

Inuit Family Caregivers Respite Strategy

In 1999, Health Canada established the *First Nations and Inuit Home and Community Care Program* in the North “to provide basic home and community care services that are comprehensive, culturally sensitive, accessible and equitable to that of other Canadians and which respond to the unique health and social needs of First Nations and Inuit.”

The program, presently being implemented, is supposed to enable people with disabilities, chronic or acute illnesses and the elderly to receive the care they need in their home.

According to the Inuit Home and Community Care officer of the implementing organization, the federal government initiative does not involve addressing any of the needs of the family caregivers including the need for respite. We know that there is a heavy reliance on unpaid family caregivers in Inuit communities to provide home care.

Pauktuutit believes it is essential to clearly identify the needs for respite of Inuit family caregivers in the North, as well as develop and implement an Inuit-specific strategy to address these needs. **(We are grateful to the J.W. McConnell Foundation for funding this important three year project).**

A steering committee was formed with representatives from 6 communities and 4 home care coordinators. a meeting was held on April 20-22, 2004 in Ottawa

Present

Sarah Webb – Nain, Jenny Ussak – Arviat, Vivianne Khouzam - Kuujjuaq, Ruth Budgell – Inuvik, Marjorie Storr – Aklavik, Elsa Cheeseman – Cambridge Bay, Deloras Flowers – Rigolet, Leana Audlakiak – Qikiqtarjuaq

Absent

Mathew Tiriraniaq – Gjoa Haven, Minnie Elisapee Morgan - Kangiqsualujjuaq

Staff

Geri Bailey – Pauktuutit Project Coordinator, Catherine Carry – Pauktuutit Project Director, Gela Pitsiulak – Pauktuutit Executive Assistant, Merryl Hammond – Evaluator

Guests

Faye Porter – VON Canada, Karin Kettler – NAHO, Sipporah Enuraq – NAHO, Joanne Lucarz-Simpson – Health Canada, Sean Van Liempt – Health Canada, Jennifer Dickson – Pauktuutit Executive Director

Roda Grey – ITK (regrets), Katherine Pearson – McConnell (regrets)

The agenda for the meeting was extremely full. We reviewed the health care system, home and continuing care, home care in the North, and VON and its role in the McConnell projects.

The goals and objectives of the meeting were:

- To develop a sense of identity for the Steering Committee
- To introduce key players
- To clarify key definitions

- To increase understanding of the cultural/historical context of care giving in Inuit society
- To increase SC understanding of caregivers (Voice, Choice, Respite as Outcome)
- To outline strategies for Phase II of the project
- Establish a draft Inuit Family Caregiver's bill of rights
- To get SC feedback on the draft evaluation framework
- To evaluate the meeting and plan next steps for SC functioning

To ensure everyone was speaking the same language, we discussed key definitions to make them Inuit specific. (Attached Appendix 1)

There was much discussion about the heavy reliance on family caregivers in the North. It is an expected way of life as they all want to keep family in their home communities for as long as possible but realize that they are providing care for which they are not trained, get little or no support and only receive respite when they are stressed to the maximum and respite is seen more as a failure than the right of every caregiver.

In the past, the family had been an indestructible unit of interdependence and traditional teachings. Today more people work outside the home but when a relative requires care sometimes the breadwinner must give up paid employment and care for his/her family member. This is done because of the strong family ties and the desire to keep family at home.

Although all caregivers felt they would not change their decision to care for family, they felt there were areas that needed improvement. The caregivers also found that there was little appreciation or support available for the caregiver, that they are often overburdened by responsibilities and that home care was too often treated as a low priority. As a group they loved: having positive outcomes as service providers; the commitment they have as caregivers; and the teaching and learning that occurs with the care recipients. Things they disliked included: not being helped, recognized or supported; conflicts with the care receivers; the isolation they feel from other members of the community; and not getting resources when they need it.

It was agreed that caregivers were the experts in terms of giving care to the care receivers and that it must be within this context that support systems and resources are developed. There was some discussion for the need to develop support groups for caregivers so they can share their experiences and get support when they needed it.

It was noted that without effective respite, you could end up with two sick people instead of one. "Respite is an essential service" was suggested as a statement that everyone agreed with. Respite care should ideally be something the care recipient can enjoy and not be treated as punishment. Respite care was in the "inner circle" of health care whereas respite for caregivers was not yet. This needed to be reconsidered and aligned with the priorities and needs of caregivers.

The group was asked to identify gaps and barriers in regards to home care. The primary gap was the lack of a wide range of resources available to support caregivers, the lack of

recognition, their isolation, the lack of formal respite, the “dumping” of patients in communities and language issues.

Strategies and solutions to address the gaps and barriers included increasing the awareness of caregivers through a variety of means from radio programs to educating youth. To empower caregivers, setting of limits and boundaries for caregivers was needed. Medication and other training and orientation for caregivers, counseling during and after the care giving process, establishing an association of Inuit family caregivers and developing healing circles for caregivers to provide support to each other were suggested by the group.

The group felt it was important for them to have an identity. They developed a logo which clearly identifies them “*Family Caregivers - - Gaining Strength Through Respite*”. This logo will be used on promotional materials to help raise awareness of family caregivers during the next part of the project.

A teleconference call will be held on June 2nd, 2004 to update the committee on the next steps. Pauktuutit staff will be interviewing people in the selected 6 communities to complete the needs assessment and to add to valuable information already collected during the meeting. These interviews will be done during June and July after the steering committee has approved the questionnaire.

In August / September, staff will be visiting the 6 participating communities to partake in an awareness campaign to foster caregiver recognition and rights. Pauktuutit will be producing a CD that will be heard on radio and made available to all Inuit communities.

