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Enhancing Mental Health Care Across the Lifespan for Ontarians with Developmental Disabilities

Introduction

The Centre for Addiction and Mental Health (CAMH) strongly supports the Select Committee on Developmental Services' goal to address the urgent need for a comprehensive developmental services strategy for Ontarians with developmental disabilities and dual diagnosis. Examining the education, employment, social, recreational, housing and respite needs of people with developmental disabilities/dual diagnosis across their lifespan is critical for enhancing the lives of these individuals and their families. CAMH also believes that the mental health care needs of this population must be a critical component of any developmental services strategy.

People with developmental disabilities have a two to threefold increased risk of an additional diagnosis of mental illness. Right now, 1 in 2 Ontario adults (under 65) with a developmental disability have a dual diagnosis.ⁱ Many of these individuals have a serious mental illness and/or experience significant behavioural challenges that can, without access to specialized mental health services from childhood through adulthood, leave them and their families in crisis. Others remain in hospital, unable to participate as full citizens because appropriate health, mental health and behavioural services are not available to them in their communities. As a service provider to individuals with dual diagnosis and their families, CAMH is acutely aware of the challenges of accessing mental health care and related supports for people with a dual diagnosis. This has to change. Ontario needs enhanced collaboration between community agencies and specialized services to provide better primary and secondary mental health care to people with a dual diagnosis.

Defining 'Dual Diagnosis'

Dual diagnosis is not a medical diagnosis. It is an administrative term that refers to individuals who have a developmental disability as well as a mental illness and/or challenging behaviours such as aggression, irritability and non-compliance.

Autism Spectrum Disorder (ASD) is the most common developmental disability amongst the dual diagnosis population.ⁱⁱ ASD is associated with extremely challenging behaviours. These behaviours are frequently due to an underlying mental illness, but are sometimes directly related to ASD. Mental illness and challenging behaviours are displayed by individuals across the autism spectrum, but those with high functioning

autism (where IQ is in typical range) are actually *more* likely to have a dual diagnosis than those with lower functioning autism.ⁱⁱⁱ

Dual Diagnosis Across the Lifespan

Children, Youth and Transitional Age Youth (Young Adults)

Challenging behaviours amongst those with ASD can begin at a young age. Signs of mental illness tend to emerge later in childhood (between the ages of 9 and 12) and by adolescence, 53% of teenagers with ASD will have a mental illness.^{iv} Mood and anxiety disorders are the most common mental illnesses affecting 40% of all adolescents with ASD.^v

Children and adolescents with a dual diagnosis often have difficulty accessing mental health care and other services that they need. It is particularly difficult for those who have high functioning autism and a mental illness. These individuals are often refused services from the mental health system (because it is claimed that they are too complex and should be in the developmental disabilities system) and the developmental disabilities system (because it is claimed that they are too high functioning and should be in the mental health system). This problem is exacerbated during the transition from adolescence to adulthood when these individuals lose access to school-based services. Any improvements in mental health and behaviour as a result of these supports slow down after adolescent individuals with ASD leave high school.^{vi}

Adults

Many young adults and adults with a dual diagnosis struggle throughout their lives. More than 80% demonstrate poor outcomes across a variety of domains. Only 22-30% have a high school diploma, 33-56% are employed (though only 12% work independently), 38-56% live with their parents, and only 4-8% live independently.^{vii}

Given that many people with a dual diagnosis live with their families, caregiver burnout is common. Parents report a high degree of long-term stress from coping with challenging behaviours. Much of this stress is due to a lack of support in the community. Parents report that there is insufficient or deficient primary care, a lack of specialist assessments and care, a lack of service planning, very long wait times to get into services (including respite and crisis services,) and a lack of inter-sectoral collaboration.^{viii}

Without access to mental health care in the community, people with a dual diagnosis and their families can reach a breaking point and increasingly parents, in the absence of meaningful and effective alternatives, are abandoning their children to hospital. Currently at CAMH, approximately 75% of parents of inpatients in the Dual Diagnosis program had reached a point where they were no longer able to care for their adult

child at the time of hospital admission. While short-term hospitalizations are sometime necessary when people with a dual diagnosis are experiencing an acute episode of mental illness, long-term hospitalizations are detrimental to these individuals. Patients who are ready for discharge, but must stay in hospital because there is no place for them to go in the community, inevitably lose the gains they have made. This leads to deterioration of the patient and increasing difficulty in finding them suitable places to live. This scenario is happening on a repeated basis across the province.

People with a dual diagnosis have higher rates of psychiatric hospitalizations and re-hospitalizations than people without a developmental disability. They also visit emergency rooms more, are younger when admitted to hospital, display higher rates of aggression and have significantly longer inpatient stays.^{ix} The average length of stay for current clients in CAMH's Dual Diagnosis program is 23 months. Most of these individuals are young males with autism who have displayed serious aggression or inflicted life-threatening self injury. Most were admitted to hospital after many visits to emergency departments and/or brief hospitalizations and all of them were over-medicated at the time of admission. In approximately 4 months, CAMH was able to treat these individuals with the tertiary care that was needed, but 90% of these individuals are now stable and cannot be discharged due to a lack of appropriate services in the community. This long-term hospitalization not only jeopardizes the clinical gains made by these clients, but makes access to these specialized beds for other clients with dual diagnosis virtually impossible. Ironically, the cost of a long-stay hospitalization is more than double that of high support community based housing – a far better alternative for these clients who experience a much better quality of life.

Case Studies

Alex's Story

Alex is a 32 year old man with a complicated diagnosis of congenital bilateral deafness, pervasive developmental disorder (Autism), and Tourette's Syndrome. He moved through the school system with assistance from specialized supports, gained some work experience, and lived in supportive housing in the community.

In 2009, Alex's father passed away and this event affected him deeply. He began to act in bizarre ways, showed a decrease in his daily living skills and became aggressive towards the staff in his home. He had several admissions to hospital and was diagnosed with having a major depressive episode with psychotic features. Alex moved back into his mother's home and had several community supports (crisis workers, respite care, SSAH), but no clinical supports (assistance with medication, assessment and treatment of his difficult behaviours, support with daily living skills). Without access to these services, Alex's life continued to be unstable. He did not take his medication consistently, he moved around amongst his family members' homes and he continued to act aggressively towards his mother.

At age 30, Alex attacked his mother. He was charged with assault, and is now on a forensic inpatient unit at CAMH. These units are not conducive to supporting someone with multiple needs such as Alex, and are likely increasing his dangerous behaviour. His aggression towards himself and others has continued to escalate, which has further reduced his ability to participate in meaningful activity. Alex has had several seclusion events and at times has had to be mechanically restrained. Now, to keep himself and others safe, he is continuously observed by two staff. Alex would fare much better in a community home with less noise and disruption, wide and open spaces for him to access as needed, and the staff and resources with training to support his needs as an adult with autism and hearing impairment.

Jane's Story

Jane is a young woman in her 30's who has been diagnosed with a mild intellectual disability, Alcohol Related Neurodevelopmental Disorder and Post Traumatic Stress Disorder along with various medical difficulties including asthma, hypothyroidism and pre-diabetes.

Jane's family history includes physical and sexual abuse and child welfare involvement. She was apprehended by the Children's Aid Society at the age of 16, but has continued to maintain strong and positive extended family connections. Jane tried living in many different community settings, but was unsuccessful due to extremely high emotional intensity and reactivity, marked impulsivity, and chronic self-injurious behaviors (e.g. swallowing/inserting objects, drug overdoses). These behaviours led to intense use of emergency room services (up to 100 visits in a single month), more than 300 police contacts and charges due to disruptive behaviour and assault. Over the last 6 years she has lived primarily in hospitals and jail (two 1-year terms). She has also rotated through various shelters.

Jane was discharged from CAMH in October 2011 after a 17 month stay. Her discharge from hospital followed intensive planning and collaboration between the Dual Diagnosis program, a specialized community housing program (with additional funding from the Developmental Sector), and 2 case managers who had worked with Jane for many years (one from the developmental sector and one from the mental health sector). Jane was involved with planning the transition and had made visits to the home prior to discharge. She had a private living area within a group home and was provided with behavioural and psychiatric supports from CAMH. A crisis prevention and management plan was established to try to minimize emergency room usage.

Upon transfer to the community program, Jane only stayed in the home for a few days before her challenging behaviours arose again. She ended up in a shelter, spent a second year in jail and was then re-admitted to CAMH in February 2013 where she remains today. The main purpose for her current hospitalization is detention, not

treatment. Reflecting on her last discharge, it is clear that Jane needs intensive outpatient clinical supports and a less controlled environment (as the more controlled the environment, the more there is an increase in her self injurious, aggressive and regressive behaviour). Discharge planning at this time is focused on finding a rural location with the capacity for less intrusive observation (via technology) and the ability to provide more specialized clinical supports appropriate to behaviours associated with a personality disorder. This environment will require additional funding for the staffing supports required, but will cost less than the current inpatient environment.

Good Solutions Exist

Many reports and research studies have offered solutions to the systemic and service delivery challenges discussed here (e.g. National Coalition on Dual Diagnosis reports to the Mental Health Commission of Canada). Good clinical solutions are outlined in the 2008 Ministry of Health and Long-term Care's and the Ministry of Community and Social Services' update on the Joint Policy Guideline for the Provision of Community Mental Health and Developmental Services for Adults with a Dual Diagnosis. This Guideline recognizes the complexity of dual diagnosis and recommends a long-term multifaceted service response with effective cross-sector collaboration to ensure the provision of appropriate services. The Guideline builds upon the Ministry of Health and Long-term Care's Making it Happen Implementation Plan and Operational Framework Documents for mental health reform (1999), which describe available service based on level of need:

- ***First-line*** prevention, assessment and treatment by frontline healthcare providers, including general practitioners, with support from adult or child psychiatrists;
- ***Intensive*** mental health assessment, treatment and support services provided in community or hospital settings that focuses on people with serious mental illness of any kind including those with a developmental disability; and
- ***Specialized*** mental health programs provided in community or hospital settings that focus on serving people with serious mental illness who have complex, rare and unstable mental illness.

The assumption is that this continuum of services and supports is available to those with a Dual Diagnosis. It was also recommended that people receive the least intrusive service possible based on assessment of need.

Despite these recommendations, five years later people with a dual diagnosis and their families continue to experience problems getting the mental health care that they need. Only 20% are receiving care through inter-professional Family Health Teams;^x intensive services are seen as 'band-aid' solutions that are crisis-focused, lack long-term care planning and do not provide interdisciplinary care;^{xi} and there is a significant shortage of specialists able to provide services to those with the most complex mental illnesses.

Two Key Priorities

Ontarians with a dual diagnosis and their families need access to good mental health care now. Continuing to miss opportunities to provide necessary care is creating unnecessary stress and suffering to thousands of people in our province. To address this situation, CAMH recommends 2 key priorities for the Select Committee to take into consideration to address the mental health care needs of people with a dual diagnosis.

1. Strengthen primary care

Where possible, people with a dual diagnosis should receive mental health assessment and treatment from front-line health providers. This will require investment to ensure that inter-professional clinical services are available and integrated in primary care settings. Front-line health care providers need enhanced education and training on how to best provide services to people with a dual diagnosis. Consistent standards of care are also required. Review and implementation of the existing primary care guidelines^{xii} and accompanying clinical tools and training will be a good first step.

2. Develop effective secondary care

When people with a dual diagnosis have a serious mental illness, they should have access to the mental health assessment, treatment and supports that they require to become and stay well. These mental health services should be tailored to individual need, offer interdisciplinary care, and be population-based so that services are provided within smaller catchment areas. Secondary care needs to be well-linked to both primary and tertiary care so that people can easily move between levels of care based on their changing mental health needs. Secondary care also needs to be closely connected with intensive and specialized housing, respite and support programs as these are key social determinants of mental health.

It is imperative that primary and secondary mental health care be available early (beginning in childhood), be inclusive of all people with a dual diagnosis (including those with high functioning autism), reflect that this is a lifespan condition, and be personalized to meet the unique needs of each individual and their family.

By investing 'upstream' in primary and secondary mental health care, crisis situations can be avoided and the over-reliance on expensive tertiary or specialized care can be minimized. This is a better and more effective solution for people with a dual diagnosis, their families and all Ontarians.

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