Needs and Circumstances of People with Disabilities, those with Intellectual Disabilities and Government Response in Nova Scotia

Expert opinion prepared for a Nova Scotia Human Rights Board of Inquiry
MacLean, Delaney, Cain and the Disability Rights Coalition v. Nova Scotia
File Number H14-0418

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Introduction

I have been retained by Dalhousie Legal Aid Service (DLAS), lawyers for the Disability Rights Coalition, to give an opinion concerning certain issues raised by the human rights complaint in *MacLean, Delaney, Cain and the Disability Rights Coalition v Nova Scotia*. I have been engaged by DLAS to prepare a report that addresses the following issues:

1. Prevailing social attitudes towards persons with disabilities, and particularly persons with intellectual disabilities in Canada, and how those attitudes have changed over time, as well as the extent to which the prevailing social attitudes towards people with disabilities, especially people with disabilities who require supports and services to live in the community, influenced the development of social policy with respect to housing and treatment by the social welfare system, of such persons in Canada, and in particular, Nova Scotia.

2. Describe the general characteristics of the group of persons who qualify for the Nova Scotia Disability Supports Program (DSP)? Please situate this group of persons with disabilities within the social and historical context of Canadian society. This includes the general characteristics of the group of persons with disabilities who require supports and services to live in the community in terms of their socio-economic status, life expectancy, access to healthcare, education, employment, health, criminalization, vulnerability as victims of abuse and other relevant characteristics.

3. Define what is meant by an “institution” such as they exist for participants of the DSP in Nova Scotia and how those same institutions differ from community living.

4. Explain the impacts of being placed in an institution for participants of the DSP program as well as the phenomenon known as “institutionalization” including if relevant the physical, mental, health, and developmental effects of living in an institution. What experiences do those same DSP participants who are placed in institutions lose that they would otherwise experience if they lived in the community, with reference to the following circumstances:
    a. people with disabilities who require supports and services to live in the community who reside in institutions;
    b. people with disabilities who require supports and service to live in the community, who reside in the community in the absence of appropriate supports and services (e.g., including those living with family or independently).

5. Provide your opinion whether all persons with intellectual disabilities are capable of living in the community, assuming appropriate supports and services are available.

I acknowledge that it is my duty to provide opinion evidence in relation to this matter that is fair, objective, non- partisan, and relates only to matters that are within my area of expertise. It is also my duty to provide such additional assistance as the Nova Scotia Human Rights Board of Inquiry may reasonably require to determine the matters in issue, and that this duty prevails over any other obligation I owe to any party on whose behalf I am engaged.

The report is divided into three main sections:

- My expertise to report on the matters in this report
- Report on the issues as identified above
- Conclusions

Expertise

My CV attached to this report presents in detail the expertise I drew upon in preparing this report. In summary:

- Thirty years of experience in disability-related policy research in Canada and internationally.
- A PhD that examines the law, science and ethics of the right to legal capacity as it relates to people with intellectual disabilities.
- Project direction and senior research role in many national and international research initiatives on various aspects of disability-related policy.
- A series of professional research reports considering various aspects of disability-related policy in education, disability supports, employment, disability supports funding and delivery, legal capacity.
- Several publications including both articles and books covering various aspects of disability-related policy.
- Specifically, in the Nova Scotia context – Technical support to the ‘Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program, and for that Committee preparation of the 2013 *Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program.*

1. Prevailing societal attitudes and how these have changed over time

Changing understandings of disability

Public attitudes and public policies concerning people with disabilities are rooted in an evolving understanding of disability which has shifted over time.[1] Historically, disability was seen as a

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[1] This section draws on a chapter I prepared for collection of papers on intellectual and developmental disability. See Michael Bach, Changing Perspectives in Developmental Disability, in Michael H. Wehmeyer, Ivan Brown, Maire Percy, Karrie A. Shogren & Alan Fung, eds., *A Comprehensive Guide to Intellectual & Developmental Disabilities,* Second Edition (Baltimore: Paul H. Brookes Publishing, 2017).

deficit or ‘deformation’ of a person’s intellectual, physical, sensory, communication or psychological characteristics. Disability was something inside the person and the focus was exclusively on diagnosis, treatment, cure and prevention. In this model, if a person could not be cured of disability, social and economic exclusion was justified and at best they might be able to access segregated services. In this approach, it is assumed that persons with disabilities, especially significant disabilities, cannot participate as full members of society.

This is largely a ***bio-medical approach*** to disability. Disability is constituted against the backdrop of assumptions about ‘normal’ developmental pathways and benchmarks of cognitive, communicative, physical, mobility and sensory competencies. This approach has been institutionalized in many ways, for example through IQ and diagnostic testing of intellectual disability. Diagnostic tests to determine ‘basal mental ages,’ functional capacities, and syndromes are all part of a diagnostic regime today. Diagnoses have served various functions in the process of service institutionalization – admittance, placement, service planning and evidence of competency sufficient for recognizing legal capacity to act independently.

The bio-medical diagnostic regime in the field of intellectual disability has multiple sources. By the end of the 18th century, the Royal College of Physicians in England was responsible for the licensing of “madhouses” under the English poor laws and thus began the bio-medicalization of disability and societal responses. By mid-19th century, resident physicians were required in madhouses of more than 100 people. In the same period, the Association of Medical Officers of Hospitals for the Insane was established, and the organization published a diagnostic manual that included such categories as “mania,” “melancholy,” “monomania,” “dementia,” “moral insanity,” “idiocy,” “imbecility,” “general paralysis,” and “epilepsy”[2]. The manual is one of the precursors of the Diagnostic and Statistical Manual of Mental Disorders, now widely used to “diagnose” intellectual, developmental, and other disabilities.[3]

By the late 19th century, Alfred Binet developed in France the first intelligence tests to assist in identifying children who were not progressing in school. The test was adapted and became in the early 20th century one of the common instruments for diagnosing mental retardation. The test was designed to measure the subject's capacity on various skills including those associated with mental and cognitive processing. Upon applying the test, a “mental age” score is attributed, compared with the respondent's chronological age, and the degree of intellectual disability is thus ascertained. Standardized IQ measures were later developed for different age ranges, and normal deviations constructed as a means of identifying as “mentally retarded” or intellectually disabled those who fell below the normal range. Psychometric tests have been developed that now enable detailed quantifiable measurement of intellectual disability and intelligence.

Alongside this bio-medical approach, a ***habilitation and rehabilitation*** approach to disability

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[2] D.N. Weisstub, *Enquiry on Mental Competency: Final Report* (Toronto, 1990).

[3] American Psychiatric Association, *Diagnostic and statistical manual of mental disorders,* 5th ed. (Washington, DC: Author, 2013).

evolved, based on the idea that individuals could still progress along developmental pathways or recover from injury or illness, in ways that do not necessarily meet the 'normal' benchmark, but to maximize their capacities. This approach emerged in the 1940s, 1950s and 1960s as the custodial models of institutionalization of people with intellectual disabilities began to be questioned and as behavioural and other therapies and assistive technologies developed. Drawing on Binet, this approach drew on tests to measure how closely individuals met "developmental" targets at each age. The discrepancy in measures on language, motor, and behavioural development assisted in defining various categories of "developmental" or "intellectual." By the 1960s, "adaptive behaviour" testing was designed to measure behaviour as an indicator of intellectual disability. Various adaptive behaviour scales were designed, aberrant behaviour typologies constructed and new "disorders" were added on this basis to the categories of diagnosis of intellectual disability.[4] The aim was to assist in identifying therapies and interventions to develop or rehabilitate cognitive, communicational or mobility capacities.

The habilitation/rehabilitation approach and the emergence of disability as a human rights issue helped set the stage for what has come to be known as a ***social and human rights*** approach to disability. In this approach, disability is understood as the result of the interaction between some of a person's characteristics, sometimes called 'impairments', with the physical and social environments in which people live. With this approach, the focus of intervention shifts to changing the social, economic and environmental barriers that surround the person, and to providing the person with supports needed to fully participate. For example, a person who uses a wheelchair in effect only becomes disabled when there is no ramp to access a building; or when other supports are not available to access opportunities on an equal basis with others; or when others devalue the person in some way because he or she uses a wheelchair for mobility.

The UN Convention on the Rights of Persons with Disabilities (CRPD), ratified by Canada in 2010, characterizes disability in just this way:

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.[5]

This framework of approaches to understanding disability – bio-medical, habilitation/ rehabilitation and social/human rights models – has been recognized as a useful tool for examining approaches to changing public attitudes, law and policy with respect to persons with

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[4] For an overview of testing and assessment see Hogg, James and Norman V. Raynes, eds., *Assessment in Mental Handicap: A Guide to Assessment Practices, Tests, and Checklists* (Cambridge, Mass.: Brookline Books, 1987).

[5] Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106, 76th plen. Mtg., U.N. Doc A/Res/61/106 [adopted by consensus at the UN on Dec. 13, 2006] [CRPD]. Canada signed the CRPD on March 30, 2007 and ratified it on March 11, 2010. The CRPD came into force on May 3, 2008, Article 1 (online: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html).

disabilities.[6] While these different approaches have evolved historically, one has not operated to the exclusion of others in any particular law or policy framework. In fact, it is the concurrent operation of these models that helps to understand conflicting approaches to disability in the current period.

These models can be applied to the Nova Scotia context to help reveal the nature of evolving public attitudes and policies and their dynamic interplay throughout the province's history. The following sections highlight some of the ways in which these approaches to disability took root in the Nova Scotia context. The following is not intended as a comprehensive 'history' of law and policy development in Nova Scotia. Rather, it is a selective analysis that reveals the operation of these different approaches and helps to explain what could be characterized as a misalignment today in Nova Scotia of public policy and public attitudes concerning disability. The evolution of distinct approaches shaping and reflecting public attitudes and policies can be examined through four over-lapping phases of development.

- Poor Law, Poverty and Public Responsibility
- Early Re-thinking of 'Mental Deficiency' and Institutions – Nova Scotia Royal Commissions 1926 and 1944
- The Welfare State Response to Disability in Nova Scotia
- Emergence and Support of the Social Model and Individualized Approaches to Disability Supports

Poor Law, Poverty and Public Responsibility

A series of 'Poor Relief' Acts were adopted in Nova Scotia beginning in the 1760s. In 1763, the Province's General Assembly passed two Acts – 'An Act to enable the Inhabitants of Several Townships within this Province to maintain their Poor' and 'An Act for regulating and maintaining an House of Correction or Work-House, within the town of Halifax, and for binding out poor Children.'

Together, this legislation provided for assessing the inhabitants of a township for funds to: "support and maintain the poor" through 'outdoor relief' or provision of income support provided by the 'Overseer of the Poor' appointed by the township; establish in Halifax a poor house (already in place at that point) to provide 'indoor' relief for the 'sick' and the 'weak' who were unable to work; and, for 'binding' out poor children who could not be cared for by their families. 'Binding' out essentially indentured children to serve as domestic help to other families who were to train them in 'husbandry' and other skills, families who received financial support for this purpose.

The poor law regime was eventually extended to other municipalities in the province, including provisions for 'overseers of the poor' to be appointed. In 1886, for example, the Legislative Assembly of Nova Scotia adopted the *Act respecting Public Charities* which provided authority to the provincial Commissioner of Public Works and Mines to enter into agreements: "with any

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[6] See, for example, Marica H. Rioux, Lee Ann Baser and Melinda Jones, eds., *Critical Perspectives on Human Rights and Disability Law* (Leiden: Martinus Nijhoff Publishers, 2011).

city, town or municipality, for the support of provincial paupers in any poor house established or maintained by such city, town or municipality.” While there were various amendments to the legislative framework – including increasing provincial regulation of municipal poor houses, introduction of provincial assistance to some groups of the poor including persons with disabilities, and expansion of the system – the main elements of the municipal poor relief system remained in place in Nova Scotia to 1958.

In the intervening decades, many steps were taken by the province to address the needs of persons with disabilities as these came to be understood through successive developments. At first, these developments came through the rubric of the predominant bio-medical or ‘health’ rather than ‘welfare’ approach. In 1857, the ‘Provincial Hospital for the Insane’ opened in the Mount Hope area of Dartmouth, and in 1858 the "Act for the Management of the Hospital for the Insane" was passed providing for appointment of a board of Commissioners and for transfer of people with mental health disabilities from poor houses to the hospital.

Well into the early 20th century, the poor house was the primary vehicle for public assistance to those in need. A 1912 amendment to the *Poor Relief Act* provided that Overseers of the Poor could “require any poor person applying to them or to any charitable society for relief, to go into and to be lodged, kept and maintained in any poor house”.

By 1921 the province took steps to formalize separate provision for those known in public policy terms at the time as ‘mentally defective persons’, defined in the 1921 “Act Respecting the Establishing of an Institution for the Custody, Treatment, Care and Education of Mentally Defective Persons” as

> persons in whose case there exists from birth or from an early age mental defectiveness so pronounced that they require care, supervision, and control for their own protection or for the protection of others, or, who by reason of such defectiveness, appear to be permanently incapable of receiving proper benefit from the instruction in ordinary schools, and persons who display some permanent mental defect coupled with strong vicious or criminal propensities on which punishment has had little or no deterrent effect.

The bio-medical approach to intellectual disability was firmly entrenched by this period – and with it a whole set of assumptions as reflected in the 1921 definition that the disability was inherent to the person and itself the cause and constitution of ‘defectiveness’. The ameliorating effects on public understanding that the habilitation/rehabilitation approach would bring were not yet articulated. The Poor Relief Act evolved through amendments in the first half of the 20th century to extend an almost exclusively bio-medical approach by providing for municipalities to establish poor districts, and with the approval of the Minister of Public Welfare to “erect, acquire, purchase, alter, add to, improve, furnish, and equip a building as a poor house for the accommodation of the poor” (S.N.S. Poor Relief Act, 1954, s. 10).

Early Re-thinking of ‘Mental Deficiency’ – Nova Scotia Royal Commissions 1926 and 1944

Two provincial Royal Commissions, less than twenty years apart, provided opportunity to consider the evolving system of poor relief and with it the understanding of mental disability on which it was based: The 1927 *Royal Commission Concerning Mentally Deficient Persons in Nova Scotia*, and the 1944 *Royal Commission on Provincial Development and Rehabilitation* and the Volume IV ‘Report on Public Welfare Services’. Both Commissions considered: the issues facing people with disabilities and society in this context; responsiveness of the contemporary forms of assistance to meet the needs of persons with intellectual and other disabilities; changing attitudes towards the place of these groups in society; and, recommended directions to put these evolving ideas into law, policy and practice.

Royal Commission Concerning Mentally Deficient Persons in Nova Scotia – 1927

By the 1920s, growing concern about the scale of relief required and the conditions of poor houses for people with intellectual and mental health disabilities, led to the appointment in 1926 of a Nova Scotia Royal Commission to “inquire fully into and concerning […] “number of mentally deficient persons in the Province”, “conditions under which such persons are living”, “effect of such persons upon the general welfare of the Province”, “ways and means of dealing with mentally deficient persons in their own interest and that of the general public”, and “Any matter relating to the present care, custody, control and means of support of mentally deficient persons in the Province”.[7]

The Commission reported on “public sessions” held with a range of churches, charitable societies and professional associations, including Church of England, Catholic Church, Nova Scotia Teachers’ Union, Red Cross Society, Victoria Order of Nurses, and others. As well, it reported on an extensive survey by the Canadian National Committee for Mental Hygiene (now the Canadian Mental Health Association), which included visits to 100 private homes throughout the province, and thirty-five institutions including municipal homes and a county jail where six children with ‘mental deficiency’ had been placed. Based on these sources, the Commission concluded (p. 40):

- 3% of school aged children were ‘mentally deficient’, but less than 1% of adults
- Living conditions of this group in many cases were “intolerable and unfit for human beings”, a large number were “living in deplorable conditions”.
- The “social, moral and economic welfare of the Province is gravely menaced by the presence of such large numbers of mentally deficient persons living under such conditions”.
- Immediate steps were needed, including “means for supervision and guidance of the feeble-minded in the Community, especially those on parole from the Training School and graduates of the Auxiliary Classes.

The Commission considered three broad directions (pp. 42-43):

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[7] Nova Scotia, Report of the Royal Commission Concerning Mentally Deficient Persons in Nova Scotia (Halifax: Printed By Order of the Government, 1927).

1. A eugenics approach which "would sterilize all persons found to be mentally deficient, below a certain point". This was rejected as a "not feasible solution". Interestingly, Alberta adopted provision for this approach the next year with the 1928 Sexual Sterilization Act.
2. A "second scheme, which was advocated by many until quite recently […] to segregate for life the mentally deficient in Institutions. This was rejected in part because of "prohibitive cost" but also because "careful investigators" found "that it is unnecessary, as very many of the mentally deficient may under favorable conditions become valuable citizens."
3. The third approach considered was "to ascertain the mentally deficient while they are young, and to provide for them adequate training so that they may take some useful place in the life of the Community, together with segregation in Institutions for life for those of very low-grade and those who cannot be trained to adjust themselves to their environment."

The Commission recommended adoption of the third scheme, including compulsory establishment of 'Auxiliary Classes', scholarships for teachers who would train to teach children in these classes, travelling 'mental hygiene clinics', and a provincial Training School for 'mentally deficient' persons. The recommendations were adopted to a certain degree, and the Nova Scotia Training School was opened in Brookside, near Truro just a couple of years later in 1929.

The attention of the Commission to the causes of poverty, the lack of family and community supports, the place of people with intellectual disabilities in the community, an emerging vision of 'valued citizens' and a call for concerted provincial attention signals this Commission's report as a pivotal point in laying foundations for a habilitation approach to intellectual disability, and even the early building blocks of a social model, in its reference to citizenship.

Royal Commission on Development and Rehabilitation – 1944 – Volume IV. Report on Public Welfare Services

By the early 1940s, the system of poor houses, its underlying culture, the terrible conditions, overcrowding and growing numbers dependent on this institutional model were increasingly called into question. In his *Report on Public Welfare Services* for the Nova Scotia Royal Commission on Provincial Development and Rehabilitation, George F. Davidson, then Executive Director of the Canadian Welfare Council, found that:

> The poor relief system in Nova Scotia is outmoded and outdated in every sense of those words. […] Based on the Elizabethan Poor Law principles which prevailed at the time of the colony's early settlement and first legislative enactments providing for the poor, this legislation has never been subjected to comprehensive and through-going revision…[8]

Davidson went on to recommend that:

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[8] Nova Scotia, *Report on Public Welfare Services*, Volume IV, Nova Scotia Royal Commission on Development and Rehabilitation (Halifax: King's Printer, 1944), para. 190.

> The system of local poor houses and county homes should be abolished in favour of a program of relief to persons in their own homes whenever this is possible. Persons should not be forced into institutions (as presently provided in Section 12 of the Poor Relief Act) merely because they lack the necessary means to maintain themselves. The effect of such a policy is inevitably to create dependency rather than to relieve it. To the extent that county institutions are maintained at all, they should be regarded as specialized welfare institutions for the care and maintenance, not of persons in need of relief, but rather of persons requiring for a special reason (e.g. health) careful attention in an institution, of a type which cannot be provided for them in their own homes. [9]

The county homes and asylums, he recommended, were to be reserved for adults in need because of intellectual disability, mental health issues or because of infirmity from aging or physical disability. Davidson recommended greater separation of populations within this system, to the extent that individuals could not be supported to live at home. He also recommended expansion of the Nova Scotia Training School to provide training facilities and custodial care for children and youth with intellectual disabilities, including those with significant disabilities.

Importantly, Davidson also found that many municipalities could not shoulder the costs of 'indoor' and 'outdoor' relief and recommended an increased role for provincial government financing.

Taken together these two Commission reports are revealing of a significantly changing approach to intellectual disability in the first half of the 20th century, from the 150+ years of poor law which preceded them:

- A clear rejection of a eugenics approach, being adopted in other parts of Canada, the U.S. and Europe
- That with the right supports individuals would become 'valued citizens'.
- Institutions are not the answer to poverty: "Persons should not be forced into institutions… merely because they lack the necessary means to maintain themselves" (Report on Public Welfare Services, 1944, para. 195(d)).
- That institutionalization was for those for whom needed supports could not be provided at home or in the community.

By 1944, then, the habilitation/rehabilitation approach to disability was beginning to take root in the province, and with that a recognition that a larger role for government was needed. Disability was increasingly a public matter to be considered an important element of the emerging welfare state in the province and at the federal level.

Modernizing a Welfare State Response to Disability in Nova Scotia

Many of the 1944 Royal Commission recommendations for changing the poor relief system

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[9] Nova Scotia, *Report on Public Welfare Services*, Volume IV, Nova Scotia Royal Commission on Development and Rehabilitation (Halifax: King's Printer, 1944), Recommendation O, at para. 195(d).

were formally adopted in the 1958 *Social Assistance Act,* which ended almost 200 years of statutory development initially based on the English Poor Laws. The Act explicitly sought to shed the province of its 'poor law' language and culture, beginning with the name of the Act itself.

Part I of the Act provided for "Provincial Assistance" to three groups:
(a) to a woman who has in her care and custody one or more children
(b) to a person who has in his care or custody one or more children, who have been abandoned or are not being maintained by their parents, parent or surviving parent; or
(c) to a person who has in his care and custody one or more children whose parents are dead or are permanently disabled.

Part II provided for "Municipal Assistance" to a "person in need", which was defined more expansively than the Poor Relief Act that it replaced, as: "a person who, by reason of adverse conditions, is in need of assistance in the form of food, shelter, fuel, clothing, medical care or other necessities" (s. 15(e)). In subsequent amendments to the Act in 1966 a person in need was defined as: "a person who, by reason of adverse conditions, requires assistance in the form of money, goods or services" (s. 17(g)).

Part II also made changes in terminology – for example, from "poor district" to "municipal welfare district"; from "overseers of the poor" to "welfare officers". The Act provided for the establishment of "welfare committees" in each municipality responsible for providing assistance through municipal homes, consolidating various poor houses and homes for aged persons and disabled persons under this legislation.

The Social Assistance Act was expanded in the 1960s to incorporate provisions for provincial financial assistance to persons with disability who were found unemployable (Social Assistance Act, 1966, S.N.S. 1966, c. 13, s. 7), and was further amended in 1967 to provide "supplemental assistance" to persons with disabilities. Amendments in 1968 provided that individuals under 'Predecessor Acts' including the Blind Persons' Allowances Act and the Disabled Persons' Allowances Act would receive income assistance under the Social Assistance Act (section 54).

The system was further developed throughout the 1970s with the adoption of the Homes for Special Care Act in 1976, which provided for provincial regulation of homes for the aged and disabled persons and consolidating the Boarding Homes Act and provisions for this purpose from the Social Assistance Act, Part II.

Regulations to the Home Care Act were adopted defining the types of facilities regulated under the Act as follows:[10]

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[10] Nova Scotia, Homes for Special Care Regulations, made under Section 19 of the *Homes for Special Care Act* R.S.N.S. 1989, c. 203, O.I.C. 77-1261 (October 11, 1977), N.S. Reg. 127/77 as amended up to O.I.C. 2011-365, (October 4, 2011), N.S. Reg. 284/2011 and including N.S. Reg. 261/2011, effective February 16, 2012, online: https://novascotia.ca/just/regulations/regs/hsc7393.htm.

> s.4(5) The term “community based residential facility” means any building or place where persons receive supervisory care in a residential and family environment and the care is provided by persons who are not their parents, and includes all of the following:
> (a) a group home;
> (b) a developmental residence;
> (c) a small option home.
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> s.5(1) The primary purpose of community based residential facilities, adult residential centres, and regional rehabilitation centres shall be to encourage, foster, and promote the social, educational and vocational development and well-being of the residents for the purpose of integrating the residents into the community as self-sufficient and independent individuals.

In 1977, the Family Benefits Act was passed, consolidating the provisions for provincial assistance, then contained in Part I of the Social Assistance Act, defining its purpose in s. 3 as follows:

> The purpose of the family benefits under this Act is to provide assistance to persons or families in need where the cause of need has become or is likely to be of a prolonged nature.

Section 4(k) of the Family Benefits Act defined a “person in need” for the purposes of the income assistance authorized under the Act as “a person whose monetary requirements for regularly recurring needs determined under the regulations exceed his income as determined under the regulations.”

With the income assistance provisions in Part I of the Social Assistance Act, including income assistance for persons with disabilities, transferred to the Family Benefits Act, the provisions of the Social Assistance Act were left to focus on ‘Municipal Assistance’ which included funding for disability supports services and provincially-funded activity centres, work activity programs, sheltered workshops and sheltered employment.

For the purposes of municipal disability supports services, the definition of “persons in need” remained as it had been: “a person who, by reason of adverse conditions, requires assistance in the form of money, goods or services”. The Social Assistance Act obligated the municipal social services committees established under the Act to “furnish assistance to all persons in need, as defined by the social services committee, who reside in the municipal unit” (s. 9(1)).

These definitions stayed in place until the repeal of the Family Benefits Act in 2001 with the adoption and coming into force of the Employment Support and Income Assistance Act. Throughout this legislative evolution the understanding that needs of persons with disabilities could be addressed in a way that ameliorated disabling conditions and that it was a public welfare responsibility to do so gains more and more solid foundation in the legislation.

With the Social Assistance Act, the Family Benefits Act and the Homes for Special Care Act the legislative pillars of a provincial welfare state response to disability income and support needs, including obligations on municipalities and the province to meet those needs, were firmly established in the period 1958 and beyond. However, the institutional legacy of the poor relief system begun in the 1760s, and still pervasive in the lives of persons with disabilities and the design of services, meant that welfare state response to this group often entrenched an institutional model. The bio-medical lens on disability, which reveals persons as 'defective' in some ways and is used to justify institutionalization and social exclusion, is still very much operative even though elements of a rehabilitation and social model approach begin to appear in law and policy in this period. The consolidation of a provincially-funded and regulated residential facility system through the latter half of the 20th century bears this out, and it resulted in Nova Scotia having among the highest rates of institutionalization of persons with intellectual disabilities in Canada.

Emergence and Support of the Social Model and Individualized Approaches to Disability Supports

Throughout the last few decades of the 20th century there were growing calls in Nova Scotia for deinstitutionalization and individualized community-based supports – effectively to embed a social and human rights model in law and policy. The inclusion of equality rights protections in the *Canadian Charter of Rights and Freedoms* for persons with disabilities reflected the embedding of this approach to disability in the constitutional framework, though it did take a sustained campaign by the disability advocacy community to convince the Prime Minister, cabinet and members of Parliament that the *Charter* should reflect a social and human rights approach to disability.[11]

Several developments in the 1980s and 1990s highlight changing attitudes about people with disabilities, the voice of this community in public policy dialogue, and the convergence of ideas for change among many service providers, academics, professionals and policy officials about the importance of a social model approach.

One platform for helping to consolidate and promote these changing attitudes was arguably the adoption of the 1989 Nova Scotia *Disabled Persons Commission Act*, the purposes of which are:

> (a) provide for the participation of disabled persons in the development of Government policies and programs relating to or affecting disabled persons;

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[11] See Yvonne Peters, From Charity to Equality: Canadians with Disabilities take their Rightful Place in Canada's Constitution. In Deborah Stienstra and Aileen Wight-Felske, eds., *Making Equality: History of Advocacy and Persons with Disabilities in Canada* (Concord, ON: Captus Press, 2003).

(b) establish a central mechanism to ensure that the concerns of disabled persons respecting policy and program development and delivery are conveyed to the appropriate departments of the Government; and
(c) ensure that the concerns of disabled persons will be promoted in and considered by the Government, especially in matters of policy and where the concerns affect several departments of the Government (1989, c. 4, s. 2).

While the Commission's recommendations have no direct policy impact, the purposes of the legislation reflect a public recognition that the voice and concerns of people with disabilities must inform public policy in the province. This is a key element of a social and human rights approach to disability – the full citizenship of people with disabilities requires proactive mechanisms to address their historic disadvantage, including opportunities for their voices to be heard in and to help shape policy development.

Distinct from the Commission's activities and reports, many consultations, reports and position statements throughout this period pointed to the need for a new approach, for example:

- The Mentally Disabled Population of the Halifax County Region: Needs and Directions - A Plan for the Future (Department of Community Services, August, 1989)
    - The Homes for Special Care system and existing policies and programs lead "to a facility/program driven system as opposed to a client/needs driven system" (p. 35). Need for a more individualized approach to planning and providing community-based supports to be more responsive to individual needs.
- Moving Towards Deinstitutionalization: A Discussion Paper (Department of Community Services, February, 1995)
    - Recognizes the community living advocacy for deinstitutionalization, and that the province needs to take steps in this direction. Proposed a policy direction as follows:
      Deinstitutionalization requires the development of community based services for those persons' who are moving from institutions and for those who have similar needs but have remained in the community. These services must be comprehensive enough to provide an acceptable quality of life and allow full community inclusion. (p. 2).
- Report of the Review of Small Options in Nova Scotia (Department of Community Services, April, 1998)
    - Given that community-based alternatives are the preference of people with disabilities, a delivery system is needed that "promotes independence and choice and provides flexibility, while at the same time minimizes structure, intrusiveness, and government intervention" (p. 28).
- Joint Statement of Principles of the Canadian Association for Community Living and People First of Canada (2013):
    - WE, INDIVIDUALLY AND COLLECTIVELY, call on all Governments throughout Canada to take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of their right to full inclusion and participation in the community by:

  - Acknowledging that institutions for persons with disabilities have no place today and placing a moratorium on all admissions to institutions;
  - Affirming that the unjustified segregation of individuals with disabilities is discriminatory, and that the provision of community-based services to persons with disabilities is the most appropriate option;
  - Supporting the right of all people with disabilities to live in the community as equal citizens; and
  - Committing the necessary resources to support the development and provision of quality, comprehensive community-based alternatives to institutional care which ensure adequate supports to people with disabilities and their families and enable people with disabilities to live in the community with choices equal to others.
- Position Statement on Deinstitutionalization of the Nova Scotia Association for Community Living (2010).[12]

These and other reports, public consultations and position statements extending into 2000 and beyond point to some key conclusions:

- Institutionalization is a violation of human rights and with Canada's ratification of the UN CRPD, a comprehensive strategy was needed to close congregate facilities and to support people to live in the community, consistent with obligations under the Article 19 of the CPRD.
- Principles of choice, autonomy and integration and inclusion in the community should guide policy and programs.
- A system of individualized supports that enabled people to become 'valued citizens' in the community, as the 1927 Royal Commission had imagined, were not yet in place. This change was critically important to deliver on emerging policy goals.
- The categorical approach to defining need and placement of individuals in funded facility options was antithetical to an individualized approach to meet income and support needs of people with disabilities.

Misalignment of Public Policy and Public Attitudes in Nova Scotia

Despite some convergence of views in Nova Scotia about the need to change the system consistent with a social and human rights approach to disability, the required policy decisions have not yet been taken. Calls from community and advocacy groups began in the 1980s for an individualized approach to disability-related supports, more consistent with a social and human rights approach to disability. These calls were sustained through 2000 and beyond – for example, the 2001 'Kendrick Report' on community-based options for Nova Scotia[13] and the

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[12] See, for example, Nova Scotia Association for Community Living, Position Paper on Deinstitutionalization (2010), online: https://nsacl.files.wordpress.com/2012/09/nsacl-position-paper-on-deinstitutionalization-december-2010.pdf.

[13] M. J. Kendrick, An Independent Evaluation of the Nova Scotia Community Based Options Community Residential

2013 report of the Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program', *Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program*.[14] However, these calls for changing funding and service delivery have not yet been responded to with needed policy changes. A still largely categorical approach to defining needs appears to be in place, where people are assessed according to need categories (some version of 'Level 1, 2, 3, etc.') and those levels of need are then matched to program options.

This categorical approach appears to be legislatively reinforced with changes to the legislative definition of need in the Employment Support and Income Assistance (ESIA) Act of 2000, which amended the definition in the Social Assistance Act. Up to that point, the definition of need in the Social Assistance Act had clearly and comprehensively stated a social model approach, as: "a person who, by reason of adverse conditions, requires assistance in the form of money, goods or services". The definition reflects the early seeding of a social model in the 1944 Royal Commission Report, as quoted above, to the effect that "Persons should not be forced into institutions… merely because they lack the necessary means to maintain themselves."[15]

Yet, section 22(1) of the ESIA Act of 2000 amended the definition of Social Assistance Act as follows:

> Clause 4(d) of Chapter 432 of the Revised Statutes, 1989, the Social Assistance Act, is repealed and the following clause substituted:
> (d) "person in need" means a person who requires financial assistance to provide for the person in a home for special care or a community based option;

This amendment makes clear that financial assistance for disability-related supports will be provided only for those program options that fall within the parameters set by third parties, including service providers, as authorized by government funding mechanisms, as opposed to a framework that explicitly provides for an individualized approach. Thus, the change could be interpreted as a reversion to a bio-medical approach to disability. The legislation and regulations provide some scope for interpretation and some individualized funding arrangements have been put into place in Nova Scotia since the coming into force of this legislation, but only on a relatively minimal basis. Undoubtedly, the previous definition was applied in policy and programs to refer to a limited set of largely institutional options but it was, nonetheless, more consistent with an individualized approach: "assistance in the form of money, goods or services" and explicitly lent support to program development in the direction away from facility or program based options, unlike the 2000 statutory amendment.

Service System (Halifax: Nova Scotia Department of Community Services, 2001).

[14] Department of Community Services, Choice, Equality and Good Lives in Inclusive Communities: Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program (2013), online: https://novascotia.ca/coms/transformation/docs/Choice_Equality_and_Good_Lives_in_Inclusive_Communities.pdf.

[15] Nova Scotia, *Report on Public Welfare Services*, Volume IV, Nova Scotia Royal Commission on Development and Rehabilitation (Halifax: King's Printer, 1944), para. 195(d).

This definitional restriction parallels the fiscal tightening that started in the mid-1990s with the termination of federal-provincial cost-sharing arrangements for social services under the Canada Assistance Plan. This shift in fiscal federalism corresponded with the Nova Scotia government taking over financing of municipal social services in the mid-1990s. Just at the time that the calls were growing for more individualized and community-based approaches, the province imposed a moratorium on placements in community-based options for persons with disabilities (begun in 1995-1996) resulting in over 1100 persons now on waiting lists for supports – either because they have no supports at all, or because their current placement is inappropriate.[16]

It became clear post 2000 that the institutional model was still deeply embedded in law, policy and the culture of disability in the province, and would remain so. In a 2011 submission to the Standing Committee of Community Services of the Legislative Assembly of Nova Scotia titled "A Place Called Home" the 'Community Homes Act Group' told the Committee:

> *Since 2000, progress on deinstitutionalization in Nova Scotia has stalled. Newfoundland and Labrador had implemented a policy of full deinstitutionalization in 1982 and Ontario closed the last of its large institutions in 2009. While these and most other provinces increased efforts to downsize institutions and offer community-based options, Nova Scotia lacks any current deinstitutionalization commitment.*

The group's brief began with a quote from a staff member of residential services agency about the conditions they observed in a congregate residential facility:

> *I admire the courage of persons with disabilities who get up every morning and withstand the insults, the frustrations, the stares, the rejections and humiliation. For them, life is very challenging. Isn't it the height of injustice that at the end of the day, many of them return to the place they live – the place they call home - only to find another trial to be endured?"*

Providing a few examples of current situations, the report stated, "There are many more examples of people with developmental disabilities whose mental health issues are exacerbated by inappropriate housing."[17]

A 2011 review by Deloitte, Touche on the Braemore Home, mandated by the province after a series of complaints, found the following:

> Based on expert observation, interviews and extensive analysis, it is clear that Braemore's service model is based on an outdated medical model rooted in its history as a hospital-linked service.

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[16] Department of Community Services, Department of Community Services and the Disability Support Program Transformation Update: October 2016 Community Sessions (2016).

[17] Community Homes Action Group, Community Homes Action Group, A Place Called Home, Presentation to the Standing Committee on Community Services, a Legislative Committee to the House of Assembly, Nova Scotia (May 17, 2011).

> In this “culture of care” (custodial) rather than the preferred practice of a “culture of support” (participative living), staff “do for” the people living there. In a culture of support, the people living there do for themselves while the staff support them to participate with as much independence and motivation as possible.
> The difference between these two approaches establishes institutional attitudes, priorities and norms about the participation, quality of life and future for the people who live at Braemore.[18]

This finding reveals the continued tension between a custodial approach – rooted in a longstanding bio-medical perspective on disability – and one that looks to the supports needed to overcome the social, economic, architectural and cultural barriers to people with disabilities participating in society on an equal basis with others, as required under the *Charter* and the CRPD.

Following the release of the Braemore report, discussions with the then Minister of Community Services led to the appointment of the Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program. The Institute for which I am Managing Director was engaged by the government to provide technical support in developing the terms of reference for the committee, facilitating a process for the committee to undertake its work, provide background research, and assist in preparing the analysis and report.

The Committee examined key issues in transforming disability supports to the individualized approach many had been calling for and laid out a ‘Roadmap’ for deinstitutionalization and transitioning to a person-directed and person-centred individual support system for the province. The Department of Community Services issued a 2016 report on progress in implementing those recommendations. It recognizes that one of the major challenges that remains is that residential supports funding for people with disabilities is still tied to the ‘cost of beds’ (a categorical approach to defining needs) and not individual participant support needs.[19]

How then are we to understand the continued misalignment between public attitudes about the place of people with disabilities in society, and the entrenchment of a disadvantaging bio-medical and custodial approach to disability? This tension continues in public policy development despite the obligations to ground disability-related law and public policy on a social model and human rights foundations. Part of the reason appears to be that public attitudes are in fact “ambivalent” as Michael Prince, a leading analyst of disability-related policy in Canada suggests, in his analysis of the findings of the first national survey on Canadians attitudes towards people with disabilities.[20] He quotes from the findings of that survey to show

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[18] Deloitte and Touch LLP, Operational Review of Braemore Home Corporation: Final Report (2011), online: https://novascotia.ca/coms/noteworthy/Braemore_Home_Operational_Review.pdf.

[19] Department of Community Services, Department of Community Services and the Disability Support Program Transformation Update: October 2016 Community Sessions (2016).

[20] See Michael Prince, Pride and prejudice: The ambivalence of Canadian attitudes toward disability and inclusion. (Toronto: Institute for Research and Development on Inclusion and Society, 2009).

that a categorical approach to thinking about disability, clearly informed by bio-medical assumptions, still shapes some attitudes:

> Some argue that it is important for people to become familiar with people who have either physical or mental disabilities. Some argue that class sizes are now larger and that teachers are stretched; integrating children with special needs into classes in the mainstream may compromise the quality of education. Some felt that if there is a way to "categorize" physical and mental disability, then it might be possible to integrate some students with disabilities and to offer special segregated opportunities to others [such as for children with learning and behavioural disabilities]. [21]

Little wonder that a categorical approach is still reflected in public policy and service delivery. Elsewhere, Prince concludes from a comprehensive analysis of the history of disability-related policy and politics in Canada, that people with disabilities are "absent citizens." Gains in embedding a social and human rights in law and policy is not an inevitable, progressive march of history:

> For many persons with disabilities there is a substantial contradiction between political expressions of full citizenship and their personal experiences of social inequality. This contradiction may well be unending given fundamental differences in the interests and power resources […] In fact, the country's record of reform is not a series of progressive measures consistently moving toward higher levels of access and inclusion.[22]

Whether a realignment of power and resources will materialize in Nova Scotia, sufficient to secure the self-determination, equality and full citizenship and inclusion of persons with intellectual and other disabilities who require supports to live with power over their own lives and with dignity in the community, remains to be seen.

That said, it is my opinion, based on my work with the Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program, that were it up to leading community representatives on the Committee[23] the transformation to an individualized system would be well underway. Among this broad cross-section of advocacy and service provider groups, which included representation of the Adult Residential Centres/Regional Residential Centres (ARC/RRC) Association, there was strong commitment to advancing a law, policy and service delivery system fully consistent with a social and human rights approach to disability. This included support for the individualized planning, funding and support arrangements that would be required, as recommended in the *Roadmap* report.

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[21] Environics Research Group, *Canadian Attitudes Toward Disability Issues, A Qualitative Study, Final Report* (2004).

[22] Michael Prince *Absent Citizens: Disability Politics and Policy in Canada* (Toronto: University of Toronto Press, 2009), p. 224-225.

[23] See Appendix A for a list of community representatives and participants, in Department of Community Services, Choice, Equality and Good Lives in Inclusive Communities: Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program (2013), p. 53, online: https://novascotia.ca/coms/transformation/docs/Choice_Equality_and_Good_Lives_in_Inclusive_Communities.pdf.

The report also includes recommendations for community-led mechanisms that would tap and grow the existing capacity of community agencies and organizations to ensure a successful transformation. Community members on the Joint Committee recommended and committed to activating the following mechanisms for this purpose,[24] pending the resources and commitment from the government to proceed. Recommended mechanisms include:

1) ***Legal Capacity and Supported Decision Making Provincial Advisory Group*** – to provide guidance in developing a policy and program framework to advance promotion and protection of the right to legal capacity and supported decision making, and to play the lead role in designing and convening a provincial forum to bring stakeholders together to develop a long-term plan.
2) ***Facility Restructuring Advisory Committees*** (one for each ARC/RRC participating in pilot) – to advise on the restructuring of the facilities in each pilot site, bringing together key stakeholders.
3) ***Residential Services Transformation Advisory Group*** – with representation from both government and service providers to provide input into the transformation of the community-based residential services system, and to establish two Working Groups which would address specific issues related to the transformation:
    (a) ***Waitlist Management Working Group*** – would coordinate response to the waitlist with the introduction of person-directed planning/navigation, the Personal Disability and Family Supports Program, individualized funding, restructuring of facilities, group homes and developmental residences, and activation of the housing strategy.
    (b) ***Crisis Response and Specialized Networks Working Group*** – would guide development of the proposed 'Community-based Networks of Specialized Supports' and address emerging individual cases and system response through the SPD Transformation period.

4) ***Employment Focused Community Action Groups*** (one for each Adult Service Centre participating in pilot) – with representation from the Centre, employers, government, disability community and the employment services system, would guide the pilot initiative to increase access to competitive employment and consider implications for restructuring of Centre programs and community capacity.

The cross-section of shared community commitment to the principles, recommendations and community-based mechanisms to guide transformation is evidence of a strong constituency of community leaders, actors and capacity to implement needed reforms consistent with the social and human rights approach to disability.

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[24] See Department of Community Services, Choice, Equality and Good Lives in Inclusive Communities: Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program (2013), p. 37, online: https://novascotia.ca/coms/transformation/docs/Choice_Equality_and_Good_Lives_in_Inclusive_Communities.pdf.

2. General characteristics of persons who qualify for the Nova Scotia Disability Supports Program (DSP)

> Describe the general characteristics of the group of persons who qualify for the Nova Scotia Disability Supports Program (DSP). Please situate this group of persons with disabilities within the social and historical context of Canadian society. This includes the general characteristics of the group of persons with disabilities who require supports and services to live in the community in terms of their socio-economic status, life expectancy, access to healthcare, education, employment, health, criminalization, vulnerability as victims of abuse and other relevant characteristics.

The Disability Supports Program serves about 5300 children youth and adults, many with intellectual and multiple disabilities, including complex health and behavioural challenges. Many require intensive supports. However, there is a range of need, and evidence from elsewhere indicates that those with even the most complex needs can be supported to living the community and to direct their own lives.

This group faces significant disadvantage in many areas:

Much of the presentation of these statistics is drawn from research I have directed and reports I have prepared drawing on existing sources.[25]

Precarious housing situations:

- The Canadian Association for Community Living estimates that between 100,000 and 120,000 adults with intellectual disabilities face a housing and supports gap.[26] Almost 25,000 Canadians with more significant intellectual disabilities have core housing need.
- Adults with intellectual disabilities are over-represented among the estimated 35,000 homeless population in Canada on any given night. Available evidence points to a much greater likelihood of being homeless than in the general population,[27] with intellectual disability a pre-disposing factor to homelessness and vulnerability for this group;[28]

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[25] Much of the statistical analysis and policy implications in this presentation are drawn from two reports I have contributed to preparing, with many of the sections copied directly, including: IRIS – Institute for Research and Development on Inclusion and Society, *Disability and Inclusion-Based Policy Analysis* (2013), online: https://irisinstitute.files.wordpress.com/2012/01/is-five-190142-iris_disability_inclusive_lens_eng.pdf); IRIS – Institute for Research and Development on Inclusion and Society, et al., Housing Issues for People with Disabilities in Canada. Submitted to The UN Committee on the Rights of Persons with Disabilities For its Review of Canada's initial report under the CRPD (2107), online: http://www.cacl.ca/sites/default/files/Housing%20Issues%20for%20People%20with%20Disabilities%20in%20Canada%20-%20Final%20-%20March%2014%2017.pdf).

[26] Canadian Association for Community Living, My Home My Community (2016), online: http://www.cacl.ca/area/safe-and-inclusive-communities.

[27] For U.S. prevalence study, see P.M. Oakes and R.C. Davies, "Intellectual disability in homeless adults: a prevalence study," *Journal of Intellectual Disability* (December, 2008), 12(4):325-334.

[28] C. Mercier and S. Picard, "Intellectual disability and homelessness," *Journal of Intellectual Disability*

- 13,200 adults with intellectual disabilities aged 30 and older live with their parents because they do not have the resources or community support to live in their own homes. Their families have unsustainable caring responsibilities, are draining life savings and have 'Nowhere to Turn' – as a recent Ombudsman's report names the problem for the estimated 10,000 adults with intellectual disabilities waiting for residential services in Ontario. For too many people with intellectual disabilities, lack of access to housing and supports results in "institutionalization by default".[29]
- Adults with intellectual disabilities are over twice as likely as others to still be living at home with one or more parents, increasingly in situations where senior parents remain the primary support for the adult son or daughter.
- Almost 30,000 adults with intellectual disabilities reside in congregate residential facilities and group homes in Canada, based on their diagnostic label. The clear majority of these are what would be considered in Nova Scotia as small options homes, most with 3-4 individuals with intellectual disabilities living together. In Nova Scotia, the DSP supports about 150 individuals in these arrangements. About 400 are in group homes and developmental residences of 5 'beds' and more, many in residences of 8-10 'beds'. Combined with the almost 1000 persons with significant intellectual and mental health disabilities currently institutionalized in larger facilities in the province – Adult Residential Centres, Regional Rehabilitation Centres, and Residential Care Facilities – these congregate facilities make Nova Scotia the most institutionalized province on a per capita basis in Canada in terms of congregate facilities larger than 3-4 individuals.
- Many want a home of their own but cannot, because of scarcity of affordable housing and of staff support outside the residential facility. There appears to be a re-emergence of these congregate options.[30] While not visibly homeless, this group would be defined as the 'invisible' homeless, people who are denied basic autonomy about their living environment.
- An estimated 10,000 adults with intellectual disabilities under the age of 65 are living in hospitals, nursing homes or long-term care facilities because they cannot get the personal supports and affordable housing they need.
- An estimated additional 60,000 Canadians with mild intellectual disabilities have never been identified in surveys of Canadians with disabilities.[31] Studies of people with

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Research (April 2011), 55(4):441-9).

[29] Ombudsman of Ontario, Paul Dube, Nowhere to Turn. Final Report. Investigation into the Ministry of Community and Social Services' response to situations of crisis involving adults with developmental disabilities (2016), online: https://www.ombudsman.on.ca/Files/sitemedia/Documents/NTT-Final-EN-w-cover.pdf.

[30] See Housing Study Group (Developmental Services Sector – Ontario Ministry of Community and Social Services Partnership Table), *Ending the Wait: An Action Agenda to Address the Housing Crisis Confronting Ontario Adults with Developmental Disabilities* (2013), online: http://www.dsontario.ca/news/ending-the-wait/.

[31] Statistics Canada and Employment and Social Development Canada are aware that the disability surveys conducted to date have done well in capturing adults with moderate and severe disabilities but miss many adults with mild disabilities. To improve coverage, these two departments have joined forces with academics and the disability community through a 'Technical Advisory Group' and have developed a strategy that will better capture ALL Canadians who experience barriers because they have limitations in their activities related to a health problem or disability-related condition.

intellectual disabilities on a global level point to an estimated 1% to 3% of population having mild to severe intellectual disability, which equates to 0.3–1.0 million in Canada.

Income, Employment and Supports:

- The employment rate for working-age adults with an intellectual disability is only one-third of the employment rate of people without a disability (25.5% compared to 75.5%).
- The average income for working age persons with an intellectual disability who are working is less than half of that of Canadians without a disability.
- Significant numbers of adults with intellectual disabilities remain enrolled in segregated day programs/workshops.
- In many provinces and territories, on-the job support (such as co-worker support) is often of insufficient duration to enable a successful transition to and maintenance of long-term employment.
- More than 30% of people with intellectual disabilities report unmet need for help.
- People with intellectual disabilities report that current systems of support are too often rigid and unresponsive to their individual needs.

Personal Choices, Health Care Status, Security and Safety:

- Slightly more than half of people with an intellectual disability report they make none or only some of the decisions about their everyday activities.
- Almost half (47%) of the Canadian public is “not very” or “not at all” comfortable being around people with intellectual disabilities.
- People with intellectual and cognitive disabilities:
    - face among the highest rates of physical and sexual abuse in communities across Canada – four times more likely to be victims of violence than the general population.
    - are more than twice as likely as their non-disabled counterparts to be living in inadequate housing;
    - have a 75% poverty rate, among those who are not living with family members.
- People with intellectual disabilities are three-to-four times more likely to die preventable deaths than the general population.

3. What is an Institution and how does it differ from Community Living

As noted in the final report I assisted in preparing on “Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program”:

> *Within and across jurisdictions there are often differing definitions and understandings of what constitutes ‘an institution’ or ‘institutional care’. For the purposes of the Nova Scotia transformation process, an institution will not be defined by size (i.e. the number of residents) but rather as any residential care where:*
>
> - *residents are isolated from the broader community and/or compelled to live together;*

- *residents do not have sufficient control over their lives and over decisions which affect them; and*
- *the requirements of the organization itself tend to take precedence over the residents' individualized needs.*

In the Canadian context, People First of Canada and the Canadian Association for Community Living define an institution as "*any place in which people who have been labeled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise control over their lives and their day to day decisions. An institution is not defined merely by its size*" (www.institutionwatch.ca).

The ways in which these institutional environments differ from living in the community, can best be characterized by three main criteria, as identified in Article 19 of the UN CRPD, on 'Living Independently and Being Included in the Community':

> *States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:*
>
> *a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*
>
> *b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*
>
> *c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

For the almost 1,500 persons with intellectual and other disabilities in congregate care facilities (including group homes and developmental residences) in Nova Scotia, in my opinion, these criteria are not being met. Based on stereotype, stigma and lack of access to needed disability supports, these individuals are denied choice, opportunity for social and economic inclusion and experience pervasive deprivation of their liberty. This is all because they lack an entitlement to the supports needed to meet their disability-related needs – despite the commitment of Nova Scotia to meet these needs under its policy goals and its statutory commitments and obligations to persons with disabilities.

4. Impacts of Institutionalization and Deinstitutionalization

Explain the impacts of being placed in an institution for participants of the DSP program as well as the phenomenon known as "institutionalization" including if relevant the physical, mental, health, and developmental effects of living in an institution. What experiences do those same DSP participants who are placed in institutions lose that they would otherwise experience if they lived in the community, with reference to the following circumstances:

a. people with disabilities who require supports and services to live in the community who reside in institutions;
b. people with disabilities who require supports and service to live in the community, who reside in the community in the absence of appropriate supports and services (e.g., including those living with family or independently);

a) People with disabilities who require supports and services to live in the community who reside in institutions:

People are institutionalized in residential facilities for persons with disabilities, and increasingly in nursing homes for the aged, for a wide range of reasons. The group of individuals who are institutionalized have varying needs for supports. The rationale for institutionalization is that the nature of the disability is so complex, or of such a level of severity, that the specialist services of an institutional environment are the only way to meet a person's needs effectively and safely. This assumption belies a stereotype, not borne out by the research evidence as noted below and as such profoundly disadvantages this group because of the deprivation of liberty and social and economic exclusion that results from institutionalization.

The disadvantage, discrimination and deprivation that comes with being confined to institutions has been exposed through various studies and reports:

- The 1927 and the 1944 Nova Scotia Royal Commissions, cited above, spoke of the appalling conditions in institutional facilities that housed persons with disabilities in the province.
- While physical conditions of facilities would have improved since then, the basic problem of crowding and lack of choice remain. For example, a 2009 review of the conditions of the 50 bed Adult Residential Centre 'Riverview Home Corporation' found the following:

> *The issue of space, overcrowding and the lack of privacy for clients was central to many of the discussions held with staff. The staff particularly noted the lack of an adequate number of bathroom facilities for the number of clients on most Units… Staff noted that the frustration clients often feel as a result of the crowded conditions and lack of quiet, private space is quite apparent. The staff stated that*

> *they consider these conditions as a significant factor in conflict between clients and the on-going behavioral difficulties that many individual clients experience.*[32]

- For the past almost 50 years there has been a sustained body of work about the abysmal conditions in institutional facilities in Nova Scotia and across Canada.
- As community services and supports began to demonstrate success in supporting people with very complex needs as early as the 1970's, and with the adoption of anti-discrimination and human rights laws in Canada in the 1980's, the movement for deinstitutionalization grew among parents and professionals. With the shift to a social and human rights understanding of disability, the demonstrated success of community supports, and a profound transformation in the statutory human rights framework in Canada at both the provincial and federal level in the 1980's, most governments increasingly came to see deinstitutionalization of people with intellectual and other disabilities as public policy in the public interest.

b) People with disabilities who require supports and service to live in the community, who reside in the community in the absence of appropriate supports and services (e.g., including those living with family or independently):

This group faces significant disadvantage and discrimination because they lack needed income and supports:[33]

- ***Disproportionately in 'core housing need' –*** Over 13% of the population in Canada has a disability – over 4 million people. Over 400,000 adults with more significant disabilities have "core housing need", the standard Canadian federal definition of deficient housing affordability, quality, and/or adequacy. We estimate there is a larger group than this because current national surveys are not capturing people with milder disabilities.[34]
- ***More likely to be homeless –*** On any given night in Canada, about 35, 000 people are homeless or living in shelters, and an on annual basis there are 235,000 homeless

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[32] Report on Riverview Home Corporation. Prepared for Department of Community Services: Services for Persons with Disabilities (December 2009).

[33] Much of the statistical analysis and policy implications are drawn from a report I have contributed to preparing, with many of the sections copied directly, IRIS – Institute for Research and Development on Inclusion and Society, et al., Housing Issues for People with Disabilities in Canada. Submitted to The UN Committee on the Rights of Persons with Disabilities For its Review of Canada's initial report under the CRPD (March 2017), online: http://www.cacl.ca/sites/default/files/Housing%20Issues%20for%20People%20with%20Disabilities%20in%20Canada%20-%20Final%20-%20March%2014%2017.pdf.

[34] Statistics Canada and Employment and Social Development Canada are aware that the disability surveys conducted to date have done well in capturing adults with moderate and severe disabilities but miss many adults with mild disabilities. To improve coverage, these two departments have joined forces with academics and the disability community through a 'Technical Advisory Group' and have developed a strategy that will better capture ALL Canadians who experience barriers because they have limitations in their activities related to a health problem or disability-related condition.

Canadians.[35] It has been estimated that 45% of the homeless population are people with disabilities or living with diagnosed mental health conditions.

- ***Experiencing higher rate of poverty*** – Many people with disabilities face difficulty maintaining steady employment, especially better-paid jobs. Among working-age adults with disabilities the rate of poverty is twice as high as for Canadians without disabilities (20% vs. 10%).
- ***Facing constrained housing options –*** Affordable housing prices, tenure options, and locations are all more restricted at lower incomes:[36] Over 30% of adults with disabilities live in rental housing. Almost 45% of this group live on low incomes compared to 25% of renters without disabilities. Among lone parents, people with disabilities are much more likely than people without disabilities to have low income (34% vs.20%).
- ***Discriminated against –*** People with low or irregular income and especially recipients of social assistance, all of whom are disproportionately disabled, often face discriminatory screening-out practices by landlords, related to both disability and ability to pay.[37] Disability is often a barrier to obtaining housing and sustaining stable residency. Many landlords discriminate based on certain disabilities,[38] including evictions for disability-related behaviours and failure to accommodate disability-related needs.
- ***Disadvantaged in compounded ways: disability discrimination plus racialized status –*** There is well-documented discrimination in rental housing markets based on racialized status. African Canadian renters indicate negative stereotypes are often encountered, "such as that African Canadian tenants are more likely to be involved with drugs or be violent and that racialized people are dirty." [39] When layered with disability stereotypes racialized minorities face even more barriers.
- ***Living in unstable housing situations –*** People with low income and high rent/income ratios are at higher risk of rent arrears and consequent eviction. They are more likely to be subsequently screened out based on such tenancy records.[40] If landlord disputes arise, certain disabilities may create a disadvantage in dealing with them.[41]
- ***Without adequate supports and accessible housing options –*** People with physical disabilities often require accessibility features that are not available in many properties; people with psychosocial or intellectual disabilities often require a support worker to help them meet tenancy obligations, but too few are available. Available stock, openings (turnover), and the locations of social and supportive housing are far more limited than

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[35] S. Gaetz et al., *The State of Homelessness in Canada 2016* (Canadian Observatory on Homelessness, 2016), 12.

[36] W. Grigsby et al., "The Dynamics of Neighborhood Change and Decline" *Progress in Planning* (1987) 28:1-76.; G. Suttor, *Rental Housing Dynamics and Lower-Income Neighborhoods in Canada* (Research Paper 235, Neighborhood Change Research Partnership, University of Toronto, 2015), 26-27; Ontario Human Rights Commission [OHRC], *Minds that Matter* (2012) 45.

[37] OHRC, *Minds that Matter*, 54; Sylvia Novac et al., *Housing Discrimination in Canada: The State of Knowledge* (Ottawa: Canada Mortgage and Housing Corporation, 2002).

[38] OHRC, *Minds that Matter*, 52-53.

[39] See for example, Ontario Human Rights Commission, *Right at Home: Report on the consultation on human rights and rental housing in Ontario* (2008), online: http://www.ohrc.on.ca/en/right-home-report-consultation-human-rights-and-rental-housing-ontario.

[40] OHRC, *Minds that Matter*, 52.

[41] OHRC, *Minds that Matter*, 56.

for private-sector rental.[42] Only 19% of people with disabilities living in low-income households report receiving all of the support they need with everyday activities. Social housing access policies can also put people with disabilities at a disadvantage.[43]

- ***Living in sub-standard housing*** – The factors above result in people with disabilities more often living in poorly maintained rental housing,[44] or housing of other low quality or space, e.g. rented rooms, and in neighbourhoods with disadvantages. Among people with low income, 16% of those with disabilities live in housing in need of major repairs, compared with 10% of those without disabilities.
- ***Experience difficulty exiting from homelessness –*** The scarcity of supportive housing makes it difficult to exit from homelessness. Limited funding constrains providers in meeting their duty to accommodate, e.g. paying for support staff or physical modifications.[45]

5. Whether all persons with intellectual disabilities are capable of living in the community, assuming appropriate supports and services are available

People with intellectual and other disabilities have been placed in institutional facilities based on a pervasive understanding that the needs of individuals, their limited potential for normal development, and the 'burden' that care would impose on families and communities left few or no other options. My research and that of others points to many key findings from research on deinstitutionalization. Regardless of level of disability, people with intellectual disabilities who move from institutional facilities to live in the community benefit substantially. Research I have undertaken on deinstitutionalization in Canada[46] points to positive outcomes for individuals in five main areas, regardless of severity of disability:

(a) Self-determination, health and well-being
(b) Personal relationships
(c) Access to needed supports
(d) Educational and economic integration
(e) Community access and participation.[47]

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[42] Suttor, *Rental Housing Dynamics*, 32-33.

[43] OHRC, *Minds that Matter*, 48.

[44] OHRC, *Minds that Matter*, 45.

[45] OHRC, *Minds that Matter*, 57.

[46] I played the role of principal researcher in two major studies on deinstitutionalization in Canada that together focused on deinstitutionalization efforts in 6 provinces: The Right Futures Project: Final Evaluation Report" (Toronto: Roeher Institute, 1998); and Towards Inclusion: National Evaluation of Deinstitutionalization Initiatives (Toronto: Roeher Institute, 1999). Other research I have conducted focuses on community support needs and services for people with a range of intellectual and other disabilities, who have lived in institutional facilities and/or the community.

[47] See James W Conroy, *Deinstitutionalization of People with Mental Retardation and Developmental Disabilities in the United States: Was This Good Social Policy?* (Havertown, Pa: Center for Outcome Analysis, 2002).

In general, this research supports the findings of extensive research on deinstitutionalization in the US that finds that the four main reasons given for keeping individuals in institutional facilities (severe intellectual disability, medical fragility and complex health needs, challenging behaviour, and advanced age) are unsupported by any general body of evidence.

Self-Determination, Health and Well-Being

- Research in health promotion points to the positive relationship between health status and self-determination (defined as having one's autonomy respected, having a vision or plan for one's life, and the resources and opportunities to pursue that plan). My research, using a self-reported health status scale (like those in large-scale health status surveys used by Statistics Canada), confirms this for people with intellectual disabilities who have been deinstitutionalized. For people with more profound disabilities the health status report was filled in by a family member or support worker.
- My research on deinstitutionalization, as well as my research on individualized approaches to planning, funding, and supporting individuals in the community[48] all point to improvements in several individual capacities – communication, behaviour, often agility/mobility – that come with 1) deinstitutionalization, and 2) individualized approaches based on individual needs, strengths, vision, and accountability of support staff to individuals.
- Findings drawn from both qualitative research I have conducted, and relatively small survey samples, are confirmed by much larger-scale research conducted in the US by James Conroy, an internationally renowned researcher on deinstitutionalization, and others. Research in the US indicates that individuals identified as 'severely' or 'profoundly' disabled show the greatest gains in "adaptive behaviour" (conceptual, communication, social, and practical life skills) after moving from institutions to the community. Some of the larger, longitudinal studies in the US have been undertaken as integral elements of court-ordered deinstitutionalization. I believe the findings from US studies are generalizable to the Canadian context because individuals move from similar institutional facilities to similar kinds of community options in this province.
- The deinstitutionalization process is key in helping to foster a sense of self-determination by providing the opportunity for individualized planning before an individual leaves the institution, and ensuring that resources are in place to deliver on the identified needs in the plan. Experience with deinstitutionalization in Canada and the US point to the importance of individualized planning processes for assuring effective outcomes in the community. Planning tools and approaches to create individualized, future-oriented plans have been developed to assist people with

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[48] The Roeher Institute, *The Power to Choose: An Examination of Service Brokerage and Individualized Funding as Implemented by the Community Living Society* (1991); *Family-Driven Networks of Support: Evaluation Report* (1996); *Evaluation of The Choices Project in Thunder Bay, Ontario* (1997); *Individualized Quality of Life Project: Final Report* (2000).

mild, moderate, and more severe disabilities move to the community with needed supports.

- There remain many issues to address in assuring adequate health planning and community supports for people with disabilities and more complex health needs. Concerns have been raised that the health status of individuals with intellectual disabilities moving from institutional to community facilities will be placed at greater risk and face a higher risk of mortality as a result. However, findings of the study using data from California, on which this claim has been made, have been systematically refuted by researchers in the field.[49]
- Despite some research showing either status quo or improvements in health status after moving to the community for most individuals, even for those with more profound disabilities and complex needs, there remain concerns about whether people with intellectual disabilities can obtain health care they need in the community. I have undertaken research with Dr. Daune MacGregor, Paediatric Neurologist at the Toronto Hospital for Sick Children, and Dr. Yves Talbot, Program Director of the Department of Family and Community Medicine, Mount Sinai Hospital in Toronto, that outlines a health planning model that addresses many of these concerns (*Health Care Planning Innovations Project Report*, The Roeher Institute, 1996). It is reasonable to expect that a similar model would be put into place in service agencies and communities where individuals currently living in institutions in Ontario would move. As part of its deinstitutionalization strategy, the Ontario government put into place a specialized health care network to support people with complex behavioural and health needs to live in the community (see http://www.community-networks.ca/.)

Personal Relationships

- My research on deinstitutionalization and on forming intentional personal networks for individuals living in the community point to 1) positive changes in attitudes of families, staff and the general community that come with more individualized community supports; and 2) the importance of personal relationships for improvements in adaptive behaviour. Both family and community members who were initially resistant to deinstitutionalization and community living change their views once individuals move to the community. Because of effective individual planning and placement, family members often begin to see the individual and their potential in a new light. Positive support grows as family and community members get to know the individual and begin to imagine a future for them in the community. Positive attitudes increase as families and community members witness the often-dramatic improvements in individuals' skills and capacities after they move to the community.
- Research has found that intentional building of personal networks of families and friends to assist in ongoing individual planning, building connections to the broader community, and providing opportunities for inter-personal relationships and caring,

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[49] K.C. Lakin, "Observations on the California Mortality Studies", *Mental Retardation* (1999) 36, 395-400.

contribute positively to individual health and well-being even for people with complex needs, and possibly especially so. Research has found that support networks address the social isolation of individuals, the major factor that leaves individuals with developmental disabilities vulnerable to violence and abuse in both institutional facilities and the community (See John Lord and Alison Pedlar, *Life in the Community: Four Years After the Closure of an Institution*, 1990. This is also a major finding of a study of The Roeher Institute on violence against people with disabilities, a study I participated in designing and that was published at The Institute when I was employed there as Senior Researcher.[50] Other research cited in this study points to the high risk of violence for people with disabilities living in institutional facilities.

Access to Needed Supports

- One of the major changes for people with intellectual disabilities who move from institutions to the community is access to individualized planning supports as part of the deinstitutionalization process. Every major deinstitutionalization effort in Ontario and across Canada in the past 30 years has focused on providing individuals in the institution with access to planning supports. This support assists an individual and family to think about an individual's possibilities and future in the community, for some for the first time in their lives. This vision or life plan provides a context for making decisions about the kinds of supports and services an individual will need to live in the community. My research has shown the critical importance for successful outcomes of having such a planning process in place. Follow-up research on deinstitutionalization of individuals moving from the Tranquille facility in BC similarly shows the importance of an individual planning process that begins in the institution and is ongoing, to identify and respond to changing individual needs and circumstances.
- Research has shown how individual planning processes can identify a range of support needs – daily living support, communication supports, behavioural intervention and supports, vocational supports. Research also shows that for many individuals – often those who require the most intensive supports when they first move to the community – the need for formal, paid supports declines as individuals develop new capacities and community supports develop. For example, the national study of deinstitutionalization and the evaluation of The Right Futures deinstitutionalization initiative in Newfoundland show that over the first year after deinstitutionalization intensity of supports was reduced for 30% of individuals (e.g., two-to-one supports reduced to one-to-one; intensive behavioural supports reduced to respite supports for caregivers; or paid support staff reduced as individuals obtain unpaid supports of others, such as on the job co-workers, family, friends, other community members who include individuals in community activities).

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[50] The Roeher Institute, *Harm's Way: The Many Faces of Violence and Abuse against Persons with Disabilities* (1995).

- Research indicates that there are issues that need to be addressed about community living arrangements established for post-institutional care, including high turnover of staff and challenges in arranging needed health care and other services. US research points to similar findings and to the need to address ongoing community service issues. However, these are not insurmountable challenges. Funding has been allocated to individuals moving from institutional facilities, which has provided funding security for purchase of needed supports. As well, while the national deinstitutionalization evaluation showed high turnover of staff in many situations, the evidence still points to successful outcomes and the building of lasting relationships with families and community members. US research cited in this report points to similar findings and to the need to address ongoing community service issues. If we are to be guided by the evidence on outcomes, the fact that there are challenges needing to be addressed does not in and of itself provide a rationale for retaining individuals with complex needs in institutions.

Educational and Economic Integration

- Deinstitutionalization is associated with greater opportunities for educational and economic opportunities. In the research I conducted, over 50% of men, and just over 20% of women, became involved in some form of education/training, volunteer work, or paid employment. These were opportunities that most individuals had not had access to while living in the institutional facility. Many barriers persist to more equal gender participation, and to expanding opportunities. Other research I have conducted on employment shows that people with severe disabilities can participate in education, training and employment with adequate supports.[51] Living in the community is the first step in gaining access to these opportunities for most individuals with intellectual disabilities.

Community Access and Participation

- Increased access to community life is a major outcome of deinstitutionalization for individuals with disabilities across the range of severity. National research I conducted showed that over 80% of individuals deinstitutionalized regularly attended community facilities, gatherings or events with “some,” “several,” or “lots” of opportunities to contribute to and/or be involved in their community. About 25% of individuals increased their contact over the first year after deinstitutionalization. This level of community access contributed to overall improvement in community attitudes and personal growth and well-being. Individuals do, nonetheless, face barriers to greater participation – ongoing need for greater funding, inaccessible community facilities, lack of transportation, and negative attitudes based on disability being key barriers.

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[51] The Roeher Institute, *On Target? Canada’s Employment-Related Programs for Persons with Disabilities* (1993).

Conclusion

The evidence and analysis I provide in this report leads me to some main conclusions in response to the five questions I examined:

1. Prevailing societal attitudes and how these have changed over time
2. General characteristics of persons who qualify for the Nova Scotia Disability Supports Program (DSP)
3. What an Institution is and how it differs from Community Living
4. Impacts of institutionalization and deinstitutionalization
5. Whether all persons with intellectual disabilities are capable of living in the community, assuming appropriate supports and services are available.

First, the bio-medical, habilitation/rehabilitation and social/human rights approaches to disability, which have been used as a framework to track and analyse the development of law and policy in jurisdictions in Canada and internationally, can be usefully applied to the Nova Scotia context. There are clear threads of each model in attitudes, law, policy and practice, beginning with the adoption of the Poor Law into Nova Scotia in the 18th century. As in other jurisdictions, there is a unique evolution of these approaches in the province. In Nova Scotia, the Royal Commissions of 1927 and 1944 articulated in public policy recommendations, and reference to public attitudes of the time, an emerging recognition of people with intellectual and other disabilities as having potential to be 'valued citizens', deserving of training opportunities, and of services needed to live in the community.

Pillars of the welfare state in Nova Scotia – Social Assistance, Family Benefits/Income Assistance, Homes for Special Care – were designed to some extent on these changing perspectives, but were also heavily indebted to their poor law predecessor. The institutional legacy from that earlier era, combined with the deeply entrenched bio-medicalization of disability beginning in the 18th and 19th centuries remains firmly rooted in Nova Scotia, even as new pathways come to light through the lens of the social and human rights approach. This is evident as recent reviews of facilities in Nova Scotia show – a custodial culture in the system, stigmatization, over-crowding, lack of choice. Overall, the system is driven by categorical approaches to defining need, matching those assessments with constrained residential options and reliance on congregate care facilities.

Second, the tensions between these three approaches now concurrently operating in Nova Scotia helps to explain the conflicts, misalignment and 'ambivalence' in public attitudes and public policies. As Michael Prince, quoted in this report, suggests the tensions in advancing a social and human rights, citizenship-focused, approach to disability services and supports are not new. They appear at the provincial and federal levels throughout history in the Canadian context. However, the fact that ambivalences exist in public attitudes, or that these models can now be found to be operating concurrently in the policy, program and service delivery framework for disability services and supports, continue to impede full community inclusion. The social and human rights model is not just another 'approach' to designing the system. Its purpose is to reveal the ways in which disabling barriers are produced and human rights are violated based on a deficit-based approach to disability. The norms underlying the UN CRPD in its purposes and provisions, and human rights and equality rights legislation in Canada direct that deficit-based accounts of disability can no longer be permitted to serve as barriers for community living and inclusion.

Third, in applying a social and human rights lens to the current context, it becomes clear that the disability supports system in Nova Scotia is broken and has been for a long time. People, especially with unmet disability-related needs, many of them complex, and many families are suffering profoundly as a result. There are some excellent examples of person-centred support approaches in Nova Scotia, meeting the needs of people with complex disabilities in ways that enable their citizenship and community inclusion, but they remain a small minority. Far too many individuals currently supported by the Disability Supports Program, and the growing numbers on waitlists, daily have their rights to citizenship and inclusion denied. Many are forced to live in unsafe situations not of their choosing and are left without the basic supports they require for daily living that measures up to any reasonable benchmark of dignity and self-determination.

Fourth, as the research referenced in this report shows, the 'reasons' for keeping the 'status quo' – a largely facility-based system, with some individualized social model approaches on the margins – are not borne out in the evidence but perpetuate stigmatizing and stereotypical views regarding people with disabilities. People with even the most challenging needs can be supported to live more independently in the community, able to have power over their lives. This is possible when the investments and instruments are put into place to deliver person-directed planning and develop responsive community-based supports. Individuals who at first are considered unable to function beyond the facility, actually develop new skills and capacities. People seen as unable to have friends or connections in the community, develop new relationships. Families who were reluctant prior to deinstitutionalization, become solid supporters. Neighbors and others who encounter individuals change their minds.

Fifth, the Joint Government-Community 'Roadmap' process and outputs makes abundantly clear that there is a clarity of purpose among those community leaders and organizations most invested in the system, including representative organizations of people with disabilities and their families. The mechanisms for building community capacity to deliver on the ambitious goals and steps needed to shed Nova Scotia of its poor law and institutional history have been thought out and agreed upon. They have yet to be sufficiently activated for a real transformation of the system to take place.

It is my conclusion that until the needed steps are taken to fully transform the existing system, including the steps anticipated in the 'Roadmap' report, unmet need, social isolation, violent victimization, preventable deaths, entrenched poverty, homelessness, lack of opportunity and a perpetuating stigma will pervade the lives of many, many Nova Scotians with disabilities, especially those with intellectual disabilities and more complex needs. As the Royal Commissions of the first part of the 20th century began to see, and as those bringing a social and human rights lens to this issue in Nova Scotia in the 1980s and beyond have acutely perceived – these outcomes are not inevitable. They are the consequences not of an inherent and often projected 'deficit' of a person, but of the legal, policy and program frameworks designed and implemented through public authorization. As such, they can be changed.

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