Home and Community Care: Living with dementia - at the intersection of formal and informal care in Canada

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Issues

• Situating home care in Canada
• Three key policy and organizational challenges
  • Scopes of practice
  • Scheduling of services
  • “We share the care”: family/ informal carers
• Future challenges
Situating Home Care in Canada

• 2.6 million clients annually (↑ 55%: 2008-2012)
• ~36,000 home care workers
• Outside Canada Health Act: Mixed economy of care providers

• Changing landscape: service delivery more intense:
  ◦ smaller # of clients receiving more hours of care
  ◦ more specialized care (↑ nursing, ↓ housework)
  ◦ Acute, post-hospital focus; move from prevention
More than an a baker’s dozen...

• Patchwork: variable access, availability, costs, wait times: “a crapshoot”; “checkerboard ... situation” (Seggewiss, *CMAJ*, 2009)

• “....where Canadians live, rather than what they need, determines access to services, residency requirements, the payment of user fees, and the continuity of service providers” (Shapiro, 2002, *Health Transition Fund Synthesis*).
Scope – Schedule of Services

• Scope of services:
  • Care Plans - Training
  • Client complex needs: ↑ “Delegation of task”
  • Task-shifting

• Scheduling of services
  • ‘Revolving door’ = many workers: one client
  • Threats to ‘relational’ aspects of care
  • Initiatives: Wages: cluster/ neighbourhood care
Family & friends: Mind the Gap

- 98% (sample 131,000 older adult home care clients) received assistance from informal caregiver (CIHI, 2010).

- Most caregivers are spouses and children (CIHI, 2010).

- Family and “informal” carers:
  - Assumed availability
  - “Private trouble” - Ignored in policy
  - System reactive not supportive
The narrative – the challenge

• Projected 68% of older people with dementia (~500,000) will live in their own homes by 2038—almost triple (ASC, 2010).

• Worker shortages: wage parity – residential care

• Initiatives: Home is Best™ (Fraser Health Authority, BC); “Home First” (Ontario), “Better at Home”