

Fifty Years of Community Living!

Reflections on a Social Movement in the Midst of Change

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John Lord gave the closing comments at the 50th Anniversary Conference of the Canadian Association for Community Living in Ottawa in November 2008. This is a summary of his reflections.

The deliberations this week have captured both the strengths and the struggles of the community living movement over the last fifty years.

We heard stories and saw films that can break your heart. These experiences recalled for us that abuse and neglect that people with disabilities have experienced too often over the decades. Images of maltreatment are very deep in the minds and souls of our brothers and sisters, our sons and daughters, and ourselves as family members. We know that the wounds of years and years of segregation and institutionalization will not heal easily. But, the conversations and the process this week feels to me like we are clearly on a healing journey.

I want to applaud People First of Canada for making the film *The Freedom Tour*. This film challenges all of us to know the history of people with disabilities, as painful as it may be. Along with *The 'R' Word*, these films are vivid reminders of our past and current struggles. As the community living movement celebrates 50 years of important work, it is vital to remember this old story. Sadly, we heard this week that many Canadians are still living 'institutionalized' lives. We also heard of renewed deinstitutionalization efforts by this movement to insure that every citizen with a disability can live in the community.

As a social movement, the community living movement has experienced many positives in its history. Several provinces have closed large institutions and many people with disabilities are living full lives in community. This is a movement that has taught the world about social inclusion and has advocated for years for communities to welcome diversity. This movement has come to understand the true meaning of citizenship.

The reflections shared by the ‘accidental activists’ during this conference demonstrate the courage and wisdom shown by many family leaders over the years. The wisdom of Jo Dickey, Audrey Cole, and Paulette Berthiaume should inspire us to be open to change. Their vision and insights reflect what I have recently been calling a New Story.

Notice how these three remarkable women ask such good questions. This is a trademark of the New Story, the willingness to ask the right questions and to gather the right people together to assist with change. As we have learned this week from many of the sessions on innovative approaches, the ‘who’ question becomes as important as the ‘what’ question. Who can I invite? Who can I connect with around this issue?

Author Melanie Panitch refers to these extraordinary women as ‘accidental activists,’ I think now is the time for leaders in this movement to become ‘intentional activists.’ To be an intentional activist means to ask probing questions, to bring people together around a common vision, to use our values in action, and to be strategic about social change.

There is no doubt that we need a New Story – a new narrative, a new way of talking about the purpose and vision of the community living movement. In the last few years, I have been honoured to have researched numerous innovative approaches across Canada, and have called insights from this research a New Story. A New Story is like a new paradigm, with new language, new directions, and new connections.

As we move toward a New Story, we need to allow time for acknowledgement and healing, as we use the pain and suffering of our past to ensure that history stays in the past. It is time to leave the old story behind. Catherine Frazee reminded us this week that the United Nations, when setting out the Conventions on the Rights of Persons with Disabilities, apologized to people with disabilities. “We are sorry,” said the U.N. This apology is enormously important as part of our healing journey.

As this conference showed, we are moving toward a New Story in lots of interesting ways. The new National Report Card on Inclusion provides a new way of describing the state of our communities and our country. The CACL work on supported decision-making outlines new ways of seeing all people as full human beings with all sorts of possibilities. It is clear from our conversations this week that this movement is building a new mind-set, creating new knowledge, and raising new expectations in communities.

Social movements have always been about re-framing ‘what is’ to ‘what could be. I noticed this week that many of us are learning how to “think and act like a social movement.” This approach to the way we work means recognizing the importance of social networks in everything we do. It is

through conversations and connections that we learn how to think creatively and act collaboratively. As Margaret Wheatley says, the world does not change one person at a time; it changes through networks and relationships.

I want to briefly highlight the essence of the New Story that I have identified through my research and illustrate these points with insights from this week's conference.

First, *values are the foundation of the New Story we are creating together.* The centrality of values has a long Canadian tradition from many of our historians such as George Grant and John Ralston Saul. You can think of values as the bedrock of community life. As Michael Bach said so clearly yesterday, the community living movement has learned over the years to be both vigilant and intentional about values.

The two values that ground the current work of this movement have come up over and over again at this conference; self-determination and community. We can think of self-determination as the expression and freedom of each person to be able to make personal choices about their own life. These choices are always embedded in community, which includes the social fabric of families, neighbourhoods, and other personal relationships. Community is what gives us social meaning and enables us to belong and feel included. When self-determination and community work hand in hand, they create the context for citizenship. As this movement is learning, participation, contribution, and belonging are the essence of citizenship.

Second, *the new narrative we are creating is grounded in principles*. We can think of principles as guideposts that help us move toward our shared values and vision. Let me highlight three New Story principles that were prevalent this week and have also emerged from several studies on innovation and change.

- To maximize life for a person or a community, we intentionally build on strengths and gifts. We are gradually moving from scarcity thinking to asset thinking. One of the great challenges for all disability movements is that most governments continue to think scarcity and deficits, not capacity and assets.
- Relationships are central to everything we do. In social movements, people and networks matter. Whether conference sessions have been about strengthening the family movement, enhancing employment opportunities, or reducing poverty, networks and partnerships have been central to new ways of working. This movement is slowly learning that we cannot be effective working in silos – we must engage the wider world in our enterprise.
- In this regard, communities must be engaged in the issues that impact citizens with disabilities. In the old story, communities were seen as a barrier, not a resource. In the New Story, collaboration is central to the work we do. We learned this week that we cannot build inclusive communities unless we collaborate with others in innovative ways. We are only beginning to understand the power and potential of community and hospitality.

What is central to these principles, and others that enhance citizenship, is that they focus on building capacity and connections, not just services. Think how the world of disability would change if we took seriously the idea of building the capacity of each individual, family, and community!

The third element of the New Story is the understanding that *new functions and structures will be required if the values and principles are going to work for people*. We cannot keep the same structures of so many community living organizations if we hope to see people fully experience the New Story. New and separate functions are emerging that are challenging traditional organizations to change. Individualized funding and independent facilitation are just two functions that several provinces have been exploring. In addition, autonomous family and peer groups are beginning to take hold in several parts of the country. As we learned this week, some service providers are changing in response to these emerging trends and innovations. In many ways, changing functions and structures is the most difficult work because it often requires shifting from entrenched practices toward new ways of thinking and acting. The challenge is exacerbated in some service systems where we have created a generation of gatekeepers for the status quo. What we really need to do is open the gates and embrace the New Story!

The conversations today clearly reflected a New Story. Even the questions and topics we explored together are helping us to re-frame what is important for the community living movement. How do we support people with disabilities to find freedom and genuine self-determination? How do we organize for genetic justice? How do we mobilize a national grass-roots

family-led movement? How do we advance a poverty reduction agenda?
How do we contribute to a global impact on inclusion?

Many common themes were woven throughout the conversations on these topics; the need for social justice, the value of diversity, the importance of community development, the struggle between policy and practice, and the need to re-energize this family-led movement.

We live in challenging, turbulent times. It has been said that remarkable times call for remarkable solutions. Gandhi said, “We need to be the change we want in the world.” Our three accidental activists live Gandhi’s truth, and they inspire us to do the same. For many of us, it will be a challenge. But, if we are clear on our vision and values, build meaningful personal networks, and work collaboratively with others, we can begin the journey with confidence.

Also, if people with disabilities are going to take their rightful place in our communities, we need to be intentional about building a new narrative, one that moves us from welfare to citizenship. As community living organizations struggle with the New Story, they will need to learn what they should hold and what they should seed with others. As examples, progressive organizations understand that autonomous family groups and independent facilitation both need to be valued and situated outside service systems.

Finally, I sensed this week that some key elements for social change are coming into alignment. The United Nations Convention on the Rights of Persons with Disabilities gives the disability movement a tool that is both

simple and profound. The large number of on-the-ground innovative initiatives across Canada can inspire us to move toward a New Story. The growing family movement in several provinces gives us a key vehicle for change. The new federal legislation that created the Registered Disability Savings Plan is an example of moving disability into the arena of citizenship. As provincial governments consider how to transform their disability systems, the community living movement can now point to conditions, research, and experiential evidence to tell them how to do it! As Victor Hugo wrote 200 years ago, “There is nothing more powerful than an idea whose time has come.”

At the end of the day, these times require wisdom, which I found in huge supply in your conversations this week. I firmly believe, as British Columbia’s Anne Mortiffee sings, “It is within every one of us to be wise.”

Thank you for including me in these conversations and best wishes in building a New Story together!