



Council of Senior Citizens' Organizations of British Columbia
(COSCO)

Conference on Seniors' Health, Housing and Income in a
Global Age-friendly Community

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The Nexus Between Aging and Disability

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March of Dimes Canada/Ontario March of Dimes
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Ladies, Gentlemen and special guests,

It is a real pleasure to join you at this important conference and sharing opportunity. Today I am going to address you on the topic of aging and disability but with a particular agenda in mind. I have had the pleasure of being co-host of the first International Festival of Conferences on Caregiving, Disability, Technology and Aging, FICCDAT in 2007. My goal is to expand our reach with the Festival and ensure consumer involvement. Today I invite the Council of Senior Citizens Organizations of BC to be a part of the Festival in 2011. When I asked your President, Art Kube, to consider joining the Festival, he said to come and tell us about it at the COSCO conference. Let me first tell you that the organization of which I am President and CEO. March of Dimes has been in existence since 1951, working with people with physical disabilities, and we have seen a lot of changes. A significant change is in the legal status, protection of and societal acceptance of people with physical disabilities as people like everyone else. Whether as a community service and health organization, the disability/rehabilitation sector or a private citizen, one notices the phenomena of change and development in this regard. I am one who is excited and happy knowing society now acknowledges that people of all abilities make

contributions to us all. March of Dimes has been at the forefront of policy advocacy, service innovation, and the promotion of the independence of people with disabilities for many decades.

From this vantage point, we see that people with physical disabilities are living longer, living outside of institutions, surviving even with severe limitations or clinical conditions and this introduced new issues for Canadian society to consider. The demographic changes in general, i.e. that of an aging population, magnify the perception of increasing disability due to the extended life expectancy and lower birthrates, both due to the gains made by educational, medical and technological advances. The temporarily able-bodied might think that there really is a division in society between those who have special needs and those who don't. I would argue that there is no such division as most of us are simply TABs and as we age, we will surely have a visual loss or hearing loss, some physical or cognitive limitations associated with grower older. Thus, the area of specific interests to me is the nexus between "Growing Older with a Disability" and "Aging into a Disability". These have been two separate fields until now – the disability movement and the seniors' movement have actually spawned two professional areas of practice and different areas of social policy. There are many historical facts, social and political reasons for the separate development of these two movements, two areas of medical specialization, two fields of study. But the demographics are forcing convergence of these two populations and recognition of the commonality of their needs, interests, rights, and desires. The juncture of these two fields is an opportune place for new research, policy, and practice. The greatest percentage of people who have a disability are over 65. While only 12.4% of the population in Canada is 65 years of age or older, 40.3% of seniors have a disability.

The disability movement of the 70s was largely led by young activists eager to ensure that they would lead active and integrated lives in the community, outside of institutions, with integrated rather than segregated education, in real employment rather than sheltered workshops, and in housing among their peers, not in seniors' residences, as was the custom in those days. Many did not even consider that they might some day become senior citizens, as people who were had conditions such as quadaplegia, Muscular dystrophy,

MS and Cystic fibrosis did not survive to the age of 65. Senior citizens in the 1970s were focused on issues of poverty and substandard services rather than disability. The Grey Power movement was led by outspoken retired professionals who wished to maintain their lifestyle, and did not focus on the impact of aging on health and disability.

Over the past 30+ years, changes to both groups have resulted in greater commonalities that affect both groups. People with disabilities are living longer, and are experiencing the effects of growing older with a disability. The general population is also living longer and healthier lives. The result is that the senior citizen population has three distinct segments: people who have chosen not to retire, often into their 70s, and have much in common with their younger peers, people who have retired, but remain highly active, healthy and independent, and a largely older population who are experiencing frailty and complex chronic disease resulting from a variety of ailments or disabling conditions. This latter group has different life experiences, but some of the same health and service needs as those people growing older with a disability.

Of note is that in Toronto, at Bridgepoint Hospital they are focussed on serving people who would at least three or more chronic diseases. This has led Bridgepoint to coin new terms like arthrostokoma, indicating the incidence of arthritis, stroke, and glaucoma in one individual or osteocanceritis for another combination and neurodiabetes for a third. Their current fund raising campaign highlights the convergence of multiple disabilities in single individuals and they quote that 40% of baby boomers are directly affected, and that this situation is now the biggest challenge to the sustainability of the healthcare system. At March of Dimes, we've not been as sophisticated at naming diseases, but our clients with physical disabilities often have other impairments, and those aging may have cognitive issues, greater frailty and new sensory deficits or health issues.

It strikes me therefore that our focus needs to be on advancing the disability movement, ensuring access to the best healthcare, community supports, and quality for all ages. On the policy front, this should mean joining to push for inclusion, accessibility, and equality

Without Compromise in our society. The poly-framework has already been laid for full participation by people with disabilities, or to repeat a phrase coined in the 70s, “no decisions about me, without me”. People with disabilities have clearly articulated that they want to be included in matters that affect them. Seniors are people who have been included in the decisions affecting their lives and they are not about to suddenly abstain from their own lives, not willingly. Age is not the barrier that disability may be. Of paramount concern for people who age are their physical health, and their cognitive capacity. Experience at March of Dimes with people who have chronic physical conditions and are deteriorating is that delivery of service to them is increasingly difficult, complex, and costly. I cannot yet tell you how we are going to address all of these issues, but I need to raise them with you, and based on what I have seen at this conference, most of this is not unknown to you. Hopefully, our collective efforts will lead to new programs, policies – everyday solutions.

So, what is the new frontier that needs addressing and for which our Festival of International Conferences is an important forum? Let me offer you several ideas. In Ontario, we feel quite blessed that the provincial government proclaimed the Accessibility for Ontarians with Disabilities Act, as well as earlier legislation to benefit people with disabilities, such as employment equity, human rights, building codes, transportation services, housing, income and employment supports and inclusive education and to continually identify and prevent barriers to access and equality.

In Canada, our collective effort should be on developing a strategic vision for a Canadians with Disabilities Act, national legislation to create a framework for access to all services, facilities, and opportunities. There could be a focus on setting standards to enshrine access and equality.

A second national initiative is one we also have experience with at March of Dimes. We administer a \$10.7M Home and Vehicle Modification Program, which delivers grants to people in Ontario of all ages who require a home or vehicle modification to facilitate independence. This important program relates to the agenda to achieve “aging in place” as a sine qua non of good healthcare policy. To create such a National Home and Vehicle Modification strategy

would require getting all of the provinces on board, focusing on community care, engaging caregivers and health professionals, a true commitment to a health maintenance agenda, and safe and accessible homes that promote the greatest degree of independence. Our nine-year-old program has demonstrated that the need is there. Once people understand how a home modification can be of benefit, the demand rises. According to our analysis, this will save the government a huge amount of money by keeping people out of institutions, which is the current goal of all community care providers and all governments. Over the course of the next year we plan to analyze our database to better understand how the funds we allocate are most often used, i.e. what modification is of greatest need, what are the trends in terms of the length of stay of people at home as a result of an accessibility modification, and how do modifications affect the recipients' overall quality of life? We know, for example, that the \$2M program that we inaugurated was quickly absorbed, as was the extension to \$9M, and at the current rate of requests our program could deliver over \$35M this year, and this is just to eligible applicants. However, the government has not yet granted us anything like an expansion to the current \$9M. However, it has committed \$600M to long-term community care so surely there needs to be an adjustment in the allocation so that people can stay in place while aging.

The third area of social policy that I believe needs national attention with provincial and territorial agreement is the development of a National Caregiver Strategy. Canada is definitely falling behind some other industrialized countries like the United Kingdom, Australia, and New Zealand in addressing the important contribution of informal caregivers of whom there are estimated 3-5 million in Canada. The care of caregivers needs to be a universal concern, for they are very vulnerable to becoming disabled themselves, and are most surely getting older, though I acknowledge that younger adults and even children are often caregivers for parents, and even grandparents.

While I am not going to provide you with a lot of research information on these areas of great need, I do want to enlist your support for these priorities. My role is not that of researcher but as an administrator, ensuring that the services we develop is responsive, high quality, cost effective, and relevant to achieving the goal of

independence for people with disabilities. Much of my reflection comes from what I learned at the Festival of International Conferences in 2007 where concepts were reinforced across all of the conferences. I will elaborate on this shortly.

As a social planner for the aged and handicapped, at the Social Planning Review Council of BC in the 1970s, I had first hand experience with the concept of segregating issues for the elderly and people with disabilities as they were seen to be two distinct populations. Today there are fewer boundaries. Society has advanced, and in the process, we have achieved improvements for all. Activism has become acceptance, partnerships are sine qua non for developing service and social policies, applied research in the field with users' involvement is sound practice, and everyone in society appreciates that the allocation of resources, which are finite, is a huge responsibility, which needs to be shared between government and the public. I am sure that many people don't believe that the government shares that decision-making, but I do. It's called the electoral process. So if we are wanting to make a change we need to ensure we have informed decision-makers, and that we have an understanding of each other's concerns and priorities because there is a relative ranking of all the interests of society as a whole. I'd like to emphasize that we need a shared agenda across the disability and the aging spectrum, shared resources, shared planning and shared services.

Five years ago when I invited executives from major community support organizations to meet and discuss the issues that we were experiencing as demand for services rose from our existing clients, we were not sure how the allocation or sharing of resources could meet the need. But, we discovered experience was shared and noted that increased resources only meant more service to existing clients and not the ability to serve new clients. We associated this fact with people living longer, deteriorating conditions and the loss of informal or family support. My colleagues were from CNIB Ontario, Canadian hearing Society, MS Society, Parkinson's Foundation, Toronto Rehabilitation Institute, Ontario Partnership on Aging and Developmental Disabilities, and many others. Our understanding was common. We concluded that we needed more information on how better to assess these complex needs, develop maintenance

programs, increase flexibility in our services, share knowledge and training with staff across the different disabilities, coordinate service delivery, and even create new configurations for service, and provide support to the family or informal caregiver. This is no small agenda and we didn't undertake to solve it on our own. We initially thought a conference on Aging with a Disability would help to bring all of the players together, but we hadn't yet identified all of the players. In mid 2004, I had the opportunity to speak to Dr. Geoff Fernie, Vice President of Research at Toronto Rehabilitation Institute. He is an internationally renowned biomedical engineer who is associated with both the Faculty of Medicine and the Faculty of Engineering at University of Toronto, as well as being a leading authority on issues affecting both the elderly population and people with disabilities. Geoff commended our effort and noted that his conference on Aging with Technology held two years prior was to be repeated, so we decided it best to run the two conferences in one event. Once word was out that we were going to host two conferences, Aging with a Disability and Technology and Aging, it became apparent that the complexity of the challenges facing seniors with disabilities required a much more interdisciplinary and coordinated approach to policy and service. Hence, we added conferences on Advances in Neurorehabilitation, Improving Medical Device Usability, and Caregivers: Essential Partners in Care. Canada had not seen an international conference for caregivers in the past and holding one was well supported by major alliances of carers in the United Kingdom, in Europe, the US and elsewhere. One of the most interesting phenomena was that scientists, particularly those discussing neuroscience who thought their conference would be separate and apart, even if under a common event infrastructure found that consumers and caregivers attended their sessions, involved and eager to be informed and to share their experiences with academics. What a surprise they had to find that people of all walks of life were interested in the research that was being done, especially when it affected them. What a surprise to find caregivers attending the conference on technology and developers of technology attending conferences with practitioners in social service. Everyone found there was much to share in five parallel conferences. We created overlapping events, exhibits, symposia, and workshops. With over 1300 people in attendance from 32 countries, having 700 presentations. The Festival was a resounding success.

What has arisen from the Festival includes research collaboratives, most notably the United Kingdom and Canada looking at aging and mobility, the inaugural meeting of the International Alliance of Carer Organizations and the publication of a book on Technology and Aging. Some of the principles that were articulated, and will of course be emphasized at the next Festival include:

1. the importance of people remaining in their communities and actively accessing its resources;
2. the benefit of people receiving services in their home and support for the informal caregiver to be able to have both caregiver and recipient of care remain healthy;
3. the importance of leaving control in the hands of the recipient of care for as long as possible and learning to facilitate empowerment in decision-making even for people whose cognitive abilities begin to slip;
4. the need to adapt service to changing needs whether the recipients' needs are diminishing, increasing, or shifting between those two dimensions.

As people live longer, even people with disabilities, we need greater research on how this will impact our social and economic systems. We shouldn't automatically conclude that everything is simply more costly, and put restraints on, but rather we should find new mechanisms for delivering services that are cost effective, and new partners with whom to deliver that service. The business sector is fast recognizing the fantastic financial wallop that is going to be carried by people over 50. Responses to the needs will come from more than just government, but from all sectors in society. As new products and services evolve, new ways to deliver them evolve, new disciplines to serve evolve, and people take on new roles, there will be much change and much to be excited about.

Let me provide more examples of impactful programs. At March of Dimes, we have a program called Befriending[®], which helps people find friends who share a common interest, with one party being a person with a disability. One of the most rewarding outcomes, of course, is that the people with disabilities provide no less friendship than the people who have no disabilities, so it really is a bilateral

relationship. That's the meaning of mutual support. At March of Dimes we foster peer support groups for people who survived the Polio epidemic but today have Post Polio Syndrome, and for those who have had a stroke and are back in the community post-rehab. We know from experience, as well as from the literature, that peer support validates the experience a person is having, creates bonds of understanding and friendship, leads to greater knowledge through shared experiences, and helps people to rebuild their lives. People sustain one another. We see this in all kinds of social and cause-related movements, be it the women's movement, the disability movement, the seniors movement, the groups for addicted teens and struggling addicts. There is no end to the possibilities that peer support brings and it lessens the burden on the health care system dramatically.

At March of Dimes, we are all about empowerment, participation, and independence for people with disabilities. Our most important partner is the consumer who defines his, her goals, directs his, her own care, demonstrates solutions for problems that he or she experiences, and helps us to understand how we can meet his, her needs. So in developing the Festival, FICCDAT for 2011, we intend again to partner with our consumers, caregivers, governments, businesses, health and social service agencies and the academic research community. We want to see members of COSCO participate and we invite COSCO to become a Steering Committee member, to help plan the Festival, to help us better understand what people in BC are saying, doing, needing, and help build a society across Canada that fosters friendly communities, accessible communities, safe communities. In 2011 we anticipate there being at least nine conferences including potentially an age-friendly stream sponsored by the International Federation on Ageing, a conference on emergency preparedness for vulnerable people, care for the caregiver population, aging with a disability, disability and technology, advances in neurorehabilitation, universal design and home modifications, and an unique conference that we have been a part of for the last nine years, called Independence, Community, Participation, and Empowerment or ICE, which brings together people who have severe disabilities including speech impairments and who speak with augmentative communication devices. It's been a privilege for me to attend ICE conferences in the past, and listen to

people who speak through voice synthesizers, electronic screens and other media to communicate. No one left behind, no decision about me without me, and we will all be creating a society that's more inclusive. I look forward to answering your questions.

I look forward to seeing some of you in 2011 if not before, and I thank you very much for the opportunity and the invitation to be with you.