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A Personal Reflection on the Final Phase of Institutional Living in Ontario¹

I had a unique opportunity, during the 1990s when I was part of a team conducting a longitudinal research project, to visit all the institutions that were still open in Ontario. These were called Schedule 1 Facilities, a term used to describe institutions that were owned and operated directly by the Ontario Ministry of Community and Social Services. Schedule 1 Facilities decreased both in number – many were closed during this decade – and in population, as residents were slowly moved to communities across Ontario. Deinstitutionalization was well underway.

I tried to observe carefully what the conditions were in these facilities, and how the process of deinstitutionalization was unfolding. You see, I recognized that this was a once-in-a-lifetime opportunity to experience the last stage of a service approach that would no longer exist in just a few years.

Some of what I saw and heard did not support the view that institutions were the appalling places that many claimed them to be. There were a number of interesting day programs, and there were many areas of the facilities that were set up to carry out all manner of recreational activities. The institutions had on staff many medical and rehabilitation professionals who had developed considerable expertise by specializing in developmental disability. The residents had developed friendships and relationships with other residents and staff, many of whom had worked there for many years. Some facilities went to more than a little trouble to modernize the living environments of residents, and to personalize them to reflect the tastes and interests of each resident. I recall, for example, visiting a man in his “room” (a space within room dividers) that was decorated with many sweaters from his favourite sports teams. On a visit to another facility, I met a woman who had a cozy living space that featured a beautiful rocking chair sitting on a round mat next to an end table and lamp. A hand-knit afghan lay on top of an attractive bedspread. I remember joking, “All you need now is a cat and a cup of hot chocolate.” There were positive aspects to living in these facilities, and in our research we certainly collected evidence that some of the residents enjoyed their lives there.

The words and actions of many of the people who worked in the facilities supported this view. I met front line workers

1 This editorial contains opinions that are solely those of the author; they are not intended to be comprehensive or to reflect the views of the Ontario Government, the Ontario Association on Developmental Disabilities, or any other individual or organization.

who made a concerted effort to ensure that the men and women with developmental disabilities could express their unique interests and abilities. I met managers who made personal sacrifices in an effort to make life better for the residents, and to make work more enjoyable and rewarding for their staffs. I met many caring and forward-thinking staff members at all levels who kept up with current disability thinking and who treated the residents with respect and dignity. These people accepted the current situation and tried to improve life for people who lived in the facilities, although, contrary to what is often believed, many of them recognized that life in an institution was neither ideal nor equitable and openly discussed this view in thoughtful ways.

Yet the very nature of the facilities worked against their success, and ultimately worked to ensure that the institutional era would soon end. Many were physically cut off from other communities, some decidedly so. Southwestern Regional Centre was perhaps the most obvious example of this. Built in a rural area southwest of Chatham, Ontario that was a long distance from communities of any size, it was a rambling, behemoth set of buildings seemingly surrounded by farm fields as far as the eye could see. People's lives were provided for inside, but it seemed there was really nowhere to go outside. The very scope of the facilities meant that they had to be run according to schedules and routines. Meals arrived at set times. Lights were turned on and off at set times. Programs and activities took place according to time schedules. Routine can be comforting, but within the facilities routine tended to dominate in an inexorable way and to control most aspects of people's lives. The ways that the days unfolded had an effect on staff members, and I talked with and observed many who adhered to their scheduled duties with not more than minimum enthusiasm or effort. A common response to suggestions for improving life within the facilities was that there was little hope that such efforts would pay off for the types of residents who lived there. There seemed to be little room for creativity or innovation in many instances, something that seemed to be dampened even more by lethargic staff response and this appeared to me to be more the case as it became obvious that the facilities' days were numbered.

I visited wards in Schedule 1 Facilities that were very overcrowded, and where there was little opportunity for stimulation. One ward housed more than 30 men in a large living room area, a dining room, and several bedrooms, each of which held four single beds and no other furniture. Other wards I visited had very little furniture because staff did not want the furniture destroyed. Many wards did not allow residents to have access to their own or others' belongings, for fear of damage and loss. In one ward, toothbrushes, toothpaste, and other toiletries were all kept in a locked cupboard and could only be accessed with a staff member's permission. Some wards did not allow residents free access to go outside, even to go out into a fenced-in area. Some offered no activities for the residents to engage in, and it seemed to me that many of the so-called negative behaviours I observed and was told about (aggression, rocking, destroying objects, defacing surroundings, self-abuse, and others) might be averted if the residents were more engaged in interesting and stimulating activities. My suspicion in this regard is supported to some degree by reports in this issue that negative behaviours that were expected when residents moved from the facilities to community settings did not always materialize. Thus, in addition to the structure of the facilities themselves working against their own success, the way daily life was structured and carried out within the facilities was a constant reminder that the institutional era was quickly fading, and provided outsiders even more reason to suggest that they should be closed as quickly as possible.

On March 31, 2009, the last three Schedule 1 Facilities in Ontario were closed permanently. The road toward the closures was at times smooth, and at other times quite rocky. The process had been a long and often arduous one, as the logistics of moving people who had lived in the facilities for many years to suitable community settings, and satisfying the interests of staff, families, government, the facilities, the community agencies, and the new communities themselves, all had to be taken into account (see Radford, 2011, for a fuller description). Ultimately, the closures were achieved because there was a recognition that the institutional era for people with developmental disabilities in Ontario had reached the end of its road.

Throughout the process of downsizing and closing the facilities, I had not advocated strongly for the quick closure of the institutions at all costs. I was more concerned with the quality of life of people with developmental disabilities both in community living settings and within the facilities, and with disability professionals taking a person-centred approach that focussed on enhancing life for each person, no matter where they lived. Still, I was honoured to be asked by the Ontario Ministry of Community and Social Services to provide a positive comment for their press release that announced the closing of the final three institutions in March 2009. Ontario disability services were moving forward, joining – and in some senses leading – the worldwide trend to recognize the right of people with developmental disabilities to live in the communities that are open to us all.

The four articles that comprise the “deinstitutionalization” section of this issue are designed to help inform readers about the institutional era, and to help them understand how it all turned out according to those most closely affected. The first article by Brown and Radford gives an overview of the growth, and then the decline, of institutions (initially called idiot asylums) for people with developmental disabilities in Ontario. It borrows heavily, with permission, from the excellent chapter by Radford (2011) on the history of developmental disabilities in Ontario in the Brown and Percy (2011) text *Developmental Disabilities in Ontario* (3rd edition). There are other accounts of this history, such as Simmons’ (1982) seminal book *From Asylum to Welfare*, and there are new sources to be discovered. For instance, this first article includes intriguing details on the purpose and finances of Ontario’s first asylum, the Orillia Asylum for Idiots, which was opened for operation in the fall of 1876.

The three articles that follow offer an interesting and important look at how those most closely affected (excluding residents) assessed the closure of the final three Schedule 1 Facilities by the Ontario Ministry of Community and Social Services. This last phase of deinstitutionalization, termed the Facilities Initiative between 2004 and 2009, was evaluated in a series of four studies led by researchers from Brock University (Griffiths, Condillac, Owen, Frijters, Martin, & Hamelin, 2012). The *Family*

Feedback on the Closure of Institutions for Persons with Intellectual Disabilities in Ontario reported on the perceptions of family members of former facility residents concerning community adaptation (Griffiths, Owen, & Condillac, 2015a); the *Facilities Initiative in Ontario: A Survey of Community Agencies* gathered outcome information from community agencies that received residents from the last three institutions in Ontario to close (Griffiths, Owen, & Condillac, 2015b); and *The Ontario Facilities Initiative: Perceptions of the Deinstitutionalization Process* explored “the nature of the deinstitutionalization process from the perspectives of family members of former facility residents, community agency staff, former facility staff, planners, and behaviour consultants” (Owen, Griffiths, & Condillac, 2015, p. 49). Together, these three articles offer strong support to the views that institution-to-community adjustment was accomplished fairly quickly and easily by most people, and that former institution residents enjoy a fairly high quality of life in the community. These overall results support research carried out by my colleagues and me in the 1990s (Brown, Raphael, & Renwick, 1997; Brown, Renwick, & Raphael, 1999), and analyses of outcomes of deinstitutionalization in other countries (for a full exploration, see Griffiths et al., 2009). Such results also assure us that, in closing the institutions, we took the best course.

The final article in this section is important for two reasons. First, it provides an interesting example of one way that the voices of people with developmental disabilities can be heard in research and reporting in academic journals. The *Journal on Developmental Disabilities* and other journals need to promote such methods, and explore how they can evolve into valued methodologies and sources of information. Second, and particularly pertinent to the content of this section, it records the views of two women who experienced life in institutions and who now face some struggles with our community-based service system as they try to live successfully in their communities. It is important to hear and understand their lived experiences in institutions just for the sake of doing so, but it is distressing to read that they find several of the controlling, discriminatory, and service-centred practices of the institutions are being used in community services as well. This

sounds the alarm that policy and services are not in tune with the real lives of people with developmental disabilities and their families, something that has been supporting recently in the academic literature as well (e.g., Schalock & Verdugo, 2012; Schippers, Zuna, & Brown, 2015). We need to be very careful not to repeat the mistakes of the past.

The institutional era spanned 133 years of Ontario's history, from 1876 to 2009. Although they no longer exist, it is important for us to understand the growth and decline of our institutions. They played a major part in the evolution of how we have conceptualized disability and how we treated people whom, over the decades, we called idiots, feeble-minded, mentally deficient, mentally retarded, developmentally handicapped, and now developmentally disabled. Elements of the past – both helpful and detrimental – linger on, and in our quest to provide the best possible lives for people who are now community residents I believe it is essential to thoroughly know our past.

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