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Time for Action on Unpaid Caregiving: Research Points the Way

Ottawa – The current situation for caregivers in Canada is inequitable, out of step with community values, and unsustainable. It deserves urgent attention in this election campaign.

Changes in economic roles, an ageing population, the growth of non-traditional families, and public and private cost-cutting, all shift increasing responsibility for caregiving to the community and family, and particularly onto the shoulders of women.

Two new publications summarize the state of knowledge on caregiving in Canada, place it in an international comparative context and propose key principles for redistributing responsibility for care, along with proposals for further research.

A Healthy Balance: Caregiving Policy in Canada, a background report, and *A Healthy Balance: A Summary Report on a National Roundtable on Caregiving Policy in Canada*, were prepared by CPRN's Family Network in collaboration with the Healthy Balance Research Program (funded by the Canadian Institutes for Health Research and jointly led by the Atlantic Centre of Excellence for Women's Health, the Nova Scotia Advisory Council on the Status of Women, and the Institute of Population Health at the University of Ottawa).

The Healthy Balance Research Program includes ongoing consultation with Aboriginal, African Nova Scotian, and immigrant communities, as well as women with disabilities. The research reports document the particular difficulties women in these communities experience regarding access to helping resources, traditional gender roles and inflexibility in support programs. These experiences should be addressed in policy development.

Among the research findings:

- Almost 60% of caregivers for seniors are women.
- About 48% of caregivers are between the ages of 60 and 74.
- They tend to be married or living in common law relationships.
- 76% of male and 45% of female caregivers are in the work force.
- 19% of female and 7% of male caregivers work part-time.

Four trends have accompanied the shift from collective to increased individual responsibility for care;

- *Cost containment in health, income security and social services*, which limits support for unpaid caregivers, and affects women disproportionately.
- *Increased privatization of health and continuing care* leaves caregivers and receivers to cover costs of private services, or leaves unpaid caregivers to fill the gap with additional care.
- *A shift from institutional to community-based health and continuing care* increases demands on unpaid caregivers as they try to support the care receiver in the home or community.

- *Increased geographic inequity in health and social services delivery* results in different support and eligibility criteria and co-payments from region to region across the country.

“Unpaid caregivers in Canada are doing more than ever before,” says David Hay, Director of the Family Network. “More hours of care and work, more juggling of multiple responsibilities, more managing of multiple services and providers, more negotiating and advocating for care, more complex care. The situation is, quite simply, unsustainable.”

The costs of caregiving are both economic (out-of-pocket expenses for drugs or medical supplies, employment related), and non-economic (decline in social, emotional and physical well-being).

The papers propose a values, or principles-based framework to guide policy choices to ensure they are driven not simply by cost reduction, but recognize caregiving as socially worthwhile. This perspective underlines collective responsibility and the shared interest of governments, employers, communities and families in sustainable caregiving.

Among the principles the authors say should guide policies for caregivers:

- The caregiving environment must meet the needs of both caregiver and receiver – we cannot assume the home is the best location for care.
- Caregiving must be voluntary – we must not force individuals to be caregivers.
- Caregivers must have choices over what, and how much, care they will provide.

The kinds of support caregivers need include: information on available supports; recognition, validation and support from family, community, employers, governments and health care providers; training and skill development; respite and help with daily caregiving; emotional and financial support.

“It’s time to replace the patchwork of caregiving benefits now available in Canada,” says Hay, “with a basic level of fair and appropriate supports for this work, which is so central to our economic and social well-being.”

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Note: the CPRN roundtable was hosted by the Healthy Balance Program (funded by CIHR with Carol Amaratunga, Brigitte Neumann and Barbara Clow) and the Hidden Costs, Invisible Contributions Project (funded by SSHRC with Janet Fast and Janice Keefe).

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