

Securing Self-Determination: Building the Agenda in Canada by Michael Bach

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Much has been written and said in recent years of the need to better protect and promote the self-determination of persons with intellectual disabilities. In Canada, a number of initiatives are underway to address the legal, policy, and service delivery structures which have resulted in systematic removal of this basic citizenship right from so many adults with disabilities. It has been over twenty years since the first efforts to establish policies to secure greater self-determination for people with intellectual disabilities. Since that time, this agenda has advanced substantially, even if the obstacles are now appearing that much more complex and formidable.

Exclusion from citizenship and self-determination is rooted in concepts of what it means to be a person worthy of recognition and respect, and in the laws which have sought to secure and construct this figure. To advance the agenda for change, we must reach back to question the classical conceptions of "reason" inherited from Plato and others, and entrenched in centuries-old conceptions of state responsibility for those deemed to be on the "other side" of reason. Unless we do so, the agenda for securing greater self-determination will remain theoretically weak, and ineffective in policy, programmatic, and practical terms. It will remain limited, as it is now in many settings, to a skills-based conception, rather than a rights-based one. That is, the focus will be on whether people have the skills and capacity to make this or that decision, and on the strategies to teach them to do so, rather than on the structural conditions which have removed their right to exercise self-determination in the first place. As long as self-determination is seen as a skill, as much research and many service evaluation models suggest it should be conceived, then it will be left up to the researchers, psychometrists, and service providers to determine when people reach the threshold of skill to recover their citizenship.

There is no singular event that marks the moment in Canada at which the multitude of personal hopes for greater self-determination, and the personal pain of its denial, reached a collective consciousness and became a public concern. But there are some major milestones along the way. One of the moments that has had enduring effect in creating a public concern and accountability for securing greater self-determination, was in the mid 1970s in British Columbia. A group of parents, known as the Woodlands Parents Group, named after the institution where their sons and daughters lived, stepped back to analyse why it was that their family members were incarcerated, and what would give them the rights to self-determination entrenched in various national and international human rights instruments. The group had been galvanized, in part, by Gunnar Dybwad's visit to the Woodlands facility in 1976 and his subsequent report to the media about the deplorable conditions for those living there. As the parents met together, remembering and reviewing their stories about why it was that their sons and daughters had been placed in the institution, they came to two conclusions: individuals lacked control over the funding that was being used to keep them in the facility, and they lacked the planning support to assist them in purchasing and arranging needed supports in the community.

The Group presented a proposal to the provincial government for “individualized funding” and “service brokerage”, tools they proposed would give individuals the power they were lacking. Individualized funding would be allocated to individuals on the basis of their personal goals and plans for support in the community, and a service broker accountable to the individual, and not to the government or community service providers, would assist the person in arranging needed supports. While the proposal was adopted and funded to a certain extent, the model of individualized funding and service brokerage was never fully adopted in British Columbia. The legacy of the Woodlands Parent Group lies in the conceptual framework for funding and supports that grew out of their fundamental commitment to self-determination. Over twenty years later, policies, programs and demonstration initiatives for individualized funding for disability-related supports are being adopted across the country, and internationally.

At the same time that the parents movement was formulating a framework for individualized funding and service brokerage, the Independent Living Movement, first in California and later in Canada, was reaching the same conclusions about the relationship between funding, control over disability-related supports, and self-determination and inclusion in society. Throughout the late 1970s and 1980s various “direct-funding” pilot projects for people with physical disabilities were established in provincial jurisdictions in Canada. A body of experience, policy development, and program evaluation demonstrates both the viability of this approach to funding, and its necessity in ensuring that people are able to guide their lives toward the personal and collective aims they choose.

Despite the legacy of a framework to secure individualized funding, the necessary policy and program conditions have not been adequately formulated or adopted on a national scale. Political, legal, service delivery and policy barriers now restrict wider implementation of individualized funding and independent planning supports. In reviewing some of these barriers and how they have been addressed, additional conditions for securing self-determination become visible, and a future agenda for change becomes clearer.

One of the most entrenched barriers to individualized funding and to self-determination more broadly is the legal distinction entrenched in law between the competent and incompetent. Rooted in 14th Century English statutory law, and reflected in various competency-related laws such as guardianship provisions, this legal distinction has been one of the major obstacles to people with intellectual disabilities obtaining control over their funding for disability-related supports. Capacity to enter service contracts and employ support providers is questioned, and often this status is denied solely on the basis of having an intellectual disability. Orders of supervision in institutions, formal guardianship orders, interpretations by Canada’s tax department, Revenue Canada, liability and other requirements on physicians and financial institutions to ensure legal capacity to make decisions, have all conspired to deny decision-making status. Efforts to overcome these legal barriers have been promoted through work by various groups in Canada to develop a “supported decision-making model”, as an alternative to guardianship.¹

A number of common elements define the model of supported decision-making advanced in legislative proposals, and already enacted in statutory provisions for the “reform” of guardianship law in Canada. 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 right to decision-making supports to enable equality before and under the law, without discrimination on the basis of disability. Second, the model recognizes that a person’s will and intent can form the basis of a competent decision-making process which does not remove person’s decision-making rights. Third, the model acknowledges that decision-making assistance is often required by any individual - interpreter assistance, facilitated communication, assistive technologies, plain language, etc. Legal provisions have been adopted in British Columbia, Manitoba, and the Northwest Territories, that legally validate these elements of a supported decision making model.

Nonetheless, thresholds of legal capacity persist, even if they have been redrawn to include in the category of the legally “competent” those that would have otherwise lost their decision-making rights. A more fundamental challenge remains: that is, providing the theoretical and moral foundations for re-casting the highly individualized notions of self-determination that dominate guardianship and contract law, and public policy more generally. Rather than a notion of the self-determining person as one who acts as a rational and freely contracting agent, one is needed that connects the exercise of self-determination to community. In his book *Liberalism, Community and Culture*, Canadian philosopher Will Kymlicka, puts the lie to the idea that we make and exercise personal decisions that guide our lives outside of a relation to our communities, identities, language, and culture.² While he and other philosophers who critique highly individualistic notions of self-determination have not generally extended their perspective to include people with intellectual disabilities, the implications can be drawn.³

Challenges that women and people of colour made to the notions of personhood and rationality which excluded them from citizenship and democratic participation, now have to be taken up by and with people with intellectual disabilities. Otherwise, the appeal to self-determination will remain a hollow one, and a “skills-enhancing” programmatic response will continue to mark the limits of the political understanding of disability, difference, and rights. A growing body of work in moral philosophy, “narrative ethics”, that starts with an assumption that persons come into being through the stories they and others tell about themselves, is a useful source to mount the challenge.⁴ The labels that people with intellectual disabilities live under are only one way of telling their stories. If we could reconstruct the telling, we might begin to question more completely the standards of competence that Brock and Buchanan, for example, have established as the ground of personhood - standards that suggest to maintain personhood you must be able to

demonstrate and communicate “psychological continuity” in a way that others can understand.⁵

We have seen in recent years in Canada the foundations being built - in terms of philosophy, law, and individualized approaches to planning and funding - to secure decision-making rights. Beyond the need for a continued philosophical and legal analysis to further rattle a limiting construct of self-determination, communities, labour unions, and governments are realizing that there are more than philosophical choices to be made.

If individualized planning and funding of disability-related supports are conditions of greater self-determination, then a fundamental restructuring of the funding mechanisms for thousands of community service agencies is required. There are communities in Canada which have begun to move in this direction. In the city of Thunder Bay, Ontario, for example, community service agencies agreed in the early 1990s to shift from a block-funded approach to disability-related services, to an individualized funding approach. A new community governance structure was established to steer the transformation. The community board created an autonomous service brokerage agency to assist individuals and families in planning and negotiating the individualizing of dollars. Over the same period deinstitutionalization initiatives were mounted in six provincial jurisdictions in Canada, all using individualized funding mechanisms to transfer dollars out of institutions, and into the control of individuals and families to purchase needed community supports.

These transitions have not been easy, nor are they fully complete. A number of issues are being raised.

- What is the role of existing community agencies and the status of labour agreements, as dollars are individualized?
- How are agencies to individualize their block-funded dollars, when many of them are tied up in services delivered to groups rather than individuals?
- How can the control over dollars and decision making be transferred to individuals and families without over-burdening them with the administration of those dollars and the management of the services they purchase?
- What is to become of the rights of unionized workers, as a framework of rights and contractual status to hire and fire workers is established for individuals and families?

Some are now arguing that it is a zero sum game. If individuals with disabilities are to obtain rights, then workers will have to lose them. Such a position divorces the relationship between rights and community, and wins the former for some, at the expense of community inclusion for all. The claiming of rights is only one of the steps to building community; without a community that recognizes and works towards securing the rights of all of its members, the claims become divisive rather than constructive.

There are no simple or singular answers to these questions. What has become clear over the course of these initiatives in Canada, is that while individualized planning and

funding are necessary conditions to secure self-determination, they are not sufficient. Other conditions are needed as well. Legal requirements to construct the “incompetent” of our society continue to hamper the realization of rights and respectful communities. Individuals need well-supported and sustainable support networks to assist them in obtaining this respect, in planning, making decisions, and managing their disability-related and other supports. Both individuals, families, and their support networks require planning and management supports that are accountable to them, and not to service providers and government funders exclusively. Community development strategies are needed to build inclusive communities for people.

People require more than individualized funding to become full members. The funding can give them access to supports, and the contractual status and resulting recognition that they are full members of society and communities. But until the educational, employment, recreational, housing, and other sectors begin to better fulfil their human rights obligations to include and accommodate people with disabilities, individualized funding will still only be able to buy “placement” in communities.

There are simply not enough disability support dollars in current public sector budgets, even if they are individualized, to buy all the support necessary for inclusion. And even if there were, people would quickly become consumers more than members in their communities.

In addition, new community governance structures are needed to help manage the transition. Structures are needed that are broadly representative, that can address the various interests of people with disabilities, families, service providers, unions, and funders, and that can build a common ground of respect and recognition to keep the process of transition moving. Finally, we have learned in Canada that without more accountability in government for delivering on existing human rights commitments, and without a more enabling policy framework, communities will not have the tools they need to govern funding and development of supports that lead to inclusion.

The disability rights movement has been gaining momentum in Canada in recent years. It has been propelled in part by the securing of equality rights and freedom from discrimination on the basis of disability, entrenched in the 1980s in the Canadian constitution and in provincial territorial/human rights codes. But the movement is confronting its own “dilemma of difference”, to adopt the term from the movement for equality rights for women. In an age of increasingly competitive labour markets and the withdrawal and devolution of government services, self-reliance and independence seem to mark, more than ever, what it means to be a citizen. The capacity of bio-genetic technologies to assist in selecting a human population that meets this standard intensifies the dilemma more than ever.

When one’s difference means that supports are needed for full inclusion and participation, when one cannot achieve the cultural standards of self-reliance without them, then equality seems fleeting. Individualized funding initiatives are reaching the threshold of their success in the face of this demanding cultural icon. Until we manage a fuller philosophical and legal reconstruction of personhood, the conditions we now know are

needed to realize self-determination are likely to remain on the periphery of social policy, rather than at its centre. The cost will be the denial of personhood to a growing proportion of our society.

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References:

1. For example see, Joint Working Committee (Interministry Committee on Issues Affecting Dependent Adults and the Project to Review Adult Guardianship) (1992), "How Can We Help? A new look at self-determination, interdependence, substitute decision making and guardianship in B.C."; Canadian Association for Community Living (1992), "Report of the CACL Task Force on Alternatives to Guardianship," Toronto: Author; Ontario Association for Community Living (1992), "Brief to the Standing Committee on the Administration of Justice," Toronto: Ontario Association for Community Living.
2. Will Kymlicka (1989), *Liberalism, Community, and Culture*, Oxford: Clarendon Press.
3. For critiques of self-determination which could be usefully applied to a critique of the legal marginalization of people with intellectual disabilities see, for example, Iris Marion Young (1990), *Justice and the Politics of Difference*, Princeton: Princeton University Press; Sue Sherwin (1992), *No Longer Patient: Feminist Ethics & Health Care*, Philadelphia: Temple University Press.
4. See, for example, Hilde Lindeman Nelson, ed. (1997), *Stories and their limits: narrative approaches to bioethics*, New York: Routledge.
5. Allen E. Buchanan and Dan W. Brock (1989), *Deciding For Others: The Ethics of Surrogate Decision Making*, Cambridge: Cambridge University Press.