PERSONAL RELATIONSHIPS OF SUPPORT BETWEEN ADULTS: THE CASE OF DISABILITY

By: The Roeher Institute

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EXECUTIVE SUMMARY

With improvements in health status, the aging of the population, and life-saving and sustaining technologies, adults with disabilities represent a growing proportion of the population in Canada. Yet they are one of the most excluded and marginalized groups in Canadian society. This is primarily because they, and their families, are often unable to obtain personal supports they require in ways that are accountable to them; in ways that assist them to pursue their aspirations; and in ways that foster their social and economic participation.

For many adults with disabilities the nature of personal relationships through which needed support is provided defines the extent of their well-being and equality. With this understanding in mind, this paper outlines a conceptual framework for considering legal and social recognition of close personal support relationships involving adults with disabilities. The paper explores how the legal and social constructs that govern these relationships situate both the providers of support, and the recipients. It finds that in large measure these constructs situate the parties to these relationships in different and *un*equal positions with respect to other adults in Canadian society.

Relationships reviewed

Five common types of personal relationships of support involving adults with disabilities are examined, including:

1. ***With Family Members*** - Where a birth family member (parent, sibling, adult son/daughter) or spouse provides care to a family member on an unpaid basis (the most common relationship for adults with disabilities).

2. ***With Paid Support Provider (or 'caregiver', providing live-in / live-out personal care)*** - Where a person is paid to provide personal care (may include toiletting or bathing assistance to home making assistance and support to participate in employment and the community). The relationship to be considered is one where the paid person is in close personal relationship to the disabled person (either live-in or live-out relationship), and spends significant periods of time with the adult with a disability.

3. ***Supported Decision-Making Network*** - Where one or more persons are included in a disabled person's personal network to assist in making personal, financial, and health care decisions, especially where that person's legal competence may be in question without the decision-making support they provide (now recognized in law in a few jurisdictions in Canada).

4. ***Alternate Family*** - Where a disabled adult lives with a non-birth family, and family members are paid to provide support (this model is being used more and more as an alternate to institutional and group home care). While the funding arrangement may be similar to foster care, the relationships to be explored are where an adult with a disability lives with a family, members of whom are to include that person as a family member.

5. ***Adult Home Sharing*** - Where two or three adults, at least one of whom is disabled, choose to live together, and where a non-disabled adult is provided some remuneration for being available to provide personal support to the disabled adult on an as-needed basis. This is a more informal relationship than one with a paid support provider.

Findings

The review finds that these relationships of support are highly valued by both providers of support and adults with disabilities. It also finds that adults with disabilities are usually constructed socially and legally as passive and dependent recipients of care. Research shows that, in fact, they make significant economic, domestic, emotional, and other contributions in the context of the relationships of support they are a part of. When these relationships of support are defined by interdependence, reciprocity, dignity, and mutual respect, they bring health and well-being to both adults with disabilities and those providing care or support.

Nonetheless, these relationships are under significant stress. Family members take on an enormous burden of support, unrecognized, uncompensated, unsupported. The consequence is reduced health status, social isolation, and lost economic independence and opportunity. Income tax provisions, workplace accommodations, community supports are not in place to adequately meet their needs in playing the support role they do. These disadvantages affect a significant number of Canadians. In 1991, almost 900,000 adults with disabilities who required support, relied exclusively on family members. The number is likely much higher today. Relationships with paid support providers are also under stress from low wages, inadequate benefits, and the limited funding available for purchase of needed paid supports.

Relationships with supported decision-making networks, alternate family members and ‘homesharers’ suffer from lack of legal recognition of these relationships, and thus clarity about the responsibilities and obligations these relationships bring. Supported decision-making networks can help to sustain the legal capacity and self-determination of individuals whose level of individual capacity might otherwise diminish their legal rights. But the status of these networks remains unclear and without foundation at the federal level and in many provincial/territorial jurisdictions (although some other jurisdictions like British Columbia, Saskatchewan, Manitoba, and the Northwest Territories are moving in this direction).

For the purposes of this paper, the legal and policy framework affecting, and sometimes regulating and recognizing, these relationships is defined in four areas:

- basic income supports for adults with disabilities and family members (tax provisions, social assistance, CPP/QPP, workers compensation)
- funding and delivery of disability-related supports (tax provisions, provincial/territorial program and individualized funding for supports)
- provisions for the legal status of individuals and members of their personal networks to make and assist in making personal decisions (in some provincial substitute and alternative decision-making legislation, legislated as reforms to guardianship law)
- labour law and regulation (governing collective bargaining in provision of paid supports, parental and family benefits and leave, and duties to accommodate in human rights codes).

To date this framework of law and regulation has not adequately addressed the disadvantage experienced by adults with disabilities, and those with whom they have close relationships of personal support.

Directions to Consider

A framework of principles should guide development of options to address the current inadequacies in law and policy. Self-determination, full citizenship, and equality are advanced for this purpose. The analysis makes clear that the close personal relationships outlined are an important condition in realizing these principles in people’s daily lives. Drawing upon these principles, a number of directions for more adequately recognizing close personal relationships of support involving adults with disabilities are suggested:

- Review federal statutes to critically examine the terms and categories that constrain people with disabilities as dependent, and of unequal social and economic value (e.g., “infirm dependent”).

- Recognize and support the right to full citizenship and self-determination of individuals with disabilities in a range of federal and provincial statutes and policies. In acknowledging the link between communication capacity and self-determination, greater statutory recognition could be considered for the right to ‘effective communication’ (as in *Eldridge*) and to the role of support networks in realizing this right.

- Establish clearer options for legal recognition of support networks, and domestic support relationships (family, alternate family and homesharing). The ‘registered domestic relationship’ status would not provide an adequate legal framework to accord these relationships the status they deserve. Nor does the *Criminal Code* recognition of a person’s responsibility to “provide necessaries of life to a person under his charge” provide an adequate model of responsibility and obligation. It denies the reciprocity that defines the relationships reviewed, the nature of the assistance provided, and the contributions that adults with disabilities themselves make. Options to register different kinds of significant personal relationships - like supported decision making network - might be considered.

- Strengthen the economic independence of both parties to support relationships (e.g. labour market policies for adults with disabilities and income support/replacement measures; fairer and more comprehensive tax measures recognizing family as well as non-family care providers; wage and benefit measures for paid caregivers; eligibility of family carers as paid caregivers).

- Provide more adequate access to needed direct, and back-up supports - funded home care, attendant services, etc. - through tax provisions enhanced federal - provincial transfers and direct transfers to individuals.

- Recognize and support the paid employment status of family caregivers, alternate families and home sharers where they commit to a significant caregiving relationship. Workplace flexibility, benefits, and a right to leave are essential for viable caregiving relationships. Changes to Employment Insurance, federal and provincial labour standards and human rights codes (re: prohibition of employment discrimination and duty to accommodate on the basis of relationships of caregiving support) could be considered to expand the focus beyond the parent-child caregiving relationship.

- In human rights provisions, clearly extend to family members who have significant caregiving responsibilities for family members with disabilities, protections from discrimination in employment practices on the grounds of family status.

- Establish common principles (or “framework agreements”) to guide sectoral, collective bargaining for paid caregiving that affirm status and primacy of decision-making rights of individuals with disabilities, and collective bargaining processes that fully represent individual and family interests, while also affirming labour rights.

This report has not developed detailed proposals for these options. The purpose has been to explore whether or not relationships of support involving adults with disabilities were worthy of consideration under the initiative of the Law Commission of Canada. The analysis clearly suggests they are. Elaboration of the options awaits more detailed analysis, now that their broad outlines can be drawn. Undoubtedly, development and implementation of the options requires action by both Parliament and provincial and territorial legislatures. However, Parliament can show leadership in certain areas, such as developing registration options to accord status to different relationships of commitment and support, and strengthening the right to effective communication and protections in human rights code provisions. Such leadership could send the message that the state in Canada is committed to making self-determination, citizenship and equality defining of the close personal relationships of *all* Canadians.

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INTRODUCTION

The Law Commission of Canada has launched an initiative to consider Parliament's approach to recognizing and supporting close personal relationships between adults.[1] The initiative grew out of a concern that when Canadian law has focused on personal relationships, it has tended to take marriage of spouses of the opposite sex as the paradigm of human relationships worthy of state recognition. Distinct recognition of common law relationships, and same sex unions is beginning to take hold, but remains full of contradictions and inadequacies. Non-conjugal domestic relationships of support are a growing phenomenon, and there is even less recognition of these. While there remain many questions about what forms legal recognition of these relationships should take, even their consideration does not exhaust the concern.

This paper contributes to the Law Commission's initiative through examination of personal relationships involving care or personal supports to an adult with a disability. These types of personal relationship have largely not been on the public agenda. They appear dimly, if at all, in the light cast by Canadian law. The overall purpose of this paper is to consider what relationships of support involving an adult with a disability should come within the ambit of the Law Commission's concern, and to develop a conceptual framework of these relationships. Further, it is to outline the interest of the state in supporting and regulating these relationships, and to critically review what forms this support/regulation currently takes in law and public policy.

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[1] See Law Commission of Canada (2000), *Recognizing and Supporting Close Personal Relationships between Adults: Discussion Paper* (Ottawa: Law Commission of Canada).

A study of state recognition of issues faced by adults with disability in relationships of marriage, common law relationships, and same sex unions is beyond the scope of this paper - although issues of personal support are central to these issues. A full examination of the particular issues of disability in the context of these relationships is clearly worthy of consideration. The paper does touch on adults in non-conjugal domestic partnerships - though not in those specific terms. The aim here is to introduce other forms of close personal relationships of support that have been outside the terms of discussion to this point.

Why Study Personal Relationships of Adults with Disabilities?

The proportion of adults with disabilities in Canada is growing due to aging, and advances in medical care. They are an important part of Canadian society, and make important contributions in their relationships, communities and society. Yet they continue to face barriers to full equality and citizenship, rendering them one of the most vulnerable category of persons in our society. People with disabilities share a history of exclusion, institutionalization, and forced sterilization. They continue to face higher rates of poverty, illiteracy, labour force exclusion, violent victimization, social isolation, poor health status, and unmet need for supports than the general population. The recent Supreme Court of Canada decision in *Eldridge* clearly articulates this history:

> It is an unfortunate truth that the history of disabled persons in Canada is largely one of exclusion and marginalization. Persons with disabilities have too often been excluded from the labour force, denied access to opportunities for social interaction and advancement, subjected to invidious stereotyping and relegated to institutions.... This historical disadvantage has to a great extent been shaped and perpetuated by the notion that disability is an abnormality or flaw. As a result, disabled persons have not generally been afforded the "equal concern, respect and consideration" that s. 15(1) of the Charter demands. Instead, they have been subjected to paternalistic attitudes of pity and charity, and their entrance into the social mainstream has been conditional upon their emulation of able-bodied norms.... One consequence of these attitudes is the persistent social and economic disadvantage faced by the disabled. Statistics indicate that persons with disabilities, in comparison to non-disabled persons, have less education, are more likely to be outside the labour force, face much higher unemployment rates, and are concentrated at the lower end of the pay scale when employed….[2]

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[2] *Eldridge* v. *British Columbia (Attorney General)*, (1997) 141 D.L.R. (4th) 577.

Many of these disadvantages evolve in the context of personal relationships of support involving an adult with a disability, and could be addressed in that context. Yet many forms of relationship that are particular to adults with disabilities are not granted full recognition. Nor are social policies designed to strengthen the capacities of persons in some types of relationships to support each other to the fullest degree possible.

People with disabilities engage in the same relationships as other Canadians. They are spouses, friends, and lovers, mothers, fathers, sisters, brothers and sons and daughters. They are also grandparents, aunts and uncles, cousins and so on. Like everyone else, they have friendships with varying degrees of intimacy. The ways they structure their relationships vary as they do for other people, according to their cultures, their personal preferences, their communities and other factors. The difficulties encountered in the general population in the forms of state recognition of close personal relationships - same sex marriage and common law relationships, non-conjugal domestic relationships, etc. - are also faced by people with disabilities.

Unlike most other Canadians, many people with disabilities are also in relationships that are characterized, at least in part by personal care or support that is related to disability. This is because people with disabilities often require personal supports and care to the extent that others may not, or that are different than what others may require. For many individuals the personal relationships through which this care is provided are central to their well-being and equality.

Yet these are also relationships under chronic stress - where family members are providing care without adequate back-up, or paid caregivers are providing care for low pay and inadequate benefits. The consequence for individuals with disabilities is limits to their social and economic opportunities, their full control over their lives, as well as high rates of abuse. For those providing personal support, whether paid or unpaid, the consequences may include not only stress and frustration, but also isolation, and lost economic and social opportunity. Understanding the nature of these relationships and how they can be supported is critical, as the proportion of the adult population with disabilities grows.

In focusing on relationships of personal support, it is important at the outset to make clear that in such relationships adults with disabilities are not simply passive recipients of care. As the research reviewed makes clear, they also contribute in important ways in those relationships, ways that often go unrecognized. This recognition is often denied because of the powerful and negative stereotypes which circulate in our culture - stereotypes which dehumanize people, and portray them as unproductive, non-contributing individuals, unable to fully be agents of their own lives (Tremain, 1996a; Barnes and Mercer, 1995; Silvers,1995; Rioux, 1994). These stereotypes perpetuate an "us and them" mentality that is a barrier to developing personal relationships of care and support defined by reciprocity and recognition of contribution. As Lutfiyya (1988) states:

> people with disabilities are separated from their families and communities, cast into roles of dependency and passivity, and even when physically present in some community settings, are kept at a social distance from other members in the community" (p. 2).

The popular misconception about the dependence of people who require personal supports, is also reflected in law and public policy. Policies that require adults with disabilities who are on social assistance to be identified as "unemployable" as a condition of access to needed supports, is a case in point. In fact, research suggests there is frequently interdependence in personal relationships involving people with disabilities. In one study, for example, disabled women said their adult caregiving relationships were characterized by reciprocity and interdependence. That is they received support, but they also gave it (Walmsley, 1993). As Walmsley describes, many disabled women are themselves in roles of caring (i.e., mothers themselves or providing care for their disabled parents).

What do we mean by personal relationships involving supports to others or “caring”?

Many relationships involve caring or providing supports to others. A father may cook for his child, a woman may listen to her housemate in times of emotional distress. A man may do an extra turn at the dishes when his gay partner is trying to meet an important deadline. All sorts of exchanges and transactions happen within families, between friends, and in communities. Often these exchanges involve practical or emotional support, as described above. They may also involve financial or economic support. For example, a mother helps her adult daughter pay her university tuition or rent, or a brother invites his recently unemployed sister to live with him until she becomes more financially secure.

Definitions of social support encompass a range of activities in relation to exchanges of resources. Dunst, et al. (1989) define social support as “the resources - potentially useful information and materials - provided to individuals or social units (e.g., a family) in response to a need for aid and assistance” (p. 124). Social support includes “physical and instrumental assistance; attitude transmission; resource and information sharing; and emotional and psychological assistance” (p.124). O’Brien & O’Brien (1991) suggest social support arises from at least four distinct experiences: “ feeling attached to emotionally important people; having opportunity to engage in shared activities; being part of a network of people who can be approached to share information and assistance; and having a place and playing a variety of roles in economic and civic life” (p.11).

Everyone draws these kinds of practical and emotional support from others with whom they are in a close personal relationship. When these kinds of social support are provided in the context of relationships among non-disabled adults they are ‘normalized’ and tend to be the very ‘stuff’ of a relationship. However, when provided in the context of a personal relationship involving an adult with a disability, the supports are much more visible. People with disabilities may require more support in particular areas like personal care than non-disabled adults. As well, many tend to be more socially isolated, which means that the personal supports have to be purchased from others, making the support a ‘service’ that is funded, regulated, delivered and, therefore, much more visible. Non-disabled adults live in a world designed to meet their needs and thus the supports they receive tend to be seen as ‘universal’ and therefore ‘natural’. Stairs to a building entrance are not seen as a technical aid or device for non-disabled adults, although ramps to the same entrance are seen as such for an adult who uses a wheel chair. Secretarial assistance is not generally seen as “paid personal support”, although a “job coach” for a woman with an intellectual disability is. A car is not seen as technical mobility aid, but a wheelchair is.

It is a guiding hypotheses of this paper that the different legal and social constructs governing provision of supports to adults with disabilities situate both the providers of support, and the recipients in different and *un*equal positions with respect to other adults in Canadian society. It is in this light that the paper critically reviews five types of personal relationships. These relationships were selected because they reflect major relationships of caring available to disabled adults outside of institutional care. Some point to emerging relationships developed to specifically advance the equality, dignity, and inclusion of people with disabilities (e.g. supported decision-making).

1. ***With Family Members*** - Where a birth family member (parent, sibling, adult son/daughter) or spouse provides care to a family member on an unpaid basis (the most common relationship for adults with disabilities).

2. ***With Paid Support Provider (or 'caregiver' providing live-in / live-out personal care)*** - Where a person is paid to provide personal care (may include toiletting or bathing assistance to home making assistance and support to participate in employment and the community). The relationship to be considered is one where the paid person is in close personal relationship to the disabled person (either live-in or live-out relationship), and spends significant periods of time with the adult with a disability, and provides intimate care..

3. ***Supported Decision-Making Network*** - Where one or more persons are included in a disabled person's personal network to assist in making personal, financial, and health care decisions, especially where that person's legal competence may be in question without the decision-making support they provide (now recognized in law in a few jurisdictions in Canada).

4. ***Alternate Family*** - Where a disabled adult lives with a non-birth family, and family members are paid to provide support (this model is being used more and more as an alternate to institutional and group home care). While the funding arrangement may be similar to foster care, the relationships to be explored are where an adult with a disability lives with a family, members of whom are to include that person as a family member.

5. ***Adult Home Sharing*** - Where two or three adults, at least one of whom is disabled, choose to live together, and where a non-disabled adult is provided some remuneration for being available to provide personal support to the disabled adult on an as-needed basis. This is a more informal relationship than one with a paid support provider.

Drawing on current literature, these five relationships are reviewed below with particular emphasis on characteristics of the relationships, demographics of these relationships, value of the relationship to individuals involved, and current challenges and issues in supporting these relationships. It is important to note that these are not mutually exclusive relationships. An individual may have a primary support relationship with his or her natural family, be home sharing or living with an alternate family, receive paid caregiving, and have a support network that includes family, friends and a community advocate. The overlapping nature of these relationships presents particular challenges in sorting out decision-making and support roles, accountabilities among those involved in the relationships, and the distribution of benefits and resources among them. In the discussion that follows, characteristics, values, and challenges associated with each of these relationships is discussed in terms distinctive to that particular relationship. This is to assist in clarifying the nature of these relationships, and not to suggest that these relationships are discrete “options” for individuals. Increasingly, adults with disabilities are shaping their lives through some mix of these relationships.

In subsequent sections, state interest and regulation in these relationships are outlined, through a review of selected policies and programs, and a review of case law where these relationships are relevant in some way. The final sections lay out a conceptual framework for linking state policy provisions, to the valued characteristics of the personal relationships outlined, and to state interests in self-determination, citizenship, and equality.

PART ONE

REVIEW OF PERSONAL SUPPORT RELATIONSHIPS

I. With Family Members

A. Characteristics of Relationships

1. The actors

The personal support provided by a family member is the most common type of caregiving relationship experienced by adults with disabilities. With deinstitutionalization and the move to community-based care, family members are increasingly expected to take on responsibilities of caregivers to their disabled family members. There is increasing public recognition in the research literature that families are the primary source of support for persons with long-term disabilities. (Francell, Conn, & Gray, 1988; Hatfield & Lefley, 1987; Seltzer & Kraus, 1997)

Family caregivers are considered to be members of a person’s birth family, that is, a parent, adult child, or sibling. By some definitions, spouses may also be considered family caregivers. The definition of family caregiver may need to be called into question, however. Definitions of family are shifting as issues of rights for same sex partners are raised; reconstituted families formed through divorce and remarriage increase, gender roles shift, family members migrate, and families take on new forms. As Carpenter (1998) points out, many families of children with disabilities create more extended families with members not necessarily related by blood that carry out the functions typical to the traditional family. These self-defined families include neighbours, friends, work colleagues, church members, education professionals, and volunteers.

2. Activities in personal support

Caregiving involves family members in a number of different behaviours and events in the context of the family (Singer & Irwin, 1989). Turnball & Turnball (1986) and Zetlin (1986) identify a number of caregiving activities related to: economic well-being, domestic/health care; recreation; socialization; self-identity; affection; and educational /vocational training (Singer & Irwin, 1989; Turnbull and Turnbull, 1986; Zetlin, 1986). Specific kinds of tasks include:

- assistance with daily living such as meal preparation, shopping, housework, heavy chores, personal finances, personal care (washing, grooming, dressing, eating), or help getting around the home;
- advocacy;
- individual planning and decision making;
- transportation; and,
- assistance to participate in educational, social and economic activities.

3. Structure

The ways that family relationships are structured to provide support to a disabled family member varies. Structure may be determined by where different people participating in the relationship live. Do they live in the same home? The same building? Different residences? Is it a formalized support network; or an informal family commitment? Does one family member provide all or most of the care and support to a disabled family member? Is it shared? Does it affect their other responsibilities?

The structure of the family caregiving relationship may also be affected by whether or not the family is connected to a support network. Family personal support networks are defined as "the persons or institutions that come into contact with and are a primary source of help to the family and individual members" (Dunst et al., 1989, p.124).

4. Changeability

Family caregiving relationships do not always stay the same. The needs of disabled adults for caregiving support from their families could change over time - their disability may become more or less severe, their access to other forms of support, such as paid support, may change. Family capacity to provide support may also shift, as parents age, or family composition changes, through death, divorce, or migration.

The changeability of caregiving relationships, particularly in relation to aging parents' capacity to provide care to their adult children with intellectual disabilities, has recently become an area of concern for researchers and community living activists.[3] Families are finding that older parents' need for assistance alters the nature of the relationship. It may become more reciprocal as parents begin to rely on their disabled son or daughter for support. Aging parents are also raising questions about future sources of personal support for the family member with a disability, and for parents who may, themselves, acquire a disability with age.

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[3] The term "community living" refers here to the movement to enable people with intellectual disabilities to live in the community, supported on the basis of principles and values of citizenship, self-determination, membership and participation. The movement is closely aligned, in terms of principles and values with the independent living movement. The latter tends to refer to people with physical disabilities. The relationships under review in this paper include people with disabilities generally.

5. Reciprocity

Research shows that caregiving relationships are often reciprocal. Walmsley (1993), for example, found that the adult caregiving relationships of disabled women were reciprocal and interdependent. In a publication undertaken for Status of Women Canada, The Roeher Institute (2001) found that while reciprocity was sometimes indirect (i.e., a woman would be supported by a sister and support her brother, who in turn would support her sister), in whatever form it was highly valued and considered a necessary element of caregiving relationships. Recognition and valuing of reciprocity ensured that caregiving relationships were characterized by interdependence rather than dependence.

Many adults with disabilities who live with their families contribute in a variety of ways. The literature exploring contributions made by adults with disabilities to their family “caregivers” is sparse. Heller, Miller and Factor (1997) looked at the role that adults with intellectual disabilities played in supporting their parents and found they contributed as companions to their parents, and by doing chores. In a review of the literature they pointed to other contributions made by adults with intellectual disabilities or mental illness, including social support (Greenburg, 1995; Greenburg, Greenly, and Benedict, 1994; Horwitz, Reinhard and Howell-White, 1996) strengthening family ties, instilling greater compassion, joy and fulfillment (Abbott and Merideth, 1986; and Turnbull, Guess and Turnbull, 1988), providing meaning to families lives; doing chores, contributing financially through Social Security income, and keeping parents from feeling lonely (Heller and Factor, 1988). In research reviewed, people with disabilities point to making contributions in a number of ways: through earnings from paid work; belonging to community organizations; providing emotional support to friends and family; raising children; doing housework and cooking; fixing things; babysitting; and providing support to community members who were elderly or ill.

B. Demographics of Relationships

The statistical analysis for this research is based on unpublished data from the Statistics Canada Health and Activity Limitation Survey of 1991 for Adults in Households (HALS). HALS allows for identification of who provided persons with disabilities help in everyday activities (e.g., meal preparation, shopping, personal care, housework, personal finances). Those who provided support include family members, friends/neighbours and community-service providers. In 1991, among persons with disabilities residing in households, aged 15 and over who were in need of supports, almost 900,000 obtained those supports exclusively from family members (see Table 1).

Table 1: Who Helps? (Adults 15+ who require help with everyday activities)

Those Providing Help	Adults 15+ Requiring Help	Percent
Family Only	892,834	48.8
Friends Only	97,668	5.3
Family & Friends	119,299	6.5
Family, Friends & Agency	53.027	2.9
Family & Agency	245,551	13.4
Friends & Agency	21,385	1.2
Agency Only	248,792	13.6
No help but needed	150,153	8.2
Totals	1,828,709	100

Source: The Roeher Institute (based on HALS 1991)

While there is public perception that people with disabilities living outside of extended care facilities, are largely supported in group homes or supported living units, in fact over 90% live in their own homes, on their own with family members or others, in owned or rented units (see Table 2). The vast majority must develop relationships of support with paid and non-paid others for their basic survival and well-being.

Table 2: Housing (People with disabilities aged 15+, HALS 1991)

OWNED		
Type of Housing	**Adults 15+ with Disabilities**	**Percent**
Own Home	2,190,075	64.3

RENTED		
Type of Housing	**Adults 15+ with Disabilities**	**Percent**
Private (apartment, townhouse, condominium or house)	902,810	26.5
Rooming, Boarding or Lodging Home	91,465	2.7
Public, Non-profit or Community Housing	132,935	3.9
Co-operative Housing	26,270	0.8
Group Home	57,750	1.7
Temporary, Transition or Emergency Housing	5,370	0.2

Totals	3,406,675	100.0

Women play a much larger role in providing support to disabled family members than men. Because HALS does not distinguish on the basis of gender among sibling caregivers, parents, or other family members (e.g., aunts, female cousins and grandmothers), HALS underestimates the extent of female involvement in informal care within the family, probably by a considerable margin. (HALS only accounts for gender among spouses and sons/daughters).

It can be conservatively estimated that about 650,000 persons with disabilities received help with routine activities of everyday living from women in the same family in 1991. An estimated 720,000 women provided this support (see Table 3). The largest number of female caregivers are wives / common law partners of males who have disabilities. The second largest number of female caregivers are daughters of females with disabilities.

Table 3: Persons with disabilities receiving informal help with one or more everyday activities from caregivers in the same family (HALS 1991)

Gender of Persons Receiving Help	Relationship of Caregivers to Persons Receiving Help	Number of People Receiving Support	Minimum Number of Female Caregivers	Subtotals
Male	Wife / female partner only	247,350	247,350	247,350
	Daughter(s) only	36,990	36,990	36,990
	Wife / partner and daughter	72,230	144,460	144,460
Female	Husband / male partner only	325,410		
	Daughter(s) only	184,940	184,940	290,660
	Husband / partner and daughter	105,720	105,720	
Total		972,640	719,460	719,460

* 325,410 females received help from husbands/male common law partners only.

C. Value of the Relationship

One of the main societal values of family caregiving is the cost-savings to governments from family members providing supports on a voluntary basis to other adults. For adults with disabilities, the major value is the support, personal valuing, and independence that can come with family caregiving relationships. Without such supports individuals could find themselves in state-funded acute care facilities, long-term care institutional facilities, or the criminal justice system (where people with disabilities tend to be over-represented).

For individuals involved, the value of family caregiving relationships differs between families. Like other families, those with members with disabilities may be more or less characterized by healthy relationships, co-dependence or interdependence, dysfunction, caring, commitment and so on. Like other families, the strength and mutual supportiveness of the relationships between a disabled adult and their family members is affected by conditions such as poverty or economic security, isolation or community connectedness, the stress or life satisfaction of members.

For people with disabilities and their families, these conditions may also be affected by access to disability-related supports for the individuals with a disability, and for other family members. Access to disability-related supports promotes equality within the relationship for both the persons with a disability and the family member providing disability-related support. For both the disabled person and family members, access to formal disability-related supports promotes interdependence, creates social and economic opportunities, allows them more choices and reduces risks of stress, abuse and breakdown of the relationship (The Roeher Institute, 2000, 1997).

This is not to say that formal, paid relationships ought to replace family relationships in the lives of people with disabilities. Both are needed, and should be recognized and promoted in law and policy. Further, even when paid supports are available, family relationships can offer qualities like love and companionship that are more difficult to foster, and not necessarily present or suitable in paid support relationships.

1. Source of love and companionship

One of the main qualities usually found in family relationships is that people in the relationship love and care for one another. In the context of family support relationships, care is more than just the activities performed or resources exchanged. Caring tasks occur within a context in which people care *about* each other, as well as *for* each other. (Qureshi & Walker, 1989 in Walmsley, 1996, p.329). A number of studies have shown that mutual love, affection, friendship and companionships are qualities highly valued in family supportive relationships, and are described by families as a benefit of caregiving (Singer, 1996; Lord & Ochnocka, 1995.) As Singer points out, caregiving relationships offer love, concern, affective support and emotional support and therefore should be considered part of the national wealth of a society (p.19).

2. Strengthens families

Family caregiving has become a preferred choice of care by many families. According to Singer (1996), the most important benefit is the "... commitment that binds families, friends, and communities" and is "...a fundamental human link that serves as a foundation for the larger society" (p.19). In this way supportive relationships strengthen families. They create opportunities for members to display their competence, are enabling, and empowering, according to Hobbes (1984), bringing people together for the exchange of resources (Dunst et al., 1984, p.127). Singer outlines how families that engage in caregiving develop (or maintain) strong family ties, a sense of family, cooperation and positive interactions with one another (Singer, 1996, p.20-21).

3. Roles with meaning and purpose

Participating in a relationship that involves caregiving and support also has the benefit of participants fulfilling roles characterized by meaning and purpose. Singer's 1996 review of literature on family benefits of caregiving include the following values in the caregiving relationship: increased life satisfaction, sense of purpose and positive feelings of self-satisfaction and accomplishment (Singer, 1996, p.20-21).

This is true for both the person with a disability and other family members. In mutually supportive relationships, adult children with disabilities often assume new roles as parents age. One study found that helping a parent that was ill or recently widowed provided individuals with a sense of pride in being able to offer help. For family members, this act of care involves "learning new skills and perceptions, acquiring a sense of purpose and self efficacy, and gaining emotional closeness and faith" (Singer, 1996).

4. Enables community living

For adults with high support needs, the presence of family caregivers may make the difference between living in an institutionalized setting, like residence or group home, and a home in the community, either on their own or with family. This is especially true, if as Singer and Irwin (1989) point out, families are provided adequate resources to do so.

Families play an important role in community participation and integration of children, and likely do so for adults as well. Lord & Ochocka (1995) suggest that families serve as vehicles for disabled family members to participate in the community, and have a role in the socialization in regards to leisure skills development, recreation and participation (p.22).

5. Fosters independence

For individuals with disabilities, engaging in family support relationships, particularly mutually supportive ones, fosters independence. Singer (1996) found that parents' caring was perceived as instrumental in fostering the disabled person's independence. He found that when individuals had needed support from their families, they were more independent, had more community living skills, were less likely to become homeless; and had lower rates of hospital use (Singer, 1996 pp.21-22).

While research demonstrates the value of family caregiving relationships, some authors also caution that too much reliance on family caregivers could result in dependence, rather than independence (The Roeher Institute, 2001). Support between family members needs to be balanced with other forms of support, so that both the person giving, and receiving support have choices as to the degree they participate in that activity with each other.

D. Challenges and Issues

1. Multiple roles

Research shows that families caring for disabled members often must take on a number of demanding and conflicting roles - nurse, service coordinator, case manager, advocate, trainer and educator (Kirk, 1998; Petr, et al., 1995, Havestock, 1992). These responsibilities demand extensive time, and often require that parents reduce labour force participation or exit the paid labour force all together. Lack of workplace flexibility, adequate benefits and leave provisions mean that the needs of a family member with caring responsibilities for someone with a disability are not fully accommodated (The Roeher Institute, 1998). The extent of responsibilities can take a major toll on parents' physical, emotional, and psychological health (Kirk, 1998, Bradley, et al., 1995).

2. Lack of supports puts stress on families

Study after study shows that supports to individuals with disabilities and their families are often insufficient. This puts stress on families, who are expected to compensate for gaps in service in their unpaid, and often unrecognized roles as caregivers. Studies of parents (mainly mothers) providing the bulk of care of disabled family members describe them as often depressed, anxious, fatigued, and with reduced health status, as a result of limited of supports like respite care (The Institute, 2000). Emotional distress has also been found to be common in fathers and siblings. Many experience intermittent or chronic stress and many families described themselves as unhappy as a result (Heller et al., 1997, p. 5).

Research suggests an important role for formal services is in providing parents' back up supports. The use of formal services predicted both lower caregiving time demands and lower perceived caregiver burdens (Haveman et al., 1997). The authors suggest that formal services can reduce the amount of time families spend in providing direct care, which would give them more time to provide emotional support to all family members (p.423). This is especially true for those living in poverty. Singer & Irwin (1989) draw attention to the "overriding burden placed on families by the convergence of poverty and caregiving" (p.22).

3. Gendered responsibility

Gender has emerged as a major issue in the unpaid caregiving literature over the past few decades. Census data shows that women continue to provide the bulk of caregiving on an unpaid basis (Status of Women Canada, 1998)[4], as the earlier section on demographics shows. In terms of providing disability-related support to families, the literature repeatedly shows that women take on the bulk of the responsibilities for personal care, homemaking, advocacy, nursing and so on (Heller et al., 1997, p. 412). This is true whether or not they are in the workforce (Marcenko and Meyer (1991) cited in Heller et al, 1997). In fact, when a family member has a disability, and unpaid responsibilities are greater, traditional gender roles seem to be even further entrenched (Heller et al, 1997, p.407). Even in families where fathers spend more time helping, one study suggests this does not reduce the time spent by the mother. In fact, it was associated with mothers spending more time (Heller et al., 1997, p. 414).

The literature suggests that new ways are needed to support families in light of the “dramatic contemporary revision of traditional gender roles” (Singer, 1996 p.13). Many theorists concerned with issues of gender and/or unpaid work (Rubin, 1975; Kramarae and Treichler, 1985; Haraway, 1991; Walmsley, 1993) have argued that women are socialized by a series of social and cultural restrictions and expectations to fulfill caregiving and domestic roles, without financial compensation. Doing so limits their social and economic opportunities. Shifting gender expectations also encourage women to participate in the paid labour force, in effect adding new responsibilities without easing the traditional ones. Now many women must juggle multiple roles as caregivers and as paid workers. For women caring for children with disabilities,

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[4] HALS does not distinguish on the basis of gender between sibling, extended family and parental caregivers, accordingly underestimating the extent of female involvement in informal care within the family, probably by a considerable margin.

there appears to be a triple burden - domestic work, paid work, and providing disability related care to a family member with a disability.

Women's unpaid contributions tend to be invisible in social policy. O'Brien & O'Brien (1991) assert that different types of caring are homogenized under the term "natural support" by policy makers who minimize the contribution of family caregivers (p.14). According to Finch (1989), policy makers overlook women's contribution, "dismissing it as the proper feminine response to a private family trouble, her concerns get left out of decisions about taxation and public spending" (O'Brien & O'Brien, 1991, p.14).

4. Sibling relationships

Policy issues also arise with respect to support provided by siblings. Much of the literature on family caregiving examines the experiences of parents and children. However a growing body of research is concerned with siblings. Siblings are often involved in the lives of their brothers and sisters with disabilities. Growing up, many siblings, especially sisters were thrust into positions of surrogate parenting or caregiving (Stoneman, Brody, Davis, & Crapps, 1987; Wilson, Balcher, & Baker, 1989) (Selzter et al., 1997).

Throughout life, siblings relationships and experiences shift and change (Begun, 1989; Johnson, 1998; Swados, 1991; Zetlin, 1986). According to the literature, these relationships are influenced by how the family perceives disability, how parents react to challenges related to disability and overall family adaptation patterns (Selzter et al., 395).

Despite the importance of the sibling relationship - especially in light of the fact that aging parents may not be able to continue to provide disability-related support for as long as it is needed - there has been inadequate attention in policy making to the needs of sibling caregivers (Selzter et al., 1997, p. 395). Their responsibilities may last much longer than those of parents.

5. Cultural differences

Another issue that arises in the literature on family caregiving is the importance of addressing cultural differences. For example, in a study on the needs of older families from diverse ethno-racial and cultural backgrounds, who are caring for a family member with a disability in their home, McCalllion, P.M., Janicki, M., & Grant-Griffin, L.(1997, p.347) found cultural differences along the following dimensions:

- family perceptions about disability (i.e. shame)
- who is included as part of the family (multi-generation, extended or nuclear)
- who provides care (gender, family role)
- how the family makes decisions about care
- family expectations
- the availability of supports (formal and informal) to the family
- why families moved (immigrated?)
- willingness to accept formal services
- the family's first language
- family concerns regarding service providers.

Cultural differences between families in these areas draw attention to the need for policy approaches that responded to families needs in diverse ways.

Research points to the importance of access to formal paid supports as a measure to ensure independence, interdependence and reciprocity, but also suggests that when formal caregiving is not preferred, family contributions should be adequately compensated. Formal supports are not always preferred. According to Doty (1986) the ‘viability’ of relying on informal caregivers for the long term care needs of older disabled sons and daughters is a major issue for families as parents age. Some families actively avoid contact with service providers because of past negative experiences with the service providers and cultural norms regarding use of community services. According to McCallion et al., (1997, p.348), conventional service interventions may clash with cultural traditions and responsibility for the care of family members.

6. Caregiving across the life span

Research has also examined *differences in caregiving across the life span*. Families in different life stages have different experiences, different access to supports, and family members’ relationships with one another also change. Farber (1975) found that as a child moves toward adulthood, caregiving becomes more taxing. As the child reaches adolescence and adulthood, parents may still be involved in parenting tasks more typical in families with younger children. According to Johnson & Catalano (1983), the “wear and tear” hypothesis predicts that the long-term caregiving demands and accumulation of stressors result in a depletion of physical and psychological resources (Haveman et al, 1997). However, Townsend, Noelker, Deimling, & Bass (1989) suggest that there is a better adjustment to the caregiver role over time. These contradictory findings suggest that the disability-related needs of disabled family members are not the factor determining family well-being. The nature and extent of supports to families are key factors in shaping outcomes.

Shifts in eligibility for support services indicate a number of expectations in social policy that for many families are not realistic. Supports seem to be most available to families of young children either in the home or through special education. As children get older they are expected to become more independent, and are considered more the responsibility of the family than the state. By the time they are adults many lose access to the supports and services they enjoyed as adolescents, often through school (i.e. recreation, school health support services). As a result, they have to rely exclusively on families and friends to assist them.

At the same time, as people get older their relationships change, and what they consider to be appropriate in their relationships change. Few adults in their twenties or thirties prefer to be bathed by their parents. Yet adults with disabilities who live their parents experience restricted access to attendant services. If they choose to live with a sibling, or a roommate, or on their own, they cannot be counted as a "dependent" for tax purposes, even if that person, or a non-residing parent, expends considerable resources providing practical and financial supports. In a recent study, young women reported that they chose to leave their parents' home so that they could access paid supports, and give their mothers and siblings a break (The Roeher Institute, 2000b).

7. Barriers to reciprocity

While people with disabilities have repeatedly emphasized the importance of reciprocity in relationships with family members and others (Walmsley, 1993, The Roeher Institute, 2000) they face a number of difficulties in this regard. The contributions of the disabled adult in the caregiving relationship is not always recognized. Women interviewed for a recent study were concerned that their contributions were not always acknowledged. Even when they felt overburdened themselves by caring responsibilities, they were seen as always being on the receiving end of support. One woman interviewed for the study explained it this way:

> I supported my father all through my mother's deterioration. I've been the one whose been there to talk to him and provide support. But when it comes right down to it, he sees me as dependent and helpless. In reality, he is reliant on me. If you were to ask him, he'd say his wife is in a nursing home and his daughter is quadriplegic. One of my brothers will go over and spend an hour cleaning the eaves-trough, and isn't he wonderful? The hours of support I provide don't count.

Women in the study also pointed out that they didn't always have the opportunity to contribute in ways they felt were meaningful or significant. Limited access to disability-related support, or inflexible structures of support made it difficult for them to do things for others as much as they may have wanted — while at the same time forcing them into positions where they had to rely on more support than they wanted from a family member or friend. When this happened it threw their personal relationship off balance, making them feel dependent, a burden and guilty (The Roeher Institute, 2000).

II. With Paid Support Providers

A. Characteristics of the Relationship

Many people engage in relationships where one party is paid to be in that relationship - for instance, students and teachers, counselors and therapy clients, or housekeepers and the people that employ them. The concern in this paper is about very specific types of paid relationships involving disability-related supports, in particular intimate, ongoing caregiving support. A number of different types of workers fall into this category, each addressing different kinds of support needs on the part of individuals with a disability, including attendant service workers, home care providers, and other personal support workers.

1. Attendant service workers

Attendants are individuals hired to provide personal care services, generally to individuals with physical disabilities who require assistance with activities of daily living, or working. Job descriptions of attendants vary according to who they work for, and what is needed by their client or employer. Generally they provide personal assistance in getting in or out of bed, dressing, bathing and other grooming, going to the bathroom and so on. They may also provide assistance in eating, driving, using the bank machine, and the like. While some attendant care job restrictions may place limits on the activities of workers, such as the amount of weight that can be lifted, or excluded home care activities (cleaning, cooking), or sexual assistance, generally the attendant takes direction from the person with a disability for whom they work, acting as their “arms and legs”.

In Canada, attendant service providers work within a number of job models. Although the names of these services vary by province, the basic models remain similar, including the following:

- *Supportive Housing Projects or Supportive Housing Living Units (SSLU’s*) are regular apartment buildings with a built in attendant agency for those tenants that have disabilities. Attendants, acting as employees of the agency, serve clients on a rotational or on-call basis in their own apartments.

- *Attendant care* outreach agencies provide services to people in their private homes or apartments. The agency sends staff out to provide pre-scheduled service to clients.

- *Direct funding* provides persons with disabilities funding to become employers of an attendant staff. They hire, pay and manage employees to provide services to them. A relatively new option, this funding mechanism is available only on a limited basis.

These models of funding and service provision structure the nature of the relationship. Under the first two, the relationship is triangular - the attendant is an employee of an agency, and the person with a disability is a client of the agency. The relationship is a consumer, or client, to a staff person. Under direct funding the relationship is one of employer and employee between two individuals.

2. Home care provider

Although attendant services and support worker services may be delivered under the auspices of homecare, for the purposes of this report we have made a distinction between these, and home care providers. Home care providers are understood to be individuals who provide service related to care of the home, or practical tasks around the home, as opposed to personal care. This would include activities such has housekeeping, cooking, repairs, odd jobs and so on.

These distinctions between attendant care workers and homecare providers are not always made. The agency or the direct funding employer determines job descriptions, and may have one staff person perform both roles. In other cases, different people perform the different roles. Home care is generally provided through the same models of service outlined above.

3. Support workers

Support workers generally work with individuals who have an intellectual or developmental disability (they may also have other types of disabilities). Their role involves a range of tasks such as supporting independent living, teaching life skills, community integration, assistance with financial planning and budgeting, sex education, attending appointments, individualized planning, community outreach, family liaison, and personal care. The types and amount of tasks a support worker does in relation to any individual depends on that particular individual's support needs, their living situation and their access to other forms of support.

Support work is delivered through a number of different models. These include:

- *Individualized funding*, which like direct funding, provides funding directly to individuals and/or their families to hire, fire and train their own support workers.

- *Supported Independent Living,* where individuals with disabilities live in their own homes or apartments and receive outreach support through an agency. The amount of support varies from person to person according to their needs.

- *Group Homes,* which offer 24-hour care in a semi-institutionalized environment located in the community.

4. Community based

In the past, relationships of support between individuals with disabilities and paid workers generally happened within the context of institutional settings. Institutions had dramatic effects on the quality of possible relationships - and tended to be clinical and distant, often fraught with abuse. According to Dumaresq and Lawton (1999), since the 1970s families and advocacy groups placed enormous pressure on government to redirect financial resources from institutional care to community care. As a result, the movement towards community care led to the deinstitutionalisation of people with disabilities. Government funds were directed to communities to establish agencies, and to professionals whose mandate is to provide services and supports to people with disabilities and their families (p.509). These authors refer specifically to the community living movement, which involved mainly people with intellectual disabilities and their families. At the same time, the independent living movement was underway. Consumer organizations of people with disabilities put similar pressures on government to provide supports to individuals with disabilities to support them to live independently.

As a result of these changes, most of the relationships referred to in this section on paid caregivers now happen in the context of the community and of the independent lives of people with disabilities. The exception is supports provided in group homes, which are a semi-institutional setting.

5. Fictive kin

One characteristic of some support worker relationships is the phenomena of what has been referred to in some research as “fictive kin”. According to Karner (1998, p.3) the support provided by a paid caregiver can maintain the values and ideals of support provided by family members, including both privacy and intimacy. Caregiving is viewed in this sense as a “dynamic process.... that is accomplished within a cultural context with attendant meaning, symbols, and rituals for the participants.” Caregivers experience a wide range of relationships that vary with regards to generation, gender, and individual family histories. Care-giving tasks are also shaped by the worker’s cultural understanding of the process. According to Gubruim & Buckholdt (1992), this understanding “propels the assignment of the kin relationships to non-family who embody the special characteristics of the family.” In this respect they suggest that paid caregivers can be thought of as ‘fictive kin’ when they perform the same tasks as family members in a support relationship, have affection for a person, and assist them in realizing their personal aims.

6. Individualized

Regardless of the service model under which disability-related supports are provided, in community-based settings (a person's private home or otherwise) there is a growing trend to provide them in an individualized manner. Every individual has different support needs. Some need only ten hours of attendant service per week, whereas others need 24-hour care. Increasingly, in the case of adults with intellectual disabilities, service providers work as part of a team. (Dumaresq & Lawton, 1999). Ideally, needed professionals will work closely with people with disabilities and their families, to shape individualized service agreements and service plans that are action oriented and based on a person's own goals (p.519).

7. Time-based

Relationships involving paid caregivers happen within the context of fixed sets of time. The relationship is, to a great extent, defined by the length of employment of a paid caregiver, and by their daily work hours. Tarlow suggests that caring is best understood as a process that consists of eight overlapping aspects: giving time; being there; talking; sensitivity; acting in the best interest of the cared for; caring as feelings; caring as doing; and reciprocity (p.57). Tarlow (1996) states:

> To begin caring, there must be people present, time to do the tasks of caring and a vehicle for facilitating the process-talking. Next, the caring person has to be sensitive to the needs of the other, act in the best interest of the other, be emotionally invested, and , most important, do helpful things for the other. The person cared for must then respond in such a way as to perpetuate the process, which involves reciprocity"(p.57).

Time given in caring is one measure of the caring relationship. Time invested in the caring relationship can nurture and allow the cared-for person to flourish (p.60-61). The concept of ‘being there’ implies that the one doing the caring is available and welcoming in whatever way possible to the recipient of care. The sense of ‘being there’ diminishes when time is structured by the terms of employment in the caring relationship. Clearly defined boundaries in these types of social relationships limit the amount of time and ‘being there’ for the cared person.

8. Motivation and personal attachment

By definition, close personal relationships are based on shared feelings of affection and concern between individuals. In paid caregiving relationships, this is not necessarily the case. Individuals do not always enter into the relationship because they are interested in, or care about the other person, but because a person needs the support, or because it is their paid job. Nevertheless, the literature on caregiving and persons with intellectual disabilities pays considerable attention to the feelings and motivations which enter into these relationships. Tarlow found that the nature of motivation in such relationships changes with the social context. Motivations of volunteers for example, are linked to a sense of public concern. Motivations that characterize family caring, on the other hand, are related to personal attachment and described as “... intense, physical and passionate emotions” (p. 71)

In another study, women with disabilities had differing views and preferences as to the role personal feeling played in their relationships with attendant care workers. Some wanted the relationships to involve personal feelings, caring and affection. Others wanted to avoid emotional interactions with attendants, and just receive the personal care services they needed. In the same study, attendants expressed the similar variability (The Roeher Institute, 2001).

9. Personal knowledge

In relationships of support with a paid caregiver, personal knowledge of the adult with a disability is an important ingredient. This is especially important where individuals may communicate in ways different to the dominant languages in a culture, and where their physical and intellectual differences make them the subject of negative attitudes and stereotyping by the broader community. A national study of deinstitutionalization in Canada found that development of positive attitudes toward people with disabilities among community members was closely associated with knowing them personally. The study also found a clearly demarcated difference in the value and respect accorded an individual with a disability, depending on how well a caregiver knew the individual as a person (The Roeher Institute, 1999). It has also been argued in a review of selected legal cases that personal knowledge of an adult with an intellectual disability is a factor in whether a person is considered competent or incompetent (The Roeher Institute, 1993).

10. Reciprocity

Noddings (1996) explores what it means to be a ‘caring professional.’ Her discussion focuses on the basic nature of professionalism, which applies to all caring professions. She describes caring as a “particular kind of relation between a carer and a cared for”(p.161). Relationships may be mutual, there may be an exchange of reciprocity, a shared responsibility of giving and receiving. She suggests that when we care, or we are in a carer position - our consciousness exhibits two fundamental characteristics: a receptive mode (i.e., we attend to the person non-selectively and are mentally engaged in the individual’s plans, pains and hopes); and we are propelled forward by our need to help further the individual’s plans, relieve their pain, or actualize their hope (p.161) . In the relationship there is an exchange of verbal and nonverbal cues, which helps the service provider monitor the effects of her or his efforts and complete the relation of caring. (p.161).

B. Demographics of the Relationship

It is not possible with existing data sources to identify the numbers of adults with disabilities receiving paid personal supports, but the figures available indicate a large group even with the limited data available. As Table 1 indicates, just over 15% of people with disabilities age 15 and over (almost 570,000 people in HALS 1991 estimates), who are living in the community use paid supports provided by an agency. This represents about 30% of all individuals with disabilities who indicate they require assistance for disability-related needs. This figure compares with the later, 1996 National Population Health Survey, which estimates that 520,000 adults with disabilities age 18 and over receive some form of home care services from an agency. An additional group, for which national data does not exist, use the services of paid support providers who are not attached to an agency, They include those who employ paid support staff out-of-pocket or using individualized or direct funding programs.

Existing data sources do not indicate the intensity of these relationships or whether they constitute “close personal relationships”. A few trends suggest that these relationships are likely to increase substantially in the next decade: aging of the population (and thus an increasing proportion of adults with disabilities); the trend toward deinstitutionalization and increased provision of home care; and that fact that many family caregivers are aging themselves and will become less able to provide the extent of support they now do.

C. Value of the Relationship

Research on relationships with paid staff suggest that there can be a positive impact for both the recipient of support and the provider.

1. Provide needed support

The primary value for individuals and families of the paid support provided is simply that it helps to meet their needs, and eases the difficulties that come with lack of support. How that support is provided, and the extent to which it is accountable to individuals and families makes all the difference. Dumaresq & Lawton (1999) point to a number of characteristics in a professional that are valued by individuals and families: honesty, flexibility and being a good listener; understanding of people's needs; validating concerns and needs; being respectful of the caring parent's knowledge about their own children and families; a focus on abilities; empathy for the sense of isolation they feel; realistic expectations; appreciation of people's desire for a happy and fulfilling life; respect for human rights; and a caring, non-judgmental attitude (p.514).

2. Bridge-builders

Lord & Ochnocka (1997) suggest that paid caregivers can play important roles as 'bridge-builders' to the community for the adults they support - where they take responsibility to connect people with community settings and relationships.

3. Promote empowerment of individuals

Jones, et al. (1996) suggest that relationships with paid caregivers can be empowering where empowerment is understood as:

- enabling a person to exercise control over decisions of a personal nature;
- ability to influence one's environment;
- support to participate in individual/family-professional partnerships and collaboration;
- community participation and leadership in organizations.

To do so, paid caregivers must practise:

- empathy and concern (genuine concern, understanding, sensitivity, nonjudgmental attitude, ability to put oneself in the shoes of the family);

- flexibility (in regards to what works for families, value and respect for the family's viewpoint, sensitive to family needs and culture, respectful of self-determination and not impose one's own values);

- enabling attitudes (humility, the role of an educator, nonjudgmental, respectful of families knowledge about their needs, open to learning, maintains a balance in the relationship) (Jones et al, 1996, p.95-96).

Roles and activities of professional service providers that foster empowerment through paid caregiving include:

- a collaborator (generate new ideas and alternatives for families);
- an advocate (within and outside the family system);
- emotional support and encouragement (validate feelings and choices);
- supportive and trusting environment).

D. Challenges and Issues

1. Violence and abuse

People with disabilities face extremely high rates of violence and abuse by paid caregivers (The Roeher Institute, 1995). Up to 60% of women with intellectual disabilities and 40% of men have been sexually abused either in childhood or adulthood; for people who are deaf the figure is 50% of women and 50% of men. For people with other physical disabilities, and mental health problems, the figures are similarly high. The literature points to a number of reasons for this vulnerability: the social isolation of people with disabilities, the physical power imbalance between most paid or non-paid caregivers and people with disabilities, and the stress of providing supports without adequate financial remuneration and other back-up resources.

2. Status of paid caregivers

While the notion of "fictive kin" may help to illuminate characteristics of what are considered positive paid caregiving relationships, the term may also serve to limit understanding of their nature. Fitting new kinds of relationships - like paid caregiving - into a traditional family/kinship model, may reproduce elements of those relationships that do little to advance other values like those of self-determination, autonomy, and equality of both disabled adults and their support providers. For example, a fictive kin model may position the disabled adult as a person entirely in need, rather than as a contributor who hires paid caregivers as a resource. As well, it may help to justify the gendered divisions of labour which characterize personal care in families generally, divisions which appear to be reproduced in paid caregiving (with the disproportionate number of women providing home care and related personal support services). Cantor (1991) suggests "we cannot expect women at the lowest rungs of the economic ladder to subsidize the homecare of the elderly." (p. 343)

3. Wages and benefits

Research suggests that the status of disability-support workers has declined with the shift from institutional to community care. Those who provide community-based disability-related supports tend to have low wages; variable access to benefits, training, and workers compensation; long hours and shifts; and odd hours.

4. Limited access to paid supports

Access to paid supports is dependent on other relationships in the lives of people with disabilities. When people with disabilities live with family, they are less likely to access supports. Eligibility for paid supports is often determined on the basis of supports available in the natural family that can be provided on a voluntary basis. However, fiscal restraint has led to expectations that families should carry a burden of care that many are simply unable to do in a way that fosters the self-determination, citizenship and inclusion of people with disabilities.

5. Requirements of paid staff

Funding and delivery systems increasingly require paid caregivers to be accountable to the choices of the people they support. With this shift individual questions are being raised about limits to the control a person can exercise over paid staff.

For example some are questioning the role of paid caregivers in providing sexual assistance. Given the importance of sexuality to one’s well-being and self-determination, what should the requirements of paid staff be? Should they be required to physically assist a person without physical dexterity - in sexual expression through masturbation, and/or through relations with sexual partners? What are the controls a person can exercise, and how should those thresholds be defined?[5]

III. Alternative Family and Adult Home Sharing

Many people with disabilities are not able to live independently on their own. They may not want to, or be able to live with natural family members or obtain adequate support from them. From the demographic review outlined above, many do not want to, or are not able to access group living arrangements funded through governments and community service agencies. Indeed, some provinces invest very little in this option. For those who require 24-hour or very extensive personal care, funding may not be available to purchase needed supports for an individual to live on his or her own. With these trends, “alternate family” arrangements and adult home sharing are becoming more widely used as another option for adults with disabilities. Both of these options are briefly outlined below.

A. Alternate Family

Used primarily for adults with intellectual or developmental disabilities, alternate family options are based on the idea that all people should have the opportunity to live in a family unit, and have support needs met in that environment, as an alternative to more restricted (i.e. institutional) environments. In the provincial scheme in Newfoundland, for example, an alternate family is generally expected to include a married, heterosexual couple, with natural children.

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[5] For a review of these issues see, Kyle Stone, "Sex and Disability: Whose job should it be to help disabled people make love?" *Eye Magazine*, Aug. 12, 1999; “Facilitated Sex and the Concept of Sexual Need: disabled students and their personal assistants”, in *Disability and Society*, Volume 14, Number 3, pp. 309-323; Attendant Care Action Coalition (1999) “Principles to Guide the Development of Attendant Services in Ontario”.

Criteria for applicants include motivation, community standing, adequate and stable income. Education, religious practices, neighbourhood, are all explored to facilitate appropriate ‘matches’.

Alternative family options are equivalent in many ways to foster families for children, with the important distinction that, in principle, adults are to choose their own alternate family from those willing and considered able to play this role. The arrangements are intended to foster relationships and inclusiveness equivalent to a positive natural family environment. Families are expected to include a person with a disability as a family member, and to provide social and other supports as needed, respecting the right of the individual to privacy and to make his or her own decisions.

The provincial department of social services generally plays a role in accepting applicants, making referrals, determining eligibility both for the individual and the alternate family applicant. Funds equivalent to board and lodging are provided to the alternate family, plus stipends depending on the nature and level of social and behavioural support that might be required. All supports to be provided by a family are not compensated, as in the case of a paid caregiving relationship - even though some of the tasks can be very similar.

Once an arrangement is approved, a formal contract is usually signed between the alternate family and the province or service agency facilitating the arrangement, and the individual. The contract specifies the rights and responsibilities of the alternate family provider and the individual.

B. Adult Home Sharing

Adult home sharing has long been an informal arrangement that un-related adults make to provide mutual support. It often involves an elderly person who may not want to leave his or her primary residence, but who has additional space and need for support after the death of a partner; and involves also spouses who, as they age (and become more disabled) need additional support short of formal homecare (e.g. to shovel walks, help with light maintenance). Increasingly, arrangements are being made through service agencies to assist younger adults with disabilities to live more independently in the community by linking with a non-disabled adult to share an apartment or house.

While informal arrangements have evolved to support adults outside of their natural family, in the past 15 to 20 years some community agencies have intentionally started to play a “matching” role, linking people looking for a place to live with those seeking informal, live-in support and companionship. “Matching” agencies conduct preliminary interviews with those in “demand” and those with “supply” to recommend appropriate matches, and may conduct criminal checks. They are available to assist in making the match, working out expectations and responsibilities, and in the case of matches made explicitly to support an adult with a disability, may arrange a stipend for the support person - not as a wage, but as compensation for time commitments made to the individual with whom he or she is home sharing.

This arrangement is still not well understood by policymakers, as a recent case in Quebec makes clear - *Brunette* v. *Quebec*. The case involved an older woman with “severe” and “chronic” disabilities on social assistance who arranged to rent a room to a man with an intellectual disability in exchange for a low rent and his assistance in household chores. The province required the woman to reimburse social assistance benefits of over $55,000 after it was determined that she had received benefits while in an undeclared spousal relationship with the man providing support - this even though the man had a girlfriend. The ruling was eventually overturned by the courts. It is a good example of what is termed in a review of case law below of "pigeon-holing", where governments and courts use very limited models of what constitute adult personal relationships to interpret what are, in fact, hugely diverse relationships and arrangements.

C. Demographics of the Relationships

There is no specific data on numbers of adults with disabilities living in alternate family and adult home sharing arrangements. HALS 1991 estimates suggest that in that year about 140,000 adults with disabilities were living in economic family households (living with adults other than natural family members, or in group home living arrangements). This variable is as close as we can get at this point to a national-level statistic on adult home sharing and alternate family arrangements. Table 4 provides a comparison of economic family and census family (or those living with natural family members) households involving one or more adults with a disability.

Table 4: Adults with Disabilities in Census and Economic Families

Census Family	
Living with parent(s), and/or siblings	275,000
Male partner with a sibling	1,050,000
Female partner with a disability	915,000
Male lone-parent families	32,000
Female lone-parent families	155,000
Total	2,427,000
Economic Family	
Shared living with one or more adults with a disablilty (outside of group home arrangements)	140,000
Total	140,000

D. Value of the Relationships

The research conducted on adult home sharing and alternate family arrangements is limited, but points to many of the values attributed to relationships in both family caregiving and paid caregiving arrangements. The arrangements foster a person's independence in the community, can enable relationships of reciprocity and mutual support, and can act as a bridge to the wider community for a person with a disability. They enable an adult with a disability to establish non-familial and non-paid relationships with others, which have been for some a source of social isolation in the community.

E. Challenges and Issues

Those living in adult home sharing and alternate family arrangements share some of the challenges that family caregivers and paid caregivers face. While these arrangements have not been extensively researched, four key challenges emerge from the limited experience (The Roeher Institute 1999, 1997).

First, expectations for support can be very high, and needs can shift and change over time, without the providers having needed back-up supports. A high degree of flexibility and commitment by the alternate family and adult homesharer is usually required to make the arrangements work. Lack of back-up supports often leaves these care providers in a situation similar to family caregivers. Meeting needs for supports can lead to stress and breakdown of the relationship. In the case of alternate families and homesharers, the commitments are usually not as long-term as natural family members, nor the attachments as deep - though this does occur. Thus, these latter arrangements can be changed by the providers more easily than where family caregivers have become the primary source of care. Alternate families and adult homesharers can terminate the relationship.

Second, those in receipt of alternate family and home sharing support often benefit from a network of advocacy and/or support outside of the alternate family to ensure they are supported to make decisions, to negotiate any conflicts that may arise with the alternate family, to ensure they receive the support they are entitled to, and that they are protected from neglect and abuse. There has been variable success in ensuring such supports are available.

Third, alternate families and homesharers are also paid caregivers. However, the compensation is often limited, does not provide benefits, and because providers are not employees, the arrangements usually do not provide coverage for workers' compensation. Limited compensation combined with often inadequate back-up supports from agencies or other service providers means this option is more limited than it might otherwise be.

Fourth, the status of alternate family providers and adult homesharers is often unclear. Does a person sharing an apartment with an adult with a disability have obligations to provide care beyond those negotiated - to meet needs which may emerge through the course of the relationship? Does the fact that one has chosen to share a home with a person with a disability explicitly because that person has a disability, in return for some income and in-kind benefits, impose certain obligations and fiduciary duties? Or, if a person with a disability provides an exchange of often un-compensated services (home maintenance, personal care, etc. as in the Brunette case), and has thus experienced lost economic opportunity, should the individual providing such services have any claim to support after the relationship ends? Is there a threshold, in terms of length of the relationship, or amount of service provided, which would determine the validity of such a claim? Would imposition of such obligations threaten the viability of these support arrangements - which have proven cost-effective for supporting people with disabilities in the community in a way that can advance their independence and inclusion?

IV. Supported Decision-Making Network

Supported decision-making networks were developed by people with intellectual disabilities and family advocacy organizations as a model to provide adults with decision-making assistance. The aim was to provide the assistance for health care, personal, and other financial decisions that would limit the call by third parties (e.g. physicians, financial agents, service providers) for 'substitute decision making' on the basis that the person was legally incompetent to make decisions. Substitute or guardianship provisions were recognized by many to represent the antithesis of the underlying principles of community and independent living - individual autonomy and self-determination. People with disabilities and their advocacy organizations suggest that from a human rights perspective guardianship represents removal of fundamental rights and discrimination on the basis of disability. Yet they also recognize that people often need assistance to make their own decisions.[6] Conventional decision making approaches have not provided a solution to those who want to maintain their status as a legal person, but who also want and require assistance in making decisions.

The institution of guardianship has come under question because of concerns about the ease with which guardianship is obtained, the costs and court procedures associated with awarding guardianship, and the fact that guardianship becomes a means of social control. The assumption that guardianship will provide protection for the person under the order is an unfounded one given the abuses that some guardians have inflicted. Moreover, the assumed protection provided by a guardian carries with it a cloak of paternalism (Herr and Hopkins, 1994). Guardianship provisions have also been criticized for using vague and conflicting criteria for appointment of guardians, for failing to limit and monitor guardians' authority, for denying due process rights, and for confusing disability with incapacity to make decisions (Gordon and Verdun-Jones, 1992).

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[6] See Canadian Association for Community Living, "Brief to the Standing Committee on Administration of Justice, March, 1992"; Ontario Association for Community Living, "Brief to the Standing Committee on Administration of Justice, February, 1992"; "Motions Made by People First of Ontario," Provincial Board of Directors Meeting, Toronto, Saturday, June 20, 1992.

A. Model of Supported Decision-Making

A model of "supported decision-making" has been developed in Canada through a number of consultations in the early 1990s. The model goes substantially further than the alternatives to guardianship outlined above, in that it removes the distinction between the competent and the incompetent as the basis for retaining and exercising decision making rights. In British Columbia public consultations led to the development of the mechanism of representation agreements, which some view as the basis for implementing a form of supported decision-making.[7] Community consultations have been held in a number of jurisdictions to develop alternatives to guardianship. A supported decision-making model has been articulated as an outcome of these consultations.[8] In 1991 the Canadian Association for Community Living appointed a task force to consider alternatives to guardianship, given the impetus for reform that was visible in provincial and territorial jurisdictions. That task force prepared a report outlining a supported decision-making model and the kinds of legislative provisions that would need to be incorporated in order to reform current decision-making requirements and practices.[9] During the same period the Ontario Association for Community Living also undertook to prepare a report on supported decision making, as the basis for a submission concerning proposed substitute decision-making legislation in Ontario.[10] These various proposals point to a number of common elements of a supported decision-making model that emerge.

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[7] See Joint Working Committee (Interministry Committee on Issues Affecting Dependent Adults and the Project to Review Adult Guardianship), "How Can We Help? A new look at self-determination, interdependence, substitute decision making and guardianship in B.C." Vancouver: May, 1992.

[8] See, for example, "Community Consultation Report on Supported Decision Making," Whitehorse, Yukon: Yukon Association for Community Living, December 2, 1991.

[9] See “Report of the C.A.C.L. Task Force on Alternatives to Guardianship,” Toronto: Canadian Association for Community Living," August, 1992.

[10] See Ontario Association for Community Living, "Brief to the Standing Committee on the Administration of Justice," Toronto: Ontario Association for Community Living, January 1992.

First, supported decision making is based on a set of guiding principles which emphasize the persons' right to self-determination and autonomy, the presumption of capacity, and the right to decision-making supports in order to enable equality before and under the law, without discrimination on the basis of disability.

A second key element of the model is the recognition that a person's will and intent can be the basis of a competent decision-making process which does not remove the person's decision-making rights. This recognition keeps the person's wishes and will at the centre of the decision-making process, while requiring that the process rather than the person be held responsible for a competent decision based on the person's will.

Third, supported decision making requires the recognition of the decision-making assistance of others. Decision-making assistance can take many forms from interpretation, to advocacy, to information, and consultation. These supports contribute to making the decision-making process a competent one, where persons are not fully able to make decisions without assistance from others. According to the supported decision-making model, where decision-making assistance is provided in the context of personal relationships in which the person has expressed trust, the validity of this assistance should be recognized.

Fourth, a new system of accountabilities is necessary to make supported decision making effective, and consistent with the principles of self-determination and presumption of capacity. Third party interests, persons providing decision-making support, and the state all have roles to play in ensuring a competent and accountable decision-making process.

The proposals for supported decision making all emphasize that alternative standards of competent decision making need to be constructed if rights to self-determination are to be protected for people with intellectual disabilities. As long as the conventional standards prevail -- that individuals have to be able to fully understand the nature and consequences of decisions, and to assess the relative benefit/harm ratios of different choice options -- people with intellectual disabilities will continue to be at risk of losing their fundamental rights. The supported decision-making model does not rely on the traditional standards of competent decision-making. Rather, the model focuses on establishing the conditions for a competent decision making *process*, one in which the decisions are made which accord with the will and intent of the person whose capacity to make decisions on his or her own is in question.

B. Demographics

There are no national data sources on extent of supported decision-making networks. Some questions in the Health and Activity Limitations Survey and the National Population Health Survey refer to a person's social supports, but these do not provide proxies adequate to the notion of supported decision-making network.

Policy and program evaluation suggest that this form of relationship is growing, as more and more individuals move to community arrangements where decisions about health care, finances, support staff, etc. need to be made. This is especially the case where some form of individualized funding of supports is established - providing individuals with the funds to purchase needed disability-related supports and thus the power to make decisions about who will provide them supports, where, when, and on what terms. Supported decision-making networks have been actively fostered in initiatives where such funding arrangements are established for adults with intellectual disabilities. In these initiatives, the majority of individuals who are involved tend to develop such networks (The Roeher Institute, 2000, 1999, 1997).

Qualitative and survey research of these initiatives suggest that mothers play a primary role in support networks, but that fathers and siblings are also actively involved although to a lesser extent. The make-up of networks is diverse involving family members, friends, volunteers, community advocates, and sometimes paid staff (The Roeher Institute, 2000, 1999).

C. Value of the Relationship

Research suggests that the value of support networks lies in four areas. First, networks have been established as a means to assist people in making decisions in ways that prevent imposition of guardianship and substitute decision-making orders which constitute a removal of the right to self-determination, at least with respect to some decision-making areas. They can help to ensure that an individual's broader civil rights -- to marry, have and raise children, participate on boards of directors of community organizations -- are exercised. These civil rights continue to be in question because of concerns by third parties about legal capacity. Adults with intellectual disabilities, especially, face significant -- if legitimate -- concerns from third parties about child-raising, for example, which have led to interventions by child welfare services to remove children from the homes of their parents, solely on the basis of a parent's intellectual disability. Support networks provide a legitimate way of assisting the individual, and meeting the interests of the state in the nurturing and care of children.

Second, such networks play a role in providing planning supports, and in developing a vision for a person's life in the community. As a group of people committed to a person they hold and communicate that vision. The development of a shared vision for a person's future, which is held by those close to the person, has been found to be directly associated with increasing personal relationships (and thus a reduction in social isolation); development of personal communication, physical and other capacities; increased social and economic participation and growing respect and value of the person by the wider community (The Roeher Institute, 2000, 1999, 1997).

Third, support networks act as a “bridge” to the wider community introducing and linking the person to other personal relationships and social and economic opportunity. Support network members play a role in interpreting and communicating a person’s wishes to the wider community, and thus help to break down the social barriers that tend to stigmatize and devalue persons based on their intellectual and other disabilities.

Fourth, support networks have been found to introduce cost-effectiveness into the funding and delivery of support services to adults with disabilities because they take on a major role, on a voluntary basis, in administration and management support for an individual’s living and support arrangements (Bell, 1998; The Roeher Institute, 1999).

D. Challenges and Issues

Four key challenges have been identified in fostering and sustaining support networks.

First, the burden on support networks of administering and helping to manage support arrangements can be extensive. In some situations, this leads to a breakdown of the network. Recruiting, managing, and coordinating support staff, providing planning and decision-making support to individuals, and managing finances of support arrangements requires investment of time and resources. On a voluntary basis, this can place too much stress on a support network to maintain its viability without back-up supports to the network itself.

Second, support networks undergo various shifts and transformations as new people become part of the network, an individual's needs and wishes change, and as the capacities of the network itself develop or decline. Sustaining networks through these transitions requires back-up support that is not always available.

Third, liabilities of support network members are not clearly established. Are they liable for contracts and agreements they support an individual to enter, and/or for decisions an individual makes that may place him or her, and others, at unjustifiable risk? Are support network members *de facto* employers in individualized funding arrangements where Revenue Canada determines that individuals are not capable of entering into employment contracts for paid caregivers (see The Roeher Institute, 1999)? Such situations have evolved leading some members of support networks to withdraw their status as formal network members.

Fourth, concerns have been expressed that support networks may hinder individual autonomy in some areas, and take on the role of decision-maker themselves, thus defeating the intended purpose. As well, some in the independent living movement are concerned that the model may be unduly applied to people with physical disabilities and have the effect of restricting autonomy. Measures are needed to ensure that support network members are provided education, that individual choice to have a network is protected, and that checks and balances are in place to prevent neglect and abuse by networks.

E. Summary of Characteristics and Value

The research reviewed suggests that the five types of personal relationships outlined above have common characteristics. The relationships:

- enable provision of needed personal care and assistance in a manner that is individualized and respectful of individual choice (as distinct from the institutionalized supports/care that has been the only option for many people with disabilities whose families could not support them)
- assist individuals to develop a personal life plan and identity that is shared with and valued by others
- are a source of personal knowledge with which to counter negative stereotypes
- constitute and enable personal relationships where disabled adults are respected and valued
- provide a source of companionship, affection, mutual respect, and dignity
- are a source of advocacy support to individuals to address societal barriers and entrenched discrimination
- provide a continuum of support even as individuals' needs and wishes change.

These characteristics persist across a diversity of settings, involve people living in or outside of a person's home, and reach into all aspects of a person's life.

For those involved, these relationships are valued when they:

- enable reciprocity
- recognize interdependence and rights of both adults with disabilities and caregivers
- make contributions by an individual possible
- provide a communication network for people who do not communicate in dominant languages of the culture
- promote value and respect of a person
- support people to make their own choices (self-determination, empowerment)
- build bridges to the community - for social, economic, political, and cultural participation

- encourage personal attachments, companionship, love
- create shared vision for a person’s future
- advance social, economic, and political participation
- strengthen families - through mutual care and support
- enable and make possible life in the community
- foster independence.

PART TWO

FORMS OF STATE SUPPORT AND REGULATION

The five types of personal relationships outlined above are shaped by a number of statutory and policy provisions. A comprehensive review of provisions affecting these relationships is beyond the scope of this study. Rather than providing a full inventory, provisions selected here illuminate the range of policies and statutes affecting these relationships.

Four kinds of provisions are in place that affect the relationships under review - including provisions for:

- basic income supports for adults with disabilities and family members
- funding and delivery of disability-related supports
- establishing decision-making status - provisions for the legal status of individuals and members of their personal networks to make and assist in making personal decisions
- labour law and regulation

The following overview indicates that many of the ongoing issues and challenges identified in research on the personal relationships are rooted in disincentives in policy and program arrangements in these four areas. The extent to which personal relationships are characterized by the valued qualities identified in the research is directly influenced by these arrangements.

I. Basic Income Support

Basic income support provisions directly affect the nature and quality of relationships that adults with disabilities have with other adults. To the extent people can obtain income to adequately meet their living expenses, they relieve family caregivers and others they have close relationships with, of meeting these expenses on their behalf. And to the extent that public income schemes create incentives for family members in these relationships to provide some income support (through private trusts, for example), these relationships can enhance economic security for adults with disabilities.

In addition to private earnings, adults with disabilities gain basic income support through sources much like other Canadians -- provincial/territorial social assistance for those in need, Canada Pension Plan/Quebec Pension Plan, federal Old Age Security and Guaranteed Income Supplement, federal and provincial personal, retail, and property tax credits, private sector pension benefits -- through employers and through individuals' own retirement savings plans, and financial trusts for which individuals are named beneficiaries. Depending on the cause and onset of disability, and relationship to the paid labour market, adults with disabilities also acquire income for living through workers' compensation, veterans' benefits, and private insurance benefits and settlements related to disability.

There are some specific tax provisions to support family caregivers, and to encourage private savings for support of a family member with a disability:

- A “wholly dependent person” personal credit can be claimed, where the person is “wholly dependent for support on the individual (as long as the person is a relative).

- An “infirm dependants credit” can be claimed for support to individuals over the age of 18 (as long as the person is a relative).

- A “caregiver credit” can be claimed where a person shares accommodation with a relative over the age of 18 who is dependent on the person because of mental or physical infirmity (as long as the person is a relative).

- To encourage savings for dependents with disabilities, lower tax rates are applied to trusts where a “preferred beneficiary” is designated - one group eligible for this designation being those who are eligible for the disability tax credit, or who are dependent on another individual because of mental of physical infirmity.

- Upon a person’s death, his/her Registered Retirement Savings Plans (RRSPs) and Registered Retirement Income Funds (RRIFs) can be transferred to a child or grandchild over the age of 18, if he/she is dependent by virtue of physical of mental infirmity - without imposing any immediate tax liability on the recipient.

These provisions are intended to recognize through tax credits to carers their personal contributions, and to enable financial assistance to persist over a person’s life time even if family members are no longer alive.

A. Disincentives to Promoting Valued Personal Relationships

Despite various income provisions, adults with disabilities tend to be poor, on fixed incomes (estimates are that about 30% of adults on social assistance have disabilities), and without secure attachment to the paid labour force (Axworthy, 1994). Over 365,000 adults with disabilities have non-reimbursed, out-of-pocket expenses for disability-related supports. The depth of poverty and out-of-pocket expenses places burdens on family members, which can contribute to the stress on these relationships and lead to the breakdown of reciprocity and respect for the person. In current policy and program arrangements, there are a number of disincentives to promoting economic security for adults with disabilities and recognizing family and others' contributions, as well as the contributions that people with disabilities make in their support relationships.

- Tax credits for family caregivers are limited and do not begin to compensate for lost economic opportunity or the costs of care, where family members are the primary and/or only source of care. Moreover, these are not refundable tax credits and thus are of no benefit to family caregivers living in poverty whose incomes are below the threshold for paying income tax.

- Eligibility criteria for use of caregiver credits require that an adult with a disability be constructed as "wholly dependent" in order to access the credit, thus entrenching the idea that adults with disabilities are dependent, and relationships of caring are one-way rather than reciprocal and shaped in part by the economic and other contributions of the person with a disability.

- Eligibility for tax credits for those providing support are restricted to specified relatives. This limits tax recognition of personal relationships of support to family members and paid caregivers (through recognition of attendant care under the medical expenses tax credit, for example). Those providing support through alternate family, homesharing, or a relationship where a support person is not paid and non-family, are not recognized or compensated.

- Cause of disability remains a major criterion determining differential access to income supports, in spite of the consequences and costs being very similar regardless of the cause. For example, those acquiring disability at their place of paid employment are usually assured supports through workers' compensation schemes, CPP/QPP and/or disability insurance plans. People born with a disabling condition have no such entitlement.

- Criteria for access to social assistance can often limit a disabled adult from pursuing employment opportunities, thereby limiting the financial contributions that can be made in the personal relationships he/she is a part of.

- Disabled adults who are beneficiaries of financial trusts, established by parents or others, face difficulty in some jurisdictions in obtaining eligibility for social assistance benefits while protecting the financial investment. This is changing. Under 1996 reforms in B.C., for example, trust funds up to $100,000 are no longer considered assets for the purposes of determining eligibility of adults with disabilities for social assistance. Trust fund payments are exempted from income tests if the funds are used to purchase disability-related supports.

- Significant discrepancies exist between the income support systems to which people with and without disabilities over the age of 65 have access, largely related to employment participation. For all persons over the age of 65 there are more supports, benefits and pensions available if they have had paying jobs. However, the majority of people with physical and intellectual disabilities have had limited opportunity to participate in the labour force. In 1998, CPP reforms tightened the eligibility to benefits for people with disabilities directly and indirectly by requiring greater attachment to the labour force as a condition of eligibility. Disadvantage is compounded if individuals with disabilities are women, persons of colour and First Nations people. The consequences are entrenched poverty, and additional pressures on relationships of support.

II. Funding and Delivery of Disability Supports

Funding for disability supports tends to fall largely under provincial jurisdiction. A variety of cost-sharing mechanisms were in place for the federal government to exercise its spending powers to assist in financing these supports. Those mechanisms have been consolidated largely in the Canada Health and Social Transfer, which provides a federal to provincial block transfer with few federal conditions attached. The federal government plays a direct transfer role to assist in covering the costs of supports to individuals with disabilities and their family members through various provisions in the tax system -- the disability tax credit and the medical expenses tax credit, for example.[11]

At the provincial level, the kinds of supports outlined in the review of the five personal relationships are funded, contracted and/or delivered by: provincial and territorial governments, quasi-governmental agencies, and the private insurance sector. Funding and services are delivered primarily through community agencies, but increasingly through individualized funding as well.

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[11] For a review of federal disability-related tax provisions, see David Duff (1992), *Disability and the Federal Income Tax Act* (Toronto: Williams Research.Com Inc.).

A. Community Agencies

Delivery involves the following kinds of community service agencies:

- community agencies usually funded by the public sector (e.g. disability-specific agencies like Outreach services for attendant care, local Associations for Community Living, Supported Independent Living agencies, as well as more generic agencies like Family Service agencies, child welfare agencies, etc.)[12]

- health and social service agencies within the public sector (e.g. social workers and behaviour management specialists that operate within local or regional offices of provincial social service departments, public sector home care agencies in some jurisdictions, as well as larger publicly-funded institutions - rehabilitation centres, psychiatric facilities, residential institutions for people with intellectual disabilities, long-term care facilities)

- voluntary organizations (e.g. which include many of the community agencies funded to provide services, but also encompasses local charitable organizations which provide funding for disability supports in some communities - Lions Clubs, Rotary Clubs)

- disability advocacy organizations(e.g. local Independent Living Centres, Learning Disability Associations, Associations for Community Living (often service providers as well), and informal networks and coalitions).

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[12] A national directory of disability organizations published by the Abilities Foundation lists, in the voluntary sector alone, over 5,000 disability-specific organizations in Canada. This does not include the generic community agencies (eg. home care providers, community health centres), or public sector and private for-profit sector agencies providing supports to people with disabilities.

Together, these organizations deliver disability supports to those involved in the personal relationships outlined above. Supports can include technical aids and devices, supported residential units, rehabilitation services, attendant services and other personal supports, counseling, vocational and other information services, advocacy services, peer support, environmental accommodations. While most of the organizations that deliver these supports are non-profit, disability-related supports are also delivered by some for-profit enterprises e.g., those that contract with Workers' Compensation Boards, insurance agencies, employers, and individuals to deliver rehabilitation services.

These organizations have significant responsibilities: they determine who gets what kinds of supports and on what terms, thereby crucially affecting the quality of life of people with disabilities (e.g., the extent to which they can move about society, interact with others, access education and training opportunities, the labour market etc.).

B. Individualized and Direct Funding

In addition to delivery of supports through agencies, a growing number of funding arrangements are being established to provide individuals and families with funds directly, in order to purchase their needed supports. "Consumer control" is increasingly a driving principle for designing funding and service delivery arrangements. Most provincial governments now have some policy and program framework for individualized funding, although the extent of such arrangements varies across the country. Alberta has probably gone the furthest in developing a policy and delivery system in this regard.

As indicated in the research reviewed above, such arrangements provide individuals with far greater control over key decisions in their lives, improve accountability of support providers to individuals and families, advance individuals' social and economic participation, expand personal relationships, improve personal capacities, foster greater respect and value of persons, and give paid caregivers a greater sense of job satisfaction.[13]

C. Disincentives to Promoting Valued Personal Relationships

A number of disincentives persist in policy and program arrangements to promoting personal support relationships characterized by the valued qualities outlined in the previous section. These disincentives work to limit individual choice and restrict access to needed supports, thus leaving individuals to rely more on family members than may be viable (thereby threatening those relationships), or leave them without access to the extent of paid caregiving supports they require (thereby leaving them without the bridge building, personal assistance, and source of value and respect to ensure their citizenship and inclusion). Disincentives include:

1. Unmet costs of disability

The costs associated with having a disability, including assistive devices and attendant and other support workers are not adequately addressed by the current system of income and disability supports. This leaves those who do provide supports facing unmet need, and/or inadequate remuneration. Such conditions undermine the capacity of personal relationships to ensure equity for caregivers, and quality for recipients of support. Restrictive terms of entitlement and eligibility are primary factors for limiting access. Eligibility rules often act to restrict access to services and supports rather than ensure that people receive the support they

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[13] For an overview of individualized funding initiatives in Canada see The Roeher Institute, 2000; 1997; 1993b. For an analysis of initiatives in the United States and internationally see Powers, 2000; and Tilley, 2000.

need. Under the current complex system of health and social services, qualification to receive support is based on various factors including age, cause of disability and level of income.

2. Age and disability limitations

When determining eligibility for support, the biological and chronological aspects of aging tend to be emphasized. However, in the case of some types of disabilities, the process of aging advances earlier than for most people. For example, Puccio, Janicki, Ottis, & Rettig (1983) suggest that people with intellectual disabilities begin to show signs of old age during their 40s. There is also evidence of increased incidence and significantly earlier onset of Alzheimer's disease among persons with Down Syndrome (Lott & Lai, 1982; Lendon et. al., 1997; Schupf et. al., 1998). Other disability-related eligibility criteria restrict access to supports by cause of disability, severity of disability, and long-term persistence of disabling condition. People with chronic mental health problems for example may only need intermittent, short-term supports, but eligibility criteria often restrict supports in these circumstances. Categorical entitlement to support by either age or disability fails to address the actual needs and circumstances of individuals and restricts access to appropriate support.

There are many examples within the current system of supports where age is a criteria for receiving support. For example, Alberta Health's ‘Aids to Daily Living’ program pays 100 percent of the cost of equipments for persons aged 65 and over. Younger individuals must make a financial contribution. In Ontario, the ‘Assistive Devices Services’ program, while available to people of all ages, has age restrictions on some items. In British Columbia, eligibility for special support services (e.g., adult day care, respite care and diagnostic and treatment services) through the Ministry of Health, is determined not only by age, but also health status, residency and citizenship (British Columbia, 1994b).

Age-related and other restrictions have the effect of forestalling greater economic independence for adults with disabilities, and thus limiting their contributions to the personal support relationships in which they participate.

3. Limited investment in paid caregivers

Provincial funding and contracting policies for disability-related services tend to limit the wage scales and benefits packages for paid caregivers to low levels. Many studies point to the underfunding of paid caregiving, the high turnover that results, and the consequences for undermining the quality of personal relationships with adults with disabilities. These impacts are not configured into the funding formulas for allocating funding for paid caregiving supports.

4. Exclusion of family members as paid caregivers

Most provincial disability support policy guidelines exclude family members from being paid caregivers under publicly funded arrangements. Alternate family care providers and homesharers can be paid as long as they are not natural or birth family members. This categorical distinction between paid caregivers presents three main difficulties:

- Alternate families are considered more worthy of public investment than natural families as providers of support, raising questions of horizontal equity;
- Those who may know a person best -- his or her particular communication systems, needs, and preferences -- are not in a position to be compensated in the support relationship to the same extent as others who are paid for providing similar services. This differential treatment risks the potential for developing caring and supportive personal relationships.

- Where provincially-funded individualized funding arrangements are used, and an individual becomes a legal employer, provincial restrictions on hiring family members as employees may be an unjustifiable regulation on employers in receipt of provincial funds, and contributes to lack of clarity about who the real employer is.

5. Supply-side funding of paid caregivers

By and large, paid caregiving is funded through a supply side approach. That is, the funding tends to flow to the providers of disability supports, rather than the consumers. This funding approach gives power to service agencies and paid caregivers to determine the terms and conditions of supports provided. We have seen that this presents an imbalance of power which undermines the capacity for support relationships to promote reciprocity, empowerment and self-determination of adults with disabilities, and their personal development. Much of the research on services to people with disabilities identifies this power imbalance as the major source of difficulty in paid caregiving relationships.

6. Lack of options for status of support relationships

A domestic partnership approach does not resolve the issues of legal rights and responsibilities these relationships raise. Domestic partnership is a new civil status instituted in a growing number of jurisdictions and its adoption has been proposed for the federal jurisdiction (Cossman and Ryder, 2000). The status is meant to ensure legal recognition of intimate, economically interdependent relationships between two adults living in a conjugal or non-conjugal relationship outside of marriage. It provides for legal rights and responsibilities equivalent to marriage. Some of those in alternate family or homesharing arrangements may choose to register as a domestic partnership if this status were available, but most would likely not find in this relationship the approach to obligation and rights they are looking for.

Nor does the *Criminal Code* (s.215) recognition of a person's responsibility to "provide necessaries of life to a person under his charge" provide an adequate model of responsibility and obligation. It denies the reciprocity that defines the relationships reviewed, the nature of the assistance provided, and the contributions that adults with disabilities themselves make. If used as the model for legal articulation of rights and responsibilities, it would entrench the notion that adults with disabilities are to be 'under the charge' of others, and that care is about those with capacity providing support to one "unable to provide himself with necessaries of life." It is precisely this model of personal support relationships that have undermined the self-determination, citizenship and equality of adults with disabilities.

III. Decision-Making Status

People with disabilities tend to face a diminished decision-making status institutionalized through various competency-related and decision-making provisions in federal and provincial/territorial statutes in Canada. Their genesis dates back hundreds of years (Bach, 1999; Bach et. al., 1994; Savage and McCague, 1987). Legal provisions state principles for personal, financial, health and other decisions; limit certain freedoms on the basis of legal competence (e.g. the right to marry); determine access to the justice system and can shape the liability of caregivers; and outline procedures for determining the legal competence of persons, application for partial or full substitute decision making, and the awarding and monitoring of those decision-making powers. These various provisions structure the status of some adults with disabilities, and of those who participate in their support networks.

The term "incompetent" has been the predominant term used in statutory law and jurisprudence to refer to the legal incapacity of a person. In the past decade, the term incompetent is increasingly being replaced in statutory law and jurisprudence by the term incapacity. While the two terms are roughly equivalent, usage is changing because in the words of a report of the Law Reform Commission of Nova Scotia, for example, the term "incompetent" is considered "offensive" to those deemed as such or who bear this status.[14] The term incapacity may be less offensive in that it suggests that a person's *capacities* are being judged where incompetence has implied a judgement of the *person* him or herself. However, this semantic distinction does not make a difference in the legal status of a person labeled under either term; the outcome is the same - removal of the right to self-determination or other civil and political rights.

Many people with mental disabilities do have their legal competency questioned and their right to self-determination removed, but the one does not *necessarily* lead to the other. As legal analysts note, mental disability is not to be equated with legal incompetency or incapacity (Robertson, 1987). The former term refers to a determination of intellectual ability, the latter refers to a legal status. However, it is on the basis of mental or intellectual disability that the legal right to self-determination is often removed, and the legal status of incompetence imposed.

There is a vast body of competency-related law. Reviews of this body of law in the Canadian context have been undertaken (Robertson, 1987; Savage and McKague, 1987; Rozovsky and Rozovsky, 1990; Gordon and Verdun-Jones, 1992). Even a description of this body of law as a whole is beyond the scope of this paper. Historically and in current legal practice these areas of

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[14] See Law Reform Commission of Nova Scotia (1993), *Discussion Paper on Adult Guardianship in Nova Scotia* (Halifax: Law Reform Commission of Nova Scotia).

statutory law and jurisprudence establish the primary means by which a person is declared incompetent or lacking in requisite capacity to make decisions.

Guardianship and substitute decision-making laws are provided in various statutory instruments of provincial and territorial governments. These provisions determine standards of capacity for making health care, property and financial, and personal care decisions, and outline procedures for applying for substitute decision-making orders, and for making these orders. In most jurisdictions full or partial substitute decision-making orders can be instituted, specifying those particular areas of decision making to be vested in a private or public substitute decision maker.

Revenue Canada establishes rules concerning who can be considered an employer, and carry out the necessary responsibilities. Rulings have been made which have refused some adults employer registration on the basis that they lack capacity. This has placed individuals' support networks in a position of having to adopt an employer status themselves, rather than acting as supporters to individuals in that capacity.

Competency-related civil law includes, for instance, contract law where the rules related to incompetency do not expressly prohibit people with intellectual disability from entering contracts, but require that a person be capable of understanding what arrangement he or she is entering. A contract may be considered void if the other party has knowledge, or should have imputed, that the person they were contracting with was incapable of understanding the terms of the contract.[15] However, if the contract is to provide for the 'necessaries of life' exceptions to this defense can be made.

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[15] This rule was first clearly established in *Imperial Loan Co.* v. *Stone* [1892] 1 Q.B. 599 at 601 (C.A.).

In the law of torts, a defendant escapes liability under intentional tort if deemed incapable, by virtue of a mental disability, of forming intention and therefore acting involuntarily, or of appreciating the act was wrong. Mental disability or insanity can also be used as a defense in negligence cases if it can be proved that a person's mental condition resulted in an inability to appreciate and exercise a duty of care.

In family law, there are restrictions on the right to marry if a person is considered incapable as a result of a mental disability, and parental rights can be removed for this reason as well. Marriage and separation agreements can be declared void, for the reason that one party was incapable of understanding the nature of the action and its consequences at the time of making the agreement, similar to any other contract.

With respect to political rights, up to 1984 in Ontario elections, later than this date in other provinces/territories, and up to 1989 in federal elections, people with mental disabilities could be denied the right to vote in federal elections if living in an institutional facility.

People with mental disabilities can also be denied the opportunity to sit as directors of incorporated organizations if they have been found to be of "unsound mind" (for example, the *Canada Business Corporations Act*, if their disability is considered to render them incapable of carrying out their responsibilities. Under statutes governing professions, individuals found to be temporarily or permanently of "unfit" mind, can lose their right to practice.

In the area of criminal law, there are various aspects to the issue of legal incompetency and mental disability. The issue of credibility of testimony by people with mental disabilities in cases where there is alleged physical, sexual, and other forms of abuse against them has been of particular concern to the disability and legal communities. This group experiences proportionally high rates of abuse of all forms, and relatively few cases that proceed to trial (The Roeher Institute, 1995). Certain tests must be met under the *Canada Evidence Act*, related to understanding what it means to tell the truth and ability to communicate evidence (capacity to observe; to recollect, and to communicate[16]), or Crown counsels are unlikely to prosecute, and cases are therefore unlikely to proceed to court. Some provisions have been made in amendments to the *Criminal Code* and the *Canada Evidence Act* to ensure that such cases have a better chance of proceeding to trial - allowing a person to give testimony who does not understand the nature of an oath, but does understand what it means to tell the truth; or allowing a person to give evidence through closed-circuit television in cases related to sexual abuse (prior to 1992 this was only available to individuals under the age of 18).

There are no comprehensive statutory requirements related to provision of communication assistance in civil or criminal litigation, however protocols are being established to ensure that police, Crown attorneys, and judges provide for a variety of accommodations in investigations and proceedings of the court - personal support, technical assistance, interpreters and interveners, etc.[17] As this body of law develops, there will undoubtedly be limitations on what counts as communication assistance. However, this is one place where support networks could

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[16] This criteria of what it means to “communicate evidence” were established in a Supreme Court of Canada decision, *R.* v. *Marquard* [1993] 4 S.C.R. 223.

[17] See for example, the specification of forms of accommodation in Ontario, Ministry of the Attorney General (January 15, 1994), Victim/Witness with Special Needs, *Crown Policy Manual* (Toronto: Ministry of the Attorney General).

make a dramatic impact on access to the justice system for people with disabilities, if their interpretive and decision-making assistance were fully acknowledged and supported.

Conventional standards of competent decision making are articulated in both statutory law and jurisprudence. Four key criteria have been identified for informed consent and competent decision making: 1) that the decision is made in a voluntary way; that individuals have legal capacity to make decisions; 3) that they have the mental capability; and 4) that individuals are informed of the nature, benefit and risks of any particular option they might choose (Rozovsky and Rozovsky, 1990). Capacity to receive and evaluate information effectively, communicate decisions, and make reasonable judgements are criteria of competent decision making that are found in guardianship and decision-making legislation in most provincial/territorial jurisdictions.

A number of models of decision making have developed in law and policy in recent years that are presented as alternatives to guardianship, and as remedies to some of the limitations of the institution of guardianship. Most, but not all approaches leave fully intact the distinction between the competent and incompetent on which traditional decision-making institutions rest. Nonetheless, they do go some distance in making less intrusive and less restrictive the removal of decision-making rights from some persons, and vesting them in substitute decision-makers. To a greater or lesser extent, these approaches create some status for supported decision-making networks -- most clearly in the B.C. Representation Agreements and the Manitoba model for supported decision making, outlined below.

A. Power of Attorney

Provisions under some guardianship laws in Canada authorize the appointment, by a competent person, of a power of attorney for financial and/or personal care decisions. This provision enables individuals to plan for a time when they may no longer be considered by others to be competent to make their own decisions. A power of attorney is a document containing the written authority for a named individual to act on behalf of the person completing and signing the document (the principal or donor). The document gives the "attorney" the legal power or capacity to perform actions on behalf of the donor and a power of attorney can be limited or general in scope. It can state that the attorney may only do certain things, such as receive and bank a person's income and pay bills, or it can allow the attorney to perform all of the transactions that the donor could perform without specifying what these shall be.

In its original form, a power of attorney is an arrangement designed to address situations where a mentally *competent* individual needs the services of another to carry out certain transactions or make decisions while he or she is temporarily indisposed. Thus, the concept of the enduring power of attorney is a departure from the fundamental principle of donor competency. An enduring power of attorney may continue to have effect despite the onset of mental impairment and the donor's consequent inability to direct, monitor, and supervise the actions of the agent or attorney.

While such provisions respect a person’s wishes about who will exercise authority as power of attorney, when such powers will be exercised, and for what purposes, the provision still leaves in place the distinction between the competent and the incompetent. Powers of attorney can only be appointed by persons deemed "competent", and when authority is exercised under a power of attorney decisions are still being made by a person with power <u>over</u> a person who is no longer recognized as a person able to exercise decision-making rights (Brock and Buchanan, 1991).

B. Mentors and Legal Friends

In recognition of the limitations of traditional guardianship, legislation is developing in some European countries that provides for a "mentor", an individual who is appointed to assist a person in decision making. Swedish legislation, for instance, has replaced guardianship with two other forms of decision making authority -- mentors and administrators. In place since 1976, this legislation provides for the appointment of mentors who provide decision-making assistance, act as representatives for individuals to whom they are appointed, and can make decisions for them provided they are in accordance with the wishes of the individual. The mentor has powers equivalent to those of a person acting as a power of attorney. Under the Swedish guardianship law, mentors are appointed by consent of the person to whom assistance and substitute decision making will be provided given the consent by the individual for specific decisions. The courts can also appoint mentors where the person is considered incapable of giving consent. In these cases the mentor must continue to act according to the wishes and intentions of the individual.

The legislation also provides for appointment of an "administrator" where the individual objects to the decisions of the mentor, but where the individual's own decisions would seriously jeopardize what are considered to be his or her interests. The administrator plays a similar role to a guardian or substitute decision maker under guardianship law in Canada, and has authorities similar to those made available under adult abuse and protection legislation in the Atlantic provinces.

Provisions similar to those for mentorship are found in the status of "legal friends" in the Australian jurisdiction. A legal friend is appointed by the courts to assist persons whose capacity to make decisions has been questioned, or where they are deemed incapable in this regard. The role of the legal friend is to provide decision-making assistance, and to act as a substitute decision maker where required, provided that the decisions respect the wishes of the individual.

The provisions for "mentorship" and "legal friend" as a means for providing assistance in decision making represent real advances in the direction of a supported decision-making model. The legislation requires that mentors act in accordance with the wishes of individuals even if they are considered incapable of making their own decisions, and also recognizes the validity of providing decision-making assistance as a means of supporting people to exercise their decision-making rights. Nonetheless, mentors are awarded the power to make substitute decisions, albeit within a stricter set of parameters than guardians appointed under guardianship law in Canadian jurisdictions. According to research on the mentorship system these parameters are not always respected, especially the requirement that mentors follow the wishes and seek the consent of the individual. Thus some mentors carry out their responsibilities as traditional guardians (Herr and Hopkins, 1994).

C. Surrogate Decision Making

New York State has implemented a "surrogate decision making" program to enable substitute decision making with respect to particular health care interventions, when the patient's capacity to give informed consent is questioned, or when the patient is deemed incapable of giving informed consent. The program was established as an alternative to judicially appointed substitute decision making for persons with mental disabilities in state operated or state-licensed facilities. Certain health care decisions cannot be addressed through this program, including decisions related to emergency procedures, the withdrawal or discontinuance of life-sustaining treatment, sterilization and the termination of pregnancy. The use of the program is triggered when a physician files a declaration with the program that a psychiatrist or psychologist has deemed the person incapable of giving informed consent for a particular procedure, indicating how the proposed treatment would benefit the person and whether the patient has expressed any views on the treatment. A panel of volunteers, with representation of health care professionals, families and advocates, attorneys, and others with expertise, meet to consider the request for a surrogate decision maker to agree to the treatment.

The primary advantage of surrogate decision making over guardianship is that it awards substitute decision making for a particular decision, thereby removing decision-making rights on a very time-limited basis. It also establishes that incapacity and the need for substitute decision making must be demonstrated for each decision. While this may add administrative and other costs to the decision-making infrastructure it does go some greater distance than plenary or partial guardianship in protecting the due process rights of individuals with respect to decisions that affect them. Nonetheless, as in the other alternatives to guardianship, surrogate decision making rests on a distinction between the competent and incompetent, and on the removal of decision-making rights, even if only on a very time-limited basis, for the latter group.

D. Legal Provisions for Decision-Making Assistance

There are statutory innovations in a few jurisdictions in Canada to provide status to support networks as decision-making ‘assistors’ rather than substitute ‘deciders’. Under the B.C. *Representation Agreement Act* people can enter into an agreement with a person or a group of persons (e.g. support network) to assist in making decisions. The Act provides for registration of such individuals or networks to secure their status in the decision-making process related to health care, financial or other decisions. The agreements enable a person to voluntarily select and empower one or more individuals to assist, support, act or make decisions on his or her behalf when s/he is no longer considered capable of making decisions independently. The agreement can be written to specify the conditions under which representatives' substitute decision-making authority will come into effect, and the nature of assistance that will be provided. In order to enter representation agreements adults must be considered capable of providing consent -- that is understanding the nature, purpose, and consequences of the agreement they are entering. However, provisions are not in place that require competency testing to enter representation agreements. The Act makes provision for more flexible standards of competence than those usually found, including communicating a desire to have a representative assist in decision making, demonstrating choice that expresses approval or disapproval of others, awareness of the role of the representative(s), a trusting relationship with the representative.

These provisions are one area in law where close personal relationships involving a person with a disability are recognized, and in a manner which promotes the self-determination of a person (by creating more flexible standards for competency to make a decision, and by acknowledging that the defining feature of the relationship is one of trust rather than simply caregiving or dependence).

Representation agreements are a mechanism for granting authority similar to that of powers of attorney. The key difference is that they allow for a range of decision-making assistance, short of substitute decision making.

In Manitoba, the *Vulnerable Persons Living with a Mental Disability Act* recognizes in s.6 "supported decision making" as a means of "enhancing the self-determination, independence, and dignity of a vulnerable person." The Act provides for an individual to take advantage of a "support network" in providing assistance to make personal care or property decisions, thus limiting the need to resort to substitute decision-making arrangements. A provincial policy is being implemented to provide back-up support and assistance for the development and sustaining of personal support networks given the growing understanding of the challenges such networks face. Similar legal provisions have been passed into guardianship law in the Northwest Territories.

In Saskatchewan, Bill 48, *The Adult Guardianship and Co-Decision Making Act* was recently passed, but is not yet proclaimed. The Act creates a status for a "personal co-decision-maker", a person which can be appointed by the court under s.14(1) upon a finding that a person's "capacity is impaired to the extent that the adult requires assistance in decision-making in order to make reasonable decisions." The co-decision-maker is to provide advice to the adult, but is to "acquiesce in a decision made by the adult." This is another kind of mechanism to enable supported decision making to be given effect.

E. Disincentives to Promoting Valued Personal Relationships

The bulk of existing provisions do not clarify the legal status of support networks. While some jurisdictions provide statutory recognition of their role in individual planning support and decision-making assistance, this is not universal. As well, federal statutory and regulatory provisions regulating employment standards (who can act as an employer of paid caregivers for example), access to the justice system, and legal liability have not adequately addressed the nature and status of support networks, in order to ensure that network members can provide assistance without being fully responsible for an individual's actions and decisions, a *de facto* substitute decision making role. Like the alternate family and home sharing relationships, the supported decision-making relationship would not be adequately recognized with a domestic partnership status. Nor would the relationship meet the criteria of that status (two adults, living together, economic interdependency).

IV. Labour-Related Law and Regulation

Three areas of law affect working conditions and employment status of caregivers: collective bargaining rights; policies for employment benefits and leave to care for family members; and duties to accommodate on the basis of disability.

A. Collective Bargaining Rights

Regulation of collective bargaining in the disability supports sector is largely organized under provincial Labour Codes, although the federal *Canada Labour Code* covering federally-regulated agencies and industries may apply in some settings.

These laws establish rights for workers to organize trade unions and collective bargaining units, and lay out the process for applying for certification. In the current system for delivering disability-related supports, and in the current organization of collective bargaining, the majority of paid caregivers are usually accountable to employers and provisions of their collective agreements, prior to their accountability to the individual with a disability (other than with respect to acting in ways that are not criminally negligent).

Labour law remains relatively silent on the potential conflict between the rights of people with disabilities and the rights of organized labour, although there is clearly an imbalance of power between the two. The potential conflict is likely to intensify as more individually-focussed, funded, and directed systems of support develop.

B. Parental and Family Benefits and Leave

Parental benefits and leave are provided under both federal and provincial/territorial legislation. While these benefits do not cover adult family members, with one exception, it could be argued that such rights could be extended to make the non-paid caregiving relationships discussed in this paper more viable. For this reason, these provisions are briefly outlined below.

The federal *Employment Insurance Act* provides for a maximum of 30 weeks of parental benefits, including a maximum of 15 weeks of maternity benefits, 15 weeks of paternity benefits and 10 weeks of sickness benefits to take time from employment to attend to a child upon their birth, adoption, and/or illness. The federal government has proposed extending these benefits to a maximum of 50 weeks.

The *Canada Labour Code* provides parents working in federally-regulated industries and agencies with a right to 24 weeks of unpaid leave to attend to a child upon his or her birth or adoption. Provincial/territorial employment and labour standards legislation provide for parents' rights to unpaid leave to attend to a child for similar reasons. British Columbia is the only jurisdiction where this right is extended to family-related leave, so that a person can provide care to any of his or her immediate family, up to a total of 5 unpaid days per year.

C. Duties to Accommodate on the Basis of Disability

Under a number of provincial, territorial and federal human rights codes, employers and those making services available to the public have a duty to make needed accommodations to prevent discrimination on the basis of disability, sex, religion, and other prohibited grounds. This duty has also been established through case law.[18] Interpretations have been given by the Ontario Human Rights Commission that the duty to accommodate in employment "may arise when a person's family status (i.e. parent/child relationship) results in or causes a conflict with a requirement, qualification, or practice in the workplace." (The Roeher Institute, 1998, p. 8). Where family members are caring for a member with a disability this is a particular family status, because it requires significantly different burdens of responsibility and care than where family members do not have such responsibility. On this basis, it is argued, such employees should receive accommodations in the form of additional workplace flexibility and leave.

D. Disincentives to Promoting Valued Personal Relationships

1. Issues with collective bargaining rights

Review of the research on support relationships that promote respect and dignity suggests that the current structure of accountabilities in paid caregiving is problematic in this regard. It does not ensure respect for and accountability to the decision-making status of individuals, an essential condition of relationships of support that promote a valued place in society for adults with disabilities. Interests of labour have sometimes operated directly against what are widely considered as valid social and policy goals -- deinstitutionalization of people with disabilities, for

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[18] *Ontario Human Rights Commission* v. *Simpson-Sears Ltd.*, [1985] 2 S.C.R. 536, 23 D.L.R. (4th) 321.

example. There are numerous instances where unions have actively fought against institution downsizing and closure because of concern over a loss of jobs and lower wages in community-based services. This is in spite of the calls for deinstitutionalization and the evidence that community and independent living much better meet people's basic civil rights and improve their quality of life, regardless of their level of disability (The Roeher Institute, 1999).

Evaluation research and commentaries point to a number of concerns by individuals and by labour about the current framework of collective bargaining rights. They also identify concerns by labour with the growing trend to funding regimes that provide individuals and families with greater control in provision of disability supports and the paid caregiving relationship (The Roeher Institute, 1999, 1997; Newfoundland and Labrador Association for Community Living, 1998; National Union of Public and General Employees, 1998):

- For Individuals and Families
    - Individualized funding arrangements give individuals and families the status to make decisions, and to have paid caregivers accountable to them - the absence of which has been the major problem with disability support services.

    - Collective agreements give labour the right to determine who they will support where, when, and how, without individuals and families ever being at the negotiating table. Paid caregiving involves intimate care and contact with a person's body and life, and individuals and their families should be able to determine who provides that care and on what terms.

    - Individuals and families should not be required to negotiate collective agreements on their own with bargaining units. The demands of providing and coordinating supports is already enormous, without those additional responsibilities and stresses. Some form of association representing interests of individuals and families in the process, and acting in negotiations on their behalf, is needed.

- For Labour
    - Individualized funding multiplies employers - shifting from the service provider to individuals and their families as employers - making collective bargaining much more complex, weakening the bargaining power of labour, and instituting a labour market with a wide range and contradictory set of working conditions.
    - This model of funding introduces privatization into a sector, where governments have not had a history of demonstrating strong leadership and commitment, making it more difficult to address concerns of both people with disabilities and labour.
    - Wages are driven down and the labour market that emerges becomes less humane because individuals and families search to make their individualized dollars go the furthest: if they can hire at lower wages they can purchase more hours of support with the dollars they receive.
    - Addressing labour's concerns becomes more difficult. There is little if any structure to manage development of staff, grievances, etc.

These concerns are polarizing the disability and labour community in some regions. In Newfoundland, for example, a series of Labour Board and court cases were taken forward as individualized funding arrangements in that province ended up polarizing the disability and labour movements. Issues in question were: Who is the employer (the individual or the government funder of services)? Does labour have a right to organize collective bargaining units when the primary place of employment is an individual's home? Can a collective agreement be imposed? What are an individual's rights to change who provides his/her support?). Some disability organizations advocated for removing the right to collective bargaining from paid caregivers in the sector.

The debate in Saskatchewan appears to be moving in a more collaborative direction. There, the provincial home care association, the Government of Saskatchewan, and the union of public employees negotiated a "framework agreement" to guide collective bargaining in the area. The agreement lays out the basic principles that will shape all collective agreements, affirming the rights of people with disabilities to make decisions about whom, how, and where their care will be provided.

2. Limited rights to employment leave and flexibility

Those providing caregiving support to children and adults with disabilities face difficult working environments. They often encounter employers unwilling to provide the workplace flexibility needed to respond to emergencies, to make sure that a child or adult gets to appointments and participates in needed rehabilitation, and to provide the direct care and coordination of supports that is required. Entitlements to workplace flexibility, accommodation, and leave are not clear, and hardly available. The consequence is that caregivers, in order to carry out their caregiving responsibilities, downgrade their labour market participation, take part-time jobs, do not proceed in an upward career path, or leave the paid labour market altogether (Lero and Irwin, 1997; The Roeher Institute, 1998).

British Columbia is the one jurisdiction where caregiving responsibilities to other adults is granted some recognition in labour standards law. Even there, the provision of up to five days per year is minimal and only covers immediate family members. Alternate family and home sharing relationships are not covered where these are not immediate family members.

Moreover, parental benefits are restricted under the *Employment Insurance* Act to birth or adoptive parents caring for new children. But these are not the only significant caregiving relationships in Canadian society, as this review makes clear. Employment benefits law does nothing to recognize the beginning of new caregiving relationships involving adults (like alternate family, or new caregiving relationships as when a sibling takes over a parental caregiving role of a family member with a disability). These relationships require personal and familial adjustments similar to those of beginning to care for a new child. If family caregiving and these other domestic relationships are to be viable, attention must be given to both the employment benefits and employment leave provisions for caregivers.

V. Summary

Restrictive eligibility criteria for access to income and disability supports (e.g. emphasis on unemployability as key criterion), limited benefits, and few incentives for transition to paid employment, contribute to the continued poverty of people with disabilities, one of the poorest group of adults in Canadian society (The Roeher Institute, 1994; Council of Canadians with Disabilities, 1998; Rioux and Crawford, 1990). Persistent poverty, means that additional costs must be borne by family members with whom they live.

Approximately 25% to 30% of adults with disabilities (age 15 and over) who live in households and who require support from others, obtain some level of paid support to assist them. This leaves the significant majority of adults to rely on family, friends, and other sources of unpaid supports. The poverty that people with disabilities face, combined with inadequate access to paid supports, and lack of recognized status for individuals and support networks, places a large, unjustifiable and often too stressful burden on family and paid caregivers.

Personal relationships between family members, friends, paid caregivers and people with disabilities are an essential condition to ensure respect and value of people with disabilities by the larger community. They can provide a foundation of reciprocity for the well-being and contribution of individuals with disabilities. However, without adequate supports -- in the form of income to the individual and the family member, social supports to the family unit, workplace flexibility, benefits and leave for working caregivers, back-up supports to paid caregivers, decent pay and working conditions -- and without a recognized status for the individual and his or her chosen support network, the relationships can break down. Independence of the adult with a disability can be thwarted, the health of family carers can decline, the turnover and disrespect of paid caregivers can mount, and in some cases violent and abusive relationships are the result. The basic rights of people with disabilities, and state obligations to ensure these rights, are thereby undermined.

PART THREE

REVIEW OF CASE LAW

Research on relationships of support clearly shows how they enable a wide range of values to be realized in people's lives. The review of public policy and program provisions point to many disincentives to promoting personal relationships characterized by these values. What does case law tell us about public and private interests in promoting relationships, and advancing these values? To answer this question, a scan of Canadian case law (all court levels, including tribunals) was conducted in order to determine how the five forms of adult relationships that involve a person with a disability are defined, constructed and/or ignored in that case law, as well as the state's interest in them.[19]

There is not a significant presence of the five types of adult relationships in current case law in and of themselves: that is, case law appears to largely ignore these relationships. Instead, adult relationships involving persons with disabilities most often occurred in the context of, or as an aspect of, another form of legal dispute. The most frequently litigated issues involving these relationships are probably those within family law, followed by benefits from public or private schemes. There is some labour law on these issues (usually a caregiver's conflict in

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[19] Using a wide variety of search terms several areas of Canadian case law on QuickLaw databases were scanned, including a global database (all judgements) and a specialized database (human rights). Influence and "reach" of cases that appeared most relevant were determined through "note-ups" (i.e. searching for cases that refer to the instant case). Findings were compared to others' (e.g. Cossman & Ryder) to confirm that the major possible forms of legal governance of adult relationship had been covered through the case law review. These searches generated several thousand cases, of which approximately 750 were scanned by narrowing the field with more detailed search terms, and by limiting searches to English language, Canadian, and relatively modern case law (post-1985). A total of 66 cases were excerpted. These cases and relationships cover at least 10 (family, labour, tort, contract, property, immigration, benefits, constitutional, tax and criminal) areas of substantive law. Short summaries of the law of each area as it pertains to the issue of adult relationships are provided.

employment issues), and a large portion of tort and property law involving persons with disabilities. These last categories examine the adult relationships in two particular ways: the common law of fiduciary relationships and the duties associated with them, and as accounting methods for the costs of care for persons negligently harmed.

I. Cases and Analysis

Of the five types of relationships being examined, family caregivers and alternate families will likely involve family law issues; adult home sharing may also, as well as implicate an individual's status under various public and private benefits schemes. Paid caregiver relationships are more likely to involve labour law issues, and less likely than the previous to be implicated in family law or law related to benefits. Supported decision-making networks may involve fiduciary relationships (in tort, contract and property law). Of course, all these categories of law overlap to some degree in any case, and it is characteristic of any litigation to pick one or two aspects of a complex relation as the focal point for a conflict.

For example, a caregiver who is also cohabiting and economically interdependent with a person with a disability might either have a family law issue (are they "spouses") or a benefits issue (are they "spouses" and thus ineligible for benefits under a provincial scheme). Alternately, the major areas of private law focus on fiduciary relationships and an accounting (the remedy in a negligence action) of caregivers costs. In addition, these relationships can be scrutinized by constitutional litigation, but usually as an adjunct to determining the definition and scope of, say, disability. Finally, the tax treatment of certain credits and expenses are interpreted by the tax court.

Family law will govern how close personal relationships are formed and dissolved, and through definitions such as spouse, family and relative, determine who is included in the regulatory scheme, and who may therefore access benefits (or not be liable for costs), as well as providing normative frameworks in law. In the event of dissolution of these relationships, the division of property and spousal support contain areas that consider persons with disabilities, and may involve contract and property principles (although these also occur separately). Administrative tribunals often deal with the economic or social condition of the person with a disability, or the caregiver. These can be characterized as conflicts arising during the relationship, and in the context of the relationship. Similarly, normative definitions include or exclude people from benefits, one major example being family benefits denied under "spouse-in-the-house" regulations, which are sufficiently insensitive to economic independence in the context of cohabitation, another being the definition of employee in labour relationships. These areas share similar problems to that of family law: definitions of family or cohabitation, an employee's ambiguous status, problems of these definitions being insufficiently sensitive to the complexity and evolving nature of living arrangements. Constitutional and quasi-constitutional (human rights) litigation focuses on these statutory regimes, specifically, the definitions and scope of terms like disability or spouse.

Tort, contract, criminal and property law cases almost exclusively focus on conflicts arising within a relationship that are then made explicit, or put into a category of law, according to the facts. (For instance, intentional torts and some criminal charges can be similar, and some duties in tort are very similar to contract law). They begin by defining whether a person has a "cause of action," that is, a legally recognized right or obligation, and whether that right or obligation has been breached at common law.[20] In the cases reviewed for this research, these rights are most often characterized as fiduciary, which has a presence in all three areas, and is the nearest common law proxy to a "trusting relationship" involving one person assisting the other in meeting their interests. In a sense, these form the common law or "natural law" equivalent of the statutory rights for family, administrative and labour law. They do not appear to be as comprehensive or as nuanced as the statutory rights, but are flexible in their generality. (Fiduciary relationships arise in many contexts). One section of torts, damages for negligence, contains some interesting examples of "costing" for care of persons with disabilities.

Examples from these groupings of law are provided below, and analysis presented of the law's construction or ignorance of the complexity of these adult relationships.

II. Issues of Benefits Law

These cases usually involve appeals of a tribunal's decision to terminate or not award benefits of some sort in administrative law settings, or private contracts for insurance benefits (through employment or private insurance). They follow administrative law principles except where insurance is private, in which case the law of contract generally applies and has a special set of rules for insurers, who are often governed by statute. Generally, entitlement to a benefit is defined by regulations to a statutory scheme, which will include key terms and exclusions. (Since the number and type of tribunals and benefits schemes vary widely across the country, it is not useful to summarize the particular steps of any one case.)

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[20] These are rather abstract rights, but come with detailed indicia to test whether the right is present (say, in a tort), if that right was breached, whether damages ought to flow as a result, and so forth.

The legal principles behind these schemes have two major areas of analysis: the first is the purpose and scope of the act or contract in question, which get interpreted by the courts in the event of a conflict, *usually* with a generous reading in favour of the statute's purpose. Terms that get litigated are terms designating parties to these relationships, such as spouse, widow, beneficiary, or other terms of family/marital status that may designate a close personal relation. Capacity to enter contractual relationships can also be a factor, one that involves advice from others in the position of fiduciaries, which are examined below.

The second area is the technical requirements of judicial review or appeal of administrative decisions. These are general principles in administrative law that set out the standard or threshold that must be met in order to warrant appeal or review, and the standard of correctness of that review itself. The statute may have its own route of appeal. Decisions usually have to conform to some degree of "natural justice" or a "duty of fairness", which are basically procedural rights, as interpreted by the courts. This second area is largely the procedural aspect of challenging administrative decisions.

The benefits most often at issue in these cases are pension and welfare benefits to which some relation close to the primary beneficiary sought a right to, or, alternately, a right that the primary beneficiary sought to retain. These cases tended to turn on interpretations of key words of inclusion, like spouse,[21] on meeting some condition precedent for the benefit (being single, having some degree of disability), and/or a claim of discrimination based on human rights legislation. The reason procedure is important is that even the court's right to review a decision,

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[21] Interestingly, following family law since the 1970s, economic factors are not to be considered primary in determining questions of cohabitation as spouses.

no matter how unfair, is not easily established (see, for example, cases challenging reductions in social assistance rates).

It is instructive, for comparison purposes, to review case law litigating the denial of benefits under recent changes to social assistance plans in Ontario, Quebec, Manitoba and Nova Scotia. These form a new general objective or at least trend in "reductions" to welfare rolls in those provinces, and contain several arguments analogous to those that may be employed in examining close personal relationships of people with disabilities. Two cases seem relevant, *Brunnette* c. *Québec* (outlined earlier) and *Fernandez* v. *Manitoba*.[22]

The "benefits cases" have the potential to reflect or contain three types of relationships: family caregivers, alternate families, and adult home sharing. It is clear from these cases that:

- definitions of family are changing in case law from more traditional concepts;
- objectives of "fiscal restraint" are informing the scope and distribution of benefits (and that the courts are unlikely to intervene too much); and,
- where there is a question of the status of one member of these relationships, that question is, again very generally, answered by statutory definitions informed by principles of family law.

The state is obviously actively interested in these relationships, most notably through reductions in the breadth of social assistance, and in the overall regulation of these relationships. However, the litigation does suggest that "targeting" of benefits to the "most needy" will split these relationships into two categories, those whom the state perceives as "most needy" according to

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[22] *Fernandez* v. *Manitoba* (Director of Social Services), [1992] M.J. No. 279 (Man. C.A.), *Brunnette* c. *Quebec (Ministre de la Solidarite sociale)*, [1999] J.Q. no 5693.

criteria they develop through statutes, and those who will fall outside those categories. This sort of (fairly arbitrary) targeting has happened in Ontario, in which the reforms to the social assistance regulations were not meant to affect people with disabilities, but have had that effect nonetheless.

This area -- administrative law -- is also the site of conflict between two branches of the state: the courts, who must cede jurisdiction to statutory regimes, or find ways to trump them according to principles of "natural law", which is politically sensitive, and the executive (through statutory regimes) that enacts public law to achieve its priorities. Although state support for persons with disabilities is nominally uncontested, the most recent influential arguments and trends are toward keeping the costs of this support private, or channelling them into private forums of dispute (e.g., the civil litigation system).

III. Issues in Family Law

This area of law encompasses many of the relationships being examined, as it governs the creation of families (and therefore of a large number of caregivers), the dissolution of families (and therefore the treatment of caregivers), and some important issues within these boundaries, such as child care, custody, the division of assets and unpaid domestic labour, and issues of spousal support. This area of law is large, and only those cases were scanned in which one of the members of a family or near-family had a disability that seemed to factor in the issues at trial.

Generally, the formation of families is governed by marriage legislation (provincial), and the dissolution by the *Divorce Act*[23] (federal) as well as provincial family law acts. These codify and improve (generally) the common law of previous eras. As might be expected, these statutes generally follow traditional western concepts of families, especially the post-war nuclear family, and have been shown to be inflexible with respect to other forms of close personal relationships. The case law reflects the development of the application of these statutory schemes, and rarely reflects common law principles, except in the case of constructive trust interests in the division of property created by a partnership "tantamount to spousal."

Evolving definitions of family, especially the legal formation of families, are changing the scope of people who will have access to rights under these statutory schemes (Cossman & Ryder, cited above, review this literature). These definitions are being driven today primarily by the inclusion of new forms of partnerships into the term "spouse", and the resulting effects on rights and obligations under statutes that use that terminology. This becomes more acute for relationships involving a person with a disability upon dissolution of these relationships. It is in dissolution of family relationships that we see more case law reflecting the five relationships under examination in this paper. Three major areas of contention arise: the division of assets, which may include disability pension benefits; spousal support; and custody of children. Of these, there is some litigation on the division of pension benefits, and somewhat more on spousal support. Support, custody and the division of property each have their own statutory and common law principles, which are too detailed to summarize here.

As an example, spousal support contains one interesting and relevant aspect for the family caregivers. That is, it is fairly new in law (and it is changing) when a "need” that one spouse has

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[23] R.S.C. 1985, 2nd. Supp., c. 3 (as amended) [hereinafter *Divorce Act*].

is to be considered in determining the quantum of spousal support after the marriage or partnership. Generally, support ought to be decided with reference to all the criteria in the relevant legislation, including ability to pay, need, and other factors arising from these partnerships (per L'Hereux-Dubé J. in *Moge* v. *Moge*)[24]. Although an emphasis on a self-sufficiency model was in vogue in the 1980s, there has been a re-emergence of the consideration of "need", whether that need arose as a result (broadly speaking) of the partnership, the "fact of the marriage", or whether it was a pre-existing condition to the partnership. In short, the courts appear willing (today) to find that an ex-spouse ought to continue to provide support for the other in need after, sometimes long after, those relationships have terminated, especially when this "need" involves costs for care-giving for a person with a disability that arose during, or even before, a close personal relationship. This is interesting in that, all else being equal, the disability (which generates support needs) is the deciding factor in keeping a form of economic allegiance at law long after all other relationships have ended, and is a result of what McLachlin J. (as she then was) terms "the fact of the marriage".

We can tentatively conclude that when a caregiver relationship dissolves, especially one that involves opportunity costs and unpaid labour, the courts appear to be willing to keep costs "private" (among individuals) and out of public (reliance on other supports) where possible. The courts appear to be influenced by the general climate of fiscal restraint in public finances.

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[24] [1992] 3 S.C.R. 813. In this case a woman won spousal support for a significant duration after the marriage, notwithstanding her ability to live (financially) independently. This case established a more inclusive approach to evaluating the amount and duration of spousal support upon dissolution of a marriage. The court determined that there shall be consideration of all the factors listed in the relevant statutes, including circumstances, physical or mental conditions that pre-date the marriage, or that arise during the marriage, and that continue through separation. This tells us that, within these private relations and ex-relations, the courts are willing to recognize some form of economic allegiance based on a wide variety of factors including those that may include disabilities.

Indeed, this appears to have been an important consideration in the *M.* v. *H.*[25] case expanding the definition of spouse, and in other spousal support litigation.

Like the "benefits cases", family law encompasses most readily the family caregivers, alternate families, and often as an exclusion, adult home sharing arrangements. We can tentatively conclude that the further from traditional definitions of family (which is changing) the relationships are, the less likely they will fall under the rights enumerated in the various statutes. However, the trend appears to be toward recognizing wider forms of associations, family and non-family, that offer mutual support, *as long as* they do not intrude too much on public finances.

IV. Issues in Tort, Contract, Property Law, and Some Criminal Law

Tort law deals with persons with disabilities in at least two ways. The first is as a beneficiary of a fiduciary duty in certain trust relationships, where tort cases focus on breaches of this duty. These duties are common among doctors and patients, teachers and students, and caregivers and care subjects, and thus bear on the relationships under consideration here.

The second area of torts is in accounting for damages in negligence actions, in which a person has developed a disability, and for which the courts apportion damages. This second area does

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[25] [1999] 2 S.C.R. 3. This case has implications for the definition of spouse (and therefore a widening of categories of relations under family law and probably benefits laws), for the presence of fiduciary or trusting relations, and for the notable fact that the most persuasive arguments (as reflected in the language of the judgement) were based on keeping the costs associated with this separation borne privately (e.g., non-state).

not so much construct the relationships we are examining as provide a form of costs of those relationships, including complex calculations for future care. It would be interesting, for example, to trace the awards made by courts in a private law setting with the "benefits" and other cost mechanisms of the current public law schemes. A useful case to refer to in this regard is *Crane* v. *Worwood*,[26] which also does a decent job of reviewing the precedent case law on the subject of damages for negligence causing a disability.

Contract law is implicated in oblique ways: the case of domestic contracting arrangements between families, or more generally contracts of employment (taken up under labour law below), or in private contracts for insurance. It does not form a large part of these relationships in the cases reviewed, but has the potential, to be more significant for two reasons. The first is that capacity to enter contracts can be an issue, and may involve fiduciary aspects, and there has been some case law including fraud and breach of duty, especially with respect to seniors.

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[26] [1992] B.C.J. No. 433. In this case, the plaintiffs sought to recover damages as compensation for the financial loss their family bore when the husband and father chose to put the personal needs of his wife and child, who had been injured by the defendant, ahead of his business affairs. The plaintiffs contended that Mr. Crane's decision to stop working in his one-man advertising firm while caring for his injured wife and daughter was the loss to the firm of Air BC as a client. They quantified that loss in the amount of $400,000.00. The defendants argued that the appropriate measure of compensation was the reasonable value of the services provided, not the opportunity costs. The plaintiffs were awarded $7,500.00 to compensate them for the services which Mr. Crane rendered to them voluntarily. The court set the opportunity cost to Mr. Crane and the family at $85,000.00. The court concluded that it was a reasonable decision for a father and husband to make to put his family before his business under the circumstances. It was noted that Mr. Crane spent about 400 hours looking after his wife and daughter, providing services that they would otherwise have had to hire professional caregivers to give. In the cases examined by the court, the expenses of loss of wages incurred by the relative in providing a service that would otherwise have to be provided by a third party at the expense of the plaintiff, guide the courts as to quantum. The principle underlying compensation was the loss to the plaintiff, not the cost to relatives who render nursing to the plaintiff, pay for surgery on the plaintiff's behalf, or replace the plaintiff's loss of board and lodging. Nothing in these cases suggested that the court would use the opportunity cost as the measure of damages if it were higher than the cost of obtaining services outside the family. The maximum award under this head is the cost of obtaining the services outside the family. Where the opportunity cost to the caregiving family member is lower than the cost of obtaining the services independently, the court will award the lower amount.

The second is that at least three and maybe four of the relationships being examined here (paid caregivers, supported decision-making networks, alternate families and adult home sharing) are likely to involve some form of contractual relationships, often -- but not always -- informal contracts, and this may require some attention or regulation (either as employment or some other form of contracting).

Property law is implicated generally over a wills and estates issue, and similar to contract law, focuses on capacity to enter or execute formal legal relationships, as well as the fiduciary nature of advice on these issues. Lawyers are of course often at the centre of these litigations, which may also involve a tort (breach of fiduciary duty, or breach of standard of care). Strictly speaking, the property issues are those of capacity to enter and execute legal relationships, and the advice given by second or third parties falls under a tort duty.

In the case law review, a couple of interesting criminal cases stand akin to the tort cases: two on frauds, one perpetrated on vulnerable seniors (*R.* v. *Lush*)[27] and the other fraud allegedly due to the impecuniosity of the accused (*R.* v. *McIssac*),[28] as well as one case on alleged abuse by a caregiver upon a client (*R.* v. *J.H.*),[29] which explores the threshold for consent in a difficult caregiving environment, where discipline may be a permissible component.

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[27] [2000] M.J. No. 216.

[28] [1998] B.C.J. No. 1946.

[29] [1992] O.J. No. 2385 [hereinafter *R.* v. *J.H.*].

V. Common Law of Trusting or Fiduciary Relationships

A fiduciary duty can arise from a relationship, one that generally is characterized by one party having power or influence over another. This duty can arise in one of two ways. Firstly, as an explicit duty founded on the principles of influence, advice and or discretion (such as a lawyer, counsellor, or doctor-client[30] relation); or secondly, through a "constructive" reading of the relationships at a later trial, where, in the absence of other explicit evidence, it might "reasonably be expected" that one party will act in another's best interests.[31] One classic test for fiduciary relationships is that of Wilson J, in *Frame* v. *Smith*,[32] which has three elements: discretion or power on behalf of one party, the ability to exercise it unilaterally, and a vulnerability of the beneficiary.

Relationships involving a power imbalance arise in several contexts (tort, contract, property, criminal and even constitutional law, as with the case of the state's relationships to Aboriginal peoples). There is some debate as to whether a fiduciary duty is a distinct cause of action from

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[30] *Wynrib*, [1992] 2 S.C.R. 226 [hereinafter *Norberg*]. Doctors are perhaps the most litigated-against "caregivers," and so the law around these relationships is well-developed, although constantly changing.

[31] See *Hodgkinson* v. *Simms*, [1994] 3 S.C.R. 377.

[32] [1987] 2 S.C.R. 99. This case was an appeal of a technicality in a statement of claim before a court, part of which involved an argument over fiduciary duties with respect to children. Wilson J. makes some often-quoted comments on fiduciary duties here, although this is not considered a leading case. The plaintiff and his wife were divorced, and custody of three children was awarded to the wife. The wife had gone to great lengths to prevent access by the plaintiff including moving frequently, changing the children's surname and religion, and intercepting mail and telephone calls. The plaintiff claimed the wife and her new husband were liable for damages flowing from their wrongful interference with his relationship with his children. The appeal was dismissed. The court determined that there was no actionable tort in this situation. It would be against the best interests of the child for the court to promote litigation between parents by expanding the law of tort to create a new action to meet these circumstances. Allowing an action for breach of fiduciary obligations would be contrary to the intention of the Children's Law Reform Act, and not in the best interests of the children. Since there was no cause of action, the statement of claim was struck out.

negligence or contract. McLachlin J., in the minority judgement in *Norberg*, held that there is a conceptual distinction, holding that contract and tort do not adequately characterize the power imbalances in a fiduciary relation. Further, McLachlin J. emphasizes the exercise of power in another person's interest. McLachlin J. conceives of these relationships as primarily based in a power imbalance. Therefore, tort and contract, which at some level assume parties have equal or reciprocal power relationships, are conceived as inferior formations of the pure fiduciary duty. This area of law (pure fiduciary duty) seems relatively undeveloped.

The content of the duty is generally to be determined with reference to the context and specific facts.[33] The content of the duty will usually include a duty to avoid conflicts of interest and an obligation not to benefit at the expense of the beneficiary, but can also include the advancement of the beneficiary's best interests. In addition, damages awarded for fiduciary breaches in a family context may be different from those awarded in tort.

What do these areas of private law tell us about the five relationships that we are interested in? Broadly speaking, they do not offer good ways of describing these relationships legally, but do offer filters or types of characterizations in law, into which the five relationships might "fit", if some aspects of them were ignored.

So, the common law contains the principles that will be applied to determine if contractual relationships can be entered (capacity, and advice about entering relationships from third parties as a potentially fiduciary relationship). Second, it is possible to characterize a number of the relationships as either contractual (employer-employee), or as containing duties of care

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[33] See *Lac Minerals Ltd.* v. *International Corona Resources Ltd.*, [1989] 2 S.C.R. 574, per LaForest J.

(fiduciary, or caregiver duty of care), and the corresponding principles of private law will apply in litigation. Third, awards for damages in tort gives us at least an indicator of the way courts assign costs to care giving and caregivers.

How might the state be interested in these particular characterizations of relationships? Two aspects suggest themselves. First, the state (both executive and judiciary) appears willing and eager to reduce public costs, and therefore, to promote private arrangements, which will therefore fall increasingly under these headings of law. These are fairly insensitive to the full scope and nature of the five relationships we are examining. Second, both family and labour law are, or at least have been, areas that involve a lot of regulation because of failures in the common law to resolve these problems adequately. A central tension is thereby introduced: how to regulate but not incur costs as a state body. In this way, two elements of the state can be pitted each against the other: the executive (and legislature) seeks to reduce state regulation, which increases the court's (judiciary's) role as the arbiter of private disputes.

VI. Issues of Labour Law

Only a few cases were uncovered that dealt with paid caregivers or adult home sharing explicitly as labour law issues. In these, paid caregivers were generally in conflict with the agency that hired them, not with the person for or with whom they were working. This meant that the relationship itself was not closely examined or categorized by law, but purely the contractual or statutory issues were resolved by either a court or labour tribunal (including human rights tribunals, where these issues were implicated).

Insofar as it relates to contracts, or contracts that are supplemented or superseded by statutes (say, employment standards, or where unions are implicated, collective bargaining under labour relations acts), this area is relevant to some of the relationships examined. This is so especially if forms of private contractual relationships (entered into by individuals with state funding or private funds (i.e. insurance) are used by individuals with disabilities to contract paid caregivers. And these latter arrangements are increasingly the case.

In that event, the issues for labour law will include whether these agents can claim certain rights as people directly or indirectly employed by the state through funding, and more broadly, access to rights and really to the justice system for the "employees".

With regard to the state's interest in these labour relationships, the same comments that apply to family law and contract law apply here as well: that is, the state appears to favour non-intervention, which either precludes a recognition or enunciation of these relationships, and/or transfers the location of conflict to the private law and court system.

VII. Private versus Public Law

It is clear that a majority of these relationships are governed by public law, falling generally into family law, labour law, administrative tribunals (benefits schemes) and some constitutional and tax law. Common to all is the law of fiduciary duty, which broadly speaking describes relationships in which one person has some degree of power over another, usually in a trusting relationship. In addition, tort law captures many instances of people incurring a disability, and an accounting of the costs of those persons' future care. In the context of this investigation, contract and property cases generally focus on conflicts over the distribution of some asset (pensions, disability benefits from employment, wills or estates, etc.).

One area that covers both sides of this general division is the law of evidence, which is comprised of both common law rules relating to competence and compellability of persons with disability, and various statutes also covering these issues. The law of evidence does not form a large portion of these relationships, but does inform the interaction of persons with disabilities with the legal system, and can affect the formation and dissolution of adult personal relationships. Also, in terms of the interaction of people with disabilities with the legal system, when they are in conflict with another person, the law of evidence may limit their potential role as witnesses for their own cause. This is less a condition of the relationship than a problem of the dissolution of these relationships. Basically, witnesses can be found not competent to testify on the basis of mental capacity, which raises systemic problems in access to the justice system for those with relatively permanent mental disabilities, and for those who suffer temporary mental illnesses.

The issue of capacity affects all adults in close personal relationships being studied here – because if individuals are found legally incapacitated in one sphere, their capacity to manage relationships in other spheres can be more easily questioned and challenged. This places certain relationships at risk. For example, an individual with individualized funding, can employ paid caregivers – and thereby establish a form of equality in that relationship – only to the extent that the person is recognized as legally capable to enter an employment contract. For individuals who wish to use a supported decision-making network to assist in making life plans and decisions, the viability of this relationship rests precisely on the decision-making network *not* playing the decision-making role under a guardianship order. Rather, the relationship is based on the presumption of capacity of the individual, and a recognition that support network members do not have legal control over decision-making, or legal liability for decisions made.

In all these areas of private law, it is probably fair to summarize that the common law operates through enumerating types of relationships that give rise to some actionable right, colloquially referred to as "pigeonholes," that are meant to describe the typical form of this right (and hence these relationships). They are normative categories that are often criticized for being archaic and inflexible (and as unable to deal fairly with complex social relationships). Indeed, these criticisms led initially to the enactment of statutory schemes involving relationships, such as provincial family law acts and the federal *Divorce Act*[34] and *Evidence Act*.

VIII. Summary

In summary, case law does not "recognize" at least four of these relationships except insofar as they form a portion of disputes in family law, labour law, torts, etc., and are therefore cast as labour or tort or family issues, with a corresponding essentializing and "pigeon-holing" of the relationships themselves.

These relationships, with the exception of family caregivers, appear to be sufficiently novel, low in number, or so unrecognized by law as to preclude them from any prominence in litigation. It is also useful to recall that case law only captures those aspects of human relationships that involve a conflict so intractable as to require the state as a forum to resolve it (if at all). This means that case law can primarily "tell us" about the conflicts that arise in these relationships,

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[34] *Supra* note 23.

not about more subtle or even pervasive forms of governance or control that may also shape the relationships. It is also useful to note that litigation costs a lot of money and time, so that case law will generally reflect an income bias, especially in areas of "poverty law" (individual employment labour law, social assistance and family benefits tribunals, some criminal law, etc.).

From the perspective of the state interest in these relationships, two general conclusions emerge. The current climate of "small government" will have the effect of privatizing the costs and probably reducing access to legal solutions for people in these relationships. However, this is likely to result in a larger role for judicial (and private law) ordering of these relationships. The courts are responding to this climate by accepting the arguments that regulation may be necessary, but is most desirable when it does not result in a reliance on the state.

When reductions are made, they are often undertaken in a manner that "targets" the "most needy" and this can result in a division of these kinds of relationships into arbitrary categories, which may divide these relationships or in fact "pigeon-hole" them into completely different treatment in the legal system.[35]

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[35] This of course raises the question that haunts all these categories of law: can the "law" of courts and administrative tribunals ever adequately provide regulatory schemes or dispute resolution that will suit these relationships, or are they by nature too complex for the current systems?

PART FOUR

LINKING PERSONAL RELATIONSHIPS TO STATE INTERESTS

The preceding analysis of public policy and program arrangements and case law suggests that the state has minimized its interest in the relationships outlined above - even if it has acknowledged them. Should such relationships remain hidden from public recognition and value? Is the state's apparently minimal interest consistent with commitment to other principles and aims? Two decades of consultations, government reports, and research on the place of people with disabilities in Canadian society suggest otherwise. Indeed, the 1998 *In Unison* agreement between federal and provincial/territorial governments (excluding Quebec) lays out a "blueprint" for public policy development in the disability sector that commits governments to promoting an over-arching vision of citizenship, and promoting the self-determination and equality of people with disabilities.[36]

Together, these three principles can play a role in linking the findings about the valued characteristics of personal relationships involving adults with disabilities, and an understanding of state interest in the relationships. In effect, the research shows how the five personal relationships outlined act as a kind of "intervening variable" between public policy provision and regulation, and achievement of over-arching ethical and legal principles to which the state is committed.

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[36] See Federal/Provincial/Territorial Ministers Responsible for Social Services, *In Unison: A Canadian Approach to Disability Issues* (Ottawa: Human Resources Development Canada, 1998).

This section provides a discussion of the principles of self-determination, citizenship, and equality -- their legal foundation and how their realization is rooted in the valued qualities of relationships. The section concludes with a framework for conceptualizing the link between public policy instruments, personal relationships, and these three principles.

I. Self-Determination

The principle of self-determination bears particular importance for people with disabilities, because many have lived lives of confinement in institutions, and have had decision-making rights removed in order to obtain supports from service providers. In various efforts to shift funding systems to promote self-determination, three limited understandings of the principle have predominated. Recent research on disability and self-determination suggests that its foundation lies in personal relationships (Bach, 2000; The Roeher Institute, 1999; Ontario Association for Community Living, 1992; Canadian Association for Community Living, 1992). Three of the more limited notions about self-determination that have guided public policy development in the disability sector include:

1) The “choice” approach, which equates self-determination simply with having available ‘choices’. Increasingly disability supports and caregiving relationships promote choice for individuals; however, the range and nature of such choices may remain limited. It is not too difficult to show that any community-based initiative for supports meets the test - on paper, at least, of people having more choices. However, their status and power does not necessarily change.

2) The “consumer” approach, which tends to equate self-determination with having control over funding for one’s disability-related supports. In this approach when

funding is allocated to consumers to purchase services, by definition they have self-determination. Evaluation research suggests, however, that people can obtain the cash, but not self-determination -- if by that we mean having some vision or direction for one's life, and having the power to move towards it.

3) The "skills" approach, where self-determination is seen as a set of skills to make decisions. In this classic definition of self-determination, people are self-determining when they can meet the tests of intelligence and rationality considered necessary for making independent decisions and directing supports. By this definition, used in some initiatives for allocating funding directly to people with disabilities to purchase their own supports, those who cannot meet the "self-management" test, as it is known, cannot access individualized funding.

A fuller notion of self-determination brings into view the individual, and those who grant him or her respect for his or her decision-making status, regardless of skill. The understanding incorporates the recognition from others about a person with a disability -- a recognition that the person has 'personhood' and legal rights, an authentic self with a history and a future, a particular biography with hopes deserving of a personal vision and life plan, and is a person with capacity.

In this view, self-determination is not simply about the making of choices. People are not interested in choices simply for the sake of making them. Sometimes one would rather not have choices at all. Sometimes they're too tough to make, especially when what it is that is ultimately wanted is unclear. At the core of the principle of self-determination is the idea that individuals develop some notion of the 'good' for their own life, drawing on the values of their own culture and time, but making for themselves a unique life plan or direction (Rawls, 1979; Kymlicka, 1991; Young, 1990; Taylor, 1989). Self-determination is about the making of this personal vision, and then making choices to pursue and realize this vision. Individuals don't exercise self-determination all on their own -- they don't fashion a life plan for themselves, or pursue it outside of the values, resources and recognition they draw from their culture, communities, families and friends. Sense of self and personhood, the capacity to express intent and desire, is fueled by the recognition that others grant -- that one is valued, that one is loved, that one does have a purpose, and that one's being matters. This idea that self-determination is nourished, or starved, depending on the kinds of recognition one gets from others is firmly established in psychology, ethics, and moral philosophy. To summarize, the basic assumptions of this approach are:

- individuals are interdependent beings, therefore, one's sense of self and purpose come into being through recognition from others;
- having choices serves self-determination, but only when people are supported to exercise choices that enable them to pursue and realize a valued purpose or direction in their lives; and
- having the status (control, resources, supports) to make decisions consistent with one's purpose is fundamental to self-determination

This approach to definition shifts the philosophical and practical task of promoting self-determination from the traditional focus on what an "autonomous" person is, and the tests of rationality and capacity a person must meet in order to be granted the right to self-determination. The 'status and recognition' approach shifts the lens and asks what it means for one person to respect the self-determination of others. In others words, rather than restricting our consideration to whether a "patient" is capable of consenting to a medical procedure or whether a "bank client" can enter a contract, we ask whether and how a physician or a banker is fully respecting and promoting the self-determination of the other person. In this approach, respecting self-determination is not about ensuring that the person passes a capacity test before you engage with them as a person. It's about finding out who the person is, his or her history and hopes. It is about finding some way to communicate, or finding others to interpret, when you don't understand a person's form of communication. It's about respecting a person's right to 'effective communication', established in statutory law in the U.S. through the *Americans With Disabilities Act* and through case law in Canada (e.g. *Eldridge*). It's about finding people who know the person so they can help communicate the vision for that person's life. It's about being responsible for helping to build respectful personal relationships if a person is without family or friends who know them, so that a person can come to be seen *as a person*. It's about transferring real power, control, and status to a person so they can make decisions that allow them to find and follow their own life path.

II. Citizenship

There is a growing recognition in Canadian society that citizenship requires more than the exercise and protection of rights. Participation and inclusion in society are increasingly seen as additional, and central, elements of citizenship. 'Citizenship as legal status', and 'citizenship as participation and inclusion' are distinct, even if related, concepts.[37] New challenges in promoting citizenship emerge in the light of this broader conception, and the fostering of personal relationships that make participation and inclusion possible is at their core. Questions about how individuals are to account for, foster, and respect the diversity of others gain relevance of the highest order with this shift in thinking. This is because participation and inclusion - in public

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[37] For a review of these two theories of citizenship see Will Kymlicka and Wayne Norman, "Return of the Citizen: A Survey of Recent Work on Citizenship Theory," *Ethics* (January 1994):352-381.

governance, in the labour market, in schools - are meaningful only if one's diversity, or the diversity of one's group or collectivity is recognized and respected by others.

A conceptual link between citizenship and diversity is being forged at a time when 'difference' is increasingly defining the social and political landscape of Canadian society. In addition to long-standing racial, ethnic and linguistic distinctions, increasingly diverse social identities are forming and seeking representation and recognition on bases of gender, race, ethnicity, language, disability, economic class, age, sexual orientation, and geographic community. One of the outcomes of this trend is that the means by which individuals and groups engage with institutions of Canadian society are shifting. There are weaker attachments to political parties and a growing identification with an of array of civil society organizations and social movements.

Recently, governments in Canada have begun adopting this broader notion of citizenship to guide policy discussion and development. The 1999 "Social Union Framework Agreement" between federal and provincial/territorial governments (excluding Quebec) makes "respect for diversity" a "fundamental value" of the union, and promoting "the full and active participation of all Canadians in Canada's social and economic life" a guiding principle.[38] The federal-provincial/territorial *In Unison* accord was negotiated in light of the Social Union Framework Agreement.

This conception of citizenship as full participation can be distinguished in important ways from the more classic, post-war conception that Marshall articulated - an ideal of citizenship as a legal status constituted by civil, political and social rights (the latter being rights to health care,

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[38] See *A Framework to Improve the Social Union For Canadians: An Agreement between the Government of Canada and the Governments of the Provinces and Territories*, February 4, 1999.

education, etc.).[39] The theory he advanced situated the protection and exercise of citizenship rights as means by which inequalities of class and other divisions, like disability, would be ameliorated, moving society that much closer to realizing the value of equality. This theory of citizenship has guided much of institutional development in Canada in the past 40 years. An impressive framework of constitutional and statutory rights has been established at the federal, provincial, and territorial levels. However, while this framework of rights provides a foundation for citizenship, issues of exclusion and marginalization persist for people with disabilities - whether from the labour market, regular education, the social and cultural life of communities, from the policy-making and development process, or from a culture that values and reflects particular differences and diversity in Canadian society. Marshall's theory, that a fuller legal framework for citizenship rights would address marginalization and exclusion proved only partially correct -- a framework of civil, political, and social rights has been found to be a necessary condition for citizenship, but we have also learned that it is not a sufficient one when it comes to people with disabilities. Their full participation and inclusion requires adaptations, and in some cases reconstruction, of the institutions and organizations of society that are not manifest simply through the claiming of what is now an impressive array of citizenship rights.

With this shift in thinking, citizenship is defined not only by the extent of one's claims and the exercise of rights; it involves, as well the capacities to acknowledge, respect and accommodate the difference and diversity of others. It is as much about claiming one's own rights, as it is about the practice of 'citizenship virtues', of knowing others in ways that bring value, and support and respect. Thus, questions about how to realize citizenship rights converge with questions about how to foster a 'culture of citizenship' where one's participation and inclusion is interdependent with one's fostering the participation and inclusion of others. In this conception

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[39] T.H. Marshal (1965), *Class, Citizenship and Social Development* (New York: Anchor).

of citizenship, diversity is not an end in itself, citizenship is the end, and more broadly social well-being (The Roeher Institute, 1993). By maintaining an essential link between diversity and citizenship, concerns can be addressed about whether a society can establish limits on groups which claim their unique identity only in devaluing others (usual examples offered to challenge the diversity thesis are 'neo-Nazi' groups and ethnic-based violence). In a fuller model of citizenship than the 'citizen as legal status' approach, diverse groups and interests not only make rights claims for full respect for their diverse interests and claims. They have responsibilities to respect the diversity of others so they too can fully participate and be included in what the Canadian philosopher, Charles Taylor refers to as a "politics of mutual recognition".[40] This understanding of citizenship also accords with Minow's (1990) argument that we need not dispense with citizenship, equality, and other human rights because of their limitations, but that we should "re-conceive rights as a notion that upholds the rights in relationships among mutually dependent members of the community." (p. 301)

Promoting and fostering personal relationships that advance full citizenship (as inclusion, participation and respect for diversity) is also a way of advancing "social cohesion". Concern is increasingly registered about what many see as the fragile and diminishing quality of social cohesion in Canadian society in the face of entrenched poverty for some groups, social and economic inequalities, and discrimination and violence across differences of gender, disability, race and ethnicity, religion, income, language, sexual orientation, etc. Social cohesion is not about the absence of difference and conflict; it is more about the institutional capacity for

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[40] Charles Taylor (1992), Multiculturalism and "The Politics of Recognition" (Princeton, N.J.: Princeton University Press).

granting recognition of difference, building solidarity across differences, and managing social conflicts.[41]

The need to engender what Taylor refers to as "deep diversity" in Canadian society as a condition of a fuller citizenship and a national identity,[42] or what Young refers to as "differentiated citizenship" and the "politics of difference"[43] rest in part on the development of personal relationships of support which make possible respect, dignity and status for people with disabilities.

III. Equality

Equality is a third guiding principle advanced in research, consultations, and public policy to address the persisting exclusion and marginalization of people with disabilities. Like self-determination and citizenship, at the core of the notion of equality, is the understanding that its exercise is relational in nature. Fundamentally, it is about equal respect and concern. Equality consists, Lukes (1980) argues, in people who are "equally free from political control, social pressure, and economic deprivation and insecurity to engage in valued pursuits, and who have equal access to the means of development." The importance of mutual recognition that brings dignity and inclusion for one another is increasingly at the core of equality debates and legal

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[41] See Jane Jenson (1998), *Mapping Social Cohesion: The State of Canadian Research*, CPRN Study No. F/03 (Ottawa: Canadian Policy Research Networks).

[42] Charles Taylor (1991), Shared and Divergent Values, in R.L. Watts and D.G. Brown (eds.), *Options for a New Canada* (Toronto: University of Toronto Press).

[43] Iris Marion Young (1989), Polity and Group Difference: A Critique of the Ideal of Universal Citizenship, *Ethics* 99:250-274; (1990), *Justice and the Politics of Difference* (Princeton, N.J.: Princeton University Press).

decisions in Canada. In a recent Supreme Court of Canada decision in which equality cases under the *Charter's* s. 15 equality rights were reviewed, the Court stated:

> It may be said that the purpose of s. 15(1) is to prevent the violation of essential human dignity and freedom through the imposition of disadvantage, stereotyping, or political or social prejudice, and to promote a society in which all persons enjoy recognition at law as human beings or as members of Canadian society, equally capable and equally deserving of concern, respect, and consideration.[44]

This analysis suggests that central to the promotion of one's equality is the act of recognition by others. People with disabilities have often encountered forms of social and legal recognition that leave them without value as full human beings, as rights-bearing citizens. Given the negative stereotypes and exclusions they face, fostering more enabling kinds of recognition - that make "concern, respect, and consideration" possible must be a high priority if equality is to be secured. Research makes clear that to counter devaluing forms of recognition of people with disabilities, they must have access to relationships where others' personal knowledge of them can grow.

The reality is that many support relationships involving adults with disabilities are not characterized by a relationship of equality - as defined in philosophical terms and in jurisprudence. In these relationships, the victims of inequality of status, recognition, and decision-making power, are by and large people with disabilities. But the relationships of support they are in can also, because of the larger policy and social context, diminish equality for care providers. As we have seen, many care providers find themselves with low wages, lack of benefits, lost economic opportunity, extraordinary burden of care, limited personal control, and reduced health status. Promoting equality in relationships of support should thus be a guiding principle for relationships involving adults with disabilities (The Roeher Institute, 2001).

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[44] In *Law* v. *Minister of Human Resources Development* (1999), 170 DLR (4th) 1.

IV. Conceptual framework for linking public policy instruments, personal relationships, and state interests

The following table synthesizes the findings for this research. It situates personal relationships of the forms outlined, as dependent in important ways on the public policy framework in place - for income support, disability supports, decision-making status, and labour law and regulation. It shows how they are an intervening force between those public policy arrangements and state interests and commitments to rights to self-determination, citizenship, and equality.

Table 5: Personal Relationships, Disability and State Interests

Public Policy Instruments that Affect Personal Relationships	Valued Characteristics of Personal Relationships	State Interests, Commitments and Obligations
• Basic income support • Funding and delivery of disability supports • Decision-making status • Labour law and regulation for paid caregivers • Tax benefits	• Reciprocity • Interdependence • Value and respect • Personal knowledge • People making own choices • Bridges to community – for participation, contribution • Personal attachments, companionship, love • Shared vision for a person's future • Mutual care and support • Respect for unique communication • Life in the community • Fostering of independence	• Self-determination • Citizenship • Equality

CONCLUSION

This study has reviewed five types of personal support relationships involving adults with disabilities: those with family members, paid support providers, alternate families, home sharers, and supported decision-making networks. With the aging of the population, and advances in medical technologies, the proportion of people with disabilities in Canadian society will grow. Given the value attached to these relationships, and their centrality in securing self-determination, citizenship, and equality, demands are also likely to grow for a more enabling public policy framework for these relationships.

The initiative under which this paper was written focuses on the role of Parliament in recognizing close personal relationships. However, the method used here did not begin with a review of federal statutes. Rather, it began with the realities of a particular set of close personal support relationships involving adults with disabilities in order to characterize under what kinds of conditions and in what ways these relationships were valued by those involved. The analysis then stepped back to ask what kinds of policy and program arrangements - federal or provincial - affected the nurturing of valued relationships, and ways in which these relationships are recognized in statutory and case law. Finally, the analysis situated these relationships as intervening variables or factors in realizing state commitments to full citizenship, self-determination, and equality rights.

The analysis generated a number of findings:

- These relationships involve a significant and growing number of Canadians.
- The status of adults with disabilities in these relationships has long been undermined, by:
    - inadequate provision of paid supports;
    - economic *in*security;
    - diminished legal status in a wide range of areas (right to marry, participation on boards of directors, personal care and financial decision making, etc.);
    - lack of recognition of decision-making assistance;
    - an institutionalized imbalance of power - through labour laws and other mechanisms - favouring paid caregivers;
    - inadequate supports to family caregivers, leaving them vulnerable to sometimes unbearable stress and financial difficulty.
- Their marginalized status in relationships defined by inequality has left adults with disabilities vulnerable to neglect and abuse.
- Family caregiving is the exclusive form of support relationship for a large majority of adults with disabilities who require support, largely because of inadequate access to paid supports, and systemic exclusion from social and economic opportunity. The burden on families is enormous, and is likely to grow with the aging of the population. Yet their contribution is considered a private choice, not worthy of adequate compensation or support, even while the state makes other options for support often difficult if not impossible to obtain.

- Tax recognition of those who do provide caregiving support on a voluntary basis is restricted to immediate and extended family members. This leaves those non-family members who enter significant, non-paid caregiving relationships without even the minimal recognition or support accorded family caregivers.

- Alternate families and adult homesharers are not only in a contracted, paid caregiving relationship to an adult with a disability. They involve domestic relationships of interdependence and mutual contribution. But models for these relationships - the obligations and liabilities they can bring - are not clear.

- Family caregivers and those providing care in other domestic relationships (alternate family and home sharing) face workplace environments and employment benefit regimes that do little to recognize and support their role and relationship with disabled adults.

- For people who do access paid supports, caregivers are often underpaid, without adequate benefits and security, and the stress on the caregiving relationship shows in the negative consequences for adults with disabilities.

- Efforts to strengthen the status of people with disabilities, through the fostering of support networks is at risk without investment in building and sustaining those networks. Their recognition and active support, as a foundation for protecting rights to self-determination, citizenship and equality is required in a whole range of settings - like the justice system, health care decision making, financial and employment contracts, etc.

It is clear that the relationships reviewed in this paper cannot simply be a private matter if the values that should define them are to take hold. Their robustness in this regard depends on adequate compensation for caregivers, back-up supports, and regulation to ensure status and balance of power. Yet the courts have not been willing to advance a more proactive role for the state in establishing these conditions. The preference for the courts, Parliament and provincial/territorial legislatures has been to consign these relationships almost entirely to the private sphere. This leaves the consequences of apparently ‘private choices’ in ‘private hands’. And with this almost exclusively private responsibility, an entrenched, marginalized status for adults with disabilities has come.

Left almost entirely to the private sphere, cultural assumptions and imperatives are determinative in these relationships - not exclusively but predominantly. Disabled adults are seen as ‘wholly dependent’ on others. Their disability is seen to ‘incapacitate’ them from making decisions and exercising self-determination. They are seen as ‘consumers’, but not contributors. Unable to fully meet the criteria of personhood, the rights that usually attach are often presumed not to fully apply in this case. The consequence of such assumptions is that individuals’ legal capacity and their decision-making status, is often in question.

To address the challenges in fostering stronger personal relationships involving adults with disabilities, clearer state support and recognition are needed in eight areas:

1. Review of federal statutes with a “disability lens” to critically examine the social and legal construct of disability as a medicalized, dependent and devalued status (e.g. “infirm dependent”). These constructions contribute to a legal policy and program framework that objectifies adults with disabilities, denies their autonomy, consolidates the physical, social and economic power others hold over their person and their lives.

2. Recognize and support the right to full citizenship and self-determination of individuals with disabilities in a range of federal and provincial statutes and policies. In acknowledging the link between communication capacity and self-determination, greater statutory recognition could be considered for the right to 'effective communication' (as in *Eldridge*) and to the role of support networks in realizing this right. In the federal jurisdiction, for example, the right could be more clearly established in principles for access to health services (as determined in *Eldridge)*, and to the justice system. As well, a review of federal statutes could be undertaken (e.g. the *Canada Business Corporations Act)* with a view to ensuring that decision-making assistance is recognized as a valid support for individuals who might otherwise be considered without the legal capacity to exercise citizenship rights to participation, such as sitting as directors of organizations.

3. Establish clearer options for legal recognition of support networks, and domestic support relationships (family, alternate family and homesharing). The 'registered domestic partnership' status would not provide an adequate legal framework to accord these relationships the status they deserve. Nor does the *Criminal Code* recognition of a person's responsibility to "provide necessaries of life to a person under his charge" provide an adequate model of responsibility and obligation. It denies the reciprocity that defines the relationships reviewed, the nature of the assistance provided, and the contributions that adults with disabilities themselves make. Options to register different kinds of significant personal relationships -- like supported decision-making networks -- might be considered.

4. Strengthen the economic independence of both parties to support relationships (e.g. labour market policies for adults with disabilities and income support/replacement measures; fairer and more comprehensive tax measures recognizing family as well as

non-family care providers; wage and benefit measures for paid caregivers; eligibility of family carers to be paid caregivers).

5. Provide more adequate access to needed direct and back-up supports -- funded home care, attendant services, etc. -- through tax provisions increased federal-provincial transfers for this purpose and/or direct transfers to individuals.

6. Recognize and support enhanced financial compensation for family caregivers, alternate families and home sharers where they commit to a significant caregiving relationship. Workplace flexibility, benefits, and entitlements to leave are also essential for making these caregiving relationships viable. Changes to Employment Insurance and federal and provincial labour standards and human rights codes could be considered to expand the focus beyond the parent-child caregiving relationship.

7. In human rights provisions clearly extend to family members, who have significant caregiving responsibilities for family members with disabilities, protections from discrimination in employment practices on the grounds of family status and ensure the duty to accommodate on the basis of relationships of caregiving support.

8. Establish common principles (or “framework agreements”) to guide sectoral, collective bargaining for paid caregiving that affirm status and primacy of decision-making rights of individuals with disabilities, and collective bargaining processes that fully represent individual and family interests, while also affirming labour rights.

Much detailed work would be needed to further develop the options outlined here. But the analysis does make clear that the relationships of support reviewed in this paper are worthy of consideration under the initiative of the Law Commission of Canada. New forms of legal and public policy recognition are required.

While intergovernmental collaboration would be necessary for development and implementation of these options, the difficult politics of federalism in Canada should not restrict Parliament from taking leadership in those areas where it can. This would serve as a sign that these relationships of support do matter; that they are worthy of public recognition and support; that improving the status of adults with disabilities in Canadian society is deserving of state action with respect to personal relationships; and that the state in Canada is committed to making these relationships a place where self-determination, citizenship and equality abide and endure.

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