"Enquiring about Family Caregiving and their Cultural Differences"

Developing Policies and Practice through Targeted Research

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Recap

- Health and social policy historically assumes care takes place in the family – formal care a last resort (Hollander et al., 2007)
- Current system not established with the needs of (ethnically) diverse caregivers in mind
- Many family caregivers do not receive assistance from either family or formal services (Health Council of Canada, 2012)
- Current patchwork of services, siloed sectors and systems of care are difficult to navigate and access
- More so when factor in language barriers, cultural expectations and lack of culturally based care options

Recap con't

- Absence of standard assessment tools and resource allocation guidelines – decisions arbitrary
- Considerable variation in the mix and volume of services provided to family caregivers across, and even within, regions of the province (Williams et al., 2009)
- Growing body of evidence indicates it's important to consider the context of diversity in recognizing and supporting informal caregivers for diverse populations (Lum et al., 2011, CRNCC)
- How can research results can be translated into proactive caregiver-related policies and programs in diverse ethnic communities?

Current Information

- Hospital and Doctor focused care not Social Determinants of health – Community Care remains at the margins
- Health cost data generally does not report on caregivers (not identified in acute care)
- Policy makers, researchers, service providers often work in isolation from each other, and in silos due to geography, role, technology and time constraints
- Sectors where caregivers are involved (primary, community and LTC) often lack adequate infrastructure to create and use data

Need for Evidence

- Many things that seem to be common sense often need supporting "evidence" (build credibility, awareness to an issue, seek funding and/or standardization)
- Enhancing and validating data often involves
  - Literature reviews
  - Expert working groups
  - Consultants and Consultations
  - Researchers
  - Frontline practitioners/clinicians
- The role of evidence in the policy-making process
  - Will vary at different stages in the policy cycle
  - Inform decisions but not the only element in agenda-setting/ decision-making/ evaluation

Who Does Policy Research?

- Governments
- Non-government organizations and networks (on behalf of those affected by policy)
- Private think tanks
- Research institutes
- Academics (university setting) / consultants
- Note: each group has differing degrees of neutrality and self-interest

Different Scales in Policy Development

- Federal (Compassionate Care Leave)
- Provincial (Alzheimer Strategy)
- Regional (Aging at Home by LHIN; BoC Rx)
- Municipal (Supportive Housing – hot spots)
- Organizational (Targeted Hiring, Training, Caseloads)
- Professional (Changes in Practice)

Problem-Solving and Policy Cycle

Applied Problem-Solving	Stages in Policy Cycle
1. Problem Recognition	1. Agenda-Setting
2. Proposal of Solution	2. Policy Formulation
3. Choice of Solution	3. Decision-Making
4. Putting Solution into Effect	4. Policy Implementation
5. Monitoring Results	5. Policy Evaluation

Source: Howlett & Ramesh, 2003, p. 13

Getting on the Agenda

- How do we get this topic on the Policy Agenda?
  - *The list of issues/problems to which government officials and people outside of government pay serious attention to at any given time* (Kingdon,1984)
- Problem identification is the first and possibly the most critical stage of the policy cycle (Doern & Phidd, 1983)
  - Power, values and value conflicts are heavily linked to this process of agenda setting

Getting on the Agenda con't

- Framing of problem and implications for non-action are key
- Policy and program choices largely relate to the dominant
  - Institutions (e.g., biomedical responses to social needs)
  - Interests (e.g., medically necessary)
  - Ideas (e.g., public palatability or support)

Broad Strategies to Address Diversity Challenges

- Continue research that profiles the issue
- Translate knowledge/share what we know about current data (locally and internationally)
- Increase sectors' "literacy" about health and social system data (speak the same language)
- Identify gaps (e.g., consider care recipient and caregivers as units of care; economic scales re: impact)

(Peckham et al., 2014; Lum et al., 2011; Williams et al., 2010; Morton, 2010; Morton & Williams, 2009)

Targeted Strategies to Address Diversity Challenges

- Address linguistic barriers (without compromising privacy)
- Disseminate caregiving information through pre-established social, cultural, religious networks in formats that are relevant (aboriginal picto example)
- Understand and make allowances for caregiving within the larger cultural context (CCAC, unions)

(Lum et al., 2011; Morton, 2010; Chinese Caregiver Network, 2012)

Targeted Strategies to Address Diversity Challenges con't

- Respite that respects the culture, religion, language, and food preferences (day programs and in-home)
- Flexible work arrangements that allows for caregiving (also EI, pensions)
- Ethnic focused caregiver groups and crisis lines

(Lum et al., 2011; Morton, 2010; Chinese Caregiver Network, 2012)

Prospects for Change

- Limited possibility of big systemic change – most change happens incrementally
- Consider starting with issues that cost little with big impact
  - Supportive Housing / CCAC language example
- Service Providers may start internally and branch out
  - First Link Program
  - Ethno-specific hiring and outreach
  - Partner effectively (e.g., FHTs)
  - Evaluate, evaluate, evaluate
- Seek grants and pilot project funding to branch out

THANK YOU

QUESTIONS?

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