Presentation to the All-Party Mental Health Committee

June 29th, 2015 at 11:00 a.m.

Prevalence of Intellectual Disabilities

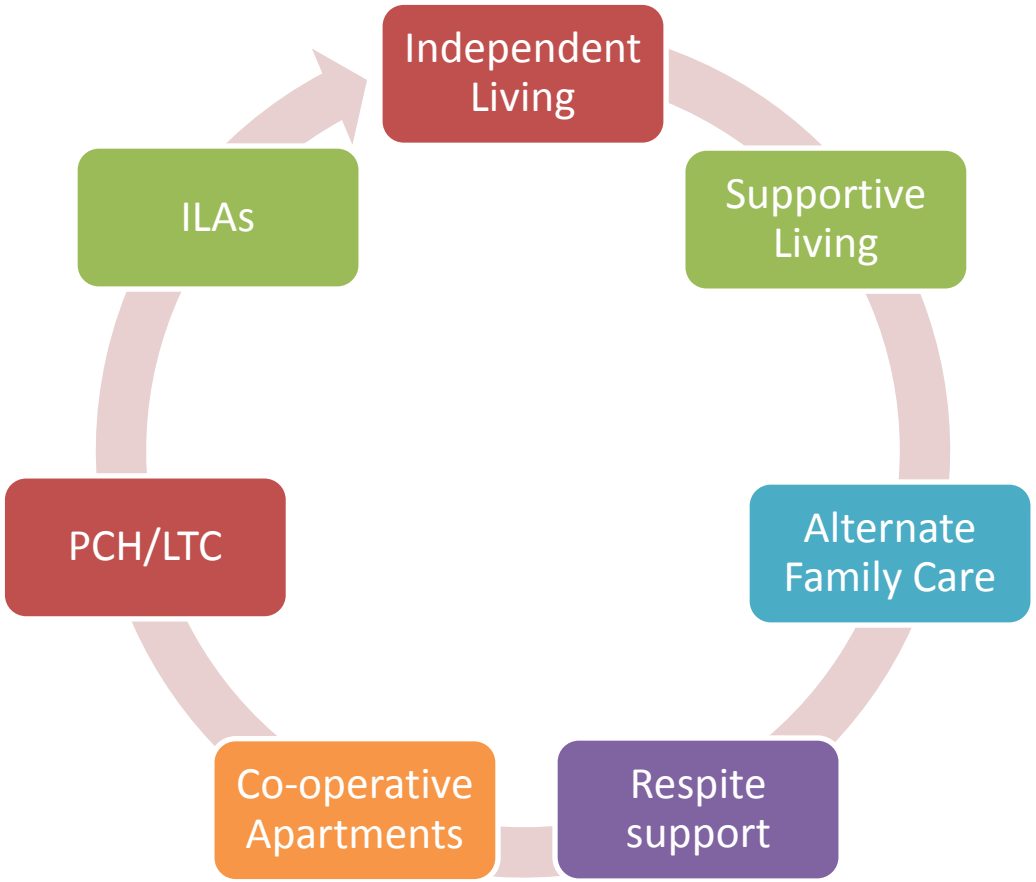
• Approximately 10.37/1000 present with intellectual disabilities (see Appendix 1); other studies equate the population to about 3%, with less than 1% in the adult age range (see Appendix 2)

• Estimates of the proportion of adults with an intellectual disability who have a dual diagnosis (intellectual disability and another mental health disorder, i.e. a psychiatric, anxiety or mood disorder) to be 30.6% (see Appendix 3)

• "Prevalence estimates suggest approximately 10-15% of people with intellectual disability present with challenging behaviors with similar estimates for high risk behaviors, including self injury and physical aggression. For people with profound and multiple disabilities, the prevalence of challenging behaviors may be much higher" (see Appendix 3)

Care Givers

Continuum of Care in Newfoundland & Labrador; Community Supports - Adults with Intellectual Disability



Independent Living

- Some individuals who present with intellectual disabilities are high functioning enough that they can manage many of their day to day living tasks, sometimes aided by family and/or friends, and still live independently.

- These individuals are usually able to utilize existing community supports to ensure vocation, education or other supports as needed to manage their day to day living.

- These individuals may live on their own, or with family members or friends. Sometimes, individuals with similar needs with live together.

- With this service population, community housing becomes difficult to locate and maintain within their fiscal constraints. A shortage of available housing, and the rise of substandard housing in Newfoundland, has made independent living all the more difficult to maintain.

- While some day-time programming exists for this service population (Longside club, Pottle centre), they are woefully underfunded and options are limited in terms of service options.

Supportive Living

• Supportive living is when staff assist a resident to remain in their home in the community, either independently or living with family. For those individuals who present with a lower capabilities for independent activities of daily living, additional supports may be required to keep them home.

• Support evaluation for families with children or adults who present with challenging behaviors are currently based on home support evaluations. Altering the assessment process to identify families who require support in managing challenging behaviours may help those families who would like to keep their family members home.

• Providing qualified, trained professional staff to assist with managing personal care, behavioral needs and/or advocating for additional services can be the key to whether a placement at home can be maintained or break down to a point where a more formalized living arrangement is required.

• The necessity of specialized training for professionals working with adults with intellectual disabilities cannot be overstated. It's important to ensure that the direct service workers who provide care are working within their scope and are trained in managing the presenting concerns they will view in working with their prospective consumers of service.

Care Givers

Alternate Family Care (AFC Home)

- Some individuals are unable to live independently, and do not have sufficient supports (i.e. Family, friends or existing community resources) to live in the community on their own, or family have become unable to manage the individual's presenting concerns.

- This option is a flexible living arrangement that enables an individual, with extensive support needs and/or challenging behaviors, to live in a family environment. If the individual can successfully live in a family environment and the family are welcoming and supportive, this support option has many benefits and positive outcomes.

- AFC homes have become more difficult to recruit for in recent years, so as existing homes close and recruitment and retention strategies struggling, AFC homes continue to diminish.

- Additionally, some individuals present with complex behaviors and/or co-occurring mental health disorders that are not conducive to a family living arrangement.

Respite support

• For those individuals who utilize supportive living and/or alternate family care living arrangements, sometimes family members or in-home supports require a break to maintain effective care. Respite services can be made available for the care providers to take a break and ensure the individual is still being looked after.

• These options are sometimes provided by family members of the service provider, or an available bed in an existing Alternate Family Care home may be utilized.

• Due to the limitation of AFC homes respite can become difficult to arrange, leading to burn out of the existing families and eventual break downs of the placement.

• A more structured availability for respite services in the community would provide support to these levels of service and assist in maintenance of placements for a longer term.

Co-operative Apartments

- The Co-op apartment program offers a private residential setting operated by an incorporated community board of directors and staffed by a live-in supervisor and relief staff. The private residences are usually rented houses and are shared by up to three adults with intellectual disabilities. The main emphasis is on skill teaching and support to enable more independent living rather than providing a permanent residence.

- Current provincial guidelines for quality assurance for the Co-operative Apartment Program do not completely align with quality standards for similar systems in other provinces, but could very easily be reviewed and adjusted to align the standards with the rest of the country.

- Co-operative apartment programs in various parts of the island experience challenges in managing mental health concerns of residents. Without a coordinated service model intended to integrate mental health management, developing a plan of care for their residents can be challenging.

- While the primary intention of the service was short-term transition until long term placements could be arranged, many individuals referred there remain there for long periods due to insufficient community resources.

Care Givers

Personal Care/Long Term Care Homes

• The Regional Health Authority's long-term care programs provide a range of residential and day services, which are mainly provided to seniors and older adults with disabilities.

• Placement options within this area are identified as Personal Care Homes, Long-Term Care homes and a new option referred to as "protective community residences" a.k.a. Dementia Care Bungalows.

• Often adults with intellectual disabilities will be placed in this form of care, due to the long term nature of their disorder. This means that a young person with disabilities in their 30's could be taking up a PCH/LTC bed, when they could be living in the community with support.

Care Givers

Personal Care/Long Term Care Homes

• *In the 1980's the Newfoundland & Labrador Government committed to community living and deinstitutionalization. Newfoundland & Labrador Association for Community Living worked in partnership with government to close several institutions and individuals with intellectual disabilities were assisted to move from the Waterford Hospital to community living under the Right Futures Project. The success of these initiatives has been recognized internationally as leading progressive social policy. In the early 1990's group homes were also closed. Individualized program planning and innovative community based options were developed; and personal care homes/nursing homes were never advanced as appropriate housing options. Since that time, home support ceilings and funding freezes have created crises in the community. Throughout the province, especially in Labrador, there is an inadequate housing stock and support service availability. Despite principled commitments and a history of successful community living and research that demonstrates that institutional placements are not appropriate for individuals with intellectual disabilities, in Newfoundland and Labrador today, individuals with intellectual disabilities are being placed in long term care centers and personal care homes. ---* **Newfoundland and Labrador Association for Community Living website, Position Statement on Supportive Living & Housing**

Independent Living Arrangements (ILAs)

• There are many ILAs provided across the province; the care provided under this format is largely provided by home support agencies.

• ILAs offer a solution to community based care that, if properly utilized, could assist with maintaining a high quality of life for adults with intellectual disabilities who present with more complex needs then any of the previous continuum options may present.

• Unfortunately, a lack of quality assurance standards for this form of care exist in the community. Establishing a set of quality standards for this service population would improve care and could assist with identifying the primary function of ILAs to ensure they are meeting their mandate.

• An expectation of outcome measurement and reporting on key indicators, as well as minimum expectations of what "qualifies" support workers, will help ensure programs are providing quality care as outlined by best practice.

When The Continuum Doesn't Work…

- **Lack of availability:** Sometimes, there aren't placements available in the continuum. The reasons for this are many and change depending on the type of living arrangement in the continuum.

- **Emergency Placement in hospitals:** When a placement isn't available in the community often the person will be brought to their local hospital's psychiatry ward, and/or transported to the Waterford hospital via ambulance, and occupy a bed there until a placement in the community can be identified. This can be weeks, or months, depending on the timeframe needed to develop a community placement. While this is not ideal, an individual who gets to this point are unable to be in the community alone and need supervision, and due to their intellectual disability diagnosis are identified as requiring mental health supports and the hospital cannot release the individual until they have someone to provide their care.

- This ties up resources in psychiatry departments, limiting their ability to manage truly acute mental health concerns that may arise and require emergency attention.

When The Continuum Doesn't Work…

- **Access to Psychiatry in the community:** Due to high demand and high caseloads, especially in rural parts of the island, it can be challenging to access a psychiatrist in a reasonable timeframe:
  - Referrals from a family physician and/or other medical practitioners can lead to very long wait lists before a psychiatrist is assigned, with wait times varying from 3 months to a year depending on demand at the time.
  - Even when a psychiatrist is assigned, high caseloads mean it can be very challenging to get in to see a psychiatrist when a resident is in crisis (appointments are often made for 2-6 months after the call). This places more expectations on ER's and hospital psychiatry when an individual is encountering difficulties with managing their mental health.
  - Lack of timely access to psychiatry can lead to an escalation in challenging behaviours, which can also lead to placement breakdowns across the continuum.

Funding: Out of Scope and/or Uncoordinated

• Funding for these supports comes from several sources: the Community Supports Home Support Budget (this service population requires a very different type of intervention), the Department of Advanced Education and Skills (income support), or via the Co-operative Apartment Program.

• If these placements could be reviewed and coordinated on a provincial level, as opposed to the cross section of departmental services that currently exists, this could create savings in the provincial budget if resources were centrally reviewed as well as the cost savings from logistical operations across departments.

• Home support budgets appear skewed as a result, because residential placements in general are more costly than standard home support arrangements as a result of the level of support and coordination required for competent service.

Alternate Staffing Model

- In ILA environments, many of these individuals are support by Home Support Workers (HSWs). HSWs have a focus on personal care, and disorders that focus primarily on the aging population. Workers for adults with intellectual disabilities have a completely different set of competencies, whom we'll refer to as "Direct Support Workers", or "DSW's".

- For identifying the skill set a DSW should present with, we recommend following the National Association for Persons with Developmental Disabilities (NADD) Direct Support Professional Competency Guidelines (see Appendix 4). This outlines the competencies staff should have, and has the option of certification if desired.

- Providing an outline for the competencies for the role helps ensure:
  - Staff have sufficient training to prepare for their role (includes training in behavioral health and mental health);
  - Have an understanding of best practice in their field;
  - Creates an environment of professionalism that the staff need to demonstrate in their capacities

Service Coordination Support

- Direct Support Workers require clinical support in the performance of their duties, as well as day to day supervision of their overall performance.

- Ensuring agencies have the infrastructure to support their direct support workers will decrease the likelihood of placement breakdown and increase the likelihood of positive outcome measurement and quality of life indicators.

- Ensuring agencies have the infrastructure and resources to manage challenging behaviors utilizing positive behavioral support strategies, as well as education to understand and work with mental disorders, will assist with ensuring advocacy for the appropriate level of support will occur.

Alternate Structure Model: Ontario

- Other jurisdictions have identified resources to support this specific population, due to the complexity in their care. For example, Ontario passed **The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008 (SPIDDA)** (See Appendix 5).

- In accordance with this act, the Provincial Government established guidelines for quality for this service population. Any organizations or agencies who provide care to this service population must meet Provincially legislated quality assurance measures (see Appendix 6).

Care Givers

Alternate Structure Model

- By doing a systemic evaluation on how to provide effective care to this service population, we can:
  - Reduce the impact to acute care environments such as E.R.'s and Psychiatry Wards;
  - Reduce the impact of long-term occupation of psychiatry beds when placements break down if community resources can be developed to accommodate the need in the community;
  - By reducing workloads of community based psychiatrists, and making them more accessible, we can ensure that patients have timely access for their care when needed
  - Determine a coordinated effort to provide care that could possibly see a reduction in overall spending across other departments of government service;
  - Improve the quality of care being offered to one of our most vulnerable populations;
  - Likely provide an overall savings to the provincial budget across multiple departments by establishing service in a coordinated fashion.

Person Centered Assessment

- Person centered assessment, especially from the agency providing care, can help communicate to the multi-disciplinary team (Psychiatry, Social Work, OT, Family Doctor) what is being seen in the residence, and assist with creating a shared vision for what the individuals needs are and how as a team care will be approached. This will also reduce the likelihood of placement breakdown.

- CG uses the *Adult Needs and Strengths Assessment; Developmental Disabilities adaptation (ANSA-DD),* a multi-purpose tool developed for adults behavioral health services to support decision making, including level of care and service planning, to facilitate quality improvement initiatives, and to allow for the monitoring of outcomes of services (see Appendix 7).

Outcome Measurement & Reporting

- CG utilizes the "Transformational Collaborative Outcomes Management", or "TCOM" (See Appendix 8), to assist with individual and program level outcomes measurement and management. Dr. John Lyons from the University of Chicago has been instrumental in the implementation of this assessment approach with the organization:

"*Human services, including health care, are often complex because of the number of different people involved in the process of care. In complex systems participants always have different perspectives and often have competing responsibilities and objectives. Transformational Collaborative Outcomes Management is a conceptual framework for managing complex system. Within this framework there is a philosophy, a strategy, and a set of tactics all designed to facilitate an effective and integrated approach to addressing the needs of people".*

- The John Praed Foundation Website

Care Givers

Recommendations

- Creation of a Departmental Division responsible for individuals with intellectual disabilities and/or neurological disorders;
- Review the feasibility or necessity of legislation establishing quality assurance measures for this service population
- Complete review of RHA community support case files to identify supports currently being provided to this service population (i.e. similar to Ken Fowlers CYFS report completed in 2008);
- Identify number of needed beds at each level of the continuum, and staff qualifications at each level;
- Issue an RFP for residential service providers to establish a professional service agreement relationship with existing service providers and to establish required quality expectations for service;
- Develop an outline for supportive living guidelines and service delivery for individuals with intellectual disabilities.

Thank you