

Voice, Choice, and Community

Remarks made at the Opening of new
Gage Transition for Independent Living, October, 1996

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A few years ago, I was asked to be one of the consultants in the re-design of a hospital-based transitional living rehabilitation service. At the time, we did not know what the re-design would look like, and frankly I was uncertain whether a hospital would be open to change and whether people with disabilities connected with the project would be comfortable in expressing their views. Because of positive relationships I had with several people who were part of the Gage Transition Centre, I did take on the consulting role and to my delight, my hesitancy was proven unfounded.

The Gage and West Park Hospital process of the last four years has demonstrated constructive institutional change and the importance of engaging people with disabilities as the champions of their own directions. These two ideas, consumer self-determination and institutional change, at first glance seem like an oxymoron; in other words, can these ideas exist together? To answer this, I think we need to look briefly at what happened here over the last four years and try to uncover whether it is a reflection of a broader trend or whether this is a unique enterprise from which others can learn.

The independent living movement in Canada at first focused mostly on developing new organizations, usually called Independent Living Resource Centres that are driven by consumers and by a philosophy that is quite distinct from rehabilitation or medical orientations. In many respects, the independent living movement or the IL movement as it is affectionately called has been very successful. There are more than twenty centres across

Canada and here in Toronto the Centre for Independent Living, known as CILT, has often been a critical bellwether of disability trends and values. The independent living philosophy represents a paradigm shift or a new way of thinking about the capacities of citizens with disabilities. The focus is on strengths, not deficits, and there is a profound belief in the capacities of people with disabilities.

The changes that have happened within Gage and West Park Hospital represent what I would call the second wave of change in the disability movement. This is where mainstream organizations and services begin to embrace the independent living philosophy and change their structures accordingly. Let us be perfectly frank; there are not a lot of examples of institutional change in Canada that strongly reflect the IL philosophy. As Stephen Lewis has said, "The culture of intolerance is everywhere." Based on my own life and research, including fifteen years of experience with one of my own children who has a disability, shouldn't we wonder why we have so many school systems that are unresponsive to children with disabilities? The culture of intolerance is also reflected in employers that refuse to hire people with disabilities, and it is reflected in service organizations that refuse to honour the diversity and strengths of all citizens. I worry, as I am sure that you do, that the current directions and agendas of both federal and provincial levels of government are giving legitimacy to the culture of intolerance. The elimination of programs such as employment equity, and the cutting of services that were promised not to happen, send a signal to people with disabilities and their families that governments are no longer willing to fight for equality.

I want to briefly highlight three elements that I think were critical in the process of change at Gage and West Park. I believe that it is valuable to reflect on these elements both for ourselves and for other enterprises that can learn from our wisdom. The three elements of change are easy to identify and remember; they are voice, choice, and community.

The Gage and West Park process for change happened in great part because "you listened." Gaining voice is a central part of the disability movement. The metaphor of voice reminds us how oppressed many people with disabilities have been. The reality is that people's voices have often been silenced. Listening is not easy at a time when the pace of life is so rapid. However, I remember vividly the powerful impact the Gage advisory committee, symbolized by Ian Parker's presence today, had on senior hospital officials. As we examined the perspectives of people with disabilities and their views on transitions, hospital leaders listened and learned.

Mind you, listening can be "unsettling." More than once in my professional life I have been blasted by consumers who thought I was "off course." Learning to listen includes trying to understand the nature of why it might be unsettling. In some ways this is a broader lesson, that life itself is uncertain and not easily predictable. While this learning is difficult, it often opens us up to new possibilities.

Having voice without real choice is like offering dessert but never providing it. Many people involved with Gage when it was mainly "bricks and mortar" knew it was not enough. They knew that a broader range of choices for transitions were absolutely necessary. In thinking about this, I was reminded of my own family life and transitions. Each of my four children has become engaged in the transition from adolescence to adulthood in very different ways. We have learned in families that transitions are both cultural (they happen for everyone), and individual (they happen to everyone in different ways). One must wonder why this has been such a difficult lesson for rehabilitation to understand?

Part of reconstructing the vision and process for transitions has meant that Gage and West Park have come to understand that genuine choice moves transitions beyond just "coping." In a series of studies on empowerment, my colleagues and I learned some years ago that personal control is critical if people are to move toward participation and choice. But control is not just a passive item we give to people. It is imbedded in our daily choices, our interaction with the environment, the support we receive, and the engagement we experience with ourselves and with others.

Gage is now located in the community, not just on one site but in many respects in multiple sites. In some ways, Gage Transition to Independent Living has become moveable and flexible. This process has recognized the power of community as distinct from service systems. Your challenge is now to be "of the community" not just "in the community." Research has shown that social support is one of the most important indicators of health. People benefit immensely from relationships with

neighbours, friends, families and from the thousands of options that are available within communities for people to participate. As the leaders of the change process within Gage and West Park intuitively knew, it is only within community that genuine choice can be realized.

“Independence” is the symbol of shifting power to the consumer and is reflected most dramatically and coherently in the independent living movement. One central notion within that movement is that people can best identify their own needs. It is ironic that this simple concept has been so difficult for service systems to embrace, even though the history of that notion goes back to Adam Smith and other philosophers of the 18th century. While independence is the symbol of shifting power to consumers, the “community” is the symbol that best represents interdependence and mutual support. Genuine community plays an anchoring role, a sense of constancy, and an opportunity for people to share common interests with fellow citizens. Meaningful relationships are the result of such community.

Albert Einstein once said, "We cannot solve problems using the same level of thinking that we are at when we created them." You created institutional change because you dared to move to a different level of thinking. You also asked what would be truly meaningful to people with disabilities? You may recall that the king in Alice in Wonderland reminded us how important meaning is, when he said, "If there is no meaning in it, that saves a world of trouble, you know, as we need not try to find any". Your process, while bumpy at times, gives us clues as to how institutional change might happen more often. There were real heroes, both staff and consumers, who knew the direction they wanted to go even if they did not

know all the details. There were senior people within the institution who were open to listening and learning. There were outside people, as advisory committee members and consultants who understood the direction of the change and could support it with research and effective planning principles. These are just some of the ingredients of constructive change.

The question now is, what next? As Gage Transition to Independent Living becomes more involved in the community, new tensions will arise, new paradoxes will emerge. One of my early mentors said, "Never stand still; stay open to change." As you stay open to change, I suspect that new relationships will emerge and new partnerships will develop as you rightly expect more from the community. In this process, people with disabilities can increase their personal relationships and their citizenship. Think of the possibilities for people to expand their involvement in the community, to build support networks, and to move from being consumers to being full citizens. I know that you have the courage and the principles which will allow you to keep open to creating more innovation in the years ahead. Best wishes in the ongoing journey of continued transitions and learning.
