



Alberta Caregivers Association

CLSC Rene Cassin

MS Society of Canada

Schizophrenia Society of Canada

Canadian Association for Community Living

*Lighthouse, Children & Families/
Le Phare, Enfants et Familles*

Pauktuutit, Inuit Women's Association

*Seniors Resource Centre of Newfoundland
& Labrador*

Building Respite Knowledge

A knowledge series on the milestones of the *Care Renewal* projects

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Issue Theme:

Sustaining the *Care Renewal* projects as creators of respite knowledge

THE J.W. MCCONNELL FAMILY FOUNDATION



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Acknowledging our Partners

The *Care Renewal* project would like to thank the following individuals and organizations for their support.

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Understanding our Beginning

The *Care Renewal: Reaching out to Caregivers* project grew out of the experience of The J.W. McConnell Family Foundation strategic funding on respite. In 1998, the National Respite Care Report (supported by the Foundation) found that “respite is not a service, but an outcome, resulting from time off from caregiving responsibilities” (Canadian Association for Community Care, 1998).

In 1999, The J.W. McConnell Family Foundation launched a three-year program in support of family caregivers across Canada. The eight organizations funded during Phase I of the Foundation’s “Respite for Family Caregivers” project confirmed that a major challenge for the Canadian health care and social services systems continues to be how respite is understood and how support is provided to caregivers. Clearly many caregivers continue to carry out their role at the expense of their own physical, mental, financial, and/or social health. The literature shows that caregivers are minimal users of the health care system and that solutions to meet their needs, do not have to be costly (Hillman and Chappell, 2000). (For more information about the Phase I projects, please consult the book *This Day is for Me* by Silver Donald Cameron).

In 2003, the Foundation extended three Phase I projects and expanded their funding to include five other projects that now identifies as *Care Renewal: Reaching out to Caregivers*. These projects were selected, as in Phase I, through a competitive selection process supported by the National Advisory Panel. The Panel was looking for innovative approaches to implementing the concept of ‘respite as outcome’. VON Canada acts as the intermediary to facilitate the knowledge exchange process and to address the policy and practice implications from this initiative. We believe that a larger impact on the quality of life of caregivers can be made through a collaborative effort to gather and disseminate the collective knowledge from all the projects.

Care Renewal Caregiver Promise

As a caregiver, you are the very heart of our caring society. We are here not only to ensure that the work you do is valued and recognized, but also to fulfill your personal need to realize yourself as a unique individual, not only as a caregiver.

You deserve to be heard, and to be able to choose how you provide your care. But most importantly, you deserve the opportunity for respite to develop your own personal life to its full potential. We will do everything we can to achieve these goals in partnership with you.

Valuing Caregivers

The following values guide the work of *Care Renewal*:

- Family caregivers must be recognized for the essential role they play in the country's health and social systems.
- Caregiving is not only an individual responsibility; it is a social and collective responsibility.
- Supports need to emphasize the *voice* and *choice* of caregivers.
- Supports need to be multifaceted, flexible, coordinated, and involve partnerships with the person requiring care, the caregiver, the provider, and the system.
- Respite refers to a caregiver's physical, emotional, psychological, social, and/or spiritual relief or renewal which results from services, activities and strategies intended to help them maintain their own health and achieve greater balance in their lives.
- Caregivers will not experience respite unless the needs of the person they provide care for are met through meaningful and appropriate levels of support and services across the country.
- The needs of caregivers change over time; therefore, supports must be flexible and responsive.

Reaching out to Caregivers

The goals of *Care Renewal* are achieved by reaching out to caregivers:

- To enhance their quality of life through direct support for their identified needs including, but not limited to, opportunities for breaks from their caregiving responsibilities.
- To work with caregivers as full partners in developing, implementing and evaluating policies and practices that affect their lives.
- To test and inform the development of policies and practices that provide flexible individualized options for responding to caregivers' varied strengths, needs and goals.
- To increase the awareness and recognition of caregivers' significant contribution to Canadian society.
- To foster a commitment by Canadian society to support caregivers.

Focusing on our Outcomes

With the support of a team of evaluators, we have integrated an evaluation process to build on our understanding of the impact of our work as we grow and develop as a project. During the Phase I projects, the concepts of voice, choice, and respite as outcome played an integral role in reporting our results. The following is a summary of the key lessons learned from Phase I:

- Information is necessary, but not sufficient, for creating respite as an outcome.
- Caregivers will not achieve respite as an outcome unless they trust that the person they care for is content, well cared for and supported.
- Providers and volunteers should strive to become partners and like “trusted family members”.
- Providers, volunteers and programs should be as responsive as possible to the priorities of caregivers and care receivers.
- The same strategies will not work for everyone. More attention is required to support caregivers in identifying what will result in respite for them.
- Respite initiatives need not be costly. Caregivers often want quite inexpensive supports and recognition.

Building on this knowledge, four other outcomes along with voice, choice and respite as outcome have been identified as part of the *Care Renewal* initiative. The first five themes focus on caregivers while the final two focusing on the overall project outcomes. The following are some of the questions we will be reporting over the next two years:

- **Voice:** Are caregivers able to define what respite means and feels to them? Are caregivers involved in developing, implementing and evaluating programs and policies that affect them?
- **Choice:** Do caregivers have access to options to meet their identified needs? Do caregivers have a choice to be a caregiver, or not to be a caregiver?
- **Respite as Outcome:** Do caregivers experience respite as part of their caregiving experience? How do voice and choice contribute to respite as outcome for caregivers?
- **Caregiver Recognition:** How do caregivers want to be recognized? How do others recognize caregivers, i.e. the general public and other stakeholders? How do we include caregivers as partners in care?

- **Caregiver Empowerment:** How do caregivers create balance in their lives? How does caregiver empowerment relate to caregiver voice? How are caregivers included in decisions that affect them in their caregiving relationship? How do we engage caregivers in a partnership without exploiting their willingness to give care?

The final two outcome categories are important yet distinct from the earlier outcomes as they do not focus directly on outcomes for caregivers. Nevertheless, they are valuable in the overall impact for the *Care Renewal* to enhance the longer-term benefits of the projects to support caregivers.

- **Sustainability:** How do we sustain the concept of 'respite as outcome'? How do we integrate our learnings to sustain the work of the projects beyond the three years of funding?
- **Knowledge Transfer and Exchange:** How can the knowledge gained from the projects (process, context, and outcomes) be effectively shared and utilized by other stakeholders (e.g., individuals, organizations, other jurisdictions)?

Evolving Definition of Respite

Our understanding of respite has evolved since the beginning of this project. The following definitions reflect the changes we have made.

"Respite refers to a caregiver's physical, emotional, psychological, social, and/or spiritual relief or renewal which results from services, activities and strategies intended to help them maintain their own health and achieve greater balance in their lives. This in turn enables caregivers to secure better quality of life and greater opportunities for community participation for themselves and family members or friends for whom they provide care and support" (*Care Renewal*, consultation with projects and other key stakeholders, November 2004).

Respite is defined as "anything that contributes to a family caregiver's emotional, spiritual, physical and/or social rejuvenation, enabling them to have the reserves and resources they need to provide care" (*Respite for Family Caregivers Phase I: Evaluation Report*, 2003).

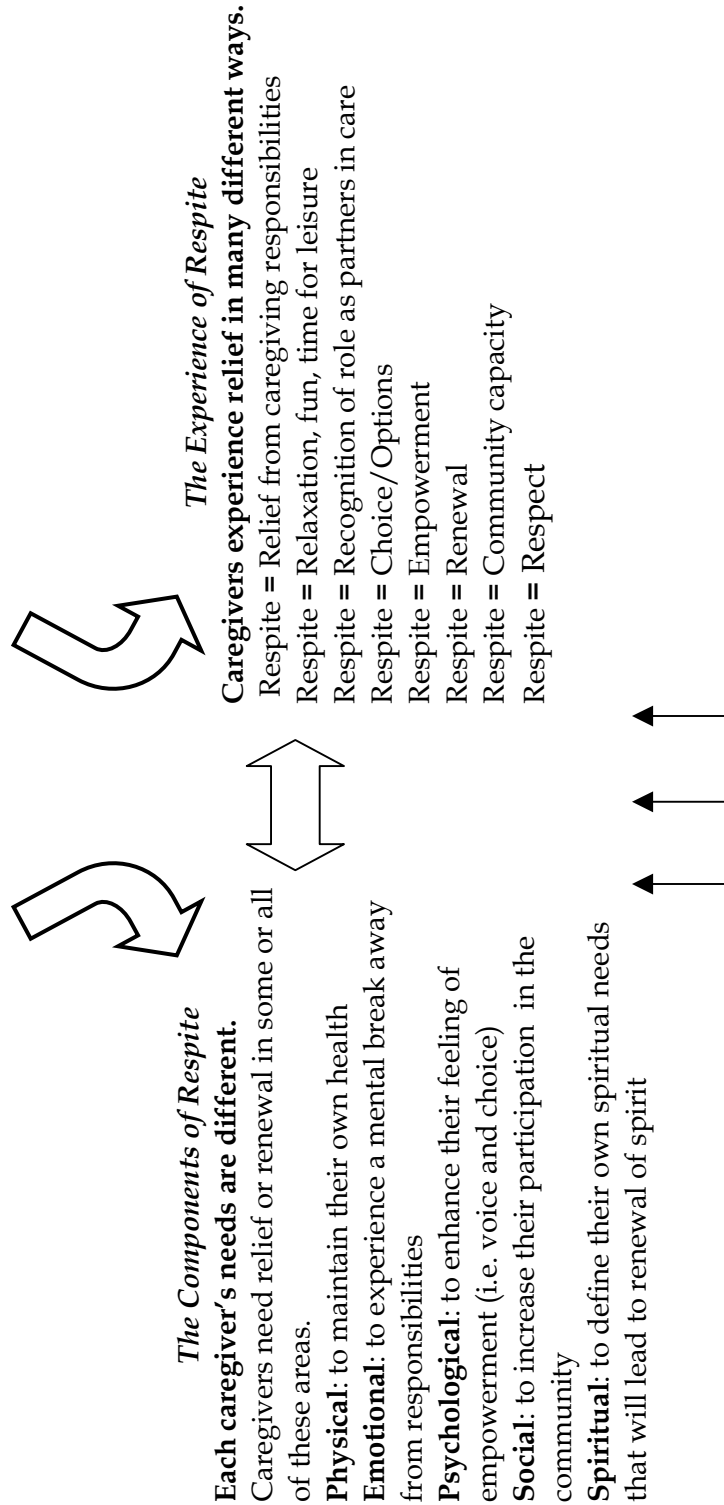


Achieving Respite

In consultation with the *Care Renewal* projects, the following visual description of respite was developed. The meaning, components, experience and foundations of respite are explained below.

The Meaning of Respite

"Respite refers to caregivers' physical, emotional, psychological, social, and/or spiritual relief or renewal which results from anything intended to help them maintain their own health and achieve greater balance in their lives."



Sharing our Care Renewal Projects

There are eight *Care Renewal* projects representing 2 national projects and 6 regional or local projects. These projects have been designed to respond to the findings of the Respite for Family Caregivers - Phase I projects. The *Care Renewal* projects share the common indicators of voice, choice, and respite as outcome. The following is a brief description of the *Care Renewal* projects, including a summary of the common indicators and other anticipated outcomes.

<i>Alberta Caregivers Association</i>	
<i>“Freedom and Friendship” Project</i>	
2004 – 2006	
This project assists caregivers to identify and pursue their personal respite needs. This is accomplished through a detailed assessment of the caregivers respite needs followed by an individualized in-home volunteer visiting program for the care receiver.	
Caregiver Voice	Caregivers have the opportunity to express and explore any personal health need or issue pertaining to them or the care recipient.
Caregiver Choice	Caregivers have the opportunity to plan, select and evaluate the volunteer-visiting arrangement to ensure it supports their own respite activities/plan.
Respite achieved by	Caregivers are able to experience a sense of <i>freedom</i> from their caregiving role while knowing the care recipient is safe and developing a new <i>friendship</i> with the trained volunteer.
Other Anticipated Outcomes	Caregivers will be able to self-monitor their own respite needs and be able to access information or supports beyond the Freedom and Friendship Program. Participation in this project will validate caregivers’ experiences and provide hope and encouragement for the future.

Canadian Association for Community Living

*“Securing Respite:
Building Effective Strategies for Family Caregivers”*

2004 - 2006

A project to help families who have a family member with a disability with information and tools to negotiate support/services to secure respite.

**Caregiver
Voice**

Family caregiver voice is prevalent within the design and process of the project. The majority of national advisory committee members for the project are family carers in addition to a focus on key informant families through focus groups and surveys. The project is explicitly designed (conceptually and practically) based on caregiver perceptions and input about respite – definitions, resources, services, utilization & implications of language, and barriers and opportunities in their local communities. Families’ input has identified the need for a tool to assist families to guide them to secure respite in ways that support and sustain family relationships characterized by principles of self-determination, full and equal citizenship, mutual recognition, respectful interdependence, security, and health and well-being.

**Caregiver
Choice**

There has been identification through caregiver voice to date in the project that resources and tools need to be designed in ways that will assist families to secure their respite by addressing issues that are key to them, whether that be economic security, barriers in communities etc. This enables a broader understanding that respite is one of a cluster of related outcomes that lead to increased choice. Family input has suggested that tool creation should account for a wide range of diversity, but at the same time provides families with: flexibility, choice, voice, accessibility, an opportunity to define their own needs and concrete ways to get respite, given their own unique circumstances.

<p>Respite achieved by</p>	<p>To a significant degree from the particular balance achieved in any situation between individual disability-related needs, family support needs, and the capacity of the community to meet those needs. Recognition that “a key element is that to have respite as an outcome it must be empathetic, organic and uniquely individualistic”.</p> <p>As a result of families’ voices in this project, the conceptual framework for understanding respite was expanded to understand respite as an outcome of the capacity of communities to be inclusive. As a consequence we are developing a tool to assist families to help build community capacity in areas it is lacking for their particular family.</p>
<p>Other Anticipated Outcomes</p>	<p><i>Knowledge Transfer:</i> increased understanding of:</p> <ul style="list-style-type: none"> ▪ The critical importance of nurturing and sustaining family caring relationships, characterized by core principles will assist in developing strategies that support an approach to address a diversity of situations. ▪ Respite options, barriers and strategies and concept of respite as an outcome and the conceptual framework. <p><i>Recognition and Empowerment:</i> through involvement in the process and project as well as through families and users of tools and information.</p> <p><i>Sustainability:</i> through the development and implementation of a tool template to be used for creating a custom tool that fits the context of a particular community and therefore making it sensitive to the local context for families to use locally, to help them negotiate respite.</p>

*Foundation for Vital Aging
and CLSC René-Cassin/ISGQ*

“Care-ring Voice Program”

2004 – 2006

Care-ring Voice is a bilingual, confidential and free, Quebec-wide telephone conferencing program for caregivers, designed as a preventative, supportive and informative resource. Through interactive tele-workshops, on a range of caregiver-specific topics, participants are provided with facilitated access to information and support in order to experience respite as an outcome.

Caregiver Voice	Caregivers determine the thematic content and direction of all teleconference workshops. Teleconferences act as a platform for caregivers to have their voices heard and recognized, as well as a sharing of their expertise and experiences with others. Caregivers who have not utilized the healthcare system or personal resources to meet the care needs of both themselves and their care-receiver gain facilitated access to assistance via our teleconferencing program.
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Caregiver Choice	Caregivers who use our program are provided with concrete information and resources, thereby enabling them to maximize usage of multiple resources, both internal (psychological, mental, spiritual) and external. Through the recognition of their invaluable role and their right to help, caregivers perceive themselves as viable candidates for healthcare assistance. A range of teleconferencing workshops provides an array of informative opportunities for caregivers to feel empowered both within and beyond their roles as a caregiver.
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Respite achieved by	Interactive workshops are driven by peer-to-peer exchanges and volunteer/professional guidance, which enables a transferring of knowledge and expertise on caregiving management strategies. Informative dialogues are complemented by a stimulating social environment that is emotionally and morally supportive, creating feelings of validation and solidarity among participants.
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Other Anticipated Outcomes	Heighten awareness of caregiving issues among the public through a province-wide, bilingual sensitization campaign- assists caregivers in self-identifying and affirms caregiving as a critical healthcare and social issue.
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Le Phare, Enfants et Familles/Lighthouse, Children and Families

“Home Respite”

2003 - 2005

Extension of Phase I project, consolidating the In-Home Program for additional families caring for children with life- threatening illnesses, in the greater Montreal area. This respite program consists of recreational activities carried out by volunteers in the homes of the gravely ill children. The objective is to offer respite to parents.

Caregiver Voice	The program stimulates and encourages the active participation of families in identifying their needs and researching solutions. Ex: Participation of parents in the board of directors and in the care committee. A newsletter “Respite” aimed at families is published 3-4 times a year.
Caregiver Choice	Parents decide when it is best for them to receive the service.
Respite achieved by	Volunteers’ visits allow parents to decide what they want to do during this three-hour period knowing that their children are in good hands. These visits also give parents the opportunity to regenerate.
Other Anticipated Outcomes	The Lighthouse has developed partnerships with caregivers’ associations and health care institutions. Regarding recognition, we found that volunteers’ visits have an impact that goes beyond the respite effect. Visits counterbalance the perception of unfairness and enable parents to regain hope that society has not forgotten them.

Multiple Sclerosis Society of Canada

“The Caring Balance Pilot Project: Supporting Caregivers and People with MS on Their Journey Together”

2003 – 2005

Pilot project designed to enable the MS Society to recognize the important role that family/unpaid caregivers play in supporting people with MS and to encourage caregivers’ own self care. The Caregiver Wellness Funding Pilot Project provided opportunities for caregivers of people with MS to apply for funding for individualized self care plans and wellness activities intended to help them to maintain their own health and well-being.

Caregiver Voice	Caregivers have been involved in all aspects of project design, implementation and evaluation as members of advisory committees. Through the Caregiver Wellness Funding Pilot Project application and evaluation process, caregivers were also provided with an opportunity to voice their views regarding ways to enable them to achieve respite and the self care/wellness outcomes they were hoping to and/or able to achieve for themselves.
Caregiver Choice	This project was designed to ensure that caregivers’ self-identified responses to their needs were funded as long as they addressed needs arising from their caregiving role and could reasonably be expected to have the potential to facilitate opportunities for respite.
Respite achieved by	Access to respite opportunities was facilitated by providing funding for various services, activities, and other costs associated with caregivers’ individualized self care plans and wellness activities.
Other Anticipated Outcomes	<p><i>Caregiver Recognition:</i> Caregivers’ evaluation feedback to date indicates that the project has resulted in recognition of caregivers by: giving visibility to caregivers’ roles as an important aspect of the daily reality of living with MS; demonstrating a recognition of caregiving-related needs and providing a response to these needs; and providing encouragement and validation for caregivers’ self care.</p> <p><i>Sustainability:</i> The overall goal is to develop a sustainable strategy for ensuring organizational commitment to caregiver voice, choice and respite and for building the related capacity within all levels of the MS Society of Canada.</p>

Pauktuutit Inuit Women's Association

"Inuit Family Caregivers Strategy"

2004 - 2006

A needs assessment of Inuit caregivers and set-up of an advisory committee: implementation of the subsequent recommendations and providing training.

Caregiver Voice

Inuit recognize themselves as family members helping another family member rather than as caregivers. Primary objective: to raise awareness and empower people in self-identifying as caregivers. It was felt caregivers would gain voice if they had an identity: a specific logo was designed. Community visits will be conducted in six Inuit communities: none of these communities have permanent physicians or hospitals; they offer a true representation of the 52 Inuit communities across the north. Interviews have been conducted with six key informants in each community.

Findings and Activities so far:

- A radio phone-in talk show to start the ball rolling in the communities
- Posters distributed to the communities to advertise activities in advance of visits
- Key informants as a support group to help plan activities - "Give a caregiver a break today"
- Bannock-making contests and traditional story-telling to get the message out (Inuit traditionally learn by story-telling and by observing)
- Interagency/family approach will: educate community members on the definition of caregiver; identify Inuit family caregivers; promote task delegation and caregiver respite early in case conferences
- Once others identify caregivers, we are working to empower caregivers to identify themselves as caregivers. This will give them voice
- Collecting recordings from community visits to become part of the CD radio messaging to promote awareness.

<p>Caregiver Choice</p>	<p><i>Need:</i> to help people understand their rights and build their knowledge base so they can make informed decisions and choices. Challenge: due to the family structure and traditional values, this may result in an attempt to impact and change tradition.</p> <p>In the larger communities, the trend to move to an economy-based society, and from extended family to nuclear family, has given some families a sense of choice. We found that the concept of “choice” only resonates with Inuit caregivers inasmuch as it relates to “choice of respite activities”. The notion of a caregiver having “choice” by choosing whether or not to accept the caregiver role had no resonance, partly because of cultural issues, and partly, no doubt, because there really are no viable alternatives for families in the North.</p> <p>Often, care recipients choose a certain family member to be their caregiver. When a caregiver has been chosen, it is disrespectful to decline the role. Other family members may blackball that person if she/he chooses not to accept the responsibility, and the person chosen regards the role as tradition, not as a caregiver. When caregiving is seen as a role rather than as tradition or duty, and caregivers identify them, their voice will be heard and become stronger.</p>
<p>Respite achieved by</p>	<p>Going out on the land, fishing, hunting, berry picking, sewing group, Bible study group, church.</p> <ul style="list-style-type: none"> ▪ Attending the community awareness activities will be a form of respite ▪ Many caregivers identified the interview as respite ▪ Steering committees identified the face-to-face meeting in Ottawa as a respite activity <p>With an interagency approach, early family conferences and task delegation, others will be trained from the start to provide alternative care.</p>
<p>Other Anticipated Outcomes</p>	<p>Public education is the first step to sustainability – knowledge is power. An Inuit-specific logo serves as an identifier, and will trigger recognition when the awareness campaign is complete. T-shirts, posters and eventually CDs will be in all communities to remind everyone to stop and appreciate or pay tribute to the people’s vital role in the health care system and the community. Already, small caregiver support groups are being established in some communities: strengthening these and assisting in the formation of others will add to sustainability.</p>

Schizophrenia Society of Canada

“National Respite Strategies for Caregivers of Individuals with Psychiatric Disabilities”

2004 – 2005

To carry out, over a two-year period, a national caregiver driven project focused on identifying and evaluating support needs and strategies specific to caregivers of individuals with psychiatric disabilities. The main activity is the development, distribution, and analysis of a survey to family caregivers and care receivers living with mental illness to identify their needs and experiences around respite. The results will be used to review existing respite initiatives and develop recommendations for best practices at all levels (national, provincial and community based).

Caregiver Voice	Caregiver voice and choice in Year 1 are reflected in the ongoing consultations with a Caregiver Advisory Group and by requesting the input of over 1000 caregivers through a survey. In Year 2 the Advisory Group will be instrumental in finalizing the project recommendations and exploring best practices for respite initiatives at all 3 levels (national, provincial and community based).
Caregiver Choice	Same as above
Respite achieved by	Since we do not engage in direct services this is not a main feature of our project. However, we anticipate that the findings from our survey could lead to assisting in the development of policies and funding decisions that may lead to broader sources of respite.
Other Anticipated Outcomes	Participating in this survey has been a tremendous asset for SSC. It has raised our profile with our provincial societies and branches/chapters many of which are operated by volunteer family caregivers. There is a great deal of interest in the survey and the results it will yield. Putting the issue of respite and family caregivers more specifically on our activities roster has opened new doors for potential collaboration. Collaboration with organizations within our own sector and with those of other sectors.

*Seniors Resource Centre Association
of Newfoundland & Labrador*

“Caregivers Out of Isolation”

2003 – 2005

The aims of the project are to:

- (1) Provide direct support to caregivers according to their self-identified needs,
- (2) Enhance awareness about issues identified by caregivers, and
- (3) Promote policy development that responds to issues identified by caregivers.

Resources include a toll-free Caregiver Line (1-888-571-2273), a quarterly newsletter, a website (www.caregiversNL.ca), and Regional Caregiver Networks throughout the province. These Networks, consisting of community groups, government agencies and caregivers themselves, host events, promote community awareness, and seek to increase supports for caregivers in their region. We are facilitating provincial collaboration between Regional Caregiver Networks, as well as supporting the development of new Networks throughout the province.

**Caregiver
Voice**

Caregiver voice is strong, with caregivers participating on every level as committee members and in regional consultations. All the project’s community awareness and policy work also emphasizes caregiver voice. During the Provincial Roundtable on Caregivers held March 2003, caregivers’ personal stories illustrated the policy recommendations presented and had a powerful impact on the attending decision-makers. Participating caregivers said, “our voices were not only listened to, but *heard*.”

**Caregiver
Choice**

Facilitates the development of tangible supports from which caregivers are able to choose. Caregivers are encouraged to discuss which supports they need to help them cope, as well as what level of care they would choose to provide if adequate supports were available. Through the project, many caregivers have become empowered: these caregivers now believe that they should have the right to have greater choice.

<p>Respite Achieved by</p>	<p>Supports including Regional Caregiver Network-organized respite-related activities like the Caregiver Day Away, a local event for caregivers to meet each other that includes information, caregiver recognition, fun and food. Most caregivers experience peace of mind and renewed energy when they talk to someone on the Caregiver Line, or read other caregivers' stories in the project's quarterly newsletter. Caregivers also experience respite through community resources they find through the Caregiver Line. Some organizations involved with the project have created respite-related programs. The project's policy work promotes the need for increased formal supports that meet caregivers' self-identified needs. In all our one-on-one contact and during workshops, the project also encourages caregivers to access informal supports for respite, where possible, such as asking other family members for help.</p>
<p>Other Anticipated Outcomes</p>	<p><i>Sustainability:</i> The Regional Caregiver Networks, increased community awareness about the experiences and needs of Newfoundland caregivers and continuation of some provincial resources such as the Caregiver Line.</p> <p><i>Recognition:</i> By the general public of caregivers' roles and the need for greater community support. There has also been self-recognition by caregivers, who had taken their roles for granted and now feel more connected with others and are more likely to seek support.</p> <p><i>Knowledge Transfer:</i> Regionally, provincially and nationally of the needs and experiences of caregivers in Newfoundland and Labrador, as well as the learnings from the Out of Isolation project.</p>

Searching for Respite Words

As stated earlier in the issue, the definition of respite has evolved over time. Here is our opportunity to interject some fun into our understanding of respite for caregivers. Find each of the following words. Enjoy!

FLEXIBLE	COMFORT	HEALTH	CAREGIVER
SPOUSE	GENTLE	LOVING	SIBLING
FAMILY	FUN	RENEWAL	RESPITE
CHILD	CHOICE	RELAXATION	FRIEND
DETERMINED	CULTURAL	SHARING	FATHER
VOICE	BALANCE	STRENGTH	MOTHER

M C E I W D E M C H F A T H E R A H C S C D N
O E T G I O E H O Y H I E I C E G D A M H I E
N P C G H E O T A T F A M I L Y N H T G I I H
O M R N E F D L A H H C X I O R I T B E L C L
I E D I A N E A E R R E R I F R V G W N D L N
T P S E E L H E E L T L R N O E O N E T S N P
A T N I T R A H R E N E W A L U L E A L A I F
X E R E B E E B I T N T I C R E G R R E A E N
A F N X D L R L S A E N L L R D E T H E I T T
L P C E Y R I M B P D D R H T I E S N N R A I
E M V O I C E N I I O C U L T U R A L O F E D
R E S P I T E T G N X U X X F U N I F L P D E
M P M F E I T G L P E E S R L L E M R I E C A
A C A R E G I V E R R D L E E T O L T A R I R
C S H A R I N G I T O E I F I C H O I C E A L
I S L A D O F C G S E I E I H F D E I I E S T

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