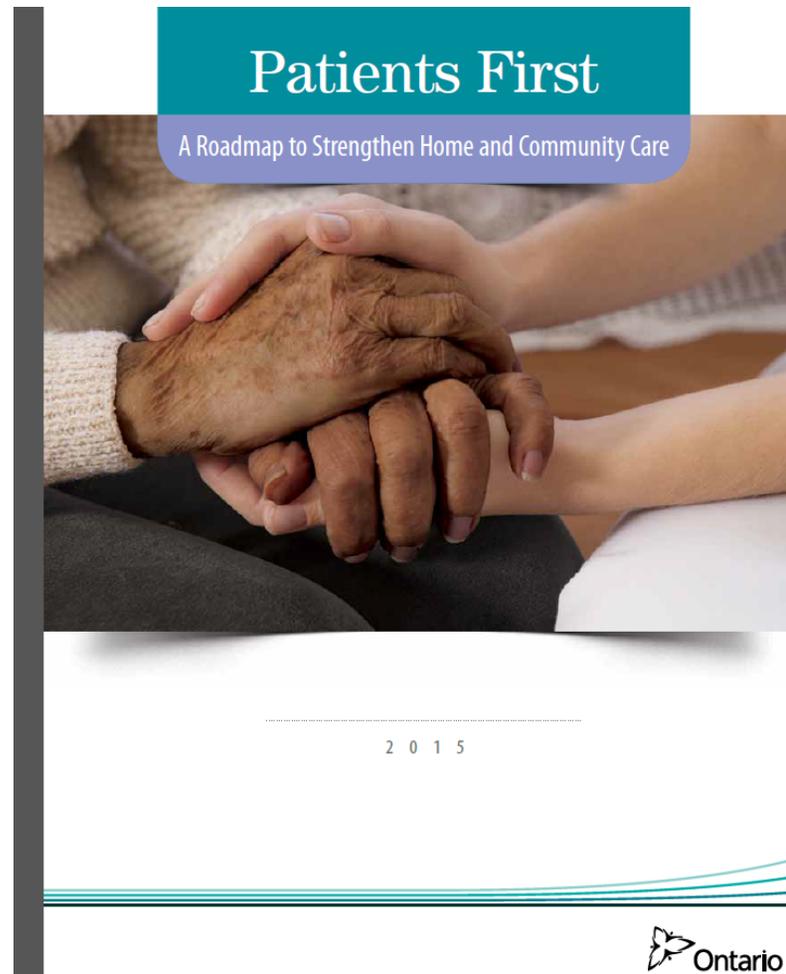
Report Submitted to the Minister of Health and Long-Term Care and the Minister Responsible for Seniors on recommendations to Inform a Seniors Strategy for Ontario.

Dr. Samir K. Sinha, MD, DPhil, FRCPC  
Provincial Lead, Ontario's Seniors Strategy

December 20, 2012



# Unit of Care: Clients and Caregivers



# Costs and Consequences

## IRPP Study

No. 58, December 2015

[www.irpp.org](http://www.irpp.org)



Ideas  
Analysis  
Debate  
Since 1972

### Caregiving for Older Adults with Disabilities

Present Costs, Future Challenges

Janet Fast

Canada needs a comprehensive strategy to support family caregivers, who bear a disproportionate share of the cost of assisting those with long-term disabilities.

Le Canada doit se doter d'une stratégie globale de soutien aux proches aidants, qui assument une part démesurée du coût des soins fournis aux personnes souffrant d'incapacités persistantes.



### The Reality of Caring

Distress among the caregivers of home care patients

Let's make our health system healthier

Ontario  
Health Quality Ontario

# What To Do: Caring About Caregivers

## IRPP Study

No. 23, November 2011

[www.irpp.org](http://www.irpp.org)



Ideas  
Analysis  
Debate  
Since 1972

### Supporting Caregivers and Caregiving in an Aging Canada

Janice Keefe

To ensure adequate home care services to seniors in coming years, Canadian governments will have to better support informal caregivers and adopt a comprehensive human resources strategy.

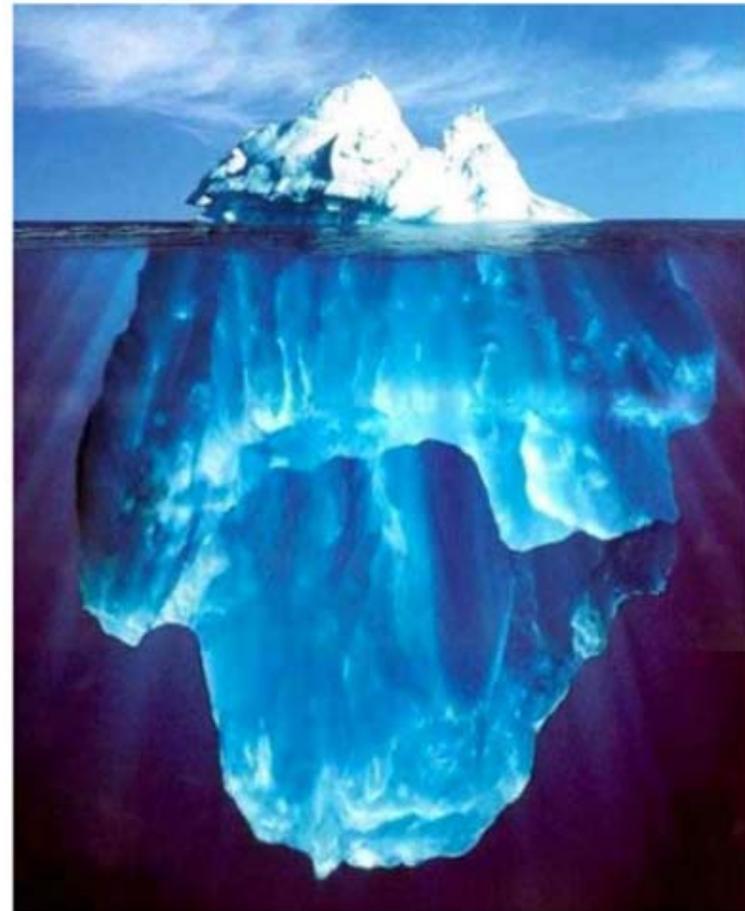
## Caring-About-Caregivers: Caregiving for the future of Ontario

Long-Range Scenario Planning Supporting Caregiving into 2033

November 27, 2009

## Caregivers: *Base of the Health Care Iceberg*

- The “backbone” of the home and community care sector (Lilly, 2011)
- The submerged iceberg (Columbo et al, 2011)
- Formal and informal care inextricably linked



Sources: Lilly. *Who really cares? Caregiving intensity, labour supply and policymaking in Canada*. 2011.  
Columbo, et al., *Help Wanted? Providing and Paying for Long-Term Care*. OECD, 2011.

*Caring for Caregivers:  
Challenging Assumptions*

Vol. 15 • No. 1 • 2015

# Healthcare*Papers*

New Models for the New Healthcare

## Caring for Caregivers: Challenging the Assumptions

A. Paul Williams, Allie Peckham, Kerry Kuluski, Janet Lum, Natalie Warrick, Karen Spalding,  
Tommy Tam, Cindy Bruce-Barrett, Marta Grasic and Jennifer Im

**Commentary from** Shari Brotman, Neena L. Chappell, Eyal Cohen, Ilyan Ferrer, Marcus J. Hollander,  
Janice Keefe, Krista Keilty, Candace L. Kemp, Tamara Krawchenko and Samir K. Sinha



<https://www.longwoods.com/publications/healthcarepapers/24321>

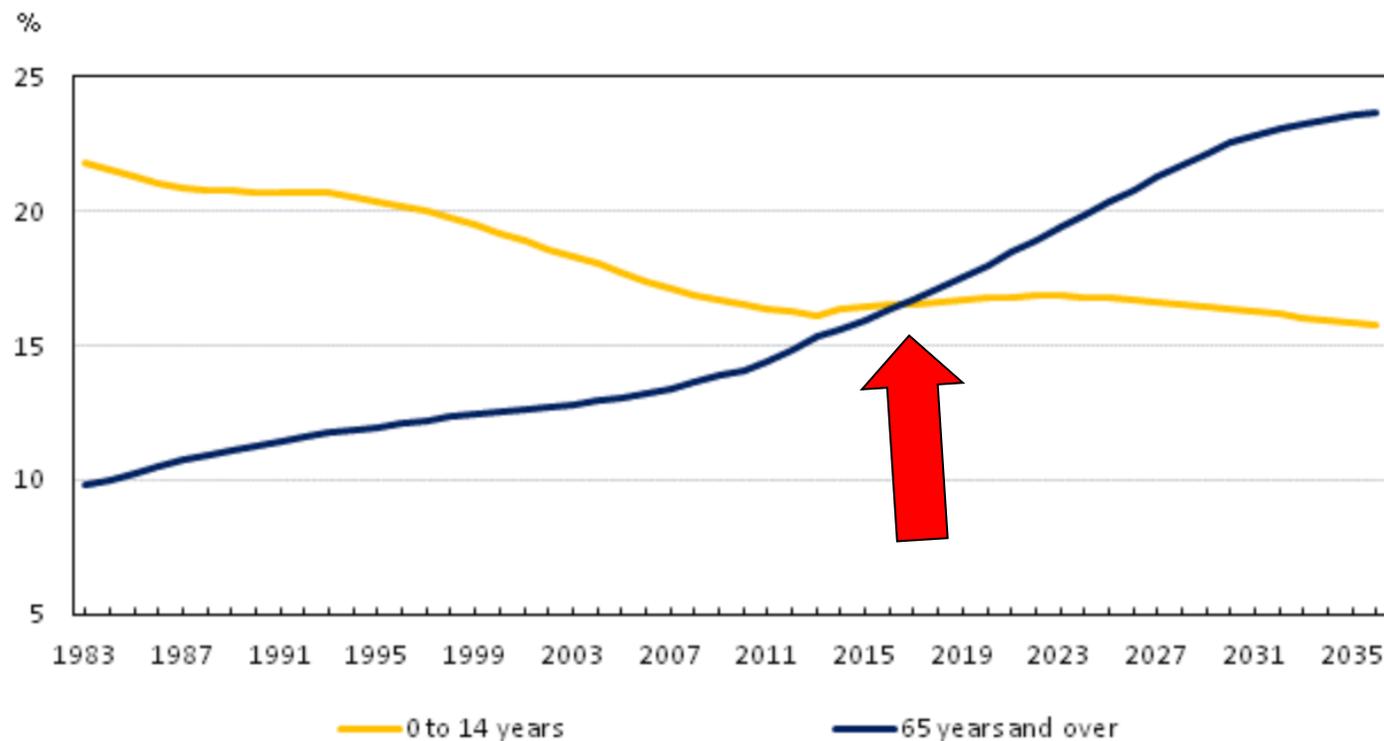
## *Assumption 1: Caregivers Ready, Willing and Able*

- Traditionally, most people were born and died at home; hospitals a last resort
- With the rise of scientific medicine, people now born and died in hospitals
- In the 21<sup>st</sup> century, care again being shifted “closer to home”
  - In hospitals, paid professionals predominate
  - In home and community, caregivers take the lead role

## *Meanwhile, Society Changed*

- Traditional caregiver pool shrinking
  - Smaller families, fewer children
  - Women more likely to participate in paid work
  - Older spouses may themselves require care
  - In rural & remote areas, younger persons first to leave
  - “Families of choice” (e.g., LGBT) may encompass fewer traditional caregivers

# Demographics Reversed: Now More Older Than Younger Canadians



**Note:** From 1983 to 2013, population estimates. From 2014 to 2036, Population Projections for Canada, Provinces and Territories, 2009-2036, medium-growth scenario (M1), Catalogue no. 91-520-X.

Source: Statistics Canada 2013 <http://www.statcan.gc.ca/pub/91-215-x/2013002/ct009-eng.htm>

## *Care Gap Widened*

- “A growing family care gap means that the number of older people in need of care is predicted to outstrip the number of family members able to provide it for the first time in 2017. ... creating a shortfall in our collective capacity to care for older generations.”

Source: Institute for Public Policy Research, UK, 2014

<http://www.ippr.org/publications/the-generation-strain-collective-solutions-to-care-in-an-ageing-society>

## *Assumption 2: This is About Older Persons*

- More persons of all ages now living longer with multiple, chronic *health and social* needs
  - “Successes in medical survivorship”
  - Infants born prematurely, those born with various congenital anomalies and/or those with chronic conditions
  - Persons with mental and physical disabilities
  - Those at end-of-life

## *It's Also About Formal Care Systems*

- Caregiver stress and burnout assumed to result from needs of cared-for persons
- Formal care systems also play a key role
  - Multiple providers, programs and services that don't talk to each other
  - Widely varying access points, assessments, eligibility criteria, service offerings, client records and user fees
  - Changing cast of unfamiliar faces in the home

## *Assumption 3: Money Alone Will do the Job*

- The lure of cash
  - Politically popular, administratively easy
  - Empower individual choice?
- Some big “if’s”:
  - “If” there are services to choose from
  - “If” caregivers have the personal resources to navigate fragmented systems
  - “If” money fails, will caregivers shoulder the blame?

## *A Promising Alternative: Supported Self-Management*

- Caregiver Framework for Medically Complex Children
  - ‘At risk’ caregivers of children living with complex medical conditions
  - Led by Hospital for Sick Children
- Caregiver Support Project for Older Adults
  - ‘At risk’ caregivers of high needs older adults at risk of hospitalization or residential long-term care.
  - Led by the Alzheimer Society of Toronto
- SMILE (Seniors Managing Independent Living Easily)
  - High needs older persons and caregivers living in urban and rural areas of south east Ontario
  - Led by VON

## *Supported Self-Management: Bolstering the Formal/Informal Interface*

- Informal caregivers supported by professional care managers (or teams) equipped with modest budgets
  - Problem-identification and problem-solving
  - Identification of health and social supports available at the local level (including non-traditional providers)
  - Co-creation of care packages tailored to individual needs and circumstances (including religious and cultural communities)
  - Ongoing monitoring and updating of care packages

## *Assumption 4: You Can Wait and See*

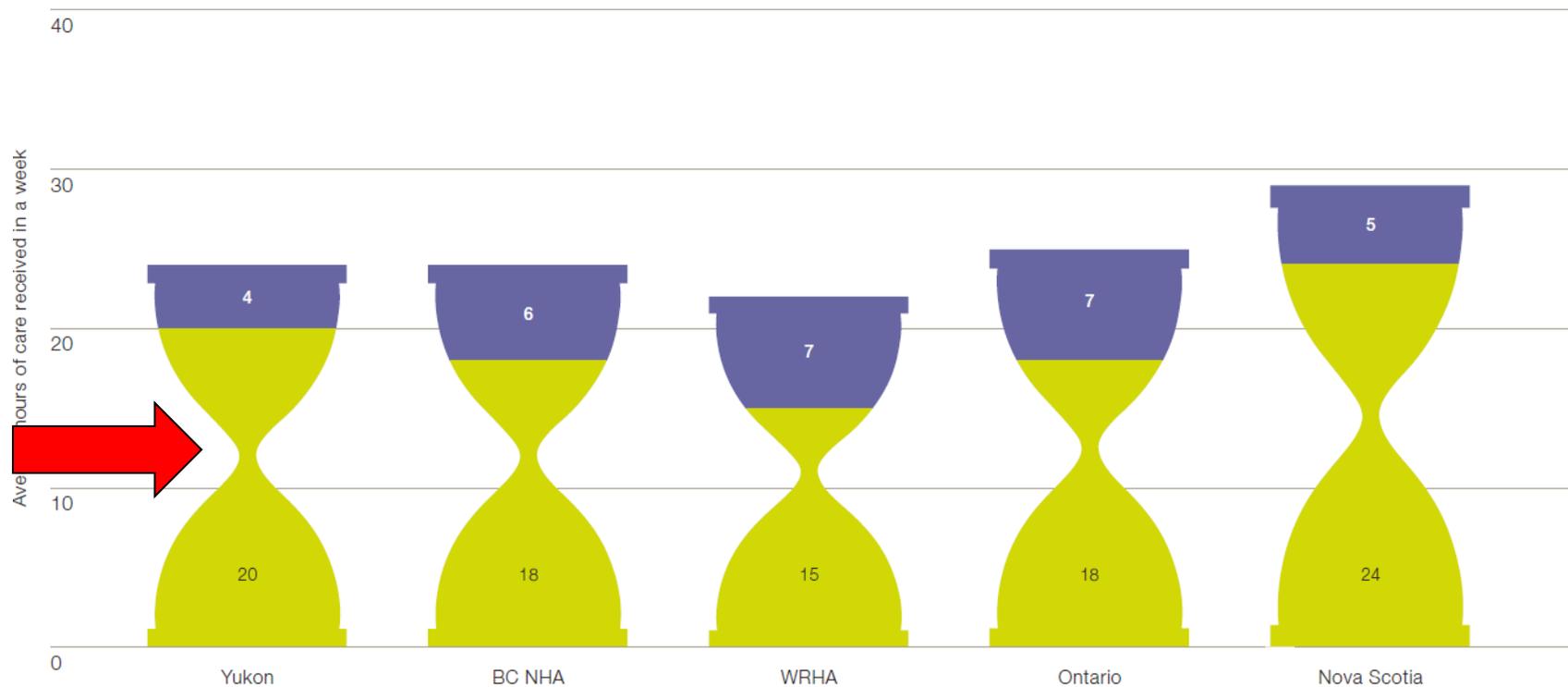
- Delay will buy time and save resources
  - Wait until the point of crisis
  - Applies equally to individual caregivers and caregivers as a group (wait until “at risk”)

# Informal Care Predominates

Average hours of care in a week provided by family caregivers and home care services

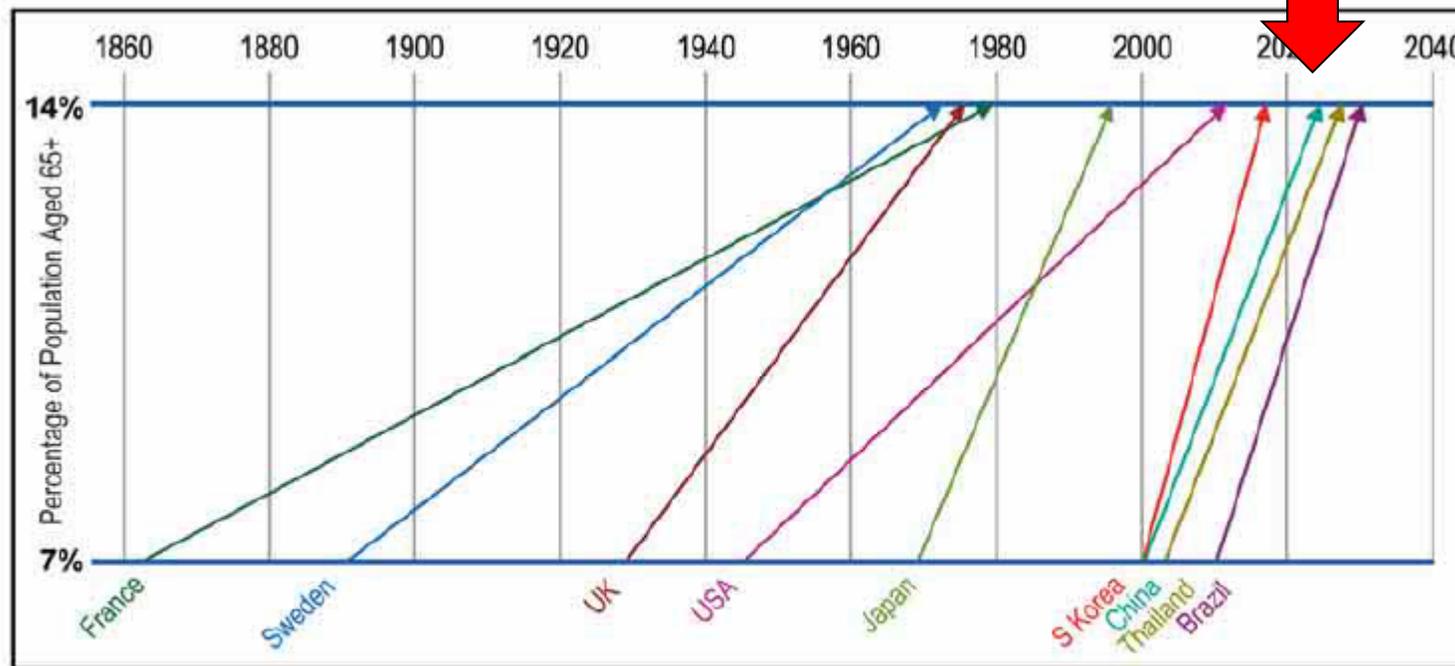
Family caregivers provide roughly three-quarters of the care to seniors.

- Average hours, home care services
- Average hours, family caregivers



Source: Health Council of Canada, *Seniors in need, caregivers in distress* (2012).

## Increasing Speed of Population Aging: 65+ Rise from 7% to 14%



Source: Kinsella K, He W. *An Aging World: 2008*. Washington, DC: National Institute on Aging and U.S. Census Bureau, 2009.

## *Assumption 5: Leave it to the Front-Line Professionals*

- Many dedicated and compassionate care managers who go above and beyond
- However, few guidelines, benchmarks, best practices
  - No universal access to home care
  - No home care service “floor”
  - Caregivers not typically considered home care “clients”
  - Little tracking, analysis of allocation decisions

## *Innovation? Inequity?*

- Leaves room for flexibility and innovation
- Also permits highly subjective and possibly inequitable decisions with little transparency
  - Who “deserves” support?
  - Should working spouses or parents get more support?  
Or less?
  - Should “means” outdo “needs”?
  - What about “families of choice”?

## *Assumption 6: Address Caregivers Separately*

- Separate assessments and care plans to validate and support the caregiver role
- Can also reinforce separation of caregiver and cared-for person and draw attention away from need to look beyond individuals to support networks

## *Go Big: Neighborhood Networks*

- Since 2005, each local area in Leeds, UK, has had its own dedicated Neighborhood Network
  - Local older people and their families get help with the everyday tasks of care, such as free or cheap transport, social activities, shopping, practical help at home, cleaning, gardening and breaks for carers.
  - Families and carers get help to juggle the demands of family, work and caring, delay entry into formal care, and reduce reliance on the NHS.

Source: <http://www.ageuk.org.uk/leeds/about-age-uk-leeds/neighbourhood-networks/>

## Japan's Open Houses: Sakura-chan & Suzu-no-ya

- Run by volunteers who offer people with dementia and carers access to all-day support in private homes
  - Volunteer training
  - Caregiver peer support
  - 24/7 help line
  - “Light touch” regulation



Source: CRNCC. <http://www.ryerson.ca/content/dam/crncc/enews/pdfs/2015/2015-fall-winter-crncc-enews-vol35.pdf>

*Part 3:*  
*Take-Away*

## *Rethink The Caregiver “Problem”*

- Informal care not “apart from” formal care systems
  - Formal system sustainability increasingly relies on informal capacity – the “base of the iceberg”
- Essential to put caregivers back into the equation when doing “capacity planning”
  - How can you plan when 70-90% of capacity is off the table?
  - Avoid load shifting that erodes caregiver base

## *Recognize and Support Caregivers*

- Scale-up and spread support initiatives that demonstrate “proof of concept”
  - Including supported self-management models which work at the interface of informal/formal care

## *Build Supportive Communities*

- “Overstretched services will struggle to provide extra care ... Adult children and partners will take on even greater caring responsibilities and more people, particularly women who outnumber men as carers by nearly two to one, are likely to have to give up work to do so.

Our plan should be to 'build' and 'adapt': to build new community institutions capable of sustaining us through the changes ahead and to adapt the social structures already in place, such as family caring, public services, workplaces and neighbourhoods.”

Source: *Institute for Public Policy Research, UK, 2014*

<http://www.ippr.org/publications/the-generation-strain-collective-solutions-to-care-in-an-ageing-society>



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