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## **A Place to Call Home: Intellectual Disabilities and Residential Services in Nova Scotia**

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### **Abstract**

Despite broader trends toward the deinstitutionalization of people with intellectual disabilities, evidence that they have a higher quality of life in the community, and recognition of community living as a human right, many in Nova Scotia remain segregated in institutional settings. This article provides insight on the reasons why people with intellectual disabilities continue to be institutionalized in the province. It is based on participant observation, document analysis, and qualitative interview research. It finds that implicated community members— including policymakers, residential service providers and workers, and advocates— hold conflicting beliefs about the purpose and necessity of large institutions, as well as the extent to which community-based group homes reflect institutional models. This paper argues that these conflicting beliefs have practical implications for disability advocates, community service providers, and policymakers in Nova Scotia and in other provinces as they attempt to improve residential services.

### **Keywords**

*Institutionalization; Community Living; Intellectual Disability; Nova Scotia, Government Policy; Advocacy; Institutional Ethnography*

## **A Place to Call Home: Intellectual Disabilities and Residential Services in Nova Scotia**

### **Introduction: Institutionalization in Nova Scotia**

According to the 2008 Report of Residential Services, over seven hundred Nova Scotians with disabilities are segregated in institutional settings (Nova Scotia Department of Community Services [DCS]). These institutions, referred to as Adult Residential Centres (ARCs) or Regional Rehabilitation Centres (RRCs), house people with a combination of physical and intellectual disabilities and mental illnesses. The institutionalization of people with intellectual disabilities<sup>1</sup> in Nova Scotia stands in contrast with the deinstitutionalization taking place in some other Canadian provinces (People First of Canada - Canadian Association for Community Living Joint Task Force on Deinstitutionalization, 2010; Wicks, 2010) and around the western world (Emerson, 2004; Bigby & Fyffe, 2006; Mansell & Ericsson, 1996).

This article begins from the premise that the institutionalization of any person with an intellectual disability is ethically unacceptable and is a violation of human rights. Disability rights activists have asserted that people with intellectual disabilities are equal citizens deserving the right to live in community settings since the 1960s (Bigby & Fyffe, 2006; Bickenbach, 2001; Scotch, 1989). Research demonstrates that people with intellectual disabilities typically experience increased physical and emotional well-being, an increased sense of safety, and more meaningful social relationships, when they live with support in the community (Johnson & Traustadóttir, 2005; Griffiths & Brown, 2006; O'Brien, Thesing, Tuck, & Capie, 2001; Young, 2006).

This article asks why people with intellectual disabilities continue to be institutionalized in Nova Scotia despite recognition of the right to community living, a broader trend toward deinstitutionalization in Canada and internationally, and evidence that people with intellectual disabilities have a higher quality of life in the community. It addresses this by drawing on participant observation with a local disability advocacy organization, an analysis of key disability service policy documents, and interviews with implicated community members. This research demonstrates that community members—including policymakers, residential service providers and workers, and advocates—hold conflicting beliefs about the purpose and necessity of large institutions. They also hold conflicting beliefs about regulations and licensing practices in community-based group homes. This paper outlines the basis for these differing beliefs. It argues that they have practical implications for disability advocates and community services providers in Nova Scotia and in other Canadian provinces as they attempt to collaborate with policymakers to move toward deinstitutionalization.

### **Background: Institutionalization and Deinstitutionalization**

Institutions became the dominant model of care for people with intellectual disabilities between the 18th and mid-20<sup>th</sup> centuries in North America and Europe. Many proponents of early institutions believed that they were ideal environments in which to protect, rehabilitate, or provide care for people with intellectual disabilities (Walmsley, 2005; Weeks, 1996; Wolfensberger, 1975). One of the earliest critics of institutionalization (Wolfensberger 1975) finds that several of the first institutions in the United States followed a developmental model. Based on Philippe Pinel's philosophy of moral treatment, they were designed in accordance with the view that residents are capable of "growth, development, and learning" (Wolfensberger,

1975, 15). They were also founded on the belief that a person with an intellectual disability is an "eternal child" who "never grows old" and therefore requires care and protection "against injury and risk" (Wolfensberger, 1975, 13). Another common perception of disability is that it constitutes a 'personal tragedy' that can and should be treated through medical means (Oliver, 1990, 2). Institutions were often considered necessary environments in which to provide medical treatment (Oliver, 1990).

In the latter part of the twentieth century, attitudes and beliefs regarding disability began to change in response to the eugenics movements during World War Two (Simmons, 1982); critical popular and academic accounts of institutional life published during the 1960s and 1970s (Davis, 2006; Simmons, 1982); normalization theory which asserted that people with intellectual disabilities should live in culturally normative environments (Wolfensberger, 1972); and the pioneering work of disability activists, originally in the United States and around the world, since the 1960s (Bickenbach, 2001; Bigby & Fyffe, 2006; Zola, 1994). Critics suggest that deinstitutionalization is also motivated by economic concerns associated with the shift from welfare to neo-liberal forms of governance in North America. According to this argument, deinstitutionalization is a way for Western governments to decrease public expenditures by closing institutions that are costly to maintain (Davis, 2006; Scull, 1984). Critics assert that policies of deinstitutionalization simply decrease public responsibility; thereby making families and the private sector responsible for supporting people with disabilities (Finch, 1984; Hankivsky, 2004).

Debate exists regarding the rationale for deinstitutionalization. Rights activists have still mobilized around the issue of deinstitutionalization to ensure that people with disabilities, as equal citizens, have choice and control regarding their living arrangements and everyday

activities (Bickenbach, 2001; Bigby & Fyffe, 2006; Scotch, 1989). Today organizations such as the Canadian Association for Community Living and People First of Canada play an integral role in promoting the right to community living (Panitch, 2004). This right has also gained recognition and support from Canadian and international political organizations. The United Nations Convention on the Rights of Persons with Disabilities (2006) – ratified by Canada in March 2010— states that all persons with disabilities have the right to live in integrated community settings, rather than in institutions.

Research suggests that the process of deinstitutionalization and the transition to living in a community settings sometimes leads to new forms of care and management that are institutional in nature (Bigby & Fyffe, 2006; Gardner & Glanville, 2009; Mansell & Ericsson, 1996). Advocacy and support organizations recognize that simply closing institutions and providing support in community group homes may not necessarily ensure the equality and integration of people with disabilities. They assert that community living extends beyond the right to live in a group home rather than in an institution and includes initiatives such as user-directed or self-managed care (People First of Canada - Canadian Association for Community Living Joint Task Force on Deinstitutionalization, 2010).

Despite broader trends toward deinstitutionalization, seven institutions, or ARCs and RRCs, exist in Nova Scotia. Each houses between 32 and 115 individuals with intellectual and physical disabilities and mental illnesses. These institutions form a part of a continuum of residential services. The continuum also includes Group Homes and Developmental Residences where four to twelve people live, and Small Options Homes where three or fewer people live with support (DCS, 2008).

## **Methodological Design**

Institutional ethnography, a method of sociological inquiry developed by Dorothy Smith (1987, 1999, 2001), was used to investigate why people with intellectual disabilities are still institutionalized in Nova Scotia despite a broader trend toward deinstitutionalization, evidence that they have a higher quality of life in the community, and recognition of community living as a human right. The purpose of institutional ethnography is to “tease out the linkages among local settings of everyday life, organizations, and translocal processes of administration and governance” (DeVault & McCoy, 2006, 751). The term ‘institution,’ in this sense, does not refer to a specific organization or structure, but rather to “a complex of relations forming part of the ruling apparatus, organized around a distinctive function” such as education, health care, or social services (Smith, 1987, 160). The aim of institutional ethnography is to make sense of the ways these relations — referred to as ‘relations of ruling’ — shape people’s everyday activities and experiences. Institutional ethnography adopts the standpoint of individuals working in local settings to critically analyze institutional structures and ideological beliefs that are often taken for granted. By showing how people experience these structures and beliefs in their everyday lives, institutional ethnography “does not substitute the expert’s ‘reality’ for what people know in the doing” (Smith, 2001, 161). Following the institutional ethnography framework, this study employed qualitative methods to gather and analyze the attitudes and beliefs of implicated community members regarding disability. These methods included participant observation, document analysis, and semi-structured interviews.

### *Research Sample And Data Collection*

Participant observation involved attending the monthly meetings of a local disability advocacy organization. Members of this organization included professional advocates,

community service providers, people with intellectual disabilities, and their family members. The discussion at these meetings often focused on ways to move toward deinstitutionalization and to develop alternative community supports. Participant observation offered insight into the positions of community members regarding institutional living.

Two documents were analyzed for this study: The DCS ' Report of Residential Services (2008), and the Homes for Special Care Act (2009). The Report of Residential Services describes the 'continuum of services' that the DCS provides for people with intellectual disabilities and describes the official policy of the DCS concerning institutionalization and deinstitutionalization. The Homes for Special Care Act outlines the province's regulations for its residential care facilities, such as the minimum amount of physical space required for residents and fire and safety codes, which are subject to governmental inspections. These documents are publicly available on the DCS website.

Following participant observation and document analysis, twelve semi-structured interviews were conducted with participants who held knowledge and experience regarding Nova Scotia's residential services system. Interview participants included two policymakers working for the DCS and involved in implementing and reviewing residential services; four service providers who held/had held managerial positions with community group home service organizations; two front-line employees working with people with disabilities; and four disability advocates. Access to policymakers was gained through a telephone call to the DCS outlining the research project. Service providers, workers, and advocates were all recruited through the contacts established while conducting participant observation. Interviews were open-ended and varied according to the type of information participants were able to share. Pseudonyms are used throughout this article to protect the identity of research participants.

### *Analysis*

Detailed fieldnotes were taken during participant observation. Notes were organized thematically to identify recurring perspectives regarding residential services that emerged during advocacy meetings. Documents were analyzed to identify the attitudes and beliefs about disability underlying housing and support policies. All interviews were recorded, transcribed, and then analyzed to identify how different participants reflected upon and explained the continued existence of institutions. Since interview participants were divided into different groups according to their roles as policymakers, service providers or workers, or advocates, a multi-level analysis was conducted by identifying and noting the frequency of themes emerging in each interview, in each group of interviews, and in all of the interviews.

### **Findings: Divergent Attitudes about Residential Services**

Divergent attitudes exist among interview participants regarding the purpose and necessity of institutions, as well as policies and practices in community-based group homes. Policymakers and an institutional worker believe that institutions are necessary to provide rehabilitation or care for people with intellectual disabilities. They also believe that strict licensing regulations are necessary to ensure the safety of group home residents. Their perspectives are closely related to those presented in policy documents. Community service providers and advocates challenge these beliefs; stating that appropriate supports for people with intellectual disabilities can best be provided in integrated community settings rather than institutions. They also express concern that regulations in group homes lead to the creation of 'mini-institutions' in the community.

### *Rehabilitation As A Justification For Institutionalization*

During interviews, two policymakers and one institutional worker all explained that large institutions are necessary because they provide the opportunity for people with intellectual disabilities to be rehabilitated. As Sandy Goode, a policymaker, stated, an institution "need not be a lifelong home," but is a transitional step that could lead to independent community living. The DCS affirms this position in the Report of Residential Services (2008). This policy document claims that the aim of ARCs and RRCs is to teach residents "with complex behavioral and skill development needs" community-oriented, interpersonal, and life skills (11). The 'continuum' model emphasizes that residents will move through services – from an ARC or RRC to a Group Home or Small Option Home, and ideally to independent living - as they develop the capacity to live independently (DCS, 2008).

The following quote from Brian Turner, a social worker who works in an RRC, also exemplifies the belief that people can be rehabilitated in institutional facilities:

Our program is about rehabilitation; it's never long-term care. We focus on getting people back into the community. Anyone that comes to us has basically failed everywhere else in the system. They come to us, we do huge amount of assessments, get programs in place, and they're able to discharge back into the community . . .

Brian Turner explained that institutionalization provides a necessary means of rehabilitation for people who may have learned to behave inappropriately while living elsewhere. He explained, for example, how people with disabilities and mental illnesses who act aggressively or violently in the community benefit from living in a rehabilitation centre. In this controlled environment residents can learn communication and anger management skills. They can then leave the rehabilitation centre and live with other people in a community setting, where they will be able to effectively communicate their needs without acting aggressively.

To rehabilitate residents who exhibit aggressive behaviour, Brian Turner stated that the continuum of services for people with intellectual disabilities should reflect the medical model of care. The medical model emphasizes acute treatment and recovery and is often used to rehabilitate people with short-term illnesses or physical disabilities (Oliver, 1990). Brian Turner's belief that institutions are necessary as a first, or 'acute,' step in the rehabilitative process echoes government policy. The Report of Residential Services states that ARCs and RRCs are well suited to provide acute treatment because residents living in them "have access to a number of professional services including medical services, nursing, psychological and psychiatry services, social work, speech language therapy, physiotherapy and occupational therapy" (DCS, 2008, 12).

*Long-Term Care As A Justification For Institutionalization*

Two policymakers and an institutional worker explained that the primary goal of large institutions is rehabilitation. These participants believe, however, that rehabilitation is not possible for some residents due to the severity of their disabilities. They all expressed that institutions are necessary because people with especially complex or severe disabilities could not be well cared for in the community. Doris Martin, a policymaker, discussed how institutions "are required in the continuum" for people with the most complex care needs, stating that "we do need all levels of support" in Nova Scotia. This might include the constant support of doctors and nurses and access to medical technologies. Brian Turner's insights exemplify this belief as well:

There will always be people who need to live in a large facility because their care needs are so high. You can't staff a small option home with three people and have twelve RNs [registered nurses] there all the time, because some of these people need RN care, and have a physician that is always on call and ready to come . . . We [the RRC] offer equivalent physical care to a nursing home. There will always be people who need that level of care.

The Report of Residential Services (2008) provides further evidence to support the need for long-term care and to justify the continued existence of ARCs and RRCs. The Report cites Brian Hennen, a local psychiatrist, who states that a "small number of individuals . . . may require continuous, specialized, experienced, collaborative, and integrated management which is unlikely to be found in most domains" (DCS, 2008,19). According to Hennen institutions are necessary because the community is unprepared to support people with severe and complex disabilities. It thus presents a risk to their safety and well-being.

*Critiques Of The Rehabilitative Model*

Four advocates and four of the community service providers challenge the view that institutions are necessary to rehabilitate people with intellectual disabilities. These participants believe that people with intellectual disabilities are capable of learning and growing throughout their lives, but are not sick and do not need rehabilitation to get better. As Doug Townsend, an advocate for deinstitutionalization who has an intellectual disability, pointed out:

We visited [an RRC] and there's a doctor's office [program] where people can learn how to go to the doctor's office. I just shake my head. When I learned to go to the doctor's office, I learned by going to the doctor's office. There doesn't need to be a program to do that. I believe there's very little rehabilitation going on. There's nothing on the other end. A lot people are there for lifetime.

Simon Kempe, a community services provider, similarly pointed out that people do not 'graduate' through support services in a linear way. Instead they require ongoing support and exposure to a variety of environments throughout their lives. When discussing her adult daughter with disabilities, Gloria Smythe, another advocate, explained:

[My daughter] has health-related problems . . . but she's not sick. She's been healthier than her 'normal' brother. When they were growing up he's the one who had the most colds and flus and things like that. She's not a sickly person. She just has different needs . . .

*Critiques Of The 'Long-Term Care' Model*

Two of the advocates and four of the community service providers further expressed the view that people should not be institutionalized simply because they need more intensive care. They assert that high levels of care and support, including medical services when they are necessary, could potentially be provided in integrated settings. As Simon Kempe explained, "[The belief is that] you have to be cared for, and therefore you have to be able to access a doctor at the ready, as opposed to as other people do within the community." He and four other participants feel that many people with intellectual disabilities should be able to access the same social and medical services that other people use in the mainstream community. They express that this would be possible if more members of the general population were knowledgeable about the differing needs of people with intellectual disabilities. If this were the case, people with disabilities would not require 'specialists,' including doctors, social workers, and therapists, who work solely in institutional facilities.

### *Institutions In The Community*

It is clear that research participants hold conflicting beliefs about the purpose and necessity of large institutions. An unforeseen finding, however, is that research participants hold contradictory views regarding licensing practices in community-based group homes. The DCS is currently attempting to make sure that all of its homes across the province are licensed in accordance with the Homes for Special Care Act. To be licensed, service providers must ensure that their group homes adhere to specific fire and safety codes, must ensure a minimum amount of physical space for each resident, and must allow government officials to conduct inspections of the home (Homes for Special Care Act, 2009).

The two policymakers who participated in interviews explained that strict regulations are necessary to ensure the quality of services and the safety and well-being of residents. These

regulations, they explained, decrease the risk of service providers or staff mistreating or neglecting residents. As Sandy Goode, one of the policymakers, explained:

The most important thing is the safety of individuals, the safety and well-being. Through licensing and standards it's very clear that service providers are providing the services to individuals, but our staff have a monitoring role to go in and make sure that the standards, the regulations, the Homes for Special Care Act, are all being met. Otherwise you could have a service provider with the most vulnerable population who could be providing food, shelter, and clothing, but at standards so poor that it puts somebody at risk.

Other research participants, contrastingly, do not feel that these regulations ensure the well-being of residents. Three community service providers and two advocates stated that attempts to mitigate and manage risk lead to the creation of community homes that reflect an institutional model. This was also a key topic of discussion throughout the meetings of a local advocacy organization. Critics of licensing practices feel that 'community homes' merely reflect the institutions they aim to replace, albeit with fewer residents. When the staff spends so much time and energy following rules developed at a bureaucratic level, they are often unable to prioritize the needs and interests of the people living in a group home. Simon Kempe explained that regulations intended to protect residents could be emotionally harmful. He stated that rules against physical contact, implemented as a means of decreasing the risk of physical or sexual abuse, stand in the way of fostering relationships between residents and staff:

We've had to go full circle in terms of how we interact with clients. So many [residents] have so few people in their lives who they can interact with by giving them a hug, who can hold them. Today [staff] can't do that because it would be interpreted by what that would mean. So they've gone to the other extreme where people don't touch [residents] at all, and that becomes difficult.

## **Discussion and Limitations of Research**

The data gathered through this research illustrates the conflicting beliefs that emerge among policymakers, service providers or workers, and advocates for community living

regarding the purpose and necessity of large institutions, as well as the purpose and necessity of regulations and licensing practices in community group homes. A limitation of this study is that participant observation and the majority of interviews occurred with people involved in disability advocacy or community service provision who support deinstitutionalization. Future research among institutional workers and policymakers would provide further knowledge of the beliefs and values of those who support institutionalization. It would also be beneficial to conduct research among more people with disabilities directly in addition to research with their family members or advocates. This would help ensure that the perspectives and interests of people using residential services are accurately represented.

*Implications For Theory: The Impact Of 'Ruling Ideas'*

Despite these limitations, findings have implications for understanding 'ruling ideas' as they are enacted in Nova Scotia's residential services system. Institutional ethnography suggests that ruling ideas about disability shape the knowledge, perspectives, and practices of people working at the local level (Smith, 1987, 1999, 2001). In this case, dominant beliefs about rehabilitation, care, and risk management, which disability 'experts' including doctors and health professionals produce, shape local policies as well as the perspectives and practices of research participants who feel that institutions are necessary for some people with intellectual disabilities.

Many advocates and community service providers who participated in this research challenge these dominant beliefs. They do not believe that people with intellectual disabilities need to be rehabilitated or kept safe, but instead require on-going support to live in the community. Rather than understanding disability as an individual medical problem or as a personal tragedy, many advocates for community living suggest that societal changes, including

the creation of a more accepting and accessible community, can enable successful deinstitutionalization.

Conflicting opinions demonstrate a disjuncture between the beliefs and values embedded in policies regarding disability, and the experiences of advocates and community service providers who encounter disability in their everyday lives. Institutional ethnography proposes that knowledge considered objective and embedded in ruling ideas often differs from people's subjective experiences (Allan, 2011, 357). People's direct experiences with disability may lead them to critically reflect on the value of human life in its various forms and reject ruling ideas about rehabilitation, care, and risk management. Those who have personal experience with disability may hold different views than policymakers or service providers who adopt ruling ideas in their work.

*Implications For Canadian Policy: Collaboration to Create a Vision for Deinstitutionalization*

This research has implications for policymakers and implicated community members in Nova Scotia and across the country as they attempt to ameliorate residential services and move toward deinstitutionalization. Patterns of abuse, inhumane treatment, and neglect demonstrate the urgency of examining and improving upon residential services for people with disabilities. In a Nova Scotia institution where 100 people live, 19 cases of physical, sexual, and emotional abuse were reported in 2008 and 2009 (Canadian Press, September 9, 2009). In another Nova Scotia institution with 134 residents, an autistic man was locked in his room and neglected for fifteen days in September 2010 (Canadian Press, February 1, 2011). Class action lawsuits were filed against the Ontario government in 2010 on behalf of people with intellectual disabilities who experienced abuse, inhumane treatment, and neglect while living in three of the province's institutions, each of which were closed in 2008 and 2009 (Institutional Survivors, 2011).

A comparison with other provinces demonstrates that Nova Scotia, where approximately 700 people with disabilities live in institutions, has unusually high rates of institutionalization. People with intellectual disabilities, however, still live in institutions across the country. Institutions designed for people with disabilities still exist in Manitoba, where 272 people with disabilities live in the Manitoba Developmental Centre, and in Alberta, where 237 people live in the Michener Centre. While other provinces have closed all of their institutions designed specifically for people with intellectual disabilities, some people with disabilities still live in nursing homes or other institutional facilities (People First of Canada-Canadian Association for Community Living joint Task Force on Deinstitutionalization, 2011). The conflicting opinions presented in this paper - and particular the continued justifications for institutionalization according to arguments of care and safety - are likely relevant in other provinces as well. A better understanding of these conflicting opinions can help policymakers understand the perspectives and interests of advocates and community service providers regarding institutionalization.

Where community group homes have been developed, some research participants express concern that they merely reflect institutional models they aim to replace, albeit with fewer residents. Group homes do not present a genuine alternative to institutions when strict regulations govern the conduct of workers and residents. The original purpose of this study was to examine why people with intellectual disabilities are institutionalized in *large* facilities. This research suggests, however, that research participants hold different understandings of what it means to be institutionalized, in either large institutions or in community-based facilities with fewer residents. In light of this finding, a further investigation of the different *ways* people are

currently being institutionalized is necessary. Such research is an important step toward developing and implementing viable alternatives to institutionalization.

<sup>i</sup> In disability studies literature, debate exists regarding the use of the term 'people with disabilities' in contrast to 'disabled people' (Traustadóttir & Johnson, 2005). On the one hand, many scholars who adhere to the social model of disability use the term 'disabled people' to emphasize that people, no matter what their physical or intellectual capacities, are in fact *disabled* by the contexts in which they live (Oliver, 1990). While this is an important argument to consider, this paper uses the term 'people with disabilities.' Traustadóttir & Johnson (2005) suggest that the majority of people with intellectual disabilities prefer this term; emphasizing that they are 'people first.' In addition, almost all research participants used the term 'people with disabilities,' and so it seemed logical to do so in this paper for the sake of consistency.

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