

Community Homes Action Group

presentation to

the Standing Committee on Community Services, a Legislative Committee to the House of Assembly, Nova Scotia

A Place Called Home

“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?”

-- A Residential Services Agency Administrator

Introduction

Community Homes Action Group is a group of concerned citizens, health care professionals, parents and advocates who have come together to draw attention to the crisis in residential options for persons with developmental disabilities and to work with the provincial government to find solutions. We have grave concerns about the quantity, quality and range of residential options available for this population.

We are concerned with what appears to be the lack of urgency attached to meeting the needs of a vulnerable segment of our population waiting for residential options with the Services for Persons with Disabilities (SPD) program of the Department of Community Services.

Over 650 individuals out of a population of approximately 5000 persons¹ with developmental disabilities are on waiting lists for services. Many of them are living in near-crisis situations while waiting for appropriate residential placements. Many others are living in types of supportive housing unsuitable for their needs and detrimental to their health.

There are serious systemic problems in our residential services program identified in the 2008 Report of Residential Services commissioned by the Department of Community Services as well as in the more recent Auditor General’s Report of November, 2010.

¹Department of Community Services evidence, Public Accounts Committee, February 2, 2011

The wait list challenges and system failures identified in these reports are having a severe impact on hundreds of vulnerable adults and children and their families.

The public discourse about persons with disabilities too often swings between heart-warming anecdotes and disturbing stories of abuse and neglect. We want to frame this conversation around the challenges every individual with developmental disabilities along with their family faces in determining the site and the nature of the place they call “home.”

These are also the challenges we face together, as a community, and as political representatives, government departments and service providers in addressing the pressing need for appropriate residential options for this population.

The System

The Services for Persons with Disabilities program provides residential and other supports to over 5000 Nova Scotians, including about 1000 children under 19 years of age. Those presently receiving services include individuals with developmental (intellectual) disabilities, individuals with dual diagnosis, individuals with long-term mental illness and individuals with physical disabilities.

The current system of services and supports for persons with disabilities includes a range of community-based options – Small Option Homes, Direct Family Support, Alternative Family Support and Independent Living Support. Residential Care Facilities (RCF), Group Homes, Developmental Residences, Adult Residential Centres (ARC) and Regional Rehabilitation Centres (RRC) are categorized as Long Term Care.

In 1996, the provincial government assumed responsibility for residential and vocational services for persons with disabilities (physical, intellectual and long-term mental illness) from the municipalities across the province.² The Department, in response to the deinstitutionalization movement, began the process of closing large institutional residences for persons with disabilities, including the Children’s Training Centres, the Halifax County Regional Rehabilitation Centre and Scotia Adult Residential Centre.

Prior to that, municipalities operated residential institutions for persons with disabilities. The origins of some of the institutions taken over by the province can be traced back to the late 19th century poor houses and asylums, those “dumping grounds for human misery”³ where no distinction was made among poverty, mental illness and mental disability. For example, the Riverview Residential Centre in Riverton, Pictou country, was originally the Pictou County Poor House, built in 1886 (the current centre was built as a stand-alone asylum in 1922).

² Report of Residential Services, June, 2008

³ “Poverty, Poor Houses and Private Philanthropy”, tracing history of poor relief in Nova Scotia from 1749 to 1996,” Communications Nova Scotia, 1996

In the early 1970s, with the closure of the Mountain View institution in Kings County, Nova Scotia was in the lead nationally in providing community supports to the most significantly-disabled persons. As Dr. Michael Kendrick stated in his report to the province in January, 2001, “it is notable that...the number of people in Nova Scotia residential institutions has declined from 1200 in 1985 to slightly more than half as much. The trend is consistent with international patterns.”⁴ Under municipal guidance, group homes and small option homes (three residents or less) replaced institutional settings.

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. Despite the recent closure of two institutions (Halifax County Regional Rehabilitation Centre and Scotia Adult Residential Centre), the data suggest a decrease of 49 persons in Adult Residential Centres and an increase of 51 persons in Regional Rehabilitation Centres, with a net result of negligible change in deinstitutionalization efforts over the last six years. (See Table 1.)

Table 1: Numbers of Residents in Adult Residential Centres and Regional Rehabilitation Centres in Nova Scotia (2004 vs. 2010)

Nova Scotia Institutions	2004	2010	Changes
Adult Residential Centres	525	476	-49
Regional Rehabilitation Centres	135	186	+51
Total	660	662	+2

In the mid-1990s, the provincial government implemented a moratorium on the development of small option homes, with the result that the number of individuals living in small option homes has declined. Between 2004 and 2010, the number of small option homes declined 11% and the number of persons accommodated in those homes has fallen by 8%. At the same time, the number of adults receiving residential supports has grown 29%, with almost all of this growth in the categories of Alternative Family Support and Direct Family Support.⁵ The Alternative Family Support Program supports individuals with disabilities in approved, private homes. The Direct Family Support (DFS) Program provides funding to enable families to purchase respite services in order to assist them in caring for family members with a disability at home. While the Direct Family Support Program provides short-term relief for families, the level of support is rarely sufficient to fully meet the needs of the individuals receiving the support or the needs of their families. Moreover, the burden of finding, training, and supervising respite providers typically resides with the family. The Direct Family Support Program

⁴ Michael Kendrick, An Independent Evaluation of the Nova Scotia Community Based Options Community Residential Service System

⁵ Department of Community Services business plans/statements of mandate

does not provide a long-term solution for exhausted aging parents eager to have their offspring settled in the community before they pass on.

In 2004, DCS provided Residential Support Services to about 3,160 individuals.⁶ The following table, based on public information from DCS, provides a comparison of residential supports by type and clients for 2004 and 2010.

Table 2. Clients by type of residential support for 2004 and 2010

Type of support	2004	2010	Changes
Alternative Family Support	75	200	+125
Independent Living Support	650	711	+61
Small Option homes	675	621	-54
Community Residence	150	n/a	
Direct Family Support	n/a	900 (est)	
Total CBO	1550	2432 (est)	
Adult Residential Centres	525	476	-49
Regional Rehab	135	186	+51
Residential Care	575	471	-104
Group Home/ Dev. Res.	375	506	131
Total Licensed Options	1610	1639	29
Grand total	3160	4071	

As the table shows, the growth in clients is overwhelmingly in the Direct Family Support program which largely funds young adults who are living with their parents/guardians. If that program is excluded, the number of clients increases only slightly, from 3,160 in 2004 to 3,171 in 2010, indicating that only 11 individuals with disabilities have transitioned into residential options over the last 6 years. In addition, there are approximately 1000 children receiving Direct Family Support or Alternative Family Support through the SPD program.

The UN Convention on Rights of Persons with Disabilities

The UN Convention on Rights of Persons with Disabilities was ratified by all provinces and the Government of Canada in March, 2010. Article 19 states:

- 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 obligated to live in a particular living arrangement;*

⁶ DCS, « Renewing the Community Supports for Adults Program, » 2004

- b. *Persons with disabilities have access to a range of in-home, residential and community support services, including personal assistance necessary to support living and inclusion in the community; and*
- 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.*

The Problems

The province of Nova Scotia is a long way from meeting the goals set out in Article 19 in the UN Convention. The Report of Residential Services, 2008 (The Report), commissioned by the Department of Community Services, stated that limitations on residential services for persons with disabilities in our province had reached a critical point and needed to be addressed.

Some of the many serious concerns outlined in The Report include:

- The system is “grid-locked.” Individuals supported by the SPD Program stay with the program for long periods, many for a lifetime. The lack of capacity means that individuals tend to remain where they are even if the type of setting is no longer appropriate to their support needs.
- Residential Care Facilities (RCF) are designated as Home for many persons with disabilities who would be most appropriately supported in the independent living support programs or in group homes.
- No standards other than licensing requirements are in place for Residential Care Facilities.
- Inconsistencies exist across the province in infrastructure maintenance, in the availability of social, vocational and recreational opportunities as well as bedroom and common area furnishings and aesthetics.
- Residential resources are inequitably distributed. In the regions with larger numbers of Adult Residential Centres and higher Residential Care capacity, fewer Group Homes and Developmental Residences have been established.
- Due to a lack of capacity within the system, some designated respite beds are being utilized for long-term residential support rather than the intended purpose of respite.
- A gap in services exists between the current Independent Living Support (ILS) program and the residential program.

There are serious gaps in the levels of support offered. For example, the Report notes there exists a gap in service for those individuals who need more than 21 hours per week

of support, but less than the 24/7 residential option. To date those gaps have not been filled.

When a vacancy for a residential placement comes up, frequently it is granted to an individual in crisis and there is little opportunity to appropriately match the needs and wishes of the individual with what space is available.

A number of individuals are supported in their family home with funding for respite and for transportation but, in many cases, trained respite care providers are not available and transport services are limited.⁷

The report also states the design of the current residential infrastructure is not conducive to an aging population. Adding urgency to the situation is the research that has shown dementia occurs 20 to 30 years earlier in persons with Downs Syndrome than in other populations. The required core competencies for staff are not directed at providing supports for the frail and elderly. A reconfiguration of staff with a new skill set mix will be required to support an aging population.

Since the 2008 Report, the number of clients requiring services continues to increase. With overall general health and medical care improvements, those with developmental disabilities are living longer. More adolescents with developmental disabilities are growing into adulthood and into the adult-based system of care. As well, there are more Nova Scotians with Autism and more very premature infants surviving at increased risk for developmental disabilities.

The system has not kept up with the population nor has it anticipated its residential needs for the future. There is already a significant number of families of adolescents and young adults on the waiting list for residential placements. The lack of planning, this gridlock, and these waiting lists are having profound effects on this population as they deal with the stress of inappropriate placement and uncertainty.

Many individuals are experiencing social isolation and enduring increasing behavioural and mental health issues while waiting for appropriate supports and placements. A senior administrator of one of the region's largest residential housing agencies traces the population's decreased mental health to the waitlists and inflexibility in the system which does not allow people to move to appropriate housing when their needs change.

The Report on the Riverview Residential Centre released in December 2009⁸, further underlined the serious problems within the system. Riverview Residential Centre is one of the province's Regional Rehabilitation Centres and is "Home" to 96 individuals with intellectual, physical and cognitive disabilities and individuals with chronic mental illness. The Report was commissioned after 22 reported incidents of abuse at the facility.

⁷ Hutchinson, P., Bryson, S., Harvey, V., LeBlanc, D., MacRea, A., McFadyen, S., Amit, H., Creating Respite Solutions for Nova Scotia Families with Chronically High Needs Children/Adult Children, 2010

⁸ Report on Riverview Home Corporation; prepared for Department of Community Services, Services for Persons with Disabilities, December 2009, prepared by: Review Team. Pgs. 6-7

The facility faces “aging infrastructure, lack of both human and capital resources, incidents of client abuse, inadequate financial management and deficient governance and control practices.” The Report listed many inappropriate examples of living situations. In one unit in the 88 year-old building, 24 residents were sharing four bathrooms. The Report states: “It was observed that bathroom areas on the units do not have doors but a curtain hanging in the doorway,” and “Frustration clients often feel as a result of the crowded conditions and lack of quiet, private space, is quite apparent.”

Our concern must always be with the people living in such facilities which are their “Homes.” What is the impact of living on crowded wards, with no privacy, no programming, no quiet, and with overworked staff? Certainly, aggressive behaviour is one expected outcome. And what are the effects on staff?

The People

Dr. Mary Tomlinson is a psychiatrist working specifically with persons with developmental disabilities within the SPD program. Dr. Tomlinson sees first hand the impact of appropriate or inappropriate residential options on vulnerable individuals.

Dr. Tomlinson has provided the following examples of persons living in inappropriate situations. Their names have been changed for reasons of confidentiality.

- Betty, 46, lives in what the Department of Community Services calls a regional rehabilitation centre. Betty has a moderate developmental delay and autism. She hates noises and mess. However, she lives on a noisy floor with people who interfere with her belongings and drive her into a frenzy. Betty needs a quiet place to live. She needs consistent staff that understands her. Betty would benefit from living in a quiet small option home.
- Lucy, mid 50's, is supported by the Department in their Direct Family Support Program. Lucy has a dual-diagnosis. Lucy lived with her mother until she died and then was sent to live with her brother and sister-in-law, where she shares a bedroom with their grandchildren when they come to stay. Lucy has no vocational or recreational supports during the day. She is lonely and needs a place she can call home which is not full of angry resentful relatives.
- Joe, 27, lives in a small option home run by a for-profit agency. He is young and verbal. The staff takes away his books and tapes and toys for “bad” behaviour, which includes being rude to his roommates or staff and throwing things. Joe attends a vocational program, but his only recreational activity is a movie once a week and TV. In his previous placement, he attended Special Olympics and dances. Joe is bored, lonely and frustrated. The staff has no training in dealing with persons with developmental disabilities. They just see him as badly-behaved and want to put him on medication.

- Mona would be very well-suited to a specialized small option home. Mona has mild developmental delay and is profoundly deaf. She went to the School for the Deaf and knows sign language. She lived in her family home until her mother died and Mona was temporarily placed in a specialized small options home for deaf people. Mona loved it there and behaved well but there was no room for her. Instead she was sent to a group home where neither staff nor residents knew sign language. The placement failed and Mona was sent to a Regional Rehabilitation Centre 500 kilometres away. Mona has since been able to move back into the small option home after a death of one of the residents. Unfortunately, this seems to be the main source of movement in this gridlocked system.

There are many more examples of people with developmental disabilities whose mental health issues are exacerbated by inappropriate housing.

One Residential services agency administrator reflects, “I admire the courage of persons with developmental disabilities who get up every morning and withstand the insults, the frustrations, the stares, the rejections and the humiliations. For them, life is very challenging. Isn’t it the height of injustice that at the end of the day, many of them have to return to the place they live - the place they call home - only to find another trial to be endured?”

We wholeheartedly agree. The challenge now is to make sure the many persons on waiting lists and living in inappropriate settings can be afforded their rights laid out in the UN Convention on the Rights of Persons with Disabilities.

The Way Forward

Community Homes Action Group believes a continuum of residential housing options is required to meet the wide range of needs of this population. The objective should be to have each individual with a developmental disability living within the least restrictive residence within their community appropriate to their assessed needs. We are prepared to continue to commit our energy and our expertise to government initiatives in this direction.

In consultation with individuals with disabilities, families, and communities, the Government of Nova Scotia needs to develop a sustainable plan to provide client-centered, least-intrusive residential options in our community.

Best Practices: The Housing for Adults with Intellectual Disabilities Research Report (CMHC, 2006) collected information via interviews and focus groups in Victoria, Ottawa and Halifax and provided some analysis. The Report stated that overall the “current system which provides housing for adults outside their family home is geared to meeting the needs of the system rather than those individuals it is meant to serve. Too

often, individuals are housed where space is available, rather than in residences suited to their specific needs.”

We agree with the Report’s assertion that an approach that allows and promotes flexibility and choice is the **best practice**. The Report defines the housing options available throughout Canada. Using a person/family-centred philosophy, in which people with intellectual disabilities or their advocates are directly involved in planning and choosing housing support services, the funding is tied to the individual rather than to an agency or facility. External licensing bodies or accreditors would ensure that the best practice model standards are instituted and maintained. Further discussion is warranted and required to establish what these best practice standards must be, given the current evidence.

In the 18 months since the fall of 2009, members of CHAG met several times with the Minister of Community Services and representatives from Services for Persons with Disabilities at the Department of Community Services. We recognize efforts are being made to address waiting lists for services. Recent announcements to expand the Independent Living Support and the Alternative Family Support Programs will assist a small percentage of the population. DCS has also developed a new assessment and information gathering system. Changes to The Homes for Special Care Act (Bill 65) in May, 2010 are intended to increase government oversight and accountability of service providers for their actions. The recent legislation, “Protection of People in Care”, extends the licensing of small option homes. However, the licensing process deals primarily with safety and physical residential qualities. The Department is following up on the Auditor-General’s recommendations but plans to spread its response over the next three years.

Given the urgent and immediate issues facing many individuals and their families, this is not soon enough. Government needs to move forward immediately with an action plan to increase the quantity, quality and range of residential options for persons with developmental disabilities. Many steps can be taken without additional resources, and others through redirection of expenditures. Budgeting, however, requires acknowledgements that present services are not reaching all in need and the total numbers of persons with developmental disabilities continue to increase.

The principles outlined by the 2008 Report of Residential Services would be an excellent guide to inform that plan. These principles are:

1. **Fostering Independence and Self-reliance.** (Ensure placement is directed at the least intrusive environment appropriate to the individual’s assessed need.)
2. **Building on Community Inclusiveness.** (Support persons with disabilities in a community where they can participate in meaningful life experiences.)
3. **Person-Centred Planning.** (Individuals should live in a home where the care is based on their needs, not the needs or deficiencies of the system)

4. **Working Collaboratively.** (Recognize the shared responsibility for continuing care between the Department of Community Services and the Departments of Health, Education, Justice, Health Prevention and Promotion, as well as the poorly-supported volunteer sector.)
5. **Developing a Sustainable and Equitable Range of Supports.**
6. **Becoming Accountable and Transparent and Maintaining Open Communications.** (Strengthen accreditation and staff support programs. Providers need to be held accountable for the outcomes achieved with public dollars.)
7. **Accessing Research and Best Practices to Guide Development.**

For a plan to be effective, government must provide leadership and resources and training that address issues of quality, governance and policy formulation. An action plan must also:

1. Involve family members and guardians on all residential services boards.
2. Explore flexible arrangements to enable families to create their own residential options.
3. Establish clear standards of care with monitoring and enforcement mechanisms.
4. Move from licensing to an accreditation process. (Standards of care which address staff training, board governance and family participation in decision making and care plans would further improve quality of life assessment in residential facilities and are available in newly-released accreditation processes of Accreditation Canada.)
5. Improve the flow of reliable information to ensure policy decisions are based on sound evidence.

It is past time for real **leadership** and for **action** to be taken to meet the residential needs of this extremely vulnerable population of persons with developmental disabilities. It is time *the place they call home* provides them with a healthy and safe residence, staffed by care-givers who are well-prepared in the skills required, overseen by boards of directors that are accountable to the government, and located within local communities that reach out to them and a province that shows it fully includes its most vulnerable constituents.

Respectfully submitted by the Community Homes Action Group on May 17, 2011:

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