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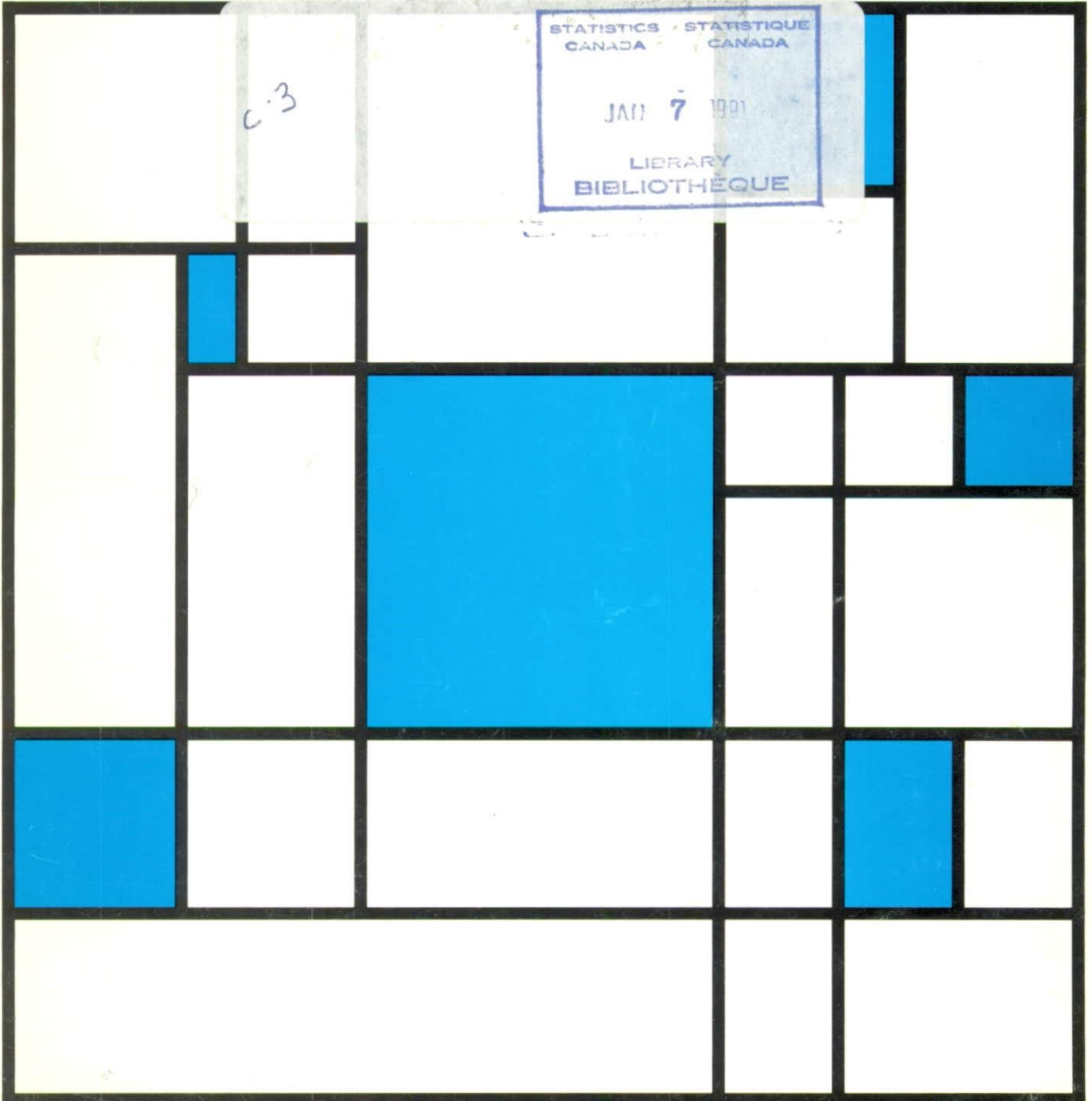# CARING COMMUNITIES

Proceedings of the
Symposium on Social Supports
Edited by: Family and Community Supports Division

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Statistics Canada
Family and Community Supports Division

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Preface

A two-day "Symposium on Social Supports" was held at Statistics Canada on March 28 and 29, 1989. The symposium was jointly sponsored by the Analytical Studies Branch and the Census and Demographic Statistics Branch of Statistics Canada; the Federal Centre for AIDS, Health Protection Branch, the Health Services and Promotion Branch, the Policy, Planning and Information Branch, the Seniors Secretariat and the Social Service Programs Branch of Health and Welfare Canada; and the National Advisory Council on Aging.

Among the more than 150 symposium participants were senior officials of several federal and provincial ministries responsible for social services, as well as prominent researchers and other specialists in the field of analyzing and developing human support services in communities. All of the participants made their contributions to the proceedings on their personal professional authority as specialists, and not as representatives of any organizations. *All statements attributed to persons in this document should be interpreted as having been made in a personal capacity, and were not intended to represent the views of any organization.* The list of participants is presented in Appendix A.

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 major block 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 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 book is to bring to Canadians an edited record of the papers presented and the discussion among this unusual gathering of specialists, in the belief that what they will read here will move them to deep and productive thought about what is becoming of their own lives, their families and friends, their communities, and even their country. It is our belief and hope that the materials contained herein will prove to be of value for many years into Canada's future; because, in some ways, this book is about issues that will preoccupy Canadians for many years ahead.

Leroy O. Stone
October 2, 1990

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Chapter 1

FOCUS ON THE HUMAN DIMENSION OF COMMUNITY SUPPORTS

Opening Address
by
Ivan P. Fellegi, Ph.D.
Chief Statistician of Canada
Statistics Canada

Welcome to Statistics Canada.

On behalf of the four organizations that are co-sponsoring this symposium, I would like to thank you sincerely for the time and effort you have taken to come here to provide us with your advice concerning the development of relevant statistical information and analysis in what is for us a relatively new area of activity.

Although the program for this meeting has been designed to ensure that each and everyone of you has an opportunity to benefit from a transfer of knowledge among diverse professional groups that have some important common interests, it is equally important that the sponsors, and particularly Statistics Canada, gain from your deliberations, insight and some sense of relative priorities concerning the needed directions of information development. Canadian communities will develop policies regarding the delivery of needed human services to families and persons; we believe that good information is a necessary condition for good policies.

When you consider the contribution of Statistics Canada and other sponsors in this very important task, you have to consider information preparation as a wide notion encompassing much more than just the simple production of books or tapes full of figures. We, at Statistics Canada, have understood that decision-makers and analysts, no matter where they come from, majoritarily want immediate access to information, that is, to figures organized in such a way as to deliver a useful message. For them, figures are elements of the intellectual product they wish to consume directly. Even if no sponsor of this symposium considers playing a first level role in the preparation of complex scientific analyses often resulting in important ideas, we will be in a better position to help if we know exactly what kind of information you want to extract from the figures you wish to obtain.

The production and sharing of money income and wealth has been a dominant preoccupation of political and business enterprise in the modern state. For most of the last 40 years, social policy has been concerned with the improvement of the income positions of relatively disadvantaged groups, either through direct transfers of purchasing power or through the subsidization of

services in major fields such as health care. While this remains an important concern, it is quite clear that the availability and quality of services provided by non-market sectors have become a matter of national concern.

Moreover, we have begun to understand that what happens in the non-market sector has a great deal to do with the weight of the burden that rests upon institutions that operate within the market sector.

Allow me to offer you just two very small examples. In a brochure entitled "Safeguarding Retirement Security and Independence from Catastrophic Expense", the Chief Executive Officer of United Insurance Group makes the following remark: "Remember, insurance does not dismiss family responsibility . . . but rather assists your family in preparing for the appropriate type of care." Recently, The Wall Street Journal published an article about the costs of social services, and in it we find explicit concern with the issue of how to value non-market services that are of enormous magnitude and importance in our society in general and in enabling business enterprises to pursue their goals in a supportive fiscal environment.

These are just two examples of evidence that the private sector is awakening to the importance and value of the development of information resources that do not deal directly with questions about money income. It may well be necessary that we supplement our concern with money as a basic unit for measurement of resources with parallel concern about using personal time as being an equally important unit that takes us into new avenues of statistical work and development.

This, for sure, does lead us to talk about why we were prompted to organize this symposium. We believe that Canada is entering a new major era where people will be concerned about the quality and quantity aspects of the various personal care and support services. Those of you who are familiar with social services offered to disabled persons or frail elderly people know how important this question is. These last years have added two new subjects of concern about the quantity and quality of personal support services, the first one flowing from the expanded role of government in child care and the other from the spread of AIDS and from social pressures that could result from it.

Concern about victims of AIDS, harnessing adequate qualified human resources for extra-familial child care, human resources needed to provide supports to the infirm elderly -- here is a formidable agenda requiring our attention. Surely, the time has come to take a very hard look at how well prepared we are to

meet the range of pressing needs for human support services. I sincerely believe that how well prepared we are as a nation involves the development of appropriate information resources. That is why I have invited you to come here and help us with your advice and guidance.

I can assure you, that I will read with deep interest the report that emerges from this symposium. I am confident that it will have a strong and lasting influence upon the future of Statistics Canada's efforts in social statistics development.

Before I turn you over to your chairperson, allow me to offer personal welcome and thanks to Alastair Clayton and Blossom Wigdor who will be your conference chairpersons today and tomorrow. As many of you know, Dr. Wigdor has recently received the Order of Canada Award.

I also want to thank Charlotte Matthews, President of NACA, for agreeing to present you with the closing address tomorrow.

Allow me, finally, to offer a special welcome to Sister St. Michael Guinan, former president of the Canadian Association of Religion and Gerontology and Professor Emeritus at The University of Western Ontario. As you will learn when she leads off the proceedings tomorrow, Sister St. Michael has direct experience with the important issues that you will be raising and reviewing. It is an honor to have this outstanding Canadian pioneer in our midst.

I hope that the next two days of discussions will be rewarding and of benefit to everyone of us. Undoubtedly, the other sponsors, that is Health and Welfare Canada, Seniors Secretariat and the National Advisory Council on Aging, will join me in thanking you again for being here to help us.

Symposium "Stage-Setter": Why We Have a Common Interest in the Strength of Community Supports

Leroy O. Stone

OBSERVATION: A COMMUNITY IS A FIELD OR NETWORK OF INTER-DEPENDENCE AMONG ORGANIZATIONS AND LESS FORMAL GROUPS, E.G. FAMILIES, THAT HAVE BEEN FORMED FOR IDENTIFIABLE PURPOSES, OFTEN INCLUDING THE PROVISION OF SERVICES TO A POPULATION THAT OCCUPIES A DESIGNATED LOCALE. ONE BASIS OF THIS INTER-DEPENDENCE IS THE FLOW OF SCARCE HUMAN AND OTHER RESOURCES AMONG THE GROUPS AND THE CONTROL OF SOME IMPORTANT ASPECTS OF THAT FLOW FROM CERTAIN KEY "CENTRES OF POWER".

Diagram of a Community
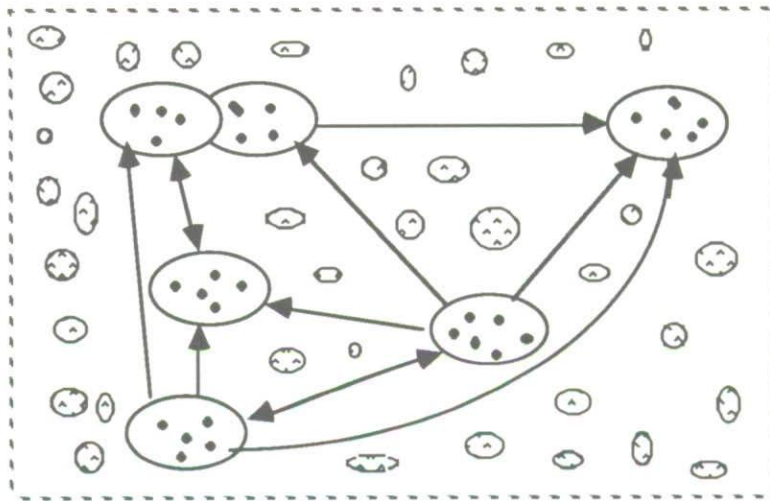
⌒ Households and families

◯ Organizations and other groups formed for a purpose, often to provide some type of service to persons, families, or other groups

• • Roles occupied by persons within the organizations
• • or other groups

↕ Two-way flow of resource inputs and outputs between two organizations or other groups

↑ One-way flow of resource inputs or outputs between two organizations or other groups

⌐ ¬ Open boundary pointing to links with other communities

N.B. An important type of resource flow not shown in the diagram is that going from households and families to organizations or other groups.

LOS '89

Some of a Community's Scarce and Vital Resources

Time

Health & Fitness

Love & Caring

Purchasing Power

Knowledge & Technology

Although some of these and other vital types of resources are most conveniently measured as properties of persons or families, accounting for them at the community level in some reasonable way is crucial in estimating the reserves that the community may have to provide additional amounts of existing services or to start new services. Services that require direct use of personal time are limited by the extent to which the time budgets of persons are already committed, and by the degree to which the prevailing values relating to loving and caring dispose persons to alter existing allocations of personal time so as to free up time for helping others. Also, effective help depends on possession of the pertinent know-how. Thus, at the community level, some way of accounting for and analyzing disposable personal time and the availability of needed know-how are essential to assessment of the potential for improving or expanding human services.

SOME BASES OF OUR COMMON INTEREST IN STRENGTHENING COMMUNITY SUPPORTS

• We share a need for certain community resource pools of limited size which provide inputs that enable us to be effective

• The receivers of our services are persons, families and households where our often separate efforts have interrelated impacts upon well-being

• Most of us rely upon getting attention and priority from the same "centres of power" in making our claims for certain public resources

Tables 1 and 2 below can be used to illustrate some of the bases for our common interest in community supports. Table 1 shows many Ottawa organizations whose operations are of potential interest in a number of different fields of social service. Table 2 is a preliminary identification of the patterns of reliance by different groups upon particular mixes of inputs.

Because these tables were drawn up in the past several days, their details need to be checked. Yet they serve to point towards some of the kinds of data and analysis that could improve the informational help for efforts to strengthen community supports. Table 2, suggests, for example, that a community needs to be concerned about the depth of its reserve of human resources available to provide help to others. That reserve is best measured in terms of some unit of personal time available to give assistance to others, which forces us to look at time as a strictly limited resource (like money) and at personal and family time budgets.

As we all know, units of personal time are not interchangeable -- we must be careful to tabulate what kind of application of personal time is needed, as well as the know-how or other special qualifications associated with it. The accounting of available human resources in these terms becomes useful when it can be compared to some estimate of requirements in the community; and particularly so when reasonable forecasts of availability and requirements can be developed, even if they are short term.

Table 1
Selection of Ottawa Community Support Organizations or Groups

	Likely to have output or input requirements of interest in two or more of the social service fields represented at the symposium
Ottawa Senior Citizen's Council	
Good Companion's (senior centre)	
Centre de jour polyvalent des aînés francophones	
Seniors Employment Bureau	x
Concerned Friends	x
Citizens Advocacy of Ottawa-Carleton	x
Widowed Support Group of Ottawa-Carleton	x
Seniors Reaching Out	x
Letter Carriers' Alert Program	
Telephone Assurance Program	
Teleshalom is a similar service for Jews	
Good Companions Legal Counselling Service	x
St. John Ambulance	x
Alzheimer Society	
OSTOP Ottawa (osteoporosis self-help group)	x
Anglican Ministry and Elders program	x
Anglicans in Mission	
Bus service for the elderly and infirm	x
Big Brothers and Big Sisters	x
Boy Scouts	x
Catholic Guides and Catholic Scouts	x
Catholic Social Services	x
Boys and Girls Clubs of Canada	x
Y-Alive teen and pre-teen club YM/YWCA	x
Children's Aid	
Family Service Centre	x
Planned Parenthood (Inc.)	
Patro d'Ottawa (social, cultural services)	x
Youth Services Bureau	x
Canadian Council for Co-Parenting	

Table 1
Selection of Ottawa Community Support Organizations or Groups -
Continued

	Likely to have output or input requirements of interest in two or more of the social service fields represented at the symposium
Crescendo Parent/Preschool Programs	x
Bereaved families of Ottawa-Carleton	x
One Parent Family Association	x
Parent Preschool Resource Centre	
Anglican Diocese of Ottawa Marriage Preparation Course	
Alcohol and Drug Addiction Residential Programs e.g. Fraternity House	x
Canadian Association for the Mentally Retarded	x
Canadian Mental Health Association	x
Canadian Hearing Society	x
Canadian National Institute for the Blind	x
AL-ANON is a fellowship of relatives and friends of alcoholics	x
Emotions Anonymous	x
Arthritis Self Help	x
Friends of Schizophrenics of Ontario	x
Juvenile Diabetics Foundation Parent Support Group	
Living With Cancer	x
Multiple Sclerosis Self-Help Group	x
Mutual Support Groups for Depression and Manic-Depression -- Ottawa-Carleton	x
National Capital Association of the Deaf, Inc.	x
The Sexually Transmitted Diseases Clinic	x
AIDS Clinic of the Ottawa General Hospital	x
The AIDS Committee of Ottawa	x
Canadian Red Cross	x
Ottawa Distress Centre	x

Table 1
Selection of Ottawa Community Support Organizations or Groups - Concluded

	Likely to have output or input requirements of interest in two or more of the social service fields represented at the symposium
Tele - Aide (Crisis Intervention)	x
Union Mission for Men (clothing, food, shelter)	x
Rape Crisis Centre	x
Elizabeth Fry Society	x
John Howard Society	x
Entraide budgétaire	x
Immigrant Services	x
Community Information Service	x
Jewish Social Services Agency	x
Service d'entraide Communautaires	x
Victorian Order of Nurses	x
Visiting Homemakers	x
YM/YWCA	x
Centre for Counselling and Pastoral Service, St. Paul University	x
Kanata Support Group for the Separated, Divorced and Widowed	x
HOPE, Helping Organize Productive Experiences -- a Salvation Army Women's support group	x
Mothers are Women (supports mothers with children at home)	x
Natural Family Planning	
Chaplaincy to University of Ottawa, Carleton University and Algonquin College	x
Anglican diocese of Ottawa Health Care	x
Anglican diocese of Ottawa Pastoral Centre	x
Anglican Social Service Centre 454	x
National Native Convocation	x

Source: Frank Jones. "Community Support Groups and Organizations in the Ottawa Area and Service Delivery Technologies Conceptually Considered". Draft paper, Population Studies Division, Statistics Canada.

Table 2
Examples of a Rough Classification of Community Services to Show Aspects of Their Resource Input Arrangements

	Funding		Labour		Buildings	
	Gov.	Char.	Paid	Vol.	Con.	Non-Con.
Ottawa Senior Citizen's Council		X		X	X	
Seniors Employment Bureau		X		X	X	
Concerned Friends		X		X		X
Citizens Advocacy of Ottawa-Carleton		X		X		X
Telephone Assurance Program and Teleshalom		X		X		X
Alzheimer Society		X		X	X	
Anglican Ministry and Elders program		X		X		X
Big Brothers, Big Sisters		X		X	X	
Catholic Social Services		X		X	X	
Family Service Centre		X		X	X	
Children's Aid		X	X		X	
Boy Scouts, Catholic Guides, Catholic Scouts		X		X		X
Youth Services Bureau		X	X		X	
Parent Preschool Resource Centre		X	X		X	
Living With Cancer		X		X		X
Anglicans in Mission projects		X		X		X
The AIDS Committee of Ottawa	X			X	X	

Legend:
Gov. = Government is thought (by Jones) to be a major source of funding.
Char. = Charitable donations are thought (by Jones) to be a major source of funding.
Paid = Paid work is thought to be an important kind of labour input.
Vol. = Volunteer work is thought to be an important kind of labour input.
Con. = Uses the same building at least four days each week.
Non-Con. = Uses the same building less than four days each week.
Source: Frank Jones. "Community Support Groups and Organizations in the Ottawa Area and Service Delivery Technologies Conceptually Considered". Draft paper, Population Studies Division, Statistics Canada.

Introduction to the Proceedings of the "Symposium on Social Supports": An Interdisciplinary Cross-Fertilization

by
Leroy O. Stone, Ph.D., F.R.S.A.
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Systems Division, Statistics Canada
Research Fellow of the Centre on Aging
The University of Manitoba, and
former Professor of Sociology
The University of Western Ontario

Purpose of the symposium

The development of this symposium was motivated by the observation that there are growing demands for certain kinds of personal-time-dependent services being made upon limited human support resources in Canadian communities. A service is said to be "personal-time dependent" when its delivery requires one or more persons to spend substantial portions of their time virtually dedicated to the operations of delivering that service. The fields in which these demands arise include services to seniors, provision of help and opportunities for the disabled, the supplying of suitable day care assistance to families with children, and support for persons with AIDS. Some 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.

As the demands for human caring and helping services grow in Canada, the *adequacy of information resources* to assist strengthening of community supports will become a matter needing urgent attention. Statistics Canada has a mandate to improve information that assists policy and program related work that deals directly with different aspects of human supports. Deep thought is needed to identify new kinds of statistics and statistical concepts that should be developed in order to improve Statistics Canada's services in this area, where relevant concerns are being felt and expressed by governmental and other community leaders and by families from coast to coast. The output from the symposium will help to facilitate these improvements of Statistics Canada's services.

Organization of this book

The papers and discussion were grouped under four broad themes. A fifth block of discussion involved presentations by the symposium's rapporteurs and audience commentary about what the rapporteurs said. The first theme was that of giving help to others. It's general questions were: what processes are involved in help giving and who are the key groups providing services to others outside of the paid labour markets? The second theme was that of patterns of need for and use of help. This theme involved highlighting key groups that

are receiving help in coping with dependency. The third theme dealt with public attitudes and opinions regarding development and delivery of community supports. The fourth theme was that of issues in integrating formal (e.g. government) and informal supports in providing assistance to those who are coping with dependency. The sequence of topics in this book follows that of the symposium themes.

This chapter is designed to focus upon some of the most important ideas that were developed or presented at the symposium. In considering both the highlights and the detailed chapter contents, it is helpful to have in mind a set of related knowledge issues and theoretical considerations.

Underlying knowledge-development issues

How does society cope with dependency? The social-service delivery concerns cited above may be said to arise because individuals or families are perceived, under certain circumstances, to have some form of dependency, and our culture places a high value on the notion that one of the legitimate functions of organized group activity is the provision of mechanisms for coping with dependency. Coping with dependency can be viewed from the perspective of those that are trying to employ coping mechanisms to help

themselves, or from that of a society in which there is a strong cultural value assigned to the processes of assisting those perceived as being dependents and who have legitimate claims upon social assistance. This social assistance may be organized through private auspices (e.g. the family) or through public (government) ones. (Appendix B provides a brief literature review on the subject of cultural variations in defining and coping with dependency.)

Underlying the design of the symposium was the knowledge issue of how society copes with dependency. Societies may be said to evolve helping systems to cope with their perceived dependency burdens. A helping system is a set of procedures designed to transfer assistance to others under rules of eligibility enforced by members of helping structures that are maintained by legitimate resource flows. Helping structures include kinship networks, friendship networks, semi-formal self-help groups, and formal groups such as private philanthropic organizations, businesses, and government. Before talking about helping systems, however, one must first define "dependency".

Toward a definition of "dependency". No formal and generally agreed upon definition of "dependency" seems to exist. However, the various uses of the term in the literature suggest that

the following is a reasonable guideline for identifying instances of dependency (i.e. it is not acceptable as a formal definition). *Dependency is indicated by repeated display of behaviour that departs unavoidably from norms about autonomous behaviour in a designated aspect of personal life.* (This principle is intended to exclude voluntary departure from those norms. Notice the idea of "norms of autonomous behaviour" -- what is autonomous behaviour, commonly called "independence", is subject to cultural construction and variation.)

The departure in behaviour from the norms of autonomy must, to be relevant here, either *give rise to need or demand for more than deemed customary supports from others, or involve a deemed forced surrender of decision-making autonomy.*

The norms of autonomy imply that there are different kinds of dependency. Designating a person as being totally or partially dependent is not useful unless we first identify what kind of dependency we have in mind. The social science literature points to three major kinds of dependency. Again, formal definitions are lacking; but indicative comments of a definitional character can be offered based on study of the existing literature. These comments concern economic dependency, functional dependency and psychic dependency viewed from a societal perspective.

Economic dependency. In connection with economic dependency as viewed from a societal perspective, the notion of dependency points to the difference between the aggregate consumption and aggregate production of those who unavoidably consume more than they produce. From this viewpoint, the societal economic dependency burden can be measured crudely by using the ratio of the difference mentioned above to the aggregate income received by all individuals in exchange for goods and services or as proceeds of investment (Senior Advisor on Population Studies 1978: para. 78).

Functional dependency. From a societal, rather than individual, perspective, we may use the concept of a "functional dependency load". The functional dependency load may be viewed as the volume, in a given time interval, of personal-support-time required by persons because of their functional deficiencies. The functional dependency burden, for the society, may be indicated by the ratio of the functional dependency load to the volume, over the same time interval, of related personal-support-time that is available.

Psychic dependency. The psychic dependency load is the

volume, in a given time interval, of personal-support-time required by persons because of their need to achieve a satisfying concept of themselves or of their life circumstances. The psychic dependency burden may be indicated by the ratio of the psychic dependency load to the volume, over the same time interval, of related personal-support-time that is available. Psychic dependency is not a proper subset of functional dependency, and thus must be separately identified for analysis.

The definitional conventions outlined above imply that some amount of mutual dependence, i.e. interdependence, is normal. Indeed, it is very difficult to imagine how there can be a society of living beings when among those beings where there is no mutual support. Mutual support presupposes some non-zero degree of dependency.

The general character of societal helping systems

Arrangements of human networks (informal and formal) are the mechanisms used in the organization of societal response to dependency. Inasmuch as these networks have parts that are integrated in ways that cause the networks to appear to perform specified kinds of work, they are properly regarded as systems. However, as the social network literature amply demonstrates, they can also, from a different perspective, be viewed as structures (which is the position taken here). These helping structures maintain helping systems (other, more abstract, types of systems).

If you have trouble grappling with the abstraction, think of two very well known and similar kinds of abstraction -- the institution of marriage, and the institution of retirement. When we talk about the institution of retirement we have no concrete objects like government agencies or families in mind. Rather we think of certain norms regarding working life, certain rules about possible separation from a job once held, and other rules about entitlement to transfer income -- all highly intangible things. Similarly a welfare (income support) system can be seen as a set of procedures designed to transfer resources under specific rules of eligibility whose enforcement is assigned to specific social roles (with accompanying authority); plus the resource flows needed to maintain those procedures.

Certain of the helping structures have strategic functions with regard to these input-resource flows, as well as to the setting or changing of the rules of eligibility for the assistance in question. We often refer to the

instruments used by these key helping structures as "policy levers". N.B. While governments can create and transfer purchasing power through symbolic instruments (e.g. a cheque) they cannot create and transfer personal-time inputs, and in certain human services these may be of a specialized character requiring long training periods and formal professional certification procedures. Hence a society that is facing a sharp rise in demand for personal-time inputs, and which is accustomed to interpreting help related social policy problems solely in terms of monetary issues, may find itself confronted with severe crises involving physical human-resource shortages. This remark applies with **particular force** to the long-term care and educational helping systems.

Personal time, the basic "energy-source" for coping mechanisms

What's fundamental, for this book, about mutual support arrangements is that to a large degree they require that individuals spend personal time in providing what economists call "services" to others. An important element of these services takes some form of psychic support -- you cannot measure their occurrence by watching any physical commodity change hands, or any movement take place, yet almost no one questions the proposition that they are critical in the quality of human life and in health promotion.

Some of the providers of services (keep in mind that only a tiny fraction of people provide no services at any time) seek no compensation beyond certain perceived direct benefit that they derive from the experience of help giving. That direct benefit could be something quite intangible -- ego support and recognition, or psychic well-being arising from being a person who "makes a difference" in some other persons' lives, or simply the build-up of a sense of social bonding in a network whereby one has the expectation that others sharing the social bonds will come to one's aid when one is needy.

Other providers of services seek compensation in the form of purchasing rights or marketplace credits (called "purchase-credits" below), which others will accept in exchange for turning over goods and services to them on demand. At any given moment, there is a volume of marketplace credits that is controlled by a small set of societal power centres.

The volume is often measured in terms of "X trillion dollars". The portion of this volume that is controlled and/or handed out by government is a subject of scrutiny so intense that many people lose sight of the broad picture and make some seriously limited analyses of the issue of dependency in our society. To many, we need only consider whether "Canada can afford the burden of government financing of social programs".

What is often lacking about that kind of focus is the way it tends to hide the fact that there is no stable correspondence between the volume of purchase-credits available in a society and the volume of real goods and services that are available for some kind of exchange. Releasing credits to people often stimulates them to contribute to the volume of those goods and services (though one has to keep in mind that persistent inflation can have the opposite result, so the process of credit expansion has to be handled with care and with hope for good luck), and denying credits to people often stimulates them to withdraw from some aspects of the wealth creation processes. Nevertheless, the two magnitudes ((1) volume of purchasing credits and (2) volume of real goods and services) do not have a stable link. There is a statistical association but it is not tight. One reason for the loose association is that people can increase or decrease the volume of real goods and services by carrying on operations outside the markets that are driven by purchase credits.

What's deeply problematic about this loose association is that vast numbers of people might be lead to confuse the two volumes, and especially to assume that if only they had enough purchase credits they would have the access they need to real goods and services.
Unfortunately, if what people want is a service that draws down other

people's reserve of disposable personal time they can quickly learn that no amount of purchasing credits can help one when the disposable personal time one is demanding simply does not exist to be supplied. (People trying to staff positions normally filled by teenagers have begun to understand just how important this idea can be.)

For a society as a whole, there may be no way to routinely get more aggregate supply of personal-time-dependent services by merely putting peoples' hands on more cash. The aggregate supply is increased when a fixed number of people either reduce the time they used to spend on non-work activities, or the time they used to spend on alternative work activities, in order to increase time spent on giving personal-time-dependent services. The supply may also be increased by bringing into the society additional people who are ready, willing and able to spend on giving personal-time-dependent services. Whether and how much a society over a given time period has any of these routes open for using purchase credits to raise the aggregate supply of personal-time-dependent services is a matter for social-scientific analysis and forecasting.

At any given time in some societies, only a tiny fraction of the populace can use purchase credits to resolve that supply problem for themselves; because as more and more people

try that route the probability of it being fruitless rises rapidly. (There is an analogy here to the world's environment crisis -- if too many countries "develop" themselves in the manner to which some of us have become accustomed we will together destroy the ecosystem that makes human life possible.)

In his review (printed below) of the papers offered under Theme 1, the Reverend Dr. James Sauer offers a graphic example of the difficulty to which I am trying to point here. "How much time is available for involvement in [self-help and volunteer service] groups", he asks. He continues: "A social policy group in Toronto estimated that commuting time in Toronto demands between 3 and 4 hours a day. Now that makes a significant cut in the amount of time available [for] giving volunteer support ... [and for] benefitting from those activities. ... I think we need a better understanding of what these constraints are and will be in the future."

What if you live in a society where major interest groups seem not to appreciate this fundamental problem, and tend to expend vast amounts of energy competing with others over access to purchase credits when the services they want to buy with those credits can't be had by more than a relative few even if the others possessed all the purchasing credits in the world? What if there are indications that in that society a

number of seemingly inexorable demographic, economic, life-style and cultural trends point to an accelerated rate of growth in demand for personal-time-dependent services during the same time period when there could be slowing rate of growth in the volume of disposable personal time?

The issue as to whether there is a coming collision between relatively fast-growing wants for personal-time-dependent services and relatively slow-growing volumes of disposable personal time available for meeting those wants was the driving question behind the March 1989 "Symposium on Social Supports" held at Statistics Canada.

The human support systems analysis approach

Also important in the conceptualization of the symposium was the idea that if communities are going to be faced with the consequences of that future collision, they would best do so by taking a "systems approach". This means that they would regard personal-time-dependent services as being delivered across a broad spectrum of programs or client groups that are linked by the fact (if by none other) that they all have to draw upon a limited community resource (the total volume, during a given period, of personal time disposable in human service delivery

actions) that may well be insufficient to meet the many demands being made upon it.

The reality of linkage among services through their reliance upon a common, limited, resource base is highlighted in the pre-lunch keynote talk given to the symposium by Dr. Ian Stewart (and printed below), a well-known former Ottawa mandarin. He points to a contest among interest groups over "shares of the pie". Although the pie to which he refers is, it seems, largely that comprised of purchase credits handed out to interest groups by government, his remarks are applicable in those communities where there already exists a sense that volunteer resources are being stressed to the breaking point by existing demands coming from various quarters.

The response to this stress brings us head-to-head with some very fundamental questions raised in Dr. Stewart's paper. "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 ...? ... What is it that determines how much of the resources that pass through the hands of government are allocated to social purposes ... ?"

Here it is helpful to interpret "giving" in a broad sense that goes well beyond giving money. For many people, social obligations are easily discharged by putting their hands in their pockets and giving money. That way they get to go on with the rest of their lives with a minimum of inconvenience. As the demand for personal-time-dependent services rises in the future, this kind of charitable giving will decline in value compared to the giving of one's time in service to others; because the cash given will not be able to secure needed supplies of alternative sources of needed personal time, unless Canadians will be ready to accept significantly greater numbers of immigrants from places where the devotion of a lifetime to delivering human-caring services is much more strongly valued than it seems to be in North America.

Under the scenario of multiple-service demand upon a limited personal-time resource base, the issue of optimization raises its head, and questions about how different programs or projects can share common functions and learn from each other become important. Also important are questions about whether the quality of the local culture and of social bonding within and between families are such as to promote a high level of willingness to provide time-dependent services.

Similarly relevant would be questions about whether the level and quality of "helping know-how" is adequate in the community. In a field such as

long-term care, for example, "helping know-how" or quality of care is a very big issue -- some people would rather die than accept certain kinds of allegedly "available help".

A "human support systems-analysis" approach drives one to bring such important questions to the table of public concern and debate. It will not help to fully occupy the seats around that table with the specialists in services to the elderly, or in child-care questions, or in the needs of the disabled, or in the social ramifications of the growing number of persons with AIDS (this list of interests is not exhaustive). A "human support systems-analysis" approach would require that all such specialists be seated around the same table.

To carry on their work, the specialists need information and analysis, and they need to tell the providers of information and analysis what issues should drive the information-and-analysis business if it is to meet the concerns of one segment of the business' clientele. Hence the Symposium on Social Supports sought to place around the same table a variety of groups that have common interests in the rising volume of demand for certain kinds of personal-time-dependent services, and in the capacity of a community to mobilize and deliver needed personal-time-dependent services.

Highlights from the discussion of Chapter 2: Patterns of giving help to others

No sooner had the meeting begun than the opportunities for intellectual cross-fertilization appeared. The papers by Hector Balthazar and Richard Burzynski brought out features of self-help groups that are worthy of study by those concerned with strengthening the quantity and quality of volunteer work being done in Canadian communities. At first glance, it may seem that self-help group formation and functioning and the provision of volunteer services are substantially different. Yet when you look again you see possibilities for people doing similar kinds of things for each other in both spheres of human cooperation. Once this is understood, one can begin to reflect upon a key facet of the self-help group -- the way in which the helper gets helped while giving help. Is there some way for us to make the experience of volunteering more rewarding in non-money terms for the volunteer? Or, is there some way to spread among more volunteers the experience of being helped while helping that seems so typical of the self-help group?

In this connection, reflection upon points made in Richard Burzynski's paper and in his responses to questions could be quite rewarding.

He is opening our eyes to the special situation of a group feared or stigmatized by most members of the "normal" society. Here we have a case where the social bonding that would prompt people to come forward and help those in need could be especially weak.

How are the persons with AIDS (PWAs) going to gain access to the volumes of personal-time dependent services they need? Only by greatly intensifying self help among PWAs and the sympathetic parts of their families. What people do for each other in these circles of intensified self help, and how they motivate each other to keep coming back to give human-caring services, could be worthy of very careful study by many groups that are not specially well favoured in our society. Richard Burzynski points out that as the effectiveness of these self-help endeavors increases, the budgetary impact of financing social services to PWAs declines, with the proviso that some minimum amount of seed money is needed to keep the structure of self-help activity among PWAs afloat (somebody has to pay the office rent and the phone bill).

In his discussion, captured below, of the papers cited above the Reverend Dr. James Sauer challenged the participants when he raised some tough questions about the quality and quantity of current scientific knowledge regarding (1) the spread of self help, (2) the mechanisms that give rise to self-help groups and to volunteering, and (3) the processes by which wants come to be perceived as legitimate needs in society. His paper is a rich source of ideas that can drive some powerfully useful and practical, though intellectually challenging, research and analysis.

The paper contributed by the National Advisory Council on Aging, presented to the symposium by Susan Fletcher, and based on research done and written up by Professor Ingrid Connidis of The University of Western Ontario, served the critical function of focussing people's thoughts on the contributions being made by seniors to the wealth of Canada (if by "wealth" we mean the total volume of goods and services created in the society, whether or not that creation takes place in cash-driven markets). That this contribution can be of service across the entire spectrum of supply of personal-time-dependent services in Canadian communities was emphasized by Mary Engelmann in the panel discussion that followed the papers. Mary Engelmann and others at the meeting called attention to the fact that gatherings, such as this symposium, are needed to help people who are preoccupied with service delivery in one area to see how they might benefit by pausing to study similar efforts taking place elsewhere in their communities; because in the process they might learn of available resources about which they have been unaware. The

comments by Mary Engelmann (printed below) and other participants made clear some of the opportunities and problems in building bridges among the different social-service-delivery specialties represented at the symposium.

Some of the opportunities became clear, as one of the audience participants pointed out, in Irene Kyle's review of the functions of family resource centre programs. Focussed so far on the services to children, the family resource centres could, it was held, become more effective and broader in their impact by creating occasions for prolonged intergenerational contacts reaching from the youngest children to the oldest grandparents.

Irene Kyle's paper is especially useful for its documentation of the wide variety of circumstances in which a family has a real need for child-care assistance. The bulk of the public discussion of this subject is in the context of families who need that help because the adult members need to go and work for pay outside their homes. Kyle's reminder that legitimate needs for child-care help arise in a much broader set of circumstances, serves to highlight the ways in which recent social trends have created the potential for an "order of magnitude" change in the volume of need for personal-time-dependent services in Canadian communities.

Highlights from the discussion of Chapter 3: Patterns of need for and use of supports

As pointed out in Gordon Barnes' discussion printed below, Brian de Vries' paper signals the importance of considering needs for and access to supports as functions of one's family status and of the position of one's family among a set of alternative "stages of the family". The paper brings out important differences between men and women, as well as among family stages, in terms of the kinds of potential informal supports they are likely to have and of patterns of frequency of contact with kin and close friends. Particularly striking are his demonstration of indications that child-rearing responsibilities may strongly influence patterns of contact with kin and friends; but that men and women differ significantly in their typical patterns.

The importance of taking a life-course perspective in considering possible access to informal supports is brought out vividly in the paper by Judy Krueckl. She highlights the key role of deep friendships in providing persons with AIDS with the social supports they may have, suggesting that the supports exchanged among gay lovers are of a quality equal to those we associate with the best heterosexual spousal relationships. The critical importance of these supports arises partly from the

relative social isolation and stigma that one often finds associated with the lives of those who become PWAs.

Donna Lero carefully documents the major gaps in current knowledge about the types and frequencies of child-care arrangements abroad in Canada today. She points out a network of key questions about usage of child-care services that need to be tackled by research and analysis, and indicates some of the plans for addressing these questions in connection with the 1989 National Child Care Survey. Like Irene Kyle, she points out a wide range of circumstances under which families may need support with child care, thus laying an intellectual foundation for improvement in the perspective from which public debate about child-care arrangements can go forward.

Using broad ethnic categories comprised mainly of persons born in Canada, the paper by Payne and Strain highlights the notion that popular thinking about ethnic differences in the use and availability of social supports needs to be revised. The expected substantial ethnic differences in patterns of use of supports, using the indicators available in the General Social Survey, fail to appear. This paper could provide support to those who have long argued that there is a

Canadian ethnic identity that now needs to be recognized in statistics about ethnic origin. Of course, in this area of well-known conceptual and statistical pitfalls, there are cautions to be raised about how far one taps ethnic identity in the General Social Survey, the small size of the sample which eliminates the opportunity to pin-point ethnic groups in sufficient detail, the theoretical framework of the research, etc. These cautions are noted below in the discussants' comments on what could turn out to be a landmark paper in the study of ethnicity in Canada.

Special note should be taken of the set of key knowledge and policy issues raised in the discussion provided by Carolyn Rosenthal and printed below. She stresses the valuable point that the principle of substitution among sources of supports should not blind us to the issue as to whether, in going from one source to another, the quality of support remains the same. Even the kind of support available may change. She emphasizes the importance of giving greater attention to psychic supports, which were not covered in the 1985 General Social Survey, and challenges analysts to provide more useful information about the quality of psychic supports available to Canadians of advanced age.

Highlights from the discussion of Chapter 4: Public attitudes and the development of community support mechanisms

The short paper by Henry Enns deserves careful reading by everyone who wishes to gain deeper insight into the mechanisms by which culture, institutional arrangements, and power relations among interest groups can create personal dependency where it need not exist. He argues that societal attitudes towards disability have been powerful forces in handicapping certain people, and that through a series of historical accidents those attitudes have evolved and have allowed the disabled to take more effective control over their affairs and opportunities, though there remains considerable room for more beneficial change.

Madeleine Blanchet offers some key insights into the roots of resistance to that change. Essentially, she supports Enns' position that much of the difficulty lies in the socio-cultural system -- in the so-called "normal" world which has in many ways imprisoned the disabled.

Dorothy Pringle's discussion offers the only systematic probing within this volume of issues surrounding the role of public opinion in influencing the allocation of scarce resources among a set of groups that are all pursuing good causes but cannot all be supported with public resources at the same time. She raises questions about who controls the taking of surveys to tap public opinion.

The general discussion which followed the presentations by Madeleine Blanchet and Dorothy Pringle, and is printed below, is rich with insights into the problems faced by those who have assumed the major responsibility of providing human supports in our society in both informal and formal settings. The lack of recognition of the social jeopardy with which society has saddled these groups is widespread, and it goes as far as benefit programs that are biased in their coverage of different kinds of valuable human caring services that people provide.

Highlights from the discussion of Chapter 5: Harnessing and integrating human and financial resources in the provision of community supports

The second day began with "stage-setting" remarks by Sister St. Michael Guinan. These remarks, as well as her easily recognized contributions to the general discussion captured below, are unique in the focus they place on attention to issues regarding motivation and value systems. The linkage of these issues to the crucial question of how wants can become legitimized as needs is brought out in her discussions.

Howard Clifford has contributed a wide-ranging review of financing/budgeting issues connected with the development of child-care services. Particularly notable here are the links he draws from questions of financing to the socioeconomic distribution of access to formal child-care assistance, to issues surrounding means testing, and to the volume and quality of labour supply in formal child-care services.

I must admit to extreme enthusiasm over the interventions and paper contributed by Margaret Duckett, who was visiting Canada (McGill University) from Australia. Preoccupied with management problems connected with the running of the symposium from event to event, I had no chance to get involved in the discussion and try to move thoughts towards the systems-analysis issues outlined above. Margaret Duckett spoke eloquently to these issues on a number of occasions during the meeting, making particularly effective comments to explain why people concerned with the social-services aspects of the spread of AIDS and those concerned with social services in other areas, in fact, have strong common interests which may not be recognized at first glance. Please regard her paper below as "must" reading; because she succinctly expresses, in words more graphic than mine above, what this symposium was all about.

The paper by Mia Elfenbaum and Nancy Kingsbury shares with the Payne and Strain paper the potential of being regarded, in the future, as a landmark piece in the accumulation of a particular body of knowledge. Both papers graphically illustrate what a significant breakthrough in Canadian social data resources the General Social Survey has been. If he is remembered in the future for nothing else, Ivan Fellegi (the current Chief Statistician) should be remembered with gratitude for the way he pioneered and stimulated the development of this survey vehicle.

The Elfenbaum and Kingsbury paper challenges us to reflect upon the popular notion that increasing multiple role-playing by women automatically means higher levels of risk of illness and negative stress. Their data show a positive association of multiple role playing with reported health status, and that this is connected (statistically) in large degree to participation in work activity outside the home. As they are careful to point out, the cross-sectional data do not permit one to answer the crucial question of how health status and role occupancy are causally linked. In some cases poor health inhibits the playing of multpile roles.

Another "must read" in this volume is Diane Richler's paper. She puts her finger on one of the most critical factors that will shape the character of

Canadian society in future generations -- the extent to which social-service programs create a built-in bias towards extra-familial types of human caring services. By failing to take a sufficiently broad perspective in addressing questions regarding societal response to dependency, analysts and the media have created an unduly heavy focus upon formal, especially government financed, coping systems. The resulting general tendency toward disregard for the caring and feeding of natural helping networks is going to be of growing concern in a society where human-care issues are becoming more urgent and the limitations of formal structures for dealing with all of them (as the cases of Alzheimer's Disease and PWAs so amply demonstrate) become better known.

Diane Richler's paper is also valuable because of the way it clearly reflects the benefits of applying a "systems approach" to the assessment of needs for and supply of supports at the community level. Through this approach, as she points out, one begins to see how institutions and prevailing attitudes create dependency for certain groups.

Formal and informal supports interact in their impacts upon those who receive social services. This interaction raises some of the most important policy issues now abroad in the field of social and health services. Why these issues are important can be seen in the paper prepared by me and Margaret DeWit, and presented to the symposium by Forrest Frankovitch. The paper shows, with a specific illustration, how the presence of informal supports and the composition of the potential support network might be meaningfully associated with the requirement for or usage of formal supports. The questions and dilemmas surrounding this sort of association will preoccupy social service designers for many years to come.

As stated above, the systems approach leads us to build bridges among separate social service 'jurisdictions' or 'turfs'. Maria de Wit's discussion provides a graphic example of the potential benefits of doing so when clearly identifiable resource shortages exist. Of particular concern here are human resource shortages, and in this connection Betty Haven's discussion provides an eloquent commentary on the importance of being systematic in human resource accounting relative to the existing and potential levels of volunteering in our society. She particularly emphasizes the notion that the single-program approach to assessing a community's human resource reserves will lead to serious blind-spots as regards the issue as to whether a community's personal-time reserve is close to exhaustion by existing uses that cut across many programs.

Many of the dilemmas and issues of priority setting that must be confronted when there are multiple claims upon a limited resource are clearly set out in Marcus Hollander's discussion. His remarks systematically develop the viewpoint that an active partnership of interests is needed in identifying the kinds of information most needed to help decision-makers in fields of social service go on with their work more effectively.

In this connection, John MacKenzie's comments are especially notable because of the emphasis they place on the need for analysts to be realistic about the processes by which groups get to make legitimate claims upon public resources. MacKenzie's discussion is also worthy of note because of the clarity with which it signals the need for analysis and information development to take a broad perspective that recognizes all the mechanisms evolved in a community to provide human supports, including the informal ones. The ability of assisted informal community effort to address personal and family needs in ways that reduce the requirement for bureaucracy is exemplified in his comments.

A number of panelists and audience participants expressed concern about aspects of the methodology used in the Elfenbaum and Kingsbury paper, particularly in questions about how the number of roles was measured operationally and about the various complex causal connections that might have lead to the reported findings. Anne Martin Matthews' discussion contains a detailed review of these considerations, and in effect sets up a rich agenda for future research on the impact of women's multiple roles in our society.

Anne Martin Matthews highlights the many crucial policy issues connecting the processes by which formal and informal supports are linked in their impacts on the recipients of social services. Decades ago the big "caring issue" in our society was how we took care of our vast numbers of children, how well we prepared them to be effective adult Canadians. Many economists who like to measure dependency burdens by counting heads are quick to tell us that today and in the future we will have a lower "dependency burden" than we did when we had to put the Baby Boomers through school and into the labour force. This kind of thinking has beclouded the fact that the societal response to that kind of dependency was an effective massive institutional response (the growth and increased diversity of the educational system) which may have little scope for being similarly applied to the big caring issues that Canada faces in the years ahead.

In that massive institutional response, we as a society, simply (to a large degree, if I am to judge from what I see my children getting in school

these days) told families to "go fish" while educational warehouses encroached aggressively upon what used to be family functions in education and socialization (my step-daughter right now is getting parenting instruction in her family course at Grade 11 -- a responsibility assigned entirely to parents when I was growing up). There was low priority for integrating formal and informal supports in the delivery of educational services.

Now there may be little chance of that happening in the context of the big caring issues of the coming years. The processes, the consequences, and the desiderata of integration of informal and formal supports are going to be front and center of public concern and debate for several obvious reasons. One has only to read and hear the impassioned pleas of gerontologists about the effects of "off-loading responsibilities on to already overburdened families" to sense how deep some of the connected issues are. It is for reasons like this that I urge you to read and reflect upon Anne Martin Matthews' comments, and especially her explanation as to why she too needs formal supports.

If you have any doubts about how deep and unavoidable are the issues surrounding the balancing of formal and informal supports, first read David Cassidy's remarks about why PWAs avoid dealing with formal organization help as it is now set up

and how unprepared formal organizations are to deal with the social-service demands connected with the spread of AIDS. Then go back and re-read Ian Stewart's list of "big macro issues". You will see the same basic questions lurking below the surface of commentary -- what's the "right" mix of private and public effort, and what kind of mix do we really want?

Now if the academic analysts who "have the public policy podium" to themselves would only stop debating "government financing" questions as if this big macro-issue can somehow be swept under the rug! What they don't seem to understand is that broad social trends may tend to strengthen or to weaken the bonds upon which private effort is built, and that what happens in this domain will have a major impact on what is perceived to be the required amount of government financing of social programs. David Cassidy's remarks open our eyes to what happens when those bonds are weakened to the point of ineffectiveness.

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Chapter 2

SELF HELP AND GIVING ASSISTANCE TO OTHERS

Self-help Movement in Canada

by
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There are many definitions of self-help groups. For our purposes, we don't need to seek a comprehensive one, it suffices to remain with key principles that can act as a general guide for what is to follow. A self-help group usually is made up of a small number of people who suffer from a common problem or condition, who meet on a regular basis to exchange information, give each other emotional support, share ways of coping and develop new ones. To belong is usually free. A group has its own autonomy and is totally responsible onto itself.

The self-help movement has experienced tremendous growth in the last decades and most indications are that it will grow even more. There are several reasons for this, chief among which are: the nature of current society; the greater demand for services and their increasing costs; and the workings of the self-help groups themselves.

There is indeed a respectable body of knowledge substantiating the idea that the lack of social supports predisposes one to pain, sickness and even death. The world of the atomic age runs in the fast lane. The rapidity of social change, the rate at which social change occurs creates problems of adaptation and affects people's capacity to relate to one another qualitatively. The inference of course is that today's relationships are deemed to be more fragile, more superficial than hitherto. Our way of life interferes with the development of deep relationships. The nuclear family rests on shaky grounds, separation and divorce are rampant, the extended family has largely disintegrated, geographic mobility has become characteristic of the work situation, and the congestion of cities has helped to destroy the sense of community. This general state of precariousness in modern day relationships has a tendency to lead to symptom formation and the search for a service, especially one that can provide camaraderie to boot. One of the striking features of a self-help group is that it usually provides warm and caring relationships. A member of a self-help group is rarely without a friend and this is no doubt communicated by word of mouth from members to non-members and serves to promote the movement.

The thesis aiming to explain this part of the growth of the movement goes like this -- the malaise in the relationship area resulting from a social environment in default predisposes individuals to symptom formation which in turn leads to a demand for service. But as institutions are no better than the society of which they are a part, they characteristically offer services that are distant, formal and in some cases uncaring. At times, services are simply experienced as bad or don't exist at all for certain conditions, faute de mieux reasons for which self-help groups get formed.

A second reason relates more to a type of political climate that's becoming more and more characteristic of the western industrialized countries. For over a decade there has been a constant and steady growth of Thatcherism in western societies, fully buttressed by Reaganism, which supports a "do it yourself approach", a turn to privatization, mainly one suspects, to reduce public supported services as a means of saving money and not unfortunately out of a real appreciation for what self help has to offer. One cannot help but make a parallel with what happened during the heyday of deinstitutionalization. You will recall that the money saved did not automatically go to communities to help individuals integrate into the community. In large part, the money stayed in institutions, though in reduced form. It is now admitted that many of the homeless today are the result of this approach. Although self help is a recognized form of help in its own right and cheap, it still requires money if proper supports for its development and maintenance are set up. Those who would support self help for budget reasons must be made fully aware that self help is not a panacea, it does not solve all problems, nor does it suit all personalities irrespective of the condition. Professional services will always be required and will always have their place.

There is a third main reason why the movement is growing, and this relates to the nature of groups themselves. There isn't time to go into detail as to the potential benefits groups can provide but it would be important to note a few of their outstanding features. There is something very special and very unique about meeting someone who is suffering from the same condition or problem, especially if there is any stigma attached to it. It can have the force of an emotional jacuzzi that confers a sense of belonging that one may never have had, as well as provide a means of identity, in kind again as one may never have had. You can imagine the cathartic release for someone who may have carried the burden of an incest experience for instance without ever having been able to reveal it.

You have undoubtedly heard of the buddy buddy system started by Alcoholics Anonymous at its inception in 1935. This constitutes a 24-hour service available to one in times of crisis. The importance of this service cannot be overestimated for were it not provided at crucial moments in people's lives, the likelihood of relapse with lord knows what consequences is virtually assured.

The helper therapy principle is the name given to that part of the helping process in a self-help group where the one giving help receives more than the one receiving the help. To understand this, one must know that in a group each member gets help, gives help and helps himself. This was first noticed in peer tutoring programs in some high schools in the United States. It was observed that not only did the helper get to know the material more by teaching it, but that he felt better about himself, his self image had received a boost. There is a striking parallel with what happens among self helpers. If we refer back to the buddy buddy system, the one who provides the service necessarily reinforces his new behaviour through helping, which has the added benefit of making him feel much better about himself. The helpee is likely to be so moved by the selflessness of the helper that the latter can become a model towards which the helpee can aspire. Moreover, the thought of the sponsor's selfless service can prove to be a safeguard against relapse, for the helpee would hate to let the sponsor down as it were. There is nothing in the formal existing therapies that is quite like this, a unique opportunity for personal change.

It would be remiss to talk about self help and not mention the principle of empowerment. Because of the expectations of getting and giving help in a group, people have a tendency to change, no matter how little. Every change empowers, and every empowerment begets more empowerment. The taste is addictive. This is why we frequently see, not surprisingly, a self-help group moving from an agenda of mutual support to one of legislative change, social change. Energy once locked is made available for other uses. The individual is free to dispose of the liberated energy and to use it independently of the source from which it came. Although self help is certainly far from being the only empowering agent, the doing for oneself and/or together among peers which the self-help process incites, increases the chances of individuals experiencing this in a group.

Besides these three main reasons why the movement in Canada has grown, other happenings in Canada have characterized the growth of self help in our country. We have witnessed the establishment of clearinghouses and a softening of

attitudes of professionals towards self help, even a surprising awakening of an interest in it on the part of many and for a few, the exercise of cooperative ventures with self helpers themselves. In addition, the Epp statement on achieving health for all gave due place and recognition to the self-help principles, and provinces have given increasing support to self-help projects and approaches. From the national centre, we have continued to publish the national newsletter *Initiative* for self-help groups, develop written materials, make films, organize meetings, always with the intent of furthering the cause. For reference to the latest National Self-Help Unit products, there is a number of copies of the latest issue of *Initiative*, the centerfold of which has a listing.

Another important development that's taken place in Canada has been the establishment of self-help clearinghouses. All clearinghouses carry out the basic functions of information and referral and publish a directory or at least have a listing of the self-help groups in their area. Most will help groups get started and maintain themselves, offering consultation when in crisis, publish a newsletter, hold fairs, and organize workshops for self helpers and professionals. Some do some form of outreach in the community, educating the general public, public relations, media coverage, presenting papers at conferences, and trying to build up

a speakers' bureau usually made up of volunteers. They advocate on the part of all self-help groups in a community. In a word, self-help clearinghouses are nerve centers from which emanate all kinds of self-help activities in a community or region. Where they exist, self help grows and flourishes, at least that has been the experience in the United States where some centres have already quite a history. Indeed, the claim is also made in Canada but with very rough statistics.

Another area where considerable energy has been spent in Canada is around the whole question of educating professionals to the self-help way. This has taken two forms, presentations at the national or provincial conferences of professional associations and by pushing to have self help as part of curricula in professional training schools. The former strategy has worked well and continues to do so, whereas the latter has been a source of frustration until this year. A number of proposals have been submitted to funders, always with no great luck. Funders would say that professional associations should press for this themselves; the schools would say that their curricula were already overloaded and that professors were asked to teach too much. Ben Gottlieb had a sophisticated and comprehensive proposal some years back that would have done a great job. Looking back, one can only say

that the proposal was ahead of its time and that were it to be presented now or perhaps even a bit later, its chances of being accepted would be much greater.

As it is now, the one that has been accepted to go ahead is a modified version of all the original ones conceived, but which nevertheless if well done, will fulfill a vital purpose. Its name "Competency Profile" suggests the product. A prototype of what an ideal professional should be to deal with self-help groups will be developed. This profile will be the result of workshops and consultations held with professionals currently working with self helpers and self helpers themselves from across the land. The product should be ready at the end of this fiscal year. Andy Farquharson of the School of Social Work at the University of Victoria is in charge of the project.

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AIDS: A Community-based Response(1)

by
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While the Canadian government has slowly increased the budget for AIDS, most federal government money is designated for mass population information and education and research. (Health and Welfare Canada, 1988.)

Given the severity of the AIDS crisis and the initial slow response from the federal government to it, local AIDS organizations developed. Community organizations have subsequently come to the forefront in the communities most affected, in order to present a full-scale assault on this disease and to provide vital services to those affected.

The community-based response to AIDS recognizes the breadth of the epidemic's impact, and so views the disease as a community problem -- a problem not fully addressed by a traditional medical model of service. Whereas the medical model relies heavily upon long-term hospital care, the community-based response is a continuum of care, creating a network of services within an individual's community to meet an array of needs, especially the health needs of People With AIDS (PWAs).

Community agencies offer services such as:

Telephone hotlines. Information often targeted towards specific groups of people; for example, the gay community, teenagers, those seeking experimental treatments, those seeking referrals to lawyers, dentists, and doctors.

Hospice care. Casey House Hospice in Toronto, for example, was established for people in the terminal stages of AIDS.

Buddy programs. Volunteers provide companionship, counselling, advocacy, and assistance with daily tasks such as cooking, cleaning, shopping, and transportation.

Education programs. Staff and volunteers provide appropriate education messages targeted to the gay community, students; in-service workshops to educators; and, general public education. Programs include for example: "Hot, Horny and Healthy" safer sex workshops and comic strip educational messages for street people and illiterate individuals.

Other community-initiated services include: counselling and support groups for PWAs as well as others affected by the human immunodeficiency virus; and legal assistance in preparing wills, powers of attorney, and in fighting discrimination battles. Many of the programs developed by agencies primarily designed to serve the gay community are used as models for groups beginning to provide similar services to other communities.

The community-based response to AIDS also incorporates Canada's strong tradition of volunteerism. Many community services are implemented by men and women, motivated by a deep sense of personal loss and concern, who are willing to work long hours as volunteers. People from all walks of life have joined the ranks -- filling compassionate, sometimes miraculous roles. In 1988, over 3,000 Canadians gave of their time and energy to support community AIDS organizations (The Canadian AIDS Society, 1988). The more than 240,000 hours given by these volunteers conservatively represents a cost saving to the Canadian taxpayer of $3.6 million (ibid.).

People living with AIDS often join the ranks of volunteers. Because AIDS differs from other life-threatening diseases in the degree to which it impairs those who have it, many PWAs lead active lives, holding down jobs and otherwise functioning as they did before their diagnosis. Consequently, they often are involved with community service agencies -- as staff, volunteers, and board members -- and provide an invaluable resource for those designing programs to serve PWA needs.

This involvement of the "patient" or client in developing services is another way in which the community-based response to AIDS differs from the traditional medical model where the service provider and service recipient each has a defined role; that is, the healthy service provider cares for the sick recipient.

Yet another essential contribution of the community-based response is targeted, grassroots education to curb the spread of HIV. Federal government funding now supports general public education about AIDS, which is important for setting the climate and making people more receptive to specific prevention messages.

Community programs have taken the crucial second step of tailoring education messages to the sensitivities and needs of specific communities. They use explicit language and images to reach individuals engaging in high-risk behaviours such as unprotected sex and the sharing of dirty needles. They also design specific messages to penetrate socioeconomic barriers, and reach people from diverse ethnic, religious, cultural, and sexual backgrounds.

Innovative community-based education programs aimed at individuals isolated from the general population include, for example, the Prostitute's Safer Sex Project in Toronto which uses sex-trade

workers to educate their colleagues about risk-reduction methods. As well, AIDS Vancouver Island employs a street outreach worker to distribute clean needles and AIDS education material to injection drug users who would not otherwise be reached.

The community-based, continuum-of-care model of AIDS services means the cost of treating AIDS is significantly lower, and the quality of life for the PWA is higher, because substantial services are provided outside the hospital through networks of medical care and psychosocial programs, which are heavily supported by volunteers.

The foundation of the community-based response is a view of AIDS as a community problem. When a community is willing to band together and help its own members, powerful things happen. Costs are reduced. Compassion becomes more than a concept. Community members are rewarded with a sense of gratification, connected to helping others in the community. People with AIDS retain their dignity when they are addressed as human beings with the same needs and desires as everyone else. The work gets done, human needs are met, and everyone benefits.

As AIDS becomes more entrenched in Canadian society, the Canadian AIDS Society must grow if this crisis is to be adequately and justly addressed at the community level.

Failure to grow and to strengthen the community-based response to AIDS, to strengthen the national response to AIDS and to plan for AIDS into the 1990's could very well result in an even greater burden being placed on the nation's health care system as the crisis worsens.

Footnotes

(1) Special thanks to the National AIDS Network for giving the Canadian AIDS Society information on the American community-based response to AIDS.

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Report on Seniors' Volunteer Work and Unpaid Help to Others

by
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Introduction

Most research about support and the elderly focuses on the support given to older persons by other, usually younger persons. This research tends to emphasize problems and needs of older people and thus, the burden experienced by supporters in providing care to older people. A consequence of this research focus is an inaccurate exaggeration of the elderly's dependency and an undeserved portrayal of older persons as a burden to their families. In fact, the majority of older persons are able to function quite independently. As well, much of the support provided to older persons who do require assistance is provided by another older person, most often a spouse. This is particularly true of men, who are more likely than women to end their lives with a spouse to care for them. Therefore, most older persons maintain relative independence either individually or as couples well into their old age. In the absence of a spouse, assistance may still be provided by other age peers, such as siblings, in-laws, friends, and neighbours.

More and more studies are documenting the support exchange between the generations and the evidence that reciprocity characterizes older parent-adult child relations. For example, in a London, Ontario study, 63% of respondents (aged 65 and over) reported that they give and receive support. About 20% of the sample gave assistance and received none and 15% received assistance but gave none. Generally, "more financial support goes from old to middle-aged and young family members than flows in the opposite direction along generational lines". As well, in many multi-generational households, it has been found that it is often the older parents who are providing a home for their adult children, not the reverse that is so often assumed.

Some research on volunteer work also records the active role played by many senior citizens. The Survey of Volunteer Activity reported that 20% of older Canadians performed some type of volunteer service in 1987. As well, many seniors are active in veterans' clubs and seniors' groups. In the past few years, voluntary groups of seniors providing help to other seniors have emerged across the country. Many of these exist thanks to funding from the federal government's New Horizons program. The National Advisory Council on Aging sees a clear need for more research regarding what older people give to others in order to balance the attention that has been paid to what they receive. The experience of the members of the Council is that seniors as a group are active individuals supportive of their families and their communities. Council members realize that seniors' continuing obligation to their families, friends and community is the source of their respect and integration into society. The Council wants to see these contributions recognized.

Thus the Council seized upon the opportunity occasioned by this Symposium to present its position which is amply supported by findings from an analysis of data from the 1985 General Social Survey. Data from this survey help throw light on the routine contributions made by older persons in everyday life, to their families, friends, neighbours, and communities.

Methodology

At this point, I would like to gratefully acknowledge the work of Dr. Ingrid Connidis and Forrest Frankovitch of The University of Western Ontario who prepared, under considerable time pressure, a comprehensive report based upon the General Social Survey conducted in 1985 by Statistics Canada. The purpose of their analysis was to examine the assistance and support given by older persons to others. Several types of help were examined including: financial donations (donating money); volunteering in

organizations (unpaid volunteer work); transportation; baby-sitting; assistance in someone else's home (housework, home maintenance, and yard work); and personal care outside the home.

Their analysis examined how many and which older persons provide these various forms of support, and who the recipients of such support were. Specifically, their study looked for differences based upon gender (men versus women), age (55 to 64, 65 to 69, 70 to 74, 75 to 79, 80 and over), marital status (married, not married), living arrangements (live alone, live with a spouse with or without others, live with others), subjective health status (poor, fair, good, excellent), education (less than secondary, completed secondary, more than secondary), and region of Canada (Atlantic, Quebec, Ontario, Prairies, British Columbia).

Obviously, income could be another important variable, but because a fairly large number of respondents did not report their income, this variable was regrettably not included in the analysis.

Results

I will take the rest of the time allotted to me today to summarize some of the findings of the Connidis and Frankovitch study.

With regard to older persons providing support, Table 1 summarizes the percentage of men and women who provide various

Table 1. Percentage Distribution of Men and Women Who Provided Various Types of Help in the Past Six Months

	Men	Women
Donating money	59	57
Volunteering	12*	16*
Transportation	26*	18*
Babysitting	14*	26*
Help in someone's home(1)	22*	18*
Personal care outside the home	2*	6*

(1) Includes home maintenance, yardwork and housework.
* There are significant differences between men and women in the likelihood of providing this type of help.
Source: Statistics Canada, 1985 General Social Survey.

forms of assistance. As can be seen, there is considerable variation according to the type of assistance provided, with the largest proportion of men and women providing financial support and the smallest proportion providing personal care outside the home. In fact, for both men and women nearly six out of ten seniors donated money. The next most likely kind of support for older men was providing transportation at 26% followed by helping in someone's home, probably home maintenance, at 22%. For older women the next most likely form of assistance after donating money was baby-sitting at 26% followed by transportation or helping in the home at 18%.

A multivariate analysis was conducted to examine the effects of the selected variables or characteristics on the likelihood of providing the various types of assistance. As Table 2 indicates there are significant differences between men and women in the likelihood of providing all forms of support except donating money. Women are more likely than men to volunteer, baby-sit, help in the home and provide personal care. Men are more likely than women to assist with transportation.

Let us examine this table in detail for each kind of support. In this table, the group most likely to provide each type of assistance is listed and an asterisk (*) denotes whether a relationship was found to be significant (e.g., the relationship between subjective health and donating money).

Donating money. Subjective health, education, living arrangements, region, and age are independently related to the likelihood of donating money. Gender is not.

Among men and women, the likelihood of donating money is affected by subjective health (the better one's health the greater the likelihood of donating money); education (the higher the education the greater the likelihood of donating money); living arrangements (those living with a spouse are more likely to donate than those living alone, who are more likely to donate than those living with someone other than a spouse); region (donations are most likely in Ontario and least likely in Quebec), and age (the likelihood of making donations increases up to the age of 74 for men and 69 for women, and decreases thereafter).

Volunteer work. For both men and women, the likelihood of doing volunteer work is affected by subjective health (the better one's health the greater the likelihood of volunteer work); education (the higher the education the greater the likelihood of volunteering); living arrangement (those living with spouse are more likely than those

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Table 2. Summary of Characteristics Associated with Greatest Likelihood of Providing Assistance(1)

Independent variables	Donating money	Volunteer work	Transportation
Subjective health	* Excellent	* Excellent	* Excellent
Education	* Post-seconday	* Post-secondary	* Post-secondary
Living arrangement	* With spouse	* With spouse	-
Region	* Ontario	* Atlantic	* Prairies
Age	* 70-74	* 65-69	* 55-64, 65-69
Gender	-	* Women	* Men

Independent variables	Babysitting	Help in someone's home	Personal care outside the home
Subjective health	* Excellent	* Excellent	-
Education	-	-	* Post-secondary
Living arrangement	* With spouse	* Alone	-
Region	* Prairies	* B.C.; Prairies	-
Age	* 55-64	* 65-69	* 55-64
Gender	* Women	* Women	* Women

(1) * implies a significant relationship; the group most likely to provide assistance is named.
Source: Connidis and Frankovitch multivariate analyses using data from Statistics Canada, 1985 General Social Survey.

living alone to volunteer; those living alone are more likely to volunteer than those living with someone other than a spouse); volunteering peaks at ages 65-69, and then declines after that age; more volunteering takes place in the Atlantic followed by the Prairies than in other regions. Women engage in more volunteer work than men.

Transportation. Subjective health, education, region, age, and gender are all independently related to providing transportation assistance. Those in better health, with higher education, residing in the Prairies, aged 55-64 and 65-69, and men rather than women, are most likely to provide assistance with transportation. Living arrangement (closely associated with marital status) is not related to providing transportation, once the effects of the other variables are taken into account.

Baby-sitting. Subjective health, living arrangement, region, age, and gender are related to the likelihood of baby-sitting. Those who are in excellent health, live with a spouse, reside in the Prairies, are aged 55 to 64 and are women are most likely to baby-sit. Once the effect of these variables is taken into account, education no longer has an impact on the likelihood of baby-sitting.

Help in someone's home. Subjective health (excellent), region (British Columbia and the Prairies), and gender (women) are related to providing help in the home. Living arrangement is related to providing help, with those living alone providing the most help. Age is also related, with those 65 to 69 most likely to provide assistance, followed in descending order by those aged 55 to 64, 70 to 74, 75 to 79, and 80 and over.

Personal care outside the home. Only education, age, and gender are independently related to providing personal care. Those with a post-secondary education, aged 55-64 and women are most likely to offer this type of care.

Now let us turn our attention to the recipients of support provided by older persons. Is it parents, children, other relatives, friends and neighbours, or organizations?

Donating money. The distribution of recipients of money from older persons is very similar for men and women (see Chart 1) and for the four older age groups, 65-69, 70-74, 75-79 and 80 and over (see Chart 2). Organizations are by far the major recipients of money from both older women and older men. The only notable difference is that a higher

proportion of the money donated by women goes to other relatives than is the case for men. There are some fluctuations by age in the proportion giving money to other recipients, but no striking differences exist between age groups.

Unpaid volunteer work. As one would expect, most volunteer work is provided to organizations regardless of gender. Men and women also list friends and neighbours as recipients of voluntary assistance, suggesting that for older persons, assistance provided to family is perhaps taken-for-granted as an expected activity, while assistance to friends and is not (Chart 3). Similar patterns are observed by age (Chart 4).

Transportation. The recipients of transportation do vary by gender (Chart 5) with men more likely than women to provide transportation to children and other relatives. Both genders provide transportation to parents, friends and neighbours, and organizations in similar proportions, and friends are the most likely recipients of this assistance. Regarding age (Chart 6), those aged 65 to 69 are most likely to provide transportation for their parents. They are also the most likely to have surviving parents. Those under 75 are more likely to provide transportation for friends than those over 75, but for all age groups friends are the most common recipients.

Baby-sitting. There are some gender differences concerning the recipients of baby-sitting (Chart 7) but children are the primary recipients (87% of men, 80% of women). Note that the child is considered the recipient of the assistance, although it is generally a grandchild who is being cared for. Men are more likely to baby-sit for children and less likely to baby-sit for other relatives and friends than are women.

Concerning age (Chart 8), those 75 and over are less likely to baby-sit for children and more likely to baby-sit for other relatives and organizations than those under 74. This may reflect the relative ages of their children and grandchildren. With increasing age it is less likely that grandchildren will be young children and more likely that grandchildren will have young children of their own. Perhaps the other relatives being cared for by the oldest respondents are great-grandchildren.

Help in someone's home. The results for this form of assistance may be somewhat misleading because traditionally male (home maintenance and yard work) and female (housework) forms of help are included in one category. As Chart 9 indicates, the most likely recipients of home care are children and friends or neighbours. However, women are more likely to provide such assistance to children, while men are

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Chart 1

Distribution of Recipients of Donations of Money Provided by Persons Age 65 and Over within the Past Six Months, by Gender of the Provider

Per cent

Type of recipient of donations
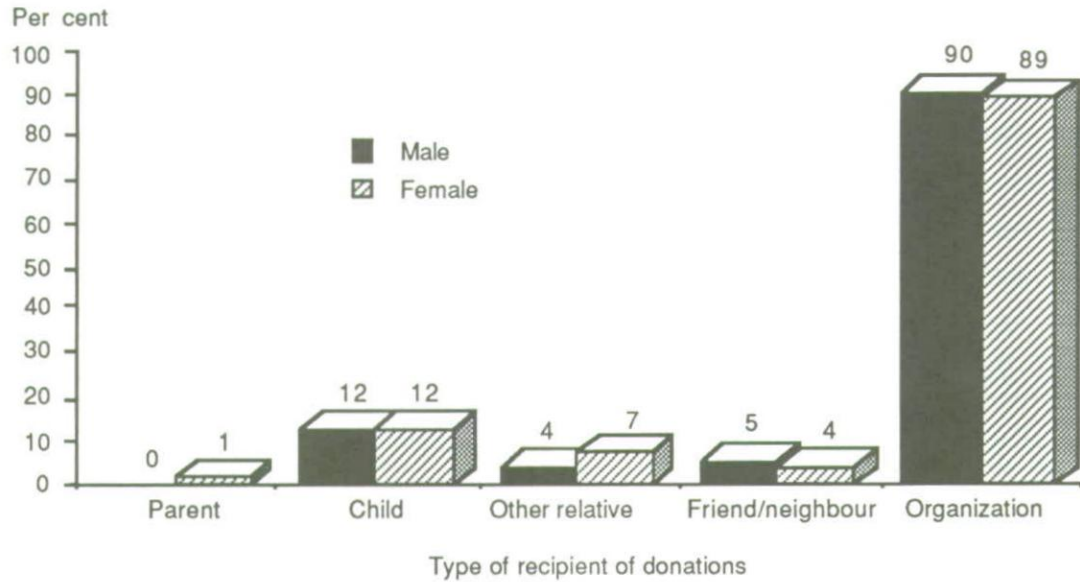
Source: Statistics Canada, 1985 General Social Survey.

Chart 2

Distribution of Recipients of Donations of Money Provided by Persons Age 65 and Over within the Past Six Months, by Age of the Provider

Per cent

Type of recipient of donations
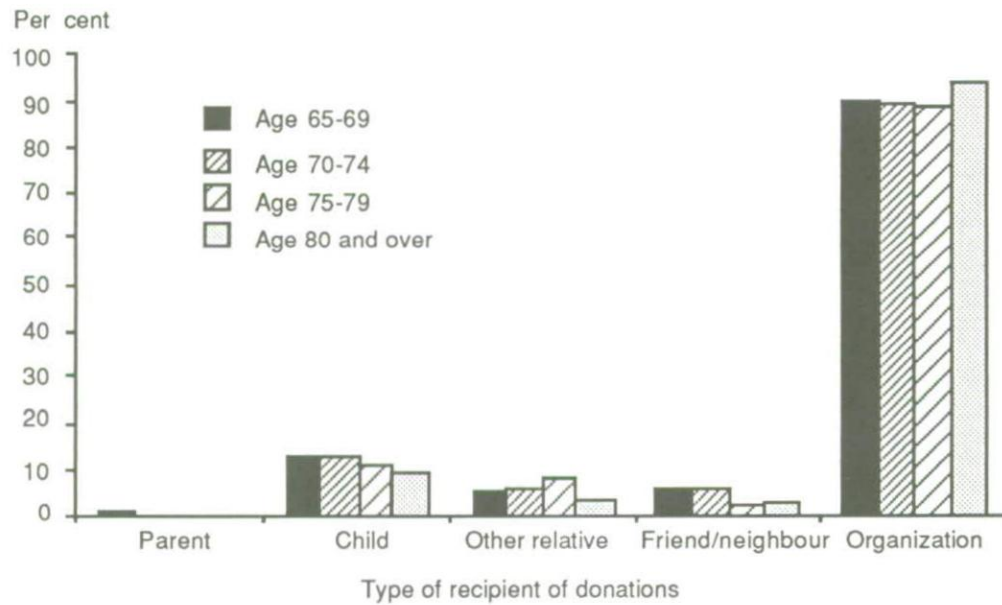
Source: Statistics Canada, 1985 General Social Survey.

Chart 3
Distribution of Recipients of Voluntary Assistance Provided by Persons Age 65 and Over within the Past Six Months, by Gender of the Provider
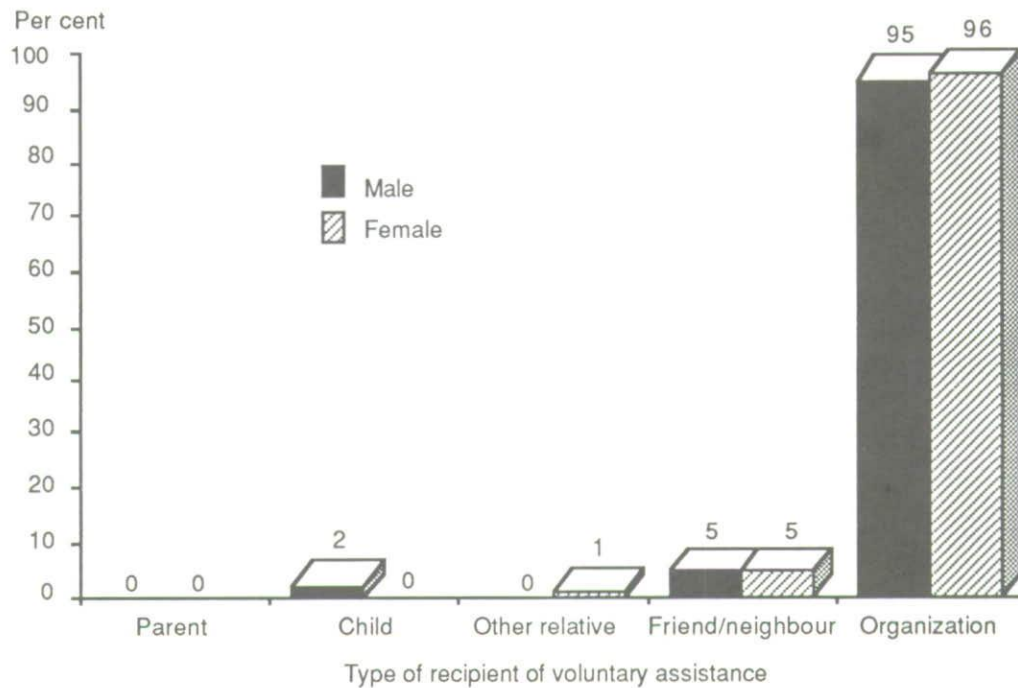
Source: Statistics Canada, 1985 General Social Survey.

Chart 4
Distribution of Recipients of Voluntary Assistance Provided by Persons Age 65 and Over within the Past Six Months, by Age of the Provider
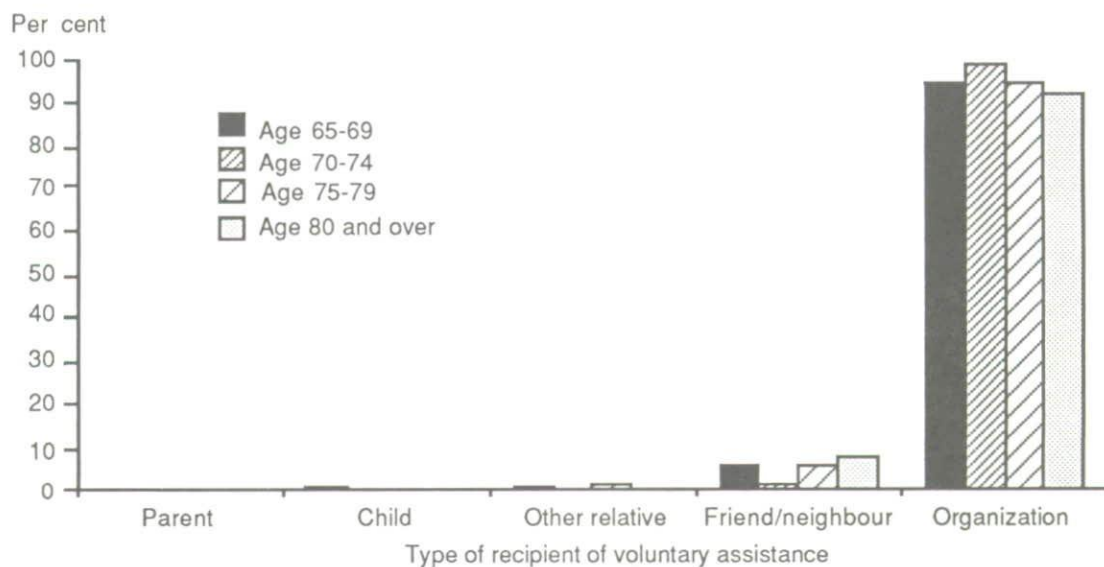
Source: Statistics Canada, 1985 General Social Survey.

Chart 5
**Distribution of Recipients of Transportation Provided by Persons
Age 65 and Over within the Past Six Months, by Gender of the
Provider**

Per cent

Type of recipient of transportation
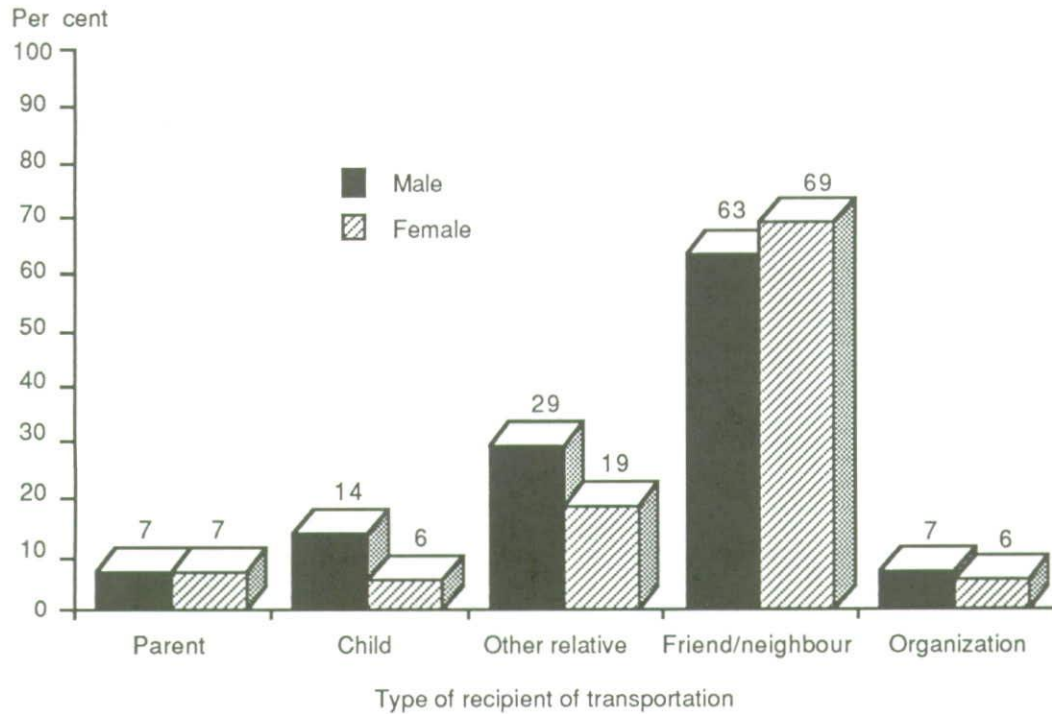
Source: Statistics Canada, 1985 General Social Survey.

Chart 6
**Distribution of Recipients of Transportation Provided by Persons
Age 65 and Over within the Past Six Months, by Age of the
Provider**

Per cent

Type of recipient of transportation
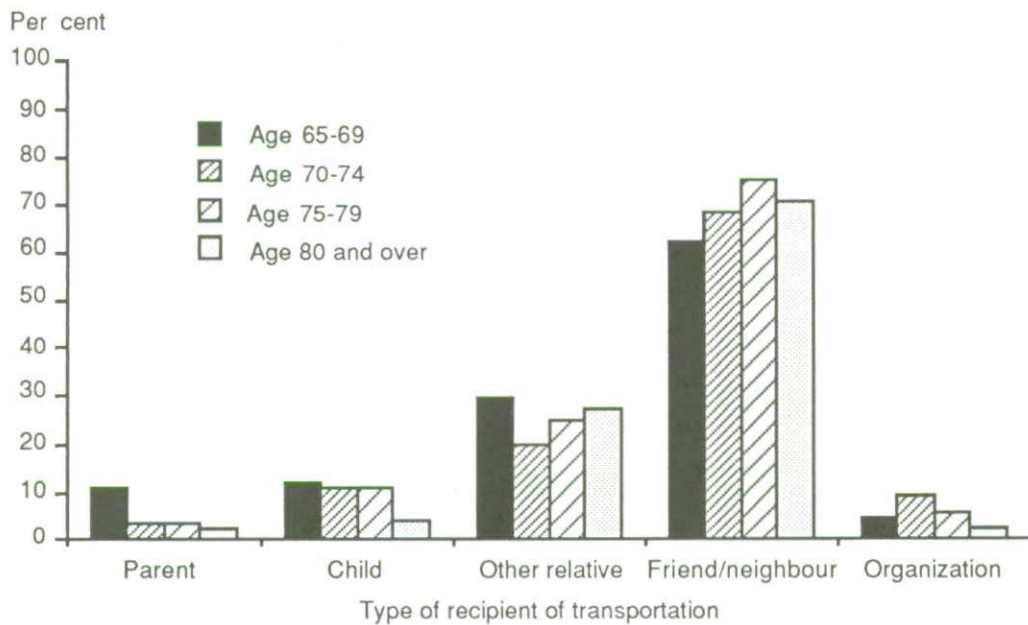
Source: Statistics Canada, 1985 General Social Survey.

more likely to assist friends/neighbours and organizations than women are. The varying nature of the tasks involved may partially explain these differences.

With increasing age (Chart 10), children are more likely to be the recipients of home care while parents and other relatives are less likely to be the recipients.

Personal care outside the home. To the extent that men provide personal care, it is more likely to be to other relatives and friends or neighbours than is true of women (see Chart 11). Children are equally likely to be the recipients of personal care provided by men and women (6%). Women are much more likely to provide personal care to their parents (22%) than men are (0%).

Regarding age (Chart 12), those aged 70 and over are more likely to provide personal care to friends and less likely to provide such assistance to children. Patterns regarding parents and other relatives are irregular.

This review of the recipients of assistance indicates that there are clear differences between men and women, and among age groups. These differences are in part a reflection of differences in traditional sex roles, and of stage in the life cycle.

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Chart 7
Distribution of Recipients of Baby-sitting Provided by Persons Age 65 and Over within the Past Six Months, by Gender of the Provider

Per cent

Type of recipient of baby-sitting
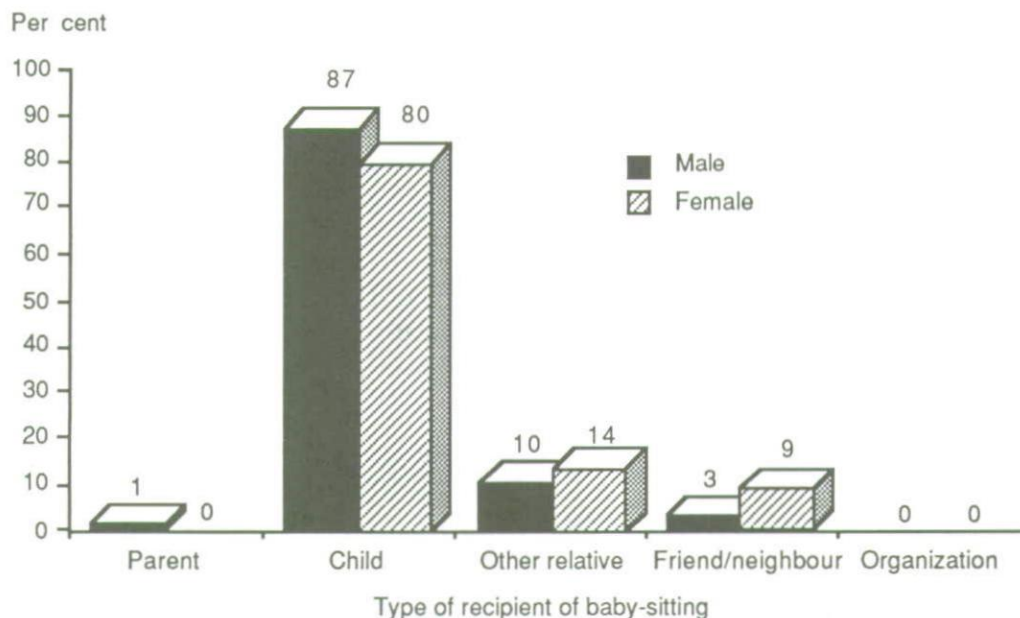
Source: Statistics Canada, 1985 General Social Survey.

Chart 8
Distribution of Recipients of Baby-sitting Provided by Persons Age 65 and Over within the Past Six Months, by Age of the Provider

Per cent

Type of recipient of baby-sitting
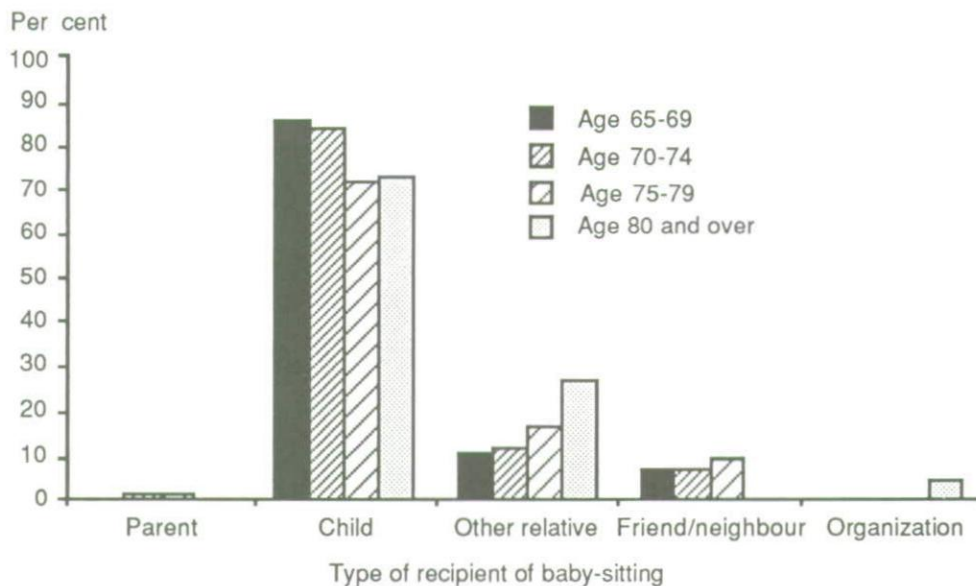
Source: Statistics Canada, 1985 General Social Survey.

Chart 9
Distribution of Recipients of Help in Home Provided by Persons Age 65 and Over within the Past Six Months, by Gender of the Provider

Per cent

Type of recipient of help in home
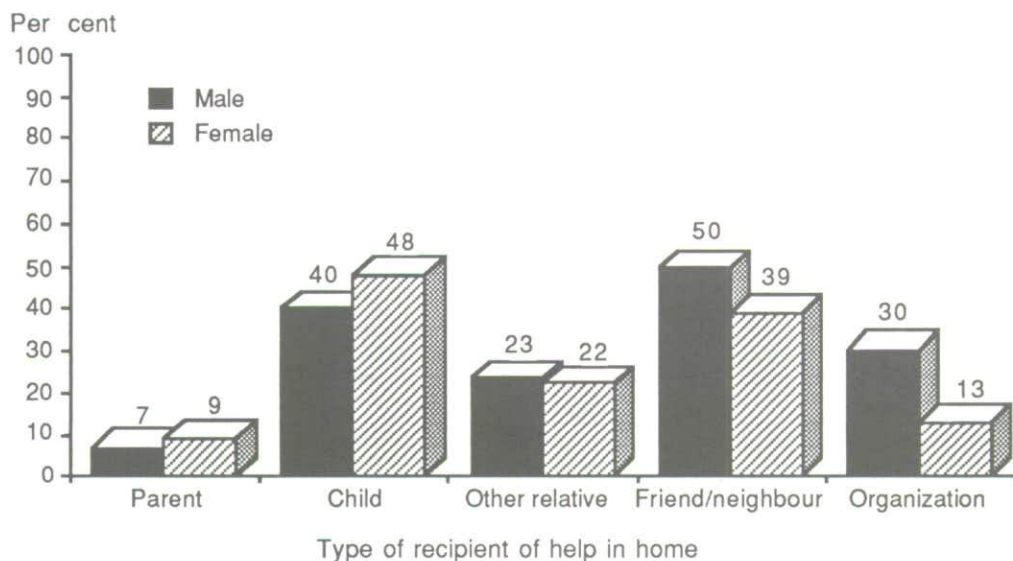
Source: Statistics Canada, 1985 General Social Survey.

Chart 10
Distribution of Recipients of Help in Home Provided by Persons Age 65 and Over within the Past Six Months, by Age of the Provider

Per cent

Type of recipient of help in home
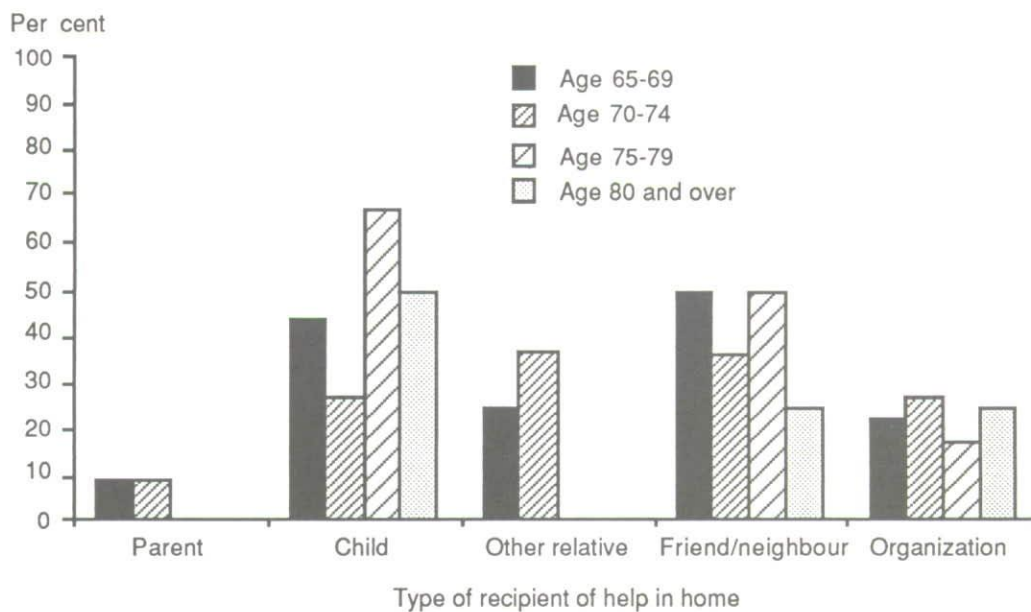
Source: Statistics Canada, 1985 General Social Survey.

Chart 11
Distribution of Recipients of Personal Care Provided by Persons Age 65 and Over within the Past Six Months, by Gender of the Provider

Per cent

Type of recipient of personal care
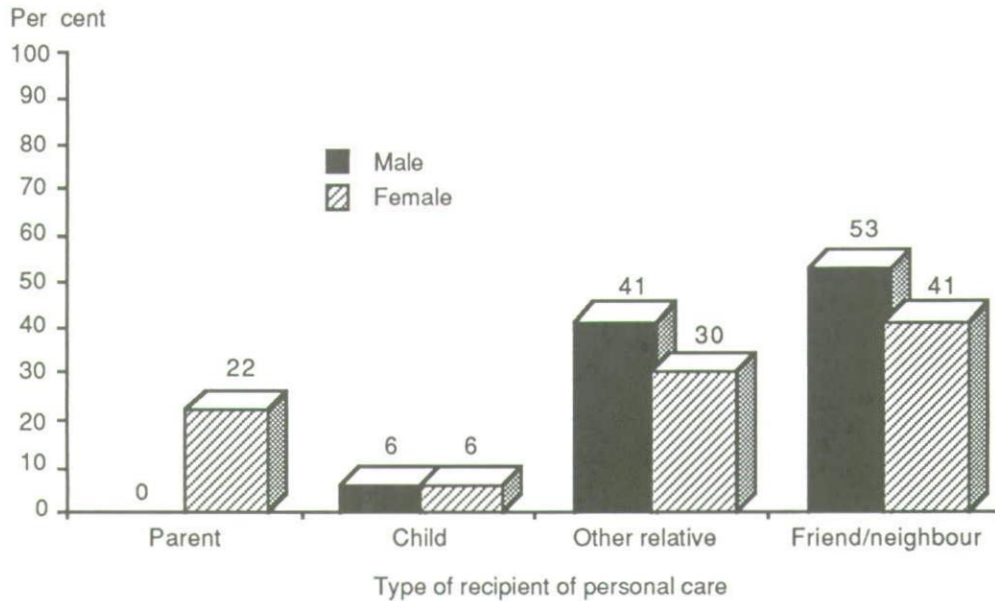
Source: Statistics Canada, 1985 General Social Survey.

Chart 12
Distribution of Recipients of Personal Care Provided by Persons Age 65 and Over within the Past Six Months, by Age of the Provider

Per cent

Type of recipient of personal care
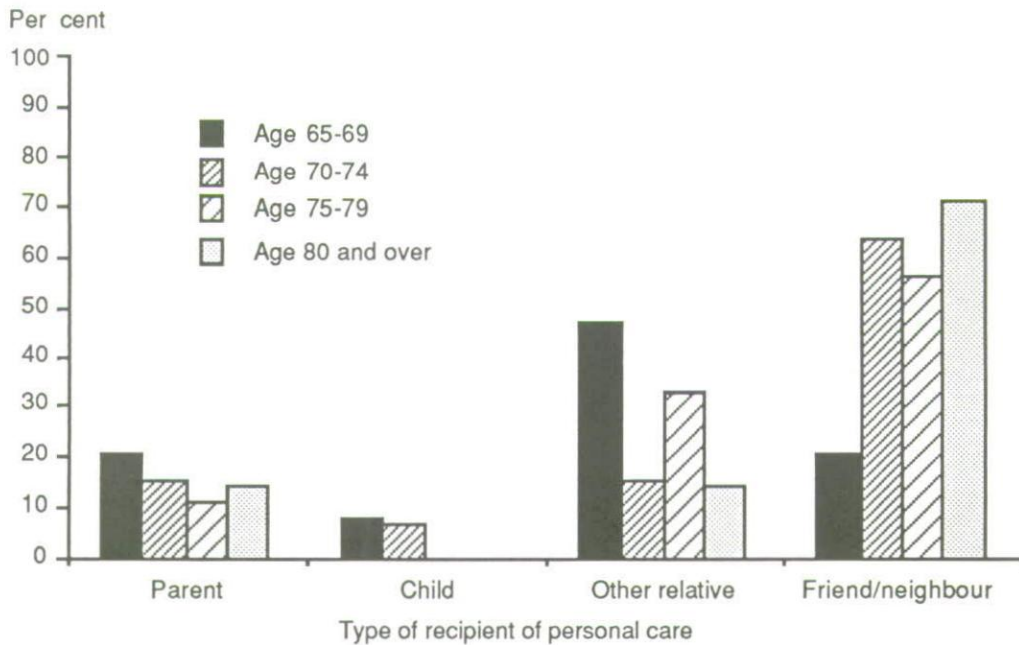
Source: Statistics Canada, 1985 General Social Survey.

Summary and conclusions

This brief review of the information collected by the 1985 General Social Survey clearly upholds the position of the National Advisory Council on Aging. That is that seniors are in fact active contributors to family members, their friends and their communities. While this study found that seniors from a variety of circumstances provide support, those in excellent health, with a post-secondary education, living with a spouse, aged 65 to 69, women, and those residing in the Prairies are most likely to provide most of the forms of assistance that were measured. Most of these findings are not surprising.

This study, however, does not provide a comprehensive review of seniors' support to others. The 1985 General Social Survey only identifies six kinds of support. It did not ask about other forms of assistance such as shopping, running errands or emotional support. Thus, the importance of seniors' contributions may indeed be far greater than is documented here.

This report is just a beginning. It has provided a glimpse of what seniors' contributions to others probably are. Obviously, much more research on this topic is needed.

The Role of Family Resource Services as a Child Care Support

by
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Child care as a family support

By now, the changes Canadian families have been undergoing over the last several decades, have been well documented. They include changes in family composition and structure, due to such things as: declining family size (between 1961 and 1985, the average number of children born to women 25-34 years of age, declined from 2.5 to 1.7); and an increase in the number of lone-parent families (in 1986, 12% of children under 6 years, were being raised in single parent families). (Special Parliamentary Committee on Child Care, 1987, p. 8)

Many families are more mobile, with parents often moving to another community to seek training or job opportunities. While families are generally smaller, children are also dependent longer, with many needing financial help from parents in order to finish community college or university, rather than being able to contribute to family finances as they once did.

There have also been dramatic increases in women's labour force participation, especially among mothers with young children. For example, the participation rate for women with children under three years of age rose from 32% in 1976 to 56% in 1986. (Statistics Canada, 1986) Changes in the economic situation, continuing inflation and the rising costs of housing have meant that in many families, it is the wife's earnings that keep the family income from falling below the poverty line.

The continued immigration of families from many countries, often with young children, has also resulted in demands for child care support to enable both parents to work to establish themselves, and/or to participate in language and training programs that will help them to adjust to their new life in Canada.

As a result of the many and complex changes described, many families are having to seek supplementary child care outside of their extended families, in order to meet their work and economic obligations.

Inadequate supply of licensed child care services

While family life and needs have changed, the licensed, "formal" child care system has not kept pace with the changes. It has been estimated that in Canada in 1987, there were over 1.9 million children under 13

years needing supplementary child care, because their parents worked or studied outside the home. At the same time, there were an estimated 243,545 licensed child care spaces available -- to serve 13% of these children. The proportion of spaces available varied by province, with a low of 4% in Newfoundland, to a "high" of 20% in Alberta. (National Council on Welfare, 1988, p. 3)

This shortage of licensed spaces in both group and family day care homes has meant that the majority of families must seek supplementary child care in unlicensed, "informal" child care arrangements. Locating, assessing and maintaining alternative arrangements, is therefore, a recurring task facing many working parents.

Families' needs for a variety of child care supports

Families' needs for child care support, however, extend beyond finding a day care space or an informal arrangement. In the study, Child Care Needs and Preferences, Lero et al. (1985), point out that traditional definitions of need are restricted to a limited range of purposes that only meet the needs of a limited number of families. "An alternative view of non-parental child care is that it is a common type of family support used to some degree by most families for a variety of

purposes." Families surveyed want and use child care for a number of reasons:

- ○ "...when parents are working or looking for work
- ○ ...while parents attend an educational institution or training program
- ○ ...care for children and support to families with special needs
- ○ ...as a means of providing children with opportunities designed to stimulate their development, promote personal competence, and enable the development of social skills...
- ○ ...as a supportive resource to families at specific times of peak need, or when the usual child care arrangements are not available; and
- ○ ...for the purpose of enabling parents to participate in volunteer or community activities, to attend to personal and family tasks, and/or as a means of allowing them time to socialize with other adults." (Lero, et. al, 1985, p. 104)

The recognition of the variety of needs families have and the need for child care programs to be more responsive, has led to the concept of a comprehensive child care system. The report by the Special Parliamentary Committee on Child Care, Sharing the Responsibility (1987), echoed this view:

"...it is only by offering support for a wide range of programs that promote the well-being of families and children that the federal government can acknowledge the diversity of families and respond in a way that allows Canadians to make informed choices about how to care for their children." (p. 33)

The committee also saw the second objective of the proposed act as contributing: "to the cost of developing a range of family support services to complement formal and informal child care...Family support services that we would like to see developed include (but are not limited to) family resource programs, information and referral services, a registry of licensed caregivers, parent education, and services for families with special needs." (p. 41)

Family resource (and support) services

The Canadian Association of Toy Libraries and Parent Resource Centres (TLRC, Canada, 1989), has described the important role family resource services play "...in creating a responsive child care system and in improving the general quality of child care arrangements. They support the development of positive

parent-caregiver-child relations. They provide opportunities for learning about parenting and child development through offering a variety of programs such as play groups, toy-lending and parent discussion groups. They also provide information about other local child care services." (p. 5)

Although family resource services have evolved in unique and different ways, and provide a range of services that vary, depending on such things as their specific history, local needs, and available funding, they nevertheless, tend to share a number of basic beliefs and common strategies.

They also reflect recent trends in social services: towards self-help and mutual aid, to creating better access to services through information and referral, through emphasis on health and wellness, and through providing preventive, less costly, services. (Weiss, 1983)

Many family resource services take a community development approach to service provision and stress the involvement of parents, volunteers, and community members in the design and day-to-day operation of programs. This approach also means that services are responsive to family and children's needs and are flexible, changing and evolving over time. Many of the programs also emphasize the importance of building

self-esteem: both in adults -- to empower them through education and support to become more confident as parents in caring for their children, and in children -- by promoting their independence and self confidence through sharing play activities and social experiences with other young children. (Cochran & Woolever, 1983)

Although the emphases may vary, many family resource services encourage children's play and development, and provide opportunities to educate adults about the importance of play in children's learning.

Most programs recognize an inter-connection between parents and "informal" caregivers. While a parent (or grandparent) may come to a resource centre for support with their own children, many move to becoming "informal" caregivers through joining baby-sitting co-ops, and taking part in drop-ins or in working in a toy library, or through the simple gesture of helping out another parent.

Because of the relative newness of family resource services, it is also important to emphasize that there is not "one model" or approach to service delivery. A given program doesn't necessarily offer any specific number or combination of component services. For example, a parent-child drop-in may change/evolve over time,

adding a toy library, a clothing exchange and a child care registry; or alternatively, a toy library may add a parent discussion group or reading classes for adults. Program differences can occur based on the mandate of the sponsoring group, the length of time the resource service has been operating, the location (rural/urban), the target groups served, the availability of funding, amount of volunteer support, and so on.

The wide variety of program components offered by family resource services can be characterized by three essential support functions; instrumental support (through the provision of material goods and services), emotional support, and information and referral to meet other needs (Unger and Powell, 1980). Some examples are as follows:

1. Instrumental support through direct services:

  ° parent-child drop-in centres
  ° play groups
  ° emergency care and parent relief
  ° toy, books and equipment-lending
  ° reading classes, ESL programs
  ° clothing exchange
  ° child birth and post-natal education
  ° often in association with nursery schools, family day care and day care services

  ° programs for children with special needs
  ° special programming for older children, e.g., drama, cooperative games and play.

2. Emotional support:

  ° parent education through workshops, discussion groups, participation in various programs
  ° support groups for immigrant women
  ° outreach through home visits
  ° informal counselling, development of life skills.

3. Information and referral to meet other needs:

  ° information exchange through newsletters, bulletin boards
  ° caregiver registries, information and referral services
  ° advocacy and focus for community planning about child care.

While the exact number of family resource centres and toy libraries in Canada is not known, TLRC, Canada, counts in its membership over 375 programs. At the end of 1988, there were 21 members from British Columbia, 27 from Alberta, 9 from Saskatchewan, 18 from Manitoba, 270 from Ontario, 12 from Quebec, 8 each from New Brunswick and Nova Scotia, 3 from Newfoundland and 1 from the Yukon.

Perhaps because of the uniqueness and rapid evolution of family resource services, terminology related to this program area is often problematic and unclear. Across the country a variety of terms are in use, to define what, on closer examination can be seen to be similar programs and services. For example, in Ontario, family resource services are referred to as child care support services, while in British Columbia, they are called "Family Places". In some areas, Boards of Education refer to the resource programs they sponsor as Parenting Programs. Federal documents often refer to them as family support services.

The phenomenal growth of these programs in Ontario is due to the Day Care Initiatives program, begun in 1981, to "improve the quality of informal child care arrangements and strengthen the capacities of parents to select and monitor such arrangements." (p. 62), and to funding from subsequent Child Care Initiatives. (MCSS, 1981)

In July 1987, Ontario published a "Survey of Child Care Support Services", which found that there were about 15 different (but related) kinds of services provided through resource centres. The most frequent services provided were workshops and discussion groups (88%), followed by play groups/drop-ins with parent or caregiver in attendance (75%), and toy libraries (58%). In addition, 37% provided community linkage and outreach services, 35% provided information about child care, 20% provided parent relief, 19% conducted home visits and 16% offered a food and clothing depot (Doherty 1987, p. 8).

The survey also found that among the 109 programs that participated, the average annual operating cost (1985-86?) was $56,527, ranging from a low of $8,700 to a high of $325,368, with just over 72% of their funding coming from the Child Care Incentive Fund. (p. 67) Unfortunately, comparative information about resource services operating in other parts of Canada is unavailable.

Weissbourd (1987) has demonstrated that the roots of family support programs have been derived from various combinations of the information-sharing focus of traditional parent education programs, the community orientation of the settlement house movement and the peer-support concepts that are fundamental to self-help groups. Current family resource programs, however, have developed their own set of distinctive characteristics. They include:

° a changed view of "parents" -- being a parent is seen as an important stage of adulthood, and parents are viewed as natural "experts", not as "vessels to be filled with appropriate information about child development". (p. 47)

° a more ecological approach to providing services, so that the child is viewed "in the context of the family, the family in the larger context of community life, social institutions and government policies". (p. 48)

° because of their interest in early learning and play, and in providing support to new parents, the focus of many programs is preventive.

° an approach to families and children based on a perspective of "wellness", building on their strengths, rather than emphasizing their problems or deficits.

° an emphasis on inter-dependence, and the recognition that all families at some time need help and support to raise their children.

° a recognition of the need for developing social support networks to counter the feelings of isolation, and loss of traditional support systems that result from the increased mobility and other changes in modern family life. "The social support network provides for individual and family relationships that are nurturing, that build on the family's capacities to cope with daily living and that help families to become involved in shaping the environment in which their future lies." (p. 49)

Examples of Canadian family resource programs

While the following examples of some Canadian Family Resource programs are not to be taken as necessarily representative of all programs, it is hoped that they will serve to illustrate some of the concepts identified above. The material I am using is taken from 26 unedited program reports submitted to TLRC, Canada, for its 1989 publication, Strengthening Families, Cherishing Children: Canadian Family Resource Services: In Theory and Practice.

An excerpt taken from Vancouver's West Side Family Place report, gives a good sense of what goes on in a typical resource centre:

"Today, a visitor would see two nannies sitting companionably in one corner of the playroom, talking over the news from home with each other, all the while keeping a careful eye on their charges as they climb up and down the stairs to the playhouse. One mother sits quietly in a corner of the playroom, a cup of coffee beside her, and flips through a magazine, while eight-month-old Jessica sits at her feet, gradually chewing, squeezing and grabbing her way through a basket of toys suitable for babies. She's entertained, too, by the antics of the other children in the playroom, and

Mom gets a precious few moments alone with her own thoughts.

Meanwhile, in the lounge area, one woman stands at the bulletin board, checking over the offerings of toys for sale, pre-schools advertised, requests for baby-sitters. Two more mothers, quietly breast-feeding their infants, discuss the best methods of birth control while nursing. They've met for the first time this morning, but the casual, friendly ambiance of Family Place encourages quick friendships, contacts and an openness and willingness to discuss and share concerns about what has after all brought them together in the first place: their children and their roles as mothers." (Corser, 1989, p. 1)

Many of the reports speak eloquently about their work to empower parents, and it is apparent how deeply this principle has been integrated into their philosophy. The Daybreak Child Centre, a multi-service program for "high risk" families and their children in St. John's, Newfoundland cites an example of family support:

"Sometimes parents will complain that a person or agency has not responded to their request in the way they had hoped. For example, the most frequent complaint is toward the St. John

Housing Authority. All too often, systems which are meant to serve families feel they know what is best for families without corroborating these plans with parents themselves. If a service program takes an approach which undermines the parent's self-esteem, then it is eroding the very foundation on which the parent's ability to parent can be developed. Parents who feel rejected or victimized often expend their energy complaining to people who are unable to do anything about the problem. They may need help in learning how to complain to the right people in the right way, expressing their needs clearly with sufficient supporting information...It is important that workable and acceptable compromises or solutions be found because living with frustration and anger, albeit at "the system", can create unmanageable stress in family relationships." (Rabinowitz, 1989, p. 7)

Jessie's Centre for Teenagers, in downtown Toronto, promotes self-esteem and mutual support:

"...practical assistance was seen as the best means of attracting young women who may have had previous negative experiences with social service or health systems. In offering

tangible services such as a swap shop (provided through clothing and equipment donations), emergency supplies of infant food and supplies, child care, food, bus tickets and twenty-four hour respite care, Jessie's demonstrates that it is aware of the daily reality of life for families living on low incomes. Jessie's also provides an environment of emotional support which comes, not only from the staff, but also from the other young women who use the centre...

Jessie's is a women's collective. This non-hierarchical structural model was chosen because it was felt to be a positive image for young women, encouraging them to exert control in their own lives, and to network with each other for personal support and growth..." (Leard, 1989, p. 6)

Many centres take great pride in reflecting the special circumstances of their communities. College-Montrose Children's Place -- a multi-cultural family resource centre -- has as its goal to "...provide a setting and programmes which enhance the self-esteem of children and adults from different ethno-cultural backgrounds while fostering respect for the culture of others. We recognize and acknowledge a variety of cross-cultural practices in child-rearing." (Ottolino, 1989, p. 1)

The Children's Place report includes some anecdotes about its participants, here is one example:

"Maria is a young Portuguese woman in her late twenties with two small children, one of whom has special needs. She lives with her husband and children in a very small one-bedroom flat in the immediate vicinity of Children's Place. Her husband is employed in seasonal work and is frequently laid off, which places the family under a great deal of financial pressure. Neither Maria, nor her husband have found it easy to adapt to life in Canada. They find themselves very isolated with few resources and lack the support of family and friends. Neighbours have reported regular incidences of violence resulting from the husband's heavy drinking.

Maria visits the centre periodically with her children. Her eldest son Daniel, is hyperactive and she finds it difficult to deal with his behaviour. Maria is very timid and finds it hard to share her problems, but slowly she has confided in one of our staff. Maria has had enough trust in the staff that she will occasionally use our parent relief programme. Our goal is to encourage her to participate in our Immigrant Women's Support group, so that she can begin to address some of the incredible stresses in her life." (Ottolino, 1989, p. 3)

Lest you be mislead, Family Resource services are not confined to urban, or inner-city areas. The Awasheshuk Resource Centre in Hornepayne, Ontario (Stefanic, 1989) for example, provides a variety of services to both native and non-native families. During the day, the resource centre operates a toy-lending library, a drop-in centre, after-school arts and crafts programs, story-telling and mother-child exercise programs; it also publishes a monthly newsletter. In the evenings, it is used by adults from the native community, for various handicraft and other programs. The centre recently established a hot lunch program to enable native students to come there for lunch instead of having to walk over a mile and back to their homes.

The North Frontenac Child Care Resource Centre in Sharbot Lake, Ontario (Seeds, 1989) operates a mobile toy library, in addition to workshops, home visits, a newsletter and an equipment loan centre. Similar to other mobile programs, it travels to a number of small communities nearby -- Arden, Plevna and Picadilly -- offering toys, books and tapes to local children and their families.

Most of these programs rely heavily on volunteers (often users) to operate the various programs; almost all have volunteer boards, whose members include representatives from the local community as well as parents, or other users of service.

Funding and other issues affecting future development

As in the case of many other social service programs, family resource services face a number of serious funding problems. Because the federal government has no specific policy regarding financial support for these services, and cost-sharing under CAP and the proposed federal child care legislation has been and remains unclear, funding for these programs is extremely variable across the country.

In the policy paper, New Directions for Child Care (MCSS, 1987), Ontario reaffirmed its commitment to fund resource services. In other provinces, funding is sporadic and with considerable effort on the part of organizers, can sometimes be obtained through health departments, public libraries, departments of recreation and culture, boards of education, United Ways, Kiwanis and Rotary Clubs and so on.

In a paper prepared for TLRC, Canada, Pitman (1989), reports on the funding challenges faced by many resource programs:

"When funding is made available it may be for a limited-time, pilot project. This can be the source of great frustration. It is difficult to attract high-quality staff for a position which may last only six months and then simply end.

These pilot projects also tend to create expectations in the community; when they are dropped there are often feelings of resentment...

...Centres applying for funding often must confront another problem: the conflict between their desire to protect the privacy of the families using their services and the desire of many funding agencies to be certain that the money is serving their target groups -- most often low income families or those on government assistance." (p. 4)

In some parts of the country, there is also another twist to the debate about the target group to be served, that is, whether or not resource services should focus predominantly on supporting caregivers and parents involved in informal child care arrangements. This debate seems grounded in the need for government to have some basis for targeting limited funds, because in practice, the distinction between serving parents at home caring for children and informal caregivers is often academic, and undermines efforts made by programs to become accessible and non-threatening.

While better government support is clearly desirable, there is nevertheless a delicate balance between maintaining the autonomy and vigour associated with volunteer-supported efforts, and succumbing to the inevitable formalization and bureaucratization that often characterize more established, less flexible services. As Pitman (1989) reports:

"Only extraordinary commitment from staff and volunteers have kept many centres afloat...Members gain a sense of ownership from working directly on the project. It remains very firmly a user-based service, and it develops a social network, which combats the isolation of young parents...When volunteer participation is required in exchange for using the service, those families who would most benefit may be deterred from joining. And volunteers (or staff) who are taxed beyond reasonable limits -- in terms of time, or skill level -- are prone to sudden burn-out." (p. 4)

Staff training is also another challenging question. Kagan, Powell, Weissbourd, and Zigler (1987) call for special centres that would train prospective staff in organizational development, community dynamics, the developmental stages of parenting, ethnic and cultural patterns of child-rearing and also employ a non-deficit, preventive approach to working with families. (p. 376) To combine this multi-disciplinary expertise with the non-deficit view of parents and users as experts, will require great sensitivity and continuing vigilance.

Although preliminary research (Long, 1983, Kagan et al., 1987, Weiss, 1983) indicates family support programs make a difference in the lives of children and are cost-effective because they save funds by reducing the need for remedial services, there is still a need for further evaluative research. Not only is research needed on family support programs themselves -- on what program elements and combination of supports are most effective and contribute to the prevention of problems -- but also, research to test out new evaluation methods that are more appropriate and can measure the impact of these complex and evolving programs on children, their families and the larger community.

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Responses to the Papers in Chapter 2

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Alberta has numerous self-help groups developing, not just those related to diseases or specific problem areas. Self-help groups are developing within the women's movement, religious communities, larger organizations, such as the YMCAs, YWCAs, community leagues, bereavement groups, widows groups, etc. We certainly see the development of self-help groups within the senior movement.

Within senior citizens' organizations, senior citizens' centres can be characterized as self-help groups. Certainly, as I listened to the papers presented, especially those on family resource centres and the one on the community-based response to AIDS, I realized the very great similarity between what is happening in these movements and what has happened within senior citizens' organizations. Yet for some reason we have not really thought about the relationship between what senior centres are doing and what these other self-help groups are doing.

I think the one thing that has impressed me, is that we can probably learn a great deal from each other, as to how to further the self-help movement effectively and how the government can most effectively support and help the self-help movement develop. I do not mean only by seeing that they get money. I think there are other ways of supporting self-help groups and we need to explore this question further.

There is another area that we have not thought about. That is the self-help movement that is developing within housing. Once again in the senior movement, we see a number of seniors' groups moving towards shared and co-op housing projects. To me these are also a form of self help or social support.

A previous paper pointed out the fact that older people contribute a great deal of assistance to others. Those of us who have worked with older people have been aware of this fact, but I do not think the general public has been aware of this at all.

Seniors are generally portrayed as being dependent, a burden, and in need of help. Yet they are a very great source of help to others, certainly to their families. One can see the things that they are doing for their adult children and grandchildren, as well as the great range of volunteer services that older people are involved in. More exploration is required into the ways in which seniors are contributing.

I also think I would like to see more exploration of what kinds of interests seniors have and how we can stimulate further their interest in providing social support and volunteering. I noticed that seniors who were doing the greatest amount of volunteering and providing the most support, are those who are healthier, better off financially, and better educated. Present trends indicate that future generations of older people will be healthier, better off financially and better educated. There is a rich resource of help to the community here, but I think we need a better understanding of what their interests are and in what ways they would like to contribute.

I know from some of the research and literature now available that it appears as though seniors may not be too interested in helping. I always thought this would be a great way for younger seniors to assist the elderly. But why are they not? Are there ways in which we could assist them to provide such help? What are their interests? I think this is an important area that needs further exploration.

I believe older people are a great source of support to their families and could be a great source of support to family resource centres. Perhaps we never considered using older people or calling on them for this help. I know there are some agencies in Alberta that feel once you are over 65 you should not be a volunteer. There are

others that do, like Meals on Wheels and senior centres. Some agencies view the older person as being dependent, helpless, and in need of help. They are not viewed as being a source of help. There are older people who want to provide assistance, but who do not know where to go and what opportunities might exist. I think this is an area we need to explore. How can we link up older people in the provision of help?

Perhaps we need to return to what was said about family resource centres. Almost every older person is a member of a family. How are they used? What is their role in the family? What is the role of a grandparent? Are they not often a source of strength and support to their family members? Perhaps they should be more involved in family resource centres.

I am wondering about the attitudes of professionals. How do those of us who are professionals view self-help groups? Are we willing to give up control? Some work is being done in this area, but perhaps we need more exploratory work. What is the attitude of professionals? How do they view the volunteer? How do they view the self-help movement? How can those of us in government best support and strengthen the self-help movement?

I think Statistics Canada and other information services could be a great source of help. As we move forward we need to know what exists. What

we do needs to be based on solid information. As we look to information services for help and guidance, it is vitally important that this information be quickly accessible and readily understood by those who are not used to working with statistics.

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There are any number of definitions that have been offered of what method is. The simplest and best has been offered by philosopher, Bernard Lonergan, who said that a method is a normative pattern of recurrent and related operations yielding progressive and accumulative results. The key terms are recurrent, progressive, and accumulative.

On the basis of this simple definition, one of the strongest impressions to emerge for me from these papers, is that a method of assessing and exploring the issues of self-help groups and community support for social needs does not emerge. Some serious consideration must be given to the methodological issues involved in the entire area.

What have I learned from these papers?

First, self help exists and in all probability is a growing

phenomenon. Most of the motivations for it appear to be socially healthy, but perhaps some appear to be less so. In this area, I would raise the distinction between cost saving versus life enhancement. I suspect policy planners see self help as a means of cost saving in times of restraint. Knowing those involved in self-help groups, they see it as life enhancement.

The papers have provided accurate descriptions of self help in some very specific areas. However, issues concerning the underlying community dynamic are not raised. For example, how have these groups emerged, why and what motivations underlie them, what is the process of group formation?

Secondly, self-help groups face problems in a number of areas, both self-identified and identified by those who work with self-help groups, in terms of training, funding, government and professional support.

Lastly, I have learned that self help is dependent on the volunteer sector. In fact they are almost co-identical, which means they face significant constraints themselves in a time of constraint, in terms of time, energy and commitment, which is being experienced all through the volunteer sector today. None of these issues has really been addressed, either in these papers, or in most of the literature on volunteerism.

How much time is available for involvement in these groups? A social policy group in Toronto estimated that commuting time in Toronto demands between 3 and 4 hours a day. Now that is a significant restraint on the amount of time available, not only in terms of giving volunteer support to community activities, but also in terms of one benefiting from those activities. At this important time in the opening up of social policy and social research looking at self-help groups, I think we need to get a better understanding of what these constraints are and will be in the future.

What do we need to know about self-help groups?

First, initial research suggests self-help groups help those involved. But we are not really sure. I have some hunches about the kind of help that is there. But further research will show, I suspect, that people in trying to meet one of their social needs, that is the presenting need, are actually meeting another whole set of needs at the same time. This is to say we are social, and self-help groups are complex communities which meet many needs at the same time, not just one or two.

I suspect a further knowledge of self-help groups in their internal and external dynamics will begin to help us understand what constitutes a healthy social system. I would challenge academic researchers, as I have recently challenged medical professionals to tell me what a healthy social system looks like.

Secondly, self-help groups provide a forum for education, trade, social empowerment, and one would suspect, social change. What questions are outstanding? The first is, I think, we have no real understanding of the dynamics involved in self-help formation.

Burzynski, for example, provides a description of a particular self-help movement, but he does not provide an explanation of the event, that is, in terms of an explanatory framework. For example, of the estimated 3,000 people involved in AIDS community groups, how many are motivated towards involvement because they have been touched personally by the issue? How many have been motivated to become involved because of another set of values, another set of personal issues? Is there a difference in the volunteer profile between the two motivational factors?

Thirdly, none of the papers even hint at the relationship of self-help groups and a larger community dynamic. Balthazar suggests a sociogenic element in the creation of self-help groups, but he is not concerned with the relationship with self-help groups to a larger social context. For those who are academic researchers, I

would suggest that some of the research in the area of sociology of religion, studying the relationship of sects and church, those smaller groups that pull away from the larger community, may offer a helpful methodological tool to understand the formation of self-help groups vis-a-vis a larger society.

Lastly, the strongest paper in terms of empirical methods was certainly that drawn from the General Social Survey. We have a wealth of facts about senior involvement in social support, but there is a missing explanatory framework. Some of the factual associations do lead to excellent research questions. For example, why is volunteering higher in the Atlantic Provinces and Prairies than in other places? In my area of religious sociology, associated facts and trends tend to follow a geographical pattern of Atlantic Canada, Central Canada and the West. This is one place where it does not. Is it related to a history and tradition of helping one another, or are there other dynamics involved, such as lower levels of urbanization or whatever? I am saying that a recognition of needs seems to have some implication in volunteer involvement. What is the meaning of that and of that mechanism?

To summarize with the theme questions, it seems to me there are three basic scientific questions which this whole area poses.

First is the empirical question on the level of self-help activity in Canada and its regions. The papers indicate that it might be quite high, but do we have an adequate base of data on which to form a conclusion. The specific areas of family support, AIDS, etc., indicate self help is a growing trend, which Balthazar echoes, but I think needs to be documented. The empirical question then is one that is still open.

The next area of questions deals with values and motivation which are still untouched at this point. What motivates people to get involved in self help or other help in social support? This question remains to be addressed. We only have the fact that some people do, some do not. This touches significantly the question of what mechanisms might be effective in stimulating the development of self-help groups. Some effort needs to be made to understand the whys of self-help genesis and personal motivation within it. I think the question of values is critical. Without that it is difficult to even draw a working hypothesis concerning the mechanisms which might stimulate their development.

Now obviously if we speak in global professional terms, that kind of research effort is overwhelming. Where do we find a limited controlled field for investigation? Let me make a rather radical suggestion. In the church as a contemporary, and in

most cases complete communities within communities, we have such a laboratory. In some quick research using my parish's congregational calendars and my own professional logs for the last two years, I discovered that a congregation of approximately 400 people has been involved in 19 different social support areas. That is areas, not programs. Programs would be well in excess of that. Those range from child care to welfare rights advocacy.

With the information that you already have in hand (Leroy Stone's "Stage-setting" paper), there were 76 Ottawa agencies identified as having a potential interest in the information arising from this forum. Of those, 18 or 23% were generated by faith communities. This list only touches the tip of the total number of programs originated by faith communities acting, in essence, as social support agencies. There is important information to be had by studying micro-communities.

None of the research touches on what I think is one of the most important questions that needs to be faced vis-a-vis social support and social policy. That is the extent to which our understanding of ourselves is shifting in such a way that many of the life issues that might be identified as wants are being translated into needs and so as entitlements with a concomitant notion that a formal social system must intervene in order to meet them.

The research question I am posing is, does the self-help movement and volunteerism in itself, pose the possibility of a significantly different social paradigm?

I suggest that the way we conceptualize our research and our information generation, will have a significant impact on the nest of questions asked and the data that we see emerging before us. That is why I began my remarks with the baseline question of method. This has not yet emerged and I hope it will emerge, at least partially, from these deliberations.

General Discussion

Network of AIDS organizations:

Question: I would like to ask Richard Burzynski if he could talk about the network of AIDS organizations across Canada and how it fits into his umbrella organization, the Canadian AIDS Society.

Response: We represent 30 community groups across Canada and we look at coordinating our response. If we are going to have a national strategy on AIDS in Canada, one thing that we want to make sure is that the community is well organized to fit into a national strategy, to avoid duplications of services, and to link up with the appropriate other agencies and organizations.

Strategy to promote self-help organizations:

Question: I would like to ask Mr. Balthazar, does the nature of the self-help groups you have observed lend itself to their organizing some kind of a national strategy to promote an organization that is more effective within the self-help groups or is it a non-structured situation to the point where that would not be able to occur?

Response: In 1980, the national unit was established at Health and Welfare and was then transferred to the Canadian Council on Social Development. As a result, one of the major strategies was to support the development of local clearinghouses, of which there are seven operating today. There are about four or five other communities thinking of doing the same thing. It makes a tremendous difference when you do have a clearinghouse in the community, because it's a center to which people can identify, and from which radiates all types of self-help activities in service to the self-help community.

Spiritual needs:

Comment: We have heard such very fine things about the aged, who also give support to others and not just receive it. And we went on to AIDS, about which we know so little. And because of our conservative attitudes

we are likely to be a long time finding out how to change attitudes, and how to do it quickly.

The discussion that followed and especially the proposed programs of mothercraft reminded me of an address given at the CAG Conference in Halifax in 1988 by Dr. Gunhild O. Hagestad, a Norwegian professor. In it she describes what might be termed a feminarchy. In Norway there seems to be adequate financial support for women of all ages. There they have experienced three generations of single-parent families; sometimes children have never known a heterosexual family or a father's love. In our plans for adequate daycare let us not forget that we need both fathercraft and mothercraft. I hesitate to speak of buddy needs in referring to families because the love between parent and child should be so much deeper than the affection between peers. However, in the absence of a father or a mother, there is need for a child's close relationship with a buddy of the same sex -- an adopted big brother or sister.

Let us remember too, that it is possible to paralyse the first bonding of loving relationships by even a generous provision of material needs only. In the Western world we have developed a high technology for assuring material abundance. We have a well advanced science of the body and its health needs but we

have neglected the yearnings of the spirit so necessary for the well-being of the whole man. By the word spirit or spiritual I mean everything in man that is not satisfied by the material. The spiritual includes the deep love that arises from human relationships and is developed mainly in that school of love that is the family. Let us provide for the needs of the broken as well as the complete family but let us never forget that all humans must have love to grow to the fullness of their humanity. So in our provision of daycare and of other social supports let us remember to provide for the whole man and woman, not just their material requirements.

Seniors as volunteers:

Comment: One of the speakers mentioned that volunteer agencies are not always interested in utilizing the talents and great expertise of seniors. I believe this could be more fully explored. In some work recently completed by the National Advisory Council on Aging, it became evident that when seniors were asked for a subjective view of their health, there was a great variance between what seniors themselves perceived their health to be and what professionals, including volunteer agencies, perceived that health to be.

Response: Attitudes of professionals regarding aging requires further exploration, as well as their attitude towards using volunteers in the whole self-help movement. But why are they reluctant to use older volunteers? Some exceptions are the whole senior centre movement, Meals on Wheels and similar programs where senior volunteers are used heavily.

Some ongoing work in Alberta indicates more interest on the part of older people in volunteering, but they do not know where the opportunities are. Somehow we need some linking up and some attitude changes. This may not be a research question, perhaps it should be directed towards those working in the community. How can we get these links established?

Comment: A further comment to clarify some of the linkages between seniors and resource centres. Here are two examples. In the reports there is a lovely story about an inner city resource centre where Chinese and Portuguese grandmothers are sitting together watching their grandchildren in a drop-in centre. These are people who would have ordinarily been isolated because of speaking another language and yet they are communicating in spite of that, through their grandchildren. Another example given was in a rural area, in a native resource centre where seniors are involved in a storytelling program with younger children. There was warmth and also the sense of sharing the culture and heritage. One is only limited by one's imagination and creativity. I am sure there are far

more linkages that could be developed if people were open to them and aware of some of the possibilities.

Volunteer movement versus self-help movement:

Comment: I am getting confused about the difference between a volunteer movement and a self-help movement. I noticed in Richard's presentation that in fact, most of the community-based AIDS groups are self help. They are peers who are helping each other. Some have grown out of areas where there is not a gay community, or an identified gay community and the health care workers have gotten together to respond to the need. That is very different than self help.

Response: At least in our example of how community AIDS agencies first began, it was entirely with volunteers. If a community has an incidence of AIDS and it bands together to do something about it, that is an example of self help. This model has been adopted by professionals involved with volunteer groups made up of persons wearing many different hats. That professional might be a nurse during the day, but at night is actually a concerned individual because his or her son has been affected by AIDS, or they work with a large problem within their own network and need the support of working with people sharing the

same kind of knowledge. The community-based model responding to AIDS has been expanded and includes autonomous self-help groups. PWA (People With AIDS) coalitions within agencies, or outside agencies, are largely comprised of such self-help groups. The empirical research and the anecdotal information presented would also suggest that this model of self-help group is not entirely exclusive of other community-based organizations.

Role of professionals in self-help groups:

Question: The senior center movement in Alberta, for example, although basically a self-help movement does hire professionals. The groups of seniors themselves often help to carry out some of the things that they wish to do. Is not the family also one of the major self-help groups?

Response: This brings up another facet which I wanted to introduce -- the need for a certain type of professional approach. The staffing component, for example, is important in getting financing from somewhere, from sources to put these programs into place on a day-to-day basis. Much of it is dependent upon the government and upon financiers who require a certain reporting procedure. They require documentation every time you receive money from them to run any kind of program, even if it is

only for accommodation. It is sort of a "Catch 22" situation, the more documentation you produce, the further you can spread out your programs and reach more people. But the more people you reach, the larger the constraints become upon pure self-support models. This requires a day-to-day administrative component, and depending upon the size of the agency, or the self-help unit, that component can range from one staff person making sure the phones are manned and the rent is paid, to 20 persons who comprise the AIDS committee of Toronto which liaises with other services on a Monday through Friday 9-4 basis. That is often not going to able to be accomplished by volunteers.

Life cycle of a self-help group:

Comment: Being involved in the self-help movement in the 70s, I began to wonder if there isn't a life cycle that we have not yet identified within the self-help movement. If we look at one of the classics, such as Alcoholics Anonymous as a form of self help, it has in fact, maintained its purity as a model over an extended period of time. We see an evolution of self help to what has almost become professionalization of self help, to a large extent. You spoke about the need for funding and the subsequent institutionalization of a variety of organizations that start with a self-help focus, but move towards institutionalizing themselves within the continuum of social services as a needed component.

Dr. Fellegi introduced the need for an information system to support this new professionalized self-help movement. In my capacity within a provincial jurisdiction which receives funding requests from a number of organizations which have had a genesis within self help but are now moving towards needing a firm and solid core funding base, I find that we naturally are faced with the need for information. We need to have some kind of sense of rationale, some quantity and quality indicators in terms of where originally the self-help concept came from and to understand it more fully. (Each self-help group that evolves has its own individual characteristics). They are not similar one to the other. They are unique within their own right. We as researchers would like to see some commonality between them in order to be able to begin to describe and quantify what is actually going on out there, in terms of activity and quality of activity. So there is a tension between the need to know and to develop some research method that will, in fact, pull all of this quantity of activity into something understandable. At the same time, the philosophy of self help does not lend itself to that because, in fact, it says it must spring from within and must be highly individualized.

I think we really have a major research dilemma here which is going to cause Statistics Canada, from its national perspective, a great deal of difficulty in determining what are the indicators, variables and

informational components that we can rely on and that we can gather consistently across the country.

Response: We are speaking about two fundamentally different things. Self-help groups, as opposed to groups that are trying to provide some sort of help for themselves, but linking it with the larger social system (that notion of empowerment). That is why I put that caveat to say that it appears that self-help groups might be growing. I am not sure that they are. The empowerment groups I think are probably growing quickly. Are self-help groups really growing?

If we begin to study the notion and nature of the self-help group, particularly that incredible paradigm of Alcoholics Anonymous which has 50 years of continuity, it is not amendable to its inclusion in social policy. It has a different dynamic that at this point has not been adequately studied vis-a-vis the larger social system and social dynamics, at least in the literature I know.

There is an emerging field of research, at least in Britain, probably stimulated by political issues, of trying to understand empirically and in terms of social dynamics, the distinction between human needs and wants and the way in which social systems apply to those. You can already begin to suspect what Weber's rationalization and routinization, etc. is involved in

understanding the way in which wants and needs become institutionalized.

Measuring psychosocial needs:

Comment: When we are speaking about quantifying existing programs and delivery, I think we should take up the point of needs and wants. I would like to see surveys of actual needs of people. We have done a lot of quantifying of medical- and clinical-type needs. We have done very little quantification of psychosocial needs, and I use the term psychosocial very broadly.

If we have a commitment to the World Health Organization's definition of health, which is very different from absence of sickness, what are we doing to start evaluating what components are part of that true definition of health when we are looking at the quality of life? What are the things that we need to be doing, either on a formal basis with legislation, on a semi-formal basis through volunteer agencies or on an informal basis through peer groups or the family? What are the real needs of each individual in society, and what is the best way to deliver those needs in an all-encompassing framework?

Problems of distinguishing needs from wants:

Comment: I would like to return to the idea that human needs and wants are

different. A society can develop a great many wants that are not needs. This brings us back to the importance of motivation. Motivation moves us to act. A society may be motivated to want and demand government help for a supply of material abundance to the neglect of maintaining individual or family competence. Yesterday we heard that self-help groups are multiplying in Canada. It was even suggested that self help may be selfish. Is it? Let us suppose that 30% of the elderly women in Ottawa are having housing difficulties and they unite to solve their problems. Is not that self help one way of loving and serving your neighbour? There is an old proverb that states "the glory of God is man fully alive". Does not this mutual self help toward providing a full life for these Ottawa women contribute to the glory of God and so carry out the command to love God and neighbour?

Let us look at our motives for assisting the victims of AIDS. I who am healthy if I love my neighbour will be motivated to help alleviate the sufferings of those condemned to the terrible death made inevitable by this disease. We are making no judgement about the cause of AIDS but expressing our reverence for human life. The devout Buddhist will never willingly destroy life. History tells us that the measure of a good society and the probability of its survival depends upon that society's esteem for human life. Perhaps we should invite the help of the great faith communities in motivating us to respect human life and to care for those among us oppressed by poverty, illness, injustice or even the consequences of their own antisocial behaviour. Self help is not selfish but it is a way of giving glory to God by assisting men and women to become fully alive. It emphasizes the individual's responsibility to develop so he or she, or they have resources to give to others.

We can waste a great deal of money and energy if we neglect motivation. I think that the help of the spiritual groups -- and here I refer to the church affiliated bodies as well as all organizations interested in the holistic development of man -- could save us time, effort and money which will be in short supply in the coming budget.

Special Pre-Lunch Address:

Social Understanding and the Formation of Public Policy

by
Dr. Ian Stewart
Ottawa

I have been asked to think out loud, and that is what I propose to do. I am going to talk about some of the issues which flow from social understandings and social scientific research into the policy formation process.

It is fair to say that I have become a little alarmed about the degree to which a gulf seems to have developed between, on the one hand, the social scientific research and the active social community, whether in self-help groups, voluntary organizations, or constituted charitable agencies, or within the agencies of government and, on the other hand, public policy makers. A gulf seems to have developed between the deliberations that proceed within those organizations and the structures and formation of public policy, and I ask myself why that is so?

Let me take you back a little in history. The Beveridge Report emerged in the Fall of 1941 in Great Britain. Even though the War was going extraordinarily badly even into 1942, the Western industrial countries, seared by the experience of the 1930s, had begun to conjecture about post-war reconstruction and the management of the post-war state. In Canada, Cyril James, who was then the President of McGill, was in charge of an extra-governmental Commission to think about reconstruction problems. As a part of that Commission, Leonard Marsh produced a report in the Spring of 1943, Canada's version of the Beveridge Report. This report focused on the comprehensive construction and financing of social services in the post-war period, very much in the fashion of its day. It was generally viewed as an astonishingly enlightening document, and what is now striking is the degree to which it was largely accepted on all sides. There was a consensus of view not only among the extraordinarily small group of public servants with authority at that time, but also among the major influences in Mr. King's Cabinet of that day.

It was partly the searing experience of the 30s which compelled everyone to commit themselves to better things in the post-war period. It was also the arrival of an increasingly accepted body of thought associated with J.M. Keynes which seemed to bring together three components of economic thought at that time -- how to manage the economy in the large, how to deal with the failures of the market and how to address the distributive failures of market

economies. The same remarkable intellectual process went forward in almost every industrial country. Bit by bit over the post-war period, the constituents of what we now call the welfare state were put in place, including its major social programs, family allowances, the development of assistance to the elderly, the gradual relaxation of the age limit at which pensions were payable, the addition of the GIS component, the addition of the CPP/QPP, and in our own time the gradual liberation of pension rules across the country to move towards vesting and portability. Similar evolutions occurred in national programs of hospitalization and medical care and in the provision of child assistance.

While all of these programs were being put in place, it is fair to say that there was a hegemony of view, a singleness of mind. If there was any contest, it was a federal struggle between decentralists and those who thought putting these dramatic programs in place would demand that Ottawa take over most of the social functions from the provinces in order that these schemes could be financed by national contributory insurance, a process denied to the federal government by the constitution. There were those who were uneasy that constitutional battles of that kind would delay the putting in place of the social underpinnings and who were therefore anxious to avoid that

struggle. The Rowell-Sirois Commission, immediately prior to the Second World War, advocated a very strongly centralist position, but by 1945-46 under Mr. St. Laurent's chairmanship of a Cabinet Committee preparing the 1945 Federal-Provincial Conference, the federal government had fallen a long way back from that position. Federal-provincial struggles with respect to the construction and putting in place of social policy were born out of that period, and the struggles go on today in very much the same way as they did then. With these contentions aside, however, there was a remarkable hegemony of view.

It is fair to say that this broad consensus began to erode in the early 1970s as Western industrial economies came under strain. But it eroded not only because of the lesser availability of resources. It eroded not only from growing political opposition on the right, those who were uneasy about the role of the welfare state. It eroded as much from the political left and from the socially-concerned community itself in a growing uneasiness with the over-bureaucratization of the social delivery process, the inhumanity of that process, against which was opposed the notion of communitarianism, the growth of self-help and voluntary organizations, the broad role of the third sector in the delivery and management of the

community's social welfare. There was a growing unease through the early 1970s with the delivery of benefits through governments and through operations of the bureaucracy, largely associated with the age-related programs, the child assistance programs and the Canada Assistance Program and its welfare structures which operate through the provinces and the municipalities. There was increasing support for the view that something had to be done to offset the mindlessness of all of that by the humanitarianism of community delivery and the licensing of the third sector in the more immediate delivery of service, care and support.

Then there were venturesome ideas in the early 1970s of how to combine that set of notions with the changing roles of women, how to combine the wage economy with new forms of commercial delivery of service in ways that would serve two purposes -- the delivery of wages to women, but also the use of women's skills in human and social care. Beyond that, there were experiments with the notion of government support for independent community projects, community services, imaginative employment programs like opportunities for youth, enormous license in the use of public funds to support community activities, without a great deal of oversight or regulation from government.

This period of experimentation collapsed as we moved into the 1980s with a growing sense that resources are no longer available, that we live in a period of resource constraint. If you watched the news last night you recognized the arguments in the threat to shut down VIA rail, and the threat to close universities. There was a special on the CBC news arguing against any further repressive cuts in the post-secondary education sector. We see an increase of what I have to call special interests out there crowding around the political process, beginning to mount their platforms to avoid being cut, in what is assumed to be a forthcoming process of enormous resource constraint. But we lack, it seems to me, any form of consensus that might provide wisdom either to the cutting process if it has to occur or which, indeed, might bring reasonable judgement to bear on the nature of that cutting process, and its division between economic, defence, and social programs.

This is the uneasy gulf that seems to have grown between you, the concerned, and policy makers. 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 between public-purposed private pursuits if you like, and private private pursuits, if I can make that distinction? What is the state of the community out there? In some state sense, what is the structure of needs? (I take the distinction that has recently been drawn between needs and wants). What is the structure of needs, if we can be sophisticated enough to separate that from the structure of wants? How much of those needs are to be served by flows of governmental resource, by professional resource, by community resource, by voluntary resource, by self-help resource? Where are the pockets of inadequate attention? What is the quality of each of these streams of help? I am struck by the fact that though we view ourselves as living in the information age, how astonishingly little information we have about all of this.

Let me go back a step to say, that one of the innovations of the wartime period, that has enabled economists, throughout the post-war period, to believe they had a better handle on the universe than all the rest of us, was the development of an accounting system, which led them to believe that they understood a great deal about both how the system worked, and what its state was, at any point in time, in broad aggregate terms. One of the dreams of that revolution was that one could not only develop what are now called the National Accounts, but one could pursue them on into their distributional ramifications -- answering who gets what, by community, by geographical territory. One would be able to disentangle employment by natures and structures of jobs, and so on. Much of that disaggregative work does indeed go forward in Statistics Canada; but we have never been able, with the same power as the National Accounts, to pull it together in a way that provides us an easy working tool, an easy compendium, an easy kind of picture that we can carry in our minds of how the socio-economic world is working and what its present state is. Similarly, we have made many brave attempts to pull together social apparatuses, that would have the power that the National Accounts have for economists. I am certain that you have all been part of the social indicators movement. You have all dreamed of modifications to the National Accounts which might begin to make them more socially useful and less raw economic accounts.

In the work that I now do with the Bureau, one of the efforts that we are pursuing, in both the National Accounts and the Research and Analysis Advisory Groups, is to urge the Bureau to move on to develop "Satellites" of the National Accounts

or to extend the National Accounts, to begin to socialize that framework a little, by developing social information that can be appended to the economic numbers. This might give us a better picture, a better portrait, a better understanding of how the social community is functioning and what the structure of welfare needs is.

One particular effort that is going forward intensively involves the health system, attempting to produce a disaggregated account of the health system which sees the remedial system, that is to say the hospital and medicare sector, as only one piece of the total system. By following the life-span of a population, we recognize that a great many things contribute to "health" and a great many things contribute to disease, which are well outside the remedial system, as we currently think of it. The health satellite accounts would make it possible to take a reading at any point in time on the structure of health of the population at large, and where in a more sensible way, if that health is not optimal, where the disease comes from and what are the optimal structures of repair. Well that is a brave undertaking and I am sure it is 10 years away before the researchers who are engaged in it, will be able to begin to deliver us vehicles that work in that way.

So there are some good ventures going on. But nonetheless my experience in the counsels of

government, and in the counsels of public policy in those towers downtown, leads me to believe that there is extraordinarily little information, intelligence and generally accepted rationality that would permit those senior bureaucrats to advise their Ministers and the Prime Minister on how to make sophisticated decisions about how to allocate the society's resources and how best to serve the welfare of the community.

In a sense, the game is further complicated because if there is not a super rationality which tells us what to do, then the world really does become a raw contest between interest groups, scrambling in raw political postures for their shares of the pie. As all of you will recognize, I would be surprised if there are not strains within the community represented here today, over the potential axes that may fall in the forthcoming weeks. Clearly there are strains between other communities, the post-secondary educational community probably being the dominant one at the moment, who in raw political terms, unable to make the rational case, are now marshalling raw politics, i.e., the media and the television documentary, to try to influence politicians in the allocation of resources.

I confess it strikes me as astonishing, in the late twentieth century, that we are so ill-served in the intellectual

structures we employ to settle questions of the allocation of community resource, and in our knowledge of what flaws are out there and where the holes in our safety nets really are. It is astonishing that we are so ill-served in a collective sense, that all of us might have in our heads very different conceptions of the structure of welfare at the moment.

Let me just say that the reason I serve on two advisory committees to Statistics Canada, is that despite what I have said, I have the firm conviction that information, research and knowledge, are ultimately likely to contribute more to the solution of our ills than provide more complexity for us, although it is often difficult to keep the faith. The reason I serve on these advisory committees, is that I view the services of Statistics Canada as very much a public good, that without public support, will lessen the capacity to deliver the raw materials and indeed some of the analysis that we all require in order to come to terms with some of these issues.

I would just like to finish with a note of strong support for this kind of conferencing and the struggle in which you are all engaged, trying to understand what is happening. I would urge you collectively back to the consideration of welfare issues as a whole.

I do detect in the material I have read, a sort of defeatist sense, that cuts are coming, that the social community is going to be on its own and have to increasingly use the third sector and the voluntary sector, the self-help sector, the charitable sector, to deal with social ills. There seems a sense that the hope for a solution to some of these problems through the auspices of government and the tax transfer process is a diminishing one. I guess I remain with a bit of that spirit of the Second World War, in believing that there is some combination of the intermediation process of governments and the tax transfer process that associates itself with communitarian processes, in an optimal way, and that there remains a role for the community at large to ensure that governments do not lose sight of social purpose.

Chapter 3

PATTERNS OF NEED FOR AND USAGE OF SUPPORTS

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

by
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Data from the 1985 General Social Survey are used to examine the number of close and distant kinships and friendships, as well as the frequencies of various forms of contact with these referent groups in terms of family stage and sex. Family stages are a way of operationalizing the life span and are defined as follows: Stage 1, pre-marriage; Stage 2, early marriage, no children; Stage 3, early marriage, children at home; Stage 4, late marriage, children at home -- full house; Stage 5, launching of children; Stage 6, empty nest; Stage 7, retired, aging family; Stage 8, widowhood. Analyses revealed sex differences in the number of kin identified (women greater than men), the number of friends identified (men greater than women), and frequencies of contact (women more frequently called or wrote, men more frequently participated in face-to-face

interactions). Differences as a function of family stage were also revealed suggesting critical junctures in the course of social relationships. These results are interpreted within a social network perspective and suggest that requirements for sources and types/forms of social support vary with sex and family stage.

Introduction

Gerontological researchers have become particularly interested in social networks because of their supportive nature and their potential usefulness for the care, continued health, and sustained independent living of elderly persons. However, basic structural and functional properties/characteristics of such networks -- indeed of such relationships -- are not well-known nor is it clear whether or how these structural characteristics vary by sex or across the life-span. It is within this context that the present report is cast. Drawing from the data collected for the 1985 General Social Survey (GSS), the numbers of close and distant kinships and friendships, as well as the frequencies of various forms of contact with these referent groups are examined in a life-span perspective.

Social networks are held to play an executive function in the psychological and physical well-being of individuals across the life-span. Networks comprise those people who are identified as important and significant by the individual whose life is of research or clinical interest. It is a way of placing significant others into an individual's sphere of relevance. Kahn and Antonucci (1980) have borrowed the term "convoy" (in their analysis and description of social networks) "to evoke the image of a protective layer . . . of family and friends who surround the individual and help in the successful negotiation of life's challenges" (Antonucci & Akiyama, 1987, p. 1).

Baltes (1979) has said that the term 'life-span' is not intended to imply that chronological age is the primary organizing variable; rather the primary focus is on processes that attain their salience in a life-span or life-course context. 'Life-span' should not be understood as communicating a sole concern with age change; the major concern is with the processes and events that occur throughout life. One way of capturing these processes/events is in terms of family development. That is, it is in the family setting where a significant number of the normative adult life events take place (e.g., marriage, childbirth, empty nest, widowhood). Therefore, the life-span may be operationalized in terms of family stages, a sequence of stages spanning late adolescence to late adulthood.

The General Social Survey elicited information on age, marital (or relationship) status, number of children and whether they lived in the family household which together allowed me to broadly classify people into the following eight stages of family development (aided in large measure by the previous efforts of Dr. Jim White).

1. Pre-marriage is my awkward term referring to those men and women who are 34 years of age and younger and who are unmarried or not involved in a common-law relationship. 2. Early marriage/no children refers to those younger than age 34, married or equivalent with no children. 3. Early marriage/children at home refers to those in the same age groups and relationship status as above with all of their children residing in the family household. 4. Late marriage/children at home -- "Full House" refers to those who are between the ages of 35 and 64, inclusive, married or equivalent with all of their children living in the family household. 5. The launching stage refers to those in the same age range and relationship status as above with at least one child living in and another outside the family household. 6. In the empty nest stage, the only change is that all children are living outside the family household. 7. The aging family/retirement stage refers to

those age 65 and older, married or equivalent, with all children living outside the family household. 8. Widowhood refers to those in the same age range, but who have lost their spouse and have no children living at home.

My approach, then, was to examine the numbers of close kin, distant kin and close friends identified by men and women at these different junctures of family development and explore variations in frequency of contact.

There are at least a couple of qualifications that should be made at this point. One is that these data are cross-sectional and not longitudinal; that is, differences that emerge are between groups at a single point in time and not individuals over the course of time. Another equally relevant qualification is that the underlying assumption of this approach is one of normative family development; alternative and blended families, for example, may offer different patterns of development. Family stages, nonetheless, offer a meaningful and theoretically rich way of examining close relationships for a significant number of individuals over the life course.

Distribution of close kin by family stage

For the purposes of the data to be discussed, close kin are defined as mother, father, children, grandchildren, and siblings not currently residing in the family household. Figure 1 presents the number of close kin in terms of family stage. Despite the exchanges that are made in family composition/membership over time (i.e., the death of parents, the birth of children and grandchildren), there is a clear linear increase in the number of close kin over the family stages. One would probably predict this. My initial intent for the calculation and inclusion of this variable was as a sort of metric against which less predictable variations in number of distant kin and close friends might be evaluated.

However, particularly in the launching and empty nest stages, an interesting and surprising sex difference emerged. That is, why should women have more family than men? (Recall that this is a measure of number.) Perhaps the answer lies not in absolute or objective terms, but rather in the subjective or perceptive appraisal of close kin. For example, women have been referred to as kinkeepers, bringing families together, organizing family functions, remembering birthdays, writing cards. Women have also been described as family monitors, observing the course of relationships and registering changes in them (more than men) and ministers of the interior focusing strongly on the inner familial world and its workings in contrast to the foreign minister status or ambassador

Figure 1
Number of Close Kin, by Family Stage

Number
of close
kin

Number of close kin reported by men
Number of close kin reported by women

Family stage

Family stage
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. Retired, aging family.
8. Widowhood.

Source: Statistics Canada, 1985 General Social Survey.

roles more often filled by men (Hagestad, 1985). It may be the performance of these roles that facilitate the reporting (and perhaps even the recollection/recognition) of the new grandchild or the inclusion of the new daughter- or son-in-law in a woman's list of close kin (events that are certainly correlates of the launching and empty nest stages). That is, keeping the kin, monitoring the family, and ministering to the interior may serve to keep family issues and family members in the foreground of a woman's frame of reference.

Perhaps this is the same rationale underlying the sex difference in frequency of contact, both in terms of visits (that is, face-to-face contact) and in terms of communication by

mail or by way of the telephone. Women are in more frequent contact with their close kin than are men, although the general pattern is the same for both sexes and might best be described as curvilinear with decreased contact leading up to the "Full House" stage and increased contact thereafter. Given that this measure concerns family members not currently residing in the household, it is understandable that frequency would decrease as children are introduced into the household and child-rearing tasks take precedence. Within the same context it is not surprising that frequency would increase as children leave (i.e., the launching and subsequent stages). It is also worth noting that this frequency of contact is probably with different people on either side of the apex. That is, before the "Full House" stage, contact is most likely with parents and siblings and after the "Full House" stage, contact is most likely with children who have left, grandchildren, and perhaps surviving parents.

Distribution of distant kin by family stage

Distant kin are defined as those aunts, uncles, cousins, nieces, nephews, and in-laws (i.e., "other relatives") with whom the GSS respondent has been in contact during the 3 months prior to the questionnaire administration. Figure 2 displays the sizable sex difference on this variable. At all stages of family

development, women identify a greater number of other relatives than men. Perhaps this difference is a consequence/concomitant of the family vigilant perspective described above. Women are typically charged with the responsibility of the dissemination of family-relevant information.

The general pattern of number of distant kin contacted is one of decline over the stages, as depicted in Figure 3. The two exceptions to this occur at the early married/no children stage and the launching stage, both of which may be attributable to marriage ceremonies. That is, the marriages of the young couple at Stage 2, on the one hand, and of the children of middle-aged parents at Stage 5, on the other, are ceremonies that bring together close and distant kin alike. The overall pattern of decrement, however, may be a combination of two (or more) factors: the increasing mortality rates of older relatives and the increasing numbers of, and focus on, closer kin. Close kin familial responsibilities may pre-empt contact with the decreasing number of distant kin.

Men have a slightly higher frequency of face-to-face contact with their distant kin. Women, alternatively, are in more frequent contact with their distant kin by way of written correspondence and the telephone. That is, women have a greater number of distant kin with whom they are more likely to keep in contact by

Figure 2
Number of Other Relatives Contacted,(1) by Sex
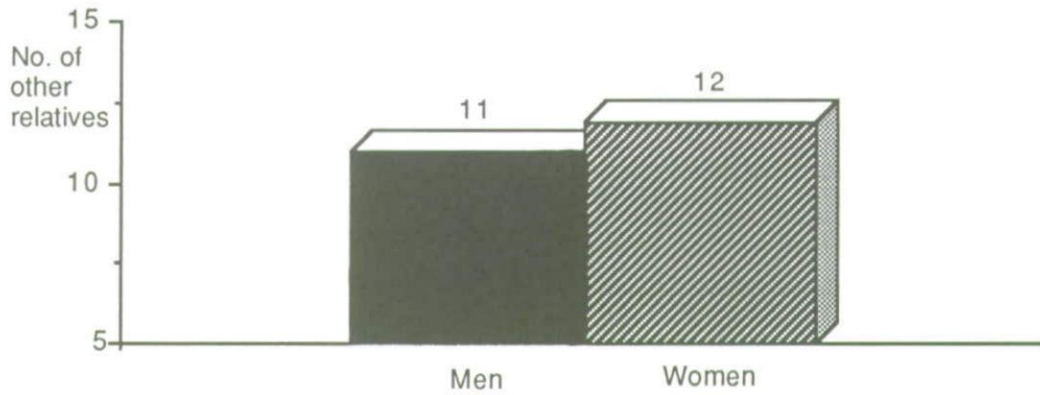
(1) Contacts in the three-month period prior to questionnaire administration.
Source: Statistics Canada, 1985 General Social Survey.

Figure 3
Number of Other Relatives Contacted, by Family Stage
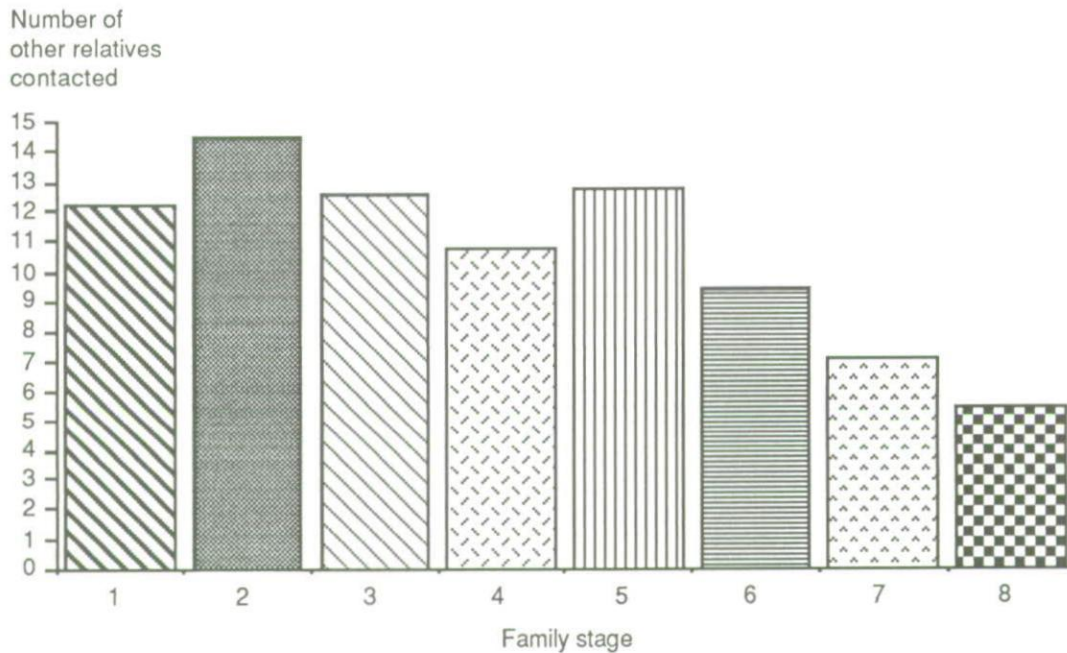
Family stage

Family stage
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. Retired, aging family.
8. Widowhood.

Source: Statistics Canada, 1985 General Social Survey.

mail or telephone; men have fewer with whom they are slightly more likely to keep in contact by way of face-to-face interactions. The greatest contact for both men and women, however, is at the early marriage/children at home stage -- contact which perhaps revolves around "birth announcements" and the flurry of familial activity accompanying the introduction of the newest family member. Reduced interaction characterizes the subsequent stages. It is worth noting, in this regard, that interactions with close kin occur on a more frequent basis than do interactions with more distant kin.

Distribution of close friends by family stage

Close friends are defined as those individuals, other than family, in whom the GSS respondent can confide and to whom he or she feels close. Figure 4 displays the relationship between sex, family stage, and number of close friends. In general, friendship number decreases during the periods of active child-rearing, increases with the launching of children, followed by further decreases in widowhood. The launching of children represents a critical juncture, at least for friendship quantity, and this is especially true for men. There is perhaps a renewed opportunity to develop friendships and re-establish old relationships that may have been set aside during the years of preoccupation with young children. Women continue on this trend, increasing their number of close friends through the empty nest and retirement years. This pattern differs

from men perhaps as a consequence of labour force status. That is, the higher participation rates in the labour force for men may have the effect of offering them what they might consider to be potential friends on a much more frequent basis. This interpretation of co-worker inclusion in the friendship realm seems justified and appropriate in light of the decrease in friendship number over the retirement years. Widowhood is associated with a decrease in friendship number for both men and women as cohort members die and the terms of interaction between friends change over the course of concomitant role transitions.

Contact with friends decreases over the course of family development although, interestingly, contact is more frequent with friends than with either close or distant kin. Men, again, have more frequent face-to-face contact with their close friends, especially during the early stages of family development, reinforcing the assertion that women are the primary caregivers for children. Correspondingly, women are in more frequent contact with their close friends by way of correspondence and the telephone, a difference that becomes increasingly exaggerated over the course of family development.

Implications for social support

These findings offer both interesting directions for future research and implications for social support. For example, the combined observations

Figure 4
Number of Close Friends, by Sex, and by Family Stage

Number
of close
friends
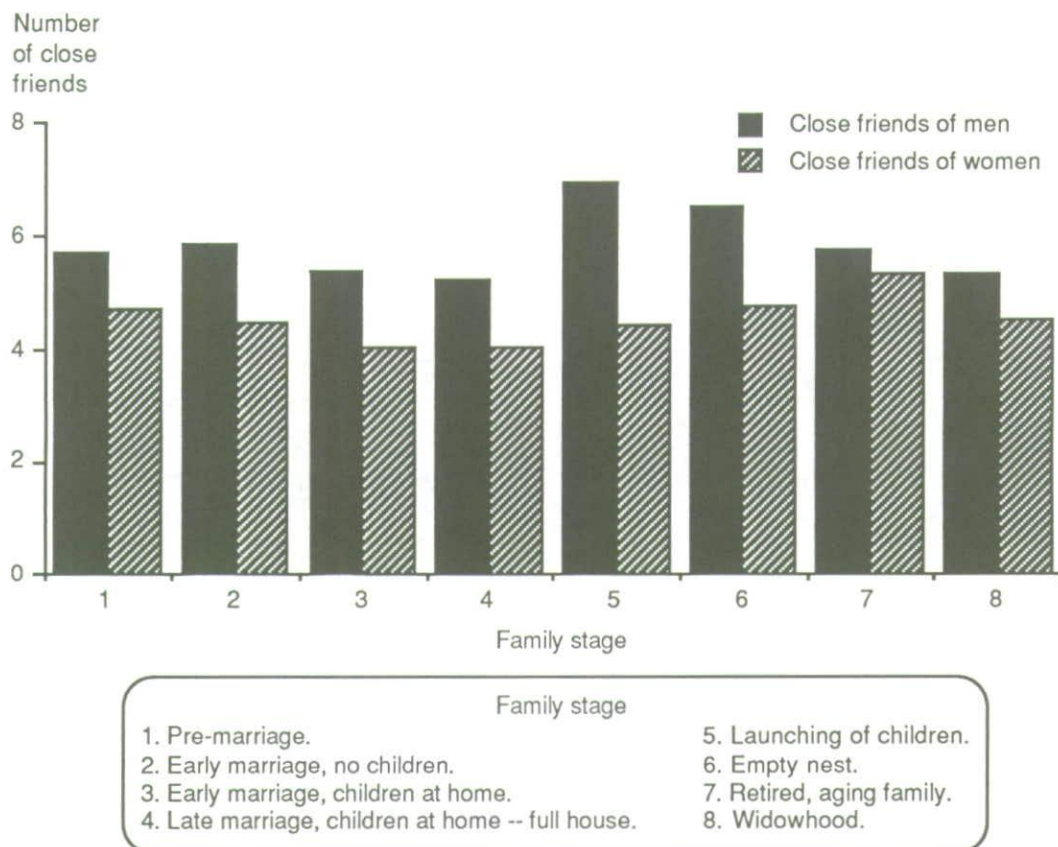
Source: Statistics Canada, 1985 General Social Survey.

that women identify a greater number of kin (both close and distant) and that men identify a greater number of close friends suggest that there may be differences in the <u>definitions</u> of friendship and kinship (of social relationships in general) for men and women. The variations in number of friends and kin according to family stage also suggest that definitions may differ as a function of position in the life course or as a function of a particular constellation of life events. These findings of subjectivity and group differences chip away at the "monolithic" and static view of friendship and kinship and also provide the basis for a broader perspective of social support with implications for who supports whom (who is seen as supportive) and what support really is.

Similarly, recall the sex difference in modes of interaction. Women have more frequent contact with their friends and kin by letter and telephone; men have more frequent

face-to-face contact (with the exception of close kin where women have more frequent contact in all forms). Perhaps these differences arise out of the social roles of, and the social constraints on men and women. Whatever their origin, they hold some interesting implications for the delivery and "receptivity" of social support.

The form that social support takes may reasonably differ for men and women at all stages of life and family development. The agents as well as the medium of support are issues to be considered.

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

by
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As an AIDS care social worker at St. Paul's Hospital I work exclusively with people with HIV disease, their lovers, families and friends. You may or may not be aware that British Columbia has the highest number of AIDS patients per capita in Canada. To date there have been approximately 480 people diagnosed with AIDS, half of whom are alive today. There is also an estimated six to seven thousand seropositive individuals in our province.

As I talk this morning I would like you to think about some of the parallel psychosocial needs of persons with AIDS and our aging population. Although many of us dread turning 65, that magical age when we go from being middle age to senior citizens, we are also grateful that we are alive.

Acquired Immune Deficiency Syndrome challenges everyone's morals, values and prejudices and is often referred to as the challenge of the eighties. AIDS commonly strikes young people between the ages of twenty to forty-five with the average age being in the early thirties.

The prevalence of AIDS in the gay communities of North America is ironic. Given our current health promotion ideology and tendency to blame people for their own disease, self-imposing risks have been regarded as the major factor in today's most pressing health problems. It is understandable then how we have managed to alienate groups of people who are already victims of prejudice because they may deviate from the norm, people such as homosexuals and intravenous drug users. And here we have a very non-discriminating virus that does not care if you are a homosexual or heterosexual, male or female, young or old. We know that AIDS can be transmitted by engaging in unprotected intercourse, vaginal or anal, with an infected partner, exchanging contaminated intravenous drug needles, transfusions from an infected blood supply or transplacentally.

As our aging population increases so does the need for better medical and psychosocial care. As we age our immune systems begin to fail us and more things go wrong. The AIDS virus attacks and destroys the immune systems of previously healthy young individuals and accelerates the aging process in a brief span of time.

Although we are now keeping people with AIDS alive longer, the

majority of PWAs live anywhere from eighteen months to two years. Their bodies are left vulnerable to a host of opportunistic infections. Some of these infections include PCP which was previously thought to only attack the lungs but is now thought to be systemic. At one time PCP was the major cause of death in a PWA, today however it is treatable. Other major opportunistic infections include toxoplasmosis which attacks the brain, lymph nodes and blood; cryptospodiosis which attacks the intestines; cytomegalovirus attacks the lungs, lymph nodes, liver, blood, eyes and intestines; mycobacterium avium which can attack the liver, lymph nodes, spleen, bone marrow, gut, brain, lungs and blood; and candida albicans which primarily infects the mouth, throat and oesophagus but is also systemic.

The majority of North American physicians practice allopathic medicine. That is, treating the disease or injury with active medical intervention such as medical and/or surgical treatment intended to bring about effects opposite to those produced by the disease or injury. With AIDS, however, given the multi-infectious complications of the disease and the cellular immune deficiency of the patient, allopathic medicine is at best a 'shotgun' approach. Physicians are often forced to use non-conventional therapies sometimes with drugs that are difficult to find information about, difficult to obtain or may have a poor prognosis.

For example, in the case of treatment for cytomegalovirus or m-avium both have poor outcomes.

There is a range of human emotions expressed at the time of diagnosis -- fear, anger, disbelief, guilt, resignation, denial, indifference and occasionally relief. For a patient who has been seropositive and symptomatic for sometime the diagnosis gives his illness legitimacy. There are many decisions for the patient to make following diagnosis -- who to tell and when, should he/she return to work, should the employer know, informing sexual partners, family, can or should they resume intimacy, getting their affairs in order.

Many of our senior citizens find themselves in dire financial straits following retirement. Private pensions and old age security are often not adequate to meet their financial needs. Many are without property or are forced to sell their home to make ends meet. The high cost of food and rent can be devastating.

For the majority of people diagnosed with AIDS financial and housing needs are critical. Many work at jobs that do not have long-term disability pension plans and/or have not contributed long enough to CPP to receive even an adequate pension. Their only other recourse then becomes welfare. In B.C., gain for the handicapped person which PWAs are entitled to is approximately $640. Like many cities in Canada today,

rent prices are astronomical leaving very little money left over for food. Many landlords do not wish to rent to PWA's. Many older apartment blocks which may offer cheaper accommodation are either not equipped for wheelchair accessibility, have no elevators, no laundry facilities, no appropriate cooking facilities, or, may be far distances from medical and shopping facilities. For the PWA on a small fixed income the high cost of medications required to maintain them throughout the course of their illness is prohibitive.

Home care supports for the elderly and the PWA's in this country are seriously lacking. Long-term care cannot meet the needs of the elderly adequately enough, leaving no option but facility placement. For the PWA there are currently no facilities willing to accept them and they do not fit into the long-term care guidelines. It is like trying to put a square peg into a round hole.

Although community based organizations attempt to meet the needs of PWA's, they are staffed with volunteers many of whom work during the day. Even if the PWA is fortunate enough to have an excellent support system, the toll on the caregivers can be devastating. For the first time in many of their lives they are being faced with the impending death of someone they love who may be demented, incontinent of stool or urine and virtually wasting away before their eyes.

The stigma of AIDS created a sense of isolation not only for the patient but for his caregivers as well. Sexuality and death continue to remain taboos in our society.

We have long recognized the existence of the grieving process and bereavement/support groups have sprung up all over North America. However, friends, lovers and families are not utilizing traditional supports and PWA's rely on self-help groups to support them. There are thousands of people in this country grieving the loss of a friend or a loved one from this disease and because of the stigma of AIDS are grieving alone.

As I said earlier we are keeping persons with AIDS alive longer and many now consider AIDS a chronic disease rather than a terminal disease. The average cost of care for one PWA from diagnosis to death today in North America is approximately $100,000 and this cost will increase as more and more people with AIDS survive this disease.

Our health care system in this country 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 aging population increases, so does the need for a better home care system and affordable housing so that people can be maintained with some dignity in their own homes.

I have only briefly touched on some of the parallel psychosocial needs of persons with AIDS and our aging population today. For those of you here who have not yet been touched by this disease, the likelihood is that you will in your lifetime and your lives will never be the same. Hopefully you will all be touched by old age and a system that will provide you with appropriate medical and social supports to enable you to enjoy your senior years.

Child Care Needs and Child Care Use Patterns

by
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Introduction

The purpose of this paper is to provide a summary of current knowledge about child care needs and child care use patterns in Canada today. Current estimates of child care needs are most often based on data pertaining to mothers' labour force participation. For example, in 1988, 58% of mothers with children younger than three were in the labour force. A reliance on maternal labour force data, however, is problematic for two reasons.

First, it overestimates the number of families needing child care because correlated information about mothers' total work hours, work schedules, and fathers' availability during those hours are not considered. Secondly, it vastly underestimates families' needs for child care for reasons other than to replace mothers' time away from home at work. Families need and use child care for a variety of reasons; almost all families need and use some child care as a necessary form of social support at some time.

Reliable and valid information on child care use patterns is unavailable at this time. Annual estimates produced by the National Day Care

Information Centre in Ottawa are based on unreliable information obtained in different ways from each province. The data, such as it is, tells us more about where children are <u>not</u> being cared for, than about where they are. A national survey conducted by Statistics Canada in 1981 provided some interesting information, but the small sample size resulted in aggregating data for children age 0-5 years old and those 6-14 years of age, which is not useful for policy purposes.

What is needed is precise, detailed information about child care patterns that:

- provides a clear picture of current child care use patterns (including combination arrangements) for a nationally representative sample of children that can be broken down by age of child and relevant family characteristics,

- goes beyond a static description of arrangements used in the reference week so that information can be obtained about annual patterns and the extent of change and stability in care arrangements,

- provides information about families as units, and

- helps determine the effects of different child care patterns on children and on their parents.

Fortunately, the 1988 National Child Care Survey recently funded by the Department of Health and Welfare's Child Care Initiatives Fund is currently underway. This study, which involves collaboration between four well-known researchers who have made a significant contribution to the field, and Statistics Canada promises to provide such information.

Estimating child care needs

Of all forms of social support, child care can be one of the most critical for parents who increasingly rely on others to help them fulfill their two major functions, described by Gwen Morgan as "1) the economic responsibility to work, to support family members, and to maintain family autonomy; and 2) the responsibility to care for the physical and psychological needs of children in a stable and nurturing environment" (Morgan, 1986:157).

Almost always, estimates of the need for child care in Canada and other countries are based on data pertaining to mothers' labour force participation. Tables 1 and 2 provide some of the data that is often cited as evidence of the dramatic increase in women's labour force participation and hence, the presumed corresponding increase in the need for supplementary child care. In 1976, 43.2% of women with children younger than 16 years of age were in the paid labour force, and the

Table 1
Labour Force Participation Rates for Women with Children,
1976, 1981, 1986, 1988
(Annual averages)

Age of youngest child	Participation rates				Per cent change 1988/1976
	1976	1981	1986	1988	
Under 3 years	31.7	44.4	56.3	58.3	+26.6
3-5 years	40.9	52.4	62.1	65.1	+24.2
6-15 years	50.0	61.2	68.6	72.9	+22.9

Source: Adapted from House of Commons, Sharing the responsibility: federal response to the report of the Special Committee on Child Care, 1987, page 8. Statistics Canada, Labour force annual averages, 1981-1988. Catalogue 71-529, March 1989.

proportion of employed mothers with very young children (under three years of age) was 31.7%. As of 1988, 67.0% of all Canadian mothers with children under 16 years of age were participating in the paid labour force, and the labour force participation rate among mothers whose youngest child was three years of age or younger was 58.3% (Statistics Canada, 1989a).

Changes in women's labour force participation are reflected in the structure and functioning of two parent families. According to national figures drawn from the 1981 Census, the "traditional" breadwinner family consisting of a single male wage earner and an at-home female spouse is now atypical, accounting for only 16% of all Canadian families -- only slightly more than the proportion of single parent families. In effect, old images of the predominant family form as one in which a mother is home providing full day-time care for children (other than when they are in school) no longer fit current realities.

While such statistics serve as a useful barometer of societal changes, exclusive or primary reliance on maternal labour force data for estimating the need (or demand) for

Table 2
Work and Child Care Arrangements 1967-1988, Selected Years

	1967(1)	1973(2)	1981	1988
Labour force participation rate of mothers(3)	21%	35%	54.5%	67.0%
Labour force participation rate of mothers with pre-school children (younger than six years of age)	16.7%	27.6%	47.5%	61.0%
Number of mothers in the labour force with pre-school children(4)	275,000	445,000	734,000	928,000
Number of preschool children with mothers in the labour force	357,000	537,000	963,000	1,277,637
Percentage of preschool children of working mothers using day care or nursery school	2%	5.6%	10.6%	16.1%
Percentage of preschool children of working mothers cared for by non-relative in or outside the home	39%	43.6%	39.7%	n.a.
Percentage of preschool children of working mothers in unpaid care	60%	49.2%	49.7%	n.a.

(1) Figures for 1967 refer only to employed mothers, not to all mothers in the labour force.
(2) Figures for 1973 refer to mothers who worked at any time during the year rather than to mothers who worked during a particular reference week.
(3) For 1967, mothers with children under age 14; for all other years, mothers with children under age 16.
(4) These figures are estimated for Status of Day Care in Canada by Statistics Canada.
Source: For 1967: Working Mothers and Their Child Care Arrangements, Women's Bureau, Canada Department of Labour, 1970.
For 1973: Statistics Canada. 1975. The labour force, September 1975. Catalogue 71-001. Ottawa: Information Canada.
For 1981: Statistics Canada, "Initial Results from the 1981 Survey of Child Care Arrangements", in The labour force, August 1982, Catalogue 71-001, and Women in Canada: A Statistical Report. 1985. Catalogue 89-503E. Ottawa: Minister of Supply and Services Canada. Fact Sheet: Status of Day Care in Canada, 1988 and Statistics Canada, Labour force annual averages, 1981-1988. House of Commons, Sharing the Responsibility: federal response to the report of the Special Committee on Child Care, page 151 and Fact Sheet: Status of Day Care in Canada, 1988, Table 3.
For 1988: Health and Welfare Canada, National Day Care Information Centre. 1988.

child care is problematic for two reasons: First, it overestimates the number of families needing child care because correlated information about mothers' total work hours, work schedules, and fathers' availability during those hours is not considered. Secondly, it vastly underestimates families' needs for child care for reasons other than to replace mothers' time away from home at work.

In 1988, 28% of mothers of children under the age of 16 (31.5% of those with preschool age children) worked part-time (defined as less than 30 hours per week). One might expect that a significant proportion of these mothers arrange their schedule so that the bulk of their work hours occur while children are in nursery school or during school hours. Additionally, American data suggests that parents of infants and young children may choose to "off-shift" their work hours so that one parent is almost always available to be with the children. While off-shifting saves money, avoids difficulties that may occur if child care is unsuitable or unreliable, and enables parents to maintain full involvement with their children, the price that parents pay for off-shifting their work schedules is little time together as a couple, and little "whole family time". The parent who works a non-day shift may also experience some of the problems that have been correlated with that work schedule,

including negative effects on health, marital satisfaction, and other indicators of personal well-being.

The second difficulty with the reliance on maternal labour force participation as the main indicator of child care needs is that it perpetuates a narrow definition of child care, since it is based on the assumption that it is (mothers') absence from the home that necessitates supplementary child care. In most studies, in fact, care provided by a father while mother is working is considered a form of child care arrangement. Yet, care by mother while father is working is simply considered normal parenting -- not child care. Is care by a father not parenting?

Furthermore, while involvement in employment and employment-related activities (including furthering one's education, participating in job training programs, and looking for work) is a main factor defining family needs for child care, families need and use child care for a variety of reasons. Almost all families need and use some child care as a necessary and desirable form of social support at some time. Appendix A lists some of the many purposes or functions provided by child care. Some of the functions may be fulfilled by a continuing form or combination of regularly provided child care. Examples include a day care centre, enrolment in a nursery school

program for an active four-year old or for a child with special needs who benefits from the additional stimulation while parents have some respite, or care in a neighbour's or sitter's home or in the child's own home that enables a parent to participate in a regularly scheduled volunteer activity or personal fitness regime. Other needs are period-specific, such as child care that is utilized during seeding or harvesting times on farms, or during the summer months when school is closed. Still other child care needs are more sporadic or unique -- such as care utilized around the birth of a sibling, for a special occasion or a family emergency, when parents or children are ill, or when regular arrangements break down. A few studies (Lero, Brockman, Pence, and Charlesworth, 1985; Tari and Semple, 1988) suggest that relatives are particularly likely to be involved in providing short-term, back-up care, as would be expected from the social support literature.

What is lacking at this time, however, is precise, detailed and reliable information about child care needs, even for the narrow purpose of supporting parents' employment and educational activities. At the present time, we simply do not know the answers to such questions as:

- How many families require care (for purposes related to parental employment and continuing

education) for infants, for preschool children, for school age children amounting to

<5 hrs/wk 5-10 hrs/wk 11-19 hrs/wk 20-29 hrs/wk 30-35 hrs/wk more than 35 hours/week?
How many families regularly require child care

- in the evenings?
- on weekends?
- in accordance with changes in shifts or other changes in work or study schedules?
- in the summer time?
- for seasonal periods?

In addition to these kinds of questions, it is also important to ask questions that take the family as the unit of analysis. How many families require care for two or more children under five years of age, or under the age of 10? These questions simply have never been asked.

Obviously, studies that would be designed to determine the full range of child care needs (i.e., including those used more broadly as a form of social support) would yield a much different picture than the one that can be derived from crude maternal labour force data.

What do we know and what don't we know about child care use patterns?

If our estimates of child care needs are imperfect, it is certainly true that

our knowledge of child care use patterns is inadequate. Currently, the data base related to arrangement use is limited and faulty. The main studies or information sources are: A) locale-specific studies of child care patterns, including a variety of needs assessment studies, and the excellent research study conducted by the Winnipeg Social Planning Council in 1985, B) the annual Status of Day Care reports produced by the National Day Care Information Centre, C) a study commissioned by the Task Force on Child Care of a non-random sample of 336 families, and D) two surveys conducted by Statistics Canada, one in 1973, the other in 1981.

All of these sources of information have some limitations. Locale-specific studies are limited for national purposes. No matter how well executed, specific locales have their own ecologies -- the demographics of the population, the characteristics of the work force, and the particular mix of programs and provincial policies that affect the availability, affordability and quality of child care alternatives.

Unfortunately, the Annual Status of Day Care in Canada reports have a number of difficulties. The main problem is that the statistics that are used are derived from reports provided by each province. Since the provinces do not maintain a standard means of counting or reporting the number of available spaces in licensed programs, the data includes a mixture of estimates; some based on enrolments, some based on licensed capacity. Moreover, spaces may be utilized by more than one child, if children attend on a part-time basis. Thirdly, the numbers reported for "centre care" include the total number of spaces in both full-time and part-time child care programs (i.e. day care centres and half-day nursery schools). While both types of programs may be licensed under the same set of regulations, they are likely to provide care to distinctly different populations. Finally, the Annual Status of Day Care reports provide more information about where children are NOT being cared for than where they are! Regardless of which set of estimates are used, formal (licensed) child care arrangements account for a minority of the children whose parents are in the labour force or are full-time students. Estimates for 1988 of the percentage of children who are enrolled in licensed child care settings, whose parents are either working full time, are full-time students, or work 20-29 hours a week are as follows:

Children	Per cent of children served
Infants: Children 0-17 months	7.6
Toddlers: Children 18-36 months	15.8
Children 3-6 years of age	33.3
Children 6-13 years of age	4.8

The study conducted for the Task Force on Child Care had a much broader scope and was designed to provide qualitative information about parents' child care needs, use patterns and preferences. Some highlights of the study were:

- Regular evening and/or weekend care was used every week by at least 25% of the sample families for work-related reasons.

- A combination of two or more non-parental care arrangements (including school) was used by 19.5% of families with an infant under two years of age, by 62.7% of families with a preschooler, and by 44.9% of families with a school-aged child.

- About 1/4 of infant and preschool children spent more than 30 hours/week in regular, non-parental child care arrangements.

- The distribution across alternative child care methods varied according to the age of the child and the mother's work status, although care by non-relatives either in the child's home or in another's home was the most common arrangement for infants and preschoolers regardless of full-/part-time status. Relatives (other than siblings or spouses) participated as regular main

caregivers less frequently than anticipated. Instead, their involvement could most often be described as back-up social support on an as-needed or as-desired basis, both for work-related purposes and to allow mothers who are not employed outside the home some respite and the opportunity to more freely attend to other personal and family-related needs.

While this study provided some interesting and novel data, its base was not a random sample and neither the sampling procedure nor the size of the sample were suitable for making population estimates.

By far, the most accurate information sources to date have been the surveys conducted by Statistics Canada. The 1973 survey was based only on mothers who worked during the previous year. While there was some differentiation of child care patterns among mothers who worked full-time versus part-time, the part-time category also included mothers who worked part year. In 1973, the maternal labour force participation rate was 35% for mothers of children younger than 16 or almost half of what it is today. Licensed day care services were extremely limited.

The 1981 survey conducted by Statistics Canada provided

considerably more interesting information. This supplement to the Labour Force Survey indicated that:

> "Of 2.2 million preschool children, 52% had some sort of non-parental care; 48% were cared for exclusively by their parents. Those who received non-parental care spent an average of 22 hours per week in one or more care arrangements".

Among preschoolers:

43% attended a nursery school/ kindergarten program,

11% were enrolled in a day care centre,

36% were cared for in their own home, and

36% were cared for in other private home.

Of those who had some non-parental care:

30% were cared for by a relative, either in their own home or in the relative's home, and

40% were cared for by a non-relative.

Unfortunately, the regularity of these arrangements was not ascertained, nor was the extent of combinations of one or more arrangements to cover parents' work hours.

Of the 3.3 million school aged children represented by the survey, after school care was most often provided by a parent. However,

5% were cared for by a brother or sister,

3% were cared for by another relative,

16% took care of themselves, and only

1% were involved in a school/community program.

While the 1981 survey could have provided even more important information, unfortunately the sample size was too small for sub-analyses. In fact, the most serious shortcoming of the 1981 survey was that children were grouped into only two age categories: Preschoolers included children 0-5 years of age; school-aged children were as young as six and as old as 14. Quite obviously, the needs of children, the availability of services, and the implications of latch-key (or self-care arrangements) is considerably different for infants, young preschoolers, 6-9-year olds and those 10 and over.

In summary, our knowledge of families' needs for child care, and the actual patterns of care that are used remains limited at this time. In addition to providing a reliable and

complete, "snap shot" of current child care patterns, it is important for research to also address such questions as the kinds of child care experiences that are typical or usual over a longer span of time. How many child care arrangements do children typically experience these days? What degree of stability or instability is there in children's lives in this regard? Who is most vulnerable to using unstable or unsatisfactory care?

Thus far, this paper has presented the bad news. Fortunately, there is good news. In May of 1988, the then Minister of Health and Welfare, the Honourable Jake Epp announced approval of the 1988 National Child Care Study. This project, which was funded under the newly created Child Care Initiatives Fund, allowed for the implementation of a comprehensive survey of Canadian families and their child care arrangements. It is being conducted by a team of four well-established scholars in child development and child care who are working collaboratively with the Special Surveys Group, Household Surveys Division of Statistics Canada. Some of the main features of the survey are as follows:

* The survey is based on a nationally representative sample of approximately 24,000 Canadian families with at least one child 12 years of age or younger. The sampling methodology has been carefully designed so that sufficient numbers of families will be obtained in each province to yield reliable estimates for provincial as well as national purposes, and to allow planned comparisons of comparable kinds of families located in different parts of Canada.

* The intent of the survey is to obtain comprehensive and reliable information about parents' child care needs, use patterns and preferences. It will also explore in considerable detail the various linkages between work, child care, and family life. For example, work schedules for each parent will be obtained, as will information on the availability of workplace benefits. Detailed information will be collected on the child care arrangements used for each child in the family 12 years of age and younger. Data will be collected on the extent to which parents feel tension in juggling work, family and child care, and estimates will be made of the extent to which care for sick children and care arrangement breakdowns impact on mothers' and fathers' absenteeism and workplace productivity.

* Child care needs and use patterns also will be considered from the broader context

previously described. The sample will include families in which one or both parents are not employed or in which mothers are at home, providing primary care. Child care that is used to enable parents to work or to study, to attend to other family needs, or for other reasons will be included, as will care methods used when families must deal with "unusual" circumstances such as illness, care arrangements breaking down, and family emergencies.

* The survey also includes questions about the nature and extent of personal and community social supports available to parents for help either with unexpected or emergency child care, for assistance in helping parents find suitable on-going child care arrangements (through community-based referral sources), and as a basic feature of their neighbourhoods and lives (e.g., the availability of recreational facilities, playgrounds, parenting groups, etc.). Such information will be useful, not only for descriptive purposes, but also for helping to test specific hypotheses about whether the availability and use of personal and community support networks (and a range of employment-related benefits and practices) help parents to find

and maintain satisfactory child care arrangements, and thereby reduce the tension and distress that they and their children might experience otherwise.

* In addition to the household survey, a parallel effort is under way to obtain reliable and standardized information from each province about its child care legislation, programs, policies, and funding arrangements. This information will be utilized to help understand the different patterns that are likely to emerge in different provinces.

Data collection was completed in October of 1988, and preliminary editing and processing of the data is occurring preparatory to the data analysis phase. Specific reports are expected to be released in three stages beginning in the spring of 1991. While this particular survey won't answer every question that might be of interest to researchers and policy planners, we anticipate that it will provide extensive and useful information on child care in Canada for many years to come. It promises to shed considerably more light on child care needs and use patterns and to add to the growing body of literature on the functions and importance of a variety of personal and formal social supports for families with young children. The broader question of the extent to

which current policies and practices contribute to, exacerbate, or ameliorate the difficulties parents experience in obtaining such support does require additional investigation. A thorough examination of current policies and practices and future alternatives might include such questions as the following: -- In what ways can parents be supported so that their two primary functions do not compete with each other? -- In what ways can parents (and 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, employers and Canadian society of a variety of alternatives, such as extended parental leave policies and benefits, a vast increase in the number of affordable, high quality child care programs and service agencies, and enhanced community support and resource programs? -- What are the best ways to help individuals and families obtain the variety of supports they need now and are likely to require in the future?

Appendix A: Purposes/Functions Served by Supplemental Child Care

1. To provide appropriate care when both parents (or a lone parent) are working, or engaged in an employment-related activity, such as:

    *full- or part-time employment,
    *attending a conference or

travelling out of town in connection with one's work,
    *engaged in farm labour
    *looking for work.

2. To provide appropriate care when parents are continuing their education or enrolled in a training or retraining program.

3. To provide care for children and support to families with special needs, such as:
    *families in which one or both parents have chronic health problems,
    *families experiencing, or at risk of experiencing significant distress,
    *families with a background of, or high risk of child abuse and neglect,
    *families with a handicapped or chronically ill child.

4. To provide children with opportunities to participate in experiences designed to stimulate their physical, intellectual and emotional development, promote personal competence, and enable the development of social skills through interactions with other children and adults.

5. To provide children with special needs (e.g., retardation, sensory impairments, etc.) with an opportunity to receive specially designed stimulation and remediation in a setting that allows social interaction with other children and adults.

6. To provide appropriate child care as a supportive resource to families at specific times of peak need occasioned by such circumstances as:

* a family illness or emergency,
* childbirth,
* seasonal employment,
* lack of availability of regular caregivers,
* school or program closings during summer months, professional development days, holidays, etc.

7. To provide appropriate care when parents are engaged in:

* volunteer or community activities,
* religious or ethnic groups/activities,
* personal or social tasks or activities,
* family tasks (with, or on behalf of family members) at which time it is appropriate or desirable to utilize supplemental child care.

Source: Lero, D.S. et al. 1985. Parents' needs, preferences and concern about child care: Case studies of 336 Canadian families. A background paper prepared for the Federal Task Force on Child Care. Ottawa: Secretary of State.

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Ethnic Variations in Family Social Support of the Elderly

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Although the ethnic mosaic of Canadian society is well recognized, ethnic variations in family support patterns of the elderly have seldom been addressed (Driedger and Chappell, 1987). Despite this lack of empirical evidence, numerous myths and stereotypes regarding ethnic families abound in both the media and social sciences literature. While the family life of some groups is idealized or glorified, the families of others are depicted as neglectful of their elderly members.

Some groups, such as the French and Ukrainians, have been labelled 'traditional' in their style of family interactions and are seen as being cohesive, respectful of family members, and assigning priority to the value systems of familism, filial piety and the collectivity. In contrast, so-called 'modern' groups, including the English, Scottish and Germans, are said to value individualism, egalitarianism, the work ethic, and the cult of youth. Further, they are characterized as having little value for, and minimal involvement with, elderly family members (Cowgill, 1986).

This traditional/modern conceptualization of ethnic groups has been criticized for romanticizing ethnic family life and exaggerating differences (Driedger and Chappell, 1987; Rosenthal, 1983, 1986). Yet relatively few studies have empirically compared support of elderly family members between the 'modern' and the 'traditional' groups. Canadian literature on ethnic variations in family social support of the elderly (see, for example, Chan, 1983; Gerber, 1983; Penning and Chappell, 1987; Rosenthal, 1984; Strain and Chappell, 1984; Sugiman and Nishio, 1983; Thomas and Wister, 1984; Wong and Reker, 1985) indicates no clear pattern of differentiation. Studies which examine differences among groups report contradictory results with some supporting the traditional/modern distinction and others refuting it. These studies do, however, suggest the traditional/modern typology discussed in the literature is too simplistic and may be misleading. Further investigation of this categorization that appears to idealize the family life of certain ethnic groups is warranted.

In particular, it is imperative that the influence of ethnicity and other factors be considered simultaneously in order to understand the unique contribution of ethnicity to variations in family social support. It is also important to consider the various dimensions of family support including both the potential for support such as family and household

size, and the actual amount of support as indicated by contact and instrumental assistance.

The remainder of this paper presents the results of an empirical examination of ethnic variations in family support patterns of the elderly. The four most prevalent ethnic groups of elderly Canadians, namely the Anglos, French, Germans and Ukrainians, are compared across various dimensions of social support. As well, the appropriateness of categorizing ethnic groups as 'traditional' or 'modern' in their style of family support is addressed.

Data and methodology

These analyses draw on data from the first Canadian General Social Survey conducted in 1985 (Statistics Canada, 1986). This national survey included personal interviews with 3,130 persons age 65 and over throughout the ten provinces. Residents in the Yukon and Northwest Territories and in institutional settings were excluded. For the purpose of this paper, four ethnic groups were selected for analysis: Anglo, German, French-Canadian and Ukrainian. Conceptually, the Anglo and German groups have been categorized in the literature as having 'modern' values, while the French and the Ukrainians are viewed as holding values in keeping with those of 'traditional' groups.

Ethnicity is a very complex, multidimensional concept that has resisted any one conclusive definition or operationalization. In the General Social Survey, self-classification of ethnic group membership was considered. Respondents were asked "To which ethnic or cultural group do you or did your ancestors belong?". Up to 5 responses were recorded per person. In order to select those who may most strongly identify with their ethnic group, only those indicating membership in one group were considered. The exception was the Anglo group which included individuals who are English, Scottish, or both English and Scottish. Only Canadian born French respondents were included.

This selection procedure resulted in the inclusion of 1,910 respondents or 61% of the original sample aged 65 and over. More than one half (57%) are Anglo, and one quarter are French (25%). Germans comprise approximately one tenth of the sample (11%), while less than one tenth (7%) are members of the Ukrainian group. This ethnic group distribution is similar to that of the 1981 Canadian Census (British, 61%; French, 28%; German, 7%; and Ukrainian, 4%) (Statistics Canada, 1984).

In terms of sample characteristics, both similarities and differences emerge among the four groups. Findings are considered significant

only if the level of statistical significance is less than .05 and the measure of association is equal to, or greater than .30. No significant differences among the ethnic groups are found for age, gender, marital status, education, date of immigration, place of birth, self-rated health, health satisfaction, or number of chronic conditions. The majority of the respondents (85%) were born in Canada, indicating that this sample predominately is, at minimum, second generation. There is a tendency for the Anglo group to have obtained higher levels of schooling than the other three groups. In keeping with this educational advantage, a significantly higher mean household income(1) is found for the Anglos when compared to the French (F=4.64, d.f.=3 and 1906, p<.01).

Generally, the ethnic groups considered here have similar socio-demographic and health profiles and these characteristics are consistent with those of the elderly population in Canada (Health and Welfare Canada and Statistics Canada, 1981; Statistics Canada, 1984).

Results

Various dimensions of family social support are explored. These include: family size, household size, contact with children and with extended kin, (2) and instrumental support from a spouse, from children and from extended kin.(3)

Household size. The four ethnic groups differ in the size of their households. The French ($\bar{x}$=2.1), on average, live with significantly more people than do the Anglos ($\bar{x}$=1.9), Germans ($\bar{x}$=1.8) and Ukrainians ($\bar{x}$=1.7) (F=8.96, d.f.=3 and 1906, p<.001). This ethnic difference remains when controlling for other factors. Although being married is the most important determinant of household size, being French rather than Anglo, German or Ukrainian also emerges as a significant predictor. Being married and being French combine with having a greater household income and less education as the significant correlates, explaining 21% of the variation in household size.

Family size. Family size also varies according to ethnic group membership. Both the French ($\bar{x}$=22.0) and Germans ($\bar{x}$=21.6) have larger families than do the Anglos ($\bar{x}$=17.2) or Ukrainians ($\bar{x}$=17.1) (F=17.24, d.f.=3 and 1906, p<.001).

The French have, on average, more children than the other three groups. They also have significantly more grandchildren than do the Anglos and Ukrainians, but are similar to the Germans. Turning to siblings, it is the Anglos who report the fewest number.

In comparing the influence of ethnic group membership on family size relative to other factors, being French emerges as significant. Belonging to this group, having less education, being married, and having more chronic health problems are the statistically significant correlates of family size. However, these combine to explain only 4% of the variance, indicating their relatively weak influence.

Contact with children and with extended kin. The majority of all respondents have in-person contact with children and with extended kin. Communication with extended kin tends to be less frequent, occurring most often on a monthly or less than monthly basis while children tend to be seen weekly or daily.

Ethnic group differences are not found for in-person contact with children (x^2=28.90, d.f.=9, p<.001; Cramer's V=.08) nor for the average amount of contact with extended kin (x^2=25.92, d.f.=12, p<.05; Cramer's V=.08). Further, ethnic group membership does not emerge in the regression analyses as important in explaining the variation in contact with either children or with extended kin. Indeed, none of the factors considered are significantly correlated with the amount of contact with children and only 1% of the variance is explained. Only age, specifically being younger, is associated with greater average

frequency of contact with extended kin. Again, the explained variance is low at 2%.

Instrumental support. Consistent with previous research (see Chappell et al., 1986 for discussion), the primary source of instrumental support is the family rather than friends, neighbours, or the formal service sector. The proportion of respondents who receive assistance from any source varies depending on the particular task. Assistance with money management (21%) and personal care (4%) is reported by only a small proportion of the sample while more receive help with yardwork (68%), housework (59%), meal preparation (48%) and grocery shopping (59%). No one ethnic group is more likely to receive help on any of these tasks than the others.

The frequency of receiving instrumental support from family members is similar for the four ethnic groups. Among those who report help from a spouse, virtually all (97%) report this assistance once a week or more. Similarly, no ethnic differences emerge when one examines the average frequency of help from children (x^2=7.96, d.f.=3,p<.05; Cramer's V=.13) or from extended kin (x^2=2.11, d.f.=3, n.s; Cramer's V=.09). Further, the regression analyses reveal that ethnic group membership is not a significant correlate for the frequency of help from either children or from extended kin.

Summary and conclusions

In this study, no clear pattern of differentiation between the 'traditional' French and Ukrainians and the 'modern' Anglos and Germans emerges. The 'traditional' French report having a larger household size and more children than the other three groups and, indeed, are more similar to the 'modern' Germans than to the 'traditional' Ukrainians. However, these differences in household and family size are not translated into differences in levels of in-person contact or of instrumental help. The groups labelled 'traditional' are not found to be advantaged over so-called 'modern' groups in terms of social support. Nor does ethnic group membership emerge as a strong predictor for any of the dimensions considered.

Overall, family support patterns of elderly Canadians are more complex than those suggested by the simplistic traditional/modern distinction. While an investigation of norms and values of members of the various ethnic groups may reveal differences that are in keeping with the traditional/modern conceptualization, actual support behaviour as examined here does not. The qualitative aspects of social support as well as the subjective component of ethnicity or the extent an individual identifies with the chosen label were not examined in the General Social Survey. Future research that compares ethnic groups needs to consider the dynamics, process and meaning of social support, actual support patterns and the subjective dimension of ethnicity.

As the ethnic composition of Canada's elderly changes, so too may the patterns of family social support. In 1986 (Statistics Canada, 1989), as compared to 1981 (Statistics Canada, 1984), the British, French, Germans and Ukrainians remained the four most prevalent ethnic groups in the 65 and over population. However, a shift is occurring due to recent immigration from predominantly Asian, African, South American and Caribbean areas rather than from Europe (Employment and Immigration Canada, 1986). As well, Canadian immigration policies which accord high priority to the reunification of family members have resulted in increasing proportions of immigrants aged 60 and over. Consequently, future research must include both a greater proportion of recent immigrants and other ethnic groups.

For both research and practice, idealizing ethnic families as highly supportive of their elderly 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. The results of this study

provide empirical evidence that questions the assumption of advantaged 'ethnic' elders.

Footnotes

(1) Income data were missing for 27% of the sample. Imputed values were assigned for the missing records using the median value of each ethnic group (see Payne, 1989 for details).

(2) Respondents who had children were asked "How often do you see your children?". Responses were coded as daily, at least once a week, or at least once a month. For persons living in the same household, daily contact was assumed. In-person contact with extended kin was calculated by averaging the frequency of interaction reported for siblings and for other relatives seen within the previous three months.

(3) Instrumental support included assistance with yardwork or snow shovelling for those not living in an apartment, housework, grocery shopping, meal preparation, money management and personal care. An index of the average frequency of help received was constructed by summing the scores on each of the six tasks and dividing by the number of tasks reported. Only those individuals who received help on at least one task were included.

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Responses to the Papers in Chapter 3

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I would like to thank Statistics Canada for the General Social Survey. They made it available to researchers quickly and with excellent documentation. We are very appreciative of that.

I would like to make some comments that might be considered as critical of the General Social Survey since they seem to affect some of the papers that I am discussing. First of all, I sympathized with Brian de Vries as he was trying to present his results and explain that up really meant down and down really meant up in Statistics Canada's terminology. I think what I would like to see come as a result of this conference is a recommendation from researchers that Statistics Canada adopt as its first commandment that thou shall not construct variables or scales where high scores mean less of anything.

The second comment I have is that since we are getting very good at these national surveys, I think it would be important to try and look at doing longitudinal panel surveys. Some of the issues cannot be adequately addressed in cross-sectional research and so when we are talking about declines with age, they can often be cohort differences rather than actual age differences, so longitudinal research is required.

I do not know if this is common in other surveys, but I was surprised at the high non-response to the income question in the General Social Survey. I do not know if the 27% missing data on income, which is the key variable that many of us use, was due to a particular format or the way the question was asked. Perhaps the public is becoming more reluctant to divulge what their income is in surveys. That seems to be a bit problematic.

I was very pleased with the paper by Brian de Vries which looked at life stages. One thing that stuck out in my mind was the low social contact during the child rearing phase, especially among females, where they spend more time in the home with children and less time interacting with friends. I believe this is now referred to as "cocooning". Two other things I was thinking about were the advent of the VCR and computer games that provide more and more home entertainment and opportunities for people to "cocoon". I do not know if that is a negative thing. I thought of one possible negative factor associated with that and that is for females with younger children. This group seems to be spending more time at home. Females in this age group tend to derive their confidantes from friendships rather than from their husbands. I was

wondering about whether these females might be at risk. We know from research done by Brown and Harris in London, that females in the lower class particularly with more children and not having a confidante type of relationship are vulnerable to depression. We also know that fewer contacts outside the home is associated with child abuse as well. I see the cocooning phenomenon as being something we ought to look into in greater detail, and find out whether there may not be some harmful effects associated with this phenomenon.

The other thing that stuck out in my mind is that Baby Boomers will not be available as much for volunteer efforts while they are raising their children, but as they get to the end of that period, we can expect that they will be looking more outside the family and be more available for volunteer type of work.

Retirement seems to be another phase where social contacts decline for men. I was thinking about this in terms of a recent article I read in the newspaper on elders and their need for social contact. They are now referring to golf courses as becoming the seniors' Seven-Eleven. Many people as they are getting older take up golf because it provides an opportunity for a lot of social contact. Maybe we will see even more of this as the Baby Boomers move into old age.

I was very struck by Judy Krueckl's presentation. The horrendous magnitude of the problem of dealing with AIDS and how none of our models really seem to apply. The medical model of treatment of chronic disease does not seem to really apply. Some of the ideas in the field of gerontology may apply, particularly the social gerontological approach that they have been advocating in Manitoba. There might be some ideas from there that could be translated into dealing with people with AIDS.

The paper by Barbara Payne and Laurel Strain was well presented and well written. What strikes me about their paper is that 85% of the respondents in the General Social Survey are born in Canada. Ethnic differences, if they existed at one time, seem to now be declining in importance. Perhaps we are now entering a phase of Canadian identity where we are homogeneous. As an alternative interpretation it may be that ethnic identity was not measured in enough detail in the General Social Survey. In the GSS you do not have all the information you might want to have on ethnic participation and language, institutions and cultures. With a stronger measure of ethnic identity you might still get some results in terms of ethnicity.

Donna Lero is to be congratulated for her work in developing the national survey. I think the National Child Care Survey is a very important project. We

need to know, and we do not know from the existing data on labour force or records kept by the provinces, where children are being cared for. I think what will probably come out of this survey is an increased recognition of the need for such things as part-time care and off-hours care for children. In Manitoba, for example, there is good level of support for full-time day care. You can get subsidies from the government, but part-time day carers are not eligible for these subsidies. So people are really looking for part-time day care. I have parents at our child development centre wanting extended hours and we have a long waiting list because we offer part-time day care.

I am also encouraged by the Child Care Initiatives Fund, I think that this will provide funding for important research that needs to be done in the field of child care. What concerns me is where will the people come from to conduct this kind of second phase of research, because there are very few training programs in Canada that are training people in applied child care. We are going to develop our programs in Manitoba and we are looking at programs in other provinces and finding out there really is not a whole lot out there in terms of training programs, especially at the Ph.D. level. I think we should be aware of the need for developing these programs.

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I was thinking of what I was going to say in terms of a nutritional standpoint to persons who are more involved in social systems than I am. I felt more and more the integral relationship that a nutritionist has in the social support system, whether it would be for child care, the elderly, the immigrant, the ethnic, individuals suffering from AIDS, because food is a basic vehicle via which a lot of social and communication networks can be easily built up.

Let us think of the life cycle? As children we are totally dependent. We are fed totally, and as we grow and develop we are expected to learn from our parents how to make wise choices. Via food as a choice, we begin to learn about other decisions in life. Young adulthood has often been looked upon as the most rebellious time. This is a time of trial and error in terms of motivation into new adventures. As adults we are put into the situation of trying to care for the very young, or infant who has to be fed. At the other spectrum, the elderly may need assistance to do shopping, meal preparation and chores around the house that may circle around food. When we think of disabled individuals, not just mental but physical, they need help in terms of food support.

We should be re-thinking who are the volunteers. Perhaps a volunteer who is helping a mother is somebody else's daughter or son, and they face the question of delegating their own time. When should an individual be motivated to share this budget of time? My experience with student programs like Students Outreach for Seniors (SOS), indicates that self-motivation to help others has to be built in earlier on in life, rather than waiting until there would be a convenient time that they would provide help.

Reacting to ethnic differences, I was really excited to hear that there was no difference in terms of the four ethnic groups that were compared. Relating to my own ethnic background, some may think that perhaps the Chinese may have a very strong family association and that parents are very well taken care of. Thinking of the situation in Canada, successful immigration means in that you melt in within a larger community. My own observation is that there are many parents 55 and over who refuse to live with their children, because they have adapted to the Canadian ways we hear about. They have motivated themselves to be very independent. I have this question to pose to the group. If we want to educate or provide a knowledge base, it is not a question of just self help or self-dependency, but also one of interaction between independent units and the question of relating between individuals.

A very personal observation with two refugee families that our college has sponsored. If the family would again have the self-motivation, going back to Sister St. Michael's remarks, the self-motivation of accepting the community as such, they would try to find ways to find their own support group. One of the two families that we have supported, is doing very well and one is not doing so well. We gave them the same type of support, providing them with the same agencies, same interpreters. One family is phoning us almost every day for every small task that they could not accomplish. The second family we almost never hear from except when they have good news. That is pretty good considering that they are refugees from Vietnam who have just been here for approximately six months.

So the question one would toss out is what should then be the strategies? My feeling is that one has to start to plant the seed in each individual at a very early age.

I am reacting to the last paper on child care. One can easily think that while an individual may be working on a different task, you can ask another mother to take care of your own children. I do not have the answer to this, but the question is, in terms of child care support, is it just a dollar value or are we going back to the time budget?

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Health and Welfare Canada

I am not a researcher, although I use research. I need it to do my work and I have used it as well from time to time to make a point. I have always been uncomfortable with research findings and statistics. I have tried to analyze my uneasiness. Basically it comes down to three things.

I find too often that research reports lack any longitudinal information or data. In that respect I share Dr. Barnes' comment. To me this is a serious lack, because what you are getting is a snapshot. It is not, before or after, or before, before. This is a snapshot of something in time. I am more than uncomfortable with snapshots. You all have seen on TV the demonstration in Seoul at the time of the Olympics. The impression you have from these snapshots is that the whole city of Seoul was under siege. A chap that I worked with was there at the time. He said that in a city of 10 million people, you would not be aware of the demonstration except if you watched for it on TV, because that was where the TV cameras were that day. They were chasing after these demonstrators. So I am very leery about snapshots. If your report is based on a survey, which is really a snapshot, it makes me somewhat uncomfortable.

The other part of the malaise is that rarely do you see in a report any historical perspective on the research, on the problem or the question that is being asked. My background is in history, my first career was a professor of history and I like to have things in perspective and that frequently is lacking in reports, or studies, or statistics or the analysis thereof.

The third reason for my malaise with research and researchers is that they convey subliminally their view of the world, or their assumptions about the world. I do not mean subliminal, like when you watch TV and you wonder if somebody is flashing something every fourteenth image telling you something or other, you do not see it, but your subconscious captures it. I am uneasy about the views, the assumptions that a researcher has in the back of his or her head, but are not conveyed clearly in the paper, because the paper is objective, empirical or claims to be. This makes me uncomfortable. I like to know more about the researcher's "conventional wisdom". How he or she feels about age-related problems, sex-related issues, about ethnicity. (I personally do not like the word ethnicity.) We have all of these things with which we have been raised, and a researcher also has been raised with, and it has not come through in the cold statistical analysis.

I do not propose to analyze the reports we heard today and rate them on the basis on my uneasiness. That would be a bit dangerous and I do not think it would be fair. But to leave you with this question and let you think about your answer. I recognize the papers we heard today were not based on snapshot surveys, so part of my commentary is in a way inappropriate, but nevertheless it is important that I share with you the malaise I have. I am not a researcher, I deal with research output.

I was pleased to note that some of the papers nevertheless dealt with longitudinal data. Professor Donna Lero's paper, for example, had some charts that provided that kind of information. Susan Fletcher's paper had some conventional wisdom about aging and the elderly as service providers. Barbara Payne's paper questioned to some degree ethnic factors, although it was based on a traditional paradigm. I think it could have thrown the research off slightly, but the researcher will leave things in and leave things out as he or she sees fit.

Let me express a non-researcher's wish to the research community. I would appreciate it if researchers would clearly identify the assumptions they have made with respect to the issue that they are analyzing. Be honest and lay it out on the table. I would also appreciate it if you could identify or provide some longitudinal information on the question that you are analyzing, or tell the reader where it is, or where it might be found, or that it does or does not exist. I would like to have your views on the context of the topic that you are analyzing. I am not asking for any historical treatise here, just how you see this thing fits in the scheme of things. That is good information to have as a researcher. This would help the non-researcher like myself and others to better understand where you come from and will greatly reduce my uneasiness with findings and statistics that we are provided with from time to time.

Dr. Carolyn Rosenthal
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I think it was very useful this morning to have a point strongly made that not only are most older people not dependent, in fact they are resources. They are givers of help as well as receivers of help. Having said that, let us consider the dependent elderly. My interest has also been primarily in what we call in gerontology "informal support", that is, the support from family, friends and neighbours. With respect to the very needy elderly, informal support tends to come overwhelmingly from family and from women. I will return to the gender issue, but first I would like to comment on the papers.

The papers by Payne and de Vries focused on the potential for and provision of informal support. The papers showed that most people have support networks and that support patterns change over the life course. Women are more active than men in these kinds of networks, especially with respect to kin. In many respects these papers confirm findings in other studies, but they add two things. One is a family life course perspective. This perspective makes us recognize that support networks are not static. There is an ebb and flow to family support and the family network. The second addition is the very important issue of ethnic variability.

The papers raised some issues in my mind that I would like to pass on to you. One is that we talk about family support or kin support, but it is very clear in both of these papers, as well as in the social support literature on the elderly, that there is a huge difference between the support provided by parents and children and the support provided by other more distant kin.

It is true we hear about a hierarchy of helping which takes this form. If you have a spouse, you get help from the spouse. If you do not have a spouse, you get help from a child. Lacking a child and a spouse, you then turn to other relatives. If you do not have another relative, you then turn to friends and neighbours and finally to the formal sector. Now in real life care-giving situations when you have a fairly dependent older person, there is in fact relatively little reliance on kin beyond spouse and children.

So we can create a kind of misconception if we talk about this hierarchy as though if one source does not work, then you go one notch down on the hierarchy to the next source. There is a term, the "principle of substitution", which basically means that if you do not have a particular relative, the next one down on the hierarchy substitutes. But the question is how effectively do they substitute? A child does not provide the same level of care or duration or extensiveness as a spouse does, but the child is a pretty good source of care. If a niece had been almost a child replacement to an elderly woman who has never married, the niece will provide care if there is no other relative available, but not for the same length of time and not to the same degree, etc. as a child would. So when you do not have close kin the informal network is much less viable than we might hope.

I think another point is that we need to differentiate among the dimensions of social support. It is all very well to talk about social support, but the various types of support are quite different. They are different in terms of who provides them and the consequences they have. We focus a lot in gerontology on instrumental support

because of the service implications, because practical help is absolutely essential. But it is not the only kind of support that is important to older people, or to people of any age.

De Vries' paper made an interesting point in that friendship contact was at a higher level than kin contact, I believe at all ages. Contact with friends, while certainly not the main basis for practical assistance, is the major basis for companionship (other than companionship from a spouse) and is extremely important in meeting people's needs for esteem, affirmation and emotional support.

As a family researcher, I would be the last person to underplay the importance of family in the lives of the elderly, but I do not think we should overplay it either. I think it is worth remembering that there does not seem to be any relationship between the amount of contact the older people have with their children and their general morale, but the amount of contact they have with their friends is positively related to morale. So although friends may not be as great a source of practical assistance, they are very important to the elderly.

It seems reasonable to me to assume that friendship contact may become more difficult, may face more barriers when people become very old. It is something that we really do not know very much about. In fact I think one "information need" is the need for

knowledge about the social lives and social networks of very old, frail or almost frail people. We seem to know quite a lot about the 65 and over population as a whole, and about the subgroup of older people who are very dependent. But there remains quite a knowledge gap. How do frail 87-year olds manage to "hang in there" and maintain some semblance of a varied social network? What kinds of assistance could the formal sector perhaps provide for them?

An interesting point about the Payne paper is that it is counter intuitive. It is very hard not to feel that certain ethnic groups are more supportive of their older members than other groups. Although it was not presented in the paper, I know that Barbara Payne also did an analysis of immigrant generation (i.e. foreign-born) respondents and still failed to find ethnic differences. I think we need to accept that, at least in this very good data set, among European and Anglo/French Canadian-born respondents we simply do not find ethnic differences in support behaviours. As was pointed out, this is not to say we might not find differences in some other ethnic groups that might be more different from mainstream Canadians. Even in the groups Payne studied, there may be differences, but not in the particular dependent variables that were examined. For example, I suspect that there are ethnic differences in ideas about how children ought to behave towards

parents; thus, perceptions about or dissatisfactions over what is going on in the family may be quite different from one ethnic group to another.

I did not have a chance to read the AIDS paper beforehand and I am still thinking about the link between AIDS and the elderly. Certainly both very dependent elderly and AIDS sufferers require support and probably get a lot of informal support. I do not know, however, if they get it from the same sources. I do not know to what extent PWAs are helped by their parents, for example. An important effect of AIDS on the elderly lies in the disease's potential to seriously impair older people's family support networks through the untimely death of adult children.

One other question regarding AIDS and social support is whether we can equate lovers with long-term spouses in terms of the kind of care that they will provide. We know that elderly spouses have had decades very often of a common history and have had many years to build up feelings of obligation to care for an ailing spouse. Do lovers of AIDS victims provide the same level of care as elderly spouses of Alzheimer Disease victims, for example?

Finally, the child care paper made me really envious, because I thought how helpful it would be to have a similar survey on elder care. We have relatively little population-based information about patterns of caring for older parents or older spouses or the needs of those caregivers. Current knowledge tends to be based on studies of clinical samples which are unlikely to be representative. It is very likely that there are some families who manage quite well and we just do not know about them, precisely because they are managing well and thus do not come to the attention of service providers.

Early in these remarks, I said I would return to the gender issue. Much of what we refer to as "family social support" comes from women. This conference's laudable plan to bring together different constituencies has, for me, underlined this gender issue. It struck me, particularly in reading the child care paper, how counter-productive it would be if child care and care of the elderly ever get portrayed as competing with one another. They are really two sides of the same care giving coin. Women have what might be called caring careers and the women who today are seeking child care, tomorrow will be looking for ways to care for their elderly or widowed mothers, while they themselves are working in the paid labour force. Some years after that they will be widowed themselves, and somewhat dependent on their families for care, on their daughters in particular. This is not something that we should take as "natural" and inevitable.

One concluding point that I think is important has been made elsewhere by Alan Walker, a British gerontologist. He has pointed out that people in our society feel very strongly that families ought to care for their elders and will do so out of feelings of obligation, even in cases where the parent has been an alcoholic or has been abusive and has perhaps done very little for the child. Feelings about obligation seem to be enough to get people to provide care, but they are not enough to get them to provide high quality care. So I hope that those of you who design programs will put your minds to thinking of ways that we can give families a choice. Many families will choose to provide as much care as they possibly can, but many probably need to be relieved of part or all of it.

General Discussion

Scope of the National Child Care Survey:

Comment: The National Child Care Survey is a collaborative project between university researchers and Statistics Canada with funding from Health and Welfare Canada, to provide information on a timely matter. More models of this kind of collaboration could be very useful.

Question: I do not know about the National Child Care Survey. Could someone briefly explain who is doing

it, when is it going to be done and when will the results be available? Another comment: Is it possible with the data available to take rural and urban differences into account when looking at ethnicity?

Response: One of the critical concerns that I have is how often we do not know what other Canadian researchers are doing until we happen to find out, sometimes by accident, rather than because we have structures that allow access to that kind of information.

Health and Welfare Canada was kind enough to provide funding so that a group could meet and discuss their common research interests in 1983. Out of that initial meeting, we started to plan as a group a program of research on day care in Canada. The study is being conducted by a group called the National Day Care Research Network. The four principals involved are myself Donna Lero, Department of Family Studies, University of Guelph as Director, Dr. Alan Pence as Co-director, University of Victoria; Dr. Hillel Goelman of The University of British Columbia, and Dr. Lois Brockman of The University of Manitoba, Winnipeg.

The study involves comprehensive interviews with approximately 24,000 families in Canada. Approximately three quarters were conducted by telephone and a quarter were face-to-face interviews. We

collaborated with Statistics Canada, specifically the Special Surveys Group in the design of the study and the survey instruments. The data was collected last September and October. It is presently being edited and we hope to begin data analysis soon. Several series of reports will emanate from it. Some are age-specific, for example, infant child care, school age child care; some are specific to types of families, such as single parent families. Another series will focus on work and family relationships, and a fourth set will examine such policy issues as the supply and demand of child care affordability and availability, child care quality, etc. Needless to say, this is a very rich data set and we anticipate being busy for quite some time.

Ethnic differences in reaching out for formal supports:

Comment: I was very glad to hear Carolyn Rosenthal open up the field of informal support to include the possibility of formal support in terms of care for the elderly. I would like to suggest that from a policy and practitioner's point of view that there is a real need for additional research on how multicultural families reach out for formal support and to what extent they do this. How ethnicity might affect their families' ability to turn to more formal patterns of caregiving for the elderly and particularly with recent immigrants and refugee families.

Familial support in non-family settings:

Comment: From my clinical experience having lovers look after a dying person that they have been living with for many years, has been an incredible experience. I have never seen such lover devotion in any heterosexual family bar none. In terms of elderly parents, particularly if the patient is in his/her 50s or 60s, we know from literature on bereavement that parents continue to bereave the loss of their children for many years and our universe was not meant this way. We were not meant to outlive our children, so it is an added burden. But very definitely partners provide wonderful support. It makes all of our jobs in health care much easier.

Competition for helping resources:

Comment: Yesterday, someone said he did not believe in research since it produced only a snapshot of society's problems and their remedies. It is true that short-term research gives us only a snapshot of one part of our community and we would like to see the total picture. But a series of snapshots can suggest an idea of the whole. Are we going to ask Statistics Canada to wait for the results of a long-term study when they must have some solutions tomorrow. Yesterday we sought information together in order to estimate our essential needs and to identify the resources available to meet these needs.

One of the things that does cause me a lot of concern is the suggestion that there may be competition between help for the elderly and help for children. I am wondering if we realize what a family is any longer. Is it a consuming unit? Is it a working out of some of the polarity of the West, male against female, children, teenagers, adolescents? Or can we come back to the idea of the family, of the school of love, wherein we are each concerned with the needs of the other? I was very interested in hearing about the stages of family needs and the emphasis again on the totality. If we fragmentize families and our own personality then we are doomed to failure.

We have so many of these resources here in Canada, but having been in Asia I can tell you what Asians say about the West: "You are the people that foster competition. You are the people that urge each party to work for itself and let the best man win". We used to be a people of good neighbours and I was struck by the words "kin" and "significant others", introduced into yesterday's discussion. Kin, what a beautiful word for it suggests the loving closeness traditional in blood relationships. Yesterday we reiterated our appreciation of the resource of a spouse in the family, so different from that of a lover, certainly with respect to its fidelity and endurance in time. It implies loving affection, so does friend. Significant others is an impersonal scientific term indicating utility rather than love. Let us use all the helps of science but let us humanize them by adding love. I think we can now put the snapshots seen in the last two days together, glimpse the risks involved and envisage the whole picture of our present resources and needs.

Response: I think we share the view in that we need many snapshots in fact over time. One has to know what snapshot you took, where did you take it and when, why? What is it all about? Then we put all our snapshots together and we have a family portrait.

New forms of the family:

Comment: A comment was made in that you could not equate lovers with spouses and that "significant others" was a very weird and impersonal term. Coming from the area of AIDS we have had to often define new terminology. I have been surprised today to hear how the family is being described, very much in terms of the traditional nuclear family. I would think most sociologists would now define the family in a much different way than the way, to my ears, that has been used here today.

When we are talking about the majority of people in North America who have died from or who have AIDS, we are talking mainly about gay men. Often they have been

isolated from their families for a number of years and we have not allowed the possibility of marriage in same sex relationships. You could have lovers who have been long-term lovers for 20 years, which to me is very much the equivalent of a spouse, but we do not have specific terminology available.

Again in terms of significant others, because many gay men have been isolated from their traditional family, "significant others", the term frequently given to lovers and very close friends, fulfill the role of family, but here again we do not have the necessary terminology to use.

I am planning to raise these issues tomorrow when I am talking about resource issues in caring for people with AIDS. They are the same universal issues but sometimes we use different terminologies, because we are talking about different groups of people fulfilling the same needs in relation to the client and I think that the language is very useful and it may be slightly different from what many of you have heard before, but it is important if you plan to generalize the people performing the same role for the client from various subpopulations.

Are the elderly helping to define research on aging?

Comment: Returning to the problem that was posed by Reverend Sauer

about the way we define our research questions determines our research. I guess my observation is, if I were at a symposium for persons with disabilities there would be a lot of people here with disabilities. They would affect how the questions were defined and in turn, how the research would be done. I am concerned whether the questions regarding the elderly and the issues that are important to the research in aging have been defined by researchers, academicians, or if they are being defined by the elderly themselves.

Response: I would like to comment on that as a member of the National Advisory Council on Aging. We have just completed a survey across Canada of people working with seniors, but mainly of seniors themselves. If you look around this room you might identify people as seniors if they are sitting back passively absorbing what has been said; but those of us who are seniors and do not look as if we are passively observing do not get identified as seniors. There are a number of seniors in this room who are working with researchers and trying to ask questions. They are very hard questions and we do not always ask the right ones, but we do try.

Need for longitudinal studies:

Comment: I have some issues to raise which may or may not be popular. There have been allusions on several

occasions today to the need for longitudinal studies, but I think both Health and Welfare Canada and Statistics Canada and certainly the National Advisory Council on Aging will agree that it is very difficult to get financial support for long-term studies, almost impossible. There have been attempts to cut back the Census which is the very best data set we have and that filters down to any other attempt to do a long-term study. It is hard but does not mean that we should not be continuously trying.

The second issue has to do once again with the snapshot approach. A lot of our best efforts at dealing with social problems and social issues are developed at the community level. At the community level we have seen a growing emphasis on doing community needs assessment with respect to specific issues and trying to figure out ways to develop our communities. Many of those studies are being undertaken by people who have little or no training in doing research and do not quite know the system for accessing Statistics Canada data or any other national or provincial forms of data.

I think that our funders who demand community needs assessment need to be aware more of that as an issue and provide some of the support that is required for people working at the community level. I also think our educational institutions have a lot to

answer for as well. We are not doing our job in terms of teaching people how to do community scale studies that are understandable by people working on the frontline and by people who are engaged in basic and theoretical research, as well as community development research.

Chapter 4

PUBLIC ATTITUDES AND OPINIONS REGARDING DEVELOPMENT AND DELIVERY OF COMMUNITY SUPPORTS

The Historical Development of Attitudes towards the Handicapped
by
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I find the topic of "attitudes" particularly interesting. It is my opinion that when we are talking about attitudes, the perspective that society very often has of disabled people is a negative attitude.

The common concept is that disabled people and sometimes not only the disabled, but other people who are in a situation of vulnerability in our society, who appear as if something is obviously wrong with them, who are sick, helpless, need care, or need strong professionals in order to provide the kind of services that are required, have failed in their own personal life situations so someone else has to help them. That is still very much of a prevailing attitude that is with us today. I would like to very briefly trace that attitude historically. In past history, I identify with three phases of how society has in fact treated disabled people.

When you look back in history, you have the images of the beggar, the cripple sitting beside the road, the Hunchback of Notre Dame. In essence, you have a very negative image of disabled people portrayed in a very demeaning way. But the interesting part is that in the first phase, as I like to call it, we see disabled people actively involved in society even though they were seen as beggars and cripples.

Then at the time of the industrial era in the western society people began being evaluated on their rate of production, all of a sudden you had a large group of people who could no longer produce the same amount as others. These people had no other income because begging at this stage in time was outlawed, and so in fact they were seen as useless people. Prior to this time when they had a role in begging, they were at least able to take the income from begging and assist the family. That was taken away from them during the industrial era and there was a large group of people who now needed to be taken care of, and society found ways of taking care of them through workhouses, workshops, through

residential programs and similar types of care programs. These programs served their purpose at that time because there was no one else providing for the needs of the disabled.

But as time went on, these types of care programs developed into larger institutions and the institutions needed professionals in order to man them. And as a result, the professionals gradually took on the role of defining what disabled people wanted, what their solutions were, and how they should be provided for in society. And so in the 1930s and 1940s, there was a mushrooming of institutional responses to the needs of disabled people, to the extent that disabled people had almost no contact with society and in fact, an intermediary group of people decided how to portray disabled people to the rest of society. I know that is a simplification but in fact, in a very general way that is what happened. It was not until the Second World War, with the development of technology, that disabled people started again to become actively involved and began to be integrated back into society.

During the period of time that I call the segregation phase, the second phase, when a mushrooming of institutional responses occurred, there was an interesting change of attitude as well, because it was during this phase of time that the attitudes, the negative images of disabled people being helpless, sick, or in need of care, were in fact developed and perpetuated into our society.

Then, a change began to take place. The wheelchair sports people started to demonstrate to society that disabled people could do certain things in the area of sports. And then there was the development of parents' organizations in the mid-sixties who were concerned about the segregation of their disabled children. And in the early to mid-seventies, the development of the consumer movement demonstrated to society that disabled people can come together to have a collective voice. That produced another very different attitudinal change. All of a sudden, society and many people working in the field, had to recognize that disabled people were very capable people. They could run their own organizations and represent themselves quite adequately to government, and they could, in fact, have quite a powerful voice in speaking for themselves.

As a result of this attitudinal change that developed, society began to take another look at the poor, helpless, crippled image of disabled people. Society began to talk about disabled people as active participants in society and this had a whole range of implications for attitudinal change.

Society as a whole began to see disabled people in a different light, and disabled people talked about wanting to be integrated into society. They formed their own organization, a consumer movement, represented in Canada by the coalition of provincial organizations of the handicapped, which in 1980 spawned an international movement called Disabled Peoples' International. This eventually spread all over the world and has had a profound impact in directing the policy initiative of the United Nations in developing the world program of action, which has now become the guideline of the decade for disabled persons. Disabled people demonstrated to society that they had skills and abilities.

Attitudinal changes started to take place; but more significantly, these changes triggered a whole range of different kinds of thinking. Concepts began to change. No longer was disability seen as only a problem of the individual. In fact, society started to redefine the whole concept of disabled people. We talked about disability as being a limitation of the individual and the handicap being a limitation of society. As a result of this kind of attitudinal change, we began to realize that society really needed to be rehabilitated, not disabled people.

But for years, the general thinking and attitude had been that the problem lies within the disabled person. It is obvious why a disabled person cannot get employment because that person has certain physical or sensory limitations. Now we have begun to see that there were barriers in society that were inhibiting disabled people from getting employment, from utilizing transportation systems, accessing buildings, or from getting into school systems.

All of a sudden this attitudinal change started to take a whole new shift in policy direction. The first example of that was the Obstacles Report which came out in 1981, where for the first time in Canadian history a clear policy directive was focused on changing the environment, changing our society rather than changing disabled people.

So attitudinal changes have a lot of impact. It is not only concepts we talk about, it is the ideas that we talk about as theoreticians. These ideas have a very profound impact on the kind of research that gets done, the kind of policies that get developed, and the kind of resources that get allocated.

In fact, as a result of the kind of attitudinal shift that I have mentioned, and the historical phases that I have reviewed, a new paradigm started to develop. Gerben De Jong from the United States was the first person to write about it. The shift in paradigm

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for disabled people has had a very profound impact in the way disabled people have started to view themselves, and also the kind of programs that have started to develop.

De Jong started by asking disabled people a number of questions in order to develop this paradigm. Then he contrasted the old with the new. The types of questions he asked were -- Who defines the problem? Where is the problem located? What is the outcome of the two ways of viewing disability? And what then is the role of disabled people under the old and this new framework? De Jong answers each one of these questions from the perspective that first of all, disabled people have started to redefine the problem. The attitudinal change has began not only with society but also with disabled people, and as a result, society has also taken on a different perspective.

Where is the problem located? Traditionally the problem was with the individual, now the problem is seen as the interaction of the individual with society. This means that we need to now focus on changing society as much as we need to focus on assisting the individual.

What is the outcome of the two ways of viewing disability? The old framework measured the outcome in terms of how much the individual had

improved, the types of skills the person had gained, whether or not the person had acquired additional daily living skills, or whether the person was best adjusted to his or her disability. The outcome of the new framework is that disabled people are in control of their own lives, in control of the decisions that affect their own lives, involved in the programs that are being planned for them, and involved in the policy decisions that have implications for them.

What is the role of disabled people under the old and the new framework? Under the old framework, they were seen as clients of social services who would cooperate with the professionals in order to get well. In order to do so, they needed to perceive themselves as sick and helpless because they needed to cooperate with someone who had the expertise. On the other hand, under the new framework, disabled people are seen as citizens with rights, actively participating in the society of which they are a part.

What is the relevance of this? Very briefly, the development of the consumer movement, and the development of this new paradigm, have also meant a shift in the way social supports systems are being organized.

In Canada, we have developed independent living centres which are

now mushrooming right across the country. They are based on the concept of disabled people helping themselves, organizing the social supports that are necessary but the control of the disabled person is always kept in focus. The disabled themselves have to decide what kinds of support they need, what kinds of support they want, and how they should be organized. As a result, some very creative things have resulted, not only in the individual lives of the disabled, but as well for the research community. Gerben De Jong has written extensively on the kind of creative research that has been done in this whole area. At an individual level, let me give you one example. In Winnipeg, we have taken someone who spent 18 years in an institution, in fact, he was 18 years in a hospital, and no one could provide the kinds of support necessary for that person to live in the community. The Independent Living Resource Centre put together a group of people, and then that group was trained with the person who had spent 18 years in an institution being in charge of the whole process. We also gave training to that person. He is presently living completely on his own, in charge of his own support system, and in fact recently got a job and is now earning an income. This is an example of what can be accomplished if policy developers, researchers, disabled people, the elderly, as well as others, could get together and find creative solutions in developing social support systems.

Do we use an informal or a formal network? In the Independent Living Centre we use both. We stress very strongly that it is important to have a friendship relationship. We develop the networks which already exist, as well as emphasize the importance that there be not only a relief for the family, but a continual process of working with the support system that people are using. We also organize formal networks. We organize peer support systems, other information referral systems, and a whole series of other types of support.

So the bottom line is that attitudes are extremely important. The attitude we adopt when we approach certain things as mentioned earlier, and what assumptions we use are all important. If we operate from an assumption that the people we are working with are sick, helpless, need to be taken care of, and do not have anything to offer, we are going to develop one kind of paradigm. If we operate under the assumption that people have skills and abilities, and can in fact participate in policy planning and research, we are going develop a different kind of approach to research.

Responses to the Paper in Chapter 4

Dr. Madeleine Blanchet
Présidente
Conseil des affaires sociales
Gouvernement du Québec

I would like to address the issue of social supports from two angles: attitudes and research. First, I would like to discuss the image projected by the media about our own attitudes and views regarding the 2 million Canadians who suffer from some form of disability. In my opinion, there is something very ambiguous or ambivalent in the way we view these persons.

On the one hand, it is obvious that Canadians are very generous, witness the famous cerebral palsy telethon which collects some $4.5 to $5 million every year in Quebec. Total contributions have never been less than $4.5 million. This represents $1 per adult Quebecer employed. This is a significant amount because there are other similar organizations, other telethons, which benefit from our great generosity. This is a clear show of compassion towards the disabled.

But does this compassion go beyond the pocketbook? Is it manifested in concrete everyday actions? Let us consider, for example, public attitudes regarding the mentally ill who have been deinstitutionalized and the issue of housing them in middle-class neighbourhoods. Recently, there was strong opposition to the establishment of a house for AIDS victims by the residents of the neighbourhood involved. In other words, whenever some "inconvenience" or "threat" to our surroundings occurs, whenever someone might disturb our everyday life, the old underlying negative attitudes surface. It is easier to build ramps for the disabled than to accept living next door to a psychotic or an AIDS victim because these people remind us of our fragility. One Canadian out of six will suffer from mental illness at one time or another. As for AIDS and its association with guilt and early death, no one wants to hear about the illness and no one can bear to see its victims.

I totally agree with Mr. Enns' view that the battle will only be won by the sick and disabled themselves.

I recently had the opportunity to travel to British Columbia and I observed that, in that province, to all appearances anyway, the development of community supports for persons suffering from a chronic disability seems to be much more extensive than in the eastern part of the country. Is this a cultural phenomenon? Is this the old Anglo-Saxon tradition which, in England, has led to more extensive community services than institutional services for seniors, children and the disabled in general? Is the attitude of

professionals in British Columbia different from our own? Mr. Enns attaches much importance to professional attitude; he stated that the professionals are the ones who are responsible to a certain degree and perhaps even fully responsible for the negative public attitudes observed. Are we not the first people who must change and accept differences in others? This would help them feel much more at ease in our society.

As for research on community supports, it seems to be expanding considerably. A number of studies have been conducted on the subject. In Quebec, for example, research by Marc Renaud and Camille Bouchard has concluded that almost all of the social supports for seniors and for the mentally or physically disabled are provided by the family and close relatives. Most of the daily care is still provided by the family. This means that many women have sacrificed their careers and continue to do so. It also means that many working women must do triple duty, i.e. care for elderly parents while caring for their own children and working at their job.

The Quebec Health Survey shows that social isolation is still a visible reality. In major centres like Montreal, many elderly people are isolated from their families. Many mothers in single-parent families are living in isolation that is detrimental to themselves and their children. Many young people who have left rural areas to work in the city and who have become unemployed or have had to go on welfare are living on the fringe of society. Thus, social isolation remains a sore that is growing like a cancer and is eating away at the fabric of urban society.

To the social researcher, there are many questions to be answered. It is very important, in my opinion, that those who make decisions on surveys keep in mind the comparability of data. The comparability of data in the Quebec and Canada health surveys, for example, has permitted a more comprehensive analysis and search for solutions.

It is also important to continue monitoring trends in time because it is fundamental to policy-making. Finally, I would like to address one last point, that of the use of research for the establishment of policies and programs.

One of the characteristics of our country is that there is little distance between academics, public and private researchers, and the political and technocratic power. The opposite is true in France and the United States. As a result, researchers can influence policies as public opinion does in general. Thus, the contents of future surveys conducted by Statistics Canada will surely influence decisions about the fate of persons in need of better support. Therefore, we

must improve our knowledge. The assumption made by Mr. Enns leads me to believe that we should conduct a survey of professional attitudes regarding persons suffering from a physical or mental disability.

Meetings of this kind are very valuable for determining the pertinence and usefulness of current and future data. Research on this subject is highly relevant for academics and decision-makers in the political and technocratic spheres. However, it is even more relevant for the 2 million disabled Canadians who can be happy if we give them their rightful place as active members of our society. It is our mission to accept them and support them.

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

I found it hard to read the paper by Mr. Enns, in terms of the history that he traces for the stance of society towards disabled people, without being impressed with the apparent influence of the professions and particularly the medical profession in determining public attitudes. I could not get beyond that, and I think, Dr. Blanchet, you were referring to that as well. It seemed that before we became an informed society, handicapped individuals were much better integrated than they were afterwards. We became knowledgeable and developed the "medical model", though I think it is a model that was adopted by essentially all the health and social professions.

In Mr. Enns' interpretation, the "medical model" has influenced public view, and he goes on to point out that the consumer movement has helped us to move beyond that point to a view of the disabled as masters of their own home, if you will, or capable of doing so and being able to influence the environment so that they can contribute.

I had referred to the phenomenon of "not in my backyard", which I think is what you were talking about, Dr. Blanchet. If that is where the disabled are, I do not think society has caught up with them yet.

I think you use the word "vulnerable" and maybe that is a better word for the range of people that we seem to be talking about today -- people who potentially could be victims in this society. Here I think of all the frail elderly, or impaired older people, the disabled, people with AIDS, and dependent children.

I think that there is still a "caring for" attitude among the professions, in a sense that the doctor, or the nurse, or the social worker knows best. But we are seeing that the vulnerable groups, or their informal supporters have taken on the professions in

terms of making demands. I am thinking here of people with AIDS and the groups that have developed to support people with AIDS, the Alzheimer Society that developed to address the concerns of patients with Alzheimer's Disease and their family care givers, and the child care movement, where parents, mothers, developed self-help groups to deal with their concerns. I am not sure that other groups, and here I include my own discipline, have caught up to the level where these consumer groups with special interests are.

That led me to the question -- what has that to do with research and how do you go about influencing public and professional opinion? Another question arises as to what has all this got to do with the distribution of social support within the community? Also, what is the attitude of the public at large towards the distribution of social support?

We have heard references earlier today about potential competition for resources, and some implications that we are not going to have endless resources. In a society in which there are not open-ended resources to support each of these needy groups, how do those resources get distributed? This is where the role of public opinion and public attitude comes in. I don't know. I am simply raising this question.

But this question raises new questions about when you do public opinion surveys. From where should they arise? Who should construct the questions? For what end should the survey be created? When I see public opinion surveys on any number of topics, I wonder why they were done -- as a way of influencing the public or as a way of illustrating the kind of information that needs to then be returned to the public? Perhaps the best illustration involves AIDS, where I think some of the public opinion surveys have identified the areas where there has been a definite need for information to try and sway public opinion. But I am still asking, what is their role and who should administer and monitor them? And then, do they in fact subsequently have an influence on the kinds of paradigms that develop and may then dominate public opinion around the distribution of resources? Because I do not have the answers to these questions, and Dr. Blanchet raised additional questions, perhaps I will end here in order to allow time for these issues to be discussed.

General Discussion

Stereotyping the disabled:

<u>Comment</u>: Bringing together the area of the disabled and AIDS, in Australia, I chaired a working party of our National Advisory Committee on AIDS that was developing strategies for reaching people with disabilities. To put it into perspective, approximately 10% of Canadians are identified as being handicapped in some way by the environment or attitudes of people around them. Similarly, in Australia, approximately 14% of Australians are identified as being handicapped. As part of our research, we wrote to every large council and agency delivering services to people with disabilities. We specifically wrote to all agencies and councils providing care and support or representing people with sensory, physical, intellectual or psychiatric impairments.

We asked the agencies and councils what services they were delivering for people with AIDS, what education they were providing in relation to AIDS for their clients, and if neither of those issues had yet arisen, what recommendations they would give the federal government to deal with this in the future. Of the over 200 agencies and councils who replied, responses basically fell into two areas. One interesting fact was that there were only four agencies in the whole of Australia that were, in any

way, dealing with AIDS in their sexual education courses for clients. The response of every other agency was either that people with disabilities of any type had no sexual activity or that AIDS is now showing us that we were right in saying that people with disabilities should not have sexual activity. As Mr. Enns pointed out, this is not necessarily related to the truth and is something that I had thought had been addressed following The Year of the Disabled some 10 years or so ago.

It became very difficult to know where to start in order to ensure that agencies and councils addressed the area of AIDS for their clients and, to go back a step in background, one of the things that had sent this committee into action was the fact that we knew that in one particular province over 200 young people with hearing impairments were HIV infected. So we knew that there was a real problem in some of the different groups of those with impairments. Can you advise if this area is, in fact, being addressed in Canada, or if it is not, what recommendations would you like to suggest occur in future?

My third point, one of the effects of this research was that it actually generated activity on behalf of some of the self-help groups, like Disabled Peoples' International, to start addressing this issue and to make sure that formal agencies started

addressing this issue concerning AIDS. Do you know of such things happening here in Canada?

Response: You have raised a number of issues. With regard to the support systems for example, the Independent Living Centres are developing here in Canada. The interesting part is that it is going much beyond disabled people. We are starting to work with other groups in this whole area because we are developing a model that a lot of other groups are starting to look at. There has been talk about the inclusion of people with AIDS and developing the kind of systems that would assist in that process. But to be honest with you, it has not yet been a significant priority within the self-help movement of disabled people. I cannot really say that there would be opposition or anything like that to it, it is simply that it has not yet been significantly brought to attention or a concern raised within the self-help movement. Within the disabled women's network, which I am not that familiar with, there may be a little more focus on AIDS but certainly within the Coalition of Provincial Organizations of the Handicapped which is a member of the Disabled Peoples International, the concern about people with AIDS has been expressed. In Canada, there have not yet been any active steps taken to address that issue.

What kind of recommendations? I think from the perspective of coalition building with other self-help organizations. This is an area that the Coalition of Provincial Organizations of the Handicapped is very much concerned about and that includes women's organizations, organizations that are dealing with the elderly, and other self-help organizations. At that level, I think it would make a lot of sense to have some cooperation and coordination. Another potential level is through the Independent Living Resource Centres, in terms of getting them to start thinking about this whole issue and working again with some of the self-help groups in their particular area.

Need to provide a structure for volunteer activities:

Comment: It seems to me that we talk about limited resources and resources are always limited; but society has to define itself and decide where it wants to place its resources. I think that that is the question because if we set up the questions as to who gets what, in terms of whether it is self-help, volunteer or professional groups etc., we really are setting up a no win situation. I would just like to underline the fact that even self-help groups, families, volunteers, all require some structure to help them perform whatever it is

they feel they can do best. But if you set up the question as to limited resources and we have to have cuts somewhere, where are you going to cut? Then I think we set up a no win situation.

Need to support those who bear most of the cost of caring:

Comment: I guess the expression "no win situation" is triggering something for me. I have been quite concerned as I have been reviewing material for another purpose, in looking at the number of women in particular, who are paying a tremendous price both emotionally and financially as they are struggling with the dual functions of ensuring their own families' economic survival and well-being on one hand, and providing the kind of care they feel their children and their elderly family members deserve. Women in particular, are disadvantaged in that respect because if they do provide the care, take time off work, they put their jobs in jeopardy. If they reduce to a part-time position, frequently forego benefits that they need, and there are the long-term implications as well, as far as pensions for elderly women and again that is putting them in a terribly vulnerable position.

Whenever we are starting off on a research project or even thinking about how we approach it, we buy a certain mind-set or context. One of the things that I am trying to deal with is the fact that we think about providing support to vulnerable populations, but we also need to think about providing support to those who could then provide support. At this point, I think women are not getting that support and so they are placed in that no win situation. We have some very abhorrent situations resulting. For me, where it really becomes clear is the case of child care. If you think about the situation of a sick child for example, what you have is parents of either sex frequently lying to an employer saying that they are ill in order to be at home with the sick child.

And there are others who have suggested that perhaps in broadening the concept of social support we might look at the social support that employers might be able to provide. Things like leave for being able to provide family care is one of the things that is being discussed at least in some circles. And to share with my colleagues in the room, there is a very interesting study going on right now by the Conference Board of Canada. They are doing a national survey of two groups -- employers and employees -- and they are looking at the extent to which workers currently are attempting to deal with work and caring for family members, both elderly and children. They are looking at how they are doing with work problems they are having, what benefits would enable them to provide better care and also looking

at the attitudes of employers in terms of their perceptions of employees' needs and what they themselves are willing to provide or consider providing in the way of benefits.

I feel that we have not always addressed the question of the cost of caring and I don't mean just the cost of providing care to vulnerable populations, but also the cost of being a caring society. I think we are caught in a transition point right now between generations that accepted the responsibilities of caring for family members as part of being a family and at a time when doing that is entailing such financial cost for some people that it puts them and the people they care for, at tremendous risk. I would like to see some of those questions addressed and find out whether or not researchers are pulling some of those things from their research studies.

Comment: I want to point out that if there is a cost to caring, as there certainly is, in the case of children, the cost of caring for an adult, whether spouse, sibling or parent places the family in even greater jeopardy financially. Care of an adult is usually given by a female member of the family and most often one who is at the peak earning period of her life, if she is employed. The rationale, in part, is that at least in the case of child care, there is an opt out provision within CPP which enables a certain degree of opting out. I am

not suggesting this is the whole answer but at least it has been formally recognized. Similar unpenalized opting out is not available to the mature adult who leaves the labour force to care for a family member. In fact the latter opting out jeopardizes both her service credits as well as income credits for pension.

It has generally been acceptable to employers to use a certain amount of sick leave for caring for emergency situations with children. Try that with a spouse or with an older family member and you are very likely to be without a job. This constitutes a second level of jeopardy that I think we are not recognizing sufficiently.

Our whole pension system is inappropriately tailored, constructed out of our social reality, to deal with individual situations of a caregiving nature which has not changed from the traditional. We are, perhaps, too willing to say "in the good old days" or "in some other society". We have no evidence in the literature to indicate that those "good old days" and those "other societies" were or are any different.

Almost all of our caregivers in the informal sector are women. Most of our caregivers in the formal system are also women, with exception of physicians. We do not have available to us even a minimum amount of information about the health status of

employees in the health occupations where women are dominant. We do not know what is the toll, which is another kind of cost, for a formal caregiver. What is the cost to these women? What is the cost to society of the caregiving in the formal sector? And if we do not know it within the formal sector, we certainly do not know it in the informal sector. What is the additional risk of being both a caregiver in the formal sector and an informal caregiver the other 16 hours of the day? We have no information that addresses these risks.

There may be some things that can be teased out of the GSS and perhaps the HIS; there are some small beginnings; but we do not have the necessary baseline data. I think we are making major leaps of faith through trying to find financial answers. I certainly think people need adequate wages and there should be equity; but, I think we must find new solutions if we hope to maintain the level of caregiving burden that we are placing on ourselves.

Alternative models for organizing supports:

Comment: I am an economist, and I think we are beginning to touch upon some of the issues that have been bothering me. I guess the problem is that we are talking about not just two models, in other words, not just the old family model where much of the care was given inside the family and

was not visible versus a very formal sector. We are also talking about at least two intermediary models. We have not really defined them very well, and I would also like to say that we are also beginning to raise the question of finances and resources.

If you look at the history of industrialization, it is a movement of work that is done in the family towards the market sector. This not only changes the quality of our life and level of production, I would also say that the history of our economy since World War II has been one where a large part of our prosperity came from the fact that we created the health and the education sectors, sectors which were very largely either not available to people before, or which were dealt with in the family.

As we moved into the seventies and eighties we have been unhappy with these sectors, partly because they are so bureaucratized and formalized and that people do not have any input or control over these areas. We are running into some political problems about how much our economy is controlled by the state, which does not mean that we really have a problem of tight resources as long as we have unemployed people, as long as we have people who are outside the labour movement and who would like to be in the labour force. There are still a lot of women, who if jobs were available, would be moving into the labour force. There are also a great many older people

who are taking retirement before they really would like to. There is still a lot of potential labour force possible.

We have to look at alternative models and I would suggest that the two intermediate models which I would like to see discussed and which have been talked about but not really defined, include a situation where you start with an informal model where people, by and large, start providing new services on a volunteer basis or on a basis which is undervalued in the market. I think the best example of that is the day care system, where most day care centers in Canada were started by parental groups who needed day care, and where they are still very underfinanced and still very largely supported by the volunteer work of the educators and some parents. The policy issue we are faced with now is whether or not we absorb that sector into the bureaucratic formal sector, whether or not we put it into the educational system which people have been unsatisfied with, or develop a new model which allows for reasonable public financing of a disinstitutionalized community-based system. I understand the Scandinavian countries have experimented with that model. I would like to have heard some discussion of that.

The other model which is perhaps less developed is a situation where you have a formal structure for what

are really self-help groups. Mr. Enns was talking about some of those kinds of models and I think the question of employer support for parental leave at home and so forth, not full-time parental leave but leave for taking care of children, older parents or relatives, is another form of that kind of support. And there again we are very reluctant to put the kind of money into it that would make it really viable. Maybe that is why we are having such trouble developing the models we really need.

Comment: If I follow correctly, we should exchange ideas on the elaboration of hypothetical models which are capable of responding to the needs of our society while resources are limited.

In the field of health administration, we should have as principle 10% to 20% of our resources to invest in the prevention of problems which we have the responsibility to resolve.

In our midst, we wish to urge seniors to take on the responsibility themselves to gain information on all available services in order that they are aware that they can use these services.

Seniors are members of our society and the majority of seniors are capable of being independent. It is not necessary to assign needs which seniors don't have. Information continues to be an economic

instrument in the long run, to make seniors feel secure and preserve their autonomy.

Need to pay more attention to the social aspects of AIDS:

Comment: I would like to say a few words to you, if I may. I know little about social support services. I spent most of my life working in infectious diseases and epidemiology.

I would like to talk to you on the subject of AIDS. When the disease was first identified in 1981, most of us thought that this was just another emerging disease like Legionnaires' disease, or toxic shock syndrome, that will go away. It did not, as we are well aware. It is still with us and will continue to be with us for probably another 20 or so years. Since the first cases were reported in February of 1982, we now have 2,512 reported cases of AIDS as of this week. This is not a great deal in comparison to many other parts of the world -- 88,000 in United States, perhaps 400,000 in the whole world and most of them unreported, but nevertheless that many cases. There was a limited response at the beginning. I think one understands the reason why.

During the first three years after the first reported cases, people did not understand the scientific and social spectrum of this illness. People wanted to put the blame somewhere else; they thought it would just go away.

Then certain things did occur. First of all, there was the discovery that the disease was caused by a virus which is now called Human Immunodeficiency Virus. That was a very important milestone because it enabled us to do several things. First, it enabled us to clean up the blood supply. By the end of 1985, the Canadian Red Cross Society Blood Transfusion Service did indeed have uncontaminated blood. At the same time, it also ensured decontaminated Factor VIII for hemophiliacs, the clotting mechanism that hemophiliacs lack.

Then something very interesting happened in October of 1985. Rock Hudson died of AIDS. Suddenly AIDS became a condition about which everyone had heard. Everyone knew something about it. There was a Gallup Poll in United States a few years ago and it was determined that more people had heard about AIDS than could name the president. I think that was indicative of something because the media started to take a vast interest in AIDS. And at first, the media was sensationalist but later they became more responsive and more educational.

You may remember, for example, two to three years ago in Ottawa, a hemophiliac was killed in a car accident and they had to pry his body out of the car. There was blood all over and they decided that they would incinerate the car. The media reported the accident but stopped at

that part relating to the incineration of the car. Had they said that the incineration was a senseless thing to do, they would have got the major message across and also some information and education; but they did not do that. Today I think you would find that an event like that would be reported accurately and then some editorial comment which I hope would be educative.

During the latter half of the 1980s, governments suddenly became involved as did others. In the beginning it was virologists, epidemiologists, immunologists and other scientists who were dealing with the AIDS problem. Then came the realization that it involved more than just these biomedical sciences. It involved the social issues, the legal issues, the ethical, economic, and societal issues, issues that medical scientists did not understand and still do not. Medical scientists could not come to grips with it very well because they did not know who to contact or who to talk to. And gradually the social scientists, if I may use that expression, came to realize that they had a role to play.

Social scientists did not understand very much about AIDS, and medical scientists did not understand much about social sciences. With gradual intermingling of the professions occurring, we are learning about each others' services, sciences, professions and disciplines. Because

as you are well aware, we do not have an effective treatment for AIDS and probably won't for a number of years. We certainly do not have a vaccine for AIDS and we probably will not until the end of this century. We know that we are left with education. Education is the only primary preventive measure that we have. We recognize increasingly the necessity for social support services.

In terms of AIDS, the recognition that social support services have to be developed has already been brought to light during this conference. We all have a part to play in the fight against AIDS. We need to do two things: (1) get the general public to understand the true transmission patterns of this disease in order to correct misconceptions which presently abound. This will do a lot towards making our role easier, and (2) provide the appropriate social support services for people with AIDS. Thus we need education and support, care to those who are dying, care to those who are very fragile in terms of their mentality, or to people who have been diagnosed as infected and therefore are probably infectious.

Chapter 5

HARNESSING AND INTEGRATING HUMAN AND FINANCIAL RESOURCES IN THE PROVISION OF COMMUNITY SUPPORTS

Special "stage-setter" for day 2:

On Harnessing our Resources
by
Sister St. Michael Guinan
Consultant in Gerontology and
Pre-Retirement Training
Professor Emeritus
The University of Western Ontario

I think perhaps what we are doing today at this symposium will prove a landmark in the development of Canada. If you read the very interesting introduction prepared by Dr. Stone, you will find that he started by describing a community. For him a community is a network of interdependence among formal and informal organizations formed to provide a flow of services needed by a part of the population designated by a certain locale. Locale here does not mean a geographical space; it signifies a social locale or a section of society, such as, children dependent on families, which themselves are interdependent with economic structures for survival. In yesterday's discussion material you will also find reference to a caring and loving society.

During yesterday's session we discovered that a caring and loving society had to be knowledgeable also. We realized that there is a great deal of knowledge in Canadian society. Statistics Canada for example knows so much about economic needs and resources but hesitates to claim adequate knowledge of the sources of social power. The word "power" is here used in a most benign sense, to indicate a source of creativity or growth, not domination. The whole tenor of our talk emphasized self help as opposed to dependency upon others as a source of social power.

We were bluntly told yesterday that the federal government has insufficient funds to continue its level of grants to all groups needing help -- e.g. the sick, the aged, single parents and their children, etc.

We are aware of Canada's national debt, of our growing unemployment, etc. But if we are to maintain Canada as a true community we must provide a continuing flow of goods and services between organizations, groups and individuals who are all interdependent.

Yesterday we spoke of the difference between needs and wants. Human wants often have little relation to real needs. They rather represent what men's minds can conceive as needs.

Yesterday we realized the prevalence among us of false attitudes to the aging. Many of our people think of the elderly only as receivers of goods and services. But, as Betty Havens and Charlotte Matthews pointed out to us, many of the elderly are givers of valuable services. They are an untapped source of social power which we have not yet learned to integrate into our society.

Yesterday we heard of AIDS and its victims. The medical profession has been searching for means of preventing and/or healing the disease. Now we must turn our attention to the human needs of those suffering from AIDS, not just in terms of money or medicine but in terms of their yearning for companionship, love, etc.

Yesterday too Dr. Henry Enns, an eloquent leader of the handicapped, outlined for us some of the resources available as well as the social assistance required by many of our physically or emotionally disadvantaged Canadians. He suggested that our society is often more handicapped by its attitudes than is the person who cannot walk. Though confined to a wheelchair this remarkable Winnipeg born person has organized a worldwide association of the handicapped which provides counselling and planning assistance for such widely divergent countries as China and Canada. The point of his remarks was that society handicapped itself by refusing to allow physically limited though gifted humans to contribute to our national well-being.

Yesterday we heard much about children and the family, with the expansion of the assistance that these require. We know that children are totally dependent on adults, for their survival. We know too that they have a potentiality for vast growth in their capacity to contribute to the material productivity of society and also to the creation and expansion of a loving, caring, culturally rich human family of man. To assure their development we must look at the needs of the poor, single parents, children's health needs, daycare, etc.

Yesterday we looked at what the federal government could offer in financial aid, educational organization and research in the above areas of our Canadian society's needs. But through both our voluntary and professional organizations we have also learned the importance of motivation for a good society's well-being.

An attitude can make you see what is not there and fail to see what is there.

I used to try an experiment for the understanding of attitudes with my university students. I showed them a picture familiar to psychologists containing an old and a young woman. Even the brightest of these students saw only what their attitude conditioned them to see -- the young girl hidden in the lines of the old crone. Many of our society, like the university student, see aging as only a physical deterioration. They fail to see the resources possessed by the elderly in wisdom, experience, as well as a lifetime of useful skills and spiritual growth.

Yesterday we heard from a Presbyterian minister. In reviewing the church activities carried on in his parish, he described groups emphasizing active self help rather than dependency on others' giving. He discovered that a number of larger voluntary and professional organizations benefitted from the work of those self-help groups.

In our discussion of community yesterday we learned something about ages and stages of family growth and full development. In Canada we see a growing trend towards a 3, 4 or 5 generation family. We sometimes think that the well-being of children is assured by their family's material productivity, good pensions for the aging years, comfortable housing, adequate health support, etc. We still have teenagers, sick and handicapped persons and lonely elders committing suicide. At the Halifax 1988 CAG Conference a Norwegian professor described the situation of the family in her country. There are adequate pensions, and abundance of daycare, openness to women for any kind of career and apparently only a small degree of poverty. Norway also has four generations of single parent families. The result is that there, children are often placed in daycare shortly after birth before the bonding of love between mother and child can occur. The outcome is that even children sometimes commit suicide because they are deprived of love. In our provision of daycare, let us remember it is not just the food, the clothing and the other material benefits that are necessary, more importantly, it is the expression of love added to the provision of food, that the child desperately needs for his development.

Today we have come to the most important part of our conference, the harnessing of our social resources. Harnessing is here used in its most benign sense. It means putting together our interdependence, finding the sources of our social power and creating and integrating the dependency with the creativity. For this we must emphasize the importance of attitudes and motivation. One significant but hitherto neglected resource is the faith-affiliated community, evidenced in the description of one parish's

self-help activities referred to above. We have other resources in the volunteer organizations of the Chinese, Italian and other immigrant groups. When we spoke about refugees in our yesterday's discussion it was said that we Canadianize them -- impose our attitudes, our motivation and our culture upon them. We could learn from their traditions which so often emphasize interdependency support.

So for effective harnessing we must consider many things. These include the integration of dependency and self help as well as the designation of our sources of social power. This also demands an openness in our attitudes and motivation so that we look beneath the surface of wants to find the real needs of our society set before us so graphically yesterday.

To adequately fulfill this task we must consider the true meaning of human life. This meaning is not always fully expressed in the various constitutions and legal documents of our modern national states. I sometimes regret that our Bill of Rights does not go as far as does the American Constitution's Declaration of the right of each American to "life, liberty and the pursuit of happiness". The Canadian Bill of Rights speaks of life, liberty and security of the person. Happiness is so very important and love is so necessary for happiness. Is security of the person enough for happiness? What about security of

the mind and spirit? Let us try today in remedying our social needs to reinstate the right to love and happiness which must be respected in a good Canadian community.

So I say to you today as you prepare to find answers to the social ills and sufferings that we discussed yesterday: look at all aspects of the problems we face. Remember that we have the resources, we have the people. Let us re-examine our attitudes and motivations and be sure that we integrate and harness these two. With the concerted efforts of our government, our professional and our voluntary segments of Canadian society we can find answers to the needs discussed yesterday and so continue to build a true loving, caring and happy Canada.

Budgetary Problems in the Development of Support Services

by
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Introduction

This paper presents some of the interrelationships between the particular evolvement of day care services in Canada and its impact on budgetary problems, program and support issues, and then identifies some of the areas in which there is a need for additional research and information.

Evaluating day care services in Canada: budgetary issues

Until recently, provinces did not collect precise data relating to the degree of unmet child care needs to assist them in their budgetary planning exercises. Often provinces felt no pragmatic pressure to do so because the need for spaces and funds so far outstripped what could be realistically hoped for in the budgetary allocations, that incrementalism was the order of the day.

Cost sharing. Another factor that influences the planning exercises is that the provinces, although responsible for day care services, do not deliver the services. Ontario and Alberta, for example, provided an 80-20 cost sharing arrangement to the municipalities who in turn set child care priorities and take responsibility for the implementation of day care services. Some municipalities operate one or more services, but as is true for all the other provinces, utilize the voluntary and commercial sectors as the main vehicles for delivery of service.

Much can be said in support of this approach, but the differing perspectives of the participating partners can create a certain amount of tension. For example, some social work oriented day care programs -- both group and family day care -- believe that an interventionary and early treatment component ought to be an integral part of the day care program. The higher operating costs incurred by these agencies often highlights some of the differences in perspectives between the deliverers of service and the funding bodies.

Likewise some municipalities, taking a significant leadership role in developing day care services, are perceived by the province as taking more than their fair share of available monies. Alberta, at least in part because of the perceived lack of financial control, assumed the responsibility for most preschool day care programs from the municipalities.

Maximum subsidy levels. Another approach to maintain financial control was the establishment of provincial

maximum subsidy levels by every province, except for Ontario, Prince Edward Island and Newfoundland.

Maximum subsidy levels are, in part at least, established on the basis of what the province believes it costs to deliver an acceptable level of care. This approach again serves to underline some of the differences in perspective between the participating partners.

A few municipalities in Alberta, believing that the quality of care they desired could not be delivered within the provincial maximums, use 100% municipal dollars to top up the subsidies. Eventually some Alberta municipalities recuperated 50% of their costs by having the province claim the expenditures through the Canada Assistance Plan.

Some municipalities in Ontario faced similar problems. Although Ontario has not established maximum subsidy levels, they have set ceilings on total allocations to regions within Ontario. Metropolitan Toronto, claiming to be carrying a burden of about $12 million in subsidized spaces beyond that which the province will cost share, is currently exploring the possibility of having the province claim these expenditures through C.A.P.

In other provinces having a maximum subsidy and no municipal involvement, the centres are responsible to raise whatever additional funding they think is required.

Surcharging. One development rising out of this situation is the practice of surcharging. In theory, parents pay according to their ability determined on the basis of a financial needs or income test. However, if a centre tacks on an additional fee beyond that which the parent has been determined capable of affording, the procedure can become self-defeating. In some instances, centres are surcharging upwards of a $100 a month.

At least one province defends this practice by stating that it would cause parents to shop around and make centres competitive. Of course, such an argument presupposes that there are other centres with vacancies accessible to the parent.

Newfoundland does not permit centres to surcharge and Manitoba limits the maximum surcharge to a dollar a day.

A frequently heard criticism of maximum subsidy levels is that it pits parent against staff. Many parental boards have agonized over this double edged sword. The board feels bonded to the staff and know that the staff are greatly underpaid. They also know that salary related costs constitute between 75% to 90% of the centre's budget. Any significant

salary increase automatically translates into higher parental fees. The higher fee sometimes causes a number of parents to remove their child from care. In fact a number of centres have been unable to honour staff settlements and were forced to close.

Nutrition. As already mentioned, there is little room for cuts in the remaining budget. Unfortunately, one area that has been the target for cost saving measures, is nutrition.

Although every province has nutritional requirements consistent with the Canada Food Guide, centres in some provinces are allowed to satisfy the requirement by having the parent send a bag lunch. The centre is to assure that the lunch sent from home is nutritious. The author, several years ago conducted an informal survey and found that many centre directors did not take action when they knew the lunch was inferior. The most common reason given was that they had a tenuous relationship with the parent and any perceived criticism of the parent would cause the parent to withdraw the child.

Eligibility for parental subsidy. Another variable which impacts significantly on day care programs is the eligibility criteria for parental subsidy. The Canada Assistance Plan Likelihood of Need Guidelines, if utilized to their maximum would accommodate a large proportion of Canadian families. The guidelines are based on GIS and OAS levels and subject to quarterly adjustments.

As of the period January-March 1989, a one-parent family with one child could receive full subsidy with net earnings under $26,184 and partial subsidy up to a net income of $39,276. A two-parent family with one child would be eligible for full subsidy up to a net earning of $30,552 and a partial subsidy up to a net earning of $45,828.

However, to date, no province is using an income test that maximizes the C.A.P. guidelines. Depending on the province, a one-parent family with one child ceases to be eligible for full subsidy between $9,000 and $13,000 and is not eligible for partial subsidy beyond $15,000. The corresponding figures for a two-parent family with one child is $10,000 and $25,000.

It should be pointed out that Ontario uses a needs test rather than an income test. In a couple of municipalities, the income levels that are subsidized come close to the C.A.P. guidelines.

As would be expected, not too many families where both parents work, are eligible for provincial subsidy. Many of the traditional social work oriented day care centres, with their higher costs, have almost no children of full

fee paying parents. It is not unusual in these centres to find that children from one-parent families constitute 90% of the enrolment.

The typical profile in ordinary non-profit centres are families (usually one parent) from low income backgrounds on full or nearly full subsidy and higher income families paying the full cost. Modest income families are not eligible for subsidy and could not normally afford the full fee.

Manitoba, in the early 1970's, documented that as the cost of service went up, a corresponding number of modest income families withdrew their children.

Provinces are faced with political difficulties when trying to address the problem of modest income families. Most provinces do not want to be seen as subsidizing children of affluent families. Consequently, the initial reaction is to move the turning point of the income test upward. This would make sense if incomes in Canada are linear in nature. The problem faced is that salaries almost double once the second parent goes to work.

Age of children	Number of children in day care	Children of above category	Per cent children served
0-17 months	15,755	206,742	7.62
18-35 months	37,108	234,683	15.81
3-5 years	152,756	458,854	33.29
6-12 years	58,007	1,213,984	4.78

In order that an inordinate amount of the second income not be required for day care, the turning point of the income test would have to be pushed out to the point that it is viewed as overly generous for one wage earner families.

Direct grants to day care centres. Manitoba, followed by other provinces, attempted to resolve the issue by providing, in addition to user fee subsidies, direct grants to the centre. The purpose of the direct grant was to maintain or improve the quality of the service while reducing the cost to the full fee paying parent.

Approximately one half of the day care budget in Manitoba, Alberta, and Quebec is composed of direct grants to the formal sector.

At this point in time, it is premature to make a judgement as to specific impacts the direct grants have on the day care system. One variable has been the emphasis on using direct operating grants for salary enhancement. A careful study to compare such variables as salary levels, program quality, and user profile (number of modest and middle income families using the service) in provinces using a significant direct operating grant with those that rely primarily on user fee subsidy is needed.

Supply and use of licensed day care spaces. Before leaving this section of the paper, a recent observation might be appropriate. A number of centres in Toronto and Ottawa are claiming that they may have to close because they have not been allocated sufficient numbers of subsidized spaces by the province.

They believe that if they were allotted more subsidized spaces they could fill their centres several times over. One likely implication is higher income families do not feel they can afford the service. Again this speaks for the need for research to determine what impact a direct operating grant might have on usage of the service.

The last part of the paper will briefly present data on resources, issues, and identify some of the areas requiring better data.

Provincial budgets for day care in 1988/89 total just over $622 million. This represents an increase of about $143 million or 30% over 1987/88. Historically, the Canada Assistance Plan shares in about 35% of provincial expenditures. Therefore the C.A.P. share would be about $217 million.

As of March 1, 1988, there were about 263,000 full-time day care spaces of which about 192,500 (73%) were subsidized.

The following table shows the number of full-time day care spaces for children by age categories where both parents work at least 20 hours a week or attend school on a full-time basis.

As can be seen from the table, children aged 3 to 5 are much better served than younger or older children. Although the degree of unmet need is obviously significant, even for the 3 to 5 year old category, additional data is required to assist in the planning exercise. The limited data to date indicates that a sizable population would not opt for formal day care services if they were available to them. We are looking forward to the information on parental preferences that will be forthcoming in the National Child Care Survey.

It should also be noted that improved data concerning the ages of children being served in day care families is needed. Not all provinces are able to provide precise data on ages of children served and in some instances provide figures based on informed estimates. Since cost and programming differs according to age of child, long-term planning is difficult without accurate age profiles.

The impact of full-time kindergarten and junior kindergarten on the type and hours of child care needed is another area where additional research would be appropriate.

Labour supply. Day care is a labour intensive service and the number of day care staff constitutes a major resource. Assuming that staffing patterns in day care centres are near the minimum provincial requirement, there are about 37,500 full-time equivalent staff.

The value of this human resource is enhanced as more provinces are recognizing the need for trained day care staff. A number of provinces are phasing in training requirements. Although every province, except for Saskatchewan, has an early childhood education course in community colleges, the requirement for training is placing additional pressures on the colleges. For example, there are 400 applications for next year's program at Algonquin College in Ottawa to fill 40 spaces.

The low salaries offered in day care centres is making recruitment of trained staff difficult. Field observations indicate that many graduates are lost to other occupations.

Reports from the Maritimes, Ontario, and Alberta indicate the difficulty of recruiting trained staff and report that the commercial sector, which has salary levels about 30% less than the non-profit sector, is especially hard pressed.

Volunteers. Volunteers constitute another significant support and resource base to child care. There are approximately 30,000 board members in the full-time non-profit day care centres.

They spend a minimum of two evenings (3 hours an evening) a month. This totals 2.2 million hours a year in support of day care services. There are obviously many other non-board volunteers who strengthen the service.

However, reports from the field indicate that it is becoming more difficult to recruit volunteers willing to serve on the board of directors. This is especially true for centres experiencing financial problems. Board members worry about their personal liability and have reservations about signing for bank loans on behalf of the centre.

Some board members express discomfort with the advocacy role requiring them to confront provincial officials with the financial needs of their centre. Some also dislike the amount of time required for fundraising activities when they feel their time could better be devoted to the program.

Other potential recruits, having heard about lawsuits in the U.S. concerning negligence, express anxiety about their own liability if a centre is sued.

The importance of the volunteer resource suggests that research into this area would be fruitful. A profile of the types of volunteers, the nature of their contribution, and an evaluation of possibilities of reducing the stress placed on volunteers and ways in which their contributions can be maximized could prove helpful.

Reports from Ontario and elsewhere indicate that the non-profit centres, particularly those with parental involvement, are most likely to be in compliance with provincial standards. It would be interesting to study the question of what role day care boards play in ensuring compliance with standards.

Summary

In summary, this paper examined some of the budgetary and support issues arising out of the unique partnerships between different levels of government and the voluntary and private sectors in funding and delivering day care services. The paper suggests that more research and information is required in four key areas.

They are:

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

2 - the impact of full-time kindergarten and junior kindergarten on the need for day care services;

3 - a follow-up of graduates from early childhood community college programs; and

4 - a profile of the contributions of volunteers and an assessment of their needs.

Resource Issues in Caring for People with AIDS

by
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The resource issues involved in caring for people with AIDS are not new; they have been identified in previous years as those required to meet the needs of the aged, of children with disabilities, of any individual requiring social support.

The difference with HIV/AIDS is, however, that in North America most of the people infected with HIV or who have AIDS are drawn from an age and sex section of the population who up till now have used the health care and social welfare systems of Canada on a relatively minor basis.

Projected demand for services

AIDS is a disease that was first reported in 1981, although numerous cases at earlier dates are now being diagnosed retrospectively. For example, an Englishman died in 1959 of what would now be diagnosed as an AIDS-defining illness; his stored tissue samples showed the presence of the Human Immunodeficiency Virus (HIV).

However, the spread of HIV infection and the subsequent manifestation of AIDS has only become readily apparent in the last decade.

Given the current official statistics on the number of Canadians with AIDS, there may be many who are not aware of the implications of HIV/AIDS. A comparison of the number of aged persons and the number of persons with HIV/AIDS requiring significant needs in the next five to seven years may prove instructive.

A rough estimate of the number of senior citizens requiring a significant degree of community support can be made by counting the number of persons aged 85 years or older. The 1986 Census of Canada reported that there were 227,765 citizens aged 85 and older in Canada. The 1992 projections estimate that there will be approximately 305,900 persons in that same age group by that time.

The Royal Society of Canada in its report (AIDS: A Perspective for Canadians) has estimated that in 1987, approximately 30,000 people in Canada were HIV infected. Since the time between infection and showing signs of severe illness averages seven to eight years, this means that by 1995, approximately 15,000 people will require (or will have required) extensive support. The remaining 15,000 people may require less extensive support, although most will need at least minimal community support. Further infections that have occurred since 1987 will only add to the above numbers.

Thus the current effects of HIV/AIDS will add a minimal further 10% increase to the expected number of Canadians requiring extensive community support in the next five to ten years. Our society is currently not geared to meet those additional requirements.

Community support systems

A number of papers have addressed the area of community support. However they have mainly focussed on social care networks. Research reports have documented the number of social relationships, the size and density of social networks, and frequency of social interactions. In assessing social care, however, consideration should also be given to the provision of meals, special transportation, homemaker/home help, nursing care and other similar types of needed support. In addition, social security, housing, labour market participation, and insurance areas such as disability insurance, also play a role in defining the usefulness of a community support system.

Traditionally, measurement of efficacy has been based on parameters such as health days gained by a specific intervention or quality adjusted life use gains. Further analysis though reveals that providing community support involves a mixture of formal, semi-formal and informal methods; none of which can realistically be considered in isolation. Formal methods, for instance, would include social security laws, health care institutions, and disability insurance. Semi-formal methods of providing community support could include counselling agencies and self-help community-based organizations, and informal methods would be support delivered by friends and relatives.

Service needs and delivery -- universal issues

The health care and social welfare systems are already being stretched to the limit in many areas by the exponential growth in the number of people with HIV/AIDS. This substantial group of new users is raising questions for government in terms of potential difficulties in overall delivery of services.

These questions are usually raised in a negative framework but it could ultimately be positive if HIV/AIDS forces attention to be paid to issues that have never been adequately addressed.

The needs of people living with AIDS or HIV-related illnesses are substantially the same as those that have been identified for other sections of the community. These include: universal access to a graduated continuum of services so that appropriate levels of support and care are available; coordination of the present complex and disjointed range of services; information and

support for the informal social network which is comprised of caregivers, family, mutual support groups and others; for caregivers, the burden of providing intensive support that may affect their own health and may cause tension and breakdown in personal relationships; ethical issues surrounding death and dying; treatment of seriously ill, disabled or terminally ill persons; the use of modern medical technology; sheltered housing and assisted independent living.

It should be emphasized that this list could be enumerated by almost any group requiring social support -- the issues appear to be universal.

Nonetheless there will be other issues that are more specific.

Special needs of people with HIV/AIDS

Problems have been encountered by many people (both those with HIV/AIDS and other diseases) requiring social security owing to delays in the granting of benefits and the added costs of health needs generated by specific illnesses. One special need of people with AIDS or HIV infection is that the above universal needs are often manifested over a much shorter time frame than the system is geared to deal with. For example, when people apply for social security benefits, those applications are usually processed in a fairly short time frame. That short time frame may nevertheless be entirely too long for people living with AIDS.

Many people living with AIDS deny that they are manifesting the first signs of a potentially lethal disease, even after they have had one or more life threatening episodes. For instance, in Australia, people with symptomatic HIV illnesses are eligible for sickness benefits and those with an AIDS defining illness are automatically eligible for an invalid pension, which provides additional benefits. (This distinction may not reflect the individual's health status since some HIV-related illnesses are as incapacitating as AIDS.) Yet despite an average two-year life expectancy following an AIDS defining illness preceded by an average three years of increasing health problems, studies have shown that those who have died from AIDS have averaged less than six months of social security benefits (Duckett, 1987).

Similar anecdotal evidence has been reported in Canada. Thus many people living with AIDS do not apply for any social security benefits until they have no remaining financial backing. In the four to six weeks required to process a claim for an invalid pension what do these persons live on in the meantime, if they are no longer employed due to the illness and they've spent all their

money because they have been denying that they are sick? So there are special issues which must be addressed over and above some of the existing ones.

In addition, given the clear evidence relating the effects of nutrition on AIDS and the immune system, access to supplementary food benefits may be seen as an essential part of adequate care (see, for example Task Force on Nutrition Support in AIDS, 1989 and Resler, 1988 and 1989). Other groups in the community such as pregnant women may have free access to such services, most people living with AIDS do not.

A further special need is the frequent occurrence of difficulties with existing services providing home help and other services which have refused to help those persons who are HIV infected. So in many cases volunteers have stepped in to provide those services on a supplementary basis and have also had to spend time and resources in educating the formal caregivers and the semi-formal caregivers about the issues concerning AIDS, so that future access will be on a more widespread basis. So it's been a double burden.

Caregivers

Problems for the caregivers must also be addressed. People with full AIDS often have a very high risk of experiencing mental distress and

mental illness arising from abnormal, organic and/or psycho-social factors. This type of behaviour places an extreme physical, economic and emotional burden on caregivers. These issues have frequently been reported in research involving care for the aged, because there is often an increased risk of progressive mental disorders, but such progression is usually within a much faster time frame with someone with AIDS and so that exacerbates some of these issues.

In addition, many of the caregivers for those with AIDS or HIV-related illnesses are themselves HIV infected. Stress is known to affect the rate of progression to AIDS and also life expectancy once AIDS or a severe HIV-related illness has been diagnosed. Therefore, poor community support may directly impact on the health of caregivers in additional ways than with other groups of caregivers.

Economic implications

One complex area in estimating the economic implications of HIV/AIDS is the monetary worth of volunteer input. When governments talk about community supports they are usually concerned with cost minimization rather than enhancement of quality of life. We have tended to measure costs where it's easy to measure -- personal direct costs and statutory authority costs (Fraser and Cox 1988). This becomes an important

issue when we are examining substitution policies, which in many cases is what we are looking at in community support systems, that we ensure we examine all the relevant inputs, and the cost to the entire society.

As we evaluate our options, it will be vital that the viewpoint of the evaluation be stated explicitly. It can be undertaken from the viewpoint of an individual, a hospital, the health care system, government or society. And different viewpoints imply consideration of different consequences and the inclusion of different cost factors.

For governments, one could take a very cynical view that the cheapest way to minimize costs is to spend nothing. That however raises ethical issues and is usually resolved in a trade off between costs and ethics. Care is not provided in some areas where it could/should and when community support is delivered, the majority of the support is delivered by voluntary agencies, families and friends. And that's something that health economists have found very difficult to cost because there are problems in identifying networks and in quantifying the cost and quality of non-professional care.

You can consider the time and resource allocation that would have been required from a professional if a non-professional had not been available, the costs of lost productivity in the paid work force of the volunteers and direct expenses of providing that voluntary care (travel expenses, rent of meeting place for organized groups, etc.). However, what are the opportunity costs? How do you value lost leisure? Leisure time has traditionally been valued at an hourly rate of 25% of the usual income of the volunteer. Now that figure does not stand any intensive evaluation, and in addition has suffered from the limitation that traditionally women have provided the majority of volunteer hours and have not been in the paid work force and thus have been costed at a zero level. Thus research in this area has contributed to a result where society does not take into account the "cost" of the services provided by these volunteers. Some real evaluation of the cost of existing community supports is perhaps overdue.

With the majority of previous social support surveys, we have tended to measure how much government puts in and how much do people need, and, not unexpectedly, found that there's a gap. This obviously raises the question of what government is doing to foster the volunteer sector. One possibility might be to allow tax deductions related to hours devoted to volunteer work. If a business lunch is tax deductible because of its potential to expand the economy, how much is an hour of volunteer time that enhances someone's quality of life worth to society? Some of the above-mentioned economic impact

issues are extremely important when we are addressing the issue of harnessing and integrating human and financial resources in the provision of community supports.

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

by
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Abstract

The purpose of this paper is to examine the relationship between women's physical health, the number of roles they occupy, and their employment status. In doing so, it draws particularly upon role accumulation theory. According to this theory, there are rewards such as privileges, status security, resources, and ego gratification that are associated with role accumulation and outweigh any costs.

The hypotheses tested were as follows:

1 - The more roles a woman occupies, the better her physical health will be.
2 - Women who are employed will be in better physical health than non-employed women.
3 - After controlling for family income and age, employment will be a better predictor of women's physical health than will be the number of roles occupied besides employment.
4 - Homemakers who had not been employed in the five years prior

to being interviewed will be in better physical health than homemakers who had had jobs and left the labour force at some time in the five years prior to the interview.

The data analysis used all female subjects of the 1985 General Social Survey (N=6105). Analysis of Variance and Multiple Classification Analysis were used.

The results are as follows:

Hypothesis 1 - The more roles women had, the better their physical health.
Hypothesis 2 - Employed women were in better physical health than non-employed women.
Hypothesis 3 - Compared to the number of roles besides employment, employment status was a better predictor of women's physical health, especially for women 40 years of age and older.
Hypothesis 4 - Homemakers who had been employed and left the labour force were in better physical health than the long-time homemakers.

Introduction

Since World War II dramatic changes have taken place in women's labour force participation. During the 1960s and 1970s, women's role in the economy shifted from a temporary and peripheral position to a permanent and integral one (Marshall and Paulin, 1987). Now, well over half of Canadian women work outside the home, and this is true for married women with children as well as unmarried, childless women (Statistics Canada, 1986). As the proportion of women who are active in the labour force rises, it is becoming increasingly important to understand how employment affects a woman's life, in particular, her physical health.

The purpose of the present study was to assess the relationship between women's work and health status. Health status was defined as a woman's perception of her general health, her self-reported health problems (as diagnosed to her previously by a health professional), and number of disability days. Research questions addressed in this study were: (a) if a woman occupies many roles, especially employment outside the home, what are the effects on her physical health? And (b) what are the effects of previous employment on a homemaker's physical health? This study involved secondary analyses of data collected by Statistics Canada in September of 1985 for the General Social Survey (GSS). Analyses were limited to the female respondents of the GSS. Research questions were examined in the context of role theory.

Theoretical framework

In an attempt to understand the relationship between women's health and employment, two contrasting views of role theory have been presented in the literature: role strain theory and role accumulation theory. Both will be reviewed.

Goode (1960) defined role strain as "the felt difficulty in fulfilling role obligations" (p. 483). The conflicts and demands of one's various roles are more than can be resolved and this leads to the experience of "role strain". According to role strain theory, as the number and diversification of one's roles increase, and the clarity and consensus of one's role expectations decrease, the role strain experienced by the individual increases.

Employed women typically occupy more diverse roles and have less consensus among their role obligations than do women who are not employed. Therefore, women who work outside the home would be expected to experience role strain. Because role strain is assumed to have a deleterious effect on health (Froberg, Gjerdingen, and Preston, 1986), women who work outside the home would be expected to report more health problems than homemakers.

Marks (1977) and Sieber (1974) have questioned Goode's theory of role strain by noting that multiple roles do not always lead to strain or overload problems. Sieber proposed that the rewards associated with one's roles may accumulate as one occupies more roles, and that these rewards may outweigh the burdens (or strains) of the roles. The sources of rewards from role accumulation are (a) role privileges, (b) status security, (c) resources for status improvement and role performance, and (d) ego gratification.

According to role accumulation theory, as the number of one's roles increases, the potential for the above rewards from these roles increases. This increase in rewards exceeds the burdens associated with multiple roles, and role strain perceived by the individual decreases. The worker role is seen as an important source of rewards (Coleman and Antonucci, 1983). Therefore, women who are employed would be expected to perceive more rewards and less role strain than homemakers. The perception of rewards from one's roles is assumed to have a beneficial effect on women's health (Verbrugge, 1983). Consequently, women who work outside the home would be expected to report fewer health problems than homemakers.

Statement of hypotheses

Few of the studies reviewed explicitly used role accumulation as the theoretical basis for generating hypotheses. Role accumulation theory predicts general benefits to

occupying a large number of roles. If this theory is applied to health, it would be expected that the greater the number of roles a person occupies, the more health advantages he or she will have. Therefore, it is hypothesized that:

1. The more roles a woman occupies, the better her physical health will be.

However, employment is seen by many not only as a role for one to "accumulate" but as a special source of benefits. Participating in a socially valued activity, such as employment, can enhance a person's sense of self-esteem and sense of accomplishment. Furthermore, it increases one's social network, thereby increasing his or her support system (MacKay and Bishop, 1984). Therefore, it is hypothesized that:

2. Women who are employed will be in better physical health than women who are not employed.

Furthermore, because many researchers found employment to be the most important predictor of good health for women, it is hypothesized that:

3. After controlling for family income and age, employment will be a better predictor of women's physical health than will be the number of roles occupied besides employment.

Most research on employment and women's health looks at employment as a dichotomous variable; women are either employed or homemakers. Welch and Booth (1977) and Anson and Anson (1987) compared long-time homemakers, to homemakers who had recently left employment and found the latter group to be in worse health than the former. Given the detrimental health effects associated with the homemaker role for women who had recently left the labour force, it is hypothesized that:

4. Homemakers who have not been employed in the past 5 years, will be healthier than homemakers who have left the labour force in the past 5 years.

Methods

The target population for the General Social Survey (GSS) was comprised of Canadians at least 15 years of age, with the exclusion of those living in the Yukon and the Northwest Territories and full-time residents of institutions. For the purpose of this study, a subsample of the GSS was used. Subjects were limited to female respondents (N=6105).

For all four of the hypotheses being tested, three measures of health, (a) general health, (b) health problems, and (c) disability days, were the dependent variables. General health was measured by respondents'

descriptions of their own health relative to others their own age. Scores ranged from poor (1) to excellent (4). Respondents were categorized as having a health problem at the time of the survey, if they had been diagnosed (by a health professional) with at least one of: (a) high blood pressure, (b) heart trouble, (c) respiratory problems, (d) diabetes, or (e) arthritis, rheumatism, or bursitis. Respondents who had no health problem received a score of 2 and those with a health problem received a score of one. Disability days referred to the actual number of days the respondent stayed in bed and/or cut down on her usual activities, for 14 days prior to the interview.

The independent variable total number of roles, in hypothesis 1, was the total number of roles occupied by a respondent. The following four roles were possible: (a) worker (those who reported their main activity as working), (b) spouse (married or living common law), (c) parent (at least one child living in the household), and (d) child (at least one parent living in the household). For each of the four roles, respondents received a score of 2 for occupying the role, and 1 for not occupying it. Scores were added so that the higher the score, the greater the number of roles occupied.

The independent variable employment was used in hypothesis

2 and 3. Respondents who reported their main activity as working were considered to have the worker role (code 2) and all others were categorized as non-employed (code 1). Those respondents who reported keeping house as their main activity were categorized as homemakers. The independent variable in hypothesis 4 was whether the homemaker had been employed in the past 5 years. Homemakers who had been employed were coded 1, and homemakers who had not been employed were coded 2.

For hypotheses 1, 2 and 4, the procedure used was one-way analysis of variance. For hypothesis 3, multiple classification analysis (MCA) was used. The MCA output consists of the grand mean of the dependent variable and deviations from the grand mean for each category of the independent variables. The deviation values are printed as both unadjusted values, and adjusted for main effects of other independent variables. Separate MCAs were conducted within four categories of the two control variables, income and age, as follows: (a) women under 40 with family income of $20,000 or less, (b) women 40 and over with family income of $20,000 or less, (c) women under 40 with family income greater than $20,000, and (d) women 40 and over with family income greater than $20,000. Age and income were controlled in this way because on preliminary analysis, when the

controls were entered as covariates with the independent variables, there were problems with interaction effects.

Results

Demographic and health characteristics. Average age of respondents was 45 to 49 years, and 45% had some secondary education. The median family income was $20,000 and the majority of the women did not report working as their main activity (66%). Just over half of the women were in the role of spouse (55%) whereas slightly less than half occupied the parental role (40%) and 8% occupied the role of child. Out of the four possible roles, over half the respondents had either no roles, or one role (55%). Approximately three-quarters of the subjects rated their health as excellent (29%) or good (50%) and the remainder rated their health as fair (17%) or poor (4%). A health problem was reported by half of the sample (50%) and the majority of subjects did not report having to take any disability days (82%).

Hypothesis 1. The more roles a woman occupies the better her physical health will be. One-way analyses of variance performed on each of the three health measures by the total number of roles occupied indicated that there was a significant relationship between total number of roles and physical health. As respondents' number of roles increased, physical health improved

significantly (See Table 1). Women with more roles (a) had better self-rated health, (b) were less likely to report having a health problem, and (c) had fewer disability days. These results, which supported Hypothesis 1, indicate that the more roles occupied by a woman, the better her physical health.

Hypothesis 2. Women who are employed will be in better physical health than women who are not employed. One-way analyses of variance performed for each of the three health variables by the role of employment indicated that employment as a main activity and physical health were positively and significantly related. Women who were in the worker role were in better physical health than women who were not (See Table 1). Employed women rated their health more positively than those without employment. Employed women were less likely than non-employed women to report having a health problem, and the women with employment took fewer disability days than those without employment. Employment was found to be significantly related to women's physical health, and Hypothesis 2 was supported.

Hypothesis 3. After controlling for family income and age, employment will be a better predictor of women's physical health than will be the number of roles besides employment that are occupied. Results of the multiple classification analyses for

Table 1
Number of Roles, Employment, Previous Employment and Physical Health. Oneway Analyses of Variance

	N	Mean	Oneway F
		General Health	
Number of Roles[a]			
0	1144	2.7483	82.6361*
1	2176	2.9609	
2	1933	3.1878	
3	737	3.2822	
4	14	3.3571	
Employment Status[b]			
Not Employed	3946	2.9100	295.7142*
Employed	2125	3.2687	
Homemakers only:			
Job Last 5 Years[c]			
No	1868	2.8009	67.2381*
Yes	665	3.1023	
		Health Problem	
Number of Roles[a]			
0	1127	1.2440	151.3587*
1	2117	1.4270	
2	1906	1.6385	
3	729	1.6447	
4	14	1.7857	
Employment Status[b]			
Not Employed	3865	1.4060	332.9882*
Employed	2093	1.6469	
Homemakers only:			
Job Last 5 Years[c]			
No	1849	1.2720	163.8193*
Yes	654	1.5398	

[a]Hypothesis 1. [b]Hyphothesis 2. [c]Hypothesis 4.
* p<.0000

Table 1
Number of Roles, Employment, Previous Employment and Physical Health. Oneway Analyses of Variance - Concluded

	N	Mean	Oneway F
		Disability Days	
Number of Roles[a]			
0	1141	1.3313	13.9451*
1	2162	1.0920	
2	1928	0.8029	
3	735	0.4245	
4	14	0.0714	
Employment Status[b]			
Not Employed	3931	1.1636	58.2301*
Employed	2116	0.5718	
Homemakers only:			
Job Last 5 Years[c]			
No	1862	1.2320	0.1443
Yes	663	1.1750	

[a]Hypothesis 1.   [b]Hyphothesis 2.   [c]Hypothesis 4.
* $p < .0000$

Table 2
Analysis of Variance for General Health, by Income Level and Age

Source of Variation	<$20,000 <40 years (n=550)	<$20,000 40 years+ (n=1370)	$20,000+ <40 years (n=1156)	$20,000+ 40 years+ (n=689)
Main Effects	2.664*	10.625***	0.777	15.602***
Number of Roles	0.667	1.231	1.035	2.291
Employment	7.384**	27.560***	0.022	50.641***

* $p < 0.05$
** $p < 0.01$
*** $p < 0.001$
Source: 1985 General Social Survey.

general health are presented in Tables 2 and 3. Occupying the worker role was a significant predictor of general health for three income and age categories: older women in both income levels and younger women with a low family income. When comparing the predictive value of employment for general health between these three age and income categories, employment is a less important predictor for young low income women than for older low income women. Employment has the greatest predictive value for general health for older women in the high income group. Number of roles besides employment was not a significant predictor of general health for women in any income and age category.

Results of the multiple classification analysis for health problem are presented in Tables 4 and 5. Employment was a significant predictor for the health problem measure for older women in both the low income and high income groups. Employment had more predictive value for the health problem variable for high income older women than for low income older women. Number of roles besides employment was a significant predictor of the health problem score for older, high income women. However, the relative ability of number of roles besides employment to predict the health score of older, high income women was lower than the ability of employment to predict the health problem score for these women.

Multiple classification analysis results for disability days are provided in Tables 6 and 7. The contribution of employment to the prediction of disability days was significant for younger, high income women, and for older, low income women. The predictive value of employment for disability days was greater for older, low income women than for younger, high income women. The number of roles besides employment was not a significant predictor of disability days in any income and age category.

Generally, in terms of predicting the physical health measures, employment has more value than the number of roles besides employment. This is the case more often for women 40 years of age and over than for women under 40. Hypothesis 3 was partially supported.

In order to help explain why employment was found to be especially important for the women aged 40 and above, the CROSSTABS procedure was done. This provided a contingency table that compares women under 40 and over 40 in terms of the number of roles besides employment that they occupy (see Table 8). Compared to women under 40, women 40 years of age and over were found to be significantly more likely to have no roles or only one role besides employment and significantly less likely to have two or three roles besides employment.

Table 3
Multiple Classification Analysis for General Health, by Income Level and Age

	N	Mean adjusted	Beta
		<$20,000 <40 years (n=550)	
Number of Roles **Besides Employment**			
0	171	3.13	
1	222	3.10	
2	139	3.11	
3	1	2.09	
			0.06
Employment Status			
Not Employed	276	3.02	
Employed	257	3.20	
			0.12
R^2			0.020
R			0.141
		<$20,000 40 years+ (n=1370)	
Number of Roles **Besides Employment**			
0	706	2.72	
1	530	2.72	
2	104	2.86	
3	-	-	
			0.04
Employment Status			
Not Employed	1209	2.69	
Employed	131	3.11	
			0.14
R^2			0.023
R			0.153

Table 3
Multiple Classification Analysis for General Health, by Income Level and Age -
Concluded

	N	Mean adjusted	Beta
		$20,000+ <40 years (n=1156)	
Number of Roles Besides Employment			
0	120	3.35	
1	363	3.24	
2	622	3.27	
3	7	3.43	
			0.05
Employment Status			
Not Employed	437	3.27	
Employed	675	3.27	
			0.000
R^2			0.003
R			0.053
		$20,000+ 40 years+ (n=689)	
Number of Roles Besides Employment			
0	113	3.22	
1	329	3.13	
2	221	3.29	
3	3	3.37	
			0.10
Employment Status			
Not Employed	389	3.03	
Employed	277	3.44	
			0.27
R2			0.086
R			0.294

Source: 1985 General Social Survey.

Table 4
Analysis of Variance for Health Problems, by Income Level and Age

Source of Variation	<$20,000 <40 years (n=550)	<$20,000 40 years+ (n=1370)	$20,000+ <40 years (n=1156)	$20,000+ 40 years+ (n=689)
Main Effects	1.065	10.522***	1.361	11.699***
Number of Roles	0.952	1.668	1.809	5.059**
Employment	1.414	26.260***	0.136	26.883***

** $p < 0.01$
*** $p < 0.001$
Source: 1985 General Social Survey

Table 5
Multiple Classification Analysis for Health Problems, by Income Level and Age

	N	Mean adjusted	Beta
		<$20,000 <40 years (n=550)	
Number of Roles Besides Employment			
0	171	1.72	
1	222	1.72	
2	139	1.73	
3	1	0.97	
			0.07
Employment Status			
Not Employed	276	1.74	
Employed	257	1.70	
			0.05
R^2			0.008
R			0.090

Table 5
Multiple Classification Analysis for Health Problems, by Income Level and Age -
Continued

	N	Mean adjusted	Beta
		<$20,000 40 years+ (n=1370)	
Number of Roles **Besides Employment**			
0	706	1.18	
1	530	1.19	
2	104	1.26	
3	-	-	
			0.05
Employment Status			
Not Employed	1209	1.17	
Employed	131	1.36	
			0.14
R^2			0.023
R			0.152
		$20,000+ <40 years (n=1156)	
Number of Roles **Besides Employment**			
0	120	1.77	
1	363	1.79	
2	622	1.74	
3	7	2.00	
			0.07
Employment Status			
Not Employed	437	1.77	
Employed	675	1.76	
			0.01
R^2			0.005
R			0.070

Table 5
Multiple Classification Analysis for Health Problems, by Income Level and Age -
Concluded

	N	Mean adjusted	Beta
		$20,000+ 40 years+ (n=689)	
Number of Roles			
Besides Employment			
0	113	1.37	
1	329	1.34	
2	221	1.50	
3	3	1.35	
			0.15
Employment Status			
Not Employed	389	1.32	
Employed	277	1.51	
			0.20
R2			0.066
R			0.257

Source: 1985 General Social Survey

Table 6
Analysis of Variance for Disability Days, by Income Level and Age

Source of Variation	<$20,000 <40 years (n=550)	<$20,000 40 years+ (n=1370)	$20,000+ <40 years (n=1156)	$20,000+ 40 years+ (n=689)
Main Effects	1.499	5.297***	2.693*	1.240
Number of Roles	1.721	0.264	1.614	1.022
Employment	1.011	15.440***	5.319*	1.427

 * p<0.05
*** p<0.001
Source: 1985 General Social Survey.

Table 7
Multiple Classification Analysis for Disability Days, by Income Level and Age

	N	Mean adjusted	Beta
		<$20,000 <40 years (n=550)	
Number of Roles Besides Employment			
0	171	0.91	
1	222	0.74	
2	139	0.69	
3	1	5.89	
			0.10
Employment Status			
Not Employed	276	0.90	
Employed	257	0.68	
			0.05
R^2			0.011
R			0.106
		<$20,000 40 years+ (n=1370)	
Number of Roles Besides Employment			
0	706	1.38	
1	530	1.49	
2	104	1.60	
3	-	-	
			0.02
Employment Status			
Not Employed	1209	1.57	
Employed	131	0.26	
			0.11
R^2			0.012
R			0.108

Table 7
Multiple Classification Analysis for Disability Days, by Income Level and Age -
Concluded

	N	Mean adjusted	Beta
		$20,000+ <40 years (n=1156)	
Number of Roles **Besides Employment**			
0	120	1.07	
1	363	0.59	
2	622	0.79	
3	7	-0.06	
			0.07
Employment Status			
Not Employed	437	0.97	
Employed	675	0.61	
			0.07
R^2			0.010
R			0.098
		$20,000+ 40 years+ (n=689)	
Number of Roles **Besides Employment**			
0	113	1.05	
1	329	1.20	
2	221	0.75	
3	3	-0.02	
			0.07
Employment Status			
Not Employed	389	1.14	
Employed	277	0.85	
			0.05
R2			0.007
R			0.086

Source: 1985 General Social Survey.

Table 8
Crosstabulations of Number of Roles Besides Employment by Age

Number of Roles Besides Employment	Age		Row Total
	Under 40 years	40 years and over	
0	463[a] 17.0%	1200 36.3%	1663 27.5%
1	1062 38.9%	1475 44.6%	2537 42.0%
2	1181 43.3%	625 18.9%	1806 29.9%
3	21 0.8%	10 0.3%	31 0.5%
Column Total	2727 45.2%	3310 54.8%	6037 100.0%

Chi-square=517.45192   D.F.=3   significance=0.00000   Cramer's V=0.29277
a=number
Source: 1985 General Social Survey.

Hypothesis 4. Homemakers who had not been employed in the past 5 years will be in better physical health than those who had been employed outside the home during that time. One-way analyses of variance done for each health variable indicated a significant relationship between homemakers' previous employment and their physical health. Homemakers who had been previously employed were in better health than long-time homemakers, in terms of general health and health problems, but not in terms of disability days (See Table 1). Previously employed homemakers had better self-rated health and were less likely to report having a health problem than long-time homemakers. There was no significant difference between the two groups of homemakers on the measure of disability days. Hypothesis 4 was rejected.

Discussion

The finding that women with more roles had better health than women with fewer or no roles is consistent with role accumulation theory (Sieber, 1974), and research done by

Muller (1986a), Nathanson (1975), and Verbrugge (1986). It was expected that the more roles women had, the better their physical health would be. The findings were as expected for all three measures of physical health: general health, health problems, and disability days.

The results of the present study support previous research findings on employment and health that suggested that employed women are healthier than non-employed women. For all three health measures, women in the worker role demonstrated better health than other women. This is consistent with several studies using self-rated general health as a measure of physical health (Anson and Anson, 1987; Jennings, Mazaik, and McKinlay, 1984; Nathanson, 1980; Verbrugge, 1983; and Waldron, Herold, and Dunn, 1982). The finding in this study that employed women were less likely to have health problems than women without employment is also consistent with the work of several researchers (Anson and Anson; Jennings, Mazaik, and McKinlay; Lewin-Epstein, 1986; Nathanson; Verbrugge, 1983, 1986). In terms of disability days, the finding that women with employment reported fewer disability days than those without employment is consistent with other studies that included a measure of disability or restricted activity days (Muller, 1986b; Verbrugge, 1983, 1986).

When comparing employment and the number of roles besides employment for their ability to predict women's health, employment is the more important predictor. This is consistent with the finding by Verbrugge (1983) that whereas employment, marriage, and parenthood were each positively related to health, employment had the strongest relationship.

The number of roles besides employment was a significant predictor of health less often than was employment and even when the role variable's predictive value was significant, its contribution to the prediction of health was smaller than was the contribution of employment. It appears likely that the finding that physical health improves as the total number of roles increases for women, is largely due to the inclusion of employment in the measure of number of roles.

Implications and suggestions for future research

The results of the present study are consistent with role accumulation theory's general proposition that as roles increase in number, the result is net gratification, not stress. The

results are also consistent with previous research that found employment to be positively related to health. Women who occupied more roles were in better physical health than those with fewer roles, and women with employment were in better physical health than those without employment.

Some caution is warranted in the interpretation of results. It cannot be assumed that increasing one's repertoire of roles or entering the labour force causes improvements in health. It is possible that the condition of one's health is a factor in the determination of whether one will occupy a role. The issue of causality was not testable in the present analysis. This issue can only be sorted out by longitudinal data. Women should be followed throughout the life cycle to determine whether roles affect one's health and /or health affects one's roles.

The present study did not look at the quality of any given role but at role occupancy. It has been suggested that it is role quality which is the more important factor in terms of health (Verbrugge, 1986). The data analyzed in this study did not include measures of individuals' role perceptions, so the connection between role quality and health could not be examined. Research would have to look at people's satisfaction or happiness with the roles they occupy to begin to address this question.

Overall, the results tend to suggest that employment has a strong positive relationship with physical health. Future research should address the contributions to health made by each major role, as this study suggests that employment is associated with better health, but it is unclear as to whether this is the only role with such an association. Research should also address whether a certain number of roles or combination of roles is associated with particularly good health.

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Competing Pressures upon Community Support Resources

by
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When I was asked to speak on the topic "Competing Pressures upon Community Support Resources" speculation about the predicted imminent budget cuts had not yet monopolized the headlines of our newspapers and the conversations of Canadians in all walks of life. Given the current mood in the country, this topic seems particularly timely.

Even before hearing Ian Stewart's remarks yesterday, the pre-budget mood was creating a visual image in my mind. As I listened to Dr. Stewart speak, the image became clearer: it was the opening scene from the movie "Jaws". I could hear the menacing beat getting louder and closer -- the tension comes from knowing that there is a threat out there, but not being sure where it is going to strike. Similarly, if there are competing pressures upon community support resources, must one group suffer for another to gain? Again, I think that Dr. Stewart set us down the right path when he suggested that in order to rationalize spending cuts one must not focus on micro issues, but must move to a macro level. Similarly, even if we were not facing budget cuts, we all know that the resource pie is limited. It is important that we try to understand what now isolates so many special groups in our communities in order to more adequately meet their needs in the future without being forced to compete to determine which disadvantaged group is the *most* disadvantaged.

I will be discussing some of the limitations of segregated services and explore a model of community inclusion. I will draw on my experience with individuals who have a mental handicap in my examples.

Thinking about potential budget cuts turned my mind to The Great Depression. I remember a story which my father loves to tell about the Sunday that his family was about to sit down for their weekly feast -- a whole roast chicken -- the best meal of the week. Just as they were gathering at the table, a family of distant cousins dropped by, and naturally they were invited to join in at the table. My grandmother, realizing that there was not enough chicken to go around, discretely whispered to each of her three sons that they should fill up on bread and refuse the chicken as it was passed around the table saying they were full. Obediently they complied, consoling themselves with thoughts of the chocolate cake to come. When the uninvited cousins had picked the bones clear, the table was cleared. The beautiful cake was carried in by my grandmother who quickly announced, "those who were too full for the main course can't have dessert!"

This is exactly what happens time and time again to Canadians who are disadvantaged, whether that disadvantage results from disability, age, illness, gender or ethnicity. A series of criteria are established for accessibility to a certain program or service. Failing to meet those criteria results in a lack of service, even if the need is great. Meeting the criteria makes available to the individual a variety of supports and services, often more than are required. For example, in many situations where families are having difficulty coping on their own with some of the challenges of a child with complex needs, they are asked to make a choice: send your child to live in a special facility at the taxpayer's expense -- often at a cost of over $200/day; or manage on your own. All or nothing. Most parents are not asking for $75,000 per year; they would like some relief -- perhaps a break for a weekend every couple of months - but except in a few provinces, no such flexible help is available. A recent study confirmed what families have long known: Canadian social service programs have a built-in bias toward the support of extra-familial forms of care (The G. Allan Roeher Institute, 1989: 60). In other words, our so-called support systems often can be tapped only by destroying the natural and loving supports which the family wants to provide.

Similar "Catch 22" situations abound in the lives of people with mental handicaps. Accessing a specialized service often means being over-served, and forfeiting participation as a valued and contributing member of society.

In the late 1960's, our association conducted a rudimentary needs and resources study to determine the dollars needed to build and operate all of the "special schools", "special group homes" and sheltered workshops which were then regarded as the panacea, in order to meet the needs of all persons with a mental handicap. My predecessors quickly realized that it was unreasonable to expect even the most benevolent government to come up with anywhere near the dollars necessary to fund such services, and that it was necessary to look for different solutions. A similar philosophy was expressed by the President of a Canadian university who was quoted in yesterday's Globe and Mail saying, "If we don't have the money, we have to use our minds."

Marcia Rioux, the Director of The G. Allan Roeher Institute has provided a new frame of reference for us in her recent paper (Rioux, 1989). In it, she documents how we as a society have labelled individuals with intellectual handicaps as socially inferior. Then, we have developed care and treatment, which includes law, policy and programs based on this label. We have created criteria for our generic programs which systematically keep out people with mental handicaps and then we struggle to rationalize the need for parallel and separate systems.

As long as we attempt to fill the resource gaps by building separate systems, we will be defeated at our own game. We risk addressing the symptoms rather than the cause of the exclusion of large numbers of Canadians from their communities and natural support networks. When we build separate systems, we automatically create competition between groups in need. When we build inclusive systems designed for the most needy we eliminate competition and build on strength.

Let me give an example. For the last few years, CACL has strongly advocated integration in education. It is the policy of our association that children who have a mental handicap should be educated in regular classes alongside their typical peers. In recent years, many school boards across the country and one provincial department of education have moved to implement such a policy, usually by transforming the former special education resources, including personnel, to support the regular system. Formal research on the efficacy of such programs is in its infancy. However, I hope that even in this research environment I may be permitted to put on my hat as the mother of three school-aged children to share an observation. Through my work I have had the opportunity to visit scores of classrooms across this country and around the world. I am consistently struck by a recurring observation: classes which are able to include children with varying degrees of handicaps are the kinds of classes where I would like my children to be. They encourage individualized learning -- not just for the child with the handicap, but for all children. They are vibrant; they foster cooperation between students, they foster cooperation between staff. They can equally meet the needs of the child who is non-verbal, the child who is blind or the child who is gifted. In short, eliminating segregated education for children with mental handicaps can strengthen education for all children.

If we start with the objective of inclusion of people with mental handicaps in our communities, we can quickly see that the way to reach our objective is not by creating a series of special services but by systematically ensuring that all social services foster such inclusion. Such an approach has ramifications for legislation, policy, research, planning, and manpower development. Lest you find the task overwhelming, let me remind you of a few wonderful examples and opportunities which have arisen at this symposium. I was delighted to hear Donna Lero call for a broader vision of why families need child care. Among the reasons were the special needs of a child with a handicap. A more traditional model would have listed the need for care of typical children and ignored children with handicaps. A system would then

be created which excluded children with handicaps, and at a later date, their parents would try to rationalize the need for a special or add-on service. Donna Lero's model includes children with handicaps from the beginning, legitimizes their special needs and potentially eliminates conflicting pressures in the future.

A similar approach could be followed with almost any of the examples cited yesterday. After AIDS education has started is not the time to ask if people who have a disability need information about AIDS too. An inclusionary approach demands that the special needs of people with a disability be considered before a plan is developed so that they are not excluded. Recent research in the area of sexual abuse shows the needless suffering caused when we exclude a group of people from receiving information about their own protection (The G. Allan Roeher Institute, 1988).

Looking at research on aging, we must remember that disabled people are growing older with the rest of the population. Let us not ignore them in our research or we risk developing policies and programs which will continue to marginalize people with disabilities.

Before leaving the issue of research, I want to underscore the need for a much broader base of information about people with disabilities.

Statistics Canada deserves to be commended for reaching out to groups such as CACL for this symposium. We are optimistic that this will lead to the development of an information base about Canadians who have a mental handicap.

Before I conclude, I want to be sure that I do not leave you with the misimpression that conciliating the competing pressures upon community resources is easy. Quite the contrary. What I am saying is that in order to resolve them we must make adjustments at a broader societal level which will foster inclusion of all Canadians into the fabric of society.This can happen only if we are prepared to dismantle some very powerful and entrenched systems. In CACL, the first system to be targeted for destruction is the institutional system (Canadian Association for Community Living, 1987). This is for two prime reasons, both of which have been learned from research and painful experience. First: there is no moral, legal or therapeutic rationale to justify the incarceration of people simply because they have a mental handicap. Second: as long as institutions continue to drain resources, there will never be enough to build up supports in the community. We need to redirect the money currently allocated to institutions into the community.

After institutions, our second major target is the segregated education

system. I have already given my reasons for favouring integrated education. The next system which needs to be challenged are sheltered workshops which systematically prevent people from participating as valued, contributing citizens in their communities. After sheltered workshops our targets are not as direct. Certainly traditional group homes are suspect as we look for ways which permit people to exercise more autonomy in developing a personal lifestyle.

At the same time that some of these old systems are being dismantled we must begin to work at a broader societal level to identify barriers to inclusion and begin to break them down while at the same time creating opportunities which maximize inclusion. Generally, these will be based on individual strengths and needs; be flexible; and build on natural supports.

We should not be conducting research on segregated services. Instead, we must focus our attention on broader societal issues such as income. An emerging research theme is self-determination: how can people with mental handicaps be given control over decisions which affect their lives? Can we enable that control by providing funds to individuals rather than to services? The G. Allan Roeher Institute is currently conducting research which will begin to answer this question. The challenge awaits us all.

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Associations Between Uses of Formal and Informal Sources of Support in Help Received by the Older Population: Main Points

by
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Purpose of this study

This analysis was designed to explore what we might learn from the 1985 General Social Survey concerning the ways in which aspects of informal sources of help may have influenced the degree or pattern of use of formal sources. This matter has been explored in a number of American studies, and in Canada by researchers like Neena Chappel, Betty Havens, and Carolyn Rosenthal, using data from the Manitoba Health Services Commission or data they have collected in local surveys. The 1985 General Social Survey offers a rare opportunity to explore this matter with a relatively large national sample.

Academic interest in social networks and related support patterns first emerged most strongly among cultural anthropologists and is now greatly influenced by the work of social psychologists. Nevertheless, there is ample evidence of attention to this subject in the work of early sociological theorists such as Durkheim (1893, 1897, 1912), Cooley (1909) and Simmel (1955). Among sociologists, the focus in recent years has been on the various functions of membership in the formal and informal social structures that are the basis of community organization. The social-psychological perspective focuses on perceptions, experiences, and person-level outcomes of support, as well as on the interactions that characterize supportive behaviour. In contrast, the macro-sociological perspective taken in this paper concentrates on questions about support resources, flows of these resources, and the group and community structures that enable support resource flows and partly determine who gets high levels of support and who does not.

The aim of this paper is to examine certain statistical reflections of aspects of relationships between the formal and informal networks which form the basis of the total <u>potential</u> support structure of the elderly person. Primary attention is focused on the nature and extent of the association between the receipt of support from formal sources and characteristics of the actual or potential informal network of family, friends and neighbours. This focus is potentially important because the best approach to understanding patterns of formal service use among the elderly rests on recognizing the often strong influence of the informal network in determining how network members gain access to and use formal services.

In modern society, formal and informal support networks frequently operate in combination with one another and are thus linked at many important junctures (Lipman and Longino, 1982). Formal support systems typically include those governmental and voluntary service agencies that are equipped to provide professional health and social services to a community's elderly residents (Branch and Jette, 1983). Informal support, on the other hand, may be received from the informal or social network which is typically comprised of some combination of family, friends and neighbours.

We assume that the effectiveness of help received depends partly upon how the integration of formal and informal sources takes place. A further motivating factor is our hypothesis that the helping capacity of the informal support network is influenced by the degree and the way in which formal sources of help are used.

In keeping with the imposed space limitations upon the discussion, the empirical materials that follow will deal with just one type of help -- that received with housework. With regard to this subject, the 1985 General Social Survey questionnaire asked respondents whether they received any help with housework, and if so who provided the help and how frequently. Those reporting the reception of such help were also

asked whether they thought they were unable to do without the help they said they received.

Our central hypothesis is that, even after taking into account the effects of measures of other variables specified in our model, meaningful variations in the intensity of use of formal services for help with housework arise from inter-group differences in use of informal sources of support and in the composition of and frequency of contacts with potential informal support networks.

Important qualifications

Before proceeding further, two qualifications deserve to be stated. First, in many cases the actual delivery of social services involving personal-time expenditure is made by individuals, whether the source is deemed to be informal or formal. Either source may be faced with substantial problems in harnessing and retaining minimally adequate supplies of suitably trained, motivated and experienced persons to deliver the services in question. It should not be assumed that by merely pointing to "formal supports" one has indicated a secure source of the human resources needed for service delivery.

Second, it is important to distinguish between an informal network and informal support, the latter reflecting a type of resource or activity which

may follow from interactions or relationships in the informal network (Cantor, 1975). Wellman (1981) provides a similar distinction between social networks and support networks, suggesting that social networks are multifaceted phenomena in which not all relations or exchanges between individuals may be viewed as supportive. Rather, some influences can be perceived as supportive while others are not (for a similar argument see also Gallo, 1982; Rundall and Evashwick, 1982; and DeWit, 1986).

The general model

Our general model, Figure 1, asserts that the primary and immediate causes of resort to formal sources for services related to activities of daily living are to be found in aspects of persons' functional, health and socio-economic statuses. However, the impacts of these variables are mediated in part by the extent and pattern of usage of help from the informal support network.

The usage of informal supports depends, in this model, upon the composition of the support network and upon pertinent cultural values and interaction patterns that tend to be maintained within the network.

In making operational our measures of aspects of use of help from informal sources, particular emphasis has been placed on the receipt of informal assistance with housework from each of close kin (spouse and children), other relatives, and friends or neighbours.

The frequency of contact with members of the informal support network is another key aspect of the relevance of informal support sources. We measured, using the GSS database, frequency of contacts with members of the potential informal support network -- spouse, children, other relatives, and close friends.

Methodology

One way to assess the predictive utility of the model, as we apply it, is to compare it to a 'blind prediction' model in a contest to see which fits the data better. The "blind" prediction model simply asserts that in every population sub-group we will have the same frequency distribution of use of formal sources for help with housework, among those who did get help with housework. The alternative prediction is that each population sub-group will have a frequency distribution of using formal sources for help with housework that depends upon its composition with regard to the variables that are key factors in explaining the propensity to use formal sources. Just how this alternative prediction was done for this paper is outlined in the text and described technically in an appendix to the full version of this paper.

**Figure 1
The Model**

- Health and functional statuses
- Income
- Education

- Cultural background (e.g. religion, ethnic origin)

- Age
- Gender
- Marital status
- Living arrangements

Formal organization service use

Usage and other aspects of informal support networks

Value system and interaction patterns within the informal support network

Composition of the *potential* informal support network

Composition of the informal support network

Findings

The model outlined above, when operationalized using the definitions and procedures explained in the full version of this paper, achieved a nearly 84% improvement over "blind prediction" in accounting for the frequency distributions of several population sub-groups with regard to use of formal sources of help with housework.

The numbers in Figure 2 are components of this 84% figure. (Arrows that have no numbers beside them were not included in the fitting of the model for the present paper.) The numbers shown in Figure 2 add to about 100% after we include the gain in predictive accuracy that the variables mutually share. Those numbers are, in effect, measures of the statistical strength (not the same as the causal strength) of selected terms in accounting for the gain in predictive accuracy that the model achieves over "blind" prediction.

Direct effects of disability and cultural background account for only 9% of the gain in predictive accuracy achieved by the model. Keep in mind, however, that these numbers arise in an exercise of statistical accounting for "cross-sectional variation".

Household composition and gender have strong direct association with the improvement of prediction accuracy (the former contributing 37% of the improvement, and gender claiming another 15%). Both of these variables are indicators of relevant aspects of the actual or potential informal support network.

Charts 1 to 5 provide information about the patterns of association that one finds with regard to some of the key variables noted above. There is time to only touch briefly upon what these charts illustrate. (Also, for related discussion see Stone, 1988, Chapter 3.)

Chart 1 shows that women aged 55 or more had a higher rate of use of organizational sources for help with housework than did men. For example, 17% of women's reports of receiving help with housework cited at least weekly help from organizational sources, while only 5% of the corresponding reports from men did so. No doubt, this differential was related to the male-female variation in age structure and marital status.

Sex difference in marital status is also a big factor behind that major male-female gap in rate of getting help with housework from one's spouse, as shown in Chart 2. Among older men, some 88% of the citations of getting help with housework were references to their spouses, while the corresponding figure was only 41% for women. The vast majority of these men were married, in sharp contrast to the women who had a substantial

Figure 2
**Variables and Selected Results in an Application of the Model**

(Only those whose names are preceded by • were actually involved in the application.)
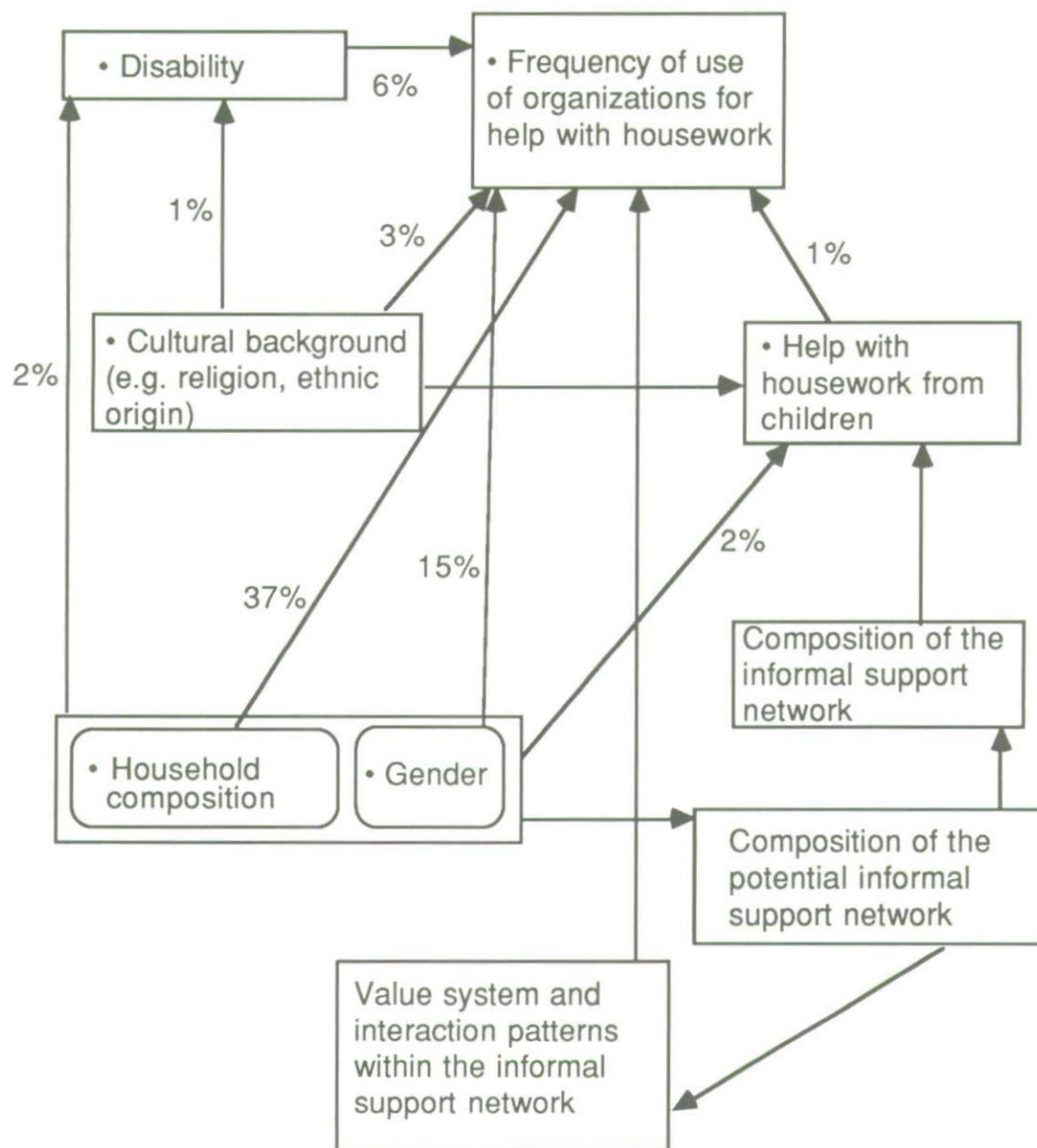
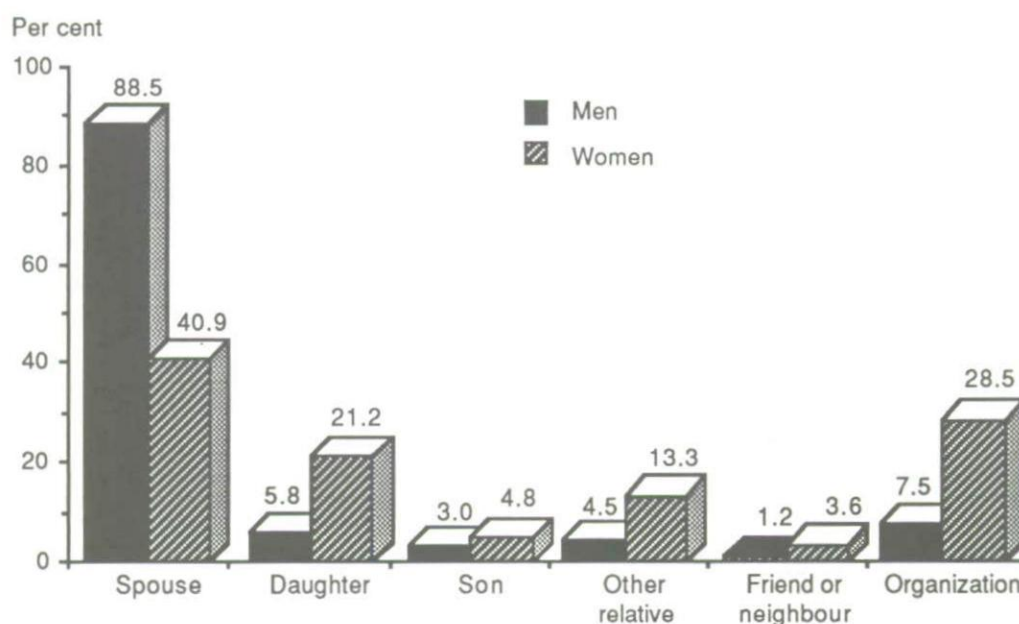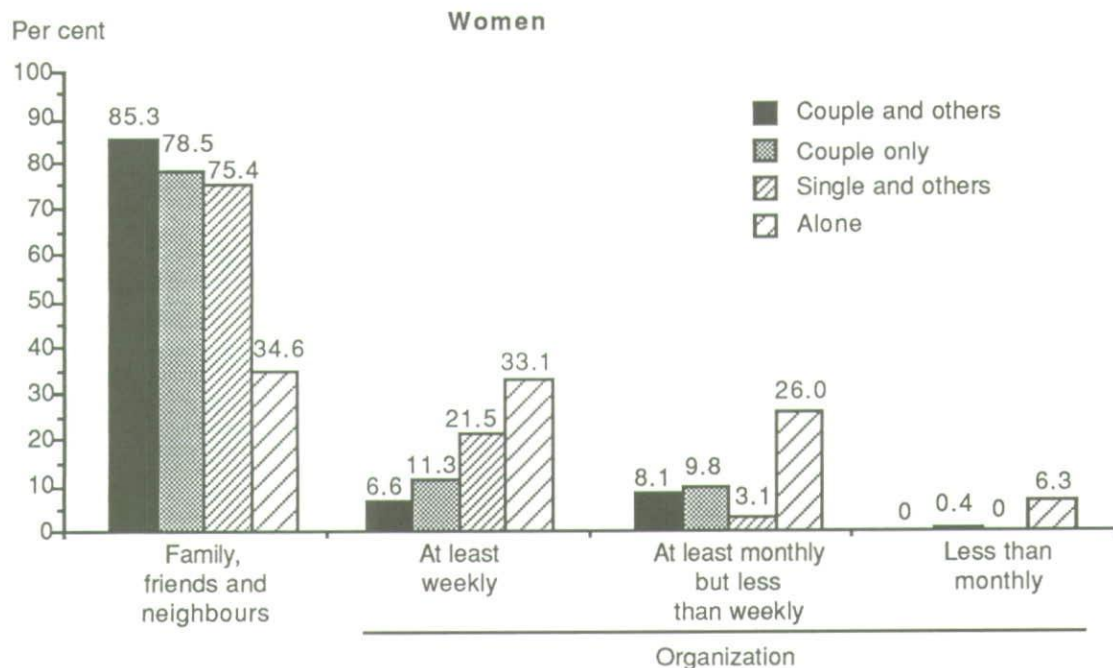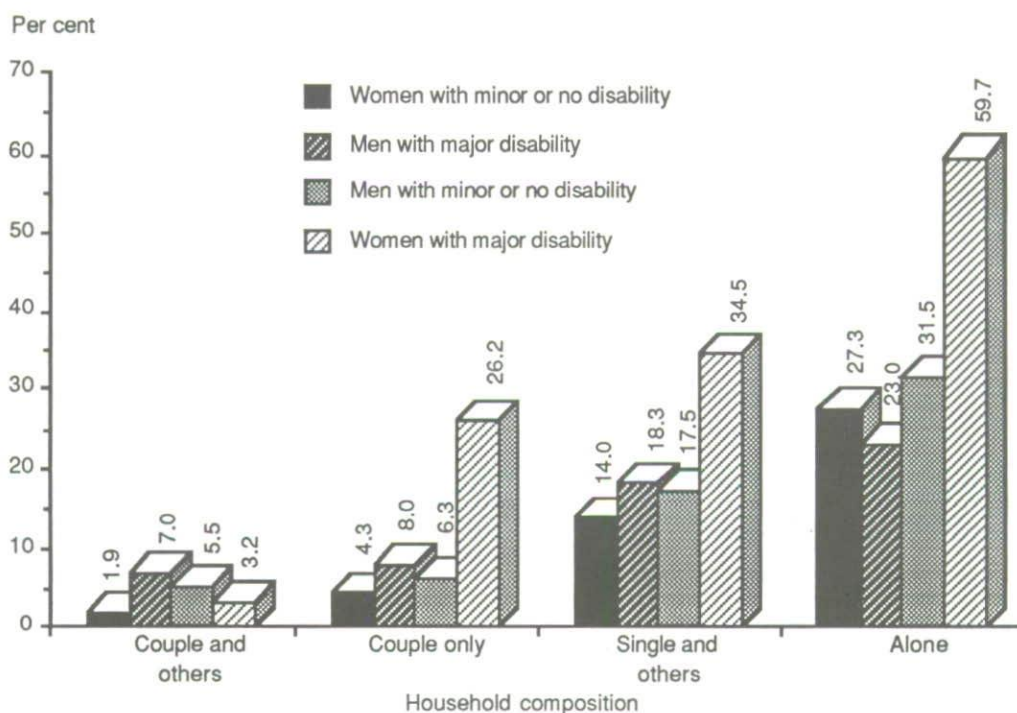**Source:** 1985 General Social Survey.

Chart 1
Relative Frequency with Which Alternative Sources of Help with Housework Were Cited, Persons Aged 55 and Over Who Said They Received Such Help, by Sex, 1985 General Social Survey, Canada

Per cent
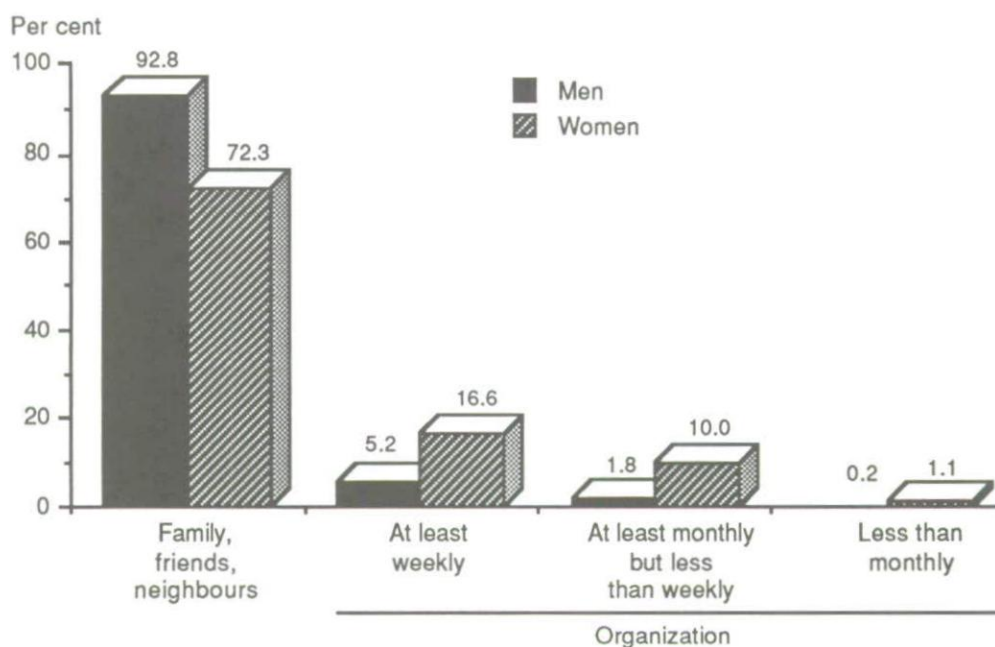
Note: The "organization" source is broken down into three frequency categories. It is possible to show these categories for the "family, friends, neighbours" source.

Chart 2
Relative Frequency with Which Alternative Sources of Help with Housework Were Cited, Persons Aged 55 and Over Who Said They Received Such Help, Showing Detailed Sources, by Sex, 1985 General Social Survey, Canada

Per cent

Source: 1985 General Social Survey.

Chart 3
Relative Frequency with Which Alternative Sources of Help with Housework Were Cited, Persons Aged 55 and Over Who Said They Received Such Help, by Sex and Household Composition, 1985 General Social Survey, Canada

Women

Per cent

Legend:
- ■ Couple and others
- ▨ Couple only
- ▨ Single and others
- ▨ Alone

Family, friends and neighbours: 85.3, 78.5, 75.4, 34.6

At least weekly: 6.6, 11.3, 21.5, 33.1

At least monthly but less than weekly: 8.1, 9.8, 3.1, 26.0

Less than monthly: 0, 0.4, 0, 6.3

Organization

Men

Per cent

Legend:
- ■ Couple and others
- ▨ Couple only
- ▨ Single and others
- ▨ Alone

Family, friends and neighbours: 97.5, 94.3, 84.7, 39.9

At least weekly: 2.3, 4.4, 13.7, 30.0

At least monthly but less than weekly: 0.3, 1.1, 1.4, 29.4

Less than monthly: 0, 0.2, 0.2, 0.6

Organization

Source: 1985 General Social Survey.

Chart 4
Relative Frequency of Reports of at Least Weekly Help with Housework from Formal Sources, Persons Aged 55 and Over, by Sex and Rated Level of Disability, and Household Composition, Canada, 1985 General Social Survey

Per cent

Legend:
- Women with minor or no disability
- Men with major disability
- Men with minor or no disability
- Women with major disability

Values shown on bars:

Couple and others: 1.9, 7.0, 5.5, 3.2
Couple only: 4.3, 8.0, 6.3, 26.2
Single and others: 14.0, 18.3, 17.5, 34.5
Alone: 27.3, 23.0, 31.5, 59.7

Household composition

Note: The relative frequency is a percentage of the total number of sources from which respondents said they got help with housework. The survey questionnaire allowed a person to list up to nine different sources of such help, if he or she said any help was received.
Source: 1985 General Social Survey.

percentage of widowed persons in their midst (see Stone and Frenken, 1988).

This factor is also important in explaining the heavier use of children, other relatives and organizations for help with housework among older women.

Living alone tends to sharply increase the rate of use of organizational sources for help with housework, as is shown in Chart 3. The frequency of citations of weekly usage of organizational sources for help with housework goes upwards steadily as we move from couples, to single persons living with others, and finally to persons living alone.

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Chart 5
Relative Frequency with Which Alternative Sources of Help with Housework Were Cited, Persons Aged 55 and Over Who Said They Received Such Help, by Sex, Level of Disability, and Reception of Help with Housework from Their Children, 1985 General Social Survey, Canada

Men

With major disability, and no help with housework from children	0 / 9.5 / 14.5 / 76.1
With major disability, and some help with housework from children	0 / 0 / 0.6 / 99.4
With no or minor disability, and no help with housework from children	0.2 / 1.9 / 5.4 / 92.6
With no or minor disability, and some help with housework from children	0 / 0.9 / 3.0 / 96.2

Women

With major disability, and no help with housework from children	0 / 7.7 / 41.3 / 51.0
With major disability, and some help with housework from children	0 / 5.1 / 2.9 / 92.0
With no or minor disability, and no help with housework from children	1.4 / 12.2 / 21.3 / 65.0
With no or minor disability, and some help with housework from children	0 / 3.1 / 1.8 / 95.1

Legend:
- Organization, less than monthly
- Organization, at least monthly
- Organization, at least weekly
- Family, friends, neighbours

Source: 1985 General Social Survey.

Chart 4 shows what seems like a big sex differential in the impact of major disability upon frequent use of organizational sources for help with housework. Among men there is only a slight difference between those with major disability and those with at most moderate disability in frequency of reporting weekly use of organizational sources for help with households. A much wider difference between the two disability categories is indicated for women, with much more frequent reporting of heavy use of organizations for help with housework among women who had major disability. This sex differential arises partly from age structure difference between older men and women. Notice that marital status is partly controlled in Chart 4.

Help with housework from kin other than spouse, and especially from children, was also associated with lowered reporting of resort to organizational sources for such help. This is shown in Chart 5, where level of disability is held constant. This chart shows notable rises in reporting frequent use of organizations for help with housework for those with major disability who got no help with housework from their children, with the pattern being especially strong among women.

Similar, but less striking profiles would be shown using data on help with housework from other relatives and from friends (excluded here only to conserve on space).

Concluding comment

To sum up, both contact with close kin and contact with friends were significant predictors of the use of formal housework services in this cross-sectional analysis. Greater than average help received from the informal support network tends to be associated with lower than average use of formal sources for help with housework, if level of disability is held constant. It is important to note that if level of disability is allowed to vary, then increased disability may bring about higher levels of use of both formal and informal supports for help with housework.

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Responses to the Papers in Chapter 5

Maria de Wit

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Since my expertise is in the field of child care, I am going to limit my remarks to this field, and I would like to talk a little more about the budgetary problems that exist and tie this idea into some of the comments that were previously made.

One of the questions raised in the paper I received from Leroy Stone had to do with the volunteer aspect of child care. Interestingly enough, the largest group of volunteers in child care, up to the recent past, has been the employees of child care centres. I started in child care in a cooperative child care centre, and I did more volunteer work than paid work while I was employed with the centre.

The current problem in the field of child care is that employees believe the policy announcements made by the federal and provincial governments and in our case, the municipal government as well, suggesting more commitment to child care and improved funding. This has resulted in staff volunteering less and a need to identify potential volunteers. This increases the funding dilemma for child care centres.

Howard Clifford said there were basically two things that influence the child care system, eligibility for subsidy and the growth of the subsidy system. I will address this restricted to the Ontario scenario since I know it better than the Canadian reality. The total budget for Child Care in Metropolitan Toronto in 1989 is $109,000,000. The Province of Ontario contributes an additional $16 million Direct Operating Grant for salary improvements.

When the Province of Ontario introduced the Direct Operating Grant last year it was anticipated that the balance of expenditures in child care programs would not exceed 4.5%. In reality, a shortage of Early Childhood Educators occurred at the same time as the introduction of the grant and the budget requests increased 12.4% over and above the funding base and the amount of the Direct Operating Grant.

Salaries for day care teachers have increased in three years from an average of $13,000 to approximately $18,000. The workers receive an additional $3,000 from the Direct Operating Grant which parents do not need to absorb in their daily fees.

We have 30,000 licensed day care spaces in Metropolitan Toronto today and approximately 19,000 of these are subsidized, approximately 80% fully and 20% partially. The full fee

population in the other licensed spaces is decreasing due to affordability. Parents may not be eligible for subsidy and yet unable to pay the full costs.

Our municipality has a user driven system for subsidized child care rather than a provider driven system. In the past, each centre was guaranteed a certain number of subsidized spaces and families accessed subsidized vacancies. Metro Toronto revoked this system and replaced it with parental choice. A family approved for child care subsidy is entitled to enroll their child in any centre with a licensed vacancy.

The demand for subsidized child care far exceeds the financial commitment from all levels of government and to ensure an equitable system it was agreed by our Municipal Council that admission would be based on a "first come, first served" basis. The provincial government was concerned about this approach, however our findings conclude that the mix of service is similar to when single parents were the first priority.

In response to volunteering at licensed child care centres, this is very limited on a day to day basis. However, the Province of Ontario's preference is for parent run child care centres. This results in numerous parental hours of contribution even though it is extremely difficult and demanding. Sixty-five per cent of

users are single parents on low income who cannot afford babysitters to participate actively. The other 35% are made up of a mix of two-parent families: low income -- immigrants -- families on Social Assistance already under stress.

There are, of course, untapped volunteer resources but without some funding assistance we may never see them actively participate in child care programs. East York, for instance, has an extremely high seniors population but they would need assistance with transportation. The funding for child care is totally dependent on a subsidized child being enrolled in a space, so where does the transportation money come from? If you assume that the centre provides the transportation, you may wish to provide the hot meal (a creative alternative to Meals on Wheels) but how do you access the necessary funding? Add to this the dilemma already identified by Mr. Clifford re liability insurance and the pattern of funding complexity increases. This is without adding the additional worry of what is a taxable benefit and what is not, i.e. the seniors meal, is it free?

Another group constantly identified as a valuable resource is teenagers enrolled in family study programs. How do we create a formal link that provides the students with credits and at the same time improves their future parenting skills? There is never a funding source for co-ordination of services.

Another dilemma around funding was mentioned by Diane Richler during her presentation. Our municipal government supports integration and this is also supported by the provincial government. Since 1981, our municipality has introduced integration of handicapped children into directly operated centres at the cost of $1 million dollars annually. This expense was to be funded through reallocation of expenditures in segregated programs but to date the Province has not reallocated the dollars and the municipality has funded the program at 100%.

I cannot end with many solutions. Howard Clifford presented four suggestions and I would suggest only one more -- that we find ways of funding creative initiatives in a simplified format without paper work overload which can only be handled by large agencies since this undermines small creative community projects.

Betty Havens
Provincial Gerontologist
Manitoba Health

I think the major task in trying to develop what to pass on as comments is how to restrict it, because every time I thought of something that one paper raised, I thought of applications across all of the other areas. I am torn between sticking to aging, which is obviously the area that I know best, or trying to make some cross comparisons. There is a bit of both in my remarks.

Initially, let me identify the area that picks up rather nicely from what Maria de Wit was saying. The budgetary problems are not restricted to day care. I think all areas will indicate that funding is a problem.

A related aspect is an area where we do not have enough information. The present data are not sufficient but I think the data could be made available rather easily if we used a little imagination. That is, we do not know the impact of block grants generally and we do not know the specific impact of block grants on access. It does not matter whether you are talking about day care, handicapped services for the physically, mentally, or sensorially handicapped, or about aging programs. In the health care areas, we do not know what the impact of block grants is on access, which should be relatively easy to determine. We desperately need that information.

We do not know, in another context, who the volunteers are and the programs in which they are involved. We do know the answer to that question within a single program. For example, we know who the volunteers are in child care, if we are working in child care. We know who

the volunteers are in the case of AIDS patients if we are working in the field of AIDS. That is, we know the volunteers in our own field; but we do not know how much crossover there is. I strongly suspect from what I see in my own community, that many people are volunteering in two or more of these areas, while others are not volunteering at all. However, we cannot prove that because the data are part of the missing information which I would hope we would begin to collect very quickly.

We do not have an accounting system that accounts for volunteerism, in any reasonable manner. That is, we do not account for volunteer hours through any system of health accounts, social accounts, national accounts or income tax accounts. Until we have that kind of accounting to tell us what volunteering means to the system, we cannot know what we must know about either the capacity of volunteerism to be developed further, or the capacity of agencies to provide additional services. All we know, and that to a very limited extent, is the impact of volunteering on the volunteer. We also have some limited information about the impact of volunteering on specific agencies. We do not have an overall view of volunteering, and in my opinion we are desperately in need of this broader information. Therefore, this is an area which we need to develop much more.

In terms of multiple roles, the paper presented earlier on women's roles, based on data taken from the General Social Survey, is a beginning to something rather interesting. The paper presented four roles. I do not know, but would ask, how many more roles you can add before too many roles become emotionally too much. I am also not sure whether care giving within the parent role, or care giving within the child role, means two roles or one role. I do not think we have adequately sorted out that differentiation. I do think we have the beginning of some information relevant to these issues within the General Social Survey.

There are some studies, but we need to bring them all together to determine how many roles we are talking about and the composition of those roles. Does role accumulation continue to be functional forever, or does it, at some point, become role strain? Are there only certain roles that lead to role strain, and others that never do? There are a whole series of questions which relate to the capacity to be a care giver, regardless of what kind of care giving, the capacity to be a volunteer, regardless of where you are volunteering, and how many multiple volunteering roles may, in fact, be too many.

We have heard about volunteer burn-out, which is another issue about which I am terribly concerned. One of the things that no one has mentioned

is, what it means to be able to develop volunteerism in this "community" that we have all been referring to, without having staffed a community development approach. I go back to the old school of community development. That concept is heavily volunteer based, but always with some paid staff to deal with those volunteers. Popular terms for such staff today are volunteer coordinators, resource coordinators, care coordinators, case coordinators. I do not care what you call them. The point is, we are really talking about dealing with vulnerable people. When a person is vulnerable, and his or her support system is being strained or is also vulnerable, that is the least appropriate time to add the task of coordinating volunteers or paid staff to that burden.

You cannot simply say that we have lots of volunteers and therefore they will be effective, unless there is some mechanism in place to use them appropriately. And yes, I think we use volunteers; but I also think we use paid staff and that we use ourselves. I do not use "use" in a negative sense. What I mean is that all of those people have to be able to work together.

The "all or nothing" issue which was raised earlier in terms of the mentally handicapped, was raised again a few minutes ago in terms of segregated versus integrated services. I would just raise one question and that is, at what point do we no longer have to worry about integration? There is

some point at which integration is no longer an issue. I am not sure whether it is when you reach 25% or 40%, but there is some kind of a "critical mass" or "critical point" when integration has happened. I do not know what that point is, and I do not know if it is the same in all fields. Therefore, I think we need to continue to study that. The paper by Leroy Stone and Margaret DeWit, relative to 35% increased predictive accuracy derived from household composition, brings the same issue into focus from a different perspective.

We are all talking about the areas of volunteerism, partnerships, and coalitions. The volunteer of one system may be the client of another system. That is fine, but let us put mechanisms in place to account for that, to learn what it is with which we are dealing. It is my opinion that we do not know that with which we are dealing.

Marcus J. Hollander
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The question of how good quality, and relevant, information can best inform decision making in health and human services has been of interest to me for some time. In his pre-luncheon address, Ian Stewart pointed out the gulf, one might even

call it a chasm, which exists between three key groups: the academic or scientific community; the active social community or service delivery sector; and, government. I would also add a fourth component, that of the actual and potential service recipients.

Dr. Stewart also called on us to look at the big picture, to look at how we got where we are, and to ask what are the critical underlying concepts and tensions, such as centralization versus decentralization, which frame our thinking about the delivery of human services.

If we are to harness and integrate human and financial resources in the provision of community supports, the theme of this session, we shall need to look at how bridges can be built over the chasms that divide academics, service providers, government, and consumers. One of the ways to do this is to bring these groups together so that a constructive dialogue can begin. This symposium serves such a purpose.

In commenting on the papers presented in this session, I shall address conceptual, methodological and analytical dimensions. I shall conclude by making a few additional comments on the question of how we can best integrate research and service delivery to provide more efficient and effective community supports.

Howard Clifford, in his paper on budgetary problems, alludes to a number of fundamental questions regarding the funding of human services. Margaret Duckett and Diane Richler also raised some of the same kinds of questions. I would like to highlight some of these questions, and to put them forward for discussion during the general discussion period which will follow. What I am going to comment on are, in fact, major policy questions, but I believe that they are also amenable to empirical analysis.

In discussing social work oriented day care programs, Mr. Clifford notes that some agencies have higher costs because they include an early intervention and treatment component and that this so-called cost problem reflects a difference in perspective between service deliverers and funders. This is reflective of the larger issue of the nature of the accountability relationship between funders and third party providers. To what extent should funders determine the policies and operating procedures of service deliverers? Who speaks for community needs and interests, provincial governments, or local community leaders, and, on which issues? What are the advantages and disadvantages of various forms of funding human services such as direct payment, tax expenditures, the use of third party providers, direct service delivery by government staff, and other such arrangements.

Another question that is raised is whether or not agencies can receive money from sources other than the main funder, usually the provincial government. How is the service delivery system affected by such actions? Will allowing agencies to obtain supplementary funds eventually lead to a cost-shift from provincial governments to municipal governments and charitable organizations, and ultimately, to the consumer and if so, how will this affect service delivery and service access?

Mr. Clifford also raises questions related to the mechanics of funding systems such as the use of caps on maximum individual subsidy levels, and ceilings on total allocations to regions. Are such caps compatible with line item budgeting or are they more appropriate to resource allocations based on average cost factors such as the Diagnosis Related Groups, or D.R.G. funding system used for hospitals in the United States? What are the implicit incentive systems in these various forms of budgeting, and how do they, in turn, affect service delivery?

In his discussion of surcharges and salaries for service providers, Mr. Clifford raises the ideological question of the appropriateness of market forces in the delivery of services and in compensation systems. Should government commit scarce resources to increasing salaries of people who are

underpaid, or use the same funds to purchase more services? Empirically, how does compensation affect service delivery with regard to turnover rates and service quality? What information can assist decision makers in making choices between the cost-effective purchase of services and the competing goals of equity and social justice for the workers who provide the services?

Finally, in the discussion of the number of spaces per day care provider, the question is raised of how pro-active funders should be in promoting amalgamations and mergers of existing service providers to allow services to continue to operate, and to reduce unit costs? All of the questions raised by Mr. Clifford's paper are critical to the area of the financial management of human services, an area which deserves considerably more study, in Canada, than it has received to date.

The papers by Mia Elfenbaum and Nancy Kingsbury, and, Leroy Stone and Margaret DeWit, can be understood as investigations which, by looking at factors affecting service need and service demand, assist in decision making regarding the patterns of resource allocation.

With regard to the paper presented by Mia Elfenbaum, it would be interesting to empirically analyze the extent to which the findings in this paper reflect the underlying concept of the social valuation of roles such

as the worker and the homemaker. It may be that the findings in this paper are reflective of a larger relationship between health status and concepts of self-esteem, and other such valuations of self. I also have a question about the conclusion of this study, that role accumulation theory is supported by the data when employment, one role, is such a high predictor of health status. It may be useful to re-analyze the data by looking at all possible combinations of the four roles discussed and the relation of each to health status in order to provide a more contextual analysis of the data.

With regard to the paper by Leroy Stone and Margaret DeWit, which was presented by Forrest Frankovitch, it intuitively seems to me that disability should have been a significant predictor of the use of formal services, and I would invite them to comment on this matter later. I would also suggest that it might be useful to conduct some supplementary analyses which disaggregate males and females by marital status. Another larger question raised by the study is how does overall resource allocation affect the distribution of formal and informal service use? Who would get what types of formal services if the budget was doubled, or was cut in half, and what decision rules would service providers use under differing resource availabilities?

Finally, with regard to methods of bridging the gaps which exist

between the main constituent groups in the analysis and delivery of human services, I would suggest that each group reach out its hand to its other partners and support new ideas that cut across existing barriers. For example, it may be useful for research agencies such as Statistics Canada, N.H.R.D.P., and provincial research granting institutions to more actively pursue a dialogue with other groups, particularly with key decision makers. This would assist in identifying the kind of information that will, in fact, assist in making policy and resource allocation decisions. When policy relevant studies are identified, perhaps research granting agencies could hold special competitions to fund such studies.

In general, I think that asking the right questions is a very important part of this whole enterprise. If researchers and service providers can get together to conduct relevant applied research, which may not contribute to the advancement of theory, a vehicle for the dissemination of such results should be available. This could take the form of new journals of applied research and analysis.

Service funders may wish to consider the development of new centres of excellence where academics, service providers, government, and consumers can come together as equals to discuss relevant issues, formulate key questions, and conduct research. There are many other possible initiatives, but the key requirements are the development of

legitimacy and support among all sectors for new initiatives and ideas that cut across traditional boundaries. This symposium has been a solid step in that direction.

John Angus MacKenzie
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In following yesterday's presentation on the evolution of self-help initiatives, with and without any form of government support, and in reflecting on Dr. Ian Stewart's comments on the impact of the reports like the Beveridge Report, the March Report, the Rowell-Sirois Report, and how they affected the evolution of social policy in Great Britain, in Canada, and elsewhere, I could not help but wonder why these reports had such a profound impact on the evolution of social policy for so many years, while many other very good reports (no doubt based on very good research) bore such little fruit as vehicles of social change. Having made this observation, I have no doubt that the reasons are many, and are beyond the scope of this symposium. Nonetheless they do bear thinking about.

At the same time, I suggest we need to bear in mind the tremendous importance of self-help groups in the evolution of social policy. When one looks at the evolution of social policy in this country, by and large, it has been incremental in nature. What usually happens is that a particular group emerges, captures the attention, the imagination, and the sympathy of the Canadian people, as a group with special needs, requiring special attention, and having a legitimate claim on public funds. This process is easily discernable when we look at the history of social welfare as it relates to such groups as the aged, the blind, and the disabled, widows, et cetera. A particular group with a particular set of needs captures the attention and the imagination and the sympathy of the Canadian people, and a new social program is born.

For each of these groups, the initial step in legitimizing their need for special consideration was the establishment of self-help groups to provide assistance and support to each other, but also I would suggest, to publicize and politicize the group situation, and in so doing, to foster the next step in institutionalizing society's response through funding and/or legislation. The problem, at least as I see it, in the provision of adequate child care and adequate care to the elder population, is that society cannot make up its mind when it gets beyond the most needy.

The situation is not helped by the paucity of information on child care arrangements which affect family members, friends, and neighbours. Much of what we hear relates to

standardized stand-alone day care centres funded or cost shared under the Canada Assistance Plan. Those who have been involved over the years on the firing line know that this form of day care represents a very very small part of the total package of child care arrangements in the country.

The simple fact of the matter is that harnessing and integrating human and financial resources in the provision of community supports in the context of child care must allow for the recognition and support of diverse yet effective child care arrangements, because they're there, and they're going to remain. And in many respects, it's good that they're going to remain.

Again, in reflecting on yesterday's and today's sessions, and in particular, Andre LeBlanc's rather strong comments on the failings of researchers, I couldn't help but to be reminded of some of the discussions I have had with ministers over the years, who continually bemoan the fact that researchers seem to be tied up in detail, in very limited fields of study, while they need advice on the more general issues, the more general concerns, and how to address them. Again, politicians complain that by the time the researchers come to realize there's a problem, define the problem, look at the methodology that's required, carry out the research, and put a report on the table, many steps have been already taken by

governments in addressing the problem -- steps which for governments are often irreversible, at least in the short term. The pressure is on and it's often not possible to wait for the long-term research although such research may be needed. Governments, in response to strong pressure groups often commit its hand early, and sometimes irrevocably.

Again, André's comments point up the fact of how quickly the Canadian mosaic is changing. The reports of the last few days bring this out and reinforce it. And yet I can't help but think as I listen to some of the presentations that we are still holding on to yesterday's assumptions about today's realities. For example, what constitutes a family? When we talked about child care needs, the matrix was interesting in that it pointed up the fact that the traditional family I grew up in constitutes a very small percentage of today's families.

Again, the matrix starts to break down in the world of reality, as it relates to the needs of seniors in areas like recreation. Our perceptions of where seniors are, in terms of recreation, I'm afraid, are far from reality. This becomes readily apparent when one gets out into the little country areas to visit seniors' clubs and councils, one is faced with a noticeable change in their programs. What started as a kind of a social gathering to deal with isolation, et cetera, under a federal New Horizons grant 10 years ago,

has gone on to provide service and to develop intergenerational initiatives. Again, one must question the extent to which our personal biases serve to create needs or expectations, and the extent to which we really are identifying and tracking real changing needs in our research and in our self-help efforts. This morning's paper on the relationship of women's physical health to multiple roles and employment begs a number of questions of relationship among the variables highlighted, which I suspect are not fully addressed in the research.

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

In the interest of time, I will restrict my comments to just two of the papers that were presented this morning, the paper by Elfenbaum, and then the one by Stone and DeWit. First of all, the Elfenbaum paper focused on the relationship between women's physical health and their employment status, and addressed an extremely important topic. Women's changing employment patterns over the past 20 years in Canadian society have had a major impact on many of the issues that we've been addressing in this conference -- issues of day care, issues of the provision of volunteer services, and social support in relation to the aged.

Particularly in the relation to population aging, women's employment is important for several reasons. First of all, we know that women by and large are the care givers. And the research has consistently told us that. For every one person living in an institutional setting, we know that there are two people with the same level of disability who are living in the community. And we know that that's possible largely because of the efforts, and the active involvement, of women: primarily in their roles as daughters, but also in their roles as sisters, as wives, as nieces, and as friends. Carolyn Rosenthal's research and Ben Gottlieb's research have confirmed that in the Canadian context.

Despite some of the initial concerns of social gerontologists that one impact of women's employment would be a reduction in these care giving roles, there is evidence that these roles are still being continued, often supplemented with formal services, in spite of the potential for role strain and role overload. Particularly in that context Elfenbaum's paper is an important building block in our understanding of the relationship between women's employment and physical health.

What I would like to suggest are some further directions we might take in the analyses of data on this important question. For example, we really need to focus not just on physical

health but also on mental health issues. There is certainly much evidence, particularly in the U.S., on the stress related impact of the multiple roles of women. These stresses may not manifest themselves in indicators of high blood pressure or diabetes, as diagnosed by a physician. It would advance our understanding of a complex issue if there were available data on mental health in relation to women's employment status.

For example, the impact of multiple roles may manifest itself in job stress, job turnover, absenteeism, and tardiness. And we know these are particular issues in relation to women's employment. John Myles raised a very important issue this morning in the question period about the role of employers, and the potential for initiatives like employee assistance plans, flex time, job sharing, and all of those kinds of programs in recognizing issues of job responsibilities and competing familial demands.

Given the changing profile of Canada's population, and the fact that we are facing a future with an inversed population pyramid in terms of the pool of potential workers in our society, we will need more women employees. We won't just have to accommodate women in the workplace, we will need them in the workplace. So these issues will become particularly important, and that's why the investigation in the Elfenbaum paper is quite timely.

But we really have to focus more explicitly than does Elfenbaum's paper on the impact of the multiple roles performed. For example, Elfenbaum's finding of the higher levels of physical health among homemaker women who had been in the paid labour force in the past may well reflect the reality that an estimated thirteen percent of women (in one U.S. employee survey) left the paid labour force because of the stresses of combining work and family care responsibilities, both child care and elder care. There have also been recent documents put out by the Women's Bureau at Labour Canada, and the Canada Employment and Immigration Advisory Committee looking at issues of how employers might involve themselves in relieving those stresses.

I think an alternative explanation to the one offered by Elfenbaum in the analysis of the G.S.S. data may be that formerly employed women report higher health not necessarily because they derive health benefits from having been employed, but because they evaluate their self-reported health so highly, relative to what it was when they were combining multiple roles. They may now have much less need than previously to have disability days.

They also may have more economic resources, and we could get into that; but there are a whole range of alternative explanations.

It is also possible that some of the results reported by Elfenbaum would differ substantially if the independent variables, that is total number of roles, was measured differently. Recall that the parent role is defined by Elfenbaum as having at least one child living in the household. And the child role is defined as having at least one parent living in the household. These definitions, I believe, may well reflect an underestimation of the involvement of these women in multiple and potentially competing roles. Some of the women in this study who were defined as not performing the child role, for example, might well be very actively involved in providing care to an aged parent who lives down the block, around the corner, in the next town. Indeed, the fact that the elder parent doesn't actually live with the adult daughter may potentially complicate rather than reduce the child role.

In addition, some of the findings about unemployed homemakers, and their levels of health, I think, may also reflect the fact that poor health was a factor in predicting whether women would enter the labour force in the first place. These are all speculations on the interpretation of the data, and it will be wonderful if the G.S.S. data allow us to refine some of these measures, and explore these issues further.

Turning to the Stone and DeWit paper, which focuses on the use of formal and informal sources of support in help received with homemaking, this is another critically important topic. That paper is really reflecting the reality that the majority of the aged are women, and that with increasing age, the likelihood of living alone and being widowed increased substantially. By the age 75 to 80, approximately two thirds of all women are widowed. In some of the research that I have been doing on widowed women and men, where I was focusing on issues of how they would access help in 12 different hypothetical situations, many of the individuals I talked to felt that as they got to the point where they weren't able to maintain the home themselves that they would "go and get a homemaker". That consistently came up as a response, and the frequency of that response led me to examine the formal support services offered by visiting homemaker agencies, to question whether or not they are in fact as readily available as my respondents appeared to assume they were (and of course they are not).

There are all kinds of issues right now in Ontario in terms of the role of the visiting homemaker programs, and the fact that many of those services are in jeopardy, particularly in rural areas. So this whole issue of the formal provision of homemaker services is a critical one. Thus, the data in the Stone and DeWit paper

are quite important, because they allow us to analyze that issue in a variety of ways.

First of all, those data show us that those who do receive formal homemaker support truly do represent an at risk group. They are elderly women with a major disability who are not receiving help from children. The data also provide evidence of the active involvement of family in the lives of the aged, and they serve yet again to debunk the myth of abandonment by family in old age.

One thing I would have liked to have seen in the charts is a clear separation of the relative contributions of friends and neighbours versus family. It would further our understanding of the relative involvement of kin and non-kin in the informal support system if the charts were able to illustrate that more clearly in terms of exactly what the relative contributions were.

The Stone and DeWit paper also allows us to examine the theme of the integration of resources, which after all is one of our foci today. And what's implicit in those data, and what's recognized in a lot of research that has been done on the relative role of the family versus the bureaucracy -- is the fact that what bureaucracy does versus what family does are different kinds of things. The Stone and DeWit paper acknowledges that, but

focuses more on the issue of what family does in terms of the provision of informal support. It has an idiosyncratic response that often formal support cannot have. It provides services on days, nights, and weekends. It is based often on an intimate knowledge of the needs and resources, and personal strengths and attributes of the individuals. These are important distinctions between the bases of the formal and informal support systems.

The paper also focuses on non-kin, which Duckett's paper this morning indicated was so important. It recognizes the aged themselves as a resource, which we do not always see in research. This paper focuses on the function of spouses as supporters in tasks of daily living, and captures that sense of interdependence which is so important to our understanding of the processes of informal support.

The Stone and DeWit paper also allows me to express a final concern I have lest we take an "either/or" approach to this notion of informal/formal support. Several of the papers which I read, and ample other data, indicate that formal support does not supplant informal support. The provision of formal services does not necessarily interfere with what families, friends, and neighbours do naturally, or do best in some way. People do not abdicate their responsibilities because of the availability of formal

support. I would like us to go away from this session this morning with a real focus on the theme in terms of the issue of integration: the integration of formal and informal support. Let's acknowledge, as so much accumulated data repeatedly show, that formal sources supplement informal sources of support. They enable informal supports to do a better job of what they're struggling, and continue to struggle, to do.

David Cassidy
Montreal

I was asked only this morning to make some comments, so I am not as well prepared as my colleagues are. I am continually amazed at all the conferences I attend, and this one too on the issue of heterosexism. Everything is related to a particular community, and gays and lesbians, in particular, are left out. AIDS now forces us to deal with them. This morning we heard several comments about inclusion in services. Gays and lesbians, especially now in relation to AIDS, are demanding to be included in services being offered by various agencies -- public, para-public, and community.

To love and to be loved; I suppose that's a goal that each of us have, whether we are male or female, old or young, whatever ethnic

background we come from, whatever part of the world we come from. People with AIDS are no different. All they want is to love and to be loved.

I want to try in the next couple of minutes, to bring out some issues to explain where people with AIDS are coming from, and why you might be, or should be concerned for them. Let me give an example, and I hope no one from Statistics Canada is present. If an average male's life span is 75 years, now I'll just take that as an arbitrary figure. For a person diagnosed with AIDS at age 21, and the average life span of an AIDS person at this point is anywhere from 18 months to two years, and treatments of course, are changing that slowly, but we'll use that as a given. So by the age of 23, that 21-year old theoretically has to live 54 years. He has to put in all his life, everything that he wants to do, to think, to be, to go, not to mention all the issues of death and dying, all into that particular time span. So if they have difficulty trying to absorb all that, one has to look at it in that sort of context.

People do not necessarily look at it, people make judgements, lots of judgements. People with AIDS have enough difficulty dealing with the issues around death and dieing, but unfortunately are not allowed to do that; they are dealing with every one else's judgements. Judging whether it is a punishment, or whether it is a

disease, "you deserve it if you did that". All kinds of other judgement issues are raised until they withdraw. So they do not seek services.

Part of the problem of agencies, is trying to make sure that they can give services if they don't know where these people are coming from. If you are from a gay background, and you go to counselling from a person who is heterosexual, who has no concept of what a gay person is, they cannot give counselling. They are a danger rather than a help. Many agencies across this country are not equipping their staff to be able to respond to these people as they come through the door.

Adequate training programs are vital. It is very unfair to plop a person down and say: "I am gay, and I am dying, and I need your help in counselling". This counsel has absolutely no background, so you are not being fair to the counsellor, to say nothing of the person with AIDS that comes through the door.

Margaret Duckett mentioned about numbers and relation to people with AIDS over the next two years. It is my opinion that her numbers are conservative. But we will not really know until we get there. But if we accept a fact of 15,000 or larger numbers of people with AIDS demanding services, or say there are 300,000 people now that are walking around as carriers. If it takes 10 years, it could take even up to 20 years, we do not know yet, we have

not been around long enough, before this disease manifests itself, we are carrying a lot of time bombs.

These numbers will manifest themselves over a period of time, but we are not preparing ourselves to respond to those kinds of numbers. Ignorance, I suppose in some sense is bliss; but ignorance in this case is catastrophic. Let me give an example of kind of care, quantity kind of care. A nurse ordinarily, on each day she's in the hospital, gives four hours of care to a patient. An AIDS person demands 13 1/2 hours of care. There is just not physically enough time for a nurse to give. But that is the example of the kind of care that is needed. And any other kind of profession, whether it is social work, or so on, is facing the same kind of increased demands, but without the resources to meet those demands.

Since people with AIDS generally come from the gay community (at least in this country so far) and a lot of cases (certainly not all) are rejected by families, or at least limited by their families, the professional is the anchor. Whether it is the nurse or the social worker, he/she is the anchor in that person's life and may be the only person they see from beginning to end. So that professional carries an extremely large responsibility for this particular person.

We've created, in Montreal, a self-help group just for social workers to be able to talk to each other to deal with those issues. This is the self-help

we needed, and we've now done it with doctors as well. We've borrowed from seniors examples of pet therapy, for instance. People with AIDS need (because of their isolation) something to give them a reason to live. Pet therapy, as we've seen with seniors, has been very beneficial.

The whole health benefit has to be researched much more extensively. At Ville-Marie we've had foster homes for children, and foster homes for seniors. We've now just taken that example and made foster homes for people with AIDS, it's a pioneer program on the continent.

Let me leave you with a couple of thoughts. One, I suppose, is acceptability of services. We have to really look at our policies, as agencies, and see why people with AIDS, or gays and lesbians do not use those services, and then correct those things. We must make those services open. We all must try to really sit back and put our judgements to the side, and give our services without limitations.

The last idea, I suppose, is the whole issue of quality of life. People with AIDS have taught me in particular, but teach, I think everybody, a lot about the beautiful things that we don't see. We see everything, but we don't really see the beauty of a sunset, the beauty of a flower, they teach us to live each day at a time, and take from that.

General Discussion

Linking the family with formal supports:

Comment: I just have a comment in reaction to Dr. Matthews' discussion in relationship to the integration of formal and informal support, because the work that I do for delivering formal services to the elderly, Meals on Wheels is a very successful program. But in terms of delivering meals to the seniors seven days a week is really an impossibility. And so the family really supported this formal situation by supplying, really, brown bag weekend meals which really completed the picture. I really congratulate you in sort of pointing out the integration of both the formal and informal setting.

Importance of employers' policies:

Question: I have a question directed mainly at Howard Clifford, but I would like to begin with a comment or an observation on behalf of a group which has been left out of this discussion, not a disadvantaged group but nonetheless a group that has been omitted. It seems to me that we are using the words "community" and "community resources" in a rather limited way. We seem to talk about government, kinship systems, social service agencies, but I have not heard any discussion of another important part of the community which controls most of the resources in our

communities, especially our time, and that is employers. For some reason, when we use the word "community" we do not count employers in, and I think for a group like this, that is a real mistake particularly since most of the support givers in our community are people who are employed and that the critical issues concern the allocation of time, and employers, to a large degree, control our allocation of time. Just in that context, I was wondering if Mr. Clifford might comment on the extent to which public policy towards day care has taken into account employment policies both in terms of actual delivery of services, and also in terms of the work time of parents and the time they need for child care.

Response: I think your point is well taken. I will respond in two ways. First of all, there is a great deal of interest on the part of employers and unions, at the moment, in becoming more involved in partnership with providing day care services, as well as beginning to look at things like job sharing, and the kinds of job benefits that would focus on family values.
 Secondly, the problem that we have had to date in day care is that we have never really put the child first. No one in their right mind would say it is good for a child to be separated for ten hours a day. The only reason we have done so is because we have always felt we were a small minority, and therefore we could never expect the larger socioeconomic institutions

to change their patterns of expectations. But I think we are coming to that critical period in time where we will be looking at shorter hours of work, maternity leave, job sharing, and other similar issues. I think we are going to see a lot more of that and I am glad you have raised this point.

Improving parents' choices when they have child care needs:

Comment: I wonder if I could just add a further comment to what Mr. Clifford has said and to pick up on the point of public policy. One of the interesting things that those of us in the child care field have been concerned about is the whole question of parental leave. Both the Katy Cooke Task Force and the Parliamentary Special Committee looked at the issue of parental leave and were concerned about a number of the provisions under maternity leave as it exists under unemployment insurance. What was interesting was that those two task forces had a number of differences of opinion about child care, but one of the areas which they were in agreement with was the need to do something. Unfortunately, in the planning around the Child Care Act, which has not gone through, there was no provision at all for these changes, and so many of us are very concerned.

As someone who has worked in the infant child care area, I am very struck

by the fact that I feel that parents do not have enough choices. If we adopted some of the policies that one would find in some of the European countries policies (that provide for extended maternity leave, or parental leave, sharing, there are a number of ways of doing it), people would have a lot more opportunity to be with their children.

This becomes an issue as well in caring for sick children. We have a situation now where a number of employed parents take time off work when their children are ill, and as a result, they are in jeopardy of losing their jobs, or else their children are being brought to day care, and it is debatable whether the children should be there because of the whole problem of infection.

Presently we are looking at some day care projects in Ontario to see if we can develop programs to care for sick children. But those of us who are struggling with that, are feeling that it would be much simpler and less costly, if in fact employers were more accommodating.

I think there needs to be a lot more consideration of these issues.

Response: I could not help thinking that when you were saying parents who care for sick children that you were saying mothers who care for sick children. And as someone who has been interested in aging, the

impact on the life career of that kind of thing is not time bound, but impacts on the total life span.

Importance of attending to the factor of motivation:

Comment: Two comments about the terms "community" and "child care community" already discussed. The unity referred to in community is always created by motivation and motivation here is a sense of belonging engendered by love. Earlier in our discussion someone voiced reluctance to interfere in any way with the present condition of the Canadian family but all societies recognize the family as a people's basic community. I think we should strengthen and expand its role in every way possible with government, neighbourhood and church support.

The new budget presents us with economic strictures and a changing government policy towards our social services enforced by world monetary upheavals and our huge debt. The Israeli faced similar economic difficulties as they began to build their new state. They actually invented an original unit of economic productivity called the kibbutz where the needs of the community, of the family, and especially of the child, had precedence over profit. They required high productivity for survival and defence. But parents in the kibbutz with one child need work only seven hours a day to allow time for

the family to be together for supper and some recreation before the youngster must return to the underground nursery where he was safe from the nightly bombings. Parents with two children need work only six hours, with three children only five, etc. To the strength of the Israeli family Israel owes its survival.

I was very interested in the paper presented concerning children with learning disabilities. The religious order to which I belong has conducted a school for the retarded in Windsor, Ontario since 1930. In the school we have been subjected to a variety of learning experiences. At first we followed a policy of segregation, then we introduced the American practice of attempting to socialize the children by placing them in classes in the regular education system. At present, we are reassessing this approach because these children seem to need at least some time in a class with their peers where they can find a place of belonging, where they feel secure. Here again the child's success or failure to learn depends upon motivation. The sister in charge of this school is convinced that every child over a certain I.Q. can learn to read and communicate. She demands that each teacher in her school must build upon this belief. In addition to the paid employees, she has the volunteered assistance of a number of retired sisters who love children and who love to teach them. They

give affectionate and patient attention to one or two children struggling to learn to read, until the youngsters feel that they have a special teacher to whom they belong.

When the retarded are introduced into the regular system the socialization development seems to proceed faster, but does it? Normal children with their growing abilities and multiplied interests soon leave those with slower intelligence behind. The latter then lose their sense of belonging in society. We need to overcome this loss by highly motivating the slow learners to develop all that they have and especially their feeling of belonging. If we can convince the whole of our society including the faculties of our general public school system that every child over a certain I.Q. level can learn to read, only then can we place the retarded in the unsegregated public schools. Our experience in this one school is that sometimes we jeopardize the slow learners' sense of belonging and sense of achievement by immersing them in the public system. So such immersion should be accompanied by supplementing the socialization process to be found there, by providing volunteers who with their personal concern and assistance will reinforce their sense of belonging.

I am open to correction on that, but I would like you to consider both sides.

Response: I think that the point being raised is a very common fear, and certainly it is a real one in terms of the risks to people who have handicaps, as for example, the children in education systems. It is interesting, though, when we look at the research that has been done with people who are handicapped, whether in the education systems, or those who have moved from institutions into the community, the findings are consistent that the handicapped would prefer the risks and the challenges of being present in the community. They can point to a number of the downsides of being in segregated and isolated situations, and overwhelmingly, the choice is for inclusion rather than exclusion.

I also believe that there is an onus on those people who are providing the supports to recognize the dangers and the pitfalls, and to build the kinds of guarantees into the system that are going to help make the rest of the community welcoming and supportive. Simply taking a child who has a handicap, for example, and dropping him/her into a class of regular students does not do it. But if the teachers understand the need for support that that child has, and helps to explain it to the rest of the class, it is no different from what happens in most families. Most people have an aunt, uncle or a cousin that if they had to put a guest list together for a family reunion, that aunt, uncle or cousin would not be at the top of the list. But they are included anyway, and arrangements and accommodations are made, and they are there at the family reunion.

Our experience in schools where children with handicaps are included in a class indicates that soon the rest of the class starts to identify that person as a member of the community, but one who may need different supports. It is not necessarily so that every person is going to choose that individual who has a handicap as a best friend, but there is a certain acceptance. When those children grow up and become the shopkeepers, the professionals, and the neighbours in the community, they are going to know the people with handicaps and they are going to have a very different reaction to people with handicaps than those of us who grew up very separated from handicapped persons. They do not have the same fears that we do.

Importance of combatting stereotypes:

Comment: I would like to make a point perhaps generalizing this, beyond looking at children with impairments, into the whole idea of how society determines how each individual will operate. There are a number of stereotypes. When we talk about the aged, my mother is just completing her Ph.D. She is acting as a fantastic role model at the university. She has been elected

twice as the student representative of the university council and is challenging a whole lot of stereotypes at that university.

When we talk about people with AIDS, one of the best ways to make people think about the human issues is to show them. Get someone with AIDS to talk to people, to find out that that person is an ordinary person and not the stereotyped vision they have.

When you are in a classroom, and one of the children has an obvious impairment, it is perhaps a matter of trying to make the other children aware that that is an impairment perhaps visible or noticeable and have them think about their own internal impairments, in terms of attitudes and values.

I think that it is very important when we look at all these things that we make sure every member of the community is a valued person for what they can offer, not for what we are expecting in terms of a stereotypical community member.

Closing Address
by
Charlotte Matthews, Ph.D.
President
The National Advisory Council on Aging

Thank you. On behalf of the sponsors of this symposium, I thank you, the participants, most sincerely for being here yesterday and today. You have contributed your ideas and thoughts, and the discussions have been most profitable. I believe we have all gained.

I especially thank the speakers. It was your thought-provoking papers that lead to the interesting and useful discussions. As well, I know we all appreciate the work of the discussants and rapporteurs. Because of their insightful commentary, we will leave the symposium with a clear picture of the commonalities and differences in the support picture for seniors, persons with AIDS, the disabled, and families with children.

Finally, I thank the chairpersons, Alastair Clayton and Blossom Wigdor. Their organization ensured that we stayed on a very tight schedule.

Clearly, the representatives of the four groups gathered here today have a common interest in the strength of community supports.

In the last two days, we have discussed our mutual concerns about the limited size of human support resources, the growing demands pressing upon these resources in most communities, the difficulties each of the four groups are currently facing in their human support needs and their anxiety about the future.

At the same time, there has been a certain amount of optimism. Seniors, disabled people, persons with AIDS, and families are not waiting for others. They are out there on the front lines, volunteering, developing self help and mutual aid groups and generally demonstrating their self-reliance. There is also evidence of a considerable amount of intergenerational and inter-group transfer of help and support. Each group is in fact not on its own. Where mutual concern did not exist before, I am hopeful that this meeting has raised awareness and promoted understanding.

This has been a meeting in which I have learned a lot and I hope you have too. Each of us will no doubt bring away various perceptions, new pieces of information, and new contacts.

As we leave the meeting, however, I believe that one need stands out. Each and every presentation has referred either directly or indirectly to the need for good planning. Each of us has a role to play in ensuring that good planning takes place in our own sphere and that it is based on sound research and analysis using the best information available. At the same time, it is clear to me that good planning cannot take place if reliable information is not available. Statistics Canada has demonstrated its willingness to play a leadership role in helping us access the kinds of data and statistics we need. We have a responsibility to let Statistics Canada know what our information requirements are. We also have a responsibility to support Statistics Canada.

In closing, I extend my sincere appreciation to Leroy Stone. His forethought in bringing together what on the surface appears to be four groups with very diverse human support needs has been visionary. His creativity and hard work have resulted in a very profitable two days. Thanks are also due to his staff who I know have been working night and day and all Easter weekend to bring this symposium to fruition.

But there is no doubt that you the participants created the success story. So again, on behalf of Statistics Canada, Health and Welfare Canada, the Seniors Secretariat and the National Advisory Council on Aging, I thank you for your contributions to this symposium. In the words of Richard Burzynski "the foundation of the community-based response is a view of AIDS as a

community problem. When a community is willing to band together and help its own members, powerful things happen." I would like to leave you with the thought that Richard's comment applies to all of our particular fields of interest.

APPENDICES AND ACKNOWLEDGMENT

Appendix A
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Appendix B

How Societies Treat Dependency: Key Points
by
Leroy O. Stone

• In some societies the perception of dependency is such that one generation is viewed as being dependent on another; but in other societies the focus is more likely to be upon the interdependency of generations.

"Acceptance of dependency within a society that observes the norm of reciprocity creates the most decisive support for the favorable attitudes towards the elderly. The emphasis on mutual obligations throughout the life cycle coupled with the necessity of repayment eliminate the need for the elderly to justify their need for care and respect on an individual basis. As a result, dependency in old age is viewed as unpleasant but inevitable, and few people envision an extended period of complete independence from those of other ages. The elderly do not view their dependency as a fatal attack on their self-esteem, and the young and middle-aged do not entertain illusions of perpetual self-sufficiency or disengagement from the old. In general, this acceptance of

dependency and old age exists independently from government efforts." (Davis-Friedmann 1983:13)

"Yet government media and individual reports document a high level of continuity with pre-1949 family values. Lifelong interdependence remains the preferred parent-child relationship among both young and old. And in most urban and rural families, elderly men and women fully realize their desire for high levels of mutual interdependence.

"When living jointly, the different generations maintain obviously close ties. Parents and children are in constant contact, share most meals, and usually pool incomes into a common household budget. Contact between parents and children who do not live jointly is more variable, and the contrast between urban and rural families is marked. When parents and children in urban areas live separately, children often journey one or more hours each week to visit the parents' home on their one free day, usually taking a small gift of food. Occasionally they visit centers on a special event, but usually the time together is spent sharing housework or doing family shopping. During the three-day celebration of the Lunar New Year, all the children make a major effort to return to the parents' home. To use this most important holiday of the year to do anything other than visit parents and siblings would be an extraordinary affront to conventional morality which few would risk.

"By contrast, rural children who live even less than an hour from their parents rarely visit on a regular basis. Instead, contacts with children living outside the village are limited to special events, such as New Year's, weddings, and funerals." (Davis-Friedmann 1983:49)

"...the commission determined that parish support for the aged was necessary because the English working classes were totally deficient in natural filial affection. Thus, it became general policy to continue to allow small amounts of out-relief to the aged without specific concern about pressuring children to contribute (Webb and Webb 1909)." (Quadagno 1984:419-420)

"In spite of the liberalization of relief policy, the issue of filial

responsibility remained a concern. The 1895 Royal Commission on the Aged Poor read into the hearings a quotation from the 1834 report regarding the neglect of kin by the working classes." (Quadagno 1984:421)

• The organization of response to perceived dependency differs markedly among cultures.

"Another way in which the elderly benefit financially by their release from the team work force is through the contribution they make to household income through their replacement of younger members as the main household workers. The most common replacement, as in the case of Chen Pingfong, is the substitution of an elderly mother-in-law for a young wife as the primary housekeeper. When young women are able to pass on most of their responsibility for children, cooking, and sewing to their mother-in-law, they can usually double their wages from the collective labor force and still have time to contribute additional income working in the household.

"Elderly fathers also make economically valuable contributions in the home,

tending the family vegetable garden and collecting firewood and kindling. In general, however, elderly women assume the bulk of the housework, and their shift out of the collective work force and into the household economy is particularly important for improving the family's overall levels of prosperity and security. As a result, elderly women seek to leave the team labor force as soon as possible, and both they and their families consider housework to be a legitimate and remunerative form of employment." (Davis-Friedmann 1983:21)

Within our society, the notion of considering housework to be a legitimate and remunerative form of employment has been viewed as being radical over most of the past half century. For example, in many Western statistical systems housework by family members has not until fairly recently been classified as an activity that generates societal wealth, and households have not since World War II tended to be viewed as sources of economic products. However, this may now change because the United States is reported to be the scene of development

of a vibrant household-based cottage industry built around or supported by micro-electronics and new information management technologies. (Estimates reported recently on Financial News Network indicate that there are now 13,000,000 home-based companies in the United States.) [Comment by L. Stone]

• Almost always the family is the main helping structure regarding functional dependency; but family obligations in this area are deeply stressed in some cultures while being regarded permissively in others.

"Throughout history the first recourse for those in need has been the family. Whether sick, disabled, poor, mentally ill or in any other way incapacitated, an individual would turn first to his or her family, and it was considered the family's duty to provide whatever help could be managed. Yet there were always those who did not have this help available. In these cases, the local community or a charitable-minded individual might take on the responsibility of providing the necessities of life. The Christian Church in what is now the Middle East set up institutions during the third and fourth centuries to care for those in need." (Forbes, Jackson and Kraus 1987:2)

"If no generalization about the extent of support can be drawn, it is still readily apparent that some older people in every colonial town had no family members either willing or able to provide support and that relief to the aged was one of the more common functions of poor relief. It also appears that the concept of family responsibility was applied liberally as best fit the needs of individual family members and was associated, at this stage, with economic rather than any punitive intent. In these early years of the colonial period, administrators of relief to the needy were neighbors in small communities, and the concept of family governance reigned, as seen by the frequency with which boarding was used as a means for relieving the aged." (Quadagno 1984:424)

"The guidelines governing the distribution of benefits for the indigent also hold children responsible by granting long-term government financial aid only to those elderly who are unable to work and are deprived of any

"responsible kin." In rural areas responsible kin are defined as sons, according to the traditional patrilineal preference, and those elderly who have surviving daughters but no sons can be considered to be childless. In urban areas, sons and daughters are equally responsible, and only those elderly without any progeny qualify for government assistance.

"Externally imposed restrictions are not the only supports of parent-child solidarity. Personal commitments also create strong bonds of loyalty. Elderly men and women repeatedly make clear that infrequent contact with adult children has only negative connotations. Separation is equated with rejection, independence with selfishness, and having minimal relations with one's children is tantamount to failure in life's work. ...

"Fundamental to these values is the assumption that through the gift of life and early nurturing, parents become eligible for a lifelong claim on their children's resources. Children provide for elderly parents, and parents turn to adult children without guilt, because both generations believe that the creation of the children's physical existence and the care given them in childhood require children to reciprocate in their parents' old age. The values instilled by this family-centered ideal of reciprocity encourage strong solidarity between elderly parents and their children in two ways. First, because obligations incurred in childhood are expected to continue throughout life, neither young nor old envision an extended period of complete independence from one another. Dependency, as experienced in childhood or old age, is viewed as a normal phase of every life. Thus the elderly need not view dependency as an attack on their self-esteem, and the young and middle-aged cannot plan for extended disengagement from the old." (Davis-Friedmann 1983:53-54)

• Where a person lacks family supports, one society may stress government-based helping systems while another may stress private philanthropic response.

"The care of the indigent sick, the insane and foundlings in Lower Canada continued to be undertaken by private philanthropy and by the

Roman Catholic Church. To extend this work and to support the hospitals already established, it became necessary to provide additional public support, and in 1801 the provincial legislature appropriated one thousand pounds per annum for three years to help religious foundations caring for foundlings, the sick and the infirm." (Forbes, Jackson and Kraus 1987:5)

"In Upper Canada, it was not the Church but municipal councils which provided relief for the destitute. However, in this pioneer, rural society, those who had established themselves and their families successfully had little patience for those who had failed to do so and, in keeping with this, local officials emphasized self-reliance and foresight." (Forbes, Jackson and Kraus 1987:5)

"Up to 1900 the history of institutional long-term care in Canada is represented by developments in Quebec, Ontario and two of the Atlantic Provinces, Nova Scotia and New Brunswick. In Quebec, private rather than public initiative remained almost universal, in spite of powers granted by the Municipal Code (1881) and the Cities and Towns Acts (1903) which permitted councils to establish houses of refuge, to support hospitals and other charitable institutions, and to support the old and infirm. The permissive legislation of Ontario regarding houses of refuge must be contrasted with the Poor Law enacted in Nova Scotia and New Brunswick, which required municipalities to provide relief for all indigent residents and established control over the poorhouses (Clark 1942, 134-35; Morgan 1980, 87)." (Forbes, Jackson and Kraus 1987:8)

• Societies evolve helping systems to cope with their perceived dependency burdens. A helping system is a set of procedures designed to transfer assistance to others under rules of eligibility enforced by members of helping structures that are maintained by legitimate resource flows. Helping structures include kinship networks, friendship networks, semi-formal self-help groups, and formal groups such as private philanthropic organizations, businesses, and government.

• Prominent classes of assistance provided by helping systems are commonly known as "income support", "education", "health care", "rehabilitation", "long term care",

"employment support", "housing assistance", etc. Each of these phrases refers to a class of services. It is quite common to hear people refer to the processes involved in providing these services in terms of the "X system" -- e.g. "the health care system", "the welfare system", "the unemployment insurance system", "the educational system".

• Who enables and maintains these "helping systems"? Most important, in terms of the sheer volume of assistance provided, are kin and friendship networks (the so-called "informal support networks"). Also important are organizations of various kinds -- philanthropic, business, government. Clearly, these organizations and networks are not the same as the "systems" mentioned above. Yet they too are systems; only they are systems of a different sort.

• The general character of societal helping (support) systems: Arrangements of human networks (informal and formal) are the mechanisms used in the organization of societal response to dependency. Inasmuch as these networks have parts that are integrated in ways that cause the networks to appear to perform specified kinds of work, they are properly regarded as systems. However, as the social network literature amply demonstrates, they can also, from a different perspective, be viewed as structures (which is the

position taken here). These helping structures maintain helping systems (other, more abstract, types of systems).

Certain of the helping structures have strategic functions with regard to these input-resource flows, as well as to the setting or changing of the rules of eligibility for the assistance in question. We often refer to the instruments used by these key helping structures as "policy levers".

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