Health Accord Newfoundland and Labrador

Organizational Submission

Submitted By: Momentum Developmental Support

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Executive Summary

Momentum Developmental Support is a licensed Home Support Agency in Newfoundland and Labrador, providing residential supports to person with Intellectual and/or Developmental Disabilities. Our mission is *Enhancing Futures* of persons with disabilities so they may live actively in their communities, regardless of their level of ability.

This submission is being provided to Health Accord NL, whose public engagement process is focused on:
a) increasing awareness of and interventions in the social factors that influence health (social determinants of health), and,
b) balancing community-based (primary health care, elder care, social care) and hospital-based services.

The purpose of this submission is to:
a) highlight the prevalence of persons with I/DD in the community,
b) highlight the impact of persons with I/DD on various Governmental Departments including health care, and,
c) propose possible solutions to presenting issues.

Prevalence Rate of Persons with I/DD:

- With a prevalence rate of 2.9% (developmental & learning disability categories combined), Newfoundland and Labrador would have an estimated population of 14,500 persons with I/DD over the age of 15 years of age.
- Approximately 13,964 would have a co-occurring disability.
- Approximately 5,725 would present with co-occurring mental illness.
- Approximately 10,000 would present with physical disabilities.
- Levels of I/DD ranked in terms of severity (utilized from DSM-5's outline for severity of I/DD):
    - Approximately 12,000 would present as mild;
    - Approximately 1,430 would present as moderate;
    - Approximately 680 would present as severe, and
    - Approximately 390 would present as profound.

Impact to Acute Health Care Centers:

Persons with I/DD are:

- Nearly two times more likely to have at least one return visit to an emergency department within 30 days of a prior visit or hospitalization (34.5 per cent vs. 19.6 per cent);
- More than three times more likely to be readmitted to hospital within 30 days of their initial discharge (7.4 per cent vs. 2.3 per cent);
- Three to four times more likely to be frequent emergency room visitors;
- Six and a half times more likely to have at least one alternate level of care day (the need to remain in hospital despite being well enough for discharge) in hospital (4.6 per cent vs. 0.7 per cent);

- 17 and a half times more likely to spend at least one day in long-term care (3.5 per cent vs. 0.2 per cent);
- Nearly four times more likely to experience premature mortality (6.1 per cent vs. 1.6 per cent);
- 29% of all visits resulted in hospitalization.

Impact of Persons with I/DD to Health Care/Other Government Supports

General Notes:

- 1 in 3 will present with a mental illness (as opposed to the public presentation of 1 in 5)
- Co-occurring primary health care (medical conditions) occur at a higher rate than the general public. Among the conditions and contributing factors to the disparities are obesity, metabolic risk factors and poor cardiovascular health, osteoporosis, falls and fractures, gastrointestinal conditions such as reflux and constipation, sensory impairment (especially eye disease), oral health, increased dementia prevalence [particularly in clients with down syndrome] and notable levels of polypharmacy.
- An estimated 10,000 adults with intellectual disabilities [in Canada] under the age of 65 are living in hospitals, nursing homes or long-term care facilities because they cannot get the personal supports and affordable housing they need.
- Reports indicate that some people with intellectual disabilities are "incarcerated by default" - sentenced to prison as a 'last resort' because community-based services have failed and there are no other appropriate alternatives available. . Prevalence rates in correction systems vary from as low as 10% to as high as 30%.
- Adults with intellectual disabilities are more than twice as likely as others to still be living at home with one or more parents.
- Homeless people are significantly more likely to have an intellectual disability than the general population.
- People with intellectual disabilities are nearly twice as likely as others with disabilities to have only partially met needs for help with everyday activities (i.e. Activities of Daily Living, Independent Activities of Daily Living).

Proposed Solutions: "Creating Capacity in our Communities"

- Intensive In-Home Family Support Program
- Therapeutic Family Support Program
- Short-Term Assessment/Crisis Stabilization Unit Service
- Supportive Independent Living Program
- Congregate Care Living Program
- Individualized Living Arrangement Program
- Emergency Placement Home Service

Proposed Solution: Implementation of TCOM Approach

- Implementation of the Transformational Collaborative Outcomes Management (TCOM) approach to support options for persons with disabilities within the Community Support Program;
- Use of the Adult Needs and Strengths Assessment for the Developmentally Disabled (ANSA-DD) to inform clinical management and placement decisions;

- Develop benchmarks for placement in the above identified array based on the ANSA-DD.

The last plan developed by the Government of Newfoundland and Labrador specifically designed to support persons with developmental disabilities was called "A Plan for the Development of Community Living Arrangements and Related Support Services for Developmentally Delayed Persons in Newfoundland and Labrador as a Practical Alternative to Institutionalization" (1982). This plan's intention was to work towards the development of community resources for persons with I/DD. Based on the above data, it is time to pick up that work and update our plans based on evidence and available data to ensure better outcomes in health.

Momentum Developmental Support is committed to supporting persons with disabilities to live and take part in their communities.

Who We Are

Overview

Momentum Developmental Support is a licensed home support agency within Newfoundland and Labrador, operating within several of the Regional Health Authorities. We provide residential supportive options to persons with disabilities. The options Momentum operates are referred to, in policy, as Individualized Living Arrangements (ILAs). These ILAs provide residential staffing care for 1 or 2 clients within a residence. Our mission is a focus on *Enhancing Futures* of persons with disabilities to live happy and successful lives in their communities. We envision a world where anyone can live in and be an active participant in their community, regardless of their level of ability.

We have strived to become a provider of choice for individuals and families who require supportive care in their communities. Momentum has been accredited by Accreditation Canada as a demonstration of our commitment to excellence and quality care. Our ability to serve our communities in this capacity over the years has helped us gain an understanding of some of the presenting needs within this sector. One area of increasing need we have identified is for supports for individuals with intellectual and/or developmental disabilities (I/DD) and/or persons living with mental illness. Residential support service requests are a continuous emergent or continue to be an emergent need for this service population. Some of the specific needs we have identified in this population are:

- Need for different competencies for workers: the skillsets needed for ongoing work with individuals with I/DD differs greatly from those of traditional in-home support services. By collaborating with various national and international organizations, we have been able to adopt a set of competencies for our front-line workers and establish alternate classifications that better reflect our clients' needs.
- Need to understand dual diagnosis: I/DD covers a range of neurodevelopmental disorders, inclusive of traumatic brain injury. When mental illness presents within the I/DD population, service provision can become more complex. We have built systems and organizational relationships to better manage this presentation in the community.
- Service Coordination: Residential care for individuals with I/DD often requires coordination at the residence level. This is intended to ensure coordination between an interdisciplinary team to meet all the quality of life needs of the individual(s) being served within the residence.
- Professional Supports: ensuring quality care in residential supports takes a team. CareGivers has a support team to ensure strong business performance in every operational facet: human resources, financial oversight, property management, programming, quality assurance and advocacy.

Leadership

Our Executive Director is Chad Perrin. He is a registered social worker with the NLASW, having obtained his Bachelor of Social Worker from the University of Manitoba and his Master of Social

Work from Memorial University of Newfoundland and Labrador, and has served as a field instructor for Memorial University's School of Social Work. Chad has been working in the social services field for approximately 16 years in the home care, mental health and child welfare sectors. Chad is a certified Dual Diagnosis Specialist (specializing in the co-occurrence of I/DD and mental illness) via the National Association for the Dually Diagnosed, was formerly a member of the Board of Directors for the Autism Society of Newfoundland and Labrador, and currently serves as a Public Interest Representative with the Mental Health Care and Treatment Review Board for the Government of Newfoundland and Labrador.

Definitions and Prevalence

Intellectual and/or Developmental Disabilities (I/DD) is an umbrella term used to capture several potential diagnoses that include (but are not limited to);

- Autism Spectrum Disorder
- Cerebral Palsy
- Down Syndrome
- Fetal Alcohol Spectrum Disorder
- Intellectual Disability
- Neurodevelopmental Disorders (as characterized by the DSM-5)
- And other developmental delays

(National Institute of Child Health and Human Development, 2016) (American Association on Intellectual and Developmental Disabilities, 2021) (Centers for Disease Control and Prevention, 2020) (Sullivan, et al., 2011) (American Psychiatric Association, 2013)

One of the challenges in understanding the epidemiological presentations of this service population, is the various definitions that exist among different international groups (i.e. World Health Organization's International Classification of Functioning, American Association on Intellectual and Developmental Disabilities, UK National Health Service, Government of Canada Public Health) and what terminology is used in the definition of a "case". In addition:

> "The picture is further complicated by continued use in other jurisdictions of the term 'learning disabilities', which the UK National Health Service defines as a condition that affects the way a person learns new things in any area of life, affects the way a person understands information, and how he or she communicates." (McCallion, Ferretti, Beange, & McCarron, 2019, p. 11)

As a result of the varying titles used to reference this service population, when reviewing prevalence rates regarding I/DD it is always important to review the jurisdiction the report was developed in and what constituted a disability in the eyes of the study. With no prevalence studies having been conducted within Newfoundland and Labrador on this topic, for the purposes of planning and this presentation we will use national data and infer based on presenting percentage of population. The Canadian Survey on Disability (2012) identifies that

0.6% of the general population present with a "Developmental" disability, with 2.3% of the general population presenting with a "Learning" disability (Statistics Canada, 2012, p. 4). Additionally:

- 96.3% of respondents who reported a learning disability also reported at least one other type of disability;
- Mental health-related disabilities had the highest rate of co-occurrence for adults 15-24 with a learning disability, while physical disability had the highest rate of co-occurrence for adults aged 25 and older (Statistics Canada, 2012, p. 5)

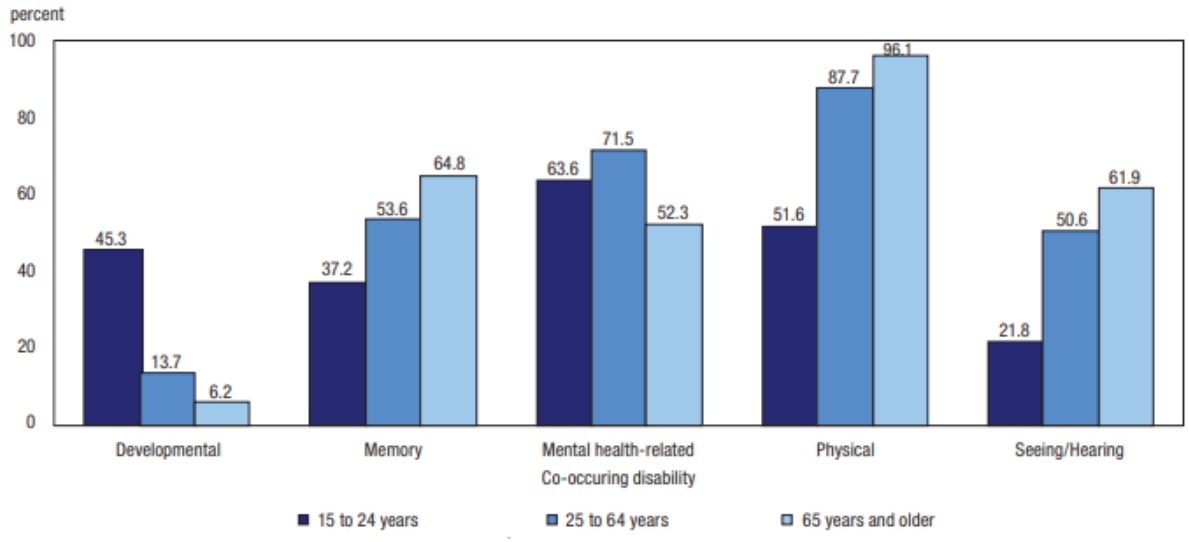

Figure 1: Prevalence of co-occurring disability types among adults with a learning disability, by age group, aged 15 years and older, Canada, 2012 **(Statistics Canada, 2012, p. 6)**

Levels of disability are also a consideration in intellectual disability: "Severity of levels (mild, moderate, severe and profound) in the USA, as defined in the DSM-5, are based on adaptive functioning in the conceptual, social and practical domains" (McCallion, Ferretti, Beange, & McCarron, 2019, p. 12).

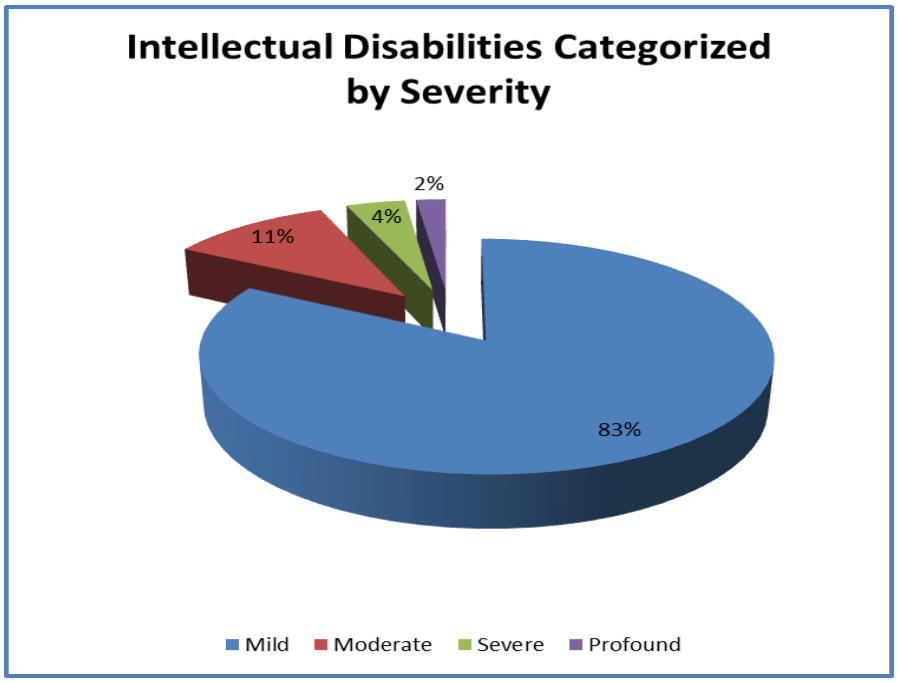

Figure 2: Intellectual Disabilities Categorized by Severity **(Fletcher, Baker, St. Croix, & Cheplic, 2015, p. 22)**

The level of an individual's disability demonstrates their disability's impact to their daily living functioning, which is often an indicator for the level of supports the individual would require to maintain independence in the community.

Based on the above prevalence rates, we can infer the following population sizes:

- With a prevalence rate of 2.9% (developmental & learning disability categories combined), Newfoundland and Labrador would have an estimated population of 14,500 persons with I/DD over the age of 15 years of age.
- Approximately 13,964 would have a co-occurring disability.
- Approximately 5,725 would present with co-occurring mental illness.
- Approximately 10,000 would present with physical disabilities.
- Regarding the level of I/DD by severity:
    - Approximately 12,000 would present as mild;
    - Approximately 1,430 would present as moderate;
    - Approximately 680 would present as severe, and
    - Approximately 390 would present as profound.

Complications in Presentations

As we can see from the above data, complications in supports for persons with I/DD are often the result of co-occurrence with either mental health related disorders, or physical health issues.

Mental Health Presentations in I/DD

Mental health issues in persons who have an I/DD occurs at a higher prevalence rate than the general population; some sources cite a prevalence rate of 33% (Hobden & LeRoy, 2009), while others cite a rate of 41% (Lunsky, et al., 2012) bringing the rate to 1 in 3 persons with I/DD. By contrast, the presentation of mental health issues in the public is 1 in 5 (Canadian Mental Health Association, 2013). However, because of the decreased cognitive skills and/or self-insight available to persons with I/DD they are often unable to recognize the signs and symptoms as being those of mental health symptoms. Indeed, loved ones and professionals involved in the care of these patients can sometimes confuse the signs and symptoms of mental illness with challenging behaviors stemming from their decreased cognition. Signs a person with I/DD may have a mental illness include (but are not limited to):

- Increased anxiety, panic or fright
- Hearing, seeing, feeling imaginary things (hearing voices is not the same as talking to oneself for company , to process thoughts, or self-talk to reduce anxiety)
- Need for instant fulfillment / gratification
- Unusual sleep patterns (insomnia or lengthy periods of sleep)
- False beliefs (delusional thinking or paranoia)
- Decline in personal hygiene
- Inappropriate expressive reactions
- Family history of mental illness
- A functional or behavioral change
- Excessive reactivity / moodiness
- Memory problems (worsening memory or change in memory)
- Accelerated speech patterns
- Changes in appetite (loss of weight or increase in weight)
- Heightened emotional sensitivity
- Self-isolation
- Lingering sadness
- Self-injurious behavior
- Suicidal ideation

(Fletcher, Baker, St. Croix, & Cheplic, 2015, p. 59)

The root cause of the higher prevalence rate of mental illness among patients with I/DD than the general population has not been firmly identified through research, however "it is proposed that there are both internal and external factors which contribute…due to interweaving influences based on a person's biology, psychology, the environment, and the social/family aspects of the individual" (Fletcher, Baker, St. Croix, & Cheplic, 2015, p. 76). As a result of these factors, supporting the mental health of persons with I/DD is a critical element for planning in development of supports.

Primary Health Care Issues in I/DD

As previously noted, the highest co-morbid disorder for persons with I/DD over the age of 25 is physical disability:

> "Poor health continues to be reported for people with an intellectual disability who have higher levels of chronic conditions, multi-morbidity and greater complexity identified in health needs and earlier mortality as compared to their peers without life-long disabilities. Among the conditions and contributing factors to the disparities are obesity, metabolic risk factors and poor cardiovascular health, osteoporosis, falls and fractures, gastrointestinal conditions such as reflux and constipation, sensory impairment (especially eye disease), oral health, increased dementia prevalence [particularly in clients with down syndrome] and notable levels of polypharmacy." (Burke, et al., 2019, p. 28)

With the potential for physical disability comorbidity in addition to the client's presenting I/DD, as well as the aforementioned potential for mental disorders, it's little wonder that persons with I/DD can become repeat consumers for service when it comes to health care services.

Over Representation in Acute Care Centers

> "It has been suggested that (emergency department) visits by people with psychiatric disorders with I/DD occur, in part, because other resources are inadequate and thus serve as a barometer of the adequacy of primary and specialty outpatient care." (Lunsky, et al., 2012, p. 602)

Emergency Rooms and other acute care centers often bare the brunt of assessment of needs for persons with I/DD. Sometimes, as a result of the co-morbidity with primary health care issues this presentation can be warranted. However, often the presentation in acute care is a symptom of either a breakdown in, or lack of existence, of the necessary supports to care for the individual in the community. A common issue that presents in Newfoundland and Labrador is a breakdown in placement due to challenging behaviors by the client. Once the physician determines the patient is medically stable, they may come to find that the person who brought them in left the client there because they "couldn't handle them". As a result, they'll continue to hold the emergency room bed until a placement option can be determined. Because of the lack of placement options in the community, and with nowhere for the person with I/DD to go, the patient would be admitted to the hospital. Since the patient has an I/DD diagnosis, they are often sent to Psychiatry wards as the diagnosis for Neurodevelopmental Disorders is covered under the DSM-5. It's not uncommon for acute care beds in psychiatry, intended to manage short-term admissions/stabilizations for breakdowns in mental health, to be taken up for months as a result of the lack of community options available for the clients.

According to a report called "Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario", Lin, et al., (2019) found the following:

> "This report highlights that the health care needs of people with developmental disabilities are just not being met. We need an integrated health care approach that can bridge silos of care, between hospital and community, and between different sectors…We found adults with developmental disabilities did worse across all five outcomes. This pattern was true regardless of age, sex, the wealth or poverty of the

> neighbourhood where they lived, or the kind of developmental disability they had." (Centre for Addiction and Mental Health, 2019)

The report also found several other key points identifying that persons with I/DD are:

- Nearly two times more likely to have at least one return visit to an emergency department within 30 days of an earlier visit or hospitalization (34.5 per cent vs. 19.6 per cent).
- More than three times more likely to be readmitted to hospital within 30 days of their initial discharge (7.4 per cent vs. 2.3 per cent).
- Three to four times more likely to be frequent emergency room visitors.
- Six and a half times more likely to have at least one alternate level of care day (the need to remain in hospital despite being well enough for discharge) in hospital (4.6 per cent vs. 0.7 per cent).
- 17 and a half times more likely to spend at least one day in long-term care (3.5 per cent vs. 0.2 per cent).
- Nearly four times more likely to experience premature mortality (6.1 per cent vs. 1.6 per cent).
- 29% of all visits resulted in hospitalization.

(Centre for Addiction and Mental Health, 2019)/ (Lin, et al., 2019)

By developing community-based solutions to support persons with I/DD, we can prevent the inappropriate use of acute care presentation and reduce the impact to emergency departments and psychiatric acute care units.

"From Institution to Institution": Presentation in Long Term Care Settings

> "An estimated 10,000 adults with intellectual disabilities [in Canada] under the age of 65 are living in hospitals, nursing homes or long-term care facilities because they cannot get the personal supports and affordable housing they need" (Canadian Association for Community Living, 2017, p. 8)

Long-term care and nursing home facilities can become a long-term solution for persons with I/DD in early life. There are far too many examples of young adults residing in long term care settings due to the nature of their pervasive needs. With an aging population in Newfoundland and Labrador, there will become a growing need for Long-Term, facility-based care for the elderly who are unable to reside at home. Many of these much-needed beds will be tied up by individuals with I/DD, whose placements would be much better served in community-based living.

In 1982, in the midst of the implementation of the international movement "deinstitutionalization", the Government of Newfoundland and Labrador released a plan intended to move patients from

facility-based living to community-based options. These options included a) individuals with I/DD living on their own or with a companion(s), b) community board or co-operative apartment residences, or c) alternate family care (foster family type arrangements for individuals with I/DD) or board and lodging options (Corbett, 1997). While some patients were relocated into these options, many more have been moved from one type of institutional care (i.e. Exon House, Waterford Hospital) to another – Long Term Care facilities. By creating community-based options and reviewing records of existing patients currently living in Long-Term Care who could be placed in more appropriate settings, we can create a system which better meets individual outcomes, create capacity for care for an elderly population while also (if planned properly) create a more economic model for per-person level of care.

"Incarceration by Default": Presentation in the Criminal Justice System

> Reports are that some people with intellectual disability are sentenced to prison as a 'last resort' because there are no other appropriate alternatives, and community-based services have failed. This has been referred to as "incarceration by default". Following sentencing, some with [I/DD] may also be sent to maximum security prisons, regardless of the nature of conviction, because of their potential vulnerability to other inmates (Riches, Parmenter, Wiese, & Stancliffe, 2006, p. 388)

In a review of literature, prevalence rates for I/DD presentation in criminal justice systems can vary drastically (Hellenback, Karatzias, & Brown, 2017) (Haysom, Indig, Moore, & Gaskin, 2014) as a result of several factors: a) the issues surrounding classification of what constitutes a "case" to be classified as I/DD, b) what level of disability would be included in the study (i.e. IQ level, severity of disability), c) the jurisdiction the study is being completed within, and d) the assessment utilized to measure for the purpose of the study. Hellenbach, Karatzias & Brown (2017) identify a prevalence rate of between 25% and 30% of criminal cases with an offender with an I/DD whose IQ would be considered mild (IQ 70-85), and also cite an additional 10% whose presentation would be considered moderate (IQ 50-69). Riches, Parmenter, Wiese & Stancliffe (2006) cite a prevalence rate of 4% of all offenders presenting with I/DD; Haysom, Indig, Moore & Gaskin (2014) cite a prevalence rate of between 10% and 17% of offenders, and Sondenaa, Rasmussen & Nottestad (2008) cite a prevalence rate of 20% of offenders presenting with a IQ <70, with an additional 31% as being within the borderline (IQ 70-79).

The fact that persons with I/DD are overrepresented in criminal justice systems (Hellenback, Karatzias, & Brown, 2017) can, like their presentation in the acute care system, be attributed to a community with insufficient resources to meet the needs of the service population. Challenging behaviors from clients with I/DD can present in a myriad of ways including (but not limited to): assaultive behaviors, self-injurious behavior with or without a clear intention of suicide, damage to property, and more. When families of origin, or community service providers, are unable to manage presenting challenging behaviors their default is often to call 911, with police responding. The challenging behaviors clients with I/DD in crisis present with, and the lack of options to provide to police for resolving the issue without criminal prosecution, can be viewed as two systemic issues: i) a

lack of community support options intended to meet client presentations where they are, and ii) a lack of clinical programming with a focus on development self-regulation skills and self-awareness.

By developing community resources to support individuals in their community, as well as developing clinical resources to support individual development, we can reduce the presentation of persons with I/DD to the criminal justice system.

"Without a Home": Homelessness and I/DD

In a fact sheet on housing and persons with I/DD, The Canadian Association for Community Living (2017) highlights some important notes:

- Adults with intellectual disabilities are over twice as likely as others to still be living at home with one or more parents.
- Homeless people are significantly more likely to have an intellectual disability than the general population.
- People with intellectual disabilities are nearly twice as likely as others with disabilities to have only partially met needs for help with everyday activities such as meal preparation, everyday housework, heavy household chores, getting to appointments/ errands, personal finances, child care because of the respondent's disability, personal care, nursing care/ medical treatment at home and moving about at home. They are also about twice as likely as others with disabilities to have none of their needs met for assistive aids / devices, such as for mobility, agility, hearing, seeing, communicating, learning and pain management.
- People with intellectual disabilities are far less likely than others to have access to paid employment and disproportionately rely on government sources of income assistance. Only 25.5% of working age people with I/DD have any paid employment compared to the national average of 75.5% (pp. 1-2).

Persons with I/DD will often continue to live with families of origin for an extended period. With the Baby Boomer generation in Newfoundland and Labrador continuing to age into their retirement and start to become medically infirm, Newfoundland and Labrador is going to have a dramatic influx of persons with I/DD who have only ever lived with their family who will require a significant level of care. With appropriate community development and the addition of necessary resources, we can ensure we have the capacity in place to manage the upcoming influx of referrals to the Regional Health Authorities.

Proposed Solution: Creating Capacity in the Community

Momentum Developmental Support has been working with the Regional Health Authorities to meet the needs in the communities we work within. By listening to feedback from their leadership, meeting with disability advocacy groups and listening to clients and families that have been in our charge, themes of recurring needs have begun to form. These needs identify a gap in Governmental policy for persons with disabilities. Additional programs and resources are necessary to permit communities to support persons with I/DD where they are, and to minimize their presentation in the

areas noted previously in this submission. As a result, Momentum has proposed the development of the below array of services to meet the needs discussed during this submission. A more in-depth discussion regarding these proposed projects can be arranged by contacting the Executive Director of the organization:

Intensive Home & Family Support Program (IHFS)

The existing Provincial Home Support Program is a system in community supports that is intended to support individuals in the community, via Home Support Workers (HSWs), with a focus towards management of primary health care concerns. However, other needs are met as well via this system.

In Momentum's experience, individuals with I/DD require two aspects not typically available in traditional home support services: a support worker role with a skill set focused on supporting individuals with I/DD (see NADSP Competencies), as well as a Service Coordination role to facilitate the care by directly supervising and support the front-line worker. This service coordination role (referred to in the program as an Individual and Family Services Manager) provides multiple functions including (but not limited to): group support work for families, group skill building for individuals, supervision of the front-line workers and providing support to meet intended outcomes, providing training and more.

One of the primary intended outcomes of this service modality is to prevent placement breakdown and allow individuals to remain in family environments longer, before eventually requiring residential supportive options.

Therapeutic Family Care

The Province currently has a Program called the Alternate Family Care (AFC) Program; this service is a residential support option designed to provide housing and social care via a family that is not the family of origin. The AFC provider is recruited and licensed by the Regional Health Authority, and compensated for the individuals care. Momentum proposes one of two solutions:

1. *Assumption of Oversight of the Existing Service*: Momentum could assume oversight of the AFC program with a focus on streamlining effectiveness of the service, building capacity within the Province for the program's continuation and offering additional resources and training to AFC providers.
2. *Offer a secondary service to the Province*: In the Provincial Department of Children, Seniors and Social Development, Level 2 care provides for the licensing of regular foster homes (akin to AFC providers), and level 3 care provides for the licensing of specialized foster homes. The Regional Health Authorities can continue to oversee the AFC program while Momentum develops a specialized Therapeutic Family Care service to attempt to keep clients in family care arrangements as long as is clinically appropriate.

Supportive Independent Living (SIL)

Newfoundland and Labrador is one of the only provinces with little to no Supported Independent Living modalities designed to support I/DD. A SIL program ideal for adults with an intellectual disability that require minimal and individualized support in areas such as finances, home management and developing community connections. People may opt to live independently or with roommates of their own choosing. Such programs are already being offered in other jurisdictions within Canada with great success.

SIL arrangements are a group of apartments in a public space, or a facility, to allow an individual(s) to live independently with the necessary supports on site. A site administrator organizes the care being arranged, with support staff available on site 24 hours a day to provide minimal supports for meals, medications, personal care or arrangement of transportation needs.

Congregate Living Arrangements (CLA)

Newfoundland and Labrador have a history within our Province of poor care being provided via what is formerly referred to as "Group Homes", where 6-12 clients were able to reside together. Care for this type of arrangement became concerning and the approach was abandoned in the 1980's/1990's.

However, there is value in developing relationships based on those with whom we live. This proposal's recommendation focuses on a housing option called "Congregate Living Arrangements" with a maximum of 3 clients living on site in residences in the community. Support staff are available 24 hours a day, a Home Manager is assigned to the site to oversee the front-line support workers and the focus is on supporting individuals to engage in community-based activities to the degree they desire.

Individualized Living Arrangements (ILA)

Some client presentations require a greater degree of interventions to maintain safety for them and others, because of the severity of their presentation. As a result, some individuals may require individualized care to meet their needs. An Individualized Living Arrangement provides that capability in a staff model similar to a CLA but focused on the complex care required for the individual in the ILA.

In addition to this proposed array of services, further services that could be considered for development in the community would be specifically designed to reduce the impact to acute care centers and psychiatric floors in hospitals.

Additional Option: Short-Term Assessment/Crisis Stabilization Unit (STA/CSU)

With the release of the Towards Recovery (2017) report by the All-Party Committee of Newfoundland and Labrador, plans are in process to reduce the inpatient capacity for the mental health hospital site. As a result, community-based resources will be required to support persons with I/DD to

prevent inappropriate presentation to acute care centers while still ensuring needed assessment and/or stabilization of persons in crisis. These crises could be the result of factors including (but not limited to): medications intended to manage symptoms beginning to lose effectiveness, onset of a new psychiatric illness, recurrence of existing mental health symptoms, or increase in challenging behaviors due to unknown reasons.

An STA/CSU residence in the community could support Clinical Assessment of the individual and monitoring of symptoms while providing observations and records to a Psychiatrist. Similar models are presently in place in several Canadian Provinces including Manitoba (Shared Health Manitoba, 2021), Alberta (Alberta Health Services, 2021) and Ontario (Canadian Mental Health Association, 2021). The program is staffed by a minimum of two staff at all times: a psychiatric nurse and crisis worker. The site is assigned a Psychiatrist from an acute care center who checks in with the STA/CSU during rounds and reviews patient profiles for determination on continued care, discharge and/or any potential presentations requiring inpatient admittance due to clinical presentation.

Patients could present at any point to the STA/CSU by physician referral/psychiatrist referral/self-referral. Timelines for admission vary depending on the service, but examples range from 3 days to 7 days, with abilities to have patients remain longer if determined necessary by Psychiatry. The service is considered a voluntary service, so no secure measures would be required on site. Other jurisdictions have multiple STA/CSU's in residences in the community in an effort to reduce the impact to acute care centers for emergency treatment only.

Additional Option: Emergency Placement Home

Placement breakdown is an unfortunate reality in management of community supports. There is a myriad of reasons why a placement might break down including (but not limited to): medical infirmity of the primary caregiver, increase in level of care required by person with I/DD beyond caregivers control, increase in level of care required by person with I/DD and they are no longer able to live independently, investigation into care of primary caregiver and person with I/DD, and more.

An Emergency Placement home is a residence in the community that is staffed, 24/7, and can accept referrals on short notice due to placement breakdown. This ensures options are available for community providers when placements break down, and works to prevent inappropriate presentation in acute care centers due to community breakdown issues. Clients can stay in emergency placements for up to 90 days while determinations are made as to next steps in the array of available services for placement.

Proposed Solution: Clinical Framework Modality for Assessment and Outcome Management

In consideration of development of an array of services, such as described in Figure 3, we must identify the way we assess the needs of the person served for a) identification of necessary treatment planning, and b) determination for placement for the individual in the array of available community options based on pre-established benchmarks.

The Inter-RAI assessment instrument used in Community Supports programming in Newfoundland and Labrador is an instrument intended to support Home Care assessment. While the Inter-RAI assessment tool does have a version of the same instrument focusing on supporting I/DD (interRAI, 2021), it isn't an option for an instrument currently available to the Regional Health Authorities. Other assessment instruments, such as the Support Intensity Scale (American Association on Intellectual and Developmental Disability, 2021) have a similar focus on assessing the presenting need of the individual.

However, collecting assessment data and the data results can be used for more than just placement decisions. The assessment that Momentum would recommend for use with the service population is called the Adult Needs and Strengths Assessment for the Developmentally Disabled (ANSA-DD). The instrument is a part of an overall clinical framework called "Transformational Collaborative Outcomes Management" or TCOM:

> "The TCOM approach is grounded in a philosophy of a single shared vision – helping people achieve their health and wellness goals as they navigate healthcare, child welfare, juvenile justice, behavioral health, education and other complex systems. By creating processes that consistently point to this shared vision, it is easier to create and manage effective and equitable systems." (Praed Foundation, 2016)

TCOM uses assessment as one part of an overall decision-making process in the course of the program (see Table 1). Data is recommended to be used and analyzed at the individual, program and system levels to support evidence-based decision making. By using assessment data from the ANSA-DD, benchmarks can be set on what scores would constitute the various levels of care through the array of proposed services. The instrument can also be used in supporting communication across health disciplines (i.e. social work, psychiatry) in regards to client presentations. By using a consistent instrument across disciplines, we can ensure that needs and presentations are being clearly communicated to the various professional, thereby assuring appropriate treatment recommendations can be provided by the necessary discipline.

	Person Served	Program or Company	System, Market or Jurisdiction
Decision Support	Service Planning Effective practices Evidence-based practices	Eligibility Step-down	Resource management Right-sizing
Outcome Monitoring	Service transitions and celebrations	Evaluation	Provider Profiles Performance/Contracting
Quality Improvement	Case Management Integrated Care Supervision	CQI/QA Accreditation Program Redesign	Transformation Business Model Design

Table 1: Grid of Tactics **(Lyons, 2009, p. 46)**

Momentum has been using the ANSA-DD for several years; in 2020 an external contractor was hired to complex an audit of assessment data as developed by the organization and provide a summary of data results and recommendations for next steps on the instruments use within the program. The report, "ANSA Needs and Strengths Assessment Analysis for Momentum Developmental Support" can be provided upon request by contacting the organization's Executive Director.

Closing Remarks

Momentum Developmental Support continues its mission of *Enhancing Futures* of persons with I/DD, by focusing on development of opportunities ensure persons with I/DD can be a part of their community, regardless of their level of ability. The efforts of Health Accord NL vision of moving towards balancing community- and hospital-based services clearly align with the efforts of our organization. Most of NL's resources for persons with I/DD, as well as mental health, are still very institutionally based and very centralized. By de-centralizing the supports we can ensure that programming and resources are available in communities all across the island, as well as provide better outcomes in a more efficient manner.

Follow-up questions, comments, or feedback of any kind regarding this submission can be directed the organization's Executive Director via the below contact information:

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