

SPEECH TO THE MUSCULAR DYSTROPHY ASSOCIATION OF CANADA

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Six years ago The J.W. McConnell Family Foundation convened a Roundtable of people with, or working with, disabilities to ask: “What can we do, if anything, to help you?” The reply emerging from their discussion was at once surprising and reassuring. Surprising, because the Roundtable participants said “Don’t ask how you can **help** us, ask in what ways **we** can contribute to the betterment of our society, how we can fulfill our duties as citizens.”

The reply was also reassuring because it affirmed that the questions we were asking throughout our program work at the Foundation applied as much to people with disabilities as to any other citizens, namely: What can the Foundation do to ensure that **everyone** has an opportunity to live to their full potential, to participate fully as citizens, to contribute their particular skills and talents to their communities?

As Judith Snow stated in her report on the Roundtable: “People are not disabled! Our culture disables people by the way they are treated. ‘Disability thinking’ erodes citizenship!”

This in fact is the approach that has guided the McConnell Foundation’s programming philosophy. It is obviously fuelled by the vision of people like John McKnight (“No community has ever been built on the needs and problems of its people. It has always been built on their gifts and capacities, and the use of the assets that are there”) and Ivan Illich, who earlier warned against over-reliance on experts and professionals who can engender a sense of helplessness in those who come to depend upon them.

That Roundtable six years ago boiled it all down to one clear message: “It is our shared responsibility to mobilize the latent capacity of **all** citizens. People with disabilities, like all citizens, have the capacity and responsibility to strengthen our communities. We must ensure that *each community member thrives and contributes.*”

This approach was the basis of our support for the **Count Me In** program, and for other such initiatives, like the Peer Support program of the Canadian Paraplegic Association. It is the point of departure also for Philia, a group of people with, and working with, disabilities which seeks to change the mindset of those working on disability issues. But we at the Foundation want to reflect it in all of our grants. When people come to the Foundation and say, “Your grant will enable us...” to meet some need or accomplish some task, we reply: “Our grant by itself will not accomplish anything – only **you** can do that.”

At best, a grant may facilitate your work; at worst – even with good intentions – it may actually undermine or hamper your efforts. Today we have been discussing the results of

the **Count Me In** program, assuredly an example of positive collaboration between grant giver and receiver. But let there be no doubt about **who** made the effort, **who** achieved the success, and **who** deserves the credit!

We probably have also all seen examples of what happens when this sort of productive collaboration doesn't take place – when money erodes people's self-confidence, displaces recognition inappropriately to the donor, and undermines an organization's vitality by the manner in which it is provided or by lack of preparation for when it runs out.

That Roundtable discussion was critical for us. It illustrated a wider truth that people here need to be aware of, that it is the disability movement that is now at the leading edge of thinking and innovating about what is arguably the most pressing social issue of our time – how to define *community*, and how to create it and sustain it? How do we nurture its qualities of inclusion and participation?

We have always considered these to be strong Canadian values. We proudly quote UN reports which refer to the dynamism of our multi-cultural cities, to the openness to pluralism and diversity which we like to think of as hallmarks of Canadian society. We see these issues played out again today in the health care debate, which pits equality (inclusion, access) against efficiency (cost).

But I do not have to tell you that these values are contested. Distrust and fear have become much more prevalent since 9/11. There is a pervasive sense that there is a faceless enemy out there, that we had better lock our doors and “keep to our own kind”. There is an insidious suggestion that we can only be comfortable with those whom we trust, and we can only trust those with whom we are comfortable.

The filmmaker Michael Moore in his recent film *Bowling for Columbine* explores what he sees as the culture of fear which is feeding violence in the U.S., and contrasts it (perhaps over-flatteringly) with what he finds in Canada. In one segment he interviews passers-by in Windsor and discovers that most say they are not in the habit of locking their doors. To test this he walks down a residential street trying the front doors of several houses, and finds that most are, in fact, open! Indeed, at one house the owner comes out to ask if he needs help, and is baffled by Moore's questioning whether he is fearful of leaving his house open.

But trust and a sense of security cannot be taken for granted, and once lost can perhaps never be recovered. In the past, the banners of tolerance and inclusion were carried by the women's movement, by the anti-racist struggle and by those fighting for gay rights. They each pushed us to expand our understanding of community (as, in a different way, did the environmental movement). Now, however, the banners are being carried by people thinking, writing and acting in the field of disability issues. Jean Vanier, Al Etmanski, Judith Snow, Jacques Dufresne, John Ralston Saul, Michael Ignatieff – they are the ones making people think about diversity, inclusion, ethics and the nature of the good life.

The questions they are throwing at us are (to quote Jean Vanier) “What does it mean to be human in a dehumanizing society, where possessions take precedence over people?” In a world of rapid change, of mobility and transience, how do we rise above the incessant message of advertising that abiding happiness can only be found in acquiring? How can we overcome what may be a natural fear of the unusual to see the qualities of diversity, resilience, and empathy which may be the requisites for humankind’s very survival?

A word of caution, however: much of the progress in the struggle for inclusion has come from arguments and challenges based on *rights*. This has proved to be an effective strategy. But let us not forget that there are rights, and there is *what is right*. The former are legislated and enforceable, but can also change. The latter is a moral imperative, and timeless. As a society, since the adoption of the Charter, we have become more litigious, we are following the American tendency to view all relationships as essentially contractual (children suing their parents, parents suing their child’s hockey coach...)

But we need to understand that inclusion and belonging are integral to *being human*, not contingent on laws. There is a huge gap between a life of enforced relationships and a life of human relationships, between compliance and true *acceptance*. As H el ene Paradis-Signori in her remarks this morning said more clearly and eloquently than I could “*Je ne fais rien par devoir; je fais ce que je fais par amour!*”

A second, perhaps more controversial word of caution: nobody working with illnesses and conditions which have a genetic basis can fail to be excited at the advances being made in biotechnology and genetics. In our enthusiasm however we must remain vigilant that a society which sets such a high value on the perfectibility of persons does not use technology to iron out all sorts of traits and human characteristics deemed “inferior”. It may be but a short step from repairing genetic mutations to correcting nature’s “mistakes” in terms of height, hair colour, sexual orientation or personality. Once again, it bears repeating that *difference* represents *potential*, *resilience* and *adaptability*.

In dealing with this we are confronting (again to quote H el ene) not “*des limites fonctionelles mais des limites humaines*”. The real challenge, in short, is not people with disabilities, it is communities *which have difficulties accepting difference*.

I was looking for a way to illustrate this when I came across a story by Stuart McLean in his book *Welcome Home: Travels in Smalltown Canada*. He tells of a young man named Trevor, who has cerebral palsy and cannot speak and doesn’t walk well; at the age of 12 he began turning up at the local bakery, and after a time was allowed to do some small jobs. He started coming every Saturday morning at 5 am, and every morning in the summer. One day he asked his teacher to write out a poem to give to the baker.

Here it is:

Happiness is the colour
of bread dough,

Happiness sounds like the
mixers turning around,

Happiness tastes like puff pastry
like cream horns,

Happiness smells like cookies straight
from the oven,

Happiness looks like bread loaves
ready for the proofer,

Happiness is being free
in the bakery.

When he read it the baker said “You know, at the time I never thought anything about having Trevor in the store. But when I read the poem, I realized that he is the highlight of all the years I have been here. He is the most important thing that has ever happened to me.”

The abiding lesson which disability has for all of us is about interdependence and the quality of human relationships. As the song says, We all need somebody to lean on... In a nutshell, it is *social isolation* that is the most disabling condition of all – and this is a condition that is increasingly widespread throughout our Western societies. How fitting that it is from the disability movement – from MDAC, its dedicated staff and volunteers – and from programs like **Count Me In** that we are finding answers to the challenge of creating community!