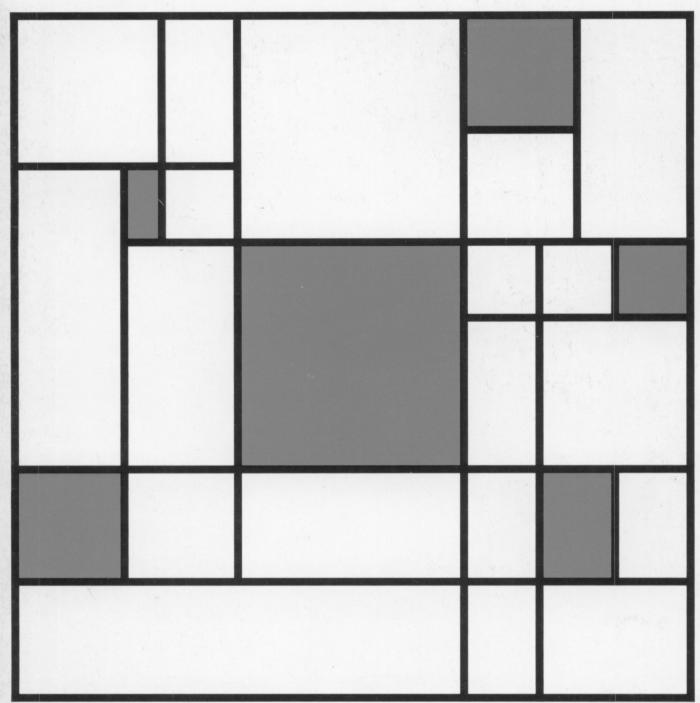
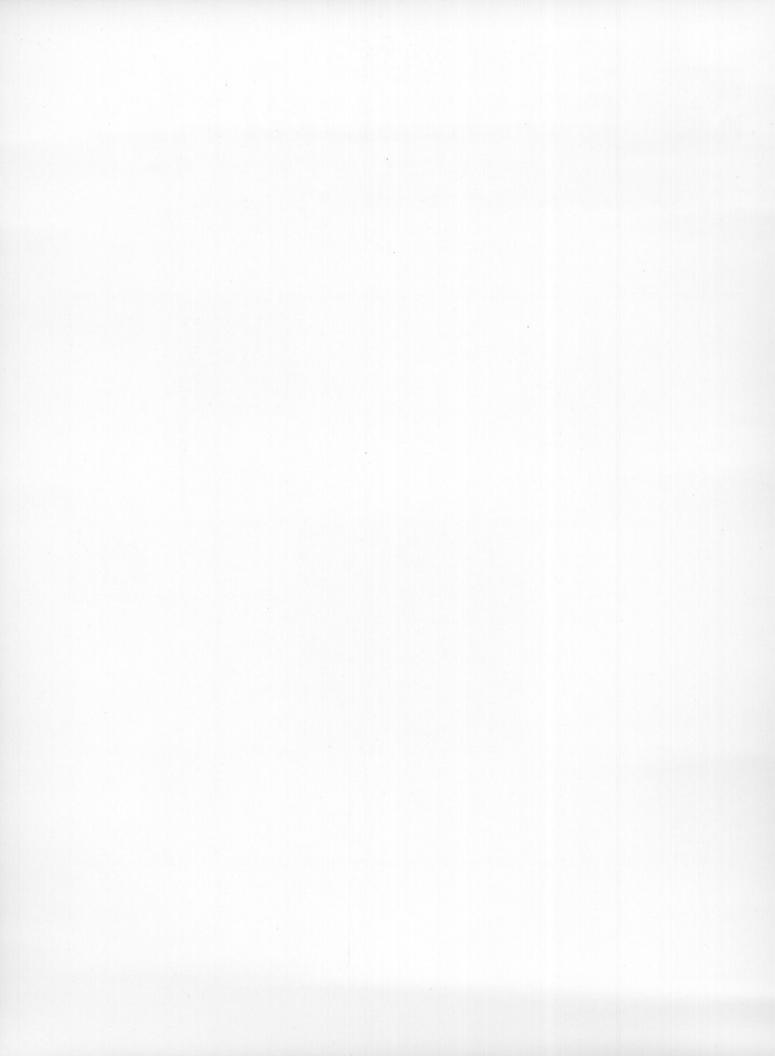


# **CARING COMMUNITIES**

Highlights of the Symposium on Social Supports

Prepared by Douglas Angus, Community Health and Epidemiology, Queen's University at Kingston







Statistics Canada Family and Community Support Systems Division

# CARING COMMUNITIES

Highlights of the Symposium on Social Supports

Prepared by Douglas Angus, Community Health and Epidemiology, Queen's University at Kingston

STATISTICS STATISTIQUE CANADA CANADA

JAN 26: 2000

LIBRARY BIBLIOTHÉQUE

Sponsored by:
Analytical Studies Branch, Statistics Canada
Census and Demographic Statistics Branch, Statistics Canada
Federal Centre for AIDS, Health Protection Branch, Health and Welfare Canada
Health Services and Promotion Branch, Health and Welfare Canada
National Advisory Council on Aging
Policy, Planning and Information Branch, Health and Welfare Canada
Seniors Secretariat, Health and Welfare Canada
Social Service Programs Branch, Health and Welfare Canada

Published under the authority of the Minister of Industry, Science and Technology

Minister of Supply and Services Canada 1991

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise without prior written permission of the Minister of Supply and Services Canada.

March 1991

ISBN 0-662-57447-8

Ottawa

The strategy of the strategy o

The paper used in this publication meets the minimum requirements of American National Standard for Information Sciences - Permanence of Paper for Printed Library Materials, ANSI Z39.48 - 1984.



#### **Foreword**

This document is a synthesis of main ideas contained in the PROCEEDINGS of the Symposium on Social Supports which was held March 28 and 29, 1989 at Statistics Canada, Ottawa.

A driving force behind the Symposium was the observation that there are growing demands being made upon limited human support resources in Canadian communities. Specialists in these fields perceive a need to view the whole set of demands for human caring and helping services in an integrated manner, so that efforts to strengthen community support resources can be designed in ways that will bring more help to a wide variety of social service endeavours.

In a forum which included statisticians and policy and program developers or advisors in fields of social services, leading analysts and experts were provided an opportunity to (1) present and discuss policy-relevant findings from ongoing or recently completed research, and (2) advise Statistics Canada concerning new kinds of statistics and statistical concepts that should be developed in order to improve Statistics Canada's services in this field.

In inviting persons to make presentations of papers, priority was given to research on Statistics Canada's General Social Survey database. The 1985 General Social Survey contained a number of questions dealing with exchanges of assistance among persons. The survey concentrated on health and lifestyles among a nationally representative sample of over 12,000 adults. There was an over-sampling of the older population for the purpose of obtaining, for the first time in Canada, a substantial body of information concerning supports exchanged among seniors and their relatives and friends.

The purpose of this report is to provide a general overview of findings and insights in the various papers and discussions recorded in detail in the PROCEEDINGS, which will be published later. The PROCEEDINGS contain many important elaborations of and support for key ideas, as well as data and research findings, that are omitted from this synthesis, and which will be of interest to social service program developers, policy advisors, researchers, and savants in the field.

Missing from this report, for example, is the rich heterogeneity of viewpoints and perspectives evident in the text of the PROCEEDINGS. This is so because the drafter of this report was asked to introduce his own perspective in order to provide a linkage between the themes and materials presented during the two days.

Douglas Angus' experience in data analysis at Statistics Canada and his later work on social and health policy issues provided him with an ideal background to achieve the overall unity of theme that was being sought for this synthesis. This achievement implies that some themes might get an unusual amount of emphasis. For example, in the early sections of this text, self-help activities and groups receive heavy emphasis relative to other major themes explored during the opening session of the Symposium. A case in point is the important actual and potential contributions of seniors to a wide variety of community support programs.

Leroy O. Stone, Ph.D., F.R.S.A. September 14, 1990

#### **Table of Contents**

	Page
Foreword	3
Introduction and Objectives Symposium Sponsors Organization of the Synthesis Two Key Concepts Defined	7 7 7 8
Stage Setting for Day One and Introduction to the Symposium	8
Theme 1. Self Help and Giving Assistance to Others	11
Overview	11
Précis of Presented Papers "Self-help Movement in Canada", by Hector Balthazar "AIDS: A Community-based Response", by Richard Burzynski "Report on Seniors' Volunteer Work and Unpaid Help to Others", by Susan Fletcher "The Role of Family Resource Services as a Child Care Support", by Irene Kyle	13 14
	15 15
Discussion	16
Pre-luncheon Address "Social Understanding and the Formation of Public Policy", by lan Stewart	17
Theme 2. Patterns of Need for and Usage of Supports	19
Overview	19
Précis of Presented Papers "Friendship and Kinship Patterns Over the Life Course: A Family Stage Perspective", by Brian de Vries	21
"A Comparison of Psychosocial Needs of Persons with AIDS and Canada's Aging Population", by <i>Judy Krueckl</i> "Child Care Needs and Child Care Use Patterns",	22
by <i>Donna S. Lero</i> "Ethnic Variation in Family Support of the Elderly",	22
by Barbara Payne and Laurel Strain  Discussion	23 24
レーラン・ロン・ロン・ロン・ロン・ロン・ロン・ロン・ロン・ロン・ロン・ロン・ロン・ロン	<b>~</b> 4

#### Table of Contents - Concluded

	Page
Theme 3. Public Attitudes and Opinions Regarding Development and Delivery of Community Supports	26
Précis of Presented Papers "The Historical Development of Attitudes towards the Handicapped", by Henry Enns	26
Discussion	27
Stage Setting for Day Two, by Sister St. Michael Guinan	29
Theme 4. Harnessing and Integrating Human and Financial Resources in the Provision of Community Supports	30
Overview	30
Précis of Presented Papers  "Budgetary Problems in the Development of Support Services", by Howard Clifford  "Resource Issues in Caring for People with AIDS", by Margaret Duckett  "The Relationship of Multiple Roles and Employment to Women's Physical Health", by Mia Elfenbaum and Nancy Kingsbury  "Competing Pressures upon Community Support Resources", by Diane Richler  "Associations Between Uses of Formal and Informal Sources of Support in Help Received by the Older Population", by Leroy O. Stone and Margaret DeWit	33 33 34 35
Discussion	36
Principal Recommendations	39
Closing Remarks, by Charlotte Matthews	41
The Participants	42

#### Introduction and Objectives

#### **Symposium Sponsors**

The Symposium on Social Supports was co-sponsored by the following government agencies:

- \* Analytical Studies Branch, Statistics Canada
- \* Census and Demographic Statistics Branch, Statistics Canada
- \* Federal Centre for AIDS, Health Protection Branch, Health and Welfare Canada
- \* Health Services and Promotion Branch, Health and Welfare Canada
- \* National Advisory Council on Aging
- \* Policy, Planning and Information Branch, Health and Welfare Canada
- \* Seniors' Secretariat, Health and Welfare Canada
- \* Social Service Programs Branch, Health and Welfare Canada.

More than 150 professionals from federal and provincial social services ministries, and researchers and policy analysts met to discuss the issues arising from the growing demands being made upon limited human support services in Canadian communities.

All participants attended the Symposium in their personal capacities as experts in one or more aspects of the issues being discussed, and not as agency representatives of any kind. A list of participants is provided at the conclusion of this report.

#### Organization of the Synthesis

The structure of this report is similar to the format of the Symposium itself. The Symposium's PROCEEDINGS were organized under "themes". Each day's activities were begun by stage-setting remarks. A feature of the first day was a pre-lunch address by Ian Stewart, chairperson of the Statistics

Canada Advisory Committee on Research and Analysis and a former Deputy Minister of Finance. The second day's discussions culminated in the presentation of "main themes and lessons" by three rapporteurs.

For each of the Symposium's "themes", this synthesis first offers introductory remarks designed to highlight major threads of thought, issues, and data or analysis requirements that seem to emerge from the pertinent papers and discussions. Then follows a précis of each paper presented.

#### Two Key Concepts Defined

The concepts of "personal-time-dependent service" and "personal-time dependency" are central to the conveyance of main ideas from the Symposium. A brief explanation of these two concepts may be helpful to some readers.

If a person gives up a portion of her or his disposable time over a period of one or more days to help another individual with tasks that the latter finds too difficult to carry out alone, then that helper is providing a personal-time-dependent service. If the individual receiving the help needs the assistance on a regular basis, then that individual has a personal-time dependency.

## Stage Setting for Day One and Introduction to the Symposium

Stage setting for the Symposium was provided in the welcoming address by Ivan P. Fellegi, Chief Statistician of Canada, and in a short statement by Leroy Stone about aspects of the organization of human communities. The following paragraphs capture selected highlights.

It is important to describe the "community" for which human supports are relevant. A community is comprised of a network of interdependent formal and informal organizations which are created to provide a flow of services needed by certain groups. For example, children are dependent upon families who, in turn, are dependent upon community created economic opportunities for survival.

It is becoming more and more apparent that governments are not equipped to respond to all aspects of the growing demand for a wide range of social and community support services, especially those related to human caring and helping. Whether it be for seniors, persons with AIDS (PWAs), the disabled, or families with children, the types of services required involve substantial amounts of *personal time* provided primarily by volunteers.

Resources with which to provide critically needed community support services are scarce. Here, the term "resources" implies more than money. It also includes personal time, health and fitness, knowledge and technology, love and caring, as well as purchasing power. Not only is the *amount* of time available important, but so is the *degree* of "loving and caring" which would so dispose individuals to commit their scarce personal time to specific activities. Once these two important predisposing factors have been accounted for, another essential requirement for effective help is "know-how".

Monetary resources are interchangeable, but units of personal time are not. Different demands for personal-time support may require different sets of skills. Consequently, it is essential to know not only what type of support is required, but also the special qualifications associated with it.

A number of demographic and social factors are slowly altering the traditional pattern of labour availability for human caring activities, as well as the demand for support that entails expenditures of scarce personal time. These changes are creating a rising need for Canadian communities to reassess the human resources available to them for supplying various kinds of support services to their constituent families and individuals.

The concept of time as a "cost" has existed quite a while. Economists refer to this phenomenon as an opportunity cost which, in effect, means that if available time is committed to one activity, then the "opportunity" of using it elsewhere has been foregone. Viewing personal and family time as scarce resources in the same way in which money resources are considered, means that it becomes critical to establish information which will allow community support services to be able to account for and allocate "time" effectively and efficiently.

A key impetus for this Symposium was concern over the ability of society to meet the potentially fast-growing wants for personal-time-dependent community support services, with relatively slow-growing volumes of disposable personal time available to meet those wants. The popular response to this kind of issue is to look for money from some source or to

offer money; but simply providing money resources in these areas may do little to ameliorate shortages of personal time demanded for human caring services.

For Statistics Canada and others concerned with information for decision making, the challenge is to develop relevant data and analysis in a relatively new avenue of statistical work. The outcomes of this Symposium were envisaged as essential inputs into this process.

#### Theme 1

#### Self Help and Giving Assistance to Others

#### Overview

It became apparent during the presentations and discussions that, regardless of whether one considers persons with AIDS (PWAs), the disabled, child care support, or seniors in Canada, there are a number of common threads with respect to self help and providing assistance to others.

Self-help or mutual aid groups have evolved because of changing societal conditions such as the increased emphasis on privatization of services, the many complex changes to Canadian families during the past few decades, the arrival of certain social stigmas, and the relatively high costs and ineffectiveness of existing formal services in dealing with particular community problems.

Furthermore, groups which provide family resource services, or services to PWAs, or volunteer work in general, share a number of basic characteristics and beliefs. All share a community development approach in which the involvement of clients/patients, volunteers, and community members is stressed. They usually comprise a small number of people experiencing a common problem. The individuals within the groups meet regularly to share information, current and new ways of coping, and very importantly, to provide each other with emotional support. Perhaps the characteristic which stands out the most is the circular relationship which exists in mutual support: each member gets help, gives help and helps him/herself. Overall self-esteem is enhanced.

Recent research reveals that help given to seniors requiring assistance is often provided by another senior, most often the spouse, or by age peers. Seniors, as a group, are active individuals supportive of their families and communities. Seniors are an active part of the community mutual aid solution.

Family resource services are a response to the many and complex changes detailed in this theme of the PROCEEDINGS. Family life has changed, and licensed, "formal" child care systems have not kept pace with those changes. Family resource services reflect recent trends in social

services, toward creating better access to services through information and referral, and toward emphasis on health and wellness and through providing preventive services.

Another important feature of this community-based, continuum-of-care approach is that, when compared to the delivery of formal support services, it is relatively inexpensive. The quality of life for the client is usually higher, since many of the services are provided within an individual's community through networks of service outside the existing institutional settings (hospitals, schools, etc.).

Yet, it should not be presumed that there are no monetary costs involved, for mutual aid groups do require some money resources if proper supports for their development and maintenance are to be set up. Even "running the office" requires a day-to-day administrative component, which often cannot be accomplished by volunteers alone.

The establishment of information clearinghouses is another important characteristic of community-based mutual aid groups. These clearinghouses act as the nerve centres from which emanate all kinds of support activities. As centres with which people can identify, they actually can stimulate an increase in the overall self-help movement in Canada. Again, better government and private sector support is desirable, but there is a delicate balance to try to maintain between this type of funding support, and the autonomy and vigour associated with volunteer-supported efforts. The key is to try to avoid formalizing and "bureaucratizing" services.

Important research questions and data/analysis requirements are evident in this area of self help and providing assistance to others. Overall, a key question is: Does the mutual aid movement, and volunteerism in itself, pose the possibility of a significantly different social perspective? This leads to these specific issues:

- \* there is not an adequate data base on which to determine the actual nature and extent of self-help or mutual aid activity in Canada and its regions;
- \* there is inadequate information to ascertain what motivates people to get involved in mutual aid and other kinds of help to persons;
- \* there is a lack of understanding of the mechanisms which might be effective in stimulating the development of mutual aid groups;

- \* more evaluation research is necessary, both with respect to the various community support programs themselves, and also with respect to new evaluation methods that are appropriate to measure the impact of complex and evolving programs;
- \* the attitudes of professionals providing formal services require further exploration, as well as attitudes towards using volunteers in the whole mutual support movement. Perhaps the development of profiles for "ideal" professionals to deal with self-help and mutual aid groups would be useful.

Thus, a major research dilemma, for Statistics Canada, is determining the indicators, variables and informational components of self help and mutual aid. Related to this is the necessity to develop surveys to determine the actual needs (especially psychosocial needs) of people. Survey results could assist policy makers in determining the best ways to address those needs in an all-encompassing framework.

#### **Précis of Presented Papers**

"Self-help Movement in Canada"

#### Hector Balthazar

Without trying to develop a comprehensive definition of self-help groups, Hector Balthazar opened his discussion of the self-help movement by highlighting their key characteristics, i.e. they comprise a small number of individuals who experience a common problem; meet regularly to share information about ways of coping and to develop new ones; give *each other emotional support* (warm and caring relationships); usually do not charge for membership; and are autonomous and responsible only to themselves.

It was suggested that, because of a number of important factors, we might expect the future growth of such groups to be significant. Among the most important reasons for this expected growth are the rising costs and relative ineffectiveness of existing formal services, the increasing need for warm and caring emotional support (especially for people experiencing problems with a social stigma), and the nature and speed of changes being experienced generally in society.

While it is acknowledged that self-help groups cannot solve all problems, they offer the unique empowering opportunity for members to get help, give help and, in the process, help themselves. The movement towards self-help groups is being stimulated in a significant way by an increasing establishment of clearinghouses.

"AIDS: A Community-based Response"

#### Richard Burzynski

For groups in society, such as persons with AIDS (PWAs) for whom the traditional medical model response is inadequate, the community-based approach, based on a continuum of care, is essential. This approach, which incorporates a high degree of volunteerism, provides a network of services within an individual's community to meet a wide range of needs, e.g., telephone hotlines, hospice care, "buddy" programs, education programs, counselling and support groups, and legal assistance. As Richard Burzynski suggested, one of the unique features of this community-based response is the involvement of the "patient/client" (as a volunteer) in developing services alongside other volunteers who come from all walks of life and who are motivated by a sense of loss and concern. All are willing to work long hours. Another unique characteristic is that education messages are tailored at the grassroots level to the sensitivities and needs of specific groups.

When community members are *willing* to join forces, powerful things happen. In the case of AIDS, the cost of treating the disease is significantly lower, and the quality of life and dignity of the PWAs higher. Many services are provided outside the hospital through networks of compassionate members whose "reward" becomes a sense of gratification through helping others. Overall, the work gets done, human needs get met and everyone benefits.

It is cautioned that, unless community-based responses such as these are strengthened, the existing health care system will have to shoulder an even greater burden as demands for services increase.

### "Report on Seniors' Volunteer Work and Unpaid Help to Others"

#### Susan Fletcher

Conventional wisdom, supported by previous research, holds that seniors are dependent and are burdens on their families. Yet, recent research is demonstrating that seniors are relatively autonomous, either individually or as couples, well into their old age. As well, there are support exchanges between the generations. In many multi-generational households, older parents are often providing a home for their adult children, and many senior citizens are actively involved in volunteer work.

Using data from the 1985 General Social Survey (GSS), the National Advisory Council on Aging (NACA) examined assistance and support given by older persons to others. The types of assistance identified by the GSS were financial donations, volunteering in organizations, transportation, baby-sitting, assistance in someone else's home, and personal care outside the house.

A multivariate analysis examined the effects of various characteristics such as health status, education, region of residence on the likelihood of providing the six types of assistance. The analysis did indeed indicate that seniors are active contributors to family members, their friends and communities. Women aged 65-69 who are in excellent health, with a post-secondary education, living with a spouse, and residing in the Prairies, are most likely to provide the bulk of the six forms of assistance asked about in the GSS.

For future versions of the GSS, it may be useful to explore other forms of assistance such as shopping, running errands, and emotional support. Obtaining further information in this regard may reveal that seniors' contributions are far greater than were shown in the 1985 data.

"The Role of Family Resource Services as a Child Care Support"

#### Irene Kyle

While many people think that child care assistance is required only because parents have to work outside the home for income, Irene Kyle pointed out that families want and use child care for many reasons beyond

just finding a day care space. For example, some of these reasons relate to parents wanting to attend educational institutions or training programs, care for children and support to families with special needs, as a supportive resource to families at specific times of peak need, to stimulate children's development and social skills, or to enable parents to participate in volunteer or community activities.

Recognition of this variety of needs has led to the concept of a comprehensive child care system which includes family resource services in addition to more traditional day care programs. Such family resource services reflect recent social trends observed elsewhere, i.e. the movement towards self help and mutual aid, and through information, emphasis on health and wellness and on preventive services, and towards creating better access to services. They also perform three essential support functions: instrumental support (through the provision of material goods and services), emotional support and information and referral to meet other needs.

In spite of the observations that family resource services face serious funding problems, that funding is variable across Canada, and that better government and private sector support is desirable, it is important to realize that there is a delicate balance between desirable funding and maintaining the autonomy and vigour associated with volunteer-support efforts. Finally, Kyle suggested that more research is needed on the family support programs themselves, and on appropriate evaluation methodologies to measure the effects of these complex and evolving programs.

#### Discussion

Remarks from the panelists, Mary Engelmann and James Sauer, and discussion from the floor underscored the similarity between what is happening in family resource centres, the community-based response to AIDS, and what seniors' centres are doing. There is much to be learned from each other to further the self-help movement effectively, especially with respect to how government can most effectively support and assist this movement.

There does not appear to be any explanatory framework which would assist us to understand the dynamics involved in self-help group formation, and the relationship between self-help groups and the large community.

Furthermore, there is a need to know what exists now in terms of self-help groups, and this information has to be accessible quickly and has to be readily understood. Further knowledge of self-help groups in their internal and external dynamics will begin to help us understand what constitutes a "healthy social system".

With respect to seniors, it was suggested that we need to explore their interests and the ways in which they are contributing (and would like to contribute) to their communities. We also need to determine how we can link up older people in the provision of help. It is quite possible, for example, that seniors could (and would) be more involved in family resource centres, whose services are targeted to non-seniors.

#### Pre-luncheon Address

"Social Understanding and the Formation of Public Policy"

#### Ian Stewart

lan Stewart, discussed the relationship between social science research and the policy-making process, and how that relationship has changed considerably over time. In the 1980s we became painfully aware that public resources were limited and that a period of resource constraint was upon us. The traditional political process, assisted by social policy research, was being crowded out by a vast collection of "special interests" which were mounting platforms to avoid being cut.

In effect, this concentration on "micro" issues has distracted our need to examine and understand the larger "macro" issues. For example, what is it that determines how much of the resources that pass through government are allocated to social purposes as opposed to economic or other purposes? What determines how much of our resources will pass through the hands of government as opposed to being distributed by private mechanisms? Of the resources that are distributed by private mechanisms, what is it that determines the level of charitable giving, the division of public-purposed pursuits? What is the state of the community out there? What is the structure of needs? How much of those needs are to be served by flows of government resource, by professional resource, by community resource, by voluntary resource, by self-help resource? Where are the

pockets of inadequate attention? Stewart remarked, what certainly was becoming quite clear during the first theme, that while we live in the "information age", astonishingly little information exists on these issues.

Without sufficient information and relevant social policy research, analysts cannot adequately advise on the necessary sophisticated decisions about how to allocate society's resources and how best to achieve the broadest optimal welfare for the community. What is left, then, is a "raw conflict between interest groups, scrambling in raw political postures for their share of the pie".

In conclusion, Stewart urged the participants to think of those key macro issues. He is convinced that information, research and knowledge likely will contribute more to the solution of our problems. The community at large has an important role to ensure that we do not lose sight of social purpose.

#### Theme 2

#### Patterns of Need for and Usage of Supports

#### Overview

Social networks are of special interest because of their potential usefulness for care, continued health and maintenance of desirable levels of independent living of people, whether they be children, seniors, or persons with special needs such as those with AIDS (PWAs) or the disabled. Of all forms of support, child care can be one of the most critical for parents who increasingly rely on others to help them fulfil their two major functions of working and caring for children. For many seniors and PWAs, there is an unmet need for assistance in their homes with the activities of daily living. Institutional long-term care cannot meet the needs of seniors sufficiently, and for the PWA there are relatively few institutions willing to accept them.

Not only are there differences in needs for support among various family stages, but there are differences between men and women. The form that social support takes may reasonably differ for men and women at stages of life and family development. For example, women have more frequent contact with friends and kin by letter and telephone, while men have more frequent face-to-face contact.

There are parallels among the psychosocial needs of PWAs and some members of Canada's aging population. While aging presents many challenges, AIDS challenges everyone's morals, values and prejudices. PWAs and many seniors experience failing immune systems, but with PWAs the process is accelerated over a very brief time period. Recognition of the grieving process has resulted in many bereavement support groups being developed. Yet, PWA's friends, lovers and families are not using these traditional supports and, instead, there is reliance on self-help groups for support.

Conventional thinking about ethnic differences in the use of supports with respect to elderly household members is challenged by research presented at the Symposium. In analysis of the 1985 General Social Survey data, no clear pattern of differentiation emerges between the "traditional" and "modern" ethnic groups in Canada. Overall, family support patterns of elderly Canadians are more complex than those suggested by the simplistic traditional/modern distinction.

For both research and practice, idealizing certain ethnic groups as having families highly supportive of their senior members and negatively stereotyping others as non-supportive is a mistake. Such an approach overlooks the costs and meanings of family social support, regardless of ethnic group membership. In fact, findings from all of the papers within this theme chip away at the "monolithic" and static view of friendship and kinship, with implications for who supports whom and what support really is.

Various research issues and data requirements emerge from the presentations made with respect to patterns of need for and usage of supports. A major research issue to examine is how women and men actually define friends and kin. For example, de Vries' research suggests that, since women identify a greater number of kin and men identify a greater number of close friends, differences in definition may actually exist. These differences should also be examined by family stage as well, for definitions may differ as a function of position in the life course or, perhaps, as a function of a particular constellation of life events.

Regarding child care supports, Donna Lero notes that we cannot rely on maternal labour force data to estimate the nature and extent of needs (or demand) for child care. Rather, what is needed is precise, detailed information about child care patterns that:

- \* provides a clear picture of current child care use patterns;
- \* goes beyond a static description of arrangements used in the typical collection period ("reference week"), the purpose being to obtain information about annual patterns;
- \* provides information about families as units; and
- \* helps determine the effects of different child care arrangements on children and on their parents.

Another major policy issue addressed by Donna Lero, relates to the broader question of the extent to which current policies and practices contribute to, exacerbate, or ameliorate the difficulties parents experience in obtaining supports. Some of the key research questions are:

\* in what ways can parents be supported so that their primary two functions do not compete with each other?

- \* in what ways can parents (and even other caregivers with dependent elder or disabled relatives) be assisted so that providing support to others does not jeopardize their own personal or economic well-being?
- \* what is the relative cost to individuals, communities, employees and Canadian society of a variety of alternatives? and,
- \* what are the best ways to help individuals and families obtain the variety of supports they need now and in the future?

Finally, regarding ethnic groups in Canada, future research should consider the dynamics, process and meaning of social support, actual support patterns, and the subjective dimension of ethnicity. Furthermore, as the ethnic composition of Canada's senior citizens changes, so too may the patterns of family social support. Future research will have to include a greater proportion of both recent immigrants and other ethnic groups.

#### Précis of Presented Papers

"Friendship and Kinship Patterns Over the Life Course:
A Family Stage Perspective"

#### Brian de Vries

Using data from the 1985 General Social Survey (GSS), Brian de Vries examined the number of close and distant kinships and friendships, as well as frequencies of various forms of contacts with those groups for men and women according to the stage of family development in which they were. Eight stages of family development were identified: (1) pre-marriage, (2) early marriage, no children, (3) early marriage, children at home, (4) late marriage, children at home -- full house, (5) launching of children, (6) empty nest, (7) aging family, retired, and (8) widowhood. Because of their supportive nature and their potential usefulness for care, continued health and sustained independent living of elderly persons, these particular types of social networks across people's life spans are considered important.

The analysis revealed that women identify a greater number of kin (close and distant) and men identified a greater number of close friends. As was noted in the introduction above, this finding suggests a difference in definitions of friendship and kinship for men and women.

### "A Comparison of Psychosocial Needs of Persons with AIDS and Canada's Aging Population"

#### Judy Kruecki

Judy Krueckl identified some of the important parallel psychosocial needs of persons with AIDS (PWAs) and many members of our aging population. AIDS challenges everyone's morals, values and prejudices; aging does not. While many of us do not really look forward to turning 65, most of us are grateful to be alive. The stigma associated with AIDS creates a sense of isolation not only for the patient but for the caregivers as well. As we age, our immune systems begin to fail us and more things go wrong. With an increasingly larger older population, the need for better medical and psychosocial care also increases. The AIDS virus attacks and destroys the immune systems of previously healthy *young* individuals, but *accelerates* the aging process in a brief span of time.

For both seniors and PWAs, home care supports are seriously lacking. For the PWAs the situation is particularly severe: few facilities are willing to accept them and they do not fit into the long-term care guidelines. Yet, even if the PWA is fortunate enough to have an excellent support system, the toll on the caregivers can be devastating. Bereavement support groups have grown all over North America, in recognition of the grieving process. However, friends, lovers and families are not using such traditional supports, and PWAs rely on self-help groups to support them.

Our health care system is already stretched to the limit with the increased costs of medical care, and the need for more acute and chronic care beds. As our older population and PWAs increase so will the need for a better home care system and affordable housing so that people can be maintained with some dignity in their own homes.

"Child Care Needs and Child Care Use Patterns"

#### Donna S. Lero

Of all forms of social support, child care is one of the most essential for parents who increasingly rely on others to help them fulfil their economic responsibility to work, and their responsibility to care for the physical and psychological needs of children in a stable and nurturing environment. Precise, detailed information about child care, which cannot be obtained

from the maternal labour force data, is needed that provides a clear picture of current child care use patterns; goes beyond a static description of arrangements used in a "reference week" (i.e. to obtain annual patterns); provides information about families as units; and, helps determine the effects of different child care patterns on children and on their parents.

In October 1988, data were collected for a large representative sample of Canadian families as part of the National Child Care Study (a collaborative undertaking by members of the National Daycare Research Network and Statistics Canada). This important survey includes comprehensive and detailed information about parental work schedules, family characteristics. and child care used for all children under the age of 13 in the sample families. As a result of this study we will have a firm and valid data base from which to assess Canadians' child care needs (from the broadest perspective); child care use patterns; concerns of parents about child care including its affordability, availability, and quality; and parental preferences. As well, this same study will provide detailed information relevant to policy concerns pertaining to the difficulties involved in balancing work and family life. Along with detailed information about parental work schedules, information has been collected about the availability of benefits and specific workplace policies that can help or hinder parents as they juggle work, family, and child care issues. The actual amount of tension parents report in juggling work, family, and child care is also assessed, along with the major factors that contribute to or reduce tension for working parents.

"Ethnic Variation in Family Support of the Elderly"

#### Barbara Payne and Laurel Strain

Making good use of the 1985 General Social Survey (GSS), Payne and Strain tear away at another piece of conventional wisdom regarding family support patterns for seniors, namely that "traditional" ethnic groups, e.g., French and Ukrainians, show distinctly different patterns of support for seniors than the "modern" ethnic groups, e.g., English, Scottish and Germans. After having compared the French, Ukrainians, Anglos and Germans across various dimensions of social support, the authors found that no clear pattern of differentiation emerges between the "traditional" and "modern" ethnic groups. For any of the dimensions examined in this study (family size, household size, contact with children and extended kin, and instrumental support from a spouse, children and extended kin), ethnic group membership does not emerge as a strong predictor. Instrumental

support includes such things as assistance with yard work or snow shovelling, housework, grocery shopping, meal preparation, money management and personal care. Overall, family support patterns of senior Canadians are more complex than those suggested by the simplistic "traditional/modern" distinction.

#### Discussion

Remarks and discussion from the panelists, Gordon Barnes, Daisy Lau, André LeBlanc, and Carolyn Rosenthal and from participants at large, resulted in a number of points for consideration by policy makers, researchers and information specialists.

An important policy/research issue which was identified, relates to the whole question as to who are the volunteers, anyway. Related to this is the determination of the best way to motivate people to share their time. It was suggested that self-motivation to help others has to be built in early life. rather than waiting until there may be a convenient time to provide help. What, then, should be the strategies? These and many other information development and policy issues were raised during the discussion period. For example, questions and challenges were raised concerning feelings of obligation to provide help to others, undue emphasis on traditional models of family structure, the extent to which different members of support networks can effectively serve as substitutes in providing a needed service, the availability of information about the lives of the oldest groups of seniors. the extent to which the same set of volunteers are involved in helping across a variety of community projects, and the quality of existing research on community needs assessments. The reader should consult the PROCEEDINGS for the detailed discussions on these matters.

In connection with the oldest groups of seniors, for example, there are a number of research questions with respect to social supports for seniors. Perhaps the most obvious is the paucity of information on the social life and social network of very old, frail or close to frail persons. Given the demographic projections which suggest that this population group will increase significantly, this question takes on added importance. Also, since we do not know very much about patterns of caring for older parents or spouses or the needs of those persons, it would be useful to have a survey on elder care.

In a related vein, both very dependent seniors and persons with AIDS (PWAs) require support and very likely they do get much informal support. Yet, we do not know if they obtain this support from the same sources. It would seem that research is warranted here, for AIDS indeed has the potential to seriously impair some older people's family support networks.

#### Theme 3

# Public Attitudes and Opinions Regarding Development and Delivery of Community Supports

#### Précis of Presented Papers

"The Historical Development of Attitudes towards the Handicapped"

#### Henry Enns

From the nature of the papers and discussions to this point in the Symposium, especially when talking about motivation and obligation, one was beginning to "feel" that "attitudes" represent an important element of effective social supports.

Using the care of disabled people in society, Enns, in his paper, traced the changes in attitudes and social support systems for this group, and suggested that such changes have much impact. He is not certain that the attitudinal change which has occurred for disabled people is transferable to all other groups requiring support, but he is sure that for disabled people it had a very profound impact on the way they have started to view themselves, and on the kinds of programs which have begun to develop. Perhaps one way to develop an attitudinal shift for other groups is to pose a number of key questions:

- \* who defines the "problem"?
- \* where is the "problem" located?
- \* what is the outcome of the old and alternative new ways of viewing the "problem"?, and
- \* what then is the role of the group in question under the old and new frameworks?

Under the new framework the disabled are seen as citizens with rights, actively participating in the society of which they are a part. The

development of this new attitude towards disabled people, has also meant a shift in the way social support systems are being organized. "Independent living centres" for disabled people in Canada were cited as excellent examples of what could be achieved if policy makers, researchers, disabled people, seniors, as well as others, could get together and find creative solutions in developing social support systems which use both informal and formal networks.

The important and essential message is that attitudes are extremely critical. If we assume that people with whom we are working are sick, helpless, need to be taken care of, and do not have anything to offer, we will develop one type of attitude. If, on the other hand, we assume that people have skills and abilities and can (in fact) participate in policy planning and research, we will develop a different approach to research and policy making.

#### Discussion

The panelists, Dr. Madeleine Blanchet and Dorothy Pringle, and the participants in general discussion, supported Enns' views with respect to the importance of societal attitudes in shaping research and policy. Certainly, there does not appear to be too much difficulty in generating funds from "telethons". However, when it comes to day-to-day activities, this "compassion" does not seem to go too far. For example, it is easier to obtain agreement on and acceptance for ramps for wheelchairs than it is to accept living next to people with psychiatric problems or persons with AIDS (PWAs).

An important element of the attitudinal problem is the attitudes of professionals. There still exists a "caring for" attitude among the professionals. For example, the doctor, the nurse, or the social worker *knows best*. It is not certain if the professionals have "caught up" with the changes in attitudes being demonstrated by consumer, self-help and other such groups. While much of the problem lies in the socio-cultural system itself, professionals should do more to change attitudes.

This, then, raises important research issues and questions. First, what is the attitude of both the public and professionals with respect to the distribution of social support? Next, how does one go about influencing public and professional opinion? Also, how do resources get distributed anyway, which is one of the important questions raised earlier by Ian Stewart? It is

important for researchers to realize that they, like public opinion polls, can influence policy. We must add to the body of knowledge, and one important void to fill is that regarding attitudes of professionals.

Another important policy/research issue relates to providing help for those who provide support. For instance, women are not getting adequate support and, hence, many women who are helping others are being placed in the same vulnerable position as the groups who are already vulnerable (PWAs, seniors, children, disabled)!

In this regard, more research should be done concerning the social support which *employers* might be able to provide. At the present time, it is generally acceptable to employers to use a certain amount of sick leave for emergency care for children. However, trying this with a spouse or older family member likely would result in losing one's job.

Several additional issues were brought to light during the discussions, which are captured in detail in the PROCEEDINGS. Among them are implications of the fact that in both formal and informal networks, almost all the caregivers are women, giving rise to a need for more information and analysis concerning the costs of caregiving. Alternative models of social support, the need to improve data comparability, greater development of time-series data and trend analysis, and the importance of working in multidisciplinary teams were among other matters discussed. A few years ago, social scientists did not understand anything about AIDS and, likewise, medical scientists understood nothing about social supports. With gradual intermingling of the disciplines taking place, we are learning more and more about each others' services and sciences, professions and disciplines.

#### Stage Setting for Day Two

#### Sister St. Michael Guinan

Acting as a "bridge" from Day One to Day Two of the Symposium, Sister Guinan emphasized that, during the first day, a number of important points had been made, some of which are:

- \* a caring and loving society had to be knowledgeable as well;
- \* society "crippled" itself by not allowing physically limited, though gifted, humans to contribute to national well-being;
- \* attitudes can make us see what is *not* there and fail to see what is there;
- \* many fail to see the resources possessed by seniors, in terms of wisdom, experience and a lifetime of useful skills and spiritual growth; and,
- \* in the provision of day care, it is not just food, clothing and other material benefits which are necessary, but more importantly, it is the expression of love added to these items which the child needs for full development.

For Day Two of the Symposium, the emphasis shifted to harnessing our community resources, a phenomenon which must consider many things. Included in these are the integration of dependency and self help as well as the designation of the sources of social power. Linked very closely to the concepts of the first three themes, this means that attitudes and motivation have to change. In order to sufficiently achieve this, it may be necessary to change some institutional and legal structures in society. Sister Guinan suggested that in order to remedy the vast amount of social needs it is necessary to emphasize the importance of love in Canadian communities.

29

And #

#### Theme 4

# Harnessing and Integrating Human and Financial Resources in the Provision of Community Supports

#### Overview

There is a whole mixture of formal, semi-formal and informal methods for providing community support. In addressing the issue of harnessing and integrating human and financial resources in the provision of community support, economic impact issues are important. As such, it is essential to concentrate on the macro issues for, as was suggested in the first day, the resource pie is limited. Yet, as important as it is to consider community supports from the perspective of cost minimization, it is equally important to look at enhancement of quality of life as well.

In evaluating community support options, it is very important to indicate from which viewpoint (e.g., society, government, health care system, hospital, or patient) the evaluation is being done. Also, while it is essential to include in costs such things as the market value of volunteer time, direct expenses such as rent of meeting places, travel expenses, etc., it is important to try to account for key opportunity costs, especially those related to "lost" leisure.

As was suggested throughout the Symposium, health care and social welfare systems are stretched tightly at the present time. By the mid-1990s in Canada, the number of persons with full AIDS will be about one-third the number of senior citizens aged 85 and over who will require much care. By adding a substantial group of new users the systems could be stretched close to their limits. From the policy perspective, especially universal accessibility, what difference will that make in terms of overall delivery of services?

Related to this issue is the relationship between informal sources of help and the use of formal services. Recent cross-sectional research presented at this Symposium suggested that contact with close kin and contact with friends were significant predictors of the use of formal housework services by seniors. With increased disability there were indications of greater use of both formal and informal supports for help with housework.

Notwithstanding the previous findings on the relationship between informal and formal services, a peculiar phenomenon of Canadian social service programs is that often they can only be tapped by destroying the natural and loving supports which one would like to provide. Indeed, this "Catch 22" situation exists in the lives of people with mental handicaps. We have created generic programs which systematically keep out people with mental handicaps, and then we struggle to rationalize the need for parallel and separate systems. By creating separate systems, an element of automatic competition between groups in need is established, a point well made in Ian Stewart's presentation during the first day of the Symposium. In this environment, there may be little chance at being able to arrive at any "win-win" situation.

In order to resolve competing pressures upon community resources it seems that there will have to be adjustments at a broader societal level which will foster more adequate inclusion of all Canadians into the fabric of society. For people with mental handicaps, it was suggested that these adjustments would have to include dismantling of some powerful and entrenched systems such as the institutional care system and the segregated educational system.

In the financing and establishment of criteria for eligibility to social support services, there may be barriers or burdens unintentionally created to impede access to the needed services. Financing via cost sharing, or maximum subsidy levels, or surcharging may actually work in this way. Indeed, in the area of child care, when budgets have to be trimmed often the target for budgetary cutbacks is nutrition. With respect to the situation where a series of criteria are established for accessibility to a certain program or service, failing to meet the criteria results in a lack of service, while meeting the criteria makes available a variety of supports, often more than required.

With respect to multiple roles which women often assume, it should not be taken for granted that this situation necessarily represents a burden. Without examining the quality of roles assumed, nor trying to establish any causal relationships, there certainly appears to be an association between women's health and the number of roles they take on if they have entered the labour force.

A number of important research/policy issues and questions, as well as implications for data requirements became evident. A key issue arises from the last observation on multiple roles. As has been pointed out previously,

cross-sectional data cannot be used to determine causality, but only longitudinal information can help us arrive at conclusions regarding cause-effect. Hence, there is a need for more and better longitudinal research in this area.

Furthermore, as was also noted, quality of any given role was not considered. In order to examine whether "quality" is the more important factor in terms of health, research would have to look at people's satisfaction with roles they occupy. It seems that employment contributes to better health, but what about other roles? As well, research should address whether it is a certain number of roles or a combination of roles which is associated with particularly good health.

Another requirement is information regarding, and support for, informal social networks. For caregivers, the burden of providing intensive support may affect their own health and may cause tension and breakdown in personal relationships. Yet we do not know what the situation really is.

Usually in social support surveys, we measure how much government puts in and how much people need, usually finding that there is a gap. However, perhaps more importantly, we should be raising the question as to what government and others are doing to foster the volunteer sector, an example of which may be allowing tax deductions for "X" number of hours of volunteer work, or paid time from one's job to perform volunteer services.

If there is an effort to integrate social support services, instead of creating a series of special services, then there will be ramifications for legislation, policy, research, planning and manpower development. As well as requiring a broader base of information about people with disabilities, we will require information which will help identify the barriers to integration or inclusion of services. This knowledge could then be used to break down these barriers and create opportunities to maximize inclusion. Again, returning to a theme discussed by lan Stewart, research must be focused on broader societal issues, e.g., income, and self-determination.

Finally, in order to be able to develop better day care support services in Canada, it was emphasized that research and information are required in four key areas:

\* impact of direct operating grants on salaries, program quality, and the ability of modest and middle income families to access the service;

- \* impact of senior kindergarten and junior kindergarten on the need for day care services;
- \* a follow-up of graduates from early childhood community college programs; and,
- \* a profile of the contributions of volunteers and an assessment of their skills.

#### Précis of Presented Papers

### "Budgetary Problems in the Development of Support Services"

#### Howard Clifford

Howard Clifford discussed day care services in Canada to illustrate the budgetary issues related to the development of support services. Likely one of the greatest problems in this area is the paucity of precise data with which to determine the extent of unmet child care needs. Other areas which create difficulties are cost-sharing arrangements where provinces are responsible for the funding but not for the delivery of services; maximum subsidy levels which are determined by what a province *believes* are the costs of acceptable levels of care; surcharging which, as a type of "extra billing", really defeats the purpose of subsidies; nutrition, which usually is one of the first items targeted in budget-trimming exercises; and rule of eligibility for parental subsidies.

Four important areas for research and information in this area of child care services were highlighted in the introductory remarks to this theme.

"Resource Issues in Caring for People with AIDS"

#### Margaret Duckett

Margaret Duckett pointed out that the economic issues related to providing community support generally are heightened significantly in the case of providing care to persons with AIDS (PWAs), particularly because the needs of PWAs are manifested over a much shorter time frame than with

other groups in society. Health care and social welfare systems already seem stretched. By the mid-1990s, the number of persons with full AIDS will be about one-third the number of senior citizens aged 85 and over who will require a significant amount of care. By adding these substantial new groups of users during the next 5-10 years, what difference will that make in terms of overall delivery of services?

Some of the universal issues which have to be considered are: access to a graduated continuum of services; for caregivers the burden of providing intensive support which may affect their own health and may cause tension and breakdown in personal relationships; ethical issues with respect to death and dying, treatment of the seriously ill, injured or terminally ill persons, the use of modern technology, etc. The volunteer caregivers for PWAs have carried a double burden. Not only have they had the responsibility for intensive emotional, physical and economic support of PWAs, but they also have had to educate the formal and semi-formal caregivers about the issues related to AIDS.

In undertaking economic evaluation of various community supports, Duckett suggests that it is important not only to consider the traditional elements such as what non-professional help would have cost if provided by professionals, the costs of "lost" productivity of volunteers and direct expenses, but also the opportunity costs of volunteer leisure time. In assessing options, all relevant inputs and costs to society have to be taken into account, such that enhancement of quality of life, as well as cost minimization are considered. Information and research requirements include careful evaluation of community supports and what government is doing to foster the volunteer sector.

An extremely important question in this regard, for example, was: if a business lunch is tax deductible because it is potentially expanding the economy, how much is an hour of volunteer time (which enhances someone's quality of life) worth to society?

"The Relationship of Multiple Roles and Employment to Women's Physical Health"

Mia Elfenbaum and Nancy Kingsbury

Using data from the 1985 General Social Survey (GSS), Elfenbaum and Kingsbury show a strong positive relationship between multiple role playing for women and health status. Furthermore, this association is

related very strongly to being employed outside the home. The authors stressed that one cannot assume from the results that increasing roles or entering the labour force causes improvements in health. It is possible that the condition of a woman's health is a factor in determining whether or not she will occupy a role. This issue of cause-effect relationships can only be sorted out by longitudinal data and research.

Another important qualification raised by the authors is that since only role occupancy was examined, and not the quality of the given role, future research should look at people's satisfaction with the roles they occupy to determine whether quality is the more important factor in terms of health. Other important and related future research issues have been discussed in the introduction to this theme.

# "Competing Pressures upon Community Support Resources"

#### Diane Richler

As Ian Stewart noted the previous day, Richler emphasized the importance of considering the "macro" issues, especially since the resource pie is limited. An idiosyncrasy of Canadian social programs is that often they can only be accessed by destroying the natural and loving supports which the family wants to provide. Nowhere is this demonstrated more clearly than with people who have mental handicaps. Generic programs are created which systematically keep out people with mental handicaps and then there are efforts to rationalize the need for parallel and separate systems. Segmentation is counter-productive. Separate systems create competition between groups in need. However with the inclusive systems designed for the most needy, competition is eliminated and strength is built upon.

Yet, starting with the objective of inclusion and creating a series of special services by ensuring that all social services foster such inclusion, creates major ramifications for legislation, policy, research, planning and manpower development. The important point made by Richler is that this approach would work almost anywhere, e.g., with persons with AIDS, seniors, child care, etc. In effect, this approach means enhancing a post-industrial attitude which tears away at the traditional, segmented industrial approach to solving problems.

In order to foster this change, it means that major adjustments will have to be made at a broader societal level. Powerful and entrenched systems will have to be dismantled, e.g., institutional system, segregated education system, and sheltered workshops. If not, there never will be enough resources to build up the supports in the community.

"Association Between Uses of Formal and Informal Sources of Support in Help Received by the Older Population"

Leroy O. Stone and Margaret DeWit

In another study which made good use of the 1985 General Social Survey (GSS), Stone and DeWit examined ways in which the informal sources of help may have influenced the use of formal sources of support. The authors use a "macro-sociological" approach to try to understand patterns of formal service use among seniors. In doing so, it is important to recognize the often strong influence of the informal network in determining how people gain access to and use formal services.

Two important qualifications were highlighted. Since delivery of social services involves personal-time expenditures, the creation and funding of formal support organizations does not necessarily mean there is a secure source of needed *human* resources. Also, it is important to distinguish between informal networks and supports, for the former does not necessarily imply that all relations or exchanges between individuals can be viewed as supportive.

Among the important findings is that if seniors receive greater than average help from close kin and friends (the informal support network), they make lower than average use of formal sources for help with housework. And, increased disability may bring about higher levels of use of *both* formal and informal supports for help with housework.

### **Discussion**

Remarks and discussion from the panelists for this theme (Maria de Wit, Betty Havens, Marcus Hollander, John Angus MacKenzie, Anne Martin Matthews, and David Cassidy), and from the participants in general, raised a number of policy/research issues, questions and requirements for data/analysis.

An important point for policy makers is to be careful just how far they go in "formalizing" support services. As an example, Maria de Wit suggested that "the largest group of volunteers up to the recent past", with respect to child care, has been comprised of the paid employees of child care centres. However, the development of explicit policies in that area is creating the perception among child care employees "that there is more for commitment" to care and funding. Again from de Wit: "in some ways that has resulted in them volunteering less", meaning that the system has to begin to identify more "potential volunteers", to recreate the number of volunteer hours cut back by the child care employees.

Another factor for policy makers to realize is that there is a "cost" of volunteering, and that people must be not only *willing* but *able* to participate as volunteers. For example, in trying to get parents on the Boards of child care centres, perhaps a large number of single parents with extremely low levels of income might truly wish to volunteer, but since their situation is such that they cannot afford a baby-sitter at night, they are unable to participate.

Also, suppose one wanted to be innovative and perhaps try to integrate resources; under the existing situation, it seems very difficult. For example, if senior citizens or teenagers were interested in volunteering in some child care centres, they probably would not be able to get involved simply because the centre may not have enough money to pay for transportation or even hot meals, the additional insurance, etc.

Given these kinds of situations, policy analysts/researchers and policy makers have to start thinking of ways to support innovative and creative initiatives. Certainly, some government money is available, but it still appears that the larger projects, as opposed to the smaller, community-based ones, obtain most of these resources.

Concern was expressed with respect to "volunteer burnout", and suddenly adding to that vulnerable person's load, the chore of co-ordinating volunteers, or paid staff, or whatever. No one mentioned what it means to be able to develop volunteerism in the "community" without having a staffed community development approach. Volunteers will not automatically be effective unless there is some mechanism in place to use them appropriately.

The volunteer of one system might be the client of another, which suggests that the single-program approach to assessing a community's human

resource reserves will lead to serious blind spots, especially regarding the issue as to whether a community's personal-time reserve is close to exhaustion by existing uses which cut across many programs.

With respect to the various agencies themselves, many are not equipping their staff with the knowledge and skills to be able to respond to people with special needs. Adequate training programs are vital. The professional, who carries a large responsibility, is the anchor between the formal and informal supports. There have to be outlets for professionals to talk to each other in order that they can adequately deal with pressures and demands being placed on them in these situations.

A final issue for policy makers to consider more carefully is the role which employers play (or can play) in this area of social supports. Since employers control most of the time resources we have, it seems that they will have to be much more accommodating in the future. Most of our support givers are people who are employed, and many of the critical issues with respect to the allocation of time rest with employers to a significant extent. Regarding women, for example, how might employers involve themselves in relieving the stress of multiple roles?

In addition to the previous policy issues, a number of research questions/issues which have data implications were identified:

- \* What are the impacts of block grants on day care?
- \* Who are the volunteers and the programs in which they are involved, and to what extent are volunteers involved in multiple programs?
- \* With respect to multiple roles, is there a certain point beyond which role accumulation becomes a strain? Are there certain roles which will lead to strain, and others which never would?
- \* What are the advantages and disadvantages of various forms of funding for support services? How would multiple sources of funding affect service delivery?
- \* What information can help decision makers in making choices between the cost-effective purchase of services, and the competing goals of equity and social justice?
- \* What about mental health issues and the impact of multiple roles, for example, on job stress?

- \* What are relative contributions of friends and neighbours, as opposed to family, in the provision of supports?
- \* Researchers should re-examine their assumptions about today's realities -- they may still be holding onto yesterday's ideas. For example, what constitutes a "family"? What are the needs of seniors? To what extent are our personal biases serving to mold and create needs or expectations, and to what extent are we really identifying and tracking *real* changing needs in our research, and in our self-help efforts?
- \* Certainly the use of formal and informal support in help received with homemaking is an important topic, but are the formal support services about which we talk (e.g., cleaning, etc.) as readily available as we appear to assume they are?
- \* It may be useful for research agencies such as Statistics Canada, the National Health Research and Development Program and provincial research granting bodies to more actively pursue a dialogue with other groups, especially key decision makers. This may help to identify information which would assist in policy and resource allocation decisions.
- \* It was suggested that a vehicle for dissemination of results should be available, e.g., new journals of applied research and analysis.

### **Principal Recommendations**

For the closing session of the Symposium, professors Benjamin Gottlieb, John MacDonald and James Thornton identified recurrent themes which emerged from the discussion over the two days. Then followed an open discussion about the kinds of recommendations that ought to be made to Statistics Canada. Drawing partly upon this discussion, which is presented fully in the PROCEEDINGS, and upon the texts of the other discussions, the following is a statement of the central lessons of the meeting concerning information needs.

In order to help communities strengthen their programs of developing resources to provide human caring services, the following information requirements are worthy of attention by Statistics Canada:

- (1) Supply of and requirements for human caring services: There is need for repeated estimation of the volume and attributes of human resources available to provide helping and caring services to persons and families in need. The data should permit comparisons of available resources with estimates of requirements for human caring services, showing details for broad types of regions and skills. National-level data in this area should be organized to support the development of satellite accounts on work output in such a way as to statistically integrate work in paid labour markets with work outside those markets. The measurement should rely upon the choice of some unit of personal time that can be allocated to alternative uses. Underlying this emphasis is the notion that available personal time for human services delivery is a strictly limited resource whose development and conservation deserve systematic attention if the requirements of those in need of social services are to be reasonably met.
- (2) Forecasting and planning needed changes in social services delivery systems: Longitudinal data are needed on support-related attributes of givers and receivers of major kinds of human caring services. These data are crucial to the achievement of improved forecasting and planning of changes in systems of social services delivery that will be needed as a result of shifting demographics and working life-styles.
- (3) Improving the effectiveness of the balance or mix between informal (e.g., family) and formal (e.g., government) human support services: Data are needed on patterns and processes of seeking, giving and receiving human support services, so as to support analyses designed to improve the effectiveness of links between formal and informal human support services.
- (4) Information system about self-help groups: Marked growth of self-help groups is one of the most significant recent developments in North American communities. The work performed by these groups is of a kind that formal agencies and family units have great difficulty providing, and yet without that work there is increased burden upon agencies and families with regard to human services delivery. A new information system and related analyses are needed to promote the growth of organized and usable knowledge about the self-help movement. This knowledge would assist formal organizations (e.g., government and large private sector firms) to gain insight into the actions they might take to stimulate the development of self help, and thus lower the public requirement for government interventions.

## Closing Remarks

#### Charlotte Matthews

In her closing address to the Symposium, Charlotte Matthews observed that one need truly stands out, namely, the need for good planning. It also is quite clear that good planning cannot take place if reliable information is not available. Matthews suggested rather forcefully that policy makers and researchers have a responsibility to let Statistics Canada know about their information requirements and, very importantly, they have a responsibility to support the agency.

### The Participants

The following professionals who attended the Symposium were doing so in their personal capacity as experts in one or more aspects of the issues being discussed, and not as agency representatives.

Andrew Aitkens, Communications Director, One Voice -- Seniors' Network (Canada), Inc., Nepean, Ontario

Douglas E. Angus, Executive Director, Institute for Health Care Facilities of the Future, Ottawa

John Numa Bachtold, Director of Social Work, Elisabeth-Bruyère Health Centre, Ottawa

Hector Balthazar, Program Consultant, Self Help, The Canadian Council on Social Development

Gordon Barnes, Department of Family Studies, The University of Manitoba

Bruce Baskerville, Canadian Hospital Association

Rebecca Belanger, Research Officer, Community Health Division, Health and Welfare Canada

Karl Benne, Senior Consultant, Community Health Division, Health and Welfare Canada

Richard Berger, Director General, Corporate Policy Branch, Secretary of State of Canada

Susan Berlin, National Office Project Coordinator, Canadian Healthy Communities Project

Leandre Bilodeau, Ministère de la santé et des services sociaux, Québec (Québec)

Madeleine Blanchet, Présidente, Conseil des affaires sociales, Gouvernement du Québec

Cathy Bonnah, Coordinator, P.E.P. Project, VON Canada, Ottawa

Albert F. Bowden, President, Canadian Hard of Hearing Association, Ottawa

Anne Bowlby, Ministry of Health -- AIDS Section, Toronto

Margery Boyce, Special Advisor -- Seniors, Office of the Honourable Monique Vézina, Minister of State for Seniors

Gary Bradford, Socio-Legislative Consultant, Planning and Evaluation, Department of Income Assistance, Fredericton

Alexa Brewer, Policy Analyst, Health Policy, Policy, Communications and Information Branch, Health and Welfare Canada

Satya Brink, Senior Analyst, Strategic Planning and Policy Development Division, Canada Mortgage and Housing Corporation

Linda Brown, Program Officer, Policy Development, Health and Welfare Canada

Lynn Buhler, Research Officer, Ottawa-Carleton Health Department

Joe Burpee, Chief, Quantitative Analysis, Health Policy, Health and Welfare Canada

Carol Burrows, Home Support Director, Council on Aging of Ottawa-Carleton

Richard Burzynski, Executive Director, Canadian AIDS Society, Ottawa

Heather Caloren, Director, Senior Adult Health Program, Ottawa-Carleton Regional Health Unit

David Cassidy, AIDS Community Liaison, Ville-Marie Social Services Centre, Montreal

Mary Chase, Policy and Program Consultant, Nursing Home Branch, Ontario Ministry of Health, Toronto

Ann Chudleigh, Policy Analyst, Corporate Policy Branch, Secretary of State of Canada

Elizabeth Clark, CSAM, AIDS Committee, Montreal

Janyce Clark, Transportation of Disabled Persons Program, Transport Canada

Alastair J. Clayton, Director General, Federal Centre for AIDS, Health and Welfare Canada

Howard Clifford, National Advisor, Child Care Programs, Health and Welfare Canada

John Collins, Research Associate, Committee on Gerontology, The University of British Columbia

Cora Craig, Executive Director, Canadian Fitness & Lifestyle Research Institute, Ottawa

Thérèse Darche, Conseillère, Secteur des services d'hébergement et soin prolongées

Lise Darveau, École de Services Sociaux, Université Laval

Christine Davis, Social Data Research, Hamilton

Ron de Burger, Dean, Faculty of Health Professionals, Dalhousie University

Pauline Desrosier-Hickey, Director, Program Evaluation and Analysis, Department of Health and Community Services, Fredericton

Brian de Vries, School of Family and Nutritional Sciences, The University of British Columbia and Gerontology Research Centre, Simon Fraser University

Maria de Wit, Assistant Director, Children's Services, Community Services Department, Municipality of Metropolitan Toronto

H.J. Dilling, Research Director, Educational Research Services, Scarborough

Pearl Downie, Senior Advisor, Health Affairs Directorate, Health and Welfare Canada

Grace Dramantas, Nursing Consultant, County of Lambton, Petrolia

Margaret Duckett, Consultant on AIDS in Australia, and formerly a visiting scholar, McGill Centre for Medicine, Ethics and Law, McGill University

Mia Elfenbaum, Graduate Student, Department of Family Studies, The University of Manitoba

Mary Engelmann, Director, Senior Citizens Secretariat, Province of Alberta

Henry Enns, Chairperson, Disabled Peoples' International, Winnipeg

Frank Fedyk, Senior Policy Advisor, Policy, Communications and Information Branch, Health and Welfare Canada

Ivan P. Fellegi, Chief Statistician of Canada, Statistics Canada

Susan Fletcher, Executive Director, National Advisory Council on Aging, Health and Welfare Canada

Darlene Flett, Principal, The Development Planning Associates Group, Inc., Ottawa

Forrest Frankovitch, Department of Sociology, The University of Western Ontario

Sheryl French, Health Services and Promotions Branch, Health and Welfare Canada

Adele Furrie, Program Manager, Disability Database Program, Statistics Canada

Reg Gabriel, Director, Division of Services to Senior Citizens, Department of Health, Government of Newfoundland and Labrador

David Garmaise, Program Officer, Canadian AIDS Society, Ottawa

K. Glass, McGill Centre for Medicine, Ethics and Law, McGill University

G. Goldmann, Manager, Content and Planning, 1991 Census of Population, Statistics Canada

Catherine Goodman, A/Director, Data Development and Analysis, Health and Welfare Canada

Carolyne Gorlick, Department of Family Medicine, The University of Western Ontario

Benjamin Gottlieb, Department of Psychology, The University of Guelph



Gweneth Gowanlock, Chief, Health and Social Services, Federal Centre for AIDS, Health and Welfare Canada

Mark Gromoll, Senior Economist, Transportation Services for Disabled Persons, National Transportation Agency of Canada

Sister St. Michael Guinan, Consultant in Gerontology and Pre-Retirement Training, Professor Emeritus, The University of Western Ontario

Betty Havens, Provincial Gerontologist, Manitoba Health

Lynda Hayward, Research Associate, Program in Gerontology, University of Waterloo

Nicole Henderson, Senior Analyst, Communications Secretariat, Privy Council Office

Marcia Hills, School of Child and Youth Care, University of Victoria

Marcus Hollander, Research Associate, Gerontology Research Centre, Simon Fraser University

G.D. Hutton, Director, Senior Services, County of Lambton, Petrolia

Sharon Jeannotte, Policy Analyst, Strategic Policy Planning Division, Communications Canada

Paul Johanis, Senior Consultant, Census Operations Division, Statistics Canada

John Johnston, Executive Director, Montreal Extended-Care Centre

Frank Jones, Analyst, Family and Community Support Systems Division, Statistics Canada

Arminee Kazanjian, Acting Director, Division of Health Services, Research and Development, The University of British Columbia

David Kennedy, Senior Policy Advisor, Office for Senior Citizens' Affairs

Flora Jeane Kennedy, Executive Director, Planning and Evaluation, Department of Income Assistance

Nancy Kingsbury, Associate Professor, Department of Family Studies, The University of Manitoba

Al Kirney, Policy Consultant, Policy and Program Development Directorate, Employment and Immigration Canada

Janet Knowles, Senior Policies Analysis, Seniors Directorate, Human Resources/Labour and Employment, Regina

Judy Krueckl, Senior AIDS Care Social Worker, St. Paul's Hospital, Vancouver

Irene Kyle, Director, Canadian Mothercraft Society, Toronto

Daisy Lau, Professor, Department of Home Economics, Brescia College, The University of Western Ontario

Lorraine Law, Senior Cost Sharing Analyst, Program Legislation Development, Health and Welfare Canada

Rosslyn Leatherdale, Chief, New Horizons Program, Policy and Program Development, Health and Welfare Canada

André LeBlanc, Conseiller spécial, Direction des affaires intérnationales, affaires non gouvernementales, Santé et Bien-être social Canada

Donna S. Lero, Associate Professor, Department of Family Studies, University of Guelph

Normand R. Levasseur, Director, Social Services Directorate, Indian and Northern Affairs Canada

Donna Lordon, Admininistrative Coordinator -- Medical Services, Elisabeth-Bruyère Health Centre

Jon Luetkehoelter, Continuing Care Planner, Continuing Care Division, Vancouver Health Department

John R. MacDonald, Associate Professor, Faculty of Social Welfare, The University of Calgary

Harry MacKay, Senior Researcher, The Canadian Council on Social Development, Ottawa

John Angus MacKenzie, Special Consultant, Senior Citizens Secretariat, Halifax

Michael MacLean, Executive Director, Canadian Association of Schools of Social Work

Anne Martin Matthews, Director, Gerontology Research Centre, University of Guelph

Charlotte Matthews, President, National Advisory Council on Aging, Health and Welfare Canada

Mary Ann McColl, Director of Research, Lyndhurst Hospital, Toronto

Catherine McCourt, Associate Director, Department of Health Services, The Canadian Medical Association, Ottawa

Madge McKillop, Member, National Advisory Council on Aging, Health and Welfare Canada

Mary Ann McLaughlin, Research and Development Officer, Canadian Council on Social Development, Ottawa

Mary McNamara, Supervisor/Professional Development, Nursing Division, Senior Adult Health, Ottawa-Carleton Health Department

Elizabeth McNaughton, Director, Policy Planning and Research, Department of Social Services

Marg McNeil, Regional Director, Access Management, Ministry of Health, Victoria

Pierre Mercier, Département de santé communautaire du CHUL, Ste-Foy (Québec)

Kenneth Mews, Director, CRCS AIDS Project, The Canadian Red Cross Society, Ottawa

Denise Michaud, Program Consultant, Seniors Secretariat, Health and Welfare Canada

Diane Morissette, Policy Communications and Information Branch, Health and Welfare Canada

Bev Ann Murray, Senior Policy Analyst, Research and Planning, Manitoba Community Services, Winnipeg

Scott Murray, Assistant Director, Special Surveys Group, Household Surveys Division, Statistics Canada

John Myles, Professor, Department of Sociology and Anthropology, Carleton University, Ottawa

Kathleen Naeyaert, Program Consultant, National Rehabilitation Department (Gerontology), CNIB, Toronto

Nena Nera, Social Service Advisor, Federal Centre for AIDS, Health and Welfare Canada

Marsha Nicholson, Manager, Resident Care, Homes for the Aged Division, The Municipality of Metropolitan Toronto

Elizabeth Nielsen, Scientific Project Officer, Consumer and Corporate Affairs Canada

D. Norris, Manager, General Social Survey Project, Housing, Family and Social Statistics Division, Statistics Canada

Don Ogston, Director General, Programs Development Directorate, Health and Welfare Canada

Carol O'Rourke, Office of the Senior Advisor, Status of Women, Health and Welfare Canada

Jean-Claude Pageot, Directeur, Département des sciences de loisir, Université d'Ottawa

Anne Louise Parker, Policy Analyst, Status of Disabled Persons Secretariat, Secretary of State of Canada

Barbara Payne, Department of Behavioural Science, University of Toronto

Brian Pearl, Office of the Senior Advisor, Status of Women, Health and Welfare Canada

Vera Pederzoli, Occupational Therapist, The McGill Centre for Studies in Aging, Montreal General Hospital

Louise Plouffe, Université du Québec, Hull

Steve Pomeroy, Future Housing Policy Group, Strategic Planning and Policy Development, Canada Mortgage and Housing Corporation

Suzanne Potter, Director, Disabled Persons Participation Program, Secretary of State of Canada

Brian Powell, Director of Social Policy, Economic Council of Canada

E. Praught, Manager, Cycle 1, General Social Survey Project, Housing, Family and Social Statistics Division, Statistics Canada

G. Priest, Director, Housing, Family and Social Statistics Division, Statistics Canada

Dorothy Pringle, Dean, Faculty of Nursing, University of Toronto

E. Pryor, Director General, Census and Demographic Statistics Branch, Statistics Canada

John Puxty, Director of Geriatric Services, Ottawa General Hospital

Marna Ramsden, Director, Children's Services, Community Services Department, The Municipality of Metropolitan Toronto

Diane Richler, Executive Vice-President, Canadian Association for Community Living, Downsview

John Roberts, Executive Director, Thames Valley District Health Council

Kathy Rochon, Coordinator, Early Childhood Services, Department of Health and Social Services, Charlottetown

Madeleine Rochon, Ministère de la santé et des services sociaux, Québec (Québec)

Irving Rootman, Director, Program Resources Division, Health and Welfare Canada

Ruth Rose-Lize, Département des sciences économiques, Université de Montréal

Carolyn Rosenthal, Associate Professor, Department of Rehabilitation Medicine, University of Toronto

Linda G. Ross (Coulter), Director, Research and Program Development, Homes for the Aged, Regional Municipality of Ottawa-Carleton

James B. Sauer, Presbyterian Minister and Pastor, St. David & St. Martin Presbyterian Church, Ottawa

Gordon Smith, Research Director, Review of Demography, Health and Welfare Canada

lan Stewart, Chairperson, Statistics Canada Advisory Committees on Research and Analysis and on National Accounts

Leroy Stone, Associate Director General, Family and Community Support Systems Division, Statistics Canada

Judith Stryckman, Chief of Research and Policy Development, National Advisory Council on Aging, Health and Welfare Canada

Kelly Sweet, Association Management Division, Older Adults Unit, Fitness Canada, Fitness and Amateur Sport

Daniel Thomas, Direction de la Santé Communautaire, Hôpital Sainte-Justine, Montréal

Alistair K. Thomson, Director, Health Policy Division, Health and Welfare Canada

James Thornton, Co-ordinator, Committee on Gerontology, The University of British Columbia

Michele Tremblay, Geriatric and Psychiatry Services, Department of Psychiatry, Royal Ottawa Hospital

Petr Varmuza, Project Manager, Childen's Services Division, The Municipality of Metropolitan Toronto

Maureen Vasey, Director, Project Development, Canadian Rehabilitation Council for the Disabled, Toronto

Adelaide Verdery, Assistant Director of Social Work, Royal Victoria Hospital, Montreal

Gerry Vila, Information Systems Division, Ministry of Health, Toronto

Reg Warren, A/Chief, Health Promotion Studies Unit, Health and Welfare Canada

Lillian Wells, Faculty of Social Work, University of Toronto

Lynne Westlake, Consultant, National Welfare Grants, Health and Welfare Canada

James White, School of Family and Nutritional Sciences, The University of British Columbia

Blossom Wigdor, Director, Centre in Gerontology, University of Toronto and Member, National Advisory Council on Aging, Health and Welfare Canada

Russell Wilkins, Analyst, Health Division, Statistics Canada

Valerie Wilmot, Researcher, Mental Health Division, Health and Welfare Canada

Gloria Wiseman, Analyst, Status of Women Canada

M. Wolfson, Associate Director General, Social and Economic Studies Division, Statistics Canada

Jean Wong, Senior Analyst, Communications Secretariat, Privy Council Office, Ottawa

Jean Woodsworth, President, One Voice -- Seniors Network (Canada), Inc., Ottawa

Ning Wu, Planning Associate, Ministry of Community and Social Services, Toronto

Ron W. Yzerman, Director, Program Legislation Development, Health and Welfare Canada

Cal Zacharias, National Advisory Council on Aging, Health and Welfare Canada