

Putting People First

Working Together to Support
Independence and Dignity

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Introduction

Most of us take the ability to live independently for granted. We expect to have our choices and preferences taken into account as part of our daily lives. But for some Nova Scotians, that's not always the case. They must rely on a system that doesn't always offer the support needed to live independently, to live well. We want to change that. We want the system that offers supports and services to these individuals to be focused on their needs, and the needs of their families.

Change begins with understanding—and we begin with a look at our current system. Almost 40,000 Nova Scotians, who are aging, or have mental or physical disabilities—including fragile infants, children and youth—rely on the services provided by the Continuing Care (CC) branch of the Department of Health and Wellness (DHW)—in conjunction with District Health Authorities (DHA)—and the Services for Persons with Disabilities Program (SPD) of the Department of Community Services (DCS).

Individuals who need ongoing health and other care outside the hospital, either on a long-term or short term basis access services through Continuing Care. This branch provides assessment, home care, long term care (in a nursing home or residential care facility) and protection for vulnerable adults. These services are provided by staff at the District Health Authorities or through contracted service providers.

Children, youth and adults with intellectual disabilities, mental illness and or physical disabilities are served through Services for Persons with Disabilities. The program provides support and funding for individuals and families including Direct Family Support, Independent Living Supports, Alternative Family Support, Residential placements and Adult Day programs.

While many people are satisfied with the services provided, for others, accessing these services can be challenging and confusing.

Programs and services were developed separately over many years across the two departments. That's one of the reasons why some inconsistencies exist. For example, needs assessments are handled differently, and therefore, needs are met differently. Service delivery can be at cross purposes given the varying mandates, philosophies, operating policies and the fact that administration and funding are dually managed by both departments. Not surprisingly, services can be fragmented. As a result, there are gaps in the system, which leads to gaps in

supports and services. While many individuals are receiving exemplary services, for others in need, options are limited and services are lacking. There simply aren't enough choices being offered for individuals in need at all age levels.

We know we can do better.

The current system for persons with disabilities was developed when most residential care facilities were based on a custodial/paternalistic or medical model. Despite the downsizing and closures of many large residential care facilities, insufficient attention has been paid to expanding community supports.

An individual's potential level of independence, preferences, goals and aspirations are not always considered when their needs are assessed. Individuals are sometimes assessed against available services, based on their presentation (symptoms and behaviours) rather than the supports required to improve independence within inclusive communities. For others, there are no services to meet their specific needs or there's confusion over what is required and what is available.

Nova Scotians deserve more options and choices.

A Fragmented System

We know the system can—and should—be more responsive in meeting the needs of seniors and persons with disabilities, especially those with complicated needs. It also needs to be more responsive to the needs of unpaid family/friend caregivers who are often stretched beyond capacity.

Additional challenges are faced by individuals with complicated needs, which exceed or fall outside the programs offered by either department (there are an estimated 10 to 12 new cases each year). At present there is no service option that addresses their multidimensional support needs. A collaborative approach with appropriate resources and expertise is required to facilitate community living.

These individuals may have an acquired brain injury, a cognitive or intellectual disability, mental illness—or combination of these. Behaviour may place them or others at potential risk of harm. To ensure there is dignity and respect for these individuals and their families, appropriate responses to their unique needs must be available. Today's system lacks the capacity and flexibility to effectively respond to their need for behaviour support and/or treatment.

Both departments have a shared responsibility to develop and fund a support plan for people with complex needs. In some cases, specialized expertise or skills are needed to safely and appropriately support these individuals. The resulting costs can be high, some in excess of \$150,000 per year, per person with varied results. There is a need then, to increase system capacity to offer a broad and flexible range of services, while creating efficiencies, enhancing sustainability and creating supportive, inclusive communities.

Approximately 280 people are waiting for SPD residential services. Many are in hospital—some for as long as two or more years—even though they don't need acute medical or psychiatric care at that level. Others are waiting at home, being supported by family members or aging parents who may have their own health care needs. Lack of capacity and choice in the system often leads to emergency placements that are inappropriate. This means that some people receive more intensive supports than necessary or desired. Though the cost of such supports may be higher, these intensive services and supports do not guarantee improved health and social outcomes.

The Case for Change

To date, Nova Scotia has placed a very high emphasis on out-of-home, residential or institutional placements or institutional services. We have one of the highest ratios of nursing home beds to population in the country, (for those over 75). In fact, our ratio is 20 per cent above the national average. In 2011-12, the province funded 7,693 beds in long-term care facilities at a cost of \$445 million.

The number of seniors in Nova Scotia over the age of 75 is projected to almost double between 2010 and 2036. Currently, the wait lists for residential services in both departments are unacceptably long. For example, 2,400 seniors are waiting an average of five to six months for an appropriate placement. The wait is costly, from a social, economic and human perspective.

In the past year, the wait-list for a DHW long-term care placement has steadily increased, despite the construction of almost 1,000 additional new beds (an increase of about 15 per cent). As well, more than one-fifth of those have assessments indicating they may not require the high level of care provided in a nursing home. Rather, they could remain at home if the appropriate level of home care and caregiver support were provided.

Nova Scotia is more likely, compared to other jurisdictions in Canada, to support people with disabilities in large residential settings. In fact, the Canadian Association for Community Living notes that Nova Scotia has the highest number of institutions in the country. Services tend to focus on behavioural and physical support needs rather than social supports, or an individual's preferences, goals and aspirations. This is not consistent with the expectation of persons with disabilities or their families and is contrary to community inclusion.

Some individuals with mental illness or a disability are in hospital beds while they wait for a vacancy in a more appropriate setting, some for as long as two years or more. Since hospital care is far more expensive, the financial burden on the system is greater. It can also mean that Nova Scotians in need of acute care cannot access a bed, leading to higher use of emergency services and lengthier wait lists for some treatments, further taxing the system.

Almost 300 people are waiting for an initial placement, some for years. More than 600 individuals are waiting for a change in their placement or service that would better suit their needs. And, demand is increasing.

There's an increased prevalence of people with disabilities from the baby boom generation now being cared for by aging parents. Life expectancy has increased, there are lower mortality rates and increased survival rates of infants with severe and complicated disabilities. We have seen increases in the number of individuals diagnosed with autism spectrum disorder, Alzheimer's or some other form of dementia and those with dual diagnosis.

A more coordinated approach between the departments of Health and Wellness, Community Services and the District Health Authorities/IWK would make the system easier to navigate. A clear and consistent vision for case management would also make it easier for individuals and families to access services. It would also help to close the gaps and ease the transition when moving from one program or service to another.

Through greater collaboration, we can create a more person-focused system. We can target resources strategically, building a more sustainable future.

Today, approximately \$945 million is spent each year by the two departments on continuing care and services for persons with disabilities. When the province's considerable budget and fiscal pressures are taken into account, the case for change becomes even more critical. Without new approaches focused on efficiency and better outcomes for Nova Scotians, costs will escalate rapidly over the next 20 years. An aging population, fewer people in the workforce, high rates of disability and chronic disease, outdated facilities, and a shrinking pool of caregivers will add additional pressures requiring significant funding.

We know the current system must change. We have already begun the transition.

Providing Better Care Sooner

A major innovation in both long-term care and services for persons with disabilities has been the paradigm shift to a system that supports community inclusion and away from the roots of the outdated, paternalistic, medical model. This approach encourages independence, learning, self-determination and fosters rights, options, choice and most importantly, respect.

Enhanced case management, advances in treatment, technology and scopes of practice could make it possible to offer people the support they need to stay at home and in their communities.

A number of changes have been made to provide seniors and persons with disabilities options to stay in their homes and communities longer. It's part of government's plan to provide Better Care Sooner, which recognizes the importance of person-focused care, close to home, to achieve improved health and social outcomes.

In the last budget, an additional \$22 million was invested in Continuing Care to provide more home-care supports. Investments have been made to cut the wait list within the Capital District Health Authority, ensuring those needing home care services will receive faster, more responsive services. Funds have also gone to expanding and enhancing a number of programs, like the Caregiver Benefit Program—which is doubling to \$250,000 over the next two years. It offers financial support to more low income care recipients who have a high level of disability or impairment. More people can access the \$400 monthly caregivers allowance bringing the total to 1,200. Personal income tax reductions averaging \$75 annually are being returned to 20,000 people with disabilities, or those who have a dependent with a disability.

With an additional investment of \$1.5 million in 2011-12, Community Services improved access to supports for persons with disabilities by:

- Expanding the Independent Living and Alternative Family Support programs to enable people with disabilities to live as independently as possible
- Expanding access to day programs to individuals with disabilities exiting the public school system
- Creating more spaces in day programs offering persons with disabilities opportunities for supportive employment, skills training and vocational programs, including those with complicated needs

- Implementing new income guidelines for the Direct Family Support for Children program so more families in need are able to access the program
- Developing a new support program for families caring for a family member in their home who has very high and complicated care needs

Other programs offer additional options for seniors and their families.

The *Personal Alert Assistance Program* provides financial assistance to low income seniors who live alone, receive publicly funded home care services, and who have experienced recent falls, use a cane, walker or wheelchair for the purchase of a personal alert assistance service.

A total of 44 respite beds are now available around the province in long term care facilities.

More seniors now qualify for the Senior Citizens Assistance Program with an increase in eligibility limits, meaning more seniors can stay at home longer with some home modifications.

There is also work underway through two major provincial strategies to ensure cross departmental collaboration and a person-focused approach to addressing the needs of some of Nova Scotia's most vulnerable citizens.

Nova Scotia's first mental health and addictions strategy, *Together We Can*, released in May 2012, recommended safe and affordable housing options be developed for Nova Scotians with mental health and addictions issues. A new housing strategy is being developed to do exactly that. Working together, we also want to help people age in place, living in inclusive communities with the ongoing support needed to help them with daily living. Using appropriate planning and design, hub-based support services can be developed to serve a wide range of individuals with varying support needs. Done well, these services could increase community living, enable people to live more independently, and ensure services are available to the person where they live rather than moving people to services. Costs could be reduced through more efficient service delivery, expanding the capacity to reach more citizens. A collaborative, coordinated approach across departments, the IWK and District Health Authorities can, and will, better serve Nova Scotians.

We are making progress but there is still work to do.

Reshaping the System

Vision

Nova Scotians will enjoy good lives of their choosing in inclusive and welcoming communities.

Guiding Principles

Person-focused— Individuals and their families will be treated with dignity and respect. Services and supports are responsive to the unique needs, life circumstances and stated goals and preferences of the individual and in the case of infants and children, their families.

Ability-focused—Nova Scotians will have services and supports designed to promote and enhance the individual's abilities towards self-determination, independence and community inclusion.

Independence-focused—The individual has the right to maximize self-reliance, including the attainment of gainful employment to help them forge meaningful roles in their communities and society. Supports and services will respect self-determination and the direction of one's own affairs without interference.

Home and Community Oriented—Individuals will have community based services and supports enabling them to remain living in their homes and communities rather than in residential, long-term or institutional based facilities.

Accessible—All Nova Scotians, regardless of age, social, cultural or economic circumstances will have access to services and supports, which should be coordinated, ideally, through a single entry point.

Responsive—An individual's changing needs or circumstances will be met by a flexible and responsive system of services and supports.

Sustainable—Resources will be invested strategically to ensure quality services and improved outcomes across the lifespan. New initiatives, programs or services will be accompanied by a business case to protect the ability of future generations to meet their own needs.

Accountable—Services and supports provided will encompass the obligation to report, explain and be answerable for results and program outcomes.

Socially Inclusive—The diversity of all Nova Scotians’ will be recognized and respected. Services and supports will promote social inclusion and stronger communities.

How do we get there?

Objective

Adopt a person-focused approach

- Collaborate with individuals and their families to develop a support plan that responds to the persons’ unique needs and circumstances across the lifespan
- Promote individuals’ abilities, independence and dignity
- Encourage and support the individual to lead decision making
- Offer a wider, more-varied range of supports and services
- Increase emphasis on providing effective services in the individual’s home, or in the community.
- Shift to comprehensive, proactive case management geared to the individual’s needs
- Better integrate services with primary health care, including family physicians to enhance early identification of mental and physical health needs, addictions, crisis prevention and chronic disease management
- Ensure the right mix, number and skill set of providers to support the growing population of those needing assistance
- Foster and create inclusive communities that support and respect people

Objective

Enhance and Expand Home and Community Based Services

- Expand, continue enhancing existing programs including Home Care, Direct Family Support, Independent Living Support, Alternative Family Support and Home Sharing Programs
- Offer supportive, affordable and accessible models of housing
- Expand and enhance adult day programs
- Ensure programs are socially inclusive
- Improve coordination between other levels of government offering supported employment/training
- Offer enhanced caregiver support to relieve stress, acknowledge contributions
- Increase educational and other support options to caregivers, assess needs more frequently
- Enable clients to arrange their own home support services through the flexible use of funding
- Expand the range and options for respite services
- Provide education, training and support to enable home care workers to fulfill the total mandate of the program by providing home care to those living with a mental illness and/or addiction

Objective

Reduce Reliance on Institution-Based Care

- Create diverse housing and support models that enable people to live and fully participate in inclusive communities
- Restructure, over several years, Adult Residential Centres and Residential Care Facilities by creating diverse housing and support models that enable people to live in inclusive communities
- Restructure, over several years, Regional Rehabilitation Centres to community based housing options linked to dedicated Centres of Excellence and supported by virtual care teams and networks of community and specialty supports
- Shift the focus of programs and supports offered to persons of any age from institutions to home/community-based supports
- Enhance home based supports to facilitate discharge from hospital to home rather than directly into nursing homes

Objective

Improve Integration and Coordination of CC and SPD programs

- Establish a harmonized, single entry point to the system
- Adopt a common suite of needs-assessment tools
- Improve the process to address the needs of individuals with complex needs, and those with mental health issues
- Improve and enhance joint decision making on services/ placements for shared clients
- Standardize and harmonize policies where appropriate
- Establish joint training for staff on key and shared issues such as case management, assessment, mental illness, addictions, aging, disability, communication, positive behaviour supports and challenging behaviours
- Define staffing levels and skill mix for service providers
- Establish joint or single case management for individuals who could benefit from shared services

What's Next?

Our goal is to foster a person-focused culture. Adopting a person-focused approach will mean improved mental and physical health and social outcomes, enhanced quality of life and increased levels of satisfaction. The person won't be expected to fit into the program profile being offered, rather options that are flexible, that enable independence will be embraced.

With more focus on home/family-based programs, and greater supports for the family and in the community, costs will be contained, particularly over the long term. Greater coordination and integration can reduce the current gaps in the system, while eliminating duplication. Individuals will also benefit from a more accessible, user-friendly system designed to offer services that are both responsive and cost effective.

We believe that communities are stronger when there is full economic, social, civic and cultural participation by all. Our goal is to provide the services and supports that will promote greater social inclusion and cohesion.

There will be an integrated delivery system, with single entry access so that every door entered is the right door for the person or family seeking services or information. Joint decision making and more harmonized policies will provide more immediate and better care and supports, in the appropriate setting, with appropriately trained and supported staff.

We believe the vision, guiding principles and potential actions can help to get us there. Now, we need your input.

Please examine the vision, guiding principles and potential actions, and provide your response to the following:

Does this approach bring us closer to a person-focused culture?

Do the guiding principles provide the right foundation to deliver a person-focused system?

What are the priority actions that will improve and enhance the current system to facilitate choice and community inclusion?

What are the priority actions required by caregivers and family members to further support their ability to provide care?

A synopsis of the input we receive will be compiled and shared with contributors. It will also be used to inform our plan for the future to improve and better integrate the services of Continuing Care and Services for Persons With Disabilities.

We thank you in advance for your input. The Government of Nova Scotia is committed to building a society of inclusive, caring communities. In order to do so, we must provide services that offer maximum independence and quality of life for individuals in their homes and communities. Your input brings us a step closer to achieving that goal.

Appendix

Glossary of Programs

Continuing Care

The Continuing Care branch of the Department of Health and Wellness provide services through District Health Authorities/the IWK Health Centre and contracted service providers. The branch provides assessment, home care, long-term care (in a nursing home or residential care facility) and protection for vulnerable adults.

Long-Term Care provides care and accommodations mainly to seniors who have high medical care needs. Long term care can be provided in **Nursing Homes** for persons needing a high level of care, including regular on-site nursing and professional care.

Residential Care Facilities are homes for persons who need supervisory and/or personal care.

Home Care provides personal care, meal preparation, essential housekeeping, respite as well as nursing services (dressing changes, catheter care and intravenous therapy).

Self-Managed Care provides funds to persons with physical disabilities to directly employ care providers to meet their approved service needs. The self-manager assumes full responsibility for the coordination and management of the funded service.

Home Oxygen Program provides oxygen concentrators and portable oxygen tanks and related supplies, supporting people in their own homes and long term care facilities.

Adult Protection Services are for those 16 years and older who are at significant risk of self-neglect, or experiencing abuse or neglect by others and are unable to protect themselves because of physical or mental incapacity. For those living in health care facilities and provincially licensed homes, the Protection for Persons in Care Act offers the same protection.

Caregiver Benefit is for low income care recipients with a high level of disability or impairment. If the caregiver and the care recipient both qualify, the caregiver will receive a benefit of \$400 monthly.

Supportive Care Program supports adults with cognitive impairments with \$500 monthly for home support services that would otherwise be delivered through the provincial home care program, including a reimbursement of a maximum of \$495 annually for snow removal for low income seniors or individuals.

Personal Alert Assistance provides up to \$480 annually for personal alert assistance service for low income seniors who live alone, use a cane, walker or wheelchair and have experienced recent falls.

Bed Loan Program loans hospital-type beds for at home use and is administered through the Canadian Red Cross.

Adult Day Programs provide personal assistance, supervision, health, social and recreational activities in a supportive group setting. The programs also provide respite care, training and informal support to family caregivers through District Health Authorities and private service providers.

Occupational/Physiotherapy helps to maintain optimum levels of functioning in self-care, productivity and leisure through District Health Authorities.

Services for Persons with Disabilities

The Services for Persons with Disabilities (SPD) Program serves children, youth and adults with intellectual disabilities, long-term mental illness and physical disabilities in a range of community-based, residential and vocational/day programs. These programs are designed to support people at various stages of their development and independence

Key services include:

Direct Family Support provides funding support to families caring for a family member with a disability at home.

Independent Living Supports provide funding to a person living in their own home for a service provider (up to 21 hours weekly).

Alternative Family Support Program provides funding support to people living in private, approved homes.

Small Options Home supports 3-4 people in a residential setting.

Group Home supports 4-12 people in a residential setting.

Developmental Residence supports higher needs persons in a 4-12 bed residential setting.

Residential Care Facility provides a residential option for 11-35 people with room and board and minimal supports.

Adult Residential Centre provides long-term, structured support in a larger residential setting.

Regional Rehabilitation Centre provides intensive rehabilitation and developmental supports in a larger residential setting for those with significant behavioural challenges.

Adult Service Centre offers day programming and vocational supports.

Regional Respite Service provides funding to regional organizations to offer respite and related supports to families.

Mental Health Services

Mental health services range from emergency/crisis intervention to recovery and rehabilitation services. The services are provided through District Health Authorities and the departments of Community Services/IWK and the Department of Health and Wellness.

One of the major directions of the mental health system is to base more services and supports in community settings to improve access for clients.

Emergency Health Services/Crisis Response provides immediate response to psychiatric emergencies, including a crisis line, mobile crisis outreach in the Halifax Regional Municipality and emergency room crisis team assessment and/or psychiatric consultation.

Acute Inpatient Care provides hospitalization, assessment and treatment to stabilize acute symptoms, then links with community based treatment and supports for ongoing care.

Case Management provides one-on-one support and coordination of care.

Psychosocial Rehabilitation provides ongoing goal setting and skill development for people with severe and persistent mental illness, through employment, education and housing supports.

Clubhouse Program provides employment, housing supports and social activities.

Outpatient Services provides assessment, diagnosis and ongoing treatment across the lifespan, in an outpatient, often community based clinic.

Specialty Services provides services in centralized areas of the province, building capacity in other areas through a network model of specialties.

