Review of Reports on Disability Supports and Services in Nova Scotia

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

March, 2013

Outline

- Approach to Analysis and List of Reports Reviewed
- Overview of Key Milestones, Reports, Evaluations and Submissions — Community and Government
- Common issues and recommendations raised in reports and submissions

Approach

- Co-Chairs and DCS provided list of reports to be reviewed
- Reports summarized and coded for common themes: issues, recommendations, and implications for developing a roadmap
- Summary ppt prepared

Reports Reviewed

- Michael Kendrick (for Nova Scotia Department of Community Services) An Independent Evaluation of the Nova Scotia Community Based Options Community Residential Service System - January, 2001
- NSRAA, Position Paper on Deinstitutionalization June 2007
- NSRAA, Position Paper on Person-Centered Services
- Government of NS, Report on Residential Services, June 2008
- The Riverview Home Corporation Report, Dec, 2009
- Nova Scotia League for Equal Opportunities (Summary Notes from meeting of coalition of 20 NS disability groups), Pathway to Inclusion, Independence, and Full Citizenship: A Disability Strategy for Nova Scotia – March 2010

Reports Reviewed

- NSRAA, Position Paper on Disability Legislation
- Report of the Auditor General November 2010
- Community Homes Action Group, Presentation to the Standing Committee on Community Services, a Legislative Committee to the House of Assembly, Nova Scotia - May 2011
- Operational Review of Braemore Home Corporation, October 2011
- Community Homes Action Group, Response to Discussion Paper on a Housing Strategy for Nova Scotia: A Place Called Home – November 2012
- Dalhousie Legal Aid Service (Prepared for Disability Partnership), Disability Strategy Analysis: Identifying Tools Necessary for Ensuring Government Accountability – 2012
- Government of Nova Scotia, Putting People First -2013

- How did we get to where we are today?
- 1970s Deinstitutionalization efforts begin in NS
 - Closure of Mountain View institution in Kings County
 - Relocation of residents with significant disabilities and some of the highest support needs to community represented efforts that were leading edge for their time in Canada
- Similar efforts throughout the rest of Canada, for the most part do not begin until 1980s

 1970s through 1980s five institutions for adults closed or downsized and five children/youth training centers are shut down.

- Progress on closure of institutions is perceived to have stalled during 1990s relative to other jurisdictions — i.e. New England states become "institution free" during this time period.
- At same time, other Canadian jurisdictions demonstrate more rapid and continued progress on institution closure and movement to community and begin to outpace early developments in NS. (Kendrick Report)

Department of Community Services, Moving Toward Deinstitutionalization -A Discussion Paper (1995)

- •Department of Community Services expresses its intention to develop policy based on a vision of:
 - Inclusive Society and Empowerment
 - Rights, Responsibilities and Participation

Eddie Sheppard Report (1996)

- Eddie Sheppard was killed by his roommate in 1996 in a small option home. The men had been placed together in a home, where they had only one supervisor for six hours a day
- Concerns were raised by community, service providing agencies and unions calling for increased safeguards and improvements to service and standards for small option homes

- 1996 Provincial government assumes responsibility for residential and vocational services for persons with disabilities (physical, intellectual and long-term mental illness) from municipalities
- Moratorium of development of further small option homes happens around this time

Michael Kendrick (for Nova Scotia Department of Community Services) An Independent Evaluation of the Nova Scotia Community Based Options Community Residential Service System (January, 2001)

- •The "Kendrick Report" evaluates strengths and problems with the Small Options (Community Based Options) residential supports system and recommendations focused on:
 - modernizing the system,
 - moving to personalized options,
 - strengthening role of individuals and families,
 - stimulating innovation,
 - improving safeguards,
 - introducing interim standards, and
 - Improving supports for persons with psychosocial disabilities/mental health issues in CBO system

- Kendrick Report placed strong emphasis on supporting development of personalized approaches and developing and supporting community and political leadership
- Also focused on providing flexibility within system to (re)enable innovation and called for greater role for individuals and families in design/personalizing supports

Nova Scotia Residential Agencies Association, Position Paper on Person-Centered Services

- •Outlines approaches to person-centered planning and personalized approaches to service planning, funding and service delivery
- •Identifies steps necessary for government, funders and service providers to incorporate and promote personalized approaches
- •Takes position in support of more power and control for people with disabilities over supports and living arrangements and the role of individuals and families in governance/operations of service providing organizations

Nova Scotia Residential Agencies Association, *Position Paper on Deinstitutionalization* (2007)

- •Takes position on behalf of NSRAA calling for increased urgency and emphasis on reactivating deinstitutionalization efforts and preventing replication of institutional approaches in community settings
- •Recognizes degree of influence that member agencies have over people's lives as well as role in community and family life
- •Calls for implementation of CRPD
- •Speaks out against assertion that there is a group of people who "must stay"

Nova Scotia Residential Agencies Association, *Position Paper on Disability Legislation* (2008)

- •Calls for rights based, and entitlement based legislation guaranteeing right to basic needs and to adequate support including housing, support services, education, employment and advocacy support
- •Calls for robust consultation involving people with disabilities
- •Calls for cessation of investment in approaches that create new and avoidable barriers to full participation

Government of NS, *Report of Residential Services* (June 2008)

- •2006 Department of Community Services, SDP commenced review of all residential services for persons with disabilities
- Presents/proposes a philosophical framework for SDP
- Recognizes several current issues, and in particular a "grid-locked" system in which it is difficult to provide for innovation and flexibility
- •Highlights several gaps and inconsistencies within the system

Government of NS, Report of Residential Services (June 2008) continued...

- •Makes several recommendations focused on areas of:
 - Adopting philosophical framework
 - System integration and coordination
 - Determining client need support options and placement
 - Providing residential services and supports
 - New terminology
 - Quality standards
 - Increasing capacity
 - Infrastructure requirements
 - Human Resources

The Riverview Home Corporation Report (Dec, 2009)

- Previously known as Riverview Asylum, Poor House, the Pictou County Asylum for the Harmlessly Insane, Pictou County Home and Hospital, and the Home for the Disabled
- Report commissioned after 22 reported incidents of abuse
- Scope of review focused on effectiveness, efficiency, economy, safety, and continuity with respect to the financial, operational and governance areas of RHC
- Primary focus of recommendations are on upgrading infrastructure, addressing overcrowding, HR issues and governance and financial issues

Nova Scotia League for Equal Opportunities (Summary Notes from meeting of coalition of 20 NS disability groups), *Pathway to Inclusion, Independence, and Full Citizenship: A Disability Strategy for Nova Scotia* (March 2010)

- •Position paper from coalition of disability-related organizations from 2008 Joint Standing Committee on Community Services
- •Representation from 20 major disability organizations including consumers, advocates and services providers
- •Outlines criteria for development and implementation of a comprehensive disability strategy

Report of the Auditor General (November 2010)

- Audit focused on community based options programs including:
 - The direct family support (DFS)
 - alternative family support (AFS)
 - independent living support (ILS)
 - Small option homes
- 29 Recommendations in areas of:
 - Program Evaluation and Long-range Planning
 - Assessment, Classification and Placement
 - Review and Reassessment
 - Waitlists
 - Incidents and Complaints
 - Payments for Services
 - Quality Assurance
 - Legislation

Community Homes Action Group, *Presentation to the Standing Committee on Community Services* (May 2011)

- •Reviews a number of previous reports by government and other evaluations to reissue call for leadership and an action plan to address residential needs of people with disabilities
- •Frames submission in light of Article 19 of the UN CRPD
- •Draws from *Report on Residential Services* to recommend principles articulated there, as a starting point for an action plan
- •Lists key criteria for an effective action plan

Operational Review of Braemore Home Corporation (October 2011)

- Review announced after investigation of abuse at the facility
- •Findings of failure to provide adequate care
- •Review asked to go "beyond enhancement of safety"
- "Our analysis shows that Braemore Home does not meet expectations for a well-functioning residential environment"
- "Institutionalized attitudes, coupled with ineffective organization and management practices at Braemore, have fostered complacency"
- "Neither the Department of Community Services nor Board have challenged Braemore Home to change or improve"
- "We found a general perception that changing Braemore's physical environment is impossible"

Operational Review of Braemore Home Corporation (October 2011)

- •Recommendations deal with:
 - Changing core beliefs about services for individuals with disabilities, and making fundamental improvements at Braemore Home so it can provide an enhanced quality of life for all clients;
 - Improving the ability of the DCS-SPD program to better plan for, fund and monitor residential services delivered on its behalf;
 - Increasing the capacity of the system to deliver more effective support for persons with disabilities, so that they may reach their full potential as people and citizens.
- •Recommendations speak to responsibilities and action needed by department, province and Braemore home including call for long-term vision, modernization, legislation and funding framework
- "Not band-aid solutions" but recommendations aimed at significant systemic change

Community Homes Action Group, Response to Discussion Paper on a Housing Strategy for Nova Scotia: A Place Called Home (November 2012)

- •Response to report on a housing strategy for Nova Scotia
- •Makes recommendations focused on need for an "scheduled, resourced action plan" to increase community based residential options for people with developmental disabilities, client based service delivery focused on least restrictive option, a freeze on institutional investment, reopening of small option and apartment residential choices and need for system of accreditation.
- •Highlights urgent action needed to address crisis in residential options for people with disabilities

Dalhousie Legal Aid Service (Prepared for Disability Partnership), Disability Strategy Analysis: Identifying Tools Necessary for Ensuring Government Accountability (2012)

- •Paper assisting the Disability Partnership to develop a framework for analysing proposals for a disability strategy
- •Examines six jurisdictions focused on responsible agencies, timeframes, resource allocation, information gathering, legal enactments and supporting legislation and accountability and review mechanisms
- •Call for rights based approach, grounded in UN CRPD

NS Department of Community Services, Putting People First (2013)

- •Outlines a case for change, key issues and proposes a vision, principles and objectives for reshaping the current system
- •Is currently being used in consultations with the community

General Observations

- Nova Scotia appears as one of the leading provinces in movement to community-based options through 1980s, but transformation process stalls early 1990s, and has not restarted in a substantive way since.
- Appearance currently of a potential watershed moment – though there is urgency and some degree of frustration amongst the community there is also strong passion and appetite for change and a constellation of leadership amongst both community and government
- Submissions/Reports reviewed show heavy emphasis on physical and intellectual disabilities.
 Some focus on psychosocial disabilities and mental health issues

... General Observations

- Closure of institutions and investment in personalized supports a very strong theme
- Observe a period of stagnation from mid-1990s to mid-2000s that has produced some skepticism over time about more reports and consultations.
- Sense of renewed energy since signing and ratification of UN CRPD—because it provides a framework for action

Common Themes

- Submissions and reports were reviewed and key themes identified and coded using the Guiding Principles of *Putting People First* as a starting point
- Broadly speaking, key issues raised in the submission can be associated with principles articulated in *Putting People First*
- Some key themes that bring greater clarity to these principles and others that stand alone as additional key issues

Person-focused

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

- Personalization is a common current that runs through all submissions and reports that deal with the disability supports and housing
- "Next generation" of supports is needed that can build on successes and examples within CBOs such as flexibility to adapt supports to persons homes
- Concerns about "hub" model of clustering disadvantaged persons
- •CBO system not well enough developed to respond to complex needs of individual in personalized way
- •Regional capacity exists to plan, fund, operate and oversee local personalized support arrangements

Person-focused

- There are *strong* and *weak* instances of personalization of disability supports and services—i.e. service plans can use language of personalization without strong commitment to flexibility, responsiveness and individual tailoring of support to needs as articulated by individual and their network
- Most submissions deal with personalization in its strong sense with features such as:
 - People connected with supports and housing according to their needs as opposed to available 'spaces'
 - People and their families/networks directly involved in planning and choosing their housing supports
 - Funding tied to individual rather than residence/housing
 - more power and control for people with disabilities over supports and living arrangements
 - Planning is a key feature, but is prior to and distinct from 'service planning'
 - Begins with individual articulating their plan for a good life, then enrolling necessary support and service to achieve those goals

Ability-focused

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

- Not much focus among submissions on enhancing 'abilities'
- •Many submissions raise issues of self-determination, community inclusion
- •Submissions/reports speak more clearly to the following:
 - That the purpose of supports and services is to enhance independence and community inclusion, and
 - That self-determination is a key feature in planning, design, and delivery of supports

Ability-focused

- *Self-determination* is raised frequently, particularly in areas of:
 - Choosing where and with whom to live;
 - Right to make decisions and have them respected
 - service user involvement in management and governance of service—homes in essence remain the homes "of the provider" with advisory input from families and user that is strong in some cases and weak in others
- Community inclusion raised frequently and is covered in greater detail under principle of Home and Community Oriented

Independence-focused

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

- •"Independence" a contested term
- •Independence vs interdependence independence is choice and control over ones life. It does not mean being alone or doing everything yourself
- •Supports should be geared toward least restrictive option, and option that maximizes independence, self-reliance and community inclusion

Home and Community Oriented

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

- •"Real homes," "community inclusion" and deinstitutionalization a major focus throughout submissions
- •Urgency for government to move forward with action plan to increase quality, quantity and range of residential options

Home and Community Oriented

- Specific issues raised include:
 - CBO system seen as positive where ordinary homes in community are used as opposed to purpose built homes that can lead to tendency for stigmatization and "institutional" culture
 - "shiftwork-oriented mini group homes" remains a tendency in current supports
 - Need to prevent replication of institutional approaches in community settings
 - Must stop investing in approaches that continue to create barriers to inclusion and real homes
 - Must adopt focus of "least intrusive" support
 - Mental health problems are being exacerbated by inappropriate and inadequate housing and supports
 - Need to disentangle supports from real estate

Home and Community Oriented

- Redirection of investments from large-scale institutions to community and closure of institutions is a major theme
 - Theory of a "must stay" group is false
 - Reviews of Riverdale and Braemore point to issues with current institutional model
 - Findings of failure to provide adequate care through large scale residential approaches
 - Tendency toward nursing homes must be reversed

Accessible

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

- •System is fragmented, inconsistent, difficult to navigate
- •One claim of inequitable treatment of some groups of people with specific disabilities over others who experience systematic exclusion
- •Eligibility for support should not be tied to income
- •Some submissions called for a 'navigator' and independent advocate function
- Access to information is often lacking

Responsive

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

- •Funding levels should be designed to be flexible to respond to personal need
- •Budgets determined individually in consultation with individuals and family. This has sometimes led to criticisms of inconsistency, but is an important feature of personalization and flexibility
- •System is "grid locked." Individuals who are within the 'system' have little flexibility to meet changing needs
- •Addressing individuals in crisis with available vacancies means there is little capacity to appropriately match needs and wishes of individual
- Need for seamless continuum of supports over lifespan
- •Waitlists are an issue that is raised consistently
- •Aging caregivers are an area of emergent need and no clear plan to address

Responsive

- Respite beds being used as long term support because of lack of capacity within system
- Gap in service between independent living support and residential program
- Gap in service for people who need more than 21 hrs/week of support but less than 24/7
- Insufficient support to families through Direct Family Support Program (short term relief but not community support meeting needs of families)

Sustainable

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

- •There are calls for a rights based, and entitlement based legislation guaranteeing right to basic needs and to adequate support including housing, support services, education, employment and advocacy support
- Placements being made on crisis basis is unsustainable
- •System has not improved or kept pace with the population and is not future oriented
- •Budgeting should acknowledge that present services do not reach all in need and total numbers of people in need continue to increase
- •Among community there is acknowledgement of limited resources and willingness to work toward sustainable approaches, but need evidence of action plan

Accountable

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

- •Current system sometimes "allows for" but does not assure or enable family and service user involvement in management and governance of service
- Accountability to individuals and families is a key theme
- •Home supports for the most part have oversight and influence by local communities via governance boards but many of these have been overshadowed by an "agency culture" of operation.
- •Government has been neglectful of family as a core element of a desirable community support system.
- •Suggestions that accreditation approach should replace licensing
- Need for standards of best practice

Accountable

- In context of development of action plan:
 - Need for robust consultation involving people with disabilities
 - Timely development and implementation of a disability strategy with goals, actions, timelines, responsibilities, accountability processes, measurable outcomes
 - Braemore Review contains strong recommendations dealing overall accountability in the broader system of supports
 - Stakeholders should be made aware of their role

Accountable

- Recommendations made for development of comprehensive disability strategy preferably backed by legislation:
 - should take a rights based approach
 - implementation mechanisms should consider factors of independence, mandate, possible competing demands, accountability to elected officials or parliament as a whole and participation of people with disabilities in process of benchmarking, monitoring and evaluation

Socially Inclusive

The diversity of all Nova Scotians' will be recognized and respected. Services and supports will promote social inclusion and stronger communities.

- •Need to recognize the importance of intersecting grounds of discrimination (such as gender, sexual orientation, age, visible minority, linguistic or cultural group)
- Poverty reduction strategy found that complexities of disability issues required discrete strategy

Implications for Developing a Roadmap for Transforming Supports and Services

- Concerns about stagnation and lack of action plan are prevalent
- Calls for reinvestment of resources from institutions to community supports are recurrent
- Anxieties related to adequacy of supports and dependability of supports into the future
- In development of plan, need to create space to be "forward thinking" while grounded in tangible actions
- Grounding planning and actions in CRPD as a framework