# Choice, Equality and Good Lives in Inclusive Communities

# A Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program

Submitted to: The Honorable Denise Peterson-Rafuse Minister of Community Services

by

The Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program

June 2013

The Honourable Denise Peterson-Rafuse

Minister of Community Services

Department of Community Services 8th Floor, Nelson Place 5675 Spring Garden Road P.O. Box 696 Halifax, Nova Scotia B3J 2T7

Dear Minister Peterson-Rafuse,

It is our great honor to submit to you *Choice, Equality and Good Lives in Inclusive Communities: A Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program*. We submit this report on behalf of the Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program. As Co-Chairs, we believe we have met the terms of reference you established in appointing the Committee in March 2013. In the past five months we have undertaken a systematic review of the SPD program, drawing on the many government and community reports about SPD, research in best practices and the input contributed to the 'Putting People First' consultations by individuals with disabilities, families and service providers. We have been ably supported in our work by the expertise of IRIS – Institute for Research and Development on Inclusion and Society – and are grateful for their assistance throughout this process.

Having analysed the many issues with the program, we have laid out a 'Roadmap' for redesigning the program to meet three main goals:

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

The Roadmap lays out a pragmatic transformation agenda, informed by the principles adopted by the Government of Nova Scotia for creating a system that is: person-focused, abilityfocused, independence-focused, home and community oriented, accessible, responsive and sustainable. We have proposed a five-year time-frame for the planning and groundwork to transform the system of services to persons with disabilities; however, we understand that the full transformation will likely take a decade of change. While our report points to longstanding issues with the SPD program, we emphasize that there is 'no one to blame' for the challenges we face in ensuring the program provides a solid foundation for enabling the full social and economic inclusion of Nova Scotia's with disabilities. We have been inspired by individuals with disabilities, families, community advocacy organizations, service providers and provincial government officials who are committed to examining the challenges and making the SPD program work. Their collective knowledge, vision and commitment have guided us every step of the way in developing the Roadmap we present to you in the attached report.

Madam Minister, we congratulate you on your foresight and leadership to look critically at the SPD program and to trust in the wisdom of a joint government-community effort to identify the issues, analyse underlying challenges and map a path forward. We hope we have done justice to the promise you made to Nova Scotians in announcing this initiative, and look forward to continued collaboration in moving the agenda forward.

Sincerely

Wendy Lill & Lynn Hartwell

Co-Chairs,

Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program

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# **Executive Summary**

The 'Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program' was mandated in March 2013 by the Honourable Denise Patterson-Rafuse, Minister of Community Services, to:

Develop a roadmap for transformation of the Nova Scotia Services to Persons with Disabilities Program (SPD), guided by the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

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-centred, community-based approach, guided by the principles and vision laid out in *Putting People First*, that "Nova Scotians will enjoy good lives of their choosing in inclusive and welcoming communities." In undertaking our analysis of the SPD and in developing recommendations we have been informed by the content and the intent of the United Nations *Convention on the Rights of Persons with Disabilities* which has been ratified by Canada with the full support of the Government of Nova Scotia.

#### Key Issues to be Addressed

Our work began with a review of key issues facing people with disabilities, their families, service providers and the broader community in advancing supported living in inclusive communities. Ten main issues were identified:

- Lack of effective person-directed planning supports With an individual planning process for SPD-funded supports largely focused on determining eligibility for existing options rather than responding to individual goals, strengths and needs, the process is not tapping the potential of individuals, families and communities. The result is an inefficient, fragmented and uncoordinated planning process that tends to be overly influenced by available SPD program options and is thus unable to maximize use of generic community resources and trigger innovation in the supports system.
- Lack of individualized disability supports Today, services and supports for people with disabilities and their families are fragmented, often unavailable or unaffordable, not portable across life transitions or locations, and all too often disempowering or stigmatizing to those seeking a modicum of assistance to live in dignity and to be active citizens. All too often the current *range* of options available are not adequate to meet

individual needs, with a significant gap in options/choices for people who need more than 21 hours of support per week.

- Inflexible funding that leaves little room for self-direction and choice For the most part, the funding mechanisms for the SPD program are not based on principles of selfdetermination and do not provide for sufficient flexibility. The individualized funding currently available through Direct Family Support (DFS) and Independent Living Support (ILS) is simply not adequate. Consequently, more expensive and inflexible options have to be found in more institutionalized environments, thus thwarting social and economic inclusion.
- Legal and policy barriers to making personal decisions and choices Many people with more significant intellectual, cognitive and mental health disabilities are restricted in making personal, health care and property; are isolated and without meaningful choices or the opportunity to develop a vision and direction for their own lives, and to make their own decisions. No robust legal framework for Supported Decision Making is in place to empower individuals to self-direct their lives and maximize opportunities for supported living in the community.
- **Reliance on institutional care** With some 1,100 people living in large congregate care facilities, Nova Scotia is more likely than other provinces to support people with disabilities in large congregate facilities. Significant public funds continue to be spent on an institutional model a model that universally has been proven to produce less than quality outcomes for persons with disabilities (in comparison to supported community living) and a model that has been unequivocally rejected by persons with disabilities.
- Outmoded service delivery system The current system Small Option Homes, Group Homes and Developmental Residences is not adequate or appropriate to meet current or future demand. While community service providers are doing their best with limited resources and a largely inflexible system, the reality is that once placement occurs, people essentially remain bound to that residence if they are to maintain their supports, with movement possible only in designated residences as vacancies occur. Nearly 1000 people are on waiting lists services as offered by the SPD program.
- Barriers to employment The employment rate of Nova Scotians with disabilities
  remains well below that of their counterparts without disabilities. The current array of
  various vocational and employment programs has simply not been able to assist people
  with disabilities enter the labour force at a rate anywhere similar to that of non-disabled
  persons.
- **Restricted housing options** Nova Scotia has the highest proportion of people with disabilities in the country (20 percent). Along with aging families many of whom have

been supporting adult children with disabilities long into their adulthood there is pent up demand for housing options to enable adults to live more independently. Add to these factors the high proportion of aging housing stock which poses particular challenges for accessibility and it is clear that new and a much wider array of housing options are required.

- Few options for those with complex health and behavioural support needs People with disabilities who have complex health and behavioural support needs have extremely limited options for living in the community. Currently, there is little option but institutional care for this group. Service providers do not have sufficient access to funding mechanisms or needed expertise, nor have generic health and social service systems been organized to provide needed outreach and response.
- Lack of integration between disability-specific and generic services Finally, access to disability-specific services and supports cannot, on its own, enable supported living in inclusive and accessible communities. Yet mainstream community systems present a wide range of barriers to inclusion and participation of people with disabilities in housing, transportation, education, health care, recreation and the labour market. In order to ensure long-term sustainability and effectiveness of investments in supported living in the community mechanisms are needed for integration and coordination among disability-specific and mainstream services.

#### Goals and Recommendations for Transforming the SPD Program

While we recognize that the SPD program cannot address all of these issues on its own, it can be designed to make significant headway in their resolution. With these issues in mind, the Advisory Committee recommends three major goals to guide transformation of the SPD program:

- Greater self-direction, choice and control by people with disabilities and their families
- Modernized delivery system for supports and services to advance social and economic inclusion
- > 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

Establish person-directed planning and navigation as a process available to all individuals with disabilities and their families across the lifespan.

2. Individualized Personal Disability and Family Supports

Establish a 'Disability Supports' (DSP) Program that replaces the current SPD Direct Family Supports for Adults (DFSA), Direct Family Supports for Children (DFSC), Enhanced Family Supports for Children and Adults, and Independent Living Support (ILS) programs.

3. Individualized Funding Mechanism

Establish Individualized Funding (IF) as the funding mechanism for delivering the Disability Supports Program. Individuals and families would have two payment options through Individualized Funding: Direct Funding or Third Party Administrator Funding.

4. Equal Recognition of Legal Capacity and Supported Decision Making

Establish a legal framework to promote and protect the right to legal capacity and supported decision making, and adopt related policies and guidelines in all processes of SPD program eligibility determination, assessment, decision making and delivery of funding and supports.

5. Reduced Reliance of ARCs, RRCs, and RCFs

Announce a clear commitment and take steps to phasing out, over a multi-year period, use of ARCs, RRCs and RCFs as a response to the residential needs of persons with disabilities, in concurrence with development of necessary community-based alternatives.

6. Transformed Community-Based Residential Service System

Redefine roles of current residential service agencies from a primary provision of place-based services to delivering and enabling more individualized supported living arrangements through a person-directed and individualized funding approach.

7. Increased Access to Competitive Employment

Adopt an 'Employment Focused' Framework for SPD-funded service providers delivering day programs and employability support services.

8. Equal Access to Housing

Ensure people with disabilities have access to the full range of affordable and accessible housing in the community that is available to all Nova Scotians including those options created through the provincial Housing Strategy, and by enabling access to needed disability supports regardless of choice of housing.

9. Comprehensive Community-Based Networks of Specialized Supports

Establish networks of providers of specialized health and social support services which can respond on a 24/7 basis to individual and family needs in their own homes and communities, and expand capacities of generic health and social service providers to deliver these specialized supports.

10. Coordinated and Integrated Disability-Specific and Mainstream Community Services

Establish provincial and regional-level mechanisms to coordinate and integrate government, disability-specific and mainstream systems in developing community capacity for social and economic inclusion of people with disabilities and their families.

The Advisory Committee has developed a Transformation Plan and Roadmap to implementing these recommendations over a five-year time frame, with major action steps for each of the ten recommendations being plotted over 2013-14 through 2017-18. In doing so we have been guided by our mandate to create a plan with workable proposals that taps the sense of urgency, and can be managed within a tight fiscal environment with no new major investments in 2013-14. Thus, the roadmap proposes the remainder of this fiscal year as a set-up and design year with major roll-out beginning in 2014-15.

#### **Proposed Mechanisms for Implementation**

We propose a number of mechanisms to implement the Transformation Plan and Roadmap:

- DCS Departmental Leadership The Department of Community Services would play the lead role within the provincial government for designing the Transformation Plan and managing implementation.
- Provincial and Regional SPD Transformation Advisory Groups With stakeholder representation a Provincial SPD Transformation and corresponding Regional SPD Transformation Advisory Groups would provide overall guidance.

- SPD Transformation Project Implementation Team (DCS) Reporting to an Associate Deputy Minister, the Project Implementation Team would be led by the Director of the SPD Program, with a dedicated Project Manager and support staff at the provincial and regional levels.
- Interdepartmental Working Group comprised at the Associate Deputy Minister level from Departments and agencies of Health and Wellness, Housing Nova Scotia, Labour and Advanced Education, Justice and Education.
- Community Advisory and Working Groups for SPD Transformation Advisory and Working Groups should be established to bring key stakeholders together for issuefocused planning on: legal capacity reform, facility restructuring, transformation of the residential services system, managing waitlists, crisis response and development of community-based networks of specialized care, and employment.
- Evaluation of SPD Program Transformation The scale of SPD Program transformation and the multiple dimensions of the change process will require and benefit from an ongoing external evaluation process.
- Communications Strategy In order to build understanding and support for the transformation process by various stakeholders and the general public, effective communications will be needed in announcing the transformation initiative and managing implementation.
- Coherent and Horizontal Policy Development In order to support a transformation of this magnitude, senior officials of key departments of the Government of Nova Scotia should participate in a series of workshops on disability and inclusion based policy analysis.

The Committee recognizes there is much good work and practice to build upon in Nova Scotia and jurisdictions beyond, and we have reviewed these effective policy and practice approaches in our deliberations and in developing the Transformation Plan and Roadmap.

# Introduction

In March 2013 the The Honourable Denise Patterson-Rafuse, Minister of Community Services established the 'Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program.' With representation from the disability community in Nova Scotia, service providers and government representatives, we had a forward-looking yet challenging mandate:

To develop a roadmap for transformation of the Nova Scotia Services to Persons with Disabilities Program (SPD), guided by the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

This document presents our proposed Roadmap to Transforming the SPD Program. See Appendix A for a list of the Committee Members who volunteered their time to serve on this committee.

# Context for the Advisory Committee's Work

In developing this roadmap we have been informed by the commitment of Premier Dexter to move "beyond the old institutional framework" to maximize "independence and dignity" and the December 3<sup>rd</sup>, 2012 announcement by Minister Peterson-Rafuse:

- that the province is continuing its work on improving life for persons with disabilities by working towards a more person-centered, home and community based model of supports and services; and
- the intention of the government to engage and involve the expertise of community partners in all aspects of the transformation process, and full acknowledgement and respect for their role.

In addition we have been guided by *Putting People First*, the Government of Nova Scotia's commitment to reshaping the system of supports for people with disabilities. That commitment makes clear a vision for change that has been foundational to our work as a Committee:

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

As well, the document provides a set of guiding principles which have informed our analysis of key issues and the directions recommended here for transforming the SPD Program, including:

**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, and 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.

From the outset of our deliberations we have given the fullest consideration to both the content and the intent of the United Nations *Convention on the Rights of Persons with Disabilities*. Ratified by Canada in 2010, and with the full support of the Government of Nova Scotia, the Convention affirms and guarantees full citizenship and human rights for persons with disabilities and lays out the necessary conditions for ensuring full enjoyment and exercise of these rights. We believe the Transformation Plan we have laid out will, in large measure, ensure these conditions are put into place in Nova Scotia.

See Appendix B for an overview of the methodology that guided the Advisory Committee's work.

### Starting Assumptions in Designing the Roadmap

In designing this Roadmap to Transformation of the SPD Program, we have been inspired and guided by the voices, aspirations, concerns, and frustrations of people with disabilities and their families. The public consultations of the *Putting People First* initiative made clear how urgent it is to respond to current failures of the system for far too many individuals and families.

Our starting assumptions are:

- The *Canadian Charter of Rights and Freedoms*, the Nova Scotia *Human Rights Act* and the UN CRPD guarantee equal rights, respect and dignity in all aspects of life, without discrimination on the basis of disability and require all sectors to take measures to assure that equality.
- All individuals have a unique developmental path, and may require unique interventions and supports to enable equality of outcome full participation and inclusion.
- All people can be supported to live in community.
- Families should be supported to rear children at home.
- Adults should have opportunity and support to establish lives and homes outside the family home.
- Community systems (education, health care, transportation, labour market, etc.) have obligation to include and value all members .
- Labour force participation should be the expectation for all working age adults
- Government's role will change in a transformed system from delivery to facilitation, partnership and a major (but not necessarily sole) funder.
- Financial sustainability will be achieved through:
  - reduced reliance on congregate facilities;
  - increased use of generic community services (reducing need for facilitybased duplication of services);
  - leveraging current investments in housing and vocational infrastructure;
  - reduced reliance on high-cost, acute care services (which results from supported living, independence, choice, etc.); and
  - savings from increased labour force participation of persons with disabilities.

#### Overview of the Roadmap for Transforming the SPD Program

A 'Roadmap to SPD Transformation' to address the issues we have identified and as discussed in this report requires a clear set of goals. Drawing on existing reports and reviews of the SPD program, research on good practices, the *Putting People First* public consultations and Joint Committee discussions, the following three major goals are proposed for a transformed SPD program:

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

To achieve these three goals, ten major elements of a transformation plan for the SPD program were identified, with different elements corresponding primarily to achieving one of the three goals:

#### Greater self-direction, choice and control by people with disabilities and their families

- 1. Person-Directed Planning and Navigation
- 2. Individualized Personal Disability and Family Supports
- 3. Individualized Funding Mechanism
- 4. Equal Recognition of Legal Capacity and Supported Decision Making

# Modernized delivery system for supports and services to advance social and economic inclusion

- 5. Reduced Reliance of ARCs, RRCs, and RCFs
- 6. Transformed Community-Based Residential Service System
- 7. Increased Access to Competitive Employment

#### Increased capacity and involvement of generic community systems in enabling inclusion

- 8. Equal Access to Housing
- 9. Comprehensive Community-Based Networks of Specialized Supports
- 10. Coordinated and Integrated Disability-Specific and Mainstream Services

The following report discusses each of these goals and elements of the plan to transform the SPD program, the issues they respond to, the rationale and assumptions underlying their choice and design, and proposed action steps for their implementation.

#### Building on Good Practice in Nova Scotia and Beyond

In exploring key issues and in reviewing research and good practice, the Committee has also been guided by the recognition that there is much success to be built on in Nova Scotia, and demonstrated good practices in other jurisdictions. With this experience, knowledge and existing commitment we are fully confident that stakeholders can design and implement an effective plan for ensuring access to services and supports that enable good lives for people with disabilities and their families in inclusive communities. In particular, we recognize:

- There has been a long experience and commitment in Nova Scotia to building individualized and person-directed supports and services, which is the main thrust of good practice identified in broader literature we reviewed. Thus, there is much expertise and commitment to build upon in Nova Scotia in designing a roadmap for transformation.
- There are broader factors beyond the scope of the SDP program and those who have shaped its design, managed it, and delivered funded supports under the program which shape its impact. Budgetary constraints, capacity challenges and the changing needs and desires of persons with disabilities have all been determinative in shaping the current context. It is important to remember, therefore, that there is no one 'to blame' for the wide range of issues and limitations that actors in Nova Scotia have identified. Rather, we sense there is much good will among the actors to work together, not to 'personalize' the issues, and to craft a way forward. Undoubtedly, trusting relationships need to be built and restored. While there are significant challenges ahead, and a very clear sense of frustration by many, there is also a tradition of working together, building bridges and developing a shared vision of the path forward. Those are the most important assets for transforming a system, and we sense there is an abundance of these in Nova Scotia.
- It is also important to note that Nova Scotia is not the only jurisdiction in Canada struggling with the issues identified in this report. There is a sense of urgency across Canada and in other countries around the world about how to shift systems in light of the UN *Convention on the Rights of Persons with Disabilities* and the disability community's long-standing calls for change. The challenge for governments is coming up with the right set of processes and systems to deliver on the promise of human rights commitments. There is no simple or 'tried and true' answer; the most important

thing is to head down the path of transformation, as the Government of Nova Scotia has committed to doing.

Finally, we want to acknowledge the leadership of the Minister of Community Services, senior Departmental officials and those responsible for directing and managing the SPD program for initiating and supporting this exercise. And, we also want to acknowledge the leadership of community members who have persistently identified the challenges to be addressed. The openness and willingness of both government and community to engage in this joint process signals trust and belief in co-learning and co-designing rather than 'top-down' policy making. That kind of shared leadership is essential to the process of transformation ahead, and represents an enormous strength and asset going forward.

#### **Overview of the Report**

The report is divided into the following major sections:

A major section is devoted to each of the three goals identified, the key issues and elements of a transformation plan they speak to, and proposed recommendations and action steps to guide detailed planning and implementation. Together these three goals, and proposed elements and recommendations constitute a ten-point Transformation Plan for the SPD program.

Following the presentation of this 10-point Plan, a section on 'Mechanisms for Partnership, Innovation and Sustainability' proposes a set of mechanisms to activate the key elements as part of an overall transformation planning and implementation process.

The final section of the report presents a 'Roadmap to Transforming the SPD Program' which plots out the proposed action steps for each of the ten elements of the Transformation Plan over a suggested period of five years starting with the fiscal year 2013-14.

Appendix A provides a list of Joint Committee Members, and Appendix B outlines the terms of reference and process we undertook to produce this report.

# Goal I: Self-Direction, Choice and Control

Individuals and their families have spoken loudly and clearly about their lack of choice in supports and services, that most current options are not person-directed and that institutional placement ends up being favoured over supported living in the community. In order to more fully ensure that individuals and families can in fact self-direct and exercise choice and control in their lives, the Transformation Plan identifies four main elements necessary to achieve this outcome: ensuring access to person-directed planning and navigation support in the community; individual disability supports for both individuals and families; an individualized funding mechanism to empower people to make their own choices; and equal recognition of legal capacity and support decision making.

# **Person-Directed Planning and Navigation**

#### The Issue

With a planning process largely focused on determining eligibility for existing options rather than responding to individual goals, strengths and needs, the current planning process is not tapping the potential of individuals, families and communities. The result is an inefficient, fragmented and uncoordinated planning process that tends to be overly influenced by available SPD program options and is thus unable to maximize use of generic community resources and trigger innovation in the supports system.

#### What is it

Person-directed planning is an interactive, dynamic, person-focused and person-directed, ongoing process to give direction to and make decisions about some or all aspects of an individual's life currently and into the future. The process is directed by the individual and is based upon his or her hopes, aspirations, values, goals, strengths and needs for support. An individual's decision-making supporters are included in the process as needed and requested by the individual. Person-directed navigation is an ongoing process of investigating and activating personal, community and publicly-funded resources and community systems to implement the individual's evolving plan in a coordinated, coherent and holistic manner. Planning and navigation may be carried out by the individual, with his or her chosen support network, and/or with planning support agents and navigators designated and funded to conduct these roles.

#### Transformation Recommendation #1

• Establish person-directed planning and navigation as a process available to all individuals with disabilities and their families across the lifespan.

#### **Proposed Actions**

- 1) As of April 1, 2014, implement an 18-month pilot initiative on person-directed planning and navigation in order to determine most effective and efficient delivery mechanism:
  - (a) Central Region Create and fund an independent planning support and navigation function that is by a community-based agency (given numbers on waitlist in the Central Region, it seems most reasonable to add additional planning capacity here). Pilot agency to be secured via a RFP process.
  - (b) Region 2 Restructure role of departmental care coordinators to minimize administrative duties and enable greater emphasis on the planning function.
  - (c) Regions 3 and 4 No change in delivery structure.
- 2) Undertake evaluation of pilot initiatives and comparative analysis with current approach and consider implications for wider-scale implementation of selected models.
- 3) Develop training materials and resources related to principles, standards and practices for person-directed planning and navigation.
- 4) Provide training and orientation in person-directed planning to care coordinators, independent planners/navigators, and residential and vocational providers.
- 5) Develop an online system for access to information and planning resources provided in plain language and accessible formats. Information would be developed for use by individuals, families and planners.
- 6) Initiate person directed planning/navigation process starting with all people on the waiting list and persons currently residing in Residential Care Facilities (RCFs).

#### Rationale and Assumptions

- Person-directed planning/navigation accountable to the person and/or family will lead to innovation, use of non-traditional options and increased use of generic community supports.
- Independent planners/navigators may require disability-specific training, taking account of distinct realities of people with intellectual, physical/sensory and mental health disabilities.
- The SPD program should enable person-directed planning/navigation to be undertaken in a variety of ways – from individuals and families doing their own planning (with support from online and print resources), to accessing a community resource centre for necessary support, to having the assistance of an independent planner/navigator.
- New mechanisms for delivering independent planning/navigation need to be tested in order to develop best approaches/models for Nova Scotia context.
- Prioritization for delivery of person-directed planning:
  - Individuals currently on waiting list
  - Those residing in Residential Care Facilities (given recognition in the 2008 review of residential services of the need for alternate arrangements for those individuals residing in this option).
- Person-directed planning/navigation should become the norm for all individuals and families accessing SPD services.

# **Individualized Personal Disability and Family Supports**

#### The Issue

Today, services and supports for people with disabilities and their families are fragmented, often unavailable or unaffordable, not portable across life transitions or locations, and all too often disempowering or stigmatizing to those seeking a modicum of assistance to live in dignity and to be active citizens. All too often the current *range* of options available are not adequate to meet individual needs, with a significant gap in

options/choices for people who need more than 21 hours of support per week. With funding still largely attached to 'bricks and mortar' rather than to individual support needs and their changing needs and choices, the system is 'gridlocked' and not able to respond flexibly. With an unsustainable over-reliance on aging family caregivers as primary providers of personal disability supports, families are increasingly stressed as caregivers and advocates for their family members. This is not a recipe for sustainability, much less innovation, and responsiveness.

#### What is it

*Personal Disability supports* are any good, service or environmental adaptation which assists persons with disabilities to overcome limitations in carrying out activities of daily living, and to participating in the social, economic, political and cultural life of the community. *Personal Family supports* include a range of social, economic, community and personal goods, services and benefits that enable families with a member who has a disability to maintain typical/normative family caring relationships and family wellbeing while advancing the full inclusion, self-determination and citizenship of people with disabilities. As such, there is no fixed list of disability supports – any good or service which responds to the disability-related needs of a particular individual in relation to social and economic inclusion is a disability support.

A system for delivering more individualized, flexible, person-directed and responsive personal disability and family supports is required in order to achieve a vision of social and economic inclusion. Such a system should provide flexible and personalized supports to eligible individuals with disabilities and/or their families so as to facilitate personal development; to overcome disability related barriers; enable participation in community activities; and allow for full inclusion and supported living in community.

#### Transformation Recommendation #2

 Establish a 'Disability Supports' (DSP) Program that replaces the current SPD Direct Family Supports for Adults (DFSA), Direct Family Supports for Children (DFSC), Enhanced Family Supports for Children and Adults, and Independent Living Support (ILS) programs.

#### **Proposed Actions**

- 1) Design, and implement as of April 1 2015, a Disability Supports Program. Features would include:
  - (a) A maximum monthly amount for disability and family supports that would enable adults with disabilities to establish supported living (the current maximum is widely recognized as being inadequate);
  - (b) Mechanism to approve exceptions to monthly maximum in extraordinary circumstances;
  - (c) Funding levels that apply equally to children and adults, and equally applicable for use within family home or by individual in own home outside of nuclear family;
  - (d) Provision for supports to secure respite;
  - (e) Requests for funding identified within the context of a person-directed plan;
  - (f) Funds made available via an individualized funding mechanism (outlined below in C.).
- 2) Review need for aids and devices and capacity of current delivery system, and identify how best to address gaps through the PDFS program.
- 3) Increase/reallocate funds to this program area as of April, 2015.

#### Rationale and Assumptions

- In many situations, families need additional assistance (beyond that provided by the family) to support a family member with a disability and to maximize his or her potential for full inclusion.
- Individuals with disabilities often need additional assistance to participate in all aspects of family and community life.
- Financial support provided within DSP would not provide a basic living allowance (for which other programs exist) or duplicate existing funding sources. The financial component of DSP would pertain only to disability-

related costs: to fund services and supports necessary to enable an individual with a disability to live as independently as possible or to help a family with extraordinary child-rearing support needs directly related to their child's disability.

- Program eligibility would be for all individuals and families with disabilityrelated support needs. However, provision of funding support via the program would consider the financial capacity of the family (for children) or the individual (in the case of adults) to contribute via the application of an income test. This income testing would fully consider the additional costs of disability-related supports and thus eligibility would be based on net rather than gross income.
- The DSP program should be designed to enable people with disabilities to transition to adulthood and independence according to their own aspirations (i.e. living at home with family or establishing their own home outside the nuclear family).
- The current design of the SPD Direct Family Supports (DFS) and Independent Living Supports (ILS) programs does not provide adequate resources, flexibility and responsiveness to individual and family needs to secure inclusive outcomes. To do so, the current program design would need to be shifted from reliance on 'place-based options' to provision of individualized disability and family supports as identified through person-directed planning.
- The inadequacies of the current program design often result in individuals and families seeking facility-based options because of inability to obtain adequate resources to stay within the family home, or to develop more acceptable/individualized alternatives.
- Availability of a more robust Disability Supports program will reduce demand for traditional, facility-based options and thus lead to more innovative, individualized and cost-effective options.
- Individuals on the SPD waitlist and living in RCFs who receive person-directed planning/navigation and who choose new arrangements for personal disability and family supports as a result, would access the new Disability

Supports program for this purpose, and would utilize individualized funding as provided by that program.

• It is anticipated that a number of the individuals currently on the waitlist who are residing in larger facilities (ARCs/RRCs and some developmental residences and group homes) may, in order to facilitate transition to supported living in the community, require funds in excess of the prescribed monthly maximum in the Disability Supports program. Research has shown that such transitions, within an individualized funding approach, result in less expenditure than associated with the facility placement.

# Individualized Funding Mechanism

#### The Issue

For the most part, the funding mechanisms for the SPD program are not based on principles of self-determination and do not provide for sufficient flexibility. The individualized funding currently available through Direct Family Support (DFS) and Independent Living Support (ILS) is not adequate to purchase appropriate levels of support to maximize independent and supported living in the community. Consequently, more expensive and inflexible options have to be found in more institutionalized environments. With funding largely attached 'bricks and mortar' rather than to people, social and economic inclusion is thwarted more than would otherwise be the case. The consequence is lost opportunity for the innovation, responsiveness and cost-efficiencies that come with individualizing supports.

# What is it

Individualized Funding (IF) is a mechanism by which government flows dollars to individuals and families for purchase of individualized social and health supports. Because it generates increased accountability to the 'consumer', individuals and families, and the evidence demonstrating the cost-effectiveness that comes with this more individualized approach to funding, governments are increasingly turning to this funding method over 'Block Funding' whereby governments contract community service agencies to offer services to approved 'clients' of those agencies. Individualized funding provides individuals with disabilities and/or their families with flexible, person-directed payment options for arranging, managing, and paying for a range of disability-related supports and services according to their individual needs and requirements, as detailed within a person-directed plan to help them achieve supported living in community. Individualized Funding enables individuals and families to create new, innovative service options that support individuals to live in inclusive communities.

#### Transformation Recommendation #3

• Establish Individualized Funding (IF) as the funding mechanism for delivering the Disability Supports Program. Individuals and families would have two payment options through Individualized Funding: Direct Funding or Third Party Administrator Funding.

#### **Proposed Actions**

- Develop policy framework to enable individualized funding under the Disability Supports Program via: a) direct payments to individuals and/or families or b) third party fund administrators selected by individuals/families.
- Residential providers and Adult Service Centres develop personal budgets for each of their clients, based on existing operational budgets, and the agency's best assessment of each client's proportional usage of the budget.
- 3) Phase in implementation of expanded individualized funding:
  - (a) Starting April 1, 2014, for individuals and families who access the new Disability Supports Program;
  - (b) Starting April 1, 2015, for current clients of residential and vocational service providers who wish to utilize supports via access to individualized funding – with access to a planner/navigator to assist in developing a plan and making arrangements.

#### Rationale and Assumptions

- Research on the delivery mechanisms for services and supports has generally supported policy and practice goals towards greater independence, favouring funding attached to individuals as opposed to services.
- Individualizing relationships between funders and service users builds the capacity for individuals, families and communities to participate more readily in community. With choice and flexibility in the types and ways services are

received, people are better able to live according to their personal goals and objectives, making it possible to achieve their aspirations as opposed to simply conforming to a set of outcomes typically associated with disability programming.

- The administrative burden of IF can be very onerous for individuals and families, who often lack the time and resources needed to carry out successful support plans. To be effective and usable IF must provide support for administrative functions.
- IF must ensure equity in terms of funding levels across geographic jurisdictions, levels of disability-related need, and demographic factors such as gender and age. An additional system is the provision of information, planning, and management support provided as component of IF systems. This would be seen as accommodating the needs of those who would not otherwise access the IF option.
- In general research findings support a conclusion that if implemented effectively, an individualized funding mechanism need not be any more costly than traditional services and may over time prove to be less costly.
- Individuals and families in Nova Scotia have reported positive outcomes with an individualized funding model as currently made available within the Direct Family Support and the DHW Self-Managed Support-Care Services program.
- Individualized funding is generally recognized as a key and essential mechanism to the full actualization of such concepts as citizenship, selfdetermination and community participation, with an anticipated outcome of providing people with genuine choice and control of their lives.
- Individualized funding contributes to creating a support system that moves away from 'menu selection' and the exclusive use of pre-existing services. This can be best accomplished via an allocation of public money, directly to an individual, or in the case of a child their parents, to meet their disabilityrelated needs.
- Individualized funding (IF) has two fundamental characteristics:

 The funding amount is determined by direct reference to the individual and/or family's specific needs; and

- The individual or family (in the case of a child), supported by their personal network, determine how funds are spent.

# Equal Recognition of Legal Capacity and Supported Decision Making

#### The Issue

Many people with more significant intellectual, cognitive and mental health disabilities are restricted in making personal, health care and property; are isolated and without meaningful choices or the opportunity to develop a vision and direction for their own lives, and to make their own decisions. Service provision in the disability and older adult sectors is often based on an assumption that because people need supports and care, others should make decisions on their behalf. As people age and their cognitive functioning declines, family, community members, and service providers often respond by restricting the scope of the person's decision making. Individual decision making is restricted in informal ways, and also through formally authorized substitute decision making and guardianship. Current legal, policy and program frameworks require providers of planning supports to undertake 'capacity assessments' in order to determine eligibility for some support programs, in a process that lacks the checks and balances usually associated with such determinations. No robust legal framework for Supported Decision Making is in place that would provide individuals and families a means to enhance capacity to make decisions and thereby maximize opportunities for supported living in the community.

#### What is it

Legal capacity includes the 'capacity to act', intended as the capacity and power to engage in a particular undertaking or transaction, to maintain a particular status or relationship with another individual, and more in general to create, modify or extinguish legal relationships. We all draw on the support of others in making our own decisions, either formally or informally. The United Nations *Convention on the Rights of Persons with Disabilities* recognizes the right to legal capacity without discrimination on the basis of disability, and the need for supports to exercise and enjoy this right. Tests of mental and communicative capacities may be used as a kind of functional assessment to determine whether a person needs support to make decisions, or to determine what kinds of support may be needed. However, the CRPD requires that the need for support can no longer be a reason to remove from a person the right to make his or her own decisions.

#### **Transformation Recommendation #4**

• Establish a legal framework to promote and protect the right to legal capacity and supported decision making, and adopt related policies and guidelines in all processes of SPD program eligibility determination, assessment, decision making and delivery of funding and supports.

#### **Proposed Actions**

- 1) Initiate legislative reform process to establish a legal framework to protect and promote the right to legal capacity and supported decision making.
- Develop policy and practice guidelines for all SPD program elements and contracted agencies which reflect equal recognition of legal capacity and supported decision making.
- 3) Develop training and information resources on legal capacity and supported decision making and deliver to SPD staff, and make available to individuals, families, contracted agencies and other relevant stakeholders.
- 4) In collaboration with Department of Justice and Department of Health and Wellness, establish a Provincial Advisory Group, with key stakeholders to identify issues and explore options for promoting and protecting right to legal capacity.
  - (a) Hold provincial Forum of relevant stakeholders.
  - (b) Undertake review of current legislation affecting legal capacity.
  - (c) Develop supported decision making pilot project.
  - (d) Continue and enhance training of public service and community providers in the area of supported decision making.
- 5) Host national forum on the right to legal capacity and supported decision making.

#### Rationale and Assumptions

• The equal right to legal capacity is founded on the principles recognized in the CRPD of equal respect for dignity, diversity and evolving capacities of all persons; autonomy and self-determination; and participation, inclusion and accessibility in society.

The recognition and respect of a person's 'legal capacity' empowers a person to exercise control over financial/property, health care, and person care and life decisions, and to command respect from others for his or her decisions.

- Having particular mental and communicative capacities cannot be a condition of having one's right to legal capacity respected by others. That a person who has a diagnosed intellectual, cognitive or mental health disability is unable, on his or her own, to understand, appreciate and communicate a decision does not legitimize removing that person's decision-making rights.
- Legislative reform would be required to ensure compliance with UN CRPD in particular reforms to *the Incompetent Persons Act* and the *Adult Protection Act*; and establishment of a legal and regulatory framework for making supported decision making arrangements.
- Existing capacity tests and procedures in the SPD and Home Care program would be replaced with procedures to identify and develop decision-making supports and capabilities.

# Goal 2: Modernized Supports and Services

Many reports and reviews of the disability service system in Nova Scotia have pointed to the urgent need to restructure outmoded delivery in order to better align with known good practices and government policy commitments to social and economic inclusion. Key points of transformation include Nova Scotia's reliance on institutional facilities, large congregate group homes and developmental residences, and segregated day programs and sheltered workshops. Modernizing of systems of residential and vocational services in Nova Scotia will require: reduced reliance on ARCs, RRCs and RCFs; transformation of the community-based residential service system; and a move to increasing access to competitive employment for persons with disabilities.

# **Reduced Reliance on ARCs, RRCs, and RCFs**

#### The Issue

With some 1,100 people living in large congregate care facilities, Nova Scotia has a disproportionate reliance on institutional facilities in comparison to other Canadian jurisdictions. Compared to other provinces and territories, it is more likely to support people with disabilities in large residential settings such as Regional Rehabilitation Centres and Adult Rehabilitation Centres. While at one point seen as a national leader with respect to deinstitutionalization (e.g. closures of provincial Children's Training Centres) in recent years such efforts have stalled. Significant public funds continue to be spent on an institutional model – a model that universally has been proven to produce less than quality outcomes for persons with disabilities (in comparison to supported community living) and a model that has been unequivocally rejected by persons with disabilities. Nova Scotia remains as the only jurisdiction in Canada that is not taking active measures to reduce / close its institutional facilities for persons with disabilities.

#### What does it mean

Jurisdictions across Canada and around the world are modernizing their disability support systems by phasing out large institutional residential facilities for people with disabilities given the evidence of superior outcomes (at all levels) associated with community-based service delivery as opposed to institutional models of delivery. Governments are replacing / have replaced some or all of their long term residential institutions with family and community based supports and services. Intrinsic in this transformation process is ensuring that the 'new or alternate' system of supports and services respects the rights, dignity, needs and wishes of each individual and their family.

#### Transformation Recommendation # 5

• Announce a clear commitment and take steps to phasing out, over a multiyear period, use of ARCs, RRCs and RCFs as a response to the residential needs of persons with disabilities, in concurrence with development of necessary community-based alternatives.

#### **Proposed Actions**

- 1) Take immediate steps to reduce reliance on ARCs, RRCs and RCFs including, but not limited to:
  - Provide person-directed planning/navigation support and access to the DSP for those considered to be in need of these facility placements;
  - (b) Initiative development of community-based networks of specialized care/support are in place, with capacity to respond on a 24/7 basis (as discussed in recommendation #9);
  - (c) Establish protocol and accountabilities to ensure that when an individual is referred to a facility by a health or social service professional, protocol requires the agency, DCS-Regional and DCS-Provincial to coordinate efforts and arrange an alternative.
  - (d) Develop and implement a 'last resort' short-term admissions policy, with clear procedures for exhausting alternatives in advance, and requirement for timely return to community.
  - (e) Establish coordination mechanisms with community-based providers to deal with emergency situations.
  - (f) Develop and deliver information and human resources support to management and staff of ARCs, RRCs and RCFs providers to assist and manage the reduced reliance and phase-out process.
- Establish moratorium on admissions to ARCs, RRCs, and RCFs with effect as of April 1, 2015.
- 3) Effective immediately, no expansion to ARCs/RRCs/RCFs undertaken; and any new financial investment directed only to maintenance of health / safety standards.
- 4) Develop a prototype for ARCs and RRCs to test and demonstrate restructuring/phase-out process:
  - (a) Identify at least five facilities, with at least one per Region to demonstrate the restructuring/phase-out process.

- (b) Establish Restructuring Advisory Committee for each site (comprising representation from government, facility management, labour, community leaders and specialized experts) to guide process for reducing reliance on and ultimate phasing-out the facility including development of a plan to address human resource issues.
- (c) Collaborate with government agencies (e.g. Housing Nova Scotia) and other community agencies and NGOs as necessary to assist people to return to community.
- (d) Develop, finance and test restructuring process.
- (e) Undertake ongoing evaluation/learning process.
- 5) As prototypes are developed, consider policy and program framework and incentives for scaling up with other providers.

#### Rationale and Assumptions

- People with disabilities have a right to live and to be included in the community.
- Everyone should have the opportunity to live and participate in the community they choose. They should be involved in decisions about the support they receive and have maximum control over their lives.
- It is widely accepted that continued investment in institutional care now represents poor public policy. This is because public funding is going into services that are shown to produce poor outcomes for the people served. Community-based systems which facilitate supported living, when properly set up, managed and accessed, deliver better outcomes for the people that use them: improved quality of life, better health and the ability to contribute to society. Investment in such services therefore makes better use of taxpayers' money.
- A comprehensive strategy for the eventual phase out of Nova Scotia's large residential facilities designated for people with disabilities needs to focus simultaneously on two areas: 1) measures which seek to prevent institutionalization and the need for alternative care; and 2) measures aimed

at bringing back to the community those people who are currently in institutional care.

• It is also generally recognized that the marginally increased cost of community-based service in the short-term is outweighed by its beneficial outcomes, and that overall a community-based system of supports and services is more financially sustainable and cost-effective than institutional care.

# **Transformed Community-based Residential Service System**

#### The Issue

Reports from individuals with disabilities, their families and service providers all confirm that the current system Small Option Homes, Group Homes and Developmental Residences currently supporting about 1200 people are not adequate or appropriate to meet current or future demand. In particular, there is a significant gap in providing options/choices for people who need more than 21 hours of support per week (i.e. the maximum available in the Independent Living Supports program). For these individuals the only option, to access the disability supports needed, is to seek placement in a group home or even larger facility. The current system can be characterized as one that funds 'bricks and mortar' rather than individuals. Lack of capacity and choice are frequently used descriptors of the current system. Individuals and families are clear: they want development of individualized options through a person-directed planning process. Many, many service providers concur.

# What would it mean

A transformed residential service system would realize the shared vision of individuals, families, the disability community, service providers and the provincial government for supported living in the community for all people with disabilities, including people currently living institutionalized lives. This will require phasing out institutional facilities as the government has recognized, and ending the practice of out-of-home placement simply because of lack of personal disability and family supports. Housing choices would be based on the needs and aspirations of the individual (and family), and 1,000 individuals with disabilities would be repatriated from large congregate facilities to supported living in community – to homes and communities of their choice.

#### **Transformation Recommendation #6**

 Redefine roles of current residential service agencies from a primary provision of place-based services to delivering and enabling more individualized supported living arrangements through a person-directed and individualized funding approach.

#### **Proposed Actions**

- 1) Redefine roles of current residential providers to include:
  - (a) Act as a community resource and community development catalyst to assist individuals and families in securing housing options and in implementing and managing individualized support packages;
  - Act as a third party fund administrator for individuals and families within an IF model;
  - (c) Provide management, finance and administrative support to assist individuals and families in managing their direct funding;
  - (d) Work with generic providers in communities to adapt supports and services as per individual/family plans and requests;
  - (e) Provide specialized services as needed to individualized arrangements (e.g. for complex health and behavioural support needs).
- 2) Through a piloting process, develop a prototype for Group Home (GH) and Developmental Residence (DR) providers to lead, test and demonstrate downsizing and/or phasing out of traditional block-funded residences, as a wider array of housing choices becomes available:
  - (a) Identify participating agencies;
  - (b) Collaborate with relevant agencies and NGOs (e.g. Housing Nova Scotia) to leverage current residential facility assets; expand capacity to develop generic housing; and create revenue streams to expand provision of supports to people with disabilities;
  - (c) Develop, finance and test restructuring process;

- (d) Undertake ongoing evaluation/learning process, including tracking capacity development in participating agencies and communities, cost-effectiveness and new revenue streams generated through the pilots;
- (e) As prototypes are developed, consider policy and program framework and incentives for scaling up with other providers.
- 3) Develop a policy/program framework to contract agencies (either existing or new agencies) as providers of services outlined in 1.(a)-(e) above, and to provide transitional funding as may be required. Engagement of agencies should be via a Request for Proposals (RFP) process.
- 4) Develop a policy/program and funding framework to support residential service providers in transitioning their agencies from provision of place-based services to more individualized supported living arrangements funded through the IF mechanism (including development and delivery of training resources for this purpose).
- 5) Establish a Residential Services Transformation Advisory Group to guide the transformation process of the residential services system, with two working groups:
  - (a) Provincial Waitlist Management Working Group
  - (b) Crisis Response and Specialized Networks Working Group.

#### Rationale and Assumptions

- The current range of residential options available is not adequate or appropriate, resulting in a lack of real choice for families and individuals. There are unmet and growing demands for the existing service 'menu' and largely place-based options funded through the SPD program. Currently the solution tends to be development and funding of more 'residential' options, rather than looking at increasing agency capacity for developing, delivering and managing individualized supports in ways that will enable access to the broader housing market and more individualized support arrangements.
- A number of current residential provider agencies have expertise and knowledge of providing individualized supports, resources to leverage and

build upon, and have the leadership and commitment to play a lead role in transforming the community-residential system.

- Many individuals with disabilities who wish to establish supported living outside the nuclear family home do not need or want to live in traditional 'residential options' such as group homes.
- To enable individuals and/or families to achieve their goals and aspirations in ways that make sense to them, personal disability and family supports must be attached to people, not programs, services or physical structures. Accessing needed disability and family supports should not be contingent upon living in a particular type of residential option.
- To most effectively and efficiently utilize an individualized funding approach, individuals with disabilities and their families often require third party fund administrators and/or assistance with management and administration of direct funding, and existing service providers or financial institutions could take on these roles.

# **Increased Access to Competitive Employment**

#### The Issue

The employment rate of Nova Scotians with disabilities remains well below that of their counterparts without disabilities. The current array of various vocational and employment programs has simply not been able to assist people with disabilities enter the labour force at a rate anywhere similar to that of non-disabled persons. While the primary responsibility for labour market programming for people with disabilities lies with the Department of Labour and Advanced Education, the SPD program currently funds thirty Adult Service Centres (ASCs). These service providers deliver a system of vocational services largely through segregated, sheltered day programs and represent the predominant SPD response to the employment needs of people with disabilities (particularly those with intellectual disabilities). While many of the ASCs do attempt to provide community based employment for their clients, the majority of people served remain outside the labour force. In particular, there is a recognized gap in service for individuals graduating from high school. Proven effective models of employment for persons with disabilities (i.e. supported employment, job coaches, etc.) are not common

features of present service delivery arrangements. As well, very few organizations provide fully individualized approaches to supporting individuals' employment needs.

#### What would it mean

Participation in the competitive labour force means that people with disabilities are employed and remunerated at rates equal to their non-disabled peers, and have the supports and accommodations to achieve this outcome. Individuals with disabilities can participate in the competitive labour force when there are: personal and family expectations for success; transitional supports to inclusive post-secondary education, training and employment opportunities; effective community supports; engaged and confident employers who view individuals with disabilities as an untapped source of capable and reliable employees; opportunities for entrepreneurship and small business development; and labour force participation that does not preclude eligibility for other required supports (e.g. income assistance, drug benefits, etc.).

#### Transformation Recommendation #7

• Adopt an 'Employment Focused' Framework for SPD-funded service providers delivering day programs and employability support services.

#### **Proposed Actions**

- 1) Create a senior staff position at the provincial level in the Department of Community Services with responsibility for designing implementation of an 'Employment Focused' Agenda. In doing so, coordinate the implementation with other initiatives including those of the Department of Education and Department of Labour and Advanced Education's 'Careers Nova Scotia' initiatives, the 'Nova Scotia Workforce Strategy (to ensure people with disabilities can access the generic employment supports system),' the 'Nova Scotia Persons with Disabilities Employability Table' and other relevant government and community initiatives.
- 2) As provided for under the Individualized Funding mechanism, Adult Service Centres will develop personal budgets for each of their clients, based on the portion of their operational budgets funded by SPD. This will enable individuals to use their funding to purchase alternate service for employment supports and/or community participation. Arrangements to support Service Centres in making this transition will need to be developed/negotiated with DCS.

- 3) Identify an existing Adult Service Centre within each region to pilot an Employment Focused approach. Each participating agency will:
  - (a) Facilitate/convene an 'Employment Focused Community Action Group' with employers and other stakeholders in the local community pilot site;
  - (b) Analyze current core operational budget and identify resources currently directed to securing and maintaining paid employment in community;
  - (c) Be provided with additional/reallocated resources to prioritize job identification, placement and support for all students with disabilities graduating from secondary school so as to ensure all students, including those with significant disabilities, do not enter a day program. Within each selected site, dedicated staff will:

 Focus on increasing employer awareness, capacity and confidence building (i.e. creating demand)

 Work with school(s) on transitional planning for students at the high school level / school leaving age (i.e. creating supply)

 Support development of 'Employer-to-Employer' networks which promote hiring of people with disabilities;

 Provide necessary support to those students who wish to pursue post-secondary education subsequent to high school graduation.

 Where employment opportunities are secured in excess to that needed by students leaving the school system such opportunities would be made available to interested individuals currently receiving services through the vocational centre.

4) Develop a region-wide strategy for scaling up Employment Focused initiative, based on pilot/demonstration initiative with the Adult Service Centre and collaboration with relevant stakeholders including regional Employment Resource and Career Centres.

5) Create / expand specific measures directed to increased employment of adults with disabilities (particularly youth), including:

- (a) Expand funding for employment supports (job Coaches, job site accommodations, etc.);
- (b) Increase after school and summer employment opportunities for students with disabilities;
- (c) Ensure that students with disabilities are fully included in existing Cooperative Education opportunities at the high school level;
- (d) Introduce Mentoring program within selected sites (providing support to youth with disabilities to explore career interests, develop skills and raise expectations through volunteer experiences);
- (e) Require mandatory Transitional Planning for students with disabilities within the school system. Necessary transitional supports provided;
- (f) Resources and supports made available to increase entrepreneurship and social enterprise opportunities.
- (g) Implement a province-wide public awareness campaign on the social and economic benefits of employing people with disabilities.
- 6) As part of the ongoing SPD transformation process Adult Service Centres should be mandated to:
  - Shift resources into facilitating employment opportunity/placement for all individuals supported, including community economic development as needed and appropriate;
  - (b) Integrate lessons learned from the pilot initiatives into their programming;
  - (c) Report on successes in transitioning to a more employment-focused approach.
- 7) Consider developing a pilot for transforming Adult Service Centres into employment agencies in the context of the overall provincial labour market strategy for persons with disabilities, as agencies increase their capacity to find and maintain employment for the individuals they support.

#### Rationale and Assumptions

- People with disabilities face a unique set of barriers to employment both as individuals and as a matter of policy, yet with appropriate supports can and do successfully enter the labour market, though at much lower rates than the non-disabled population.
- Potential and future phase-out of these day programs and transition of current service agency capacity to better support competitive employment for people with disabilities will occur as demand for current programming decreases. This will be accomplished most effectively by creating employment opportunities for young adults leaving the secondary school system, and thus reducing the need for new placements into these programs.
- As individuals currently served through day programs access person-directed planning and the new DSP program, they may choose alternate daytime activities including volunteering and community participation.

#### Goal 3: Inclusive and Accessible Community Systems

Access to disability-specific services and supports cannot, on its own, enable supported living in inclusive and accessible communities. The bulk of supports that any person requires to maximize their development and participate fully in social and economic life comes from mainstream education, health and social services, and from equal access to housing, transportation, labour markets, and information and communications technologies. Barriers in key sectors must be addressed in collaboration with transformation of the SPD program elements in order to maximize effective use of resources and ensure social and economic inclusion. We point to three key areas that should be addressed as part of the SPD Transformation Plan, including: access to housing; access to community-based specialized services to respond to complex health and behavioural support needs some individuals have; and collaboration and integration with mainstream community services.

### **Equal Access to Housing**

#### The Issue

With Nova Scotia having the highest proportion of people with disabilities in the country (20 percent), and 1,100 people with disabilities currently living in large congregate facilities, one of the biggest challenges in creating opportunities for supported living in the community is to address housing needs. As well, the primary source of housing and disability support for people with disabilities is the parents' home. However, with aging families many of whom have been supporting adult children with disabilities long into their adulthood there is pent up demand for housing options to enable adults to live more independently. Add to these factors the high proportion of aging housing stock which poses particular challenges for accessibility and it is clear that new and a much wider array of options are required. To enable needed innovation to occur, it is essential to create new partnerships between current disabilities revice providers and the public and private sector to enable people with disabilities to access a far greater array of housing options than currently provided through SPD funded services.

#### How does this happen

To enable inclusive lives in community, there must be an investment in people rather than buildings. People with disabilities need availability of generic housing stock (which is accessible, affordable and non-congregate) <u>and</u> access to the disability supports that will enable them to avail of this housing stock in a manner appropriate to their particular needs and preferences.

#### Transformation Recommendation #8

• Ensure people with disabilities have access to the full range of affordable and accessible housing in the community that is available to all Nova Scotians including those options created through the provincial Housing Strategy, and by enabling access to needed disability supports regardless of choice of housing.

#### **Proposed Actions**

- Ensure the Nova Scotia Housing Strategy is implemented in a manner that makes available affordable and accessible housing stock and options sufficient to meet rental and/or ownership demand by persons with disabilities.
- 2) Mandate person-directed planners funded by SPD to identify full range of housing choices as distinct from 'residential placements', and ensure that online and other planning resources provide individuals with disabilities and their families access to information for this purpose.
- 3) Effective immediately, cease funding new clustered congregate care residential options.
- 4) If disability-specific housing is required as a last resort, limit development of this option to a maximum 4 people (developed on a dispersed, neighbourhood-based approach).
- 5) Strengthen and expand Alternate Family Program:
  - Ensure appropriate training, support, reimbursement and monitoring of providers;
  - (b) Provide access to personal disability supports as required.
- 6) Facilitate 'Live-in Support' arrangements:
  - (a) Provide matching and back-up support for people with disabilities who wish to identify roommates, house-sharers for rental of housing on the private and public housing markets.

#### **Rationale and Assumptions**

- Supported living in inclusive communities means having a safe and decent home of your own, choice, and personalized assistance and support from others who care about and respect you, and having access to mainstream community services which are universally designed and accommodating of individual needs and differences.
- Supported living in not exclusively a housing issue. Simply building more disability specific housing units into which people are 'placed' cannot lead to

inclusive lives in community. People with disabilities need and have a right to choice and mobility, not to be told that in order to have their disability needs met, they must live in a particular housing unit.

- The majority of people with disabilities do not want 'residential options' or 'specialized residential facilities'. They want a safe and decent home of their own, where they can exercise choice and control, choice of where and with whom they live, where they have tenure as tenants or homeowners, and have access to needed personalized support/assistance.
- The type and level of support individuals receive should not be determined by where they live, but by their needs and requirements. Support should follow the person wherever they live; even high levels of support can be provided in ordinary housing. Separating the provision of housing from disability support will ensure that individuals will not lose their support should they decide to change their living arrangements, for whatever reason.

A dispersed housing model is preferred practice - where people with disabilities live in apartments and houses of the same types and sizes as the majority of the population live in, scattered throughout residential neighbourhoods among the rest of the population, and accessed through mainstream housing markets.

#### **Comprehensive Community-based Networks of Specialized Supports**

#### The Issue

People with disabilities who have complex health and behavioural support needs have extremely limited options for living in the community. Current restrictions on funding for direct family supports and independent living supports leave little option but institutional care for people with more complex needs. While service providers may wish to support people to live in more community-based supported living arrangements, they do not have access to funding mechanisms or community-based delivery of needed expertise to make this possible. Nor have generic health and social service systems been organized to respond to this population of people with disabilities. For many, the assumption has been that 'complex care/support' services are best attached to health care and residential facilities. The provincial government's commitment to phase out institutional approaches to supporting people with disabilities cannot be accomplished without a strategy to fill the gap in the community for delivering more specialized support services.

#### What does it mean

Research on phasing out institutional care has shown that people with complex health and behavioral needs do not have to live in institutional environments in order to receive needed specialized supports. With a community-based networks of specialized care approach needed services can be provided to individuals in their own homes. This approach is supported with 'tele-health' technologies and networks of centres of excellence to deliver services in urban, rural and remote areas. Models for delivering specialized supports through community-based 'networks' of expertise to enable people with complex health and behavioural needs to live in the community have been implemented with success in other jurisdictions and are currently being explored in the Nova Scotia context.

#### Transformation Recommendation #9

• Establish networks of providers of specialized health and social support services which can respond on a 24/7 basis to individual and family needs in their own homes and communities, and expand capacities of generic health and social service providers to deliver these specialized supports.

#### **Proposed Actions**

- Develop and implement a 'Comprehensive Community-based Networks of Specialized Supports' system to enable supported living in the community for those with complex health and behavioural support needs to:
  - Strengthen and coordinate capacity to respond on a 24/7 basis in a timely, efficient way to individuals with complex care needs in a manner that maximizes supported living in the community;
  - Support the shift from place-based/facility-based service delivery to a modernized system of support where individuals and families live in their own homes;
  - (c) Tap expertise within the current service providing system, including collaboration with District Health Authorities to access needed clinical expertise;

- (d) Create effective linkages with other community-based health services
   (primary health care, mental health and addiction services, acute and tertiary specialized services, behavioural supports, etc.);
- (e) Build capacity within generic health services system through training, education and support;
- (f) Enhance coordination of specialized care at a community and regional level to identify and respond to gaps.
- 2) To design this system, establish a Crisis Response and Specialized Networks Working Group, in collaboration with the Nova Scotia Intellectual and Developmental Disabilities Network' (NSIDDN) and the 'Mental Health Speciality Networks' to advise on:
  - (a) Creating the network on a regional basis, identifying hubs within each region responsible for building needed linkages, identifying expertise, etc.;
  - (b) Establishing a network hub (located possibly with one of the networks) to provide and coordinate information resources, technological supports (e.g. tele-health, videoconferencing, etc.), training of professionals, research and evaluation.

#### Rationale and Assumptions

- Specialized supports to meet complex health and behavioural needs have largely been attached to facility-based delivery of disability-related supports. This has meant that people with more complex needs must live in such facilities if they are to access such supports.
- Government and community-based providers of services to persons with disabilities have been challenged to develop specialized services in ways that can enable people to live at home with their families or in supported living arrangements in the community.
- With the growing adoption of person-directed individual and family supports, and the de-linking of supports to place-based and facility-based delivery new mechanisms are required to ensure individuals and families can access the specialized supports required to enable supported living in the community.

 The collaborative efforts and experience of the 'Nova Scotia Intellectual and Developmental Disabilities Network' (NSIDDN) and the 'Mental Health Speciality Networks', which in a recent evaluation have been shown to be effective, provide a good foundation on which to establish a province-wide strategy for networks for specialized supports.

### **Coordinated and Integrated Disability-specific and Mainstream Services**

#### The Issue

Mainstream community systems present a wide range of barriers to inclusion and participation of people with disabilities. In order to ensure long-term sustainability and effectiveness of investments in supported living in the community mechanisms are needed for integration and coordination among the disability-specific and mainstream services – at both regional and provincial levels.

#### What does it mean

There has been a decisive move in the Canadian and international contexts towards integrating mainstream health services, through such mechanisms as District Health Authorities and Community Health Boards, in order to develop a more effective and responsive continuum of services and to more efficiently manage scarce resources in the health care sector. Increasingly, there is recognition that broader integration is also needed across health, social and broader community systems in order to address complex issues related to: the aging of the population; increasing prevalence of disability; increased demand for community-based health and social supports to enable people to live at home in their communities; adoption of an international human rights framework including the UN *Convention on the Rights of Persons with Disabilities*; and, an anticipated UN Convention on the Rights of Older Persons, which recognize a right to living in the community with supports as paramount.

Benefits of increased integration and coordination across community systems include: cost-effectiveness; decreased reliance on facility-based long-term care for older persons and those with disabilities; enhanced quality of life; and reduced complexity in accessing services from different systems.

#### Transformation Recommendation #10

• Establish provincial and regional-level mechanisms to coordinate and integrate government, disability-specific and mainstream systems in developing community capacity for social and economic inclusion of people with disabilities and their families.

#### **Proposed Actions**

- Establish a Provincial SPD Transformation Advisory Group and corresponding regional advisory groups, with representation from government, disability-specific service providers, the disability community and mainstream community systems to:
  - (a) Advise on and monitor provincial- and regional-level implementation of the Transformation Plan for SPD;
    - Make recommendations to DCS on detailed development and ongoing implementation of the SPD Transformation Plan;
    - Identify implementation issues;
    - Ensure that all identified savings arising from the transformation of services are reinvested in SDP services;
    - Track new capacities developed and resources leveraged, and consider ways to achieve cost-effectiveness and efficiencies in developing and implementing the SPD Transformation Plan.
  - (b) Work with the SPD in identifying trends and issues arising through individual planning processes, and developing community, regional and provincial plans to respond;
  - (c) Identify issues and make recommendations related to access and inclusion in mainstream community systems (housing, education, social services, transportation, labour market, etc.).
  - (d) Advise on and facilitate training for local, regional and provincial mainstream services on access and inclusion of people with disabilities within generic systems.

#### **Rationale and Assumptions**

- Access to disability-specific supports, and mainstream housing, transportation, education, training and employment are key sectors to integrate in a coordinated community-level planning and development approach if the systemic issues related to employment, poverty, unmet housing need, transportation needs, etc. are to be effectively addressed. For example, recognizing that there are challenges in ensuring and enabling access to affordable and adequate housing points to the need for an integrated community strategy to ensure housing development takes account of the need and demand by people with disabilities.
- Broader systemic barriers related to social and economic inclusion cannot be resolved by the SPD program alone, but rather through a provincial and regional-level planning and development strategy that links leaders from across key sectors and systems.
- Integration of disability-specific and mainstream services should be coordinated at both provincial and regional levels to: respond to diverse community and regional realities in Nova Scotia; to develop sustainable plans and investment strategies for social and economic inclusion; and provide input to the DCS Minister on program issues and direction.

# Program Transformation – Mechanisms for Partnership, Innovation and Sustainability

The Advisory Committee recommends the following mechanisms, many of which have been identified in the Transformation Plan, be established to guide design, guide and manage implementation.

#### A. DCS Departmental Leadership

The Department of Community Services would play the lead role within the provincial government for designing the Transformation Plan and managing implementation. The DCS Minister would have overall responsibility and accountability for the development and implementation of the Transformation Plan development and implementation should be mandated.

#### B. Provincial and Regional SPD Transformation Advisory Groups

With representation from government, the disability community, service providers, and mainstream community systems, the Provincial SPD Transformation and corresponding Regional SPD Transformation Advisory Groups would provide overall guidance to the development, implementation and financial monitoring of the detailed SPD Transformation Plan.

#### C. SPD Transformation Project Implementation Team (DCS)

Reporting to an Associate Deputy Minister, the Project Implementation Team would be led by the Director of the SPD Program. The team would include a dedicated Project Manager, necessary support staff and a dedicated staff in each region. The team would be responsible for policy and program formulation to implement the Transformation Plan and coordinate implementation and evaluation of the various elements of the plan.

#### D. Interdepartmental Working Group

In mandating the SPD Transformation, the provincial government should identify the lead Departments and quasi-governmental Agencies which will work closely with DCS to ensure coordinated, interdepartmental policy and program development and implementation to support SPD program transformation. The Advisory Committee recommends the establishment of an Interdepartmental Working Group, which should be comprised at the Associate Deputy Minister level from Departments and agencies of Health and Wellness, Housing Nova Scotia, Labour and Advanced Education, Justice and Education.

#### E. Community Advisory and Working Groups for SPD Transformation

In addition to the mechanisms outlined above, the proposed SPD Transformation Plan should include the establishment of the following Advisory and Working Groups:

- 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.
- 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.

#### F. Evaluation of SPD Program Transformation

The scale of SPD Program transformation, and the multiple dimensions of the change process will require and benefit from an ongoing evaluation process. The Advisory Committee recommends upon initiation of the transformation process an external evaluation team be engaged for the duration of the transformation process. The evaluation team should provide both interim and final reporting to enable both formative data to be used to inform and adapt the transformation process on an ongoing basis, and summative reporting.

#### G. Communications Strategy

In order to build understanding and support for the transformation process by various stakeholders and the general public it will be critical to be transparent and comprehensive in developing and implementing a communications strategy with respect to both the overall transformation plan and each of its elements. Effective communications will be needed in announcing the transformation initiative, and at regular intervals and key implementation stages throughout the transformation process.

#### H. Coherent and Horizontal Policy Development

In order to support a transformation of this magnitude, it will be essential to ensure complimentary policy formulation and implementation across Departments. To accomplish this, senior officials of key departments of the Government of Nova Scotia should participate in a series of workshops on disability and inclusion based policy analysis.

## Roadmap to Transforming the SPD Program

Preceding sections have outlined the overall Transformation Plan for the SPD Program, identifying three major goals, transformation elements, and proposed action steps. The Advisory Committee recognizes that not all the steps can be taken at once. Some action steps provide the foundations or 'stepping stones' for subsequent actions. As well, the Advisory Committee is very aware of the resource constraints and the need to build shared commitment and trust among the many stakeholders that will ultimately make the transformation possible. At the same time, the Committee is acutely aware of the need to take bold steps in order to address the urgent and pressing gaps in services and supports to enable people with disabilities in Nova Scotia to live with dignity and value in their communities.

In order to provide guidance on putting the Transformation Plan into action, the Advisory Committee has developed a 'Roadmap' to implementation over a five-year time frame. In developing this Roadmap, we have been guided by the Terms of Reference for the Advisory Committee's work as established by the Minister of Community Services, and in particular the mandate:

- to create a plan that taps the sense of urgency, but done in a way that can move to workable proposals within a tight fiscal environment;
- To plan for no major new investments for fiscal year 2013-14, using this year to develop shared government-community commitment and leadership, and detail implementation plans, time-frames, and actionable steps that could begin major rollout in 2014-15.

With these criteria in mind, the Advisory Committee designed a roadmap that shows main steps in implementing each of the ten elements of the SPD Transformation Plan over a five-year period starting in 2013-14. We outline these steps in the following table.

## Roadmap to Transformation of the Services to Persons with Disabilities Program

SPD Program Transformation Elements	2013-14	2014-15	2015-16	2016-17	2017-18
1. Person-Directed Planning/Navigation	Design Pilot on Person- Directed Planning/ Navigation Select agency to deliver pilot in Central Region	Implementation of Pilot with priority to individuals on waiting list and in RCFs. - Central Region – Independent Planning/ navigation - Region 2 – restructured role of DCS Care Coordinators - Region 3 and 4 – status quo - Evaluation of Pilots (tender for, and begin evaluation)	Final Evaluation Report Model for delivery of Person-Directed Planning/ Navigation selected	Full Implementation of Person- Directed Planning	Implementation

SPD Program Transformation Elements	2013-14	2014-15	2015-16	2016-17	2017-18
1. Person-Directed Planning/Navigation continued	Development of training materials and resources on Person-directed planning Delivery of training to all person-directed planning to care coordinators, independent planners/navigators, and residential and vocational providers Develop online system for access to information and planning resources				
2. Individualized Personal Disability and Family Supports	Design policy and procedures for Disability Supports Program (DSP) - Budgetary implications for implementation quantified and necessary funding requests made for fiscal year 2014-15	Begin implementation of new DSP Program			>
	Review need for aids and	Proposals developed			

SPD Program Transformation Elements	2013-14	2014-15	2015-16	2016-17	2017-18
	devices and capacity of current delivery system, and consider options	for revised provision of aids and devices through DSP program			
3. Individualized Funding Mechanism	Develop policy and procedures to enable DSP funding via an individualized funding model	Implement individualized funding mechanism as part of DSP program (providing for both third party fund administrators and direct payments			
	Develop methodology and process for residential and vocational service providers to personalize budgets of clients now served	Residential and vocational service providers undertake personalization of budgets for all clients	Current clients of residential and vocational services begin accessing individualized funding, as requested		>
4. Equal Recognition of Legal Capacity and SDM	Establish Provincial Advisory Group on Legal Capacity	Initiate legislative reform process —		>	New legislation enacted
		Design and host Provincial Forum on	Design and host National Forum on		

SPD Program Transformation Elements	2013-14	2014-15	2015-16	2016-17	2017-18
		Legal Capacity and Supported Decision Making	Legal Capacity and Supported Decision Making		
	Develop policy and practice guidelines for all SPD program elements, to recognize legal capacity and supported decision making Develop related training materials and information resources	Deliver training to SPD staff and stakeholders	Develop and implement supported decision making pilot project		
5. Reduced Reliance of ARCs, RRCs, and RCFs	Design protocols and accountabilities for implementation of moratorium Develop a last resort short-term admissions policy	Establish coordination mechanisms with community-based providers to deal with emergency situations	Moratorium on admissions to ARCs/RRCs/RCFs – April 1 2015		>
5. Reduced Reliance of ARCs, RRCs, and RCFscontinued	No expansion to ARCs/RRCs/RCFs; new investment directed only — to issues of health and safety				>

SPD Program Transformation Elements	2013-14	2014-15	2015-16	2016-17	2017-18
	Restructuring ARC/RRC pilot initiatives: select participating facility in each Region and establish Facility Restructuring Advisory Committee in each site	Restructuring plans developed Begin person-directed planning and transition of individuals to supported living in the community			>
			Scale up restructuring process with other ARCs/RRCs		
6. Transformed Community-Based Residential Service System	Establish Residential Services Transformation Advisory Group, and 2 Working Groups: 1) Waitlist Management and	Develop policy and program framework for supporting agencies to transition from place-based	New contracting program for services (DCS RFPs) introduced		

SPD Program Transformation Elements	2013-14	2014-15	2015-16	2016-17	2017-18
	2) Crisis Response and Specialized Networks Begin process of redefining roles of current residential service providers	services to supporting individualized living arrangements			
	Design pilot initiatives on Group Home/ Developmental Residence transformation – select agencies	Implement pilot with selected agencies ——		Begin scale up restructuring process with other residential service — providers	-> >
7. Increased Access to Competitive Employment	Create a senior staff position to lead design and implementation of an Employment Focused Agenda	Develop policy and program framework for supporting Adult Service Centre to transition from place-			

SPD Program Transformation Elements	2013-14	2014-15	2015-16	2016-17	2017-18
	Design pilot initiatives on Employment Focused approach to service delivery targeted for youth leaving the secondary school system Select participating Adult Service Centres – 1 in each region, and convene 'Employment Focused Community Action Group' – for each site	based services to supporting individualized arrangements Implement pilots		Develop a region- wide strategy for scaling up Employment Focused initiative	
7. Increased Access to Competitive Employment continued		Begin development and expansion of specific measures to — increase employment of adults with disabilities	Adult Service		>

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SPD Program Transformation Elements	2013-14	2014-15	2015-16	2016-17	2017-18
			Centres mandated to increase employment opportunities for all individuals supported		
					Develop a pilot for ASCs to transform into employment support agencies
8. Equal Access to Housing	Coordinate with Housing Nova Scotia to ensure plans include measures for sufficient affordable – and accessible housing to meet demand of people with disabilities				>

SPD Program Transformation Elements	2013-14	2014-15	2015-16	2016-17	2017-18
	Mandate person-directed planners/ navigators to explore full range of — housing options				>
	New clustered congregate care options not funded — Limit any new disability				>
	specific housing _ development to a maximum of 4 people, on a last resort basis				>
		Strengthen and expand Alternate Family Program			>
		Facilitate Live-in Support option			
9.Comprehensive Community-Based Networks of Specialized Supports	Crisis Response and Specialized Networks Working Group – begins development of plan to develop Comprehensive Networks	Implementation of Comprehensive Community-Based Networks of Specialized Supports system			>
		Develop and			

SPD Program Transformation Elements	2013-14	2014-15	2015-16	2016-17	2017-18
		implement related information and training resources and delivery of training			
10. Coordinated and Integrated Disability- Specific and Mainstream Services	Establish Provincial SPD Transformation Advisory Group – monitoring and advisory roles begin				>

#### Conclusion

The 'Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program' was honoured to undertake the work of developing the recommendations and roadmap presented in this report. We are fully aware of the challenges ahead. Transformation of the SPD Program will take visionary leadership, steadfast commitment, and resolute determination over a four-to-five year period. Developing the proposed SPD Program elements and undertaking the action steps will require these qualities from elected leaders, government, community service providers, mainstream community systems, and disability organizations.

To put our proposed SPD Transformation Plan and Roadmap into action will require the building of effective mechanisms to detail the transformation plan, guide its implementation, and provide ongoing evaluation and adaptation as actors across all levels gather learning from the process. We urge that immediate steps be taken, as outlined in the Transformation Plan and Roadmap to establish these mechanisms. This is essential so that the needed leadership and partnerships can get to work on detailed design of the transformation and so that trust can be restored among the many stakeholders whose joint and sustained efforts will be needed over the next few years to execute the Transformation Plan and sustain momentum for change.

We are fully aware that our proposed Roadmap for change will require substantial investment beginning in 2014-15. We see this is 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; and social assistance savings and increased personal tax revenue from increased labour force participation of persons with disabilities.

We believe it is critically important to channel the sense of urgency for change among so many individuals with disabilities and families in Nova Scotia, heard so loudly and clearly through the *Putting People First* consultations. We share, along with individuals, families, the disability community, service providers and the Government of Nova Scotia, the passionate belief that change is possible; that with our proposed plan we can indeed enable Nova Scotians to 'enjoy good lives of their choosing in inclusive and welcoming communities.'

## Appendix A – Members of the 'Joint Committee on Transforming the SPD Program'

#### **Co-chairs:**

Lynn Hartwell – Associate Deputy Minister, Department of Community Services Wendy Lill – Community Homes Action Group (CHAG)

#### From community:

Jean Coleman – Nova Scotia Association for Community Living Dorothy Kitchen – Nova Scotia Disability Strategy Network Committee Linda Quigley – Nova Scotia Disability Strategy Network Committee Lois Miller – Community Homes Action Group Heather Tracey –People First Nova Scotia Linda MacDonald – Mental Health Advocate

#### From organized labour

Sarah Hollahan – Regional Residential Services, Front line worker

#### From service providers:

Carol Ann Brennan – Nova Scotia Residential Agencies & Association (NSRAA); Continuing Care Association of Nova Scotia (CCANS) Millie Colbourne – Adult Residential Centres/Regional Residential Centres (ARC/RRC) Association Marilyn Forrest – DirectioNS Nova Scotia/Adult Day Program Association Charlie MacDonald – Teamworks, Employability Table Hilary Amit – Nova Scotia Residential Agencies Association

#### From government:

Anne MacRae – Disabled Persons Commission Lorna MacPherson – Director, Services for Persons with Disabilities Lynn Brogan – Regional Administrator, Central Region Francine Vezina, Department of Health & Wellness Mike Hazelwood, Care Coordinator, Western Region

## Appendix B – Overview of the Advisory Committee's Work and Methodology

#### Introduction

The Committee was appointed by the Minister of Community Services for the process and operated according to Terms of Reference the Department established. The process was originally envisaged to include opportunity for public engagement through an online engagement process and some public consultation with identified stakeholders. However, as the *Putting People First* consultations were being undertaken at the same time as this Committee's work, and they became more extensive than originally anticipated, it was determined that these additional engagement steps would be redundant. The Committee drew on the proceedings of the *Putting People First Consultations* as we developed the proposed SPD Transformation Plan and recommendations.

#### **Objectives of the SPD Engagement Process**

- 1. To develop a roadmap for transformation of the Nova Scotia Services to Persons with Disabilities Program, guided by the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) and directed toward the following outcomes:
  - Adopt a person-centred focus
  - Enhance and expand community-based services
  - Reduce reliance on institution-based care
  - Increase the integration and coordination with other services and programs, including Department of Health and Wellness Programs
  - Ensure financial sustainability
- 2. In developing this roadmap, to identify promising practices from other jurisdictions and from the Nova Scotia experience.
- 3. In considering options, and with the lens of the CRPD, to give particular attention to:
  - a. Roles and responsibilities of government and community service provider agencies and organizations;
  - b. Needed development of a policy and program framework to enable current providers of community-based residential, day, and vocational/employment supports to ensure their delivery maximizes principles of person-centred supports, community inclusion and labour force participation;
  - c. Transformation of residential programs and services towards provision of community-based supports consistent with the identified outcomes;

- d. Transformation of community-based vocational and employment supports and services to result in labour force inclusion of working-age adults with disabilities
- e. Intersection of SPD transformation with other policies and programs including for example, but not limited to, housing, income benefits, education and transportation policies and programs – in order to maximize achievement of the outcomes.
- 4. To identify short, medium and long-term outcomes and benchmarks for guiding, monitoring and reporting on the transformation process, informed by the principle of "progressive realization".
- 5. To recommend immediate short-terms steps to trigger the transformation process.

## Joint Government-Community Advisory Committee on Transforming the Services to Persons with Disabilities Program

The engagement process was guided by the Joint Government-Community Advisory Committee, co-chaired by Lynn Hartwell, Associate Deputy Minister in DCS, and a community Co-Chair Wendy Lill, who brings recognized leadership and profile in the community and experience with the disability sector. Along with the Co-Chairs, 12 Committee members were appointed by the Minister of DCS, based on recommendations from Departmental Staff, the disability advocacy community, disability service providers and the Disabled Persons Commission. Committee members made the commitment to:

- act as individuals on the Committee, and not represent particular organizations, other than the Government representatives;
- the objectives of the engagement process;
- confidentiality.

The Institute for Research and Development on Inclusion and Society (IRIS) was engaged by the Deputy Minister, DCS to provide technical support to the Advisory Committee. IRIS assisted in designing the process, facilitated the Committee discussions under the direction of the Co-Chairs, prepared background papers on issues identified by the Committee, and assisted in preparing the Committee's report.

A secretariat, constituted by the SPD Director provided secretariat support to the Joint Advisory Committee to coordinate meetings and provide logistics support; supported the Co-Chairs and IRIS in coordinating preparation of Committee Reports; and responded to the Committee's requests for information and assist in any costing/data analysis.

#### The Process

The Committee held five face-to-face meetings between late March and early July 2013 and with IRIS's support. At these meetings, the Committee:

- reviewed previous research, consultations and briefs related to SDP and services to persons with disabilities in Nova Scotia to identify key themes, issues and broad areas for reform/redesign (analysis prepared by IRIS);
- over the course of two meetings reviewed 'Issue Briefs' in six key areas identified by the Committee as the core issues to be addressed in developing a Transformation Plan for the SPD, including:
  - Planning Assistance for Individuals and Families
  - Access to Personal Disability and Family Supports
  - Transitioning from Institutional Care to Supported Living in the Community
  - o Ensuring Status in Decision-Making and Legal Capacity
  - Access to and Support for Employment
  - Developing Community Capacity for Responsive and Effective Supports.

Each of the Briefs had six main sections:

- Current issues
- o What is meant by this core element
- Good practices related to putting this element into law, policy and practice drawing on research literature in the area
- Nova Scotia policy and program context in relation to this issue
- Key changes needed to align community supports with good practice in the Nova Scotia context
- Desired outcomes in a transformed system.
- considered analysis of SPD program expenditure and waitlists, as prepared by DCS staff
- based on review of the above, identified ten core issues and corresponding elements for a Transformation Plan, key recommendations and action steps, and the Roadmap to transformation over a 5-year period.
- closely reviewed and revised draft materials prepared by IRIS for its final report.