



Brief on Equal Access to Mental Health Services and Well-Being for People with an Intellectual or Developmental Disability

New Brunswick Association for Community Living

March 2019

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Executive Summary

This brief sets out the main issues affecting the lack of mental health responses for people with an intellectual or developmental disability (IDD) and the impact that this has on the lives of people and their families. It also provides a set of concrete recommendations that are based on current research and evidence on effective mental health responses for people with IDD. NBACL is calling for a dedicated policy framework and strategy to ensure that people with IDD have the mental health supports and services that they require and deserve.

Research evidence indicates that the rates of mental health conditions in people with IDD are 3 to 4 times higher than the general population. Yet, many people are denied access to needed mental health services because of a lack of knowledge and expertise in the system or because medical professionals (including mental health professionals) mistakenly believe that the intellectual or developmental disability in itself is the cause of the problems that people are experiencing.

The issues addressed in this brief are complex. There are a number of over-lapping factors that have contributed to the present day situation faced by people with IDD who also experience a mental health concern:

- Diagnostic overshadowing refers to professionals "overlooking or minimizing the signs of psychiatric disturbances in a person with an intellectual disability" – and attributing the person's symptoms to the disability rather than to a mental illness or other psychosocial history.[1]Diagnostic overshadowing is still prevalent today. This results in people being denied access to mental health services.
- More recently, a specific diagnostic manual for people with IDD who may have mental health issues has been developed. The DM-ID 2 offers important adaptations of diagnostic tools that are specifically designed for people with IDD. In addition, the 2018 ***Canadian Consensus Guidelines on Primary Care of Adults with Intellectual and Developmental Disabilities*** contain a number of recommended clinical practice guidelines for the diagnoses and treatment of mental health conditions in adults with IDD.[2] There is a significant concern, however, that mental health professionals are unfamiliar with the tools and thus their use and application is likely quite limited.[3]
- Anecdotal evidence strongly suggests that New Brunswick's mental health system is not meeting its human rights obligations in the provision of mental health services to people with IDD. Statements by mental health professionals that people's experiences are only a by-product of their disability (and not a mental health concern) or that the system does not have the knowledge or expertise to provide appropriate services are simply untenable from a human rights perspective.

[1] Daniel Werges, "The Other Dual Diagnosis: Intellectual Disability and Mental Illness, NADD Bulletin, Volume 10, Number 5 (2007). Retrieved from: http://thenadd.org/modal/bulletins/v10n5a2~.htm
[2] Canadian Family Physician/Le Médecin de famille canadien, Vol 64, April 2018. Retrieved from: http://www.cfp.ca/content/cfp/64/4/254.full.pdf.
[3] Brandi Kelly, *Breaking Down Silos: Innovation in Dual Diagnosis Systems*. National Association for the Dually Diagnosed (2016), p. 9.

- A significant root cause of the lack of access issue is the lack of training and expertise in the mental health professional workforce. There are a number of unique elements to providing effective mental health support to people with IDD. For example, people with IDD may have different ways of communicating that affects their ability to self-report and respond to questions. Professionals often have to use other methods of determining diagnoses of potential mental health conditions.
- Providing effective support to people with IDD requires that professionals in the mental health and behavioural fields receive adequate training. In this respect, professionals should have a general level of knowledge and skill in the areas of IDD, assessing behaviours, diagnostic practices (including those identified in the DM-ID 2 manual and the *Canadian Consensus Guidelines on Primary care of Adults with Intellectual or Developmental Disabilities*) and treatment approaches and the modifications that may be required to provide effective responses. More specialized training for professionals that want to focus on serving people with IDD would also enhance the response by providing access to highly knowledgeable and skilled people who can mentor and support those with generalist level knowledge.
- With some notable exceptions, service systems that support people with IDD who may have a co-occurring mental health condition remain fragmented. Our provincial health, mental health and disability support systems can often work in isolation and fail to address the needs of individuals in a comprehensive and coordinated way. Collaborative approaches to addressing the needs of people with IDD and a co-occurring mental health and/or behavioural conditions have been identified as a current best practice in research and practice. The 2018 *Canadian Consensus Guidelines on Primary Care for Adults with Intellectual and Developmental Disabilities* note that "interprofessional teams" "can assess and address holistically a range of health and developmental needs and, with sufficient supports, can improve outcomes of care."[4] In the Canadian context, the Centre for Addiction and Mental Health (CAMH) in Ontario (Adult Neurodevelopmental Services at the Azrieli Adult Neurodevelopmental Centre) has developed processes and standards for inter-professional collaboration for people with IDD and a mental health concern.
- One clear outcome from the lack of appropriate mental health and behavioural supports for people with IDD is the frequent use of the acute care hospital system to address personal crises or mental health conditions. People with IDD who have a mental health condition are more likely to use hospital emergency departments, be re-admitted to hospital and have longer hospital stays than other adults.
- Increasing attention is being paid to the use of psychotropic medications for people with IDD. Recent Canadian studies have found that psychotropic over-prescribing is a serious concern in both community and clinical settings. NBACL believes that similar over-prescribing of psychotropic medications is happening in New Brunswick. In 2016, the NB Department of Social Development launched a $600,000 initiative to reduce the use of such medications on seniors living in nursing homes (with significant outcomes).

[4] Canadian Family Physician/Le Médecin de famille canadien, Vol 64, April 2018. Retrieved from: http://www.cfp.ca/content/cfp/64/4/254.full.pdf, p. 260.

The lack of a strategy to support people with IDD and mental health and/or behavioural issues is having a significant impact on individuals, families and our provincial systems. There is a personal, emotional and financial cost to not having the adequate support systems.

NBACL is proposing a set of concrete solutions that we believe are workable in the New Brunswick context.

1. Create, adopt and implement a dedicated strategy to support people with IDD and a co-occurring mental health concern.

2. Create and implement specific policy standards on providing mental health services to people with IDD.

3. Develop and implement a multi-year initiative on generalist level training in the area of "dual diagnosis" (IDD and mental health conditions).

4. Develop and implement a provincial "expert" level resource on IDD and mental health and behaviour concerns to provide access to consultative support and expertise to family physicians and other "front line" service providers.

5. Develop and implement a province-wide initiative to review the use of psychotropic medications for people with IDD and to reduce the use of such medications through non-medication interventions.

6. Implement strategies developed in other jurisdictions to improve hospital care for people with IDD with a mental health condition.

7. Establish collaborative interprofessional teams to serve adults with IDD and a co-occurring mental health condition.

8. Develop, promote and use materials and resources aimed at supported people with IDD to learn about mental health and mental health conditions.

9. Explore and implement strategies to better educate and support families and caregivers that provide day-to day care to people with IDD and mental health concern.

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Background and Purpose

The mental health needs of people with an intellectual or developmental disability (IDD) continue to be unmet in New Brunswick. Research evidence indicates that the rates of mental health conditions in people with IDD are 3 to 4 times higher than the general population. Yet, many people are denied access to needed mental health services because of a lack of knowledge and expertise in the system or because medical professionals (including mental health professionals) mistakenly believe that the intellectual or developmental disability in itself is the cause of the problems that people are experiencing.

In 2015, NBACL completed and launched an eBook called *Supporting People with Dual Diagnosis* (see: http://nbacl.nb.ca/module-pages/intellectual-disability-mental-health-and-rights-based-approaches/). This resource provides a general overview of issues, assessment approaches and treatment strategies to support people with IDD and a mental health concern. More recently, NBACL has published Easy Read guides on mental wellness, anxiety and depression to support people with IDD to better understand mental health and wellness issues.

This brief sets out the main issues affecting the lack of mental health responses for people with IDD and the impact that this has on the lives of people with IDD and their families. It also provides a set of concrete recommendations that are based on current research and evidence on effective mental health responses for people with IDD.

NBACL is calling for a dedicated policy framework and strategy to ensure that people with IDD have the mental health supports and services that they require and deserve. Over the past 10 years, NBACL has repeatedly brought this issue to the attention of various government leaders and others. People with IDD and their families can no longer wait for action to happen.

Demographic and Prevalence Rates for Dual Diagnosis (IDD and Mental Health Condition)

The 2017 Canadian Survey on Disability estimates that 1% of the population aged 15 and older has a developmental disability. Other sources cite the rate as being between 1 and 3 per cent of the general population. Using the 1% rate as a conservative estimate, there are an estimated 7,720 youth and adults in New Brunswick with a developmental disability. Using a 2% rate, there are approximately 15,440 people with a developmental disability (this might be a more realistic assumption if all age groups are considered). At 3%, there would be an estimated 23,160 people with IDD in New Brunswick.

Estimates on the rates of dual diagnosis (IDD and a mental health condition) vary. The National Association for the Dually Diagnosed (NADD) estimates that 30 per cent of the population of people with IDD also has a mental health disorder. Other estimates suggest the rate of dual diagnosis is similar or even higher:

> *In the Canadian context, there are few sources of available population-based information on individuals with a dual diagnosis of ID and mental health disorder. In 2012, Bielska and Oulette-Kuntz undertook a secondary analysis of two population based surveys (2005 Canadian Community Health Survey and the 2006 Participation and Activity Limitation Survey) to estimate the prevalence of psychiatric and behavioural conditions among adults with reported ID. The proportions of individuals with a dual diagnosis of ID and a mental health condition were reported to be 30.6% (CCHS) and 44.3% (PALS)*.[5]

A recent (2018) comprehensive study in Ontario involving 66,484 adults with IDD found the following:

> *We found that psychiatric disorder diagnoses were more common in adults with DDs compared to those without DDs. Our most recent findings (Lin et al. 2016b) showed that in a two-year period, 44% of adults with DDs had a mental illness diagnosis and 6% had an addiction diagnosis (Lin et al. 2016a). Chronic diseases such as diabetes, hypertension, chronic obstructive pulmonary disease and asthma were more common among adults with DDs and a mental illness or addiction compared to those without these diagnoses (Lin et al. 2016b).*
>
> *Differential prevalence rates of mental illness are apparent by young adulthood, and specific subgroups within the DD population may be at greater risk for mental illness than others are. In a study of 18–24-year-old adults, those with autism had even higher rates of mental illness diagnoses (52%) than their counterparts with other DDs (39%; Weiss et al. 2018).*[6]

Using a conservative estimate of 30% of the population of people with IDD having a dual diagnosis, there is an estimated range of 2315 to 6950 people in New Brunswick who have an intellectual or developmental disability and a co-occurring mental health condition. Even at the low estimate level, the size of the population requiring mental health support warrants full consideration by governments and health and social service professionals.

Framing the Issues

The issues addressed in this brief are complex. There are a number of over-lapping factors that have contributed to the present day situation faced by people with IDD who also experience a mental health concern. These issues will be highlighted and summarized in order to propose recommendations for action.

[5] William Morrison and Patricia Peterson, *Supporting People with a Dual Diagnosis, Module 1: Intellectual Disability, Mental Health and Rights Based Approaches*, New Brunswick Association for Community Living, 2015. Retrieved from: http://wmaproducts.com/nbaclmodule1/.

[6] Yona Lunsky, et. al., "The Mental Health of Adults with Developmental Disabilities in Ontario: Lessons from Administrative Health Data", Healthcare Quarterly 21(1) April 2018 : 6-9.doi:10.12927/hcq.2018.2552. Retrieved from: https://www.longwoods.com/content/25521/healthcare-quarterly/the-mental-health-of-adults-with-developmental-disabilities-in-ontario-lessons-from-administrative.

Historical Assumptions about People with IDD and Mental Health

Prior to the 1960s, the prevailing belief was that people with IDD could not experience a mental health condition. In this sense, "intellectual disability and mental illness were seen as mutually exclusive conditions".[7] Behavioural issues were "regarded as relating to maladaptive learning and adverse psychosocial experiences rather than psychiatric disorders".[8] Stereotypes about people with IDD also added to these false beliefs. There were beliefs that people with "mild" intellectual disability were "worry free" and that those with "severe" disabilities were not able to express feelings "and thus not able to experience emotional distress".[9] These views mirrored the "appalling treatment" that people with IDD were subject to – including sterilization, segregation, and institutionalization.

"Diagnostic Overshadowing" and the Development of Adapted Tools to Diagnose Mental Health Conditions for People with IDD

From the early 1970s, thinking began to shift about people with IDD in general as concepts such as "normalization" and later (in the 1980s) "Social Role Valorization" began to take hold. Advocacy groups, families and some service providers pushed for change in the way people with IDD were perceived and supported to live in the community. The integration of people with IDD into community (although initially still in ways that were segregating) became a goal of government policy and programs.

By the early 1980s, leading thinkers in the field of mental health acknowledged that people with IDD were both underdiagnosed and underserved by mental health programs and services. The concept of "diagnostic overshadowing" was introduced by Reiss, Levitan and Szyszko in 1982. This refers to professionals "overlooking or minimizing the signs of psychiatric disturbances in a person with an intellectual disability" – and attributing the person's symptoms to the disability rather than to a mental illness or other psychosocial history.[10]

Diagnostic overshadowing is still prevalent today. This results in people being denied access to mental health services (as noted below). Despite this, significant efforts have taken place to provide more accurate diagnosis of mental health conditions in people with IDD using different and adapted diagnostic scales. These addressed the following problem:

> *Traditional approaches to diagnostics focus heavily on interview of the "patient" and the person's ability to self-report symptoms and answer questions. The cognitive and communication challenges many people with IDD experience may preclude reliance on this type of evaluative activity. … Communication of more abstract concepts such as mood and anxiety may be even more challenging for some individuals with IDD. Some individuals may also be predisposed to response bias. For example, they may typically and consistently respond in the affirmative or negative to closed-ended questions that attempt to obtain symptom endorsement or lack thereof. Additionally, many typical psychopathology scales are not designed to account for the impact of the individual's IDD versus a possible co-occurring behavioural health need….*[11]

As a result of these difficulties a variety of scales have been developed that have focused on a variety of factors: symptom variations that can be directly observed or fairly easily inferred from behaviours; symptoms or characteristics that cannot be attributed to the disability but instead indicate a possible

[7] Daniel Werges, "The Other Dual Diagnosis: Intellectual Disability and Mental Illness, NADD Bulletin, Volume 10, Number 5 (2007). Retrieved from: http://thenadd.org/modal/bulletins/v10n5a2~.htm
[8] Ibid.
[9] Ibid.
[10] Ibid.
[11] Brandi Kelly, *Breaking Down Silos: Innovation in Dual Diagnosis Systems*. National Association for the Dually Diagnosed (2016), p. 4.

additional mental health condition; and differential symptom presentations based on data from research studies and known expert consensus statement or guidelines.[12]

More recently, a specific diagnostic manual for people with IDD who may have mental health issues has been developed. The *Diagnostic Manual for Intellectual Disability* (DM-ID-2) was developed by the National Association for the Dually Diagnosed and provides the following:

> *The DM-ID-2 Clinical Guide was developed to facilitate an accurate psychiatric diagnosis in persons who have intellectual disabilities and to provide a thorough discussion of the issues involved in reaching an accurate diagnosis. The DM-ID-2 Clinical Guide provides state-of-the-art information concerning mental disorders in persons with intellectual disabilities. Grounded in evidence based methods and supported by the expert-consensus model, DM-ID-2 Clinical Guide offers a broad examination of the issues involved in applying diagnostic criteria for psychiatric disorders to persons with intellectual disabilities.*[13]

The DM-ID 2 offers important adaptations of diagnostic tools that are specifically designed for people with IDD. There is a significant concern, however, that mental health professionals are unfamiliar with the tools and thus their use and application is likely quite limited.[14]

In addition, the 2018 ***Canadian Consensus Guidelines on Primary Care of Adults with Intellectual and Developmental Disabilities*** contain a number of recommended clinical practice guidelines for the diagnoses and treatment of mental health conditions in adults with IDD.[15] The Guidelines distinguish between Behaviours that Challenge (BTC) and psychiatric disorders (while noting that behaviours could be a symptom of a psychiatric illness – but should not be classified as such without a "systematic diagnostic formulation"). Similarly, the National Institute for Health Care and Excellence (NICE) in the U.K. has created extensive guidelines on the diagnosis and treatment of mental health problems of people with IDD (called "learning disabilities" in the U.K.).[16]

Denial of Mental Health Services

NBACL frequently hears from families about experiences in trying to access mental health services for their loved one with IDD. Often, these experiences are ones in which the call for help is denied on one or more of the following bases:

- That the person is only experiencing issues related directly to their disability (e.g. Autism);
- That the person would not benefit from mental health services (such as counselling) since they cannot either understand or communicate well enough; or
- The system does not have the expertise to provide an accurate assessment of the mental health condition and/or provide adequate treatment.

New Brunswick is not alone in its failure to adequately respond to the mental health needs of people with IDD. American author Dr. Brandi Kelly noted the following in a recent publication entitled *Breaking Down Silos - Innovation in Dual Diagnosis Systems*:

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[12] Ibid., p. 5.
[13] National Association for the Dually Diagnosed. See: http://thenadd.org/products/dm-id-2-is-now-available/
[14] Brandi Kelly, *Breaking Down Silos: Innovation in Dual Diagnosis Systems*. National Association for the Dually Diagnosed (2016), p. 9.
[15] Canadian Family Physician/Le Médecin de famille canadien, Vol 64, April 2018. Retrieved from: http://www.cfp.ca/content/cfp/64/4/254.full.pdf.
[16] See: https://pathways.nice.org.uk/pathways/mental-health-problems-in-people-with-learning-disabilities.

Most notably, individuals with IDD who have significant challenges in communicating verbally with the treating professionals are more likely to be greeted with denials for services and/or professionals presuming any challenges or presenting problems must be due to the individual's IDD.

From the perspective of the individual and his/her family, the statements noted above can not only be concerning but also somewhat offensive and linked to "rights" issues. A typical response might be: 1) Don't all individuals (with or without IDD) deserve the right to effective behavioural health services? 2) How can a professional, program or hospital turn someone away solely on the basis of an IQ score or other disability related factor? Yet, it happens every day and in most areas we are not much closer today than we were years ago to addressing this issue. In fairness … the treatment of individuals with IDD is somewhat more complex than for those without IDD and without exposure, education, and experience most are simply not prepared to offer any meaningful treatment option(s).[17]

Non-Compliance with Human Rights Obligations

Canada has ratified the United Nations *Convention on the Rights of Persons with Disabilities*. The CRPD sets out obligations for state parties in a variety of areas, including health. Article 25 of the CRPD states that:

> States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. … In particular, States Parties shall:
>
> a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons…;
> b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
> c) Provide these health services as close as possible to people's own communities, including in rural areas;
> d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
> e) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Section 15 of the Canadian *Charter of Rights and Freedoms* provides that "every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination". Section 15 applies to "government action in the form of legislation, regulations, directions, policies, programs, activities and the actions of government agents".[18] Courts have said that section 15 "is inherently comparative in that claimants have to establish distinctive treatment (which presupposes comparison with others) based on a prohibited ground."[19] Either the purpose or effect of a law or action can be discriminatory. A section 15 claim of discrimination has to show that a distinction

[17] Ibid., p. 42.
[18] Government of Canada, Department of Justice. Retrieved from: https://www.justice.gc.ca/eng/csj-sjc/rfc-dlc/ccrf-ccdl/check/art15.html.
[19] Ibid.

(by law or action) has been made based on grounds of protection (in this case "mental disability") and that the distinction is discriminatory. In the context of people with IDD being denied mental health services, a case for a breach of section 15 equality rights is arguably very strong.

In addition, the New Brunswick *Human Rights Act* prohibits discrimination in the provision of public services on the grounds of mental disability, which includes an intellectual or developmental disability. Service providers must make reasonable accommodations for people with a disability to the point of undue hardship. The "duty to accommodate" to the point of undue hardship is a strong obligation and requires a service provider to prove any alleged undue hardship.

Anecdotal evidence strongly suggests that New Brunswick's mental health system is not meeting its human rights obligations in the provision of mental health services to people with IDD. Statements by mental health professionals that people's experiences are only a by-product of their disability (and not a mental health concern) or that the system does not have the knowledge or expertise to provide appropriate services are simply untenable from a human rights perspective. A lack of knowledge, expertise or mental health resources does not meet the test of "undue hardship", nor does it meet obligations to provide health care services on an equal basis with others (as the CRPD requires). Addressing non-compliance with human rights obligations requires concrete actions as well as changes to mental health policy in New Brunswick. It may only be a matter of time before a formal complaint of discrimination is brought forward.

Lack of an Adequately Trained Professional Workforce

A significant root cause of the lack of access issue is the lack of training and expertise in the mental health professional workforce. Dr. Brandi Kelly has noted:

> *Most professional training programs lack any inclusion of educational activities geared towards the needs of individuals with intellectual or developmental disabilities. A focus on this area is even more pronounced for professionals aiming to primarily treat adults. Researchers have noted a clear lack of appropriate training programs in North America and Canada*.[20]

Dr. Kelly notes that the lack of education and training is exacerbated by the belief on the part of many professionals that people with IDD who have a mental health condition require specialists (and as a result, many professionals prefer not to serve this population). Yet, with proper (and preferably early) exposure and adequate preparation many professionals can provide appropriate mental health services. The comfort level of professionals can be increased, although this comfort tends to decrease as the degree of the person's disability increases.[21]

There are a number of unique elements to providing effective mental health support to people with IDD:

- People with IDD may have different ways of communicating that affects their ability to self-report and respond to questions. Professionals often have to use other methods of determining diagnoses of potential mental health conditions.
- People with IDD may have one or more health conditions that may have to be considered when attempting to diagnose and treat symptoms related to behaviour and/or a mental health concern. Current guidelines suggest that a full medical exam should be completed when a person with IDD is presenting a change in behaviour to ensure that there are no physical causes for the behaviour (before considering a possible mental health related cause). In addition, social and environmental factors (poverty, isolation, mistreatment, lack of choice, etc.) may be present and affect emotional responses.

[20] Ibid., p. 41.
[21] Ibid., pp. 41-42.

- People with IDD may present symptoms differently than the general population. It has been noted that "significant research has indicated that relying solely on the criteria typically outlined for diagnosis will result in missed diagnoses and that symptoms do exist to point to appropriate diagnoses".[22]
- Methods of treatment often require modifications or may be different altogether for people with IDD. This may involve "modified versions of anger management, dialectical behaviour therapy and cognitive behaviour therapy".[23]
- There are known best practices on the use of medications for people with IDD which are consistent with efforts to reduce reliance on medications or to use them more appropriately. For example, the *Canadian Consensus Guidelines on Primary Care for Adults with Intellectual and Developmental Disabilities* (2018) provide specific recommendations on the use of psychotropic and antipsychotic medications for people with IDD.[24]

In today's context, family physicians are often called upon to provide mental health care for people with IDD in New Brunswick (without significant support from the mental health system. Nova Scotia has dedicated expertise in the area of dual diagnosis. Currently, a team of two dual diagnosis psychiatrists (Doctors Sulyman and Williams) operates with a group of OTs BT, RNs and MDs to provide support to other professionals and directly to people with IDD in Nova Scotia. In addition, the Adult Developmental Clinic of Dalhousie University's Department of Family Medicine in Nova Scotia provides support for family physicians in the community. Dr. Karen McNeil is the clinic's lead clinician which is located at the Dalhousie Family Medicine Spryfield Community Wellness Centre. The clinic provides consults, telephone and e-mail advice and education to family physicians and residents.

Providing effective support to people with IDD requires that professionals in the mental health and behavioural fields receive adequate training. In this respect, professionals should have a general level of knowledge and skill in the areas of IDD, assessing behaviours, diagnostic practices (including those identified in the DM-ID 2 manual and the *Canadian Consensus Guidelines on Primary care of Adults with Intellectual or Developmental Disabilities*) and treatment approaches and the modifications that may be required to provide effective responses. Diagnostic over-shadowing must be minimized or eliminated through proper training. More specialized training for professionals that want to focus on serving people with IDD would also enhance the response by providing access to highly knowledgeable and skilled people who can mentor and support those with generalist level knowledge.

Learning through the use of technology has developed in this field. The Centre for Addiction and Mental health in Ontario has an introductory on-line course on "dual diagnosis". Another model used in Ontario is the ECHO Model in Mental Health. It is based on a well-established model of learning:

> *Project ECHO (Extension for Community Healthcare Outcomes) is a global capacity building model that started in New Mexico, and has expanded in numerous clinical areas throughout Canada, with over 170 clinical hub sites internationally. ECHO Ontario Mental Health at CAMH and the University of Toronto is a 'Hub' and 'Spoke' model of knowledge dissemination and capacity building, which aims to exchange knowledge between academic health science centres and healthcare providers using easy videoconferencing technology. Healthcare providers become part of a learning and support community, where they receive mentoring and feedback from the team of*

[22] Ibid., p. 43.
[23] Ibid.
[24] Canadian Family Physician/Le Médecin de famille canadien, Vol 64, April 2018. Retrieved from: http://www.cfp.ca/content/cfp/64/4/254.full.pdf, p. 270. See also [24] Voluntary Organisations Disability Group, *STOMP Pledge for Social Care*. Retrieved from: www.vodg.org.uk/wp-content/uploads/2017-VODG-STOMP-PLEDGE.pdfs:/.

specialists. Working together, healthcare providers get the help and the support they need to provide care to their clients as close to home as possible.[25]

Lack of Coordination and Collaboration between Service Systems

With some notable exceptions, service systems that support people with IDD who may have a co-occurring mental health condition remain fragmented. Our provincial health, mental health and disability support systems can often work in isolation and fail to address the needs of individuals in a comprehensive and coordinated way.

There are exceptions within the New Brunswick context that need to be noted. The Integrated Service Delivery model works provincially and regionally to support children and youth with multiple needs. The early piloting of this model in Charlotte County and the Acadian Peninsula demonstrated the effectiveness of the model that is described as follows:

> *Under ISD, partners are working together to increase collaboration and coordination of service delivery. Children and youth receive appropriate services and treatment, at the right time and intensity, which contributes to positive child and youth development. This child-centered approach ensures that every door is the right door, and that children and youth are followed throughout the continuum of services to ensure that no child is left behind. As a result, it is anticipated that there would be less demand for more intense and costly tertiary services that are often required for children and youth with complex needs.*
>
> *The ISD model relies on a regional governance structure where the strengths of the community are utilized to ensure that children and youth access and receive the right services in the place where they are the most comfortable. Collaboration between the school and other services are greatly enhanced, making it easier for children and youth to access services than ever before.*[26]

The ISD approach uses Child and Youth Teams made up of professionals and paraprofessionals from various disciplines to cooperate on the determination of person's needs based on a "common plan" that is described as follows:

> *In the context of integrated service delivery/ISD, the common plan refers to a process of cooperation between all service providers for a child, youth, and/or his or her family. ISD is designed to mobilize all the skills and competencies required to ensure a collaborative and cooperative assessment of strengths, needs, and risks to be addressed. Efforts are focused on agreeing on priorities that must be addressed in order to meet needs and on the degree of services to be provided, in accordance with the mandates and responsibilities of each organization concerned.*[27]

Similar approaches to addressing the needs of people with IDD and a co-occurring mental health and/or behavioural conditions have been identified as a current best practice in research and practice. The 2018 *Canadian Consensus Guidelines on Primary Care for Adults with Intellectual and Developmental Disabilities* note the "interprofessional teams" "can assess and address holistically a range of health and

[25] See https://camh.echoontario.ca/.
[26] Government of New Brunswick, *Framework for the Delivery of Integrated Services for Children and Youth in New Brunswick*, September 2015. Retrieved from: https://www2.gnb.ca/content/dam/gnb/Corporate/pdf/ISD/en/ISDFramework.pdf.
[27] Ibid., p. 7.

developmental needs and, with sufficient supports, can improve outcomes of care."[28] Dr. Brandi Kelly has noted:

> *The need for coordination across all professionals remains important for individuals with IDD at any age. The complexities of the developmental, social, medical and behavioural needs of many individuals with co-occurring needs can only be addressed when coordination is expected, built into processes, and associated with compensated for the time professionals and providers put into this coordination. A core team of individuals committed to ensuring coordination and implementation of supports must be identified with prioritization of needs across professional areas and in the context of the individual's goals and desires. Lehrer and Ott (2009) demonstrated that the use of an interdisciplinary team approach resulted in decreased behavioural challenges, increased community participation, subjective reports of improvements in quality of life, and decreased use of medications for a group of individuals with IDD and challenging behaviours and repeat hospitalizations….*
>
> *To accomplish the level of assessment and planning described above, systems must contain mechanisms for coordination time so that all involved professionals and the individual's support system can understand the complexity of the needs and impact of one treatment approach on another.*[29]

In the Canadian context, the Centre for Addiction and Mental Health (CAMH) in Ontario (Adult Neurodevelopmental Services at the Azrieli Adult Neurodevelopmental Centre) has developed processes and standards for inter-professional collaboration for people with IDD and a mental health concern. Leading researchers and clinicians involved have noted:

> *Individuals with intellectual disability and mental health problems often present with a range of needs that span multiple providers and service systems. An effective response to this situation requires inter-professional collaboration, which makes use of the expertise of different professionals who work together towards a shared goal of providing high quality client care. Inter-professional collaboration aims to establish a partnership between health care providers and the client (including family members and other caregivers) which is a participatory and interactive relationship and provides a coordinated approach to care. Decision making is not left solely to the discretion of one care provider but involves all relevant team members as well as the client in a shared decision-making process. There are a number of benefits of inter-professional collaboration. For clients, these benefits may include better health outcomes and increased access to health care; for health care staff, greater job satisfaction and less stress and burn out; for a health care organization, greater staff efficiency and more effective use of resources.* [30]

[28] Canadian Family Physician/Le Médecin de famille canadien, Vol 64, April 2018. Retrieved from: http://www.cfp.ca/content/cfp/64/4/254.full.pdf, p. 260.
[29] Kelly, note 6, p. 49 and 59.
[30] Summers, J., et. al., *Inter-Professional Collaborative Care: A Way to Enhance Services for Adults with Intellectual Disability and/or Autism Spectrum Disorder and Mental Health Problems*, Journal of Intellectual Disability – Diagnosis and Treatment, 2016, 4, pp. 17-24. Retrieved from: http://lifescienceglobal.com/pms/index.php/jiddt/article/viewFile/3680/2162.

Discipline	Role and Function
Behavior Therapist	-conduct assessment of functional behavior and communication, social and environmental issues -establish target behaviors for intervention plan, develop observation and monitoring system -develop safety and proactive support plans, skill building programs -train caregivers to implement care plans
Developmental Services Worker	-deliver individual and group therapeutic programming -support observational data collection, implementation of behavior plans and activities of daily living
Occupational Therapist	–conduct functional, safety and risk, sensory, environmental, leisure and vocational assessments -address areas of self-care, productivity and leisure pursuits -develop sensory protocols and protocols for the use of adaptive equipment
Psychiatric Nurse	–review medical and mental health history, conduct risk and pain assessments, provide clinical impressions, educate client and caregivers about mental health conditions, medications and side effects
Psychiatrist	-conduct mental health assessment and provide psychiatric diagnosis -review medical and medication history -provide biopsychosocial formulation -liaise with general practitioner -obtain informed consent for medication -request specialist input (e.g., neurology, genetics, internal medicine) -provide clinical leadership to the inter-professional team
Psychologist	-conduct assessment of cognitive, nonverbal, adaptive, language, and social-emotional functioning -provide biopsychosocial formulation -co-lead CBT groups for high functioning individuals with ASD
Social Worker	-conduct assessment of family systems, caregiver stress, service needs -provide case management and individual, family and group psychoeducation -co-lead CBT and caregiver support groups
Recreational Therapist (inpatient only)	-develop and implement individualized or group recreational therapeutic programs -provide therapy to improve social interaction skills, leisure activity skills

The Roles and functions of professional team members are outlined in the table below.[31] CAMH notes that this model may (in the future) include a nurse practitioner to help with more extensive health assessments and to assist with monitoring medications.

Models for coordination and collaboration point to the significant benefits of these "integrative" approaches. Given the small population of New Brunswick, attention will need to be given to using resources wisely to ensure that coordination is well-managed and cost effective. The current provincial "complex case" model may have some elements that will be useful but the current practice seems to be time-consuming and limited in scope.

Acute Care Hospital System Used to Respond to Crises and Mental Health Conditions

One clear outcome from the lack of appropriate mental health and behavioural supports for people with IDD is the frequent use of the acute care hospital system to address personal crises or mental health conditions. People with IDD who have a mental health condition are more likely to use hospital emergency departments, be re-admitted to hospital and have longer hospital stays than other adults.

A recent comprehensive Canadian study involving 66,484 adults with a developmental disability in Ontario (ages 18 to 64) investigated (among other issues) the rate of repeat emergency department visits within 30 days. The study report noted:

> *Our results show that over a six-year period, 30-day repeat emergency department visits occurred more frequently among adults with DD compared to those without DD (34.5% vs.19.6%). This pattern persisted across all age groups and for both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived. While all of the DD subgroups had higher rates of repeat emergency department visits compared to adults without DD, the patterns varied by subgroup.* ***Notably, the subgroup with DD-and-MHA [mental health and addictions] had a higher rate of repeat emergency department visits (42.8%) than the subgroups with DD-only (27.6%) or MHA-only (27.1%).*** *Other research has reported that people with DD are more likely to visit the emergency department and have multiple emergency department visits compared to adults without DD. Specifically, individuals with DD and mental health and/or addictions issues were more likely to visit the emergency department than those with either DD or psychiatric disorders alone in Ontario, and DD was identified as a predictor of repeat emergency department visits following hospitalization in an Australian cohort.*[32]
> (Emphasis added)

[31] Ibid., p.20.

[32] Lin E, Balogh RS, Durbin A, Holder L, Gupta N, Volpe T, Isaacs BJ, Weiss JA, Lunsky Y. *Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario,* February 2019. Retrieved from: https://www.ices.on.ca/Publications/Atlases-and-Reports/2019/Addressing-Gaps-in-the-Health-Care-Services-Used-by-Adults-with-Developmental-Disabilities.aspx.

The report notes that this issue is "potentially avoidable" and a "practical target for intervention".[33] The report suggested:

> *Several steps may help to improve emergency department assessment, treatment and discharge processes for individuals with DD. These include 'flagging' (that is, screening for and documenting the presence of DD in hospital charts), the use of health passports and the availability of providers such as liaison nurses in the emergency department who have specialized knowledge about DD*.[34]

Another recent Canadian study on hospital readmission noted that:

> *Compared with those with mental illness only, individuals with IDD and mental illness were 1.7 times more likely to experience a hospital readmission within 30 days. Predictors of their readmission rates included being a young adult and having high morbidity levels. The high rate of hospital readmission suggests that individuals with IDD and mental illness need attention regarding discharge planning and outpatient follow-up.*[35]

A comprehensive Canadian study released in 2019 confirmed that people with IDD and a mental health concern are significantly more likely to be readmitted to hospital within 30 days of discharge:

> *Adults with developmental disabilities, compared to adults without developmental disabilities, were more likely to be readmitted to hospital within 30 days of their initial discharge in the six-year study period (7.4% vs. 2.3%). This pattern was observed for all age groups and both sexes and held regardless of the wealth or poverty of the neighbourhood where they lived.* ***Among those with developmental disabilities, persons with a mental health and/or addictions diagnosis had a particularly high rate of repeat hospitalizations (11.0%)***.[36] (Emphasis added)

Dr. Brandi Kelly has also noted:

> *When individuals with IDD do not receive needed behavioural health services, crises understandably occur. In the absence of a planned approach to treatment and support for these individuals, the emergency room often acts as the primary doorway to behavioural health services…. For those for whom acute stabilization of behavioural health symptoms is needed, hospitalization may reflect the most appropriate response. However, for those for whom other variables are at play and/or for whom access to needed preventative and treatment services is a problem, the emergency room visits and hospitalizations are most likely medically unnecessary as well as quite costly.*[37]

Anecdotally, this has been NBACL's experience with a number of people we support. Acute care hospitals have increasingly become the only option for families and other caregivers to access help. This system is not equipped to address many of the underlying mental health or behavioural issues that may be prevalent. Outside of the hospital context, the response has been to increase staff support (that is often beyond what is required to support a person's disability specific needs). In addition, many of the crises that people experience could be avoided with better access to mental health and behavioural support services. The cost of no action (for individuals, families and our health care systems) multiplies significantly.

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[33] Ibid., p. 43.
[34] Ibid.

[35] Balogh, R., et.al., *All-Cause, 30-Day Readmissions Among Persons With Intellectual and Developmental Disabilities and Mental Illness*, Psychiatric Services, 69 (3), 353-357, March 2018.
[36] Lin E, Balogh RS, Durbin A, Holder L, Gupta N, Volpe T, Isaacs BJ, Weiss JA, Lunsky Y. *Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario,* February 2019. Retrieved from: https://www.ices.on.ca/Publications/Atlases-and-Reports/2019/Addressing-Gaps-in-the-Health-Care-Services-Used-by-Adults-with-Developmental-Disabilities.aspx, pp. 2-3.
[37] Kelly, note 6, pp. 45-46.

Over Medication as a Response to Mental Health and Behavioural Issues

Increasing attention is being paid to the use of psychotropic medications for people with IDD. Recent Canadian studies have found that psychotropic over-prescribing is a serious concern in both community and clinical settings. One Ontario based study noted the following findings:

> *Overall, 39.2% of adults (n = 20,316) were dispensed an antipsychotic medication, which increased to 56.4% in a sub-cohort residing in group homes. Almost one-third (28.91%) of people prescribed an antipsychotic medication did not have a documented psychiatric diagnosis.... Antipsychotic use in IDD is common, and occurs frequently without a psychiatric diagnosis. Attention toward how antipsychotics are prescribed and monitored for people with IDD in Canada is warranted to ensure appropriate prescribing.*[38]

Similar findings have been noted in the U.K. The Voluntary Organisations Disability Group (a collective of organizations representing people with a disability) has noted:

> *It is estimated that on an average day in England between 30,000 and 35,000 people with a learning [intellectual] disability, autism or both are taking prescribed psychotropic medication without appropriate clinical justification. Long-term use of these medicines puts people at unnecessary risk of a wide range of side effects including weight gain, organ failure and even premature death. … People may be prescribed medication as a way of controlling their behaviour, even though there are alternative evidence-based approaches available.*[39]

NBACL believes that similar over-prescribing of psychotropic medications is happening in New Brunswick. In 2016, the NB Department of Social Development launched a $600,000 initiative to reduce the use of such medications on seniors living in nursing homes. A government news release noted:

> *This issue is of particular importance in New Brunswick, which has among the highest rates of antipsychotic medication use in the elderly. In 2013, the rate of this medication use was nearly two times higher in the province than in the rest of Canada….*
>
> *Fifteen nursing homes have been selected to participate in the first phase of the New Brunswick Appropriate Use of Antipsychotics Collaborative. The project will be expanded province-wide in 2017.*
>
> *Non-medication interventions, such as patient-centred approaches, have proven to be effective in managing the behavioural and psychological symptoms of dementia.*
>
> *The funding will be used to provide learning and coaching to help health-care providers at nursing homes use data to identify patients who may benefit from non-drug therapies to treat behavioural issues associated with dementia. Collecting the appropriate information about each resident will help front-line staff tailor services to support quality of care and improve the quality of life for residents.*[40]

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[38] Yona Lunsky, et.al. *Antipsychotic Use With and Without Comorbid Psychiatric Diagnosis Among Adults with Intellectual and Developmental Disabilities*. Canadian Journal of Psychiatry, 63 (6), 361-369.

[39] Voluntary Organisations Disability Group, *STOMP Pledge for Social Care*. Retrieved from: www.vodg.org.uk/wp-content/uploads/2017-VODG-STOMP-PLEDGE.pdfs:/

[40] Government of New Brunswick, News Release, May 17, 2016. Retrieved from: https://www2.gnb.ca/content/gnb/en/news/news_release.2016.05.0417.html.

In early February 2019, results of the initiative were released. A significant number of seniors had anti-psychotic medications eliminated or reduced. Behaviours for a number of people improved along with their quality of life.[41] Canadian guidelines suggest that this also be done for adults with IDD.

Impacts of Lack of Mental Health and/or Behavioural Supports

The lack of a strategy to support people with IDD and mental health and/or behavioural issues can have significant impact on individuals, families and our provincial systems. There is a personal, emotional and financial cost to not having the adequate support systems. These impacts may include:

- People with IDD being left without adequate support to help them "manage life in the community" and, as a result, coming into contact with legal systems that seem ill-equipped to address these issues;
- People with IDD becoming re-institutionalized – in jails, psychiatric hospitals, other hospital wards and other places;
- People being improperly medicated or over-medicated (with the expected side effects this can have);
- Families becoming over-stressed or burnt out because they cannot access the appropriate help for their family member with IDD;
- People being denied access to services because their needs are seen to be too difficult to address;
- People spending time at home with little to do;
- People struggling to understand what they are experiencing without any guidance or support to address their experiences in positive ways.
- People with IDD losing opportunities to become productive citizens and engaging in employment;
- Families losing income and opportunities for employment as they leave the work-force to look after their loved one with IDD;
- Professionals (including family physicians) feel over-stressed trying to address issues and needs with little collaboration from other experts;
- People staying in hospital or other institutions longer than they need to because alternative supports are not available; and
- Our hospital and corrections systems becoming over-burdened because other avenues of support have not be developed and implemented.[42]

[41] See: https://www.cbc.ca/news/canada/new-brunswick/anti-psychotic-drugs-over-prescribed-1.5006525.
[42] Adapted from: National Coalition on Dual Diagnosis, *Dual Diagnosis Position Paper: Coping with Mental Health Problems When You have a Developmental Disability*, 2009.

Recommendations for a New Brunswick Policy Framework and Strategy for People with IDD and Mental Health and Behaviour Concerns

While these issues are complex (and the solutions not easy) they do require immediate and dedicated attention at many levels. NBACL is proposing a set of concrete solutions that we believe are workable in the New Brunswick context.

1. Create, adopt and implement a dedicated strategy to support people with IDD and a co-occurring mental health concern. The strategy should have the elements identified in this brief and the recommendations that follow. The strategy should also be appropriately funded over a five year period to ensure its effectiveness.

2. Create and implement specific policy standards on providing mental health services to people with IDD. We recommend that standards of practice for mental health professionals be established by a working group comprised of professionals, community stakeholders, family members and people with IDD with lived experience of mental illness. Standards should be consistent with the 2018 *Canadian Consensus Guides on Primary Care for Adults with Intellectual and Developmental Disabilities* as well as other know research and evidence based practices in this field.

3. Develop and implement a multi-year initiative on generalist level training in the area of "dual diagnosis" (IDD and mental health conditions). This will aim to provide mental health and other professionals with generalist level knowledge and skills on effective ways to diagnose and treat mental health conditions in people with IDD.

4. Develop and implement a provincial "expert" level resource on IDD and mental health and behaviour concerns to provide access to consultative support and expertise to family physicians and other "front line" service providers. Similar models in Ontario, Nova Scotia and other jurisdictions can be used to develop a New Brunswick resource (which should include psychiatrists, specialized mental health nurses and other professionals).

5. Develop and implement a province-wide initiative to review the use of psychotropic medications for people with IDD and to reduce the use of such medications through non-medication interventions. This initiative should build on lessons learned from the *New Brunswick Appropriate Use of Antipsychotics Collaborative* for seniors in nursing homes. It should also reflect current national and international evidence based practices for reducing the use of psychotropic medications.

6. Implement strategies developed in other jurisdictions to improve hospital care for people with IDD with a mental health condition. These strategies help to support and prepare patients for hospital visits and improve hospital processes and approaches to entry and discharge of patients with IDD. They also address ways for hospitals to better support people with IDD who use emergency department services. In particular, the strategies and tools developed by the Centre for Addiction and Mental Health in Ontario should be reviewed for their application in NB hospitals.

7. Establish collaborative interprofessional teams to serve adults with IDD and a co-occurring mental health condition. Building on efforts to create Integrated Service Delivery for children and youth, a similar collaborative approach should be established for adults with IDD and a mental health issue. We recommend tapping into the knowledge and expertise from the Centre for Addictions and Mental Health (Azrieli Adult Neurodevelopmental Centre) in Ontario for consultative support in creating inter-professional teams in New Brunswick. Ideally, these teams will be developed regionally but it may make sense to establish one or two as "pilot" initiatives to enhance learning and to establish processes that will be effective in New Brunswick.

8. Develop, promote and use materials and resources aimed at supported people with IDD to learn about mental health and mental health conditions. NBACL has recently produced Easy Read guides (hard copy and on-line) on mental wellness, anxiety and depression. These guides are designed to assist people with IDD to understand what they are experiencing and how to address mental health concerns. Further work in this area is required to better support people with IDD who have a mental health condition.

9. Explore and implement strategies to better educate and support families and caregivers that provide day-to day care to people with IDD and mental health concern. Families and caregivers can face daily struggles to provide support to a family member with IDD. This can take a toll on the health and well-being of these families and requires efforts to ensure appropriate family support strategies are available across the province. This includes family respite as well as options to help manage stress and respond to the day-to-day issues involved with supporting a person with IDD who has a mental health concern. *We recommend that specific education and support strategies be developed in collaboration with family based organizations (such as NBACL)*. In this context, families can act as partners with professionals and agencies and play a role in education and professional development.

New Brunswick Association for Community Living
800 Hanwell Road, Fredericton, NB E3B 2R7
Toll Free: 1-866-NBACL-4U (1-866-622-2548)
Tel: (506) 453-4400 Fax: (506) 453-4422
E-mail: nbacl@nbnet.nb.ca Web: www.nbacl.nb.ca

New Brunswick Association For Community Living
Association du Nouveau-Brunswick pour l'intégration communautaire