

COMMUNITY HOMES ACTION GROUP
and
NOVA SCOTIA ASSOCIATION OF COMMUNITY LIVING
Joint Presentation to
The Standing Committee on Community Services,
a Legislative Committee to the House of Assembly, Nova Scotia
February 11th, 2014

“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” (Article 19).

- The United Nation’s Convention on the Rights of Persons with Disabilities

Introduction

Good afternoon. It’s a great pleasure to be here. My name is Wendy Lill and I’m here with Dr. Brian Hennen, co-chair of Community Homes Action Group (I’m the other co-chair). I’m the mother of a wonderful young man with Downs Syndrome who has guided my journey of disability advocacy for 28 years. Dr. Hennen is a family physician working to educate medical professionals around developmental disabilities. He is also a researcher on developmental disabilities internationally, nationally and provincially and he’ll be sharing some of his insights today. We’re joined by Jean Coleman, the Executive Director of Nova Scotia Association of Community Living, whose mandate is to build a just and inclusive Nova Scotia for thirty thousand individuals with intellectual disabilities and their families one community at a time.

Community Homes Action Group is a volunteer coalition of healthcare professionals, parents and advocates who came together four years ago to draw attention to the crisis in residential options for persons with developmental disabilities and to work with the provincial government to find solutions. Almost three years ago, to this day, we presented to this committee about our concerns. We are happy to be back here today, along with Jean Coleman, to talk about what we see as the possibility of real progress on this front with the development of the landmark document ***CHOICE, EQUALITY AND GOOD LIVES IN INCLUSIVE COMMUNITIES*** – A Roadmap for Transforming Nova Scotia Services to Persons with Disabilities. We want to begin by saying that we are heartened that the new Minister of Community Services has publicly endorsed this Transformation Roadmap as the way forward for the new government. We are here today to tell you about it, tell you about its importance and ask for your assistance in making it a reality. From now on, for the purposes of simplicity, we’ll just refer to the Roadmap Document.

First of all, what is it? The Roadmap Document is the product of a government-community advisory committee process, created by the previous government in the spring of 2013 to develop a roadmap for transformation of the Nova Scotia Services to Persons with Disabilities Program (SPD) guided by the UN Convention on the Rights of Persons with Disabilities. The process was tasked to address the widespread concern that our SPD system is broken, costly, providing very poor outcomes and falling far behind other provinces in terms of deinstitutionalization and meeting the basic human rights of our most vulnerable citizens. The roadmap was developed based on commitments of the Government of Nova Scotia to *reshape the system of supports for persons with disabilities by moving beyond the institutional model to a person-centered, community based approach.*

Both Jean Coleman and I were part of the community-government advisory team that created the Roadmap document and I think we'd both agree it was an unforgettable experience. Some very oppositional folks, who don't usually agree on much, came together over a four-month period and reached a surprising level of consensus. Representatives from the disability community, People First, front-line workers, service-deliverers and government officials all agreed on ten issues that needed tackling. We agreed on 3 fundamental goals to guide the work. We agreed on ten recommendations to bring about the transformation of services for persons with disabilities in this province, as well as a timetable for action. First I'll turn the floor over to Brian Hennen and Jean Coleman to talk about the population involved and the issues they're facing.

The People, the Issues

Dr. Brian Hennen: Good afternoon.

A few facts. Over 1100 Nova Scotians live in large, congregate care facilities, a disproportionate reliance on institutions than other Canadian jurisdictions. Funds continue to be spent on such facilities when we know we're getting less for the buck than if it were spent on supported community living. At the turn of the century NS had begun shutting Children's Training Centres and within the next 10 years the Halifax county Regional Rehabilitation Centre was closed. A moratorium on small options homes was instigated and still remains and we're stalled, falling behind other jurisdictions.

Meanwhile, the number of adults needing residential supports has grown with nearly 1000 on waiting lists for Special Program for Disability services. Family physician and nursing colleagues and I have run a weekly assessment clinic for adults with DD for over 3 yrs now and we are struck by the uncertainties they have about their homes, among other concerns about transportation difficulties, not having meaningful jobs and having limited social interactions. Most are capable of greater independence with appropriate supports. They are eager to live in an apartment, a foster home, a small options home, a small group home...a home offering comfort, safety and social interaction.

My research colleague, Professor Deborah Norris and grad student, Katie McTeirnan, from MSVU are present today and ready to answer questions. Their NSRF – funded research with the Intellectual Disabilities Service Needs Research Alliance over the past 5 years has completed comprehensive assessments of 147 adults with DD from the central and northern regions of NS....each was asked over 98 questions including qualitative ones....their answers revealed that half do not have a specific diagnosis or don't know if they do, 16 had Down Syndrome, 10 Autism, 6 each had Cerebral Palsy, learning disabilities and mental illness. In our presentation 3 years ago to this committee, you'll read that Mary Tomlinson, a consultant Psychiatrist, reported that 1/3 of patients referred to her for Psychiatric management did not have mental illness but showed challenging behaviours, caused or made worse by the situation they were living in. A senior residential housing administrator recently traced 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. Only 50% in Dr. Norris' research cohort see friends or family as often as they'd like. 41% live in private households, 24% in small options homes, 13% in licensed group homes. But their preferences are for living at home with a friend, relative or partner; being on their own; or living with a known caregiver or staff person.

A one day Ottawa think tank I attended concluded that family members who provide care at home to their loved ones with a disability suffer from poorer health..... due to physical and mental health stress.

A year ago a joint committee of CDHA & IWK made recommendations for improving the transition of children with chronic conditions into the adult system of care. The report "Transition of Medical Care from Youth to Adulthood: The Challenge for Capital Health and IWK" is available. I want to make one point out of that discussion. The committee had a prestigious membership...senior VP's, medical and nursing administrators, clinical department head. Let me read two sentences. " The committee quickly came to agreement that transition for youth with developmental/intellectual disability requires particular consideration. Theirs is the largest group of chronic conditions affecting children into adulthood (46% of visits) and support for this population is frequently very complex because of the severity of disability and/or co-morbidities." Coming to consensus in a few minutes, eighteen seasoned health professionals acknowledged that this population comprising the largest group of all youth with chronic conditions, requires particular attention.

Finally, Developmental Disability (Intellectual Developmental Disorder) involves both intellectual impairment and impairment in functional skills such as activities of daily living, both being evident before usual development is completed. About 1/3 have co-existing Autism Spectrum Disorder. In turn, Autism Spectrum Disorder is a neurodevelopmental condition characterized by difficulties in social interaction and communication with rigid or repetitive behaviours usually apparent by age 3.

The media, in recent months, has reported parents' concerns about delays in getting rid of inappropriate placements of Nova Scotians with DD who have complex needs. Many, with limited or no verbal language, communicate their physical and mental distress through their behaviours. Such behaviours ought to be recognized as a means of expressing distress for individuals with impairments in developmental maturation, social interaction and communication. Such behaviours ought not be categorized or treated as criminal! Thank you.

Jean Coleman: Following up on Dr. Hennen's remarks, in my role as Executive Director at NSACL, I too am very familiar with the frustration facing families as they try to navigate the system. We receive many calls from parents throughout the province who are looking for community residential and vocational options for their sons and daughters. What we have presently in the province is not working. Young people want to choose with whom and where they live and they need the right supports to do this. The Roadmap calls for focusing vocational programs on getting people into the labour force with job coaches and other forms of supported employment. Individuals with an intellectual disability want to work alongside their classmates, family and friends. That is why the Roadmap is so critical to individuals and their families. It is the first sign of HOPE that they will not be segregated, warehoused in an institution or in a vocational center but will be able to live in community with an opportunity to have a good quality of life like everyone else.

The Transformation Plan

The work of the Advisory Committee had to begin with the key issues facing people with disabilities, their families, service providers and the broader community in advancing supported living in inclusive communities. There are three major goals to guide the transformation of the SPD program are:

1. Greater self-direction, choice and control by people with disabilities and their families
2. Modernized delivery system for supports and services to advance social and economic inclusion
3. Increased capacity and involvement of generic community systems in enabling inclusion

To achieve these three goals and address the key issues that must be confronted, a ten-point transformation plan for the SPD program was designed with the following elements and recommendations.

- 1. Person Directed Planning Navigation...**so when someone needs to plan for his or her future it will be about what his or her dreams are, where they want to work and where he or she wants to live and with whom. This is all about what the person with a disability wants.

- 2. Individualized Personal Disability and Family Supports.** We need to establish a ‘Disability Supports’ Program that collapses the existing maze of programs into one that provides a straightforward path to what is needed when it is needed.
- 3. Individualized Funding Mechanism;** So when a person receives the support and funding they need, the funding goes to them not an organization and they have control over whom he hire to receive the services they need.
- 4. Equal Recognition of Legal Capacity and Supported Decision Making.** Often it is assumed that people with disabilities do not have the capacity to make decisions, sometimes they may need help from loved ones or trusted friends but they CAN make decisions with the proper supports. What I have been told is that people just wish to be included in decisions that may have a huge impact on their lives.
- 5. Reduced Reliance on Large Institutional Facilities.** Nova Scotia has the most people with disabilities living in institutions per capita in Canada. Not one person in over 35 years since I have worked in this field has ever said to me “Jean I want to live in an institution!” We need to stop admitting people to institutional like settings and find a way to support people in community. This has been done in many other provinces across the country, let alone around the world.
- 6. Transformed Community-based Residential Service System**
When people get to choose where and with whom they live and are able to hire the service provider it is going to change the way we do business in Nova Scotia. This is good because it will be all about choice. Service providers will just learn how to support people differently
- 7. Increased Access to Competitive Employment.** Vocational centers will find creative ways as will Employers to hire and support people to work for full pay in community rather than in segregated settings. Some people may not be able to work full time, maybe a few hours a day but whatever amount they can work they will receive minimum wage. People with intellectual disabilities often live below the poverty line.
- 8. Equal Access to Housing.** There must be an investment in people rather than buildings. We need available housing options that are accessible, affordable and individual with proper supports. Many people live in places that are not safe with high criminal activity and therefore they are at risk because they have so little to spend on housing.
- 9. Comprehensive Community-based Networks of Specialized Support.** People with complex needs or behavioral needs have limited options from living in community, often they are placed in institutions or nursing homes, and we need a community based system of specialized care services that can be provided to individuals in their own homes.

10. Coordinated and Integrated Disability and Mainstream Community Services. We need to develop community capacity for social and economic inclusion of people with disabilities and their families.

The Way Forward

We are fully aware that the Roadmap for change will require substantial investment beginning now in 2014-15. We see this as a transformative investment that will lead to the creation of a sustainable cost-effective system of supports. The research we have reviewed suggests cost effectiveness and savings will result in a number of areas, including: reduced reliance on congregate facilities; increased use of generic community services; tapping the resources of the housing market and Nova Scotia Housing Strategy, reduced reliance on high-cost, acute care services as a result of maximizing supported living in the community. There will also be savings to social assistance and increased personal tax revenue from increased labour force participation of persons with disabilities.

Although we feel hopeful with the creation of this Roadmap Document, we can't overstate the urgency of moving forward with it immediately. It's time to move from words on a page to real action. The crisis continues for thousands of Nova Scotians.

We need to see immediate action in the following areas:

- A substantial commitment in the upcoming budget for implementing the first steps of the Roadmap, including:
 - establishment of an Implementation Team to start rolling out the plan
 - start work on person-directed planning
 - start investing in families by increasing the amounts available to families to create community living options
 - announcement of a date for moratorium on admissions to institutional residential settings.
 - Commitment to new, professionally-supervised community-based approaches to crisis situations

In closing, the work ahead is enormous. It will require visionary leadership, steadfast commitment and resolute determination over the upcoming years and we need commitment from our elected leaders. In order to turn this around, we'll need government, community service providers, mainstream community systems and disability organizations all working together to create the fundamental changes needed if we are going to move the quality of lives of people with disabilities closer to that enjoyed by the rest of society.

We urge you all to throw your hearts and voices and energy into this process of change. Together we can create better lives for our most vulnerable citizens.

Thank you for your time and we welcome questions.

Respectfully submitted by the Community Homes Action Group: Wendy Lill (co-chair), Dr. Brian Hennen, (co-chair), Lois Miller, Sherry Costa, Dr. Ken Deal, Daniel Graham, Dr. Paula Hutchinson, Dr. Sarah Shea, Nancy Walker, Dawn LeBlanc and Dr. Susan Bryson and Jean Coleman, on behalf of **Nova Scotia Association of Community Living**, February 11, 2014