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Services for Persons with Disabilities

Report of Residential Services

June, 2008





Community Services Services for Persons with Disabilities

Table of Contents

1.	EXECUTIVE SUMMARY	2					
2.	INTRODUCTION						
3.	BACKGROUND	4					
	SCOPE						
	OBJECTIVES						
	ASSUMPTIONS						
7.	METHODOLOGY	6					
8.	LIMITATIONS	7					
9.	REVIEW FINDINGS: THE CURRENT PICTURE	7					
9.1	RESIDENTIAL SECTOR STRUCTURE AND ORGANIZATION	8					
9.2	2 RESIDENTIAL SETTINGS: THE CURRENT RANGE	9					
9.3							
9.4	SERVICE AND SUPPORT GAPS	15					
10.	MOVING FORWARD: INFLUENCING FACTORS	17					
10	.1 THE UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES	17					
	.2 "Out of the Shadows at Last"						
	.3 DEINSTITUTIONALIZATION						
	.4 JURISDICTIONAL UPDATE						
	.5 AGING IN PLACE						
	.6 NOVA SCOTIA DEMOGRAPHIC INDICATORS						
10	.7 DEPARTMENT OF HEALTH CONTINUING CARE STRATEGY	24					
11.	FUTURE DIRECTIONS: ENABLING FACTORS	25					
11	.1 PHILOSOPHICAL FRAMEWORK FOR THE SPD PROGRAM	25					
11	.2 System Structure and Organization	31					
11	.3 DETERMINING CLIENT NEED AND APPROPRIATE SUPPORT OPTIONS	33					
11	.4 PROVIDING SERVICES AND SUPPORTS IN THE RESIDENTIAL SECTOR						
12.	SUMMARY OF RECOMMENDATIONS	43					
12	.1 RECOMMENDATIONS FOR A PHILOSOPHICAL FRAMEWORK	43					
	.2 RECOMMENDATIONS FOR SYSTEM INTEGRATION AND COORDINATION						
12	.3 RECOMMENDATIONS FOR DETERMINING CLIENT NEED AND SUPPORT OPTIONS						
	ID PLACEMENT						
	.4 RECOMMENDATIONS FOR PROVIDING RESIDENTIAL SERVICES AND SUPPORTS						
	.5 RECOMMENDATIONS FOR NEW TERMINOLOGY						
	.6 RECOMMENDATIONS FOR STRENGTHENING SUPPORTS AND SERVICES						
	7 RECOMMENDATIONS FOR QUALITY AND STANDARDS						
	8 RECOMMENDATIONS FOR INCREASING CAPACITY						
	.9 RECOMMENDATIONS FOR INFRASTRUCTURE REQUIREMENTS						
13.	CONCLUSION						
14.	REFERENCES	50					
15.	APPENDIX 1 JURISDICTIONAL REVIEW TRENDS	52					

1. Executive Summary

In November 2006, the Department of Community Services, Services for Persons with Disabilities Program commenced a review of all residential services for persons with disabilities in Nova Scotia. Helen Patriquin, a private consultant, conducted the review under the direction of Mildred Colbourne, Director, Services for Persons with Disabilities Program, and with the assistance of program and regional staff working with persons with disabilities.

The consultant conducted site visits at various residential options and also distributed a questionnaire to other service providers. All information was documented and analyzed in conjunction with departmental resources, especially the program area and the regional offices.

The Services for Persons with Disabilities program area provides residential and other supports to three broad population groups:

- 1. Individuals with intellectual disabilities.
- 2. Individuals with long-term mental illness.
- 3. Individuals with physical disabilities.

Approximately 4,800 individuals with disabilities are provided services and support at this time. Another 400 individuals are currently awaiting services.

This report provides the findings, recommendations and a plan to address the action items, or areas of concern, that have been identified. Major themes were recognized throughout the review and are the focus of this report. These themes include:

- Leadership and direction for the program.
- Governance and leadership in the sector.
- Integration and coordination of services and supports.
- Programming and supports for individuals with disabilities.
- Quality and best practices.
- Eligibility criteria and assessment processes.
- Waiting lists and residential options.
- Human resource issues.
- Infrastructure issues.

This report provides a comprehensive examination of current services and supports for individuals with disabilities. It is with great gratification that we can state that because of the tremendous commitment of staff of the Department of Community Services and the many service providers throughout the sector, the system has been able to serve the needs of individuals with disabilities despite the current limitations. These limitations, however, are at a critical point and must be addressed to ensure that persons with disabilities have access to a range of services and supports that will enable them to live to their fullest potential within their communities. The plan outlined further in this document details a long-term strategy to address the gaps in residential services and supports for persons with disabilities. These recommendations have been developed following extensive consultation and review of best practices in other jurisdictions, along with current research, such as the Kirby Report (2006). While preliminary costing has been completed at this time, further work is required to specify the funding commitment required on a per year basis to move the strategy forward.

The Department of Community Services would like to thank all of those individuals and organizations that assisted in this review through participation in a site visit, completion of questionnaires, attendance at meetings, and other input. Certainly without this level of participation we would not have been able to move forward.

2. Introduction

In 2002-2003, the Nova Scotia Department of Community Services (DCS) embarked on a comprehensive review of all aspects of the Community Supports for Adults (CSA) Program, now known as Services for Persons with Disabilities (SPD) Program. The objective of the review was to identify ways to improve supports and services for persons with intellectual, long-term mental illness and/or physical disabilities.

Following an extensive consultation process, DCS released a Summary Report detailing the input of the various stakeholders. In that document, the Department identified that change was required in a number of areas including:

- Funding to service providers.
- Assessment and classification processes.
- The range of residential options available.
- Services and supports provided through Adult Service Centres.
- New enhanced programs.

A tremendous amount of progress has been achieved within the SPD Program over the past three years. In addition to the development of three new programs, an implementation strategy for these programs was developed and is being implemented region by region. Concurrently, a new funding strategy has been developed and a review of the Adult Service Centres undertaken. Work has commenced on the eligibility and assessment piece, as well as the development of new staffing guidelines. A draft philosophical framework for the SPD Program has been created and a review of infrastructure undertaken in several agencies. The profile of the SPD Program and the persons with disabilities that the program supports has also been enhanced.

This document outlines the results of the Residential Services Review process along with an action plan to move forward to enhance these services for persons with disabilities.

3. Background

The Department of Community Services provides various social programs to assist families and individuals in need in Nova Scotia. In 1996, the Department assumed responsibility for residential and vocational services for persons with disabilities (physical, intellectual and long-term mental illness) from the municipalities across the province. Along with this shift of responsibility, the Department, in response to the deinstitutionalization movement, began the process of closing large institutional residences for persons with disabilities. Large institutions were closed, including the Children's Training Centres, the Halifax County Regional Rehabilitation Centre and Scotia Adult Residential Centre.

As a result of the closing of large institutions, other residential options in communities for persons with disabilities quickly filled. Without appropriate resources in the community, long waiting lists for these services ensued. This situation was being experienced by most jurisdictions across Canada, North America and Europe as the deinstitutionalization movement took precedence.

In Nova Scotia, the *Homes for Special Care Act and Regulations* governs the operation of homes that provide care and support to persons with disabilities and seniors. This legislation pertains to homes where four or more persons are supported. In an attempt to respond to the ever-increasing pressure in the community, Small Option Homes for up to three individuals were developed. As of March 2007, 211 of these Small Option Homes exist, outside the mandate of the *Homes for Special Care Act*, to provide care and support to individuals with mild to severe disabilities.

In the meantime, the waitlists for residential services across the province continue to grow. Although three new programs have been introduced or enhanced, there is a significant lack of residential capacity in the system for all groups of individuals with disabilities. The current system of services and supports for persons with disabilities includes Direct Family Support, Alternative Family Support and Independent Living Support. These services are supplemented by residential services including Small Option Homes, Residential Care Facilities, Group Homes, Developmental Residences, Adult Residential Centres, and Regional Rehabilitation Centres. Vocational and other day programming services complement this system.

In 2002-2003, following the transfer of social services from the municipalities, the Department of Community Services embarked on a comprehensive review of all aspects of the Services for Persons with Disabilities Program. This program renewal initiative included, but was not limited to, an examination of the mandate, access and assessment, individual supports, licensing, funding methodology and legislation. The objective was to develop a renewed program model complementing the other elements of the long-term care continuum of services provided by other government programs, and establishing a full range of accessible, responsive and sustainable supports for persons with intellectual disabilities or long term mental illness and/or physical disabilities. The Residential Services Review reported in this document is one aspect of the overall SPD Program Renewal Initiative.

4. Scope

The scope of the Residential Services Review was limited to:

- Small Options.
- Residential Care Facilities.
- Group Homes.
- Developmental Residences.
- Adult Residential Centres.
- Regional Rehabilitation Centres.

5. **Objectives**

The Residential Service Review was a phased project designed to assess the capacity and appropriateness of residential services for persons with disabilities in Nova Scotia. Three broad objectives were determined:

- 1. To identify resources, capacity and demand.
- 2. To determine resident needs and realignment strategies.
- 3. To identify implementation issues.

6. Assumptions

A number of assumptions were made at the onset of the review:

- A continuum of residential options is required for persons with intellectual disabilities, long-term mental illnesses and/or physical disabilities.
- The review would be approached in phases and would inform a strategy for realignment.
- Funding, staffing guidelines, assessment and eligibility were out of the scope for the review.
- Processes would be inclusive. The involvement of significant stakeholders would be integral to the review.
- The Boards and staff of residential agencies were committed to the best interests of the individuals they serve.
- The staff of the DCS regional offices would be involved at various intervals.

- Many of the issues identified would be long-standing in nature.
- Service providers would expect changes as a result of the Residential Services Review.
- It would be important to adhere to tight time lines while assuring the integrity of the review.
- Government, as project sponsor, would exercise final approval over all releases, reports and recommendations emanating from the review.

7. Methodology

Information from several sources was analyzed to develop the recommendations outlined in this report, including:

- 1. Renewing the Community Supports for Adults Program: A Discussion Paper and the Consultation Summary Report were used as foundational pieces.
- 2. Community Supports for Adults Renewal Project: Jurisdictional Review Summary Report, which was completed in January 2004, was updated to include major changes in policy direction in the past three years in the areas of:
 - governance structures, and
 - types and ranges of living options for the populations served by the SPD Program.
- 3. A site visit and structured interview were conducted with a representative sample of provider agencies. Care was taken to ensure representation of:
 - all residential options,
 - both rural and urban settings, and
 - all four geographic regions.

The sample included 25 provider agencies, which represented 53 percent of the currently available residential capacity. Providers were invited to include Board representatives, client and family representatives, and staff representatives in providing agency information, as they deemed appropriate. Physical tours of living accommodations and common areas were conducted in 23 of these organizations.

4. A questionnaire was distributed to all provider agencies. In addition to the 25 selected provider agencies, 14 other organizations took advantage of this opportunity to provide input into the review. The thoughtful responses demonstrated a residential sector prepared to think 'out of the box' and to work collaboratively with the Department. One organization used this opportunity to

survey persons with disabilities supported by the agency. A comprehensive report was submitted detailing clients' views on the strengths of current living options as well as opportunities for improvements.

- 5. A focus group meeting was held with a community group actively soliciting government for the creation of a group home in their community. This meeting was held to gain the perspectives of family members and community leaders on the needs of persons with disabilities.
- 6. Each of the four regional DCS offices was briefed on the review and provided input into the identification of service and support gaps. The SPD Specialist in each region was the main contact between the field and the review. A briefing was later held with each Regional Administrator before the report was finalized.
- 7. Demographic data was collected and analyzed on the persons currently supported within the SPD Program and on those waitlisted for services and supports.
- 8. A literature search informed the influencing factors and trends section of this report. A bibliography is appended.

8. Limitations

It was initially intended that the review would be conducted in three phases; however, the decision was made to combine the phases and move into the action-planning phase at an earlier stage. The absence of a comprehensive and integrated data management information system within the SPD program, and between the head office and the regional offices presented challenges. Much information had to be collected manually by individuals already carrying heavy workloads both in the regional and head offices.

9. **Review Findings: The Current Picture**

The Department of Community Services, Services for Persons with Disabilities Program, is a voluntary program that provides residential, vocational and day programs for adults with intellectual disabilities, long-term mental illness and/or physical disabilities. Many of the persons supported have a dual diagnosis.

Residential services include a range of options from support to families caring for a family member with a disability in their own home, to full 24/7 residential supports. The goal is to create a range of programs that can support people at various stages of their development and independence. The regulations to the *Homes for Special Care Act* state:

"The primary purpose of community based residential facilities, adult residential centers and regional rehabilitation centers shall be to encourage, foster, and

promote the social, educational and vocational development and well-being of the residents for the purpose of integrating the residents into the community as self-sufficient and independent individuals."

The SPD program supports 4,807 children, youth, adults and seniors in residential settings and community-based supports. As well, 1,800 individuals with disabilities participate in Adult Service Centres or adult vocational and day programs. Estimated program expenditure for the fiscal year 2007-2008 is \$207,925,000.

The current residential picture was addressed from a variety of different perspectives:

- 1. Residential Sector Structure and Organization.
- 2. Residential Settings: The Current Range.
- 3. Eligibility and Assessment.
- 4. Service and Support Gaps.

9.1 Residential Sector Structure and Organization

Services of the residential program are delivered by 93 service agencies operating in 328 different sites. These agencies and sites are located throughout the province.

• Forty-five or 48 percent of these 93 service agencies are stand-alone agencies (see Table 1).

Region	# of Providers	Operating 1 Site	Operating 2 Sites	Operating 3 or More Sites
Central	24*	11	1	11
Eastern	24	11	4	9
Northern	19	10	1	8
Western	26	13	3	10
Total	93*	45	9	38
* This number i	ncludes the IWK Health C	entre. The Centre is not	included in the breakdown of	f governance sites

Table 1: Governance of Multiple Sites

• The residential program has a mixture of for-profit and non-profit service providers. The majority, more than 70 percent, are non-profit. For-profit operations are present in two types of settings: Residential Care Facilities and Small Options.

 Voluntary Boards of Directors govern the non-profit agencies. Board composition is influenced by the agency's ownership. As a general rule, Board members do not receive stipends; however, in municipally owned agencies, meeting stipends may be paid depending on the policies of the municipality.

- All agencies have funded administrative staff, the extent of which is influenced by the size and complexity of the organization.
- Adult Service Centres are governed and managed, to the most part, separately from the residential program. In three instances one Board and administration operate both a residential program and an Adult Service Centre.
- The residential sector operates in silos. There is little horizontal integration or coordination within a region or a community. Agencies are focused primarily on their own operations. In the 25 organizations interviewed, the interviewer found no instance where Boards or owner-operators met regularly with other Boards or operators in the same community to discuss the sharing of services, resources or expertise, or the preparation of joint program proposals to address service gaps.
- Several provider-based associations exist. These association affiliations facilitate the sharing of resources and expertise among member agencies. The number of associations and their specialized membership-bases does not always enable the cross-fertilization of ideas among the various types of residential settings.

9.2 Residential Settings: The Current Range

"Individuals should not have to own their home in order to have a real home. Rather, they should have the opportunity to create a home of their own that mirrors their lifestyle and identity. In supporting individuals to create a real home, a distinction needs to be made between housing, which is type of shelter that a person has access to, and home, which reflects a sense of belonging and character. A visitor should be able to discern the essence of the person who lives there."

(Alberta Association of Rehabilitation Centers, 2004)

Two groups of residential settings exist:

- 1. Licensed Homes for Special Care, which operate under the jurisdiction of the *Homes for Special Care Act*, provide support to four or more persons with disabilities.
- 2. Unlicensed Community Based Options provide supports to three individuals or less. This group includes Small Option Homes, which may support individuals with very complex needs, as well as those individuals who require minimal supports. The programs of Alternative Family Support (formerly known as Community Residences), and Independent Living Support (formerly known as the Supervised Apartment Program) are also defined as community-based options.

Types of Licensed Homes for Special Care

• Residential Care Facilities (RCFs)

RCFs were created in the early 1960's to serve ambulatory or semi-ambulatory persons with disabilities who had no major health or behavioral needs. At the time, the RCF setting was created as a 'boarding home' for mobile younger adults who were expected to be out and about in the community. Minimal services and supports were put in place.

Currently, 25 RCFs support a total 518 individuals, many of whom are living with a long-term mental illness. The average age of individuals supported in this setting is 55.5 years.

Examples of stellar commitment and pleasant, home-like surroundings exist. However, there also exists a high prevalence of communal bedrooms (in some instances three to a room), aging infrastructures, sparse furnishings, limited programming (life skills, social or recreational) and vocational opportunities. Most other provinces have either enhanced or discontinued the use of RCFs.

The lack of capacity in the system has made it very difficult to transfer residents to either higher or lower support settings when the support needs of residents change over time. Thus higher needs individuals remain in these settings and are supported by staff who hold two fewer core competencies than those working in all other residential settings. Also, more independent residents have few opportunities to move on to greater independence in the community. RCFs are potentially home to many persons with disabilities who would be most appropriately supported in the Independent Living Support Program or in Group Homes.

No standards other than licensing requirements are in place for RCFs. Inconsistencies exist across the province in infrastructure maintenance, in the availability of social, vocational and recreational opportunities as well as in bedroom and common area furnishings and aesthetics.

• Action / Discussion Item

In light of recent reports such as the "Senate Committee Report on Mental Health, Mental Illness and Addictions, Out of the Shadows at Last", the continued relevance of the RCF "boarding home" residential option in its current form must be considered.

• Group Homes (GH) and Developmental Residences (DR)

Group Homes provide developmental and rehabilitation programs for persons with disabilities within small (four to twelve persons) residential settings. Persons with intellectual disabilities, long-term mental illness, physical disabilities and dual diagnosis are supported through this residential option. Supports focus on the activities of daily living, and on interpersonal and community oriented skills. The latter includes participation in appropriate community-based day programs.

Developmental Residences provide developmental rehabilitation programs for persons with an intellectual diagnosis or a dual diagnosis. Persons supported in this option have higher support needs than those supported in the general Group Home setting. Developmental Residences are

categorized I, II or III based on the supports provided, with DR III providing the highest level of support.

At present, 77 Group Homes and Developmental Residences support 460 persons with disabilities. Due to the presence of Residential Care Facilities and Adult Residential Centres in this province, the majority of existing Group Homes support persons with an intellectual disability or a dual diagnosis. All Group Homes and Developmental Residences are non-profit and the physical premises are either owned or leased by the operator.

Programming is an integral component of Group Home and Developmental Residence settings. Residents are supported to attend appropriate day programs in the community. Group Homes and Developmental Residences are located in all regions and the infrastructure appears to be in a better physical state than many of the Residential Care Facility settings. Many Group Homes and Developmental Residences were not purpose built, and since many are home to six or more persons, most are two-storey.

• Adult Residential Centres (ARCs)

Adult Residential Centres provide long-term structured supports and services to individuals with disabilities to enhance the development of interpersonal, community oriented skills, and activities of daily living. This setting is intended to support those individuals with more complex behavioral and skill development challenges.

Due to the high level of ARC capacity in some regions, other residential settings such as Group Homes for persons living with a mental illness have not been created. It is therefore recommended that all residents in ARCs be reassessed to determine the appropriate living option.

Notwithstanding, many ARC residents have complex needs and require the structured living environments and supports provided by this residential setting. Programming is an integral component of each ARC setting. Due to the large resident base, several ARCs have been able to establish their own adult day programs, including sizable vocational enterprises.

At present the seven ARCs support 492 persons with disabilities, mainly with complex needs along with mental health issues; the largest ARC in Nova Scotia supports 115 residents and the smallest supports 32 individuals. Two are combined Adult Residential Centre and Regional Rehabilitation Centre agencies. All are non-profit and six are municipally owned.

• Action / Discussion Item

A capacity assessment of Adult Residential Centres required in the Province of Nova Scotia should be undertaken that considers present needs of residents and projected future needs.

Regional Rehabilitation Centres (RRCs)

Regional Rehabilitation Centres provides both rehabilitation and developmental programs to individuals with disabilities, who require an intensive level of support. The persons supported in this residential option have the most complex behavioral challenges and skill development needs of all persons with disabilities supported by the SPD Program.

Clients have access to a number of professional services including medical services, nursing, psychological and psychiatry services, social work, speech-language therapy, physiotherapy and occupational therapy. Day programming is intensive. Pre-vocational, vocational and life skills development are a major component of the RRC organizations. Collectively the three RRCs support 154 individuals. All are non-profit and two of the agencies have a dual ARC/RRC role.

• Small Options

In addition to the above licensed options, 211 Small Options provide a residential option for up to three adults with disabilities. It is important to note that the Small Option is not an assessed level of support but rather a living option. The Small Option model was developed in the mid-1980's by a number of municipal units as a way to move persons with disabilities more quickly into residential settings without working under the confines of *The Homes for Special Care Act*. The Small Option model promptly became the setting of choice for many individuals and their families due to the low numbers of residents in each setting and the higher probability of private bedrooms than is found in other settings.

These new residential options were administered based on individual municipal by-laws, standards and policies. During the service exchange of April 1996, the responsibility for all residential settings serving persons with disabilities was transferred to the province.

Small Options are not licensed and operate within the framework of "*Interim Standards*" released by the Department of Community Services in 1996. All three-population groups are served. Persons with very complex needs are supported in this residential option, as are those with low support needs. Individuals assessed for placement at the Residential Rehabilitation Centre (RRC) level may be supported in a Small Option setting. There is no requirement that these homes be licensed.

• Action / Discussion Item

Is it appropriate for persons with disabilities who are among the most vulnerable of society to be supported in unlicensed living options? Is this the most appropriate option for individuals with very complex needs?

9.3 Assessment and Eligibility

Department of Community Services Care Coordinators are responsible for the assessment, determination of financial eligibility and for recommending a level of support on behalf of persons with disabilities applying for admission into the SPD Program. To be eligible, an individual must complete an application and meet the eligibility criteria administered by the Department in accordance with SPD policy. The individual must also be willing to participate in a functional assessment prior to consideration for eligibility. The purpose of the functional assessment is to determine unmet needs and to recommend appropriate supports and services for the individual using the most cost effective and least intrusive service plan to meet these needs.

When completing an assessment, the Care Coordinator reviews with the individual, their family and/or support network, the range of services and supports available and assists in determining the most appropriate service or support available to meet their needs. If, in the professional judgment of the Care Coordinator, the applicant's needs would be most appropriately met through admission to the SPD Program, the Care Coordinator makes a recommendation to a Department of Community Services Field Assessment Officer with respect to an appropriate level of support. The Field Assessment Officer is responsible for approving a level of support determination for all adults applying for admission to the SPD Program.

At present the support options available for individuals with disabilities are:

Direct Family Support (DFS) Program

This option provides funding to enable families to purchase respite services in order to assist families to care for a family member with a disability at home.

Independent Living Support (ILS) Program

This option is available to eligible individuals with disabilities. The ILS Program provides up to 21 hours a week of supports and services to eligible persons who are semi-independent and require minimum support in their own apartment or home.

Alternative Family Support (AFS) Program

This option supports individuals with disabilities in an approved, private family home. Support and supervision is provided for up to two individuals unrelated to the AFS Provider. The program expands the range of sustainable options available in the community and allows individual needs to be met in a more flexible and personal manner. People in this program will receive support with basic routine-care activities such as dressing, eating, bathing, and routine home and community activities.

Residential Options

This grouping of residential support options currently includes Developmental Residences, Group Homes, Residential Care Facilities, Adult Residential Centres, Regional Rehabilitation Centres and Small Option Homes.

Admission to a residential option occurs through the DCS regional offices. The person and/or family may indicate a preference of type of setting, as well as location. Once assessment and determination of program eligibility is completed, the applicant's name is placed on a waitlist until a vacancy becomes available in an appropriate residential setting. To the greatest extent possible the individual's choice will be considered. Each regional office maintains its own waitlist and manages the utilization of all residential resources in the region. The current system can be improved to address the following:

- Eligibility and assessment is by type of residential setting rather than type of supports required. In other words, a person with a disability is eligible for admission to a Residential Care Facility, a Group Home, Developmental Residence, Adult Residential Centre or Regional Rehabilitation Centre. Consequently, the supports needed must "conform" to the placement available.
- Waitlists are maintained regionally according to regional policy. As the boundary lines between residential placements have become blurred and there has been limited capacity in the sector, a person may receive a dual classification, e.g. be approved for either a Group Home or a Residential Care Facility level of support. Consequently, one person may appear on a regional list more than once. Also one person may appear on one or more regional lists.

- A provincial waitlist does not exist. To determine the total number waiting for supports at any point in time, manual manipulation of four waitlists is required.
- Residential resources are inequitably distributed. In the regions with large numbers of Adult Residential Centre and Residential Care Facility capacity, fewer Group Homes and Developmental Residences have been established.
- There has been no designation of provincial resources. Regional Rehabilitation Centres are located only in the Western and Cape Breton regions and other regions requiring this level of support must line up in one of the regional queues. There is no way of ensuring, on a provincial basis, that the person most in need of supports will be the one who is offered placement. This contributes to a cycle of emergency situations.

Table 2: Consolidated SPD Waitlist*by Type of Placement Including the Small Options Compiled over February/March 2007

	AFS	ILS	RCF	GH-PD	GH-MD	GH-ID	DR	ARC	RRC	Total - (those in placement)	+ Individuals on SO list	Total
Central	29	38	3	6	13	22	8	7	17	143 - (22)	91	212
Eastern		2	3	1	7	17	13	3	7	53 - (10)	-	43
Northern	2	26	1	3	4	20	5	4	3	68 - (9)	-	59
Western	3	24	9	-	12	26	15	2	10 + 3 Psycho- geriatric	104 - (39)	11	76
Total	34	90	16	10	36	85	41	16	40	368 - (80)	102	390

* By Region of Residence

The four regional waitlists were examined in order to develop provincial waitlist numbers. Considerable care was taken to ensure that individuals were only counted once, however, it is impossible to guarantee the presented numbers. As the waitlist changes daily and is a snapshot in time only, the numbers depicted in Table 2 above should be considered approximate.

• Action / Discussion Item

A provincial waitlist policy does not exist and there is no single entry access point for residential admissions. What are the priorities for residential admissions on a provincial and a regional basis? What role should provider agencies have in the admission process?

9.4 Service and Support Gaps

1. The system is 'grid-locked". Individuals supported by the SPD Program stay with the program for long periods, many for a lifetime. The lack of capacity means that individuals tend to remain where they are even if the type of setting is no longer appropriate to their support needs. Special needs costs have escalated as a result.

The impact of opening one Independent Living Support (ILS) arrangement can be profound on persons with disabilities and the whole system. A provider in the Eastern Region cited the following example:

"We opened one Independent Living Support. This enabled one of our clients in a Group Home to move into a less intrusive environment. The vacancy in the Group Home meant that a person living in an Adult Residential Centre moved to a Group Home and the space generated in the ARC was filled by an individual living in a Regional Rehabilitation Centre. The RRC bed was taken by a person waiting for this type of setting. All of this happened within 24 hours."

- 2. Approximately 400 persons with disabilities in Nova Scotia are on a waitlist to access supports (see Table 2).
- 3. A policy decision is needed on whether children in care remain in the place they call "home" or do they transition to the adult residential program upon reaching their nineteenth birthday. Families with children with disabilities living at home currently receive funding and support through the Direct Family Support for Children (DFSC) Program, providing they meet the program criteria. Over 1,200 families are in this program. For the majority of these families, the DFSC Program is enabling them to provide care to their children through funding for respite and items of special requirement. There are occasions when families reach the point where no amount of respite will help to ease the day-to-day stress. These families make the difficult decision to request out-of-home support.

To date in this province, 38 children and youth with disabilities are living outside of their family home in 16 Small Option Homes. Of these, 22 have been admitted into a residential support option because their families were no longer able to support them at home, and 16 were placed due to child welfare protection concerns.

Table 3:	Children	in	Placement
	March 2	00	7

Total # of Small Option Homes in Nova Scotia	16
Children admitted at the request of family	22
Children admitted due to child protection	16
Total children and youth with disabilities in Nova Scotia living outside of family home in licensed Small Option Homes.	38

• Action / Discussion Item

Upon reaching their nineteenth birthday, should children in care remain in their current home or should they be transitioned to the adult residential program?

- 4. While the *Vocational and Day Program Review* is expected to address program capacity other issues require attention. These issues include responsiveness and appropriateness issues within Adult Service Centres and the limited pre-vocational and vocational programming available for persons with long-term mental illnesses. In addition to increasing the day programming for individuals currently supported by the SPD Program, an increase in day programming capacity will be required with any increase in residential capacity.
- 5. A flexible and responsive respite program can prevent or delay a request to have a family member leave the home. Although the residential sector is involved only in the provision of respite beds, the benefits of an enhanced respite program have been identified. At present a Regional Respite Program is offered, however, this is limited to families with children and youth with disabilities. With the implementation of the Direct Family Support and the enhancement of the Alternate Family Support Programs, an evaluation of respite services is warranted to consider expansion or enhancement to include adults with disabilities. Any decision to increase the number of respite beds in the residential sector should be predicated on evidence-based need. At present, due to lack of capacity within the sector, a number of designated respite beds are being utilized for long-term residential support purposes rather than the intended purpose of respite.
- 6. Presently there are no formal transition programs to assist individuals whose support needs have changed. Individuals whose support needs increase need to be able to move seamlessly to settings that will provide a more structured environment. With the appropriate interventions over an interim period, many individuals could return to their home settings. A parallel stream is the planned transition of persons with disabilities to a less intrusive environment. The design for a portion of the Community Homes in each region could include space for a transitional or training unit to prepare persons for more independent living.
- 7. No formal program exists to assist providers and family or alternate caregivers to appropriately support persons with complex needs and/or challenging behaviors. The development of an interdisciplinary outreach team in each region to provide this support could potentially prevent a number of emergency placement situations and enable more individuals to remain in their homes.
- 8. A gulf exists between the current Independent Living Support (ILS) program and the residential program. The current ILS program, while widely endorsed by persons with disabilities and provider agencies, limits supports to 21 hours per week. Individuals requiring a higher level of support are waitlisted for residential support, which is a more expensive support option. The development of an enhanced community-based program to bridge this gap would enable more individuals to be supported in the community and reduce the strain on the residential sector.

- 9. The support needs of the frail elderly and the frail elderly with disabilities are not homogeneous. At present the Nursing Home setting is utilized for the segment of both populations who require nursing care. Consideration needs to be given to the development of a specialized program for the frail elderly with disabilities either within the Nursing Home or SPD Program.
- 10. Private enterprise has played a strong role historically within the Nova Scotia Health and Community Services sector. Approximately one-third of the Nursing Home beds in this province are privately owned and operated for-profit. Twenty-four of the 26 RCFs are private for-profit as are one-third of the Small Options operating under the jurisdiction of the Department of Community Services.

In an environment largely devoid of standards, what incentive, other than altruism, does a provider have to go beyond the minimal licensing requirements (Sossin, 2003)? While the implementation of the new funding strategy should go a long distance in creating greater transparency, the importance of establishing standards and monitoring performance against same cannot be overstated.

10. Moving Forward: Influencing Factors

The design and capacity requirements of an appropriate residential program for persons with disabilities will be influenced by a number of factors. Some are grounded in the existing philosophy of the Department of Community Services while others are the result of comprehensive research and study. Also relevant demographic and environmental factors, while their impact cannot be precisely quantified, must be considered when projecting future demand for program supports.

10.1 The United Nations Convention on the Rights of Persons with Disabilities

In 2006, the Plenary of the United Nations General Assembly adopted by consensus the Convention on the Rights of Persons with Disabilities and the Optional Protocol. Generally the Convention is intended to ensure persons with disabilities enjoy full participation in society and can contribute to the community to their full potential. The Convention marks a shift in thinking about disability from a social welfare concern to a human rights issue, which acknowledges that societal barriers and prejudices are themselves disabling.

Article 19 of the convention has particular reference to the Review of Residential Services. It states:

- "a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obligated to live in a particular living arrangement;
- b. Persons with disabilities have access to a range of in-home, residential and community support services, including personal assistance necessary to

support living and inclusion in the community, and to prevent isolation or segregation from the community; and

c. Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs."

In March 2007, the Convention was opened for signature and ratification. Canada added its signature to the Convention on March 30, 2007.

10.2 "Out of the Shadows at Last"

Epidemiological data indicates that, each year, roughly 3 percent of the population will experience a severe mental illness and 17 percent will experience a mild to moderate mental illness. According to the 2000/2001 Canadian Community Health Survey, the rate of depression in Nova Scotia, at 8.7 percent, is higher than the rest of the country which is at 7.1 percent (Saunders, 2005).

The Final Report of the Standing Senate Committee on Social Affairs, Science and Technology, chaired by Senator Michael Kirby released its report, *Out of the Shadows At Last: Transforming Mental Health, Mental Illness, and Addiction Services in Canada* in May 2006. This report has the potential to become a watershed document in the delivery of services and supports to the persons living with mental illness in this country. The 2007 federal budget, through the allocation of funds to establish the recommended Mental Health Commission, is a positive indication of the report's potential to shape future public policy in this country.

The report indicates a national consensus exists on its vision of a "recovery-oriented, primarily community-based, integrated continuum of care". While "consistent Canadian and international evidence shows that (the) increased provision of services and supports in the community are highly beneficial", the report categorically states that what is required is "the right blend of institutional and community-based supports and services". In other words, what is required is a range of supports and services with primary emphasis on building and integrating these supports in the community.

This report also indicates that work has been found to play an important role in recovery from mental illness. "Surveys show that most persons living with serious mental illness want to work and see employment as a primary goal. But few are employed. This leads to impoverishment and reduced social engagement, which in turn may worsen mental and physical illnesses. Also, it contributes to feelings of worthlessness and depression, can lead to substance abuse, and results in dependency on income security programs for survival".

10.3 Deinstitutionalization

Deinstitutionalization is a complex process involving funding, service delivery models, models of intervention and staffing. It is a process that requires careful and coordinated planning at all levels: government planning, inter-agency planning, and person planning (Griffiths and Brown, 2006).

In 1996, the Department of Community Services released the discussion paper, *Moving Towards Deinstitutionalization*. This paper outlined "the policy directions the Department of Community Services feels should be pursued in order to effectively and responsibly replace adult institutional services with community living alternatives for persons with mental handicaps and mental disabilities".

Research from other jurisdictions has concluded that overall the benefits of deinstitutionalization for the majority of persons with disabilities outweigh the potential risks. There is a cautionary note, however, in that research has also shown that some individuals in the community may enjoy little real participation in the wider community and experience even higher degrees of marginalization (Hennen, 2006).

Nova Scotia began to reinvest in community-based supports under the Services for Persons with Disabilities Renewal Initiative. The Department of Community Services introduced three new programs for persons with disabilities as a result of research, consultation and feedback. The Direct Family Support Program was implemented in January 2005; the Independent Living Support Program was initiated in January 2006; and in June 2006, the Alternate Family Support Program was introduced. (See pages 13-14 for program descriptions).

The infusion of additional funding for these new support programs is welcomed. This front-end investment is a tangible demonstration that government is moving forward, in a strategic way, to live the philosophy embodied in the 1996 paper. This investment will need to be continued into the foreseeable future in order to support persons with disabilities in the least intrusive environment appropriate to their needs.

Today's issue, however, is not whether the direction to community living is the right one. The World Health Organization, the United Nations and indeed most countries have embraced equal rights for persons with disabilities. This includes community inclusion and the support of as many persons as possible in community settings. Today's issue is the continued relevancy of facilities in the continuum of services and supports for persons with disabilities.

Dr. Brian Hennen in a series of articles, *Priorities for Persons with Developmental Disabilities and Their Families in 2006*, indicates that the small number of individuals with severe, combined developmental disabilities, physical disabilities and mental health challenges may require continuous, specialized, experienced, collaborative and integrated management which is unlikely to be found in most domains. He sees the community environment "as not yet ready, unstable and risk-prone" to appropriately support this population. The continued availability of ARC and RRC residential options to support high need individuals is warranted in this province at this time.

• Action / Discussion Item

As capacity is increased in the residential sector it is anticipated that larger facilities will transform into "Stabilization Centres" rather than long-term living arrangements for most people who require that level of service.

10.4 Jurisdictional Update

An extensive jurisdictional review was conducted in 2003-2004 during the Community Supports for Adults Renewal Project. Care is to be exercised when comparing approaches among provinces, as the jurisdictional boundaries are not always similar.

For example, the Nova Scotia Department of Community Services, Services for Persons with Disabilities Program, has jurisdiction for services provided to support three populations of individuals: persons with intellectual disabilities, persons with long-term mental illness and persons with physical disabilities. In several other jurisdictions, the responsibility for these services may be shared among Departments and Ministries.

For this review of residential services, the focus was on major changes in policy direction and on emerging trends in service delivery over the past three years. Appendix I reports on these findings. In summary:

The Major Trend in the Provision of Services and Supports to Individuals with Long-Term Mental Illness

The major trend in the provision of services and supports to individuals with long-term mental illness is the increased emphasis and shifting of resources towards a supported housing model. The philosophy behind this shift is the promotion of individual choice of not only where individuals live but of the supports and service they may decide to access. Three predominant types of housing are emerging:

- 1. Apartment settings where individuals rent apartments and the services and supports are accessed as required or as the individual desires. There are many variations of the apartment living model: satellite apartments, block apartments with services and supports onsite, congregate living with communal meals and/or washrooms.
- 2. Group Homes where individuals are assisted in developing life skills to move on to a more independent setting. The extent to which Group Homes are used varies across the country, however, the majority of individuals living in these settings previously lived in larger facility settings and requires supports to learn or maintain life skills. Group Homes are not staffed 24 hour per day in all provinces; however, supports and services are always accessible. The occupancy range per home is between 6-10 residents.
- 3. Alternative family support where an individual lives with a family who provides or assists with access to services and supports.

The Major Trend in the Provision of Services and Supports to Individuals with Intellectual Disabilities

The major trend in the provision of services and supports to the individuals with intellectual disabilities is the expansion of residential options with a focus on smaller informal settings. The types of options that are being either utilized or expanded are:

- 1. Individualized funding which can be used to purchase residential supports from service providers, but may also be used to rent apartments or homes.
- 2. Alternative family homes where an individual lives in an approved home within a family oriented setting. While Alberta is moving away from this model, Saskatchewan has one of the most formalized programs in this regard with the greatest number of people to a home (5). In Saskatchewan all alternative family homes are licensed.
- 3. Group Homes where individuals are assisting with developing or maximizing life skills. The usual occupancy range is between 4-6 residents. All residential options tend to be licensed, accredited, or approved.

System structure and organization of supports and services for persons with disabilities has changed significantly in British Columbia, Alberta, Ontario, Newfoundland and Labrador and Prince Edward Island. In British Columbia, the responsibility for delivering disability services was removed from a branch in government to a crown agency, Community Living British Columbia (CLBC). This agency, with a board appointed by the Minister, has responsibility for the development and submission to the Minister of the broad service, funding and capital plans. Both vocational and residential supports are under the mandate of the CLBC. CLBC board members may be family members, and service providers; however, two of the board members must be persons with an intellectual disability. The intention is to move toward the creation of a number of community boards. The role and authority of these boards has not yet been defined. A Residential Options Project has been launched (2006) to increase an individual's freedom to choose from a variety of residential options.

In Alberta, the Persons with Developmental Disabilities Provincial Board have been brought back into the Ministry of Seniors and Community Supports as a specific departmental branch (2006). The six community boards that previously reported to the provincial board now reports directly to the Ministry. This change was undertaken to promote the coordination of, and consistency among, disability programs and services across the province. The community boards are responsible for assessing and prioritizing the community's needs; strategic planning for service delivery including the coordination of vocational and/or day activities; engaging with service providers, advocacy groups, families and clients; and monitoring and evaluating service delivery. Community boards have individuals with disabilities as board members or observers.

Ontario is currently reviewing, with the intent to transform, its disabilities program. Since 1987, three large facilities have been phased out. In 2004 it was announced that the three remaining facilities would be closed by March 31, 2009. The goal of the transformation is to strengthen community based supports and residential settings to accommodate the closure of larger facilities, and to meet the need for residential placements as parents of individuals with developmental disabilities age. Eligibility requirements are also under review.

Also in Ontario, the governance structure for services to persons with mental illness was scheduled to change in April 2007. The Ministry is devolving responsibilities to the Local Health Integration Networks (LHINs) to give communities more responsibility for decision-making on health related issues at a local level. It is anticipated that health services will be more integrated and responsive to community strengths, needs, and priorities.

In Newfoundland and Labrador, the Regional Health and Community Service Boards have recently assumed the responsibility for funding service providers. This devolution of funding responsibility was part of the long-term plan created when the Department of Health and Community Services assumed responsibility for the delivery of programs and services for persons with disabilities in 1998.

In Prince Edward Island, the Department of Social Services and Seniors, Disabilities and Social Programs has dismantled its five regions and assumed operational responsibilities. This was undertaken to enhance service delivery and to decrease the number of administrative units.

10.5 Aging in Place

The Nova Scotia Departments of Community Services and Health have embraced a philosophy of aging in place, defined as "growing older in the place the individual calls home until the care/ support provided by the community/government/family/agencies reach a threshold beyond which the individual can no longer safely remain in their homes".

This philosophy will have a significant impact on the residential sector. The design of the current residential infrastructure is not conducive to an aging population. Table 4 presents a profile of the residents' age and current infrastructure age and design.

	RCF	GH	DR	ARC	RRC
Average Age of Residents	55.5	44.3	40.2	54.9	44.4
Average Estimated Age of Structure *	70	58	25	57	40
Number of Structures Over 50 Years of Age	19 (76%)	19 (48%)	6 (16%)	3 (43%)	
Number of 2-3 Story Structure with no Elevators**	23 (92%)	21 (53%)	12 (32%)		-
Number of Structures with no Wheelchair Ramp	12 (46%)	26 (65%)	13 (35%)	-	_

Table 4: Residential Review – Infrastructure Highlights

* The average estimated age of structure is an inconsistent proxy for infrastructure condition, as it does not show the level of building maintenance. The average age is an indicator of the amount of investment in new infrastructures over the past 20 years. ** Most agencies will have at least one bedroom plus bathroom on the 1st level.

Adding urgency to the situation is the research that has shown dementia occurs 20 to 30 years earlier in persons with Downs Syndrome than in other populations. The required core competencies for staff are not directed at providing supports to the frail and elderly. A reconfiguration of staff with a new skill set mix will be required to support an aging population. The needs of the frail elderly and the frail elderly with disabilities are not homogeneous. A special skill set and specialized programming are required to effectively support persons with disabilities.

10.6 Nova Scotia Demographic Indicators

The May 16, 2006 Census shows the population of Nova Scotia has grown only by 0.6 percent since 2001. Only the Central Region has experienced population growth. See Table 5.

Western	2006	2001	% Population Change
Yarmouth	26,277	26,843	-2.2
Shelburne	15,544	16,231	-4.4
Digby	18,992	19,548	-2.9
Queens	11,212	11,723	-4.6
Annapolis	21,438	21,773	-1.6
Kings	60,035	58,866	1.9
Lunenburg	47,150	47,591	-0.9
Hants	41,182	40,513	1.6
Total	241,830	243,088	-0.5
Constant			
Central Halifax	372,858	359,183	3.7
Total	372,858	359,183	3.7 3.7
Iotai	572,050	339,103	5.7
Northern			
Cumberland	32,046	32,605	-1.7
Colchester	50,023	49,307	1.4
Pictou	46,513	46,965	-1.0
Anitgonish	18,836	19,578	-3.9
Guysborough	9,058	9,827	-8.5
Total	156,476	158,282	-1.2
Eastern			
Inverness	19,036	19,937	-4.7
Victoria	7,594	7,962	-4.8
Cape Breton	105,928	109,330	-3.2
Richmond	9,740	10,225	-5.0
Total	142,298	147,454	-3.6
Provincial Total	913,462	908,007	0.6

Table 5: Population Change 2001 -2006

Source: Derived from information provided through Statistics Canada2006 Community Profiles. <u>http://www12.statcan.ca/english/census06/data/profiles/community/Ind</u>

Nova Scotia has the oldest population in Atlantic Canada and the third oldest in Canada. This is significant in respect to the number of aging parents caring for adult children with lifelong disabilities and the potential impact on the future demand for residential supports.

During the course of the Review, the Department of Community Services regional office staff and the provider community cited stories of aging parents, within their own circles of friends and acquaintances, who were caring for adult offspring with disabilities. Many had not made plans for continuation of support. The research of MacLellan and Norris adds light to this situation: "Research indicates future planning can be a difficult and emotionally trying process compounded by the lack of services and suitable options, restrictive policy eligibility, previous experiences with the service delivery options, perceptions of formal support, and family dynamics arising from caring for sons/daughters with lifelong disabilities".

It was not possible, within the limits of the information available, to quantify the number of aging parents caring for adult children with disabilities at home. The Department of Community Services Eastern Regional Office, however, compiles a "planning placement" list of those individuals who have approached the office for placement at a later date. At present this region has identified 23 families who potentially may be added to the waitlist for supports and services.

The birth rate in Nova Scotia is projected to decline, with an annual 8,500 births, predicted by the year 2021. In terms of the rates of disability in Nova Scotia, in the most recent survey of persons with disabilities, 7.9 percent of Nova Scotians were identified as having severe or very severe disabilities. This is significantly higher than the national average of 5.9 percent. In addition, Nova Scotia has the lowest disability-free life expectancy in the country (Hayward and Colman, 2003).

Although the population overall is not experiencing high growth, the aging of the population and the high disability rates imply a consistent future demand on the SPD Program. When the age of the current residents in the program is factored in the equation, capacity is projected to be an issue for at least the next 15 to 20 years.

10.7 Department of Health Continuing Care Strategy

Recognition is growing of a shared responsibility for continuing care between the Nova Scotia Departments of Community Services and Health. In 2006 the Department of Health released its Continuing Care Strategy to guide program and policy development over the next 10-year period.

A number of the Department of Health's key strategic action areas have application to the Services for Persons with Disabilities Program such as:

- Developing a transportation strategy to enable greater mobility and independence.
- Expanding housing options in the community.
- Expanding the equipment loan program.
- Developing a provincial palliative care program.
- Promoting oral, hearing and vision health.
- Delivering primary care in continuing care agencies.
- Responding to acquired brain injury support and care needs.

A collaborative approach to these strategies between the two Departments would ensure an integrated and consistent program applicable to all Nova Scotians requiring continuing care services and supports.

11. Future Directions: Enabling Factors

"The significant problems we face can not be solved at the same level of thinking we were at when we created them".

(Albert Einstein)

The following factors have been identified, as necessary to enable individuals with disabilities to live to their fullest potential within their communities.

11.1 Philosophical Framework for the SPD Program

The SPD Program has operated without a defined philosophical framework to guide decisionmaking and service delivery. During the review, departmental staff and provider agencies cited the need for strong leadership and a future vision to give a "sense of direction" for the overall SPD Program. It is imperative that this fundamental framework be developed and approved as soon as possible.

A philosophical framework will consist of a vision statement, a mission statement and guiding principles. A vision is a statement of the preferred future. It is a compelling description of the state and function of an organization or system once it has implemented its strategic plan. Mission is the mandate or what a program sets out to accomplish. Guiding principles are a set of the beliefs and values that will drive decision-making as the organization/system pursues its vision and performs its mission.

Concurrent with the Review of Residential Services, SPD staff commenced work on the development of a philosophical framework for the SPD Program. During the Review, this work was presented to a focus group of Department of Community Services and Department of Health staff and as well to the DCS Regional Administrators. The consensus is that that this framework presents an appropriate direction for the province, and is the foundational piece in the residential renewal process. The framework includes the vision, mission and guiding principles for the Services for Persons with Disabilities Program.

• Our Vision

To enable individuals with disabilities to live to their fullest potential within their communities.

• Our Mission

To enhance a social support system that builds on community inclusiveness and promotes independence, self-reliance and security for individuals with disabilities.

To achieve this through the provision of a continuum of supports and services, and through leadership and collaborative relationships with individuals, families, support networks, service providers, communities and other government Departments.

• Our Guiding Principles

Persons with disabilities will be recognized for their individual abilities and their inherent worth.

We believe in:

1. Fostering Independence and Self-reliance

- Independence and self-reliance are fostered and promoted to the fullest extent possible within each person's capacity. Placement is directed at the least intrusive environment appropriate to the individual's assessed needs. Individual Program Planning (IPP) is specific to the individual with the goal of maximizing each person's ability to live his/her life as independently as possible.
- A full range of supports is developed for persons with disabilities ranging from independent living supports to more structured residential supports for individuals with complex needs. Capacity is sufficient within this range of supports to permit individuals to move freely through the continuum as their needs change. Governance structures within defined geographical boundaries facilitate ongoing strategic planning and enable adjustments to capacity as demonstrated by need.
- The system allows persons with disabilities to experience the dignity of risk.

Impact on Policy, Decision-Making and Operations

- The Independent Living Support, Alternate Family Support and Direct Family Support programs continue to expand, as appropriate, and to be enhanced to address the support needs of individuals with disabilities.
- Programming is provided within all residential settings to support persons with disabilities to attain and maintain the life skills that facilitate independence and selfreliance.
- Outreach programs support individuals with disabilities to remain in the least intrusive environment for as long as possible.
- Education is provided to DCS staff and to the provider community to understand this philosophical change.
- SPD Head Office and Regional Office staffing complements are appropriate to their responsibilities.
- Integration and coordination among service providers is encouraged and facilitated.

2. Building on Community Inclusiveness

- Persons with disabilities are supported in accessing the community so they can participate in meaningful life experiences.
- Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance to support living and inclusion in the community, and to prevent isolation or segregation.
- Relationships are developed within the business community and within the social fabric of the community to strengthen/enhance options for life, social and vocational skills development for persons with disabilities.
- Service providers of adult day programs and of residential support programs work collaboratively to ensure that persons with disabilities have access to a broad range of day programs conducive to quality of life and to the attainment or maintenance of optimal independence.
- Persons with disabilities and/or their families are supported to enable them to serve on agency Boards of Directors and to be involved in the day-to-day agency decisions that will affect their quality of life.
- Persons with disabilities reside in well-maintained and appropriate residences that reflect the character of the community. The location of these residences facilitates community inclusion.

Impact on Policy, Decision-Making and Operations

- Substantive accessibility issues and the quality of accommodations within current residential settings need to be addressed.
- Quality of life standards that reflect community inclusiveness are developed, implemented and monitored. Service providers are accountable for working collaboratively to identify and develop vocational and social opportunities and to build relationships with their local business communities.
- Decision-making around the location of new residential settings for persons with disabilities reflects the goal of community inclusiveness.
- Adult Service Centres broaden the range of vocational supports appropriate to the life cycle of persons with disabilities.
- Day programming opportunities and supportive employment for persons living with a mental illness are increased. To reflect the shared responsibility for mental health that exists between the Community Services and Health Departments, this strategy is developed collaboratively.

- As transportation is a major issue especially in rural Nova Scotia, the Departments of Community Services and Health collaborate on the development of a transportation strategy.
- Individuals with disabilities and/or their families are represented on system governance structures, task groups, committees, etc., which address issues relating to persons with disabilities.
- Mechanisms that enhance coordination between Adult Service Centres and the residential sector are promoted.

3. Person-Centred Planning

- Person-centred planning is gaining and acting upon the individual's own wishes and desires within the range of supports appropriate to the individual's needs. It recognizes that persons with disabilities have likes and dislikes, have life goals, and within individual capacity, have a level of control over their own destiny.
- An individual has the choice between a private room or a shared room.

Impact on Policy, Decision-Making and Operations

- Education to clients and families, to providers and to departmental staff is provided to understand and accept a philosophical shift - one that moves away from a custodial and paternalistic model to one which empowers and supports individuals with choice and decision-making opportunities.
- A full range of living supports from independent living supports through to facility-based supports is available to persons with disabilities. Capacity allows choice within supports appropriate to an individual's needs.
- While recognizing that some persons with disabilities desire shared bedrooms, the accommodation standard for new construction and the residences requiring extensive renovations will be primarily private bedrooms.

4. Working Collaboratively

- Government and service providers operate with a shared vision and are working together for the same ends. There is respect for the role that each party plays. Roles, responsibilities and accountabilities are clearly delineated. It is recognized that, within a fixed point of responsibility, both government and providers share the ownership of problems and their subsequent resolution. Both parties work toward win-win solutions.
- In the provider community, there is respect for diverse opinions and for the roles that various agencies play in the provision of a full range of supports for persons with disabilities.

- Government and providers seek out opportunities to co-ordinate supports and services, to share expertise and to facilitate both horizontal and vertical integration.
- The Department of Community Services works with other government departments such as Health, Education and Justice to strengthen the coordination of supports and programs. Policies and standards are harmonized between the Departments of Health and Community Services.

Impact on Policy, Decision-Making and Operations

- A communications strategy is developed to engage DCS staff and service providers in discussing the philosophical framework and its impact. This process will be intensive and will need to occur as a first step in the residential renewal initiative.
- Regular meetings, designed for two-way dialogue, with stakeholders are held.
- The responsibility for system governance, agency governance, the interface between the two, and the role of government in agency operations is clarified.
- Future initiatives, such as the development of standards, include opportunities for the meaningful involvement of providers and consumers.
- Incentives to encourage shared services and supports within the provider community are developed. Respite and outreach programs are developed on a regional basis.

5. Developing a Sustainable and Equitable Range of Supports

- All persons with disabilities are treated equitably. Persons living with a mental illness have the same entitlement to supports, as do persons with other disabilities.
- Supports residential and otherwise are distributed equitably based on demonstrated need. The range of supports put in place recognizes the fiscal limitations of the province.
- New programs and supports that cannot for the reasonable future be adequately sustained are not created.
- Providers, regardless of ownership or proprietary status, are treated fairly and equitably.
- Persons with disabilities are assured of a consistent level of accommodation, quality of life and programming, regardless of geographical location or type of residential setting.

Impact on Policy, Decision-Making and Operations

• A realignment of residential settings will be required over the longer term, which may mean a change in the type and volume of supports in some communities and the creation of new and additional supports in others.

- The future placement of children with disabilities in the children's program, as they reach the age of majority, is addressed.
- A new funding strategy to provide consistency in funding decisions among providers is implemented. The annual business planning and budgetary processes recognize the need to regularly review operating costs.
- Standards are developed, implemented and monitored.

6. Becoming Accountable, Transparent and Maintaining Open Communications

- Decisions are made on the best evidence available and are communicated with a supporting rationale.
- Responsibilities and expectations among residents/families, government and service providers are delineated in service agreements.
- Policies and standards are developed and monitored. Providers are held accountable for the outcomes achieved with public dollars.

Impact on Policy, Decision-Making and Operations

- A long-term strategy is developed to provide a robust management information system within the Department and ultimately within the provider community.
- Service agreements are developed between government, residents/families and provider agencies.

7. Accessing Research and Best Practices to Guide Development

- Policy and program decisions will be based on the best information available to guide decision-making.
- Decisions will be evidence based.

Impact on Policy, Decision-Making and Operations

- Stronger linkages with the academic community are secured both by the Department and provider agencies.
- Relevant mechanisms and staffing are in place to ensure the evaluation of new and ongoing programs, the effectiveness of standards in assuring consistent outcomes, and in the overall strategy to provide services and supports to persons with disabilities.

Recommendations

• The Department of Community Services adopts a philosophical framework for the Services for Persons with Disabilities Program; and this framework includes a vision, mission, and a set of principles to guide decision-making.

• A strategy is developed to communicate this philosophical framework, and its implications to residents/families, departmental staff and the provider community.

11.2 System Structure and Organization

Integration is the combining of parts so that they work together to form a whole. It may occur vertically or horizontally. Coordination is the organized working together of multiple parts to bring about a purposeful result. Coordination is an outcome of integration.

Provincial jurisdictions in Canada have, over the past 10-15 years, moved to integrate and subsequently coordinate services within various components of the public sector. Health service delivery is commonly referenced in this regard given the move to create regional health authorities, or a derivative therefore, in most provinces. Fiscal imperatives and the potential of operational efficiencies may have been the initial driver, but today the opportunity to align mandates and programs among numerous service agencies to minimize duplication and bridge gaps in supports and services is the primary objective. For integration to be successful, it must serve the objective of improving the range, affordability, quality, and accessibility of services and supports (Hollander, 2005).

There is virtually no horizontal integration within the residential sector. A variety of providers including those that are disability-based, faith-based and community-based characterize the sector. Providers also have varying degrees of educational preparation for their role. Forty-five of the 93 provider agencies operate one site only. The Review revealed that agencies in a close geographic proximity seldom meet or talk together and as a result, there is often limited understanding of the mandates of neighboring agencies.

Both the Kirby Report on Mental Health and the work conducted by Marcus Hollander for the Department of Health's Continuing Care Strategy advise that it is important to allow agencies, communities and regions to pursue forms of integration and coordination that are appropriate to their particular situations and circumstances. Hollander advises that integration needs to be seen as a means to achieving a goal and not as an end in itself. He identifies, as potential strategies, providing funding for "boundary spanning linkages and related activities", and making intersectoral and cross-agency collaboration a key performance requirement.

Governance refers to the part of the system with accountability for system performance, and the authority to set strategic direction and policy and to oversee general management and the use of resources. Administration is the domain that supports operations on a daily basis and includes the infrastructure for finance, information, and human resources (Kirby, 2006).

Within the residential sector currently, governance is shared between government and 93 service provider agencies. Government has the broad responsibility for the entire system - the overall planning, funding, setting of policies and standards, and the monitoring of performance. Government is ultimately accountable for the prudent use of public monies, the processes used and the achievement of desirable outcomes for the persons served. Outcomes are essentially the long-term desired impacts of public policy on a group of people.

The governance function within individual provider agencies has essentially the same accountability albeit at an organizational level rather than at a system level. Agencies should have a vision, mission, and values, and be engaged in long-term strategic planning. Likewise governing boards (and owner/operators) should be concerned about the prudent use of public monies, be seeking ways to enhance effectiveness and achieve operational efficiencies through the sharing of services and supports, and be also concerned about the outcomes they are producing.

The Review found most agencies focused on their own operations and in particular, financial stability. Several agencies commented on the need to clarify the roles, responsibilities and accountabilities of local agency boards. It became obvious during the Review that both government and provider agencies desire a collaborative relationship with respect, honesty and recognition of the interdependence and authority of each party.

The Review time lines did not permit a thorough analysis of various governance models. A best practice, however, is the strengthening of the voluntary governance system where local decision-making is vested in a board of competent and committed individuals who know their community and its needs. Boards should be accountable to realize all of the resources of the community and to become stewards of the full range of human and financial resources available.

"The appropriate role of government relates not to service delivery of social services but to ensuring and enhancing the quality, safety, fairness, accessibility, responsiveness, efficiency, equity and effectiveness of those services. This set of responsibilities entails the capacity of government (whether through legislation, regulation, policy or contract) to develop and implement standards of evaluation and accountability (Sisson, 2003)."

Recommendations

- Integration, coordination and multi-site management models are promoted by the Department, while regions and communities pursue forms of integration that are appropriate to their particular situation and circumstances.
- Integration and coordination, e.g. inter-sectoral and cross-agency collaboration, become a performance requirement in service agreements, in requests for proposals and in governance and management standards.
- The Department encourage integration and coordination by:
 - Moving towards regionally based programs for outreach support and respite programs.
 - Creating incentives that encourage providers to demonstrate coordination, collaboration and integrative behaviors.
 - Removing barriers that thwart the formation of partnerships.
- This issue is re-studied in two to three years and that other mechanisms or structures to enhance integration and coordination are explored at that time.

- Governance accountability, roles and responsibilities within the SPD Program, and the role of government in agency operations are clarified; and that Boards/owners within the provider community participate with government in this undertaking.
- Governance and leadership standards be developed; and that adherence to these standards be a performance requirement in service agreements, and in the specifications for new or enhanced programs.
- Agency governing Boards are encouraged to augment Board composition by creating a space(s) on their Boards for residents and/or their families with full voting rights.
- The Department invests in the sector's governance and leadership by funding Board and leadership/management development programs. These programs should also serve to enhance integration and coordination within the sector.

11.3 Determining Client Need and Appropriate Support Options

The current eligibility and assessment system assesses individuals by suitability for a particular type of residential setting rather than by type of supports required. Consequently, the individual must "conform" to the placement available. In those instances where the support needs exceed that available within a particular residential setting, special needs funding has been provided to make available the additional staffing required to safely support the client.

Within the continuum of SPD residential supports there are individuals who are supported in settings that were designed for higher needs individuals while others are supported in settings that were designed for individuals who are more independent. The result is that we potentially have a significant number of individuals in settings across the residential sector whose needs could be better served elsewhere. A reassessment of all individuals in residential settings and on the waitlists is required to determine precisely, over the longer term, where and how capacity needs to be increased.

Waitlists are a tool for determining supply and demand and provide a "queue" for access to the system. The Services for Persons with Disabilities Program has several access points. Waitlists are maintained regionally. One waitlist, provincially maintained and supported with technology, is essential for the Department to perform its responsibility for broad system planning.

Recommendations

- A new eligibility and assessment tool based on levels of supports is developed on a priority basis.
- All persons with disabilities currently supported in the residential sector be reassessed using this new system.
- All persons with disabilities currently on the waitlist for service in each of the four regions are re-assessed using the new system.

- A standardized format including definitions is developed for the recording of waitlist information.
- One provincial waitlist be maintained and computerized.

The SPD Program currently operates without a provincial policy framework for placement. This creates the potential for inconsistencies within, and from, one region to another. Also, at present, the service provider has the authority to decline a proposed placement. Provided the agency is properly resourced to fulfill its mandate, and the eligibility and assessment has been conducted based on level of supports required, there should be fewer instances when a provider agency would be concerned by a placement.

Recommendations

- Policies and procedures for placement be developed which address the issues of:
 - Access points to placement.
 - Priority for placement.
 - The authority of service providers.
 - Supporting individuals to achieve the highest level of independence through the right supports and service options.

11.4 Providing Services and Supports in the Residential Sector

A. Living Options

In keeping with the guiding principles developed in Section I, a full range of supports should be developed for persons with disabilities. This range should include independent living supports through to facility-based supports for individuals with disabilities and complex needs. Supports should always be directed at the least intrusive environment appropriate to the individual's assessed needs.

For Persons Living with Physical Disabilities

Due to the relatively small numbers of persons with physical disabilities identified in each region, it is difficult to develop a comprehensive, effective and sustainable program. At present, a number of younger adults with physical disabilities are being supported in Department of Health Nursing Homes where the programming is not geared to the interests of, or to maximize the capabilities of, persons with physical disabilities. In discussions with the Department of Health, it has been determined that this Department also wishes to explore how to most effectively provide supports for persons with physical disabilities. By approaching this issue collectively, a more robust program can be developed.

• For Persons Living with a Long-Term Mental Illness

At present a large number of individuals with long-term mental illness in this province are supported in Residential Care Facilities and Adult Residential Centres. Only in the Central and Eastern Regions, where a small number of Group Homes for persons with long-term mental illness have been developed, can a broader range of residential options be offered. The Senate Report, *Out of the Shadows at Last*, provides direction:

"What is required is the 'right blend of institutional and community-based supports and services"...with primary emphasis on building and integrating these supports in the community."

"...the variety of mental health treatments and services funded by ministries of health must also be integrated with the broader range of services required by people living with mental illness that are the responsibility of the various governmental departments and agencies that deal with income support, housing, employment, etc."

For Persons with Intellectual Disability and Dual Diagnosis

The United Nations Convention on the Rights of Persons with Disabilities recommends "a range of in-home, residential and community support services, including personal assistance necessary to support living and inclusion in the community and to prevent isolation or segregation from the community". A range of supports is necessary to enable all persons with intellectual disabilities to achieve their highest level of capacity and independence through the provision of the right supports and living options. Meaningful and varied day programming including vocational opportunities must also be provided.

Recommendations

- The SPD Program of the Department of Community Services and the Continuing Care Branch of the Department of Health work collectively to develop one program geared to meeting the support needs of the persons living with physical disabilities.
- The number of Alternative Family Supports (AFS) and Independent Living Supports (ILS) is increased in each region according to demonstrated current need; and following the reassessment of all current residents and those on the waiting list, that the number again be increased according to demonstrated need.
- New Community Homes for individuals with intellectual disabilities and long-term mental illness be developed, according to demonstrated need, and be designed to support between four to eight individuals; that private bedrooms be the norm with allowance for shared accommodation across the sector.
- The Departments of Community Services and Health work collaboratively to examine innovative and community-based supported housing options for persons living with mental illness. These may include, but not be limited to, clustered apartment and assisted-living arrangements. The goal should be to provide persons living with a mental illness a choice of living arrangements that supports their inclusion in the community.
- In the shorter term, the Departments of Community Services and Health work collaboratively with the nine District Health Authorities to develop a strategy for

appropriate pre-vocational and vocational programming for persons living with mental illness.

- In the longer term that the service provider community develop a strategy to engage their communities and local businesses in supporting vocational opportunities for persons with long-term mental illness.
- Capacity and programming options be increased in Adult Service Centres and other day
 programs, and that the needs of the older persons with disabilities are considered in these
 programming options.
- Following the reassessment of residents, a policy decision is made on the future of Residential Care Facilities. Is a level of support required to bridge between Independent Living Supports and Community Homes? If so, should RCFs be redesigned, for example, as Community Homes with developmental and rehabilitative programs or as cluster living/assisted living models?
- The transformation of three-bed small living arrangements (Small Options) to Community Homes, subject to the rigors of licensure, is actively encouraged. It is recognized that this will create zoning issues in many municipalities and this will need to be considered in the development of an implementation strategy on this recommendation. In the interim, the Small Option should not be a living option offered to persons with complex needs. Persons currently supported in Small Options should be able to remain in their home, if that is the wish of the person and the family, unless the person's support needs change and a more structured and intensive environment is required.
- Adult Residential Centres (ARCs) continue to provide long term structured supports and services to individuals who cannot be appropriately supported in a Community Home setting. Following the reassessment of residents, more reliable evidence will exist to determine the ARC capacity required in the sector. It is probable that excess capacity will develop in these agencies over the long term. It may be feasible to maximize this space for specialized adult day programs or specialized programs for persons with disabilities who require nursing care.
- Regional Rehabilitation Centres continue to provide supports to individuals with the most complex needs and who require both professional clinical services as well as the specialized supports available in this type of residential setting. Regional Rehabilitation Centres should be designated as a provincial resource. Decisions on the utilization of these Centres should be made centrally and should be based on a priority list for admission.

B. New Terminology

Program terminology should be changed to more accurately reflect the new philosophical framework of the SPD Program, and to assist the public to understand the various living options for persons with disabilities.

Recommendations

- Group Homes and Developmental Residences be renamed Community Homes. Specialization within this grouping would continue, e.g. Community Home for persons living with long-term mental illness, Community Home for persons with intellectual disabilities - I, II, III. This change of terminology was previously recommended in *Renewing Community Supports for Adults Program: A Discussion Paper*.
- As Small Options and Residential Care Facilities are redesigned, that the terminology also be changed to Community Home.
- Adult Residential and Regional Rehabilitation Centres be renamed, potentially as Ability/ Rehabilitation Centres.

C. Strengthening Supports and Services

Recommendations

- An inter-disciplinary outreach service is developed in each of the four regions to provide advice and programming supports to family, alternative and agency-based caregivers; and that the host agency develop a user's advisory committee to advise this service.
- A transition program is developed in each region. This program would have two separate and distinct thrusts:
 - 1. The capacity to bring individuals back into a more structured environment for stabilization over a relatively short period of time, and
 - 2. The opportunity for persons with disabilities to learn new skills and confidences in preparation for the transition to community living.
- The Departments of Community Services and Health work collaboratively on the strategic action issues identified in the Department of Health, Continuing Care Strategy to ensure equitable programs for Nova Scotians requiring continuing care supports and services.
- Initiatives designed to make respite care services more widely available to family caregivers, and better adapted to the needs of individual as they change over time be considered.
- The Department considers the development of an enhanced community-based program to support those individuals whose needs exceed 21 hours per week, but are less then a 24/7 residential option.
- The Department evaluates programs on an ongoing basis to determine the need for any other program options.

• An aging-in-place strategy is developed for the residential sector and that this strategy addresses the appropriate care setting for elderly persons with disabilities who require Nursing Home care.

D. Quality and Standards

Few would argue against the enforcement of minimum levels of health and safety in the residential sector. This is achieved through the licensure program under *the Homes for Special Care Act*. Licensure, however, is a minimal threshold to operate. It does not address the issue of qualitative performance. The ultimate test of any program is how well it supports outcomes for the persons it serves.

In the 25 agencies visited during the Residential Services Review, very few mature quality programs were found. Only one agency is accredited by an outside agency - Kings County Regional Rehabilitation Centre that has full accreditation status under the Canadian Council on Health Services Accreditation (CCHSA).

Overall insufficient attention is placed within the residential sector on defining quality, the quality indicators, and the measurement of results against performance indicators. Standards do not exist apart from those that are agency specific. This has led to a wide fluctuation in the types and quality of programming, the types and quality of community inclusion, the quality of physical structures, and the quality of accommodations including bedrooms, common areas and furnishings.

"Articulating standards and criteria for quality of care remains the single most important building block of quality assurance and accountability in the delivery of social services (Sossin, 2003)." The *Homes for Special Care Act* authorizes the Department of Community Services to be involved in "matters respecting the standard of care to be provided and maintained in a facility". The provider community has also indicated that it would welcome the Department's engagement in the identification and dissemination of best practices and innovative service delivery models to the provider community.

While quality assurance is a public issue, it does not necessarily follow that government should undertake the audits and performance reviews. The monitoring function should be separated from the standards development function to prevent a real, or perceived, conflict of interest.

Recommendations

- The SPD Program facilitates the development of standards for its residential programs;
- Providers and their affiliated associations should be involved in this exercise; and
- The SPD Program Head Office assumes the lead on the identification, discussion and dissemination of best practices in the provision of services to persons with disabilities.

E. Increasing Capacity

With 400 persons with disabilities currently on the waitlist for supports, a number of aging parents caring for adult sons and daughters in the community, the number of children in care who may potentially be transitioned to the adult program, and the high rates of disability and depression in this province, capacity needs to be increased.

Concurrently with the residential review, several initiatives were initiated which will impact residential capacity:

- 1. The redevelopment of the Cobequid Multi-Service Centre site in Lower Sackville to support 24 persons with disabilities and complex support needs. This initiative will create 13 additional RRC beds in the province. Other scenarios are being investigated for stabilization services.
- 2. The redevelopment of the former Rose Villa site to provide a Group Home/transitional program for persons with long-term mental disabilities in the Central Region.
- 3. Funding for the creation of 62 Independent Living Support (ILS) admissions and approximately an additional 30 Alternative Family Support (AFS) admissions has been provided for in the 2007-2008 fiscal year.
- 4. The approval of four new Community Homes in October 2007.

With so many variables, such as the need to reassess all individuals in residential settings and on waitlists and the inability to quantify the number of aging parents who may seek residential supports for their adult sons and daughters in the future, it is very difficult to project into the future with a high degree of certainty. Therefore, a five-year plan is recommended with emphasis on the creation of additional community supports (AFS and ILS), and the creation of 15 Community Homes spread over the same interval. The actual locations of new Community Homes in year three are to be determined by the DCS Regional Office following reassessment of individuals supported in residential settings.

In developing this five-year plan, the principles developed by the Department of Health Continuing Care Branch to guide its decisions on increasing capacity in the Continuing Care sector were examined and slightly modified to reflect the nature of the SPD Program.

Recommendations

It is recommended that decisions on the types of additional supports and the location of these supports be based on the following guiding principles:

- Persons with disabilities should have access to a full range of supports appropriate to their assessed needs; placement will be directed at the least intrusive environment appropriate to the individual's assessed needs.
- Access to supports should be fair across the province and equitable among persons with disabilities.

- Resources to increase capacity within the residential sector should be distributed according to demonstrated need.
- Location will facilitate the goal of community inclusiveness.
- Decisions will be based on the best information available.

In keeping with the direction of the SPD Program to support persons with disabilities in the least intrusive environment, flexibility will be needed to create additional AFS and ILS spaces in each Region as individuals are reassessed. Rather than allocate a specific number of AFS and ILS spaces to each Region at this time, prior to the reassessment of individuals, the creation of a reserved block of funding for new Alternate Family Support and Independent Living Supports is recommended. Regions would be able to draw upon this resource with evidence of individual need based on the new eligibility and assessment criteria.

Recommendation

 \$2 million per year is reserved in each of years 1 and 2 for this purpose. This funding has the potential to support an additional 85 individuals with disabilities in each year.

Not everyone can be appropriately supported through the AFS and ILS programs. Unless there is a parallel investment in increasing the capacity in Community Homes, the province will run the risk of under-supporting persons with disabilities. This could place the individual, the provider, government and potentially the public at risk.

Recommendations

Based on the waitlist evidence available at this time, we are recommending that additional Community Homes be added over the next five years. However, this recommendation should be revisited on an annual basis. The reassessment of clients and the standardization of waitlist criteria and maintenance will inform the ongoing need for these Community Homes. Capacity should be revisited following the reassessment of all individuals supported in the residential program, and an action plan for subsequent years developed at that time.

F. Infrastructure Requirements

The residential sector is characterized by an aged and deteriorating infrastructure. A significant number are two and three storey homes without elevators and wheelchair accessibility, and are inappropriate for an aging population. Table 4 presents a broad picture of the state of the current infrastructure. No maintenance standards exist. No capital plan exists.

Recommendations

- An assessment of all infrastructures in the residential sector be undertaken over the next three years, and that the reassessments begin with the Residential Care Facilities.
- A capital plan is developed based on the results of this assessment.

- A replacement capacity strategy is developed to augment the capital plan.
- Maintenance standards be developed and funded.

Very limited technological infrastructure exists in the sector and there is no integrated management information system to support evidence-based decision-making. Agencies run the risk of making decisions on information, which may be incomplete, and often strictly agency focused. As most decisions have a systems impact, the potential for conflicts among organizations or between agencies and government is heightened.

Recommendation

• Information systems for improved research, data collection, analysis and evaluation support be developed within the SPD Program and service provider community.

G. Human Resources

Approximately 4,000 staff members are employed in the residential sector. These employees represent the "back bone" of the sector and it is through these people that supports and services are provided to persons with disabilities. The commitment of the staff employed in the residential sector must be highlighted. It is exemplary and infused with love for the individuals they support. Examples of staff going beyond position requirements to enhance the quality of life for residents were apparent time and time again.

Human Resources: Four Major Themes

1. Inappropriate Staffing Levels

Existing staffing guidelines go back to the late 1970's and are based on the type of residential setting. These guidelines apply to direct resident care and administration/support services. These guidelines are dated and no longer a reliable measure of staffing requirements. Recognizing the limitations of the current guidelines, the Department authorizes special needs funding to supplement existing staffing patterns. The Department is in the process of developing new staffing guidelines. These guidelines, based on level of supports, and which incorporate case mix principles, are an integral component of residential renewal.

2. Recruitment and Retention

A number of agencies are reporting challenges in recruiting and retaining a sufficient number of qualified staff. This is more prevalent in rural Nova Scotia and in particular those areas not in close proximity to a community college campus. With the trend to out-migration from rural Nova Scotia and the increasing number of young Nova Scotians who are choosing to relocate to Western Canada, the situation is likely to become worse over the next three to five years.

The commitment of the Department of Health to open over 800 new Nursing Home beds by 2010, the first in their commitment to open 1,320 new long term care beds over the next eight years, will require a major investment in human resource capital. Department of Community Services funded residential agencies and Department of Health funded long-term care homes often exist in the same community. A recruitment initiative by one Department will have an impact on the other.

A SPD Program human resources strategy to identify and outline strategies related to recruitment, retention, education, and training should be developed. The continued relevancy of the training programs for residential community workers and residential rehabilitation workers should also be reviewed.

3. Appropriateness of Core Competencies

The Department has established minimum qualifications for the staff of all residential care settings. With the creation of more supports in the community, residential settings will be supporting persons with higher support needs. The appropriateness of the current core competencies will need to be examined to ascertain their ongoing relevancy. As well the Department's commitment to aging-in-place will necessitate new skill sets to support the elderly and frail.

4. Access to Continuing Education

Provider agencies spoke of the challenge to find appropriate continuing education programs for staff. During the Review, however, it was apparent that considerable expertise currently exists in specific agencies that could, and should be, tapped for the benefit of many more providers.

Recommendations

- The staffing guidelines initiative underway within the SPD Program is given priority within the 2007-2008 fiscal year.
- The Departments of Community Services and Health work co-operatively to develop an integrated human resource strategy that would bridge both Departments.
- Training programs and the required core competencies are reviewed to ensure their ongoing relevancy and appropriateness.
- The Department considers education grants on a regional basis, as an incentive for the broad service provider community to coordinate their continuing education needs.

H. Funding

The issue of funding was out of the scope of the Residential Review as it has been previously addressed in a Draft Funding Report (Hogg, 2006). The issue is referenced in this Report, as the implementation of the new funding strategy was the single most pressing issue identified by the service provider community during Review of Residential Services.

12. Summary of Recommendations

12.1 Recommendations for a Philosophical Framework

- 1. The Department of Community Services adopts a philosophical framework for the Services for Persons with Disabilities Program; and that this framework includes a vision, mission, and a set of principles to guide decision-making.
- 2. A strategy is developed to communicate this philosophical framework, and the implications of same, to individuals with disabilities/families, departmental staff and the provider community.

12.2 Recommendations for System Integration and Coordination

- 3. Integration, coordination and multi-site management models are promoted by the Department while regions and communities are permitted to pursue forms of integration that are appropriate to their particular situation and circumstances.
- 4. Integration and coordination, e.g. inter-sectoral and cross-agency collaboration, become a key performance requirement in service agreements, in requests for proposals and in governance and management standards.
- 5. The Department encourages integration and coordination by:
 - Moving towards regionally based programs for outreach support and respite programs.
 - Creating incentives that encourage providers to demonstrate coordination, collaboration and integrative behaviors.
 - Removing barriers that thwart the formation of partnerships.
- 6. This issue is re-studied in two to three years and if a marked improvement has not been achieved that other mechanisms or structures to enhance integration and coordination be actively explored.
- 7. Governance, accountability, roles and responsibilities within the SPD Program be clarified; and that boards/owners within the provider community participate with government in this undertaking.
- 8. Governance and leadership standards be developed; and that adherence to these standards be a performance requirement in service agreements, and in the specifications for new programs/creation of new residential sites.
- 9. Agency governing boards augment board composition by creating a space(s) on their boards for individuals with disabilities and/or their families with full voting rights.

10. The Department invests in the sector's governance and leadership by funding board and management development programs. These programs must also serve to enhance integration and coordination within the sector.

12.3 Recommendations for Determining Client Need and Support Options and Placement

- 11. A new eligibility and assessment tool based on levels of supports be developed on a priority basis.
- 12. All persons with disabilities currently supported in the residential sector be reassessed using the new tool.
- 13. All persons with disabilities currently on the waitlist for service in each of the four regions are re-assessed using the new system.
- 14. A standardized format including definitions is developed for the recording of information.
- 15. One provincial waitlist be maintained and computerized.
- 16. Policies and procedures for SPD residential program admission be developed which address the issues of:
 - Access points to admission.
 - Priority for admission.
 - The role of service providers.
 - Supporting individuals to achieve the highest level of independence through the right supports and service options.

12.4 Recommendations for Providing Residential Services and Supports

- 17. The SPD Program of the Department of Community Services and the Continuing Care Branch of the Department of Health work collectively to develop one program geared to meeting the support of the persons with physical disabilities.
- 18. The number of Independent Living Supports (ILS) is increased in each region according to demonstrated current need; and following the reassessment of all current residents and those on the wait list, that the number again be increased according to demonstrated need.
- 19. New Community Homes for persons with intellectual disabilities and for persons with long-term mental illness be developed and be designed to support between four to eight individuals; that private bedrooms be the norm with allowance for shared accommodation across the sector if that is the preference of the individual.
- 20. In the shorter term, the Departments of Community Services and Health work collaboratively with the nine District Health Authorities to develop a strategy for

appropriate pre-vocational and vocational programming for persons living with mental illness.

- 21. In the longer term that the service provider community develop a strategy to engage their communities and local businesses in supporting vocational opportunities for persons with long-term mental illness.
- 22. Capacity and programming options be increased in Adult Service Centres and other day programs, and that the needs of the older persons with disabilities are considered in these programming options.
- 23. Following the reassessment of residents, a policy decision is made on the future of Residential Care Facilities. Is a level of support required to bridge between Independent Living Supports and Community Home? If so, should RCFs be redesigned, for example, as Community Homes with developmental and rehabilitative programs or as cluster living/assisted living models?
- 24. The transformation of three-bed small living arrangements (Small Options) to Community Homes, subject to the rigors of licensure, is actively encouraged. It is recognized that this will create zoning issues in many municipalities and this will need to be considered in the development of an implementation strategy on this recommendation. In the interim, the Small Option should not be a living option offered to persons with disabilities and complex needs. Persons currently supported in Small Options should be able to remain in their home if that is the wish of the person and the family, unless the person's support needs change and a more structured and intensive environment is required.
- 25. Adult Residential Centres (ARCs) provide long term structured supports and services to individuals who cannot be appropriately supported in a Community Home setting. Following the reassessment of residents, more reliable evidence will exist to determine the number of ARC beds required in the sector. It is probable that excess capacity will develop in these agencies over the long term. It may be feasible to maximize this space for specialized adult day programs or specialized programs for persons with disabilities who require nursing care.
- 26. Regional Rehabilitation Centres continue to provide supports to individuals with the most complex needs and who require both professional clinical services as well as the specialized supports available in this type of residential setting. Regional Rehabilitation Centres beds should be designated as a provincial resource. Decisions on the utilization of these beds should be made centrally and should be based on a priority list for placement.

12.5 Recommendations for New Terminology

27. Group Homes and Developmental Residences be renamed Community Homes. Specialization within this grouping would continue, e.g. Community Home for persons living with long-term mental illness, Community Home for persons with intellectual disabilities - I, II, III. This change of terminology was previously recommended in *Renewing Community Supports for Adults Program: A Discussion Paper.*

- 28. As Small Options and Residential Care Facilities are redesigned, that the terminology be changed to Community Home.
- 29. Adult Residential and Regional Rehabilitation Centres be potentially renamed as Abilities/Rehabilitation Centres.

12.6 Recommendations for Strengthening Supports and Services

- 30. An inter-disciplinary outreach service is developed in each of the four regions to provide advice and programming supports to family, alternate, and agency-based caregivers; and that the host agency develop a user's advisory committee to advise this service.
- 31. A transition program is developed in each region. This program would have two separate and distinct thrusts:
 - The capacity to bring individuals back into a more structured environment for stabilization over a relatively short period of time, and
 - The opportunity for persons with disabilities to learn new skills and confidences in preparation for the transition to community living.
- 32. The Departments of Community Services and Health work collaboratively on the strategic action issues identified in the Department of Health, Continuing Care Strategy to ensure equitable programs for Nova Scotians requiring continuing care supports and services.
- 33. Initiatives designed to make respite care services more widely available to family caregivers, and better adapted to the needs of individual as they change over time be considered.
- 34. The Department considers the development of an enhanced Community Based Program to support those individuals whose needs exceed 21 hours per week, but are less then a 24/7 residential option.
- 35. The Department evaluates programs on an ongoing basis to determine the need for any other program options.
- 36. An aging in place strategy be developed for the residential sector and that this strategy address the appropriate care setting for elderly persons with disabilities who require Nursing Home care.

12.7 Recommendations for Quality and Standards

- 37. The SPD Program facilitates the development of standards for its residential programs.
- 38. Providers and their affiliated associations should be involved in this exercise.
- 39. The SPD Program Head Office leads the identification, discussion and dissemination of best practices in the provision of services to persons with disabilities.

12.8 Recommendations for Increasing Capacity

- 40. Base decisions on the types of additional supports and the location of these supports on the following guiding principles:
 - Persons with disabilities should have access to a full range of supports appropriate to their assessed needs.
 - Placement will be directed at the least intrusive environment appropriate to the individual's assessed needs.
 - Access to supports should be fair across the province and equitable among persons with disabilities.
 - Resources to increase capacity within the residential sector should be distributed according to demonstrated need.
 - Location will facilitate the goal of community inclusiveness.
 - Decisions will be based on the best information available.
- 41. \$2 million per year is reserved in each of years 1 and 2 for the creation of a reserved block of funding for new alternate family support and independent living support spaces. This funding has the potential to support an additional 85 persons with disabilities in each year.
- 42. Based on the waitlist evidence available at this time, we are recommending that additional community homes be added over the next five years. However, this recommendation should be revisited on an annual basis. The reassessment of clients and the standardization of waitlist criteria and maintenance will inform the ongoing need for these community homes.
- 43. Capacity should be revisited following the reassessment of all individuals supported in the residential program, and an action plan for subsequent years developed at that time.

12.9 Recommendations for Infrastructure Requirements

44. An assessment of all infrastructures in the residential sector is undertaken over the next two years, and that the reassessments begin with the residential care facilities.

- 45. A capital plan is developed based on the results of this assessment. A replacement capacity strategy is developed to augment the capital plan.
- 46. Maintenance standards be developed and funded. The DCS Director of Property and Facilities has advised that the need to develop maintenance standards has been identified and will proceed in the 2007-2008 fiscal year. As resources have already been secured for this exercise and as the funding strategy recommends an allocation for maintenance cost in providers' per diem funding, no additional resource requirement has been identified for same in this report.
- 47. Information systems for improved research, data collection, analysis and evaluation support be developed within the SPD Program and service provider community.

12.10 Recommendations for Human Resources

- 48. The staffing guidelines initiative underway within the SPD Program is given priority within the 2007-2008 fiscal year.
- 49. The Departments of Community Services and Health work co-operatively to develop an integrated human resource strategy that would bridge both departments.
- 50. The core competencies are revised consistent with the renewal of the residential sector and to reflect the support needs of the three populations supported through the SPD Program.
- 51. The Department makes available education grants on a regional basis as an incentive for the broad service provider community to coordinate their continuing education needs.

13. Conclusion

"The residential sector needs to let go of the past and put all its energies into moving forward".

(SPD Service Provider)

A tremendous amount of progress has been achieved within the Services for Persons with Disabilities (SPD) Program over the past three years. Three new programs, Direct Family Support, Alternative Family Support, and Independent Support have been added and four new Community Homes have been approved. Concurrently, a new funding strategy has been developed and a review of the Adult Service Centres undertaken. Work has commenced on the eligibility and assessment piece as well as the development of new staffing guidelines. A philosophical framework for the SPD Program was created and a review of infrastructure undertaken in several agencies. The profile of the SPD Program and of the persons with disabilities supported by the Program has also been enhanced.

The Review of Residential Services has shown the necessity for a philosophical framework to guide a redesign of the residential sector. Areas through which the continuum of supports and services could be strengthened have been identified including an expansion of capacity within the residential sector. The need for a strong orientation to quality service provision and for a mechanism to ensure that all residential options for persons with disabilities are licensed has also been raised.

Many of these issues are complex. It is improbable that they can be addressed without a significant investment of time and resources. The redesign will require a collaborative approach among many parties: individuals with disabilities and their families, support networks, service providers and government. The commitment of departmental staff, of the provider agencies, and of individuals and their families and support networks to appropriately support persons with disabilities and to maximize each person's independence and well-being bodes well for the future.

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15. Appendix 1 Jurisdictional Review Trends

I. What are the trends in the provision of services and supports to individuals with long-term mental illness?

Housing Services and Supports

The major trend in the provision of services and supports for individuals with long-term mental illness is the emphasis and shifting of resources towards a supported housing model. The philosophy behind this model is the promotion of individual choice of not only where the individual will live but also what supports and services they decide to access. The primary component of supported housing is access to affordable housing. The implementation of supported housing is based on research of best practices that attest that this model is the most effective.

This trend is most evident in British Columbia, Alberta, Ontario, and informally in Saskatchewan. The supported housing model is less utilized in Atlantic Canada. In Newfoundland and Labrador and New Brunswick there are some apartment programs similar to the supported housing model but to a very small degree. Nova Scotia tends to use apartment type programs (supported housing) more extensively than the other Atlantic Provinces.

The second trend is the de-linking of housing from services, where services and housing are provided by separate agencies. Again, British Columbia, Alberta, and Ontario have adopted this trend more fully and formally than other provinces. De-linking housing and services is another essential component of the supported housing model.

There are mainly three types of housing for individuals with long-term mental illness. The extent to, which they are used, varies across the country:

- 1. **Apartments** individuals rent apartments, while services and supports are accessed as required or when the individual wants. There are variations on the apartment living model: satellite apartments, block apartments with services and supports onsite, hotel style or congregate living with communal meals and/or washrooms. Apartments are usually made affordable through rent subsidies usually provided by the Ministry/Department of Health, in addition to income assistance, disability, and/or through low-income housing. Regional health authorities either provide services and supports directly or through contracts with service providers. British Columbia, Alberta, Saskatchewan, and Ontario use these types of settings more extensively than the Atlantic Provinces.
- 2. **Group Homes** are used to assist individuals to develop life skills for more independent living. The extent to which they are used varies among the provinces. In British Columbia, Alberta, Saskatchewan, and Ontario group homes are used moderately and the majority of individuals living in these settings has lived in institutional settings and need to learn or maintain life skills. Group homes are not staffed 24 hours a day in these provinces; however, supports and services are always accessible. In New Brunswick and Nova Scotia they tend to be more extensively used as the primary residential support option and be staffed at all times. The average number of residents living in a group home for individuals

with mental illness is higher (6-12) than group homes for individuals with intellectual/developmental disabilities (4-6). This is the same for all provinces included in the review.

3. Alternative Family Support - all provinces have a form of this program and it is used to various degrees; Saskatchewan uses it the most compared to other provinces.

In a few instances boarding homes are also used and these have single occupancy rooms with communal bathrooms and/or meal areas.

Vocational Services and Supports

Vocational services appear to be less available to individuals with long-term mental illness than they are to individuals with intellectual/developmental disabilities. Vocational and residential services are less coordinated at a systems level. The coordination of vocational services is usually arranged at the individual's level through regional health authority staff, residential providers (group homes mostly), or community or outreach resource centres.

Most provinces have included addiction services as part of their mental health services branch. British Columbia is one of the most advanced provinces as they are developing housing specifically for individuals that misuse and abuse substances or are recovering. These homes would have a concentration on harm reduction and addictions counseling in addition to mental health services and case management. British Columbia is also considering developing "wet" housing for individuals that continue to misuse or abuse substances.

The majority of mental health services are under the mandate of a Ministry/Department of Health (British Columbia, Alberta, Manitoba, Ontario, New Brunswick, and Prince Edward Island). There are only three provinces where the responsibility for delivery varies:

- 1. **New Brunswick** The responsibility for residential services is under the mandate of the Department of Family and Community Services; however, other responsibilities are divided between two Departments. The Department of Health is responsible for mental health intakes, assessments, and case management. The Department of Family and Community Services is responsible for assessing functional and financial needs, places the individual, and licenses the residential settings.
- 2. **Newfoundland and Labrador** Mental health services and intellectual/ developmental disability services are under one Department the Department of Health and Community Services but they are divided into two branches mental health and addictions services and community living and supportive services for adults with disabilities. Each branch supports the different populations through regional health authorities known as Regional Health and Community Services Boards.
- 3. **Nova Scotia -** Individuals with long-term mental illness and intellectual/developmental disabilities are supported through the Department of Community Services, Services for Persons with Disabilities Program through government regional offices.

The majority of Departments/Ministries have devolved responsibility for delivering mental health services to agencies similar to regional health authorities. There are only three provinces where regional health authorities are not used:

- 1. **New Brunswick** The responsibility for residential services are under the mandate of the Department of Family and Community Services, but the responsibility for mental health intakes, assessments, and case management is under the Department of Health. Therefore, all Department of Health responsibilities are delivered through regional health authorities, while functional and financial assessments, placements and licensing are delivered through the Department of Family and Community Services' government regional offices.
- 2. **Nova Scotia** The Department of Community Services provides residential supports to individuals with long-term mental illness. The Department of Health has responsibility for acute mental health programs and addictions.
- 3. **Ontario** The province is in the process of implementing a type of community governance model. In April 2007, Ontario will have 14 community boards that will deliver and contract the delivery of services to individuals with mental illness and addictions. The community governance model is more widely used for the delivery of services to individuals with intellectual/developmental disabilities namely, British Columbia, Alberta, and in a less structured way in Ontario.

II. What are the trends in the provision of services and supports to individuals with intellectual disabilities?

The main trend in the provision of services to individuals with intellectual/developmental disabilities is the expansion of residential options. Every province appears to expanding residential options and the expansion is focused on smaller informal settings. The two types of options that are being either utilized more or expanded are individualized funding arrangements and alternative family homes.

- 1. **Individualized funding** is becoming more widely available in British Columbia, Alberta, and minimally in Saskatchewan. This type of funding can be used to purchase residential supports from service providers, rent apartments/homes and purchase supports.
- 2. Alternative family homes are being expanded in all provinces with the exception of Alberta, which is moving away from this type residential model. This model is expanding for several reasons, the main reasons being its cost effectiveness. In Ontario this model is being used as part of their deinstitutionalization process. Saskatchewan has the most formalized program with the greatest number of people to a setting (5) and they are all licensed.

While the above options are part of an expansion process, group homes are still used to the same extent and have an average of four to six 6 people to a home and are always staffed.

All residential options in this sector tend to be licensed, accredited, or approved, unlike the mental health sector.

The second largest trend is a move towards a community governance model. British Columbia, Alberta, and in a less structured way Ontario are all using community governance components. The community governance model is being adopted in an effort to more effectively address the needs of individuals with intellectual/developmental disabilities by strengthening and using community resources more efficiently by assessing the community's needs and priorities. All other provinces, with the exception of Prince Edward Island, use government regional offices for service delivery, which do not have the same type flexibility and tailored approach to addressing individual and community support needs. The provision of residential options and supports and services is always under a Department/Ministry responsible for community/family services/supports.

Vocational and residential supports are not well coordinated at a systems level, but they are under the same Departmental/Ministerial mandate. Newfoundland and Labrador is the only exception, where their vocational supports are under the mandate of another department. Vocational supports appear to be more readily accessible and available to individuals with intellectual/developmental disabilities. All provinces, with the exception of Ontario, have services coordinated by case managers that are staff of a regional office or community board. Ontario uses a community-planning table where all key parties are invited to coordinate services with the individual.

Apartment programs are available for individuals with intellectual/developmental disabilities. However, there is not the same emphasis on de-linking services and housing as there is in the mental health sector.

III. Trends in meeting the support needs of individuals with complex needs and/or challenging behaviours

There are three main trends in supports for individuals with complex support needs and/or challenging behaviours:

- 1. Mental health services still tend to use inpatient, acute care and/or forensic support models to address the complex support needs of individuals with mental illness. However, the size of the settings are smaller than in the past. British Columbia and Alberta appear to be adopting smaller intensive care settings as recommended in the *Review of Best Practices in Mental Health Reform* (1997). The report has been the foundation for most of the mental health system changes in these two provinces and in Ontario.
- 2. British Columbia is using one model in particular in response to the downsizing of psychiatric hospitals. This is a tertiary care service setting where individuals who require 24-hour support, intense treatment, and high levels of staff are supported. There are three components to this type of care:
 - Acute care treatment.
 - Rehabilitation.
 - Tertiary rehabilitation.

British Columbia is also proposing a plan for a secure care centre that would support individuals who require intensive behavioural stabilization. It would be a unit of approximately 5 beds with a snozelen room and interdisciplinary specialist teams. The secure setting would support individuals who have an IQ over 70 but have behavoural challenges and complex support requirements (i.e. individuals with autism). These are individuals who cannot appropriately be supported by mental health services and addictions or Community Living British Columbia. British Columbia's new *Mental Health Act* would enable individuals to be treated in this centre involuntarily.

In four provinces, British Columbia, Alberta, Manitoba, and Ontario, they have or are developing partnerships between mental health services and intellectual/developmental disabilities programs to deliver supports to individuals with dual diagnosis and/or complex support needs.

- 1. **British Columbia** British Columbia has the Provincial Assessment Centre (PAC), which is a short-term (30-90 days) intensive treatment facility under Community Living British Columbia, but has mental health workers in the setting.
- 2. Alberta There are leads from both sectors in each of the regions and at the provincial level that work together to provide and coordinate supports to individuals accessing supports from both sectors.
- 3. **Manitoba** There is no formal agreement to support individuals with dual diagnosis who require mental health services. However, the regional health authority does provide mental health services to those that require it, while other supports are funded and coordinated by the Department of Family Services and Housing.
- 4. **Ontario** The Ontario Developmental and Services Branch and Ministry of Health is developing a framework to coordinate supports to individuals with dual diagnosis. The Ontario Developmental Services Branch is also enhancing their specialized supports and further developing two residential models (transitional accommodation and permanent accommodation):
 - "Transitional accommodation for individuals requiring 24-hour supervision and supports for activities, stabilization, assessment, specialized clinical intervention, individualized structured support, caregiver training and transition planning. Permanent accommodation for adults with persistent high-risk behaviour who require ongoing specialized support. The objective is a safe, secure, therapeutic, long-term home." *Opportunities' and Action: Transforming Supports in Ontario for People Who have a Developmental Disability.*
 - 5. Saskatchewan, New Brunswick, and Prince Edward Island These provinces have large congregate settings that provide supports to individuals with disabilities and complex needs. These centres may provide short-term or long-term intensive supports.

IV) What coordination, if any, exists between vocational and residential programming? (Include how this coordination is achieved)?

In general there is minimal coordination between residential and vocational programming in both the mental health and intellectual/developmental disabilities sectors. There appears to be three trends:

- 1. In most provinces, vocational supports are under the same mandate of the Department/Ministry that is providing residential supports. The only exception is Newfoundland and Labrador where vocational supports are under the mandate of Department of Human Resources and Labour; therefore, a caseworker from this Department is responsible for coordinating vocational supports for an individual. There is very little coordination at a systems level between vocational and residential programming beyond this.
- 2. Coordination between vocational and residential programming is more apparent at the individual's level. In some instances the regional health authority worker or government regional/community board worker is responsible for coordinating residential and vocational supports. In British Columbia and Ontario mental health services sometimes has a residential worker assist individuals in accessing vocational supports. In Ontario's disability services, Community Planning Tables (CPT) are used to coordinate services. The CPTs are made up of service providers (residential and vocational), the individual, family etc. The major difference between the two sectors is in the intellectual/development disability sector vocational supports tends to be more accessible and are subject to an individual support plan. In mental health services, if a supported housing model is used it is up to the individual to decide if they want to access vocational supports.
- 3. At a service provider level there is minimal coordination; however, some larger residential service providers may also provide vocational supports. If there are partnerships this was not explicitly stated in conversations with department/ministerial representatives; therefore, they are more likely informal.

V) What mechanism exists, if any (voluntary or mandatory) to co-ordinate services and supports among provider agencies (either at the community, regional or provincial levels).

There is virtually no formal coordination of services between service providers residential and/or vocational in either sector and if there is, it is very informal and voluntary. However, the presence or establishment of associations is more prominent in the intellectual/developmental disability sector.

There are only three provinces that have a structured approach to coordinating services and supports among service providers: Saskatchewan, Manitoba, and Ontario. Government at the provincial level, with the exception of Ontario, developed all the approaches.

- 1. **Saskatchewan** The most formal coordination is found in Saskatchewan with the Provincial Partnership Agreement. The Community Living Division, Saskatchewan Association of Rehabilitation Centres (SARC) and Saskatchewan Association signed the Provincial Partnership Agreement for Community Living. Services that are coordinated include the Provincial Training Committee and the Quality Assurance Committee. Also, SARC as a province-wide organization has approximately 100 members from both the residential and vocational sectors. It provides a number of supports to its members. These supports include the following: training, advocacy/lobbying, program/policy support, and benefit plans.
- 2. **Manitoba** The Department of Family and Housing was responsible for organizing all the service providers into a coalition, known as the Manitoba Coalition of Service Providers (the Coalition). While being a member is not mandatory, most service providers do belong to the Coalition. The Coalition meets with representatives from the Department's policy and governance branch and service delivery branch every few months to discuss shared issues and concerns.
- 3. **Ontario** The Developmental Services Branch requires regions to create Community Planning Tables (CPT). The CPT is used to assist individuals to access and coordinate supports and services. On the CPT are service providers, the individual, regional office representation, family, and perhaps a person from mental health services, if needed. It is through the CPTs that service providers are coordinated at the individual's level. CPTs are essential as individuals in Ontario rarely have case managers to provide supports and services and residential services coordination.