



Connecting to Citizenship

Social policy recommendations to
address isolation and loneliness

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“Part of facilitating relationships is taking the veils off people’s eyes so they can see the contributions that persons with disabilities make.”

Ted Kuntz, Father and Chair of PLAN

I. Summary of Recommendations

This is a compiled list of the seven recommendations made throughout this paper. The discussion associated with each recommendation can be found below the similarly numbered recommendation in *Section VI. Recommendations to Reduce Isolation and Loneliness* (starting on page 10).

1. That public leaders promote a new vision of citizenship based on contribution.
2. That funding to address the handicap of isolation and loneliness be made a national priority.
3. That a national No One Alone fund be created to address loneliness and isolation.
4. That Funders develop goals to foster the conditions in which relationships are more likely to develop by:
 - Promoting and recognizing the contributions of persons with disabilities and their families
 - Requiring that persons with disabilities have the option of direct and individualized funding or other mechanisms that support consumer control and self reliance in the delivery of their services
 - Promoting collaboration among persons with disabilities, families, service providers, neighbourhoods and businesses.
5. That expenses made by individuals and families towards the development of unpaid relationships be recognized under the Medical Expense Tax Credit.
6. That expenses towards family support, family networking and family leadership (creation of social capital) be recognized as a tax deduction.
7. That the design of research and dissemination of knowledge:
 - Reflects the importance of belonging and meaning to persons with disabilities as a research priority
 - Deepens our understanding of the connection between contribution and citizenship
 - Emphasizes collaboration between academics, disability organizations and community members.
 - Investigates and promotes new accountability mechanisms, which map and track the unique paths associated with developing relationships.

II. Introduction

Social Networks

It is impossible to imagine a good life that is void of relationships. Relationships, however, are also a springboard to other components of a good life such as having a home, making choices and contributing to others. Relationships are the social ties that bind human beings together. Relationships, for the purpose of this discussion, are reciprocal, genuine, enduring and unpaid.

The relationships, or networks of relationships of any person, can be referred to as a social network. Social networks are the source of people's and communities' social capital. People who have more relationships, and communities that have more social networks, have more social capital.

Relationships are a critical element of humanity, of identity, of belonging and of citizenship. Many notable Canadian thinkers have made this point: Jean Vanier, John Ralston Saul and Mark Kingwell, to note but a few.

Individuals who have strong social networks are more likely to have positive outcomes than those who do not. Documented positive outcomes include: greater well-being and ability to cope (Cattell); increased trust (Buskens); diminished risk of becoming disabled and improved recovery from illness (Mendes et al); better ability to deal with transitions (Hayes & Oxley). Likewise, communities that are rich in social capital are more likely to be healthy communities than those that are not (Putnam; Helliwell; Pilisuk and Parks).

PLAN Institute for Disability and Citizenship (PLAN Institute) has been developing social networks for persons with disabilities for the past 15 years to assist them in securing a good life. While a handful of groups across Canada are developing social networks around people, a body of knowledge that informs the work has yet to be developed.

In response to this knowledge gap, PLAN Institute investigated the development of social networks among a cross section of groups that are vulnerable as a result of isolation and loneliness. These groups include: persons with mental and physical disabilities; persons with mental health issues; youth and seniors.

Persons with disabilities, family members, service providers and persons who facilitate social network development, sometimes called facilitators, from across Canada were interviewed between January and June 2004. In June of 2004, facilitators and families gathered to share experiences, discuss preliminary learning and propose social policy recommendations.

This policy paper, *Connecting to Citizenship*, focuses specifically on the promotion of social networks among persons with disabilities. Founded on the learning from the above mentioned research, this paper identifies a number of levers of influence available to promote the development of social networks (see page 10) and makes a number of social policy recommendations (see page 2 or page 11). While conceived for promoting social networks around persons with disabilities, implementation of most of the recommendations, will also benefit other groups that are frequently isolated and lonely.

The Current Experience of Persons with Disabilities

Canadians with disabilities have the same aspirations as other Canadians. They aspire to:

- having a home,
- loving relationships with family and friends,
- controlling the basic elements in their lives,
- attaining sufficient financial means to live with dignity,
- pursuing their dreams and passions, and
- making a contribution.

We commonly know this set of aspirations as “a good life” (Etmanski). For the vast majority of people, a life void of relationships precludes living a good life.

It is impossible to imagine a good life without the benefit and support of genuine relationships. For many persons with disabilities, though, this is their bleak reality. Although much progress has been made, we need to do more to respond to the challenges faced by persons with disabilities. But accessible buses and taxis, elevators labelled with Braille, events translated into ASL, and other similar measures won't be enough to ensure people with disabilities belong.

The presence or absence of relationships also affect the degree to which citizenship is attained. The disability movement has been driven by the ‘rights paradigm’ over the past 50 years. That is to say, we believed that rights were the means by which citizenship would be attained for persons with disabilities. While the rights of citizens with disabilities have been increasingly entrenched in the laws, policies and institutions of Canada, true citizenship, evidenced by participation, contribution and acknowledgement of our fellow citizens, has remained elusive for many Canadians with disabilities. As a result, persons with disabilities have not had the opportunity to fulfill their obligations as citizens.

Why has citizenship remained elusive? We believe that true citizenship has remained elusive because persons with disabilities need to fulfill the same obligations and make the same contributions as other citizens do. Our recent research, as well as our experiences during 15 years

of developing social networks for persons with disability, suggests that relationships lead to contributions and fulfilling one's obligations. Thus true citizenship, which results in being valued by and belonging to a community, remains elusive for many persons with disabilities because they remain isolated.

A significant element of true citizenship is the acknowledgement of our fellow citizens. Our fellow citizens acknowledge our citizenship when they see that we are fulfilling our obligations. We can only meet our obligations when we are in relationships with others and we can only be in relationships with others when we contribute. It follows therefore that relationships are necessary in order to achieve citizenship.

Isolation is also a barrier to employment, the result of which is that persons with disabilities face high levels of unemployment and poverty.

In summary, isolation and loneliness are among the most disabling conditions. Isolation and loneliness lead to poverty, poor health and diminished citizenship, result in less support for the activities and challenges of daily life, and prevent the realization of a good life. Thus isolation and loneliness are formidable handicaps in their own right, and often their impact outweighs the disability.

Ending isolation and loneliness, therefore, will lead to better health and social indicators and the achievement of a good life. It will result in the recognition of the contributions of persons with disabilities, the fulfillment of their obligations as citizens to contribute and, ultimately, to full citizenship.

What stands in the way of persons with disabilities being in relationships? We often assume that accessible communities and adequate supports are our most significant challenges. In our work at PLAN Institute, however, we have witnessed many situations where persons live in accessible communities and have adequate supports but remain isolated. As a result, we have concluded that attitudinal barriers also must be addressed.

Our work suggests that changing widely held attitudes and, therefore, the assumption that persons with disabilities do not contribute is critical to the development of relationships for persons with disabilities. This is because reciprocity is fundamental to genuine, enduring relationships. Reciprocity requires contributions from both persons within a relationship. That is, both persons in a relationship must contribute and receive. Without this reciprocity, one of three outcomes will result:

- the relationship will not be genuine
- the relationship will not endure
- or the relationship will be charitable

Social Policy Implications

To end isolation and loneliness, social policies and programs must seek to achieve two ends:

1. Change the assumption that our family members with disabilities don't have contributions to make
2. Support the development of relationships for our family members with disabilities

Our failure to change society's assumptions will further entrench the false perception that persons with disabilities don't contribute to others. Failure to change society's assumptions will perpetuate the causes of isolation and loneliness. Failure to change these assumptions will mean that a century from now, our children with disabilities will face the same prejudices that lead to isolation and loneliness today.

The development of relationships, however, holds the potential for attitudinal changes. As persons with disabilities engage in relationships, the attitudes of those around them change. Our ultimate goal is to change the prevailing societal beliefs so that the presence of children with disabilities is welcomed and celebrated.

III. The Elements of Sustainable Social Networks

Many elements contribute to building authentic, resilient and sustainable networks. While the participants in PLAN Institute's research have approached the task of developing social networks in different manners, common elements run through all of the work of developing social networks. Those elements that have greater implications for social policy include the following:

Reciprocity

The importance of reciprocity cannot be overstated. Relationships cannot be characterized as genuine, meaningful or sustainable without the presence of reciprocity. Some would say that relationships do not exist without reciprocity. All would agree that reciprocity is critical in sustaining relationships. In other words, both parties in a relationship must receive and, necessarily, both must contribute.

One of the greatest obstacles in forming relationships is the perception that persons with disabilities do not contribute. There are two types of contribution: *being* and *doing*. In general our society values contributions of *doing* above those of *being*. For example, work, sport and performance tend to be highly valued in our society. Speaking is more highly valued than listening; achievement more highly valued than reflection. Our society tends to value courage, sacrifice and dedication over hospitality, caring and loyalty. Persons with disabilities who are more isolated and

who have fewer opportunities to participate are disadvantaged in this milieu where contributions of *doing* are favoured over contributions of *being*.

Asking

Isolation is another related obstacle. People's contributions are recognized within relationships. Thus the contributions made by persons who are isolated remain unrecognized. This creates a vicious circle wherein isolation prevents contributions from being recognized which, in turn, maintains isolation.

There are two paths by which these obstacles can be overcome. One is to change the societal paradigm so that we begin to recognize contributions of *being*. The other is to increase participation of persons who are vulnerable to isolation.

Participation, in turn, can be promoted in many ways. One method is to actively develop networks with the assistance of a facilitator – a person who takes responsibility for assisting the person in making connections with others. This breaks the vicious cycle in which isolation prevents contributions. Another method is to promote more accessible and hospitable communities.

In our research, facilitators of social networks all reported that the personal barriers experienced in asking people in the community to get involved – taking risks, fear of failure, etc. – were more significant deterrents than the barriers posed by uncaring and inhospitable neighbours and communities. Fear arises from several factors, but especially from a focus on deficiency and subsequent possibility of rejection.

The unexpected and nearly universal experience recounted by facilitators in this study, however, has been that people in the community want to be engaged and often just need a bit of support to get started. Having a context for participation, for example, a mutual interest in opera or hockey, has been an essential ingredient. The ability to identify common ground maximizes the likelihood of success in connecting two individuals.

Time, Space and Passion

George DuCharme, a pioneer in the development of social networks, shared his personal experience with other participants when he said, "It is not a short walk that we are talking about." Early in his career, George was challenged to 'walk the long walk and to walk *with* people'.

By definition, the loyalty of employees is firstly to their employers. Employers are often constrained by funding sources. In contrast, relationships with friends don't know these

boundaries. Walking *with* people is different than working *for* people. Friends don't walk away when program funding ends. The commitment within genuine relationships is different than the typical connection between persons with disabilities and service providers.

The development of relationships, however, takes time. Relationships cannot be provided with the same certainty as services. We must create spaces in our lives, in our communities and in our society for the relationships to develop. We can nurture and foster these relationships but ultimately they must develop at their own pace. This runs counter to our society, which increasingly expects its needs and desires to be satisfied immediately. It also runs counter to more traditional accountability frameworks, which require concrete outcomes and specific timelines.

It is critical that the requirement of time not be confused with failure. Sometimes the time allotted to nurture relationships is inadequate. It is critical that such situations are not confused with failure, which results in two unfortunate outcomes: first, the isolated person accumulates yet another label, that of 'can't make friends', and, second, the effort to develop relationships is abandoned, the result of which is that the person loses the opportunity to have friends present in their lives.

Facilitation of relationships and creation of community cannot be done in isolation from relationships or from outside of community. Thus, for facilitators, the boundaries between the work of building networks and their personal lives are not distinct. The gifted facilitators who do this work are called to it by their caring gene, by their desire to contribute, and by their aspiration to make a meaningful contribution. It is not a job. It is a passion, a way of life. Spirituality is an important source of both inspiration and sustenance for people who facilitate relationships and create community.

Developing relationships is more organic than our more typical work activities and structures. Hospitality takes precedence over agendas. Storytelling takes precedence over statistics. Sharing meals takes precedence over meetings. Celebration takes precedence over evaluation. Trust takes precedence over criminal record checks.

Transformation

At multiple levels, persons with disabilities, their families and people providing services all must be prepared to embrace transformation. The successful development of networks requires that isolated persons, their families and their service providers all accept a new story.

The isolated individual must accept the risks inherent in change, growth and relationships. They must be prepared to accept that their identity – their understanding of self – will fundamentally

change. The significance of this cannot be underestimated given the life history of many persons with disabilities – especially those who have experienced institutionalization or segregation.

Family members also must accept a new story for their relatives. Their relationships with the persons at the centre of networks will change as their relative gains self-determination through the independence and inter-dependence that comes with relationships. Family members will have less involvement and will experience a loss of control as the social networks develop.

Service providers can collaborate and be invaluable allies or they can be nearly insurmountable barriers because of the influence and power that they wield in the lives of the people they serve. Service providers must let go of assumptions about the people they serve, about persons with disabilities and about community. They need to support people as they change and accept the resulting changes in people's lives. They must be aware of the messages that their interactions with people send to prospective friends. They must provide an environment which supports the entry of new friends into people's lives. They must support people at the centre of networks in taking risks and they must accept a loss of control. Finally, they must accept that the presence of networks of support can complicate service provision. New friends might ask questions, raise issues and advocate for people receiving services, any of which might create pressure to change the services.

Service providers, however, are poor candidates to bear the responsibility for the development of social networks because of the potential for conflict of interest. Playing the roles of both service provider and network facilitator will ultimately lead to conflict if network members question the quality or appropriateness of services. Because of the advocacy that is inherent in unpaid relationships, the service provider may not be able to support network activities and concurrently act in its own best interest.

Facilitation of relationships and creation of communities are occurring across Canada in isolated pockets. The facilitators of networks are themselves isolated from each other and this precludes them from sharing their knowledge and experiences and supporting each other. Within this group, there is a feeling of great potential, great hope, while at the same time great fragility.

IV. Social Policy Goals

Our work suggests that to promote the development of social networks for persons with disabilities, we must all work together in removing barriers and creating incentives to:

1. Increase the awareness of the contributions that persons with disabilities make to others and to society
2. Increase the opportunities for persons with disabilities to contribute
3. Increase the involvement of family members, friends, neighbours and community members in the lives of persons with disabilities, and
4. Support the work of people and organizations who are facilitating the development of networks and creating community.

V. Levers of Influence

Funders, policy makers, community leaders, academics and service providers have a number of levers of influence with which to accomplish the aforementioned social policy goals, including:

- A. Leadership
- B. Funding and accountability relationships
- C. The relationships between governments and persons with disabilities and their families through the tax system.
- D. The research priorities of governments, policy makers and academics
- E. The commitment by governments, businesses and service providers to accessibility and inclusion within worksites and services
- F. The laws, regulations and policies established by governments
- G. The regulatory bodies established by governments

In the following sections, we will make seven recommendations that our research indicates should be given the highest priority. The research suggests that these actions would have the greatest, most immediate and most long-lasting effects in reducing isolation and loneliness among persons with disabilities.

VI. Recommendations to Reduce Isolation and Loneliness

A. Leadership

1. That public leaders promote a new vision of citizenship based on contribution.

Governments and disability organizations, as public leaders, have a golden opportunity to promote a different paradigm of disability in Canada. Constructing communications that stress the contributions of persons with disabilities and the importance of enabling those contributions would be a powerful force in changing the existing societal view that persons with disabilities are receivers rather than contributors.

In addition, public leaders have the opportunity to disseminate a new vision for citizenship in Canada. A vision of citizenship based on obligations, rather than a vision of citizenship based on rights will advance true citizenship for persons with disabilities by asserting their obligation to contribute and by recognizing the role that relationships play in achieving citizenship.

Some might argue that this undermines the basic rights enjoyed by citizens. In fact the opposite is true. Simon Weil expresses this concisely in *The Need for Roots*:

“The notion of obligations comes before that of rights, which is subordinate and relative to the former. A right is not effectual by itself, but only in relation to the obligation to which it corresponds, the effective exercise of a right springing not from the individual who possesses it, but from other men who consider themselves as being under a certain obligation toward him. Recognition of an obligation makes it effectual. An obligation which goes unrecognized by anybody loses none of the full force of its existence. A right which goes unrecognized by anybody is not worth very much.”

Furthermore, a society based on obligation is a caring, inclusive society. A society based on rights is more likely to foster an individualistic outlook where citizens feel less responsibility for those on the margins.

B. Funding Relationships

A New Funding Priority

2. That funding to address the handicap of isolation and loneliness be made a national priority.

The present disability-related funding priorities of federal, provincial and territorial governments are delineated into three components: supports, income and employment. We suggest the addition of a fourth element: actions to eliminate the disability of isolation and loneliness.

The work that is necessary to support and nurture meaning and belonging – that is, the development of relationships and community – cannot be easily categorized. It cuts across governments and the many component parts of our society.

Nevertheless the work of relationship building requires champions both within and outside of government. And it requires the designation of resources both within and outside of government to:

- Raise its profile
- Nurture it and foster mutual support
- Further research and deepen understanding
- Foster innovation
- Disseminate new ideas and learning.

A National No One Alone Fund

3. That a national No One Alone Fund be created to address loneliness and isolation.

We suggest the creation of a national *No One Alone Fund* to end isolation and loneliness among persons with disabilities. An endowed fund of \$25,000,000, along with matching private sector contributions and other donations, would represent a one-time expenditure and would create a sustained national effort that will promote the development of relationships and the creation of inclusive communities.

The Fund could support activities to achieve the goals listed above, including:

- Development of networks
- Innovative pilot projects

- Regular gatherings of those involved in developing relationships to share their learning and sustain their efforts
- Further research
- Dissemination of knowledge and experience
- Inspiration and encouragement for more individuals, families and groups to undertake this work
- Collaboration with the academic sector
- Dialogue with the service sector to deepen the understanding of the relationship between friendship and services
- Education and communication activities that redefine and deepen the general public's understanding of the contributions of being and doing
- Deepening our understanding of the role of and the development of social networks in the lives of persons with disabilities
- Fostering accountability and evaluation mechanisms that allow for surprise and track unintended consequences.

Ownership and governance of the Fund could rest in the community. Governments and community could encourage contributions and matching grants from foundations and other funders, similar to the way that the Rick Hansen Foundation has operated for the purposes of spinal cord research.

Conditions Conducive to the Development of Relationships

4. That Funders develop goals to foster the conditions in which relationships are more likely to develop by:
 - Promoting and recognizing the contributions of persons with disabilities and their families
 - Requiring that persons with disabilities have the option of direct and individualized funding or other mechanisms that support consumer control and self reliance in the delivery of their services
 - Promoting collaboration among persons with disabilities, families, service providers, neighbourhoods and businesses.

Our work suggests that three activities foster conditions in which relationships are more likely to develop:

a) Recognition of the contributions of persons with disabilities and their families

The importance of recognizing the contributions of persons with disabilities and their families in removing barriers to participation, to relationships and ultimately citizenship is discussed above, in the Introduction (see page 3) and in the Elements of Sustainable Networks (see page 6).

b) Control over funding for services

Control of funding for services is important to the development of social networks for at least two reasons. First, persons who direct their own services are perceived more positively than persons who are directed by their services. The former is likely to be perceived from a capacity-perspective and the latter from a deficit-perspective. This perception will affect their ability to engage others in relationships and will also affect the type of relationships that will result.

Second, when a person with a disability and their network control the services, there is greater assurance that services will be personalized and designed to assist the person live a good life. In other words, the person at the centre of the network will determine their own service outcomes and the services are to be accountable to the person and their network. As a result, services are more likely to support the development of relationships.

c) Collaboration among persons with disabilities, families, service providers, neighbourhoods and businesses to create hospitable and caring communities

The creation of hospitable and caring communities when persons with disabilities, families, organizations and businesses collaborate can take many forms and the outcomes of this work are not always clear or predictable. For example, L'Arche and L'Abri en Ville have created a welcoming community for persons with disabilities by collaborating with the faith community. Philia, a dialogue on citizenship, engages persons with disabilities, families, the civic sector and the business sector in dialogues to deepen the understanding of caring communities while, at the same time, sharing knowledge and experiences and promoting persons with disabilities as contributors. All of the groups involved in the PLAN Institute research project, however, shared a similar experience: this community-enhancing work is fundamental to fostering communities that are open to persons with disabilities and to disseminating the paradigm of persons with disabilities as contributors and full citizens.

These goals should be considered within the following four funding and accountability relationships:

1. The Federal-Provincial-Territorial Accountability Frameworks, which are negotiated between the Government of Canada and provincial and territorial governments under the Social Union Framework Agreement (SUFA)
 2. Contracts between the Government of Canada and disability related organizations
 3. Contracts between provincial and territorial governments and service providers
 4. Grants made by foundations and businesses to service providers and other disability related organizations.
- C. The relationships between governments and persons with disabilities and their families through the tax system
5. That expenses made by individuals and families towards the development of unpaid relationships be recognized under the Medical Expense Tax Credit.
 6. That expenses towards family support, family networking and family leadership (creation of social capital) be recognized as a tax deduction.

Families care. That's what we do.

From our caring arises a commitment to do whatever needs to be done so that our relatives with disabilities can live a good life. We contribute financially and materially. We provide love, physical care, emotional support, advice and advocacy. Families are the foundation of social networks, facilitate new relationships, and pay for facilitation and planning services.

While the Income Tax Act recognizes that there are many additional costs associated with disability, its scope is limited to medical, therapeutic and direct care costs. Additional costs associated with developing relationships and overcoming attitudinal barriers are not recognized. In other words, the costs of overcoming physical barriers that result from a disability (wheelchairs, personal care, etc) are recognized but the costs of overcoming social or attitudinal barriers (social networks) are not recognized.

We think that the costs associated with overcoming social barriers and developing relationships ought to be recognized as legitimate expenses and receive similar treatment to that of other disability related expenses under the Medical Expense Tax Credit.

Finally, we cooperate and collaborate with other families in a multitude of ways to build positive social capital within the community. We share support, experience and knowledge. We organize to achieve important goals on behalf of our relatives with disabilities. These activities are vital to

developing strong, resourceful and resilient families that can sustain the support for our family members with disabilities. In the course of these activities, families face out-of-pocket expenses such as travel, meals, conference and workshop fees. If these expenditures were more widely recognized and compensated through the tax system, families would be more empowered and the potential benefits to families would be multiplied many times over.

D. The research and dissemination priorities of governments, policy makers and academics

7. That the design of research and dissemination of knowledge:

- Reflects the importance of belonging and meaning to persons with disabilities as a research priority
- Deepens our understanding of the connection between contribution and citizenship
- Emphasizes collaboration between academics, disability organizations and community member
- Investigates and promotes new accountability and evaluation mechanisms, which map and track the unique paths associated with developing relationships.

The Government of Canada carries out and funds a significant quantity of research. The Participation and Activity Limitation Survey is the best-known disability-related research conducted by Stats Canada. The Social Sciences and Humanities Research Council of Canada (SSHRC) promotes and supports research and training in the social sciences and humanities. Provincial governments, universities and some foundations also promote the development of knowledge through research.

Our work suggests two actions in the design of research and the dissemination of results. First, that research be based on the elements of a good life as defined by persons with disabilities and their families. This includes measuring the significance of, and challenges in achieving, belonging and meaning. This changes the framing of persons with disabilities from that of service recipients to one of citizens. In this paradigm, programs and services supplement rather supplant the achievement of a good life. And second, that research is seen as an opportunity to measure and publicize the contributions that persons with disabilities make to others and to society.

The work of facilitating social networks and creating community is considered important among persons with disabilities, families, service organizations and funders. The work, nevertheless, is still in its germinal stages and learning occurs through the experiences along the way. The research conducted by PLAN Institute has demonstrated the value of gathering and sharing the knowledge that has been gained through personal experience in this work of relationship building.

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