

PERSPECTIVE: From Institution to Community Living, to Social Inclusion – Unrealized Policy Promises

Abstract

This article considers some of the major policy recommendations and legislation that informed the phasing out of Ontario's institutional system by transitioning into community living, and then social inclusion. The initial philosophy of community living that guided the process focused on programming that emphasized "normalization" to support people integrating into mainstream society. Over time, however, this objective was recognized as unrealistic for many people with complex impairments. At the same time, a critical analysis of enduring environmental barriers and social stigma led to a social theory of disability that transferred the gaze from bodily difference to a disabling society that has not accommodated diversity. This critical analysis informed a shift from community living to social inclusion. In the absence of a shared definition of this objective, tangible successes of social inclusion are difficult to determine. The authors conclude that looking to the extent that past de-institutionalization objectives have been realized can help to identify shortcomings that need to be addressed to realize social inclusion in a meaningful way.

In Ontario, political commitment to an objective of de-institutionalization formally commenced with the government's response to Walter Williston's (1971) commissioned report on the Present Arrangements for the Care and Supervision of Mentally Retarded Persons in Ontario. In Walter Welch's plan for Community Living for the Mentally Retarded in Ontario (1973), the Provincial Secretary for Social Development signalled "a new policy focus for the delivery of services to the mentally retarded centred around the concept of community living" (p. i). This policy objective of community living was operationalized in the Developmental Services Act (1974), which legislated the terms and conditions for the administration of supported living agencies that emerged to accommodate the relocation of institutional residents, which was finally concluded in 2009. Over the course of the de-institutionalization process, a shift occurred from the rhetoric of community living to a new vision of social inclusion that is reflected in the corresponding replacement of the Developmental Services Act with the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (2008). The following analysis critically examines key factors that motivated these transitions and how they inform our understanding of the success of social inclusion, and next steps to further advance this objective.

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From Institutional Care to Community Living

The Williston report concluded with a series of comprehensive recommendations that anticipated the need for strong and sustained investment in community services, as a pre-requisite to the “phasing down” (p. 65) of large institutions:

We cannot abolish the present facilities until the resources of the community have been mobilized to care for the mentally retarded in a better way. An increase in the load placed upon local health and social services without a great increase in their resources would inevitably worsen the plight of the handicapped. (p. 69)

In addition, Williston advocated strongly for comprehensive supports to families so that they would be able to raise their children at home, with a view to them eventually leaving home:

When a retarded child reaches adulthood, he should ordinarily be expected to leave home the same way as any other child. It is not good for the retarded person to live at home indefinitely where he will be consistently held in the attitude of a child. If he does not leave home when he reaches maturity, it can be very destructive for the family. The parents become increasingly anxious about what will happen to their child when they die or cannot keep him any longer. (p. 71)

The official response to Williston was expressed by The Honourable Robert Welch, Provincial Secretary for Social Development (1973). The Welch Report anticipated the passage of the Developmental Services Act, 1974, and underscored a range of services grouped into the following categories: “preventive services focusing on pre-natal care and diagnosis; case finding, diagnosis, and counselling; developmental care and special education for school-aged children and adults; vocational training; recreational programs; financial assistance; medical, dental, and legal services; and residential and treatment facilities” (p. 4). With these objectives the province indicated an intention to divest itself of responsibility for the care of people with mental disabilities, transferring responsibility for meeting daily living supports to local communities.

While this was widely recognized as a progressive transition, the failure to acknowledge the role of families and related designated supports for the daily living supports that are provided in the home was a significant omission in Welch’s report. The Government of Ontario (2006) suggests that the “community living movement [was] originally started by parents in the mid-1950s” (p. 5); and, in fact, there had always been families advocating for services to allow them to keep their children at home (Glover, 1948; Simmons, 1982). Still, institutional populations continued to rise across sixteen facilities, finally peaking at 6424 residents in 1964 (Simmons, 1982, p. 312). Simmons adds that this figure does not include individuals in psychiatric, or other types of residential care facilities. In fact, initial, modest declines institutional residencies were largely attributable to transfers from Orillia and other large facilities, to nursing homes: redistribution from one type of institutional care to another. Building community capacity on a scale to replace sixteen large scale institutional facilities would take time; but, government figures indicate that between 1975/76 and 1985/86 the “number of developmentally handicapped people served in the community increased from approximately 700 to 4,440” (Ministry of Community and Social Services, 1987, p. 5).

Once under way, a policy of community living in Ontario emphasized a program of “normalization” for people with developmental disabilities (Marshall, 1982; Minnes, Nachshen, & Woodford, 2003; Simmons, 1982). Advanced by Wolf Wolfensberger and perceived as a revolutionary approach to disability policy at the time, it supported a community living philosophy, but also “realized that deinstitutionalization and normalization were not necessarily the same thing” (Simmons, 1982, p. 197). The Developmental Services Act (1974), which formalized Welch’s policy objectives in law, also transferred the ministerial responsibility for people with developmental disabilities from the Ministry of Health to the Ministry of Community and Social Services. For pragmatic reasons this transfer made funding for the development of community services infrastructure eligible for matched federal investment through the Canada Assistance Plan (CAP) (Simmons, 1982). Equally as significant, however, is the corresponding reconceptualization

of disability as difference, rather than disease. The policy focus was still on the rehabilitation, but the distinction implies and emphasis on life skills and vocational training rather than medical intervention, which are perceived as the path to normalization.

An apparent spirit of optimism seemed to have been invested in the belief that everyone should be aspire to engage in their communities in the same way; and few people seemed to question the feasibility, much less the appropriateness of this assumption. As recently as 2006 when the province of Ontario approached completion of its objective to completely dismantle its institutional system, The Opportunities and Action Initiative articulated a vision of “fairness and equity” for people with developmental disabilities that would “[c]reate opportunities in everyday life that are the same, or as close to as possible, to norms and patterns that are valued in the general mainstream society” (Government of Ontario, p. 15). By this time, however, the practical limitations of this response had to be acknowledged as no amount of intensive of training was ever going transform people with complex impairments to a degree that would allow them to navigate their communities without significant ongoing supports. While aspiring to reach one’s potential should be everyone’s right, disability was not something to be cured.

Furthermore, an objective of normalization assumes that all people aspire to replicate the “norms and patterns that are valued in mainstream society.” This type of assimilationist rhetoric was becoming increasingly at odds with advocates drawing attention to environmental, institutional, and attitudinal barriers that continued to pose barriers to community living. Many people emancipated from the institution found themselves living in group homes located on the geographic margins of communities, still largely segregated from integrated work, learning, cultural, and social opportunities. In his analysis of contemporary disability policy planning, Michael Prince (2009) points to how the community living movement continues to call for the closure of institutions in Canadian jurisdictions where they still exist despite case evidence that indicates that many people are not only unhappy, they are unsafe in environments where they cannot count on access to round-the-clock care

and life planning. Others concur that the expectations attached to de-institutionalization have not been achieved in practice (Overmars-Marx, Thomése, Verdonschot, & Meininger, 2014).

From Community Living to Social Inclusion

A social construction of disability critically assesses institutional barriers and social stigma that construct disability and compound impairment (Oliver, 2009). Eventually, this shift in the perception of the construction of disability manifested itself in the replacement of the Developmental Services Act with the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008, which came into effect just as the final institutional placements were being closed down in Ontario.

The rhetoric of social inclusion is prolific in disability policy today, yet there is not consensus about what this term really means (Overmars-Marx et al., 2014). Some researchers argue that social inclusion is a deliberate conceptual shift from social exclusion. Carey, Riley and Crammond (2012) assert that whereas social exclusion draws attention to structures and processes in society that create unequal access to resources, social inclusion implies adaptation to the status quo. This is consistent with an orientation towards normalization and away from a social construction of disability that identifies society, its institutions and policies as responsible for disabling people with mobility or mental impairments (Oliver, 2009; Reif, 2014). Carey et al. (2012) conclude that social inclusion is a program of “social reform” while social exclusion is about “revolution” (p. 49). Researchers with the Roeher Institute (Crawford, n.d.; Cushing, 2003) have attempted to articulate a “common approach” to understanding defining and measuring social inclusion based upon the following objectives: “To participate as valued, appreciated equals in the social, economic, political and cultural life of the community; To be involved in mutually trusting, appreciative and respectful interpersonal relationships at the family, peer and community levels” (Crawford, n.d., p. 5). This attempt to articulate measures of inclusion and exclusion is interesting, but there is little evidence of direct adoption of these measures in policy.

In fact, social inclusion is not specifically defined within Ontario's Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, even though it is part of the legislation's title. However, Section 4.3 indicates quality assurance measures respecting the "promotion of social inclusion, individual choice, independence and rights." To that end, service agencies are directed to "support the participation of persons with developmental disabilities in various activities in the community, including work, recreation and social, cultural and religious events, as desired by the person with a developmental disability and identified in their individual support plan" (4.3a). Similar to the finding of Carey et al. (2012) this approach to inclusion appears to put the onus on community agencies to support the individual in adapting to the community and what it has to offer, as opposed to proposing any kind of structural re-orientation to make the community more accepting and accessible to all people, with diverse abilities. Michael J. Prince (2009) also finds that for "many Canadians, primary responsibility for social inclusion of those living with disabilities is on disabled people themselves" (p. 41). It is apparent that stigmatizing barriers endure, which comprehensive human rights legislation, from the Charter of Rights and Freedoms, to provincial Human Rights Codes, have not been able to eradicate (Joffe, 2010).

People who face stigma and social inclusion live on the margins of society; and these are people who are also predominantly poor. Most people with substantial developmental impairments cannot afford the costs of comprehensive daily living supports, and those people who do not have access to trust funds, Disability Savings Accounts or other personal insurance provisions are almost certain to be poor (Prince, 2009; Reif, 2014; Stienstra, 2012). Despite the recognition in the Welch report that financial support needs to be a pillar of successful community living, disability pensions and employment supports have not allowed people who rely upon them to live above a subsistence income. Without money, a person's sphere of activity is inevitably small (Hickey, 2012).

Discriminatory attitudes and poverty inevitably compromise personal security, which is compounded for people with impairments

that limit their ability to communicate abuse, or extricate themselves from abusive situations. Today, although supported living agencies that are funded by Ontario's Ministry of Community and Social Services are not directly operated by the province, the Ministry does define standards that government funded group home and other supported living services must maintain (Government of Ontario, 2006). However, the question of enforcement of standards is not clearly addressed in Ontario's Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008. The Ministry of Community and Social Services acknowledged in its consultations about the legislation that the developmental services sector has not had to operate under the same rigorous standards as residential facilities for children and seniors. When the Government of Ontario was preparing for the final phase of institutional closures, a consultation report to the Minister of Community and Social Services acknowledged that "there is currently a lack of regulation regarding these operations" (Parsons, 2006, p. 12). The implications of this "lack of regulation" are worth dwelling upon.

In the same year that the final institutional spaces were closed in Ontario Trish Crawford (2009) reported that resident deaths that occurred in provincially run institutions, in Ontario, triggered a mandatory investigation, but that this is not necessarily the case in community facilities. Crawford reports specifically on the life and death of June Elliot who died in a residential group home following her transfer from the Huronia facility in Orillia, where she had lived for thirty-five years. Crawford's investigation reveals that "intellectually disabled adults in group homes do not have the same protection – such as regulated staffing, nutrition and hours of care – as the elderly in nursing homes or children in day care" (p. A4). The article further reports that in the first four months of 2009 there had been 53 deaths in group homes: most, according to Ontario's Ministry of Community and Social Services, as a result of natural causes, although no breakdown is given, citing privacy concerns. In the absence of a public accountability protocol regarding incidents of injury or violence in supported living residences it is difficult to ascertain how secure people are in these residential settings, not to

mention the level of social inclusion experienced (White, Holland, Marsland, & Oakes, 2003).

One recent death, however, led to a coroner's inquest that re-affirmed the need for better policy and enforcement of standards of care for people with developmental disabilities. On April 29, 2012 Guy Mitchell drowned in a cistern, after having been sent out to retrieve water. The subsequent police investigation exposed a squalid residence with no heat, no functional plumbing, feces strewn everywhere and no food in the fridge; a place not fit for human habitation. Testimony given at the inquest indicated that it had been inspected by the caseworker overseeing the placement just two days before; however, she found nothing amiss (Clairmont, 2015a, 2015b, 2015c, 2015d). Another adult male and a female child, both with developmental disabilities, resided at this rural home. The inquest recommendations urge policy changes that more explicitly articulate residency standards, closer oversight, and more opportunities for residents to communicate dissatisfaction with their residency (Office of the Chief Coroner, 2015).

Looking Back to Plan Ahead

As Ontario shifted into the "phasing down" and subsequent elimination of its institutional system, corresponding policy objectives of community living and social inclusion have not been fully realized. On the contrary, there is a growing body of evidence that suggests that while people with intellectual disabilities may be more present in the community, they are not actually benefitting from this exposure (Overmars-Marx et al., 2014). Despite the decline of the institution, Hickey (2012) finds that many service users are still dealing with unresponsive bureaucracies in the non-profit sector.

The need for family services and supports that Williston identified in his report was not acknowledged in Welch's response on behalf of the Government Ontario, and has not been adequately addressed in subsequent, fragmented policy initiatives despite renewed emphasis on the crucial role of families in supporting children and adults with disabilities. For many families supporting a relative with a developmental disability there are multiple

barriers to social inclusion for the individual and the family. Hickey (2012) found that from an Ontario budget of \$1.5 billion for direct services to people with disabilities, only \$98 million flowed to families providing special services at home. Families are overworked, poorly organized and, therefore, are not fully effective advocates, or "end-user" stakeholders (Hickey, 2012). Furthermore, while Williston acknowledged that all families need to look forward to a time where their children will transition from home to the community we have not built capacity for this type of supported living in our communities. The toll this takes on family relationships and resources is most eloquently expressed in memoirs written by Ontario parents who have had to overcome significant administrative obstacles and very long waiting lists in order to obtain the supports that they need for their children and themselves (Brown, 2009; Edelson, 2000; Fleischmann & Fleischmann, 2012; Thomson, 2010).

The stories of people with limited or no ability to directly influence their living conditions should be very important to advocates, caregivers, and policy makers. Policy change tends to occur in response to an individual tragedy that raises community awareness, and subsequently reveals systemic crises. Indeed, it was in response to public concern expressed over the deaths of two institutional wards: Frederick Elijah Sanderson, and Jean Marie Martel, that the Ontario government decided to appoint Walter Williston to undertake his investigation of the institutional system in the province (Williston, 1971, p. 3). In 2015 the findings of the coroner's inquest into the death of Guy Mitchell have finally moved the Ministry of Community and Social Services to articulate measures to "increase the safety and security of adults with developmental disabilities who choose to live with a host family" (2015). These new measures will come into effect in April 2016.

Looking at the history of the long expansion and subsequent decline and dismantlement of Ontario's institutional system, these are still early days in the province's post-institutional era. Still, it is very clear that transitions to community living, and social inclusion have not delivered the policy objectives promised. In fact, service planners and advocates must address the reality that we are wrestling with

similar challenges to those that provoked the original institutional response in the nineteenth century: people with mental disabilities are often poor and live a marginalized existence on the fringes of the community; many are vulnerable to violence and exploitation; a disproportionate number of people with mental disabilities populate other institutions such as prisons, hospitals and long-term care facilities because they lack the supports to live autonomously with a reasonable degree of security (Reif, 2014; Stienstra, 2012). However we define it, surely meaningful inclusion must entail a range of living options that realistically is not currently available to most people who require daily living supports due to limitations in the capacity of supported living services; paternalistic attitudes that endure despite a rhetoric of inclusion and choice (Joffe, 2010); and the inability of some people to gain access to people and processes where they can safely articulate personal choices around residency and life goals.

Even the research credited for informing a policy of deinstitutionalization recognized the need for a spectrum of family as well as community service supports to allow people with developmental disabilities to live securely and actively in inclusive communities. These ranged from group homes, to specialized foster care, half-way or transition housing, and long-term care facilities (Williston, 1971, pp. 75–80) that collectively provide a better range of community living options and personal supports to meet individual needs than are currently available in most communities. Having come full circle, service recipients, planners, support workers, families and advocates can learn a lot from going back to the policy history of deinstitutionalization in Ontario. Looking critically at the extent that the recommendations of commissioned research and the promise of political objectives have been realized may help us to better understand what still needs to be accomplished to realize social inclusion for a diverse population.

Key Messages From This Article

People with Disabilities: A lot of policies for people with disabilities have talked about community living and social inclusion, but these policies need to better explain what that means so that people know what services and supports they can get to help them be included.

Professionals: People with disabilities do not experience inclusion simply by living in the community. Service providers need to be aware of the unfulfilled promises of past and existing policy in order to inform their advocacy for a spectrum of services to facilitate social inclusion.

Policymakers: In order to determine whether people with disabilities experience social inclusion, policy makers need to clearly define this term and criteria for evaluating its presence or absence.

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