Time to do it Right: Re-thinking How We Close Institutions

John Lord*

* **John Lord** is a researcher and consultant from Kitchener-Waterloo. He is the author of *Return to the Community: The Process of Closing an Institution*, a book that describes the story and research of the closing of the Tranquille Institution in British Columbia. More recently, Lord was the chair of the *Ontario Round Table on Individualized Funding*.

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The recent announcement by the Minister of Community and Social Services Sandra Pupatello that Ontario will close all major institutions for citizens with developmental disabilities is welcome news. To the Minister's credit, she admitted that Ontario was behind other provinces and needs to complete the deinstitutionalization that began in the 1970's, when Ontario was a leader in this field. The policy of closing large dreary residences for people with disabilities has had the support of all political parties in Ontario. Across Canada, community living and full citizenship is now the stated goal of all disability movements and governments. Yet, when closing institutions, making such a vision a reality has been elusive.

There are many reasons why closing institutions has ranged from dismal to moderately successful across Canada. In many jurisdictions, resources have been shifted from large facilities to community services with few changes in attitudes or approaches. Community institutionalization, where people have strict routines, few choices, and limited connection with their community, is thus a common outcome of deinstitutionalization. In many other cases, the only housing funded by governments has been group homes, resulting in congregate living and almost no opportunity for people to decide who they want to live with and where they want to live. Looking back over 25 years of closing institutions in Canada, however, gradual improvements can be identified in the way we plan closures and how we assist people in building a life in community. As government, service providers, families, and communities now begin the hard work of implementing the Ontario institutional closure policy, there are some significant lessons from twenty years of research and practice that should guide their deliberations.

First, with proper support families can be united. Many of the people returning from institutions have been away from their families and

communities for more than 20, 30, or even 40 years. As research has shown, families who are quite cautious about community alternatives can become quite supportive when they are involved in the planning process for their son, daughter, sibling, or cousin. Families are understandably often fearful of this significant change, and usually require extensive outreach from people who are facilitating the downsizing. There are many benefits to family engagement, including the fact that the person coming home can begin their new life with a social network of caring people. Building social support with families, friends and other community members has been shown to be a strong determinate of health. It goes without saying, of course, that it will not be appropriate in all cases to involve family, but it must be remembered that other community members can be invited to play social support roles.

Second, independent planners or facilitators should be available to assist each person returning to the community to develop a personal plan that is tailored to their strengths, needs and preferences. Typically, with deinstitutionalization, people are "placed" into a group home, or a service plan is developed that determines who should live together. More recently, several studies and projects have shown that better quality of life outcomes are achieved when independent planners or facilitators assist each person and their network to develop goals, community interests, social support, and specific personalized plans. The government would be wise to insure that independent facilitators are hired to support people in the significant changes they will be experiencing. Fortunately, there are places in Ontario, such as Windsor, St. Marys, and Durham Region, where independent planning and facilitation is quite well developed. Leaders from these areas will be able to assist the development of this important strategy.

Third, flexible service and funding mechanisms should guide the development of community resources. In the previous 13 closures for people with developmental disabilities in Ontario, service development and funding was mostly limited to "block funding" for community agencies to design services for people returning from the institution. Research shows that more flexible approaches are required for many vulnerable individuals. In many cases, an individuals' plan will simply not "fit" into existing agencies or

programs. What is required is the option of individualized funding and support. This means that the person, their family, and their network can build a unique plan and life in community, and can then receive direct disability support funding for that plan. The government and community agencies would be wise to build in a flexible mechanism that allows people the choice to access direct funding for their disability support needs. It has been shown that this option also contributes in significant ways to people's citizenship opportunities. The large per diems that government pays for people to live in Ontario institutions (over \$250 on average) should make the re-allocation of such funds to the community a viable strategy for creating flexible approaches that in the long run will be more cost effective than institutional living.

Fourth, engaging workers and communities in the closure process will assist institutional workers in their adjustment to a significant change in their community. There is no doubt that the three closures in Ontario will have an impact on the institutional workers and the communities where these facilities are major employers. There are understandable concerns being expressed by the Ontario Public Service Employees Union about the future of Smith Falls, Orillia, and Blenheim. Workers need to be involved in the closure planning and be given ample opportunity to apply for community jobs. In several closures in the past decade, many older workers have retired, others have changed careers, and most workers who have wanted to stay in the field have been able to find community employment with people with disabilities. At the same time, government can play a role in blunting the economic impact on the three communities.

In the mid-1980's, I spent considerable time in Kamloops, British Columbia, documenting the closure of a large institution. Both four and ten years later, I returned to see how Kamloops had adjusted to the change. To my surprise, many people told me the closing of the facility was in retrospect a very positive thing. As one city councilor told me, people with disabilities are now an integral part of community life and the attitude of "us and them" has virtually vanished. I am reminded that the closing of institutions is a significant human rights issue whose time is well past. British Columbia and Newfoundland, the only two provinces that have

closed all major institutions, have found that closing large facilities enables them to begin to address the community issues facing vulnerable citizens.

Finally, the Ministry of Community and Social Services says it wants to transform the developmental services sector, and has initiated a planning process to do just that. What better way to accelerate the transformation than to close the three institutions skillfully and thoughtfully with the best knowledge we have available. This closure initiative creates an opportunity to test out various innovations (such as independent planning, personalized options for residential services, new parent driven organizations, etc.) that are needed throughout the sector. This change can happen if the government collaborates with the community, family, and service sectors to close the three remaining institutions in the right way. There is considerable research and experience related to planning and supporting people with disabilities to return to community life. Let us hope that this final wave of institutional closures in Ontario can get it right and thus contribute to the changes so desperately needed in the lives of Ontario citizens with disabilities.