

**Towards an Ontology of Inclusion:
Re-Writing the Law, Science and Ethics of Intellectual Disability**

**Opening Plenary Presentation
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Good afternoon. On behalf of the President of the Canadian Association for Community Living, Laurie Larson, who is with us this today, our national Board and our entire federation of over 300 local associations, 13 provincial/territorial associations and 40,000 members – people with intellectual disabilities, their families and supporters who are working to be build a more inclusive Canada and global community – welcome to Halifax, and to Canada for this World Congress. We are delighted and honoured that this seminal international event is being held in Canada, and want to congratulate Vianne Timmons and the Council of IASSID for the impressive program we will participate in this week.

I want to say I am particularly honoured to participate in this Opening Plenary with the presence of Jean Vanier, who has inspired me since I was a teenager. I was introduced to him by my dad in the early 1970s when he shared with me one of Jean Vanier's early books, 'Tears of Silence.' Jean Vanier's writings and teachings have had a profound impact on my way of seeing and experiencing the world, and the paths I chose.

We are gathering at what feels to many in our Canadian Association like a precarious, contradictory, and possibly because of that, an opportune time in this country and globally. The inclusive values that Jean Vanier has done so much to breathe into life seem under threat on so many fronts.

In my opening remarks today I want to inquire briefly into the character of this moment and its implications for our relationship – between a social and human rights movement and a scientific community, going forward.

I think there is no question from the perspective of our movement for inclusion that we are in a precarious time. We are witnessing a set of values getting political traction that set the project of inclusion back; there's no question. Only one third of Canadians according to public opinion polls support inclusive education. Increasingly, so called 'mercy killing' and 'assisted suicide' on the basis of disability are seen as a 'rational' choice. A recent judgment in the Gloria Taylor case by the Supreme Court of British Columbia ruled that a prohibition against assisted suicide, as we have had under Canada's *Criminal Code* is unconstitutional, and it did so on the grounds that assisted suicide is a reasonable accommodation for people with physical disabilities. The values of equality, accommodation of difference, universal design and self-determination that we have fought so long and hard to have recognized are now being used in a way that we find repugnant and which we think will bring profound symbolic harm to a whole class of persons with significant disabilities. Our fear is that this judgment will lead people with significant disabilities to self-judge their own lives as less valuable, less deserving than others; and that it will likewise mobilize patterns of social *misrecognition* of people with significant disabilities that place them at quite perilous risk.

We have made seclusion and physical and chemical restraints on the basis of disability standard operating procedure in many parts of Canada for people with disabilities who have significant challenges in communicating, expressing and sometimes relating to others. What do we say about our underlying values when state-funded application of such procedures is the rational policy conclusion arrived at?

These are not marginal debates; they are hitting mainstream media. In our country, one of our national TV networks – Global TV - recently produced and broadcast an episode of its series on current affairs, and titled it 'Taking Mercy' – which had as guest panelists, Robert Latimer who was convicted of second degree murder of his daughter Tracy, who had cerebral palsy; his defence being that it was essentially a 'mercy killing'. Annette Corriveau, who was also on the panel, wants the right to have her two adult sons with

significant disabilities killed through removal of their feeding tubes. She went on to present her story on the U.S. show, 'Dr. Phil' where studio and viewing audience in a large majority supported her call to have her sons be killed.

And what now of the ethical arguments for 'after-birth abortion' of children with significant disabilities which medical ethicist Francesca Minerva has recently argued should be acceptable practice, much like Peter Singer has done for a number of years. Are these examples not signs that we are entering again that region which contemporary Italian philosopher Giorgio Agamben names in his historical studies of the treatment of human life, as a place where some persons, on the basis of certain characteristics, can be killed without a murder taking place?

We are living in precarious times, and also *contradictory times*.

Consider that we have made enormous headway in advancing human rights, beginning most clearly for us in Canada with recognition in the early 1980s in our Constitutionally-protected *Charter of Rights and Freedoms* - which assures equality before and under the law without discrimination on the basis of mental or physical disability. We saw incorporation of this principle in amendments to human rights codes throughout the 1980s and beyond. We saw similar recognition of equality rights in countries across the globe and internationally throughout that period, including adoption by the United Nations of the *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* and the 'Decade of Disabled Persons.' And most recently we have seen recognition of equality and human rights in international law in the United Nations *Convention on the Rights of Persons with Disabilities*.

So how do we explain what seems like a tenacious hold of regressive social values despite these advances? In order to gain understanding I think we need to look at the major shifts that took place over the past thirty years in the rules of the game between the state, civil society, individuals and families, and their relationship to the economy and public investment. At precisely the same time the Canadian *Charter of Rights and Freedoms* is being adopted and a disability rights discourse is appearing on the global stage in the early 1980s, the rules of the global economic game began to shift. The 'oil

shocks' of the 1970s and the resulting fiscal crisis faced by governments in that decade provided the rationale for Margaret Thatcher, Ronald Regan and a coterie of other international leaders who came to power at that time to launch what has become known as the 'neoliberal' economic and state agenda – the beginning of the end of the 'nanny state' to use Margaret Thatcher's terms, along with her infamous dictum that 'society doesn't exist, only individuals do.' The state was to be rolled back, corporate and personal tax reduction became part of the formula, many regulations on the economy and the flow of capital were to be lifted, all based on the trickle-down theory of economics. And for the past 30 years, though various rhetorical commitments might suggest otherwise, there has been a sustained attack by many economists and politicians on the idea that the state should finance and ensure publicly-funded services to meet basic support needs of all citizens on an entitlement basis, on the idea that the social infrastructure and social capital that holds communities together and is so essential for social and economic inclusion are worthy of public investment.

In our 'sector' so to speak, this does not mean that budgets for community living services have not increased in some jurisdictions. In some, they certainly have, but very much based on an assumption that what we do is charity. The investments are not based on an understanding that what is required are public entitlements that need to be adequately financed in order to secure the basis of equal citizenship. If we take a synchronic, or point in time, approach to analysis we can identify many progressive steps in policy and practice, though when you add them up they have been nowhere near sufficient to build the social, economic, and cultural foundations for inclusion that could act as a bulwark against the regressive trends we are now witnessing. While defensive political rhetoric may rely on the synchronic view, we must take a diachronic view – from a vantage point that looks across the last 30 year time frame to the shifts in underlying values that have been taking hold, and to the decomposition of social infrastructure and state investment over that period.

What are the implications for us of the neoliberal economic agenda we are seeing reinforced in governments' attempts to deal with the current global economic crisis? Well, first, it is based on the assumption of course that if you get the 'economics' right,

the rest will largely take care of itself, which is the rationale governments have used to justify rolling back so much welfare state investments and now in some countries the most basic of public services. However, economic trickle down hasn't quite worked out as the rhetoric promised. The data nationally and internationally is clear: we are seeing growing income inequality and increasing concentration of wealth.

Second, governments are making evident in their budget allocations that supports and services to people with disabilities are to be kept at the charity rate, not as a publicly-funded entitlements, because they tell us governments and taxpayers can't afford it. The message is crystal clear.

Third, we see increasing investment in many jurisdictions in what are seen as essential items – the 'war against terror,' border control, restricting immigration, fighting crime and drug use, penitentiary expansion, cutting corporate tax and personal income tax for those at the top end to instigate the ever-elusive economic boost. Which is why we find a growing number of people with intellectual disabilities and their families on waiting lists for the most basic supports. It's why resource teachers are not available in schools to enable full and equal access to an inclusive education. And the list goes on.

Again, this is not to deny sometimes impressive policy initiatives by governments. But they don't add up to closing the appalling inequality gap that people with intellectual disabilities face, and we've all known it for years. As the social infrastructure is pulled back, the view that society doesn't exist, that only individuals do in a kind of Hobbesian fight to the end, starts to take hold. As people become more and more insecure and vulnerable socially and economically, the bonds of social solidarity and cohesion start to pull apart. Borders get set up between certain populations based on country of origin, ethnic or racial or aboriginal status, and certainly disability. And, hate-based movements grow.

Such shifts in the relationship of governments to citizens and communities, and its economic and social consequences, underlie the resurgence of debates about the equality of human beings and mercy killing, genetic selection, and after birth abortion. There is no question that health professionals are under pressure to re-consider

lifesaving treatments and interventions of newborns with significant disabilities. It can't be afforded we're told, and we're hearing that people who have significant needs can't be supported in communities that are beginning to reel under the demands for supports of an aging population.

These are not disconnected issues. Employment rates, poverty rates, rates of violent victimization of people with intellectual disabilities have not changed much in 30 years in spite of growing legal recognition of their equality and human rights. What has changed is the role of government in relation to society. And the trends are not going to reverse I expect for a long time to come given current global economic arrangements.

So, there is little doubt that we live in precarious and contradictory times – when we can reach the zenith of recognition of human rights for people with disabilities over exactly the same period the state has progressively withdrawn the means for achieving realization of those rights in practice, and thereby leaving socially inclusive values at greater and greater risk.

But this may also be an opportune time, and here I could be out on a proverbial limb with my innate optimism, because in contradictory times our choices become clear. And the alliances we choose to create can have lasting and transformative impact. And for us in this room, that choice certainly applies to the scientific community. There is a complicated and not all together progressive history of alliance between the state, the courts and the scientific community when it comes to people with intellectual disabilities. Many histories could be written of these relationships that would reveal the politics of the scientific project and how certain pillars of the project have reinforced state compulsion to divide the population of people with intellectual disabilities – whether through the legal boundary of competent/incompetent, or justifications and assessment tools for educational placement in segregated schools or residential institutions; and many other examples.

One thing I think we can all agree on through these continuing debates is that the science of intellectual disability is not, and certainly never will nor should it be, a singular project. It needs multiple epistemologies and methodologies, including the voices,

perspectives and knowledge of people with intellectual disabilities and their families as knowledge-producers in their own right, given the essentially perspectival nature of any knowledge-making enterprise.

There is a choice for the scientific community to make at this point in our history – and that is whether as a community to recognize the UN *Convention on the Rights of Persons with Disabilities* as a foundational global consensus, once and for all, on the question of whether people with intellectual disabilities belong and do so in fully inclusive and equal ways to others. And here I am not suggesting a press release stating commitment to the cause, but an ontological and methodological commitment – seeing fundamental human equality in all realms as a fact, as an ontological starting point for the scientific project.

Remember it was not science that said “lunatics” and “idiots” exist. The law did. But it took centuries to develop forms of inquiry, institutions and agencies of scientific research that now provide a way of knowing the law’s truth and of securing *its* ontology of intellectual incompetence and deficits.

But the law is also capable of re-imagining as we have seen with the UN *Convention*, because it both reflects and shapes a social imaginary. We are entering a new era. We are imagining a form of intersubjectivity with persons with intellectual disabilities never before realized on a societal scale. We are I hope witnessing the death throes of an ethics that is desperately holding to the distinctions of the enlightenment project which associated ‘progress’ with a particular form of instrumental reason as a defining feature of what it means to be human. The UN *Convention* redefines the project – from one of dividing human populations in ways that become a breeding ground for inequality and exclusion – to one in which intellectual, learning and sensory, psychological and physical differences inspire a deeper understanding of equality and the human condition.

Where does this leave the scientific and ethical project of intellectual disability? We, along with associations of people with disabilities around the world engaged in imagining and writing the *Convention* into being, because we imagine a world where

difference need not render inequality. In redefining international law, States Parties around the world have given birth to the outlines of a radically altered social, political, legal, cultural and economic landscape, although many I would hazard to guess were not fully aware of the implications at the time. Boundaries have been redrawn. New criteria of full personhood, and full legal capacity have been established and set down in international norms and law.

As we move forward together, let us not forget that science's role in the field of intellectual disability has not been to break radical new ground, but to help execute into policy and practice what has been imagined; to help manage across the boundaries that a social imaginary and its legal embodiment have drawn. There must then be a scientific project that is up to the new task; that is up to helping to redraw the criteria of what it means to be recognized as a full person, with unique developmental paths, with diverse forms of communication – gestural, oral, written and beyond. If we take seriously the insights of child and human development theory based on principles of diversity, then surely we must go beyond our norm-referenced ways of viewing human development, to demarcating self-referenced paths, and marking progress within the unique time frames of each human being's developmental path. Drawing on insights from emerging studies in neuroscience and the formation of consciousness, intention and intersubjectivity, our shared scientific project grounded on the ontology of inclusion should shift ways of thinking. It should shape new forms of knowledge and professional practice informed by the assumption that all persons, regardless of extent of intellectual disability and the usual norms of communicative capacity do in fact have a will and preferences as the Convention safeguards in Article 12 on the right to equal recognition before the law.

Our scientific task is not to determine *if*, but *how*. Not *if* people with intellectual disabilities have a will and preference, but *how* to determine it even when its contours are occluded by our usual ways of seeing and knowing; not *if* people with even the most complex disabilities can live in the community, but *how* that is to be made possible, as Article 19 on the Right to Live in the Community promises. Not *if* students with intellectual disabilities and their non-disabled peers benefit from learning together in the

common learning environment – whether in junior kindergarten or post-secondary education – but *how* that is to be made possible. Not *if* people with intellectual disabilities benefit from being supported to exercise self-determination and making their own choices, or if such opportunities improve their quality of life, but *how* to enable others to respect and act upon the legal power they possess. It is only with such knowledge, founded on a law, science and ethics of inclusion, that we might nurture a new relationship between the state, society and people with intellectual disabilities.

The UN *Convention on the Rights of Persons with Disabilities* is a game-changer. We look forward to playing by the new rules. We hope you do too.