

DUAL DIAGNOSIS

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The Population

Developmental disability, the term used in Ontario, is referred to in the *Diagnostic and Statistical Manual IV TR* as mental retardation and is defined as:

- IQ of 70 or below, along with
- Significant limitations in adaptive functioning, i.e., in at least two of the following areas: communication, self-care, work, leisure, social/interpersonal skills, use of community resources, self-direction, health safety, functioning academic skills, and onset before age 18.

Dual Diagnosis was defined jointly in 1990 by the Ministries of Health and Long-Term Care (MOHLTC) and Community, Family and Children's Services (MCFCS) as: "individuals who have a diagnosed emotional/psychiatric disturbance as well as a diagnosed developmental disability." In 1997, the Ministries updated the 1990 definition to "individuals with a developmental handicap and mental health needs." This broader definition was adopted because individuals with developmental disabilities often present symptomatically with changes or challenges in normal patterns of behaviour for some time before receiving a formal diagnosis. According to the 1990 definition, the absence of a formal diagnosis would result in the exclusion from service.

Prevalence

The *true* prevalence of developmental disabilities in Ontario is estimated to be 2.25% of the general population, but the actual number of people receiving service is much lower, approximately 0.56% of the general population.¹ The literature on prevalence of dual diagnosis ranges from 14% to 70%, varying due to the diagnostic criteria used, the nature of the study, and whether autism is included.² A conservative estimate of 38% has been used in Ontario as the prevalence rate for dual diagnosis.³ Based on these figures it is estimated that there are 247,000 individuals with developmental disabilities in Ontario (based on 2.25%) and 93,000 individuals with a dual diagnosis (based on 38%).

In addition to the high prevalence of mental health issues, individuals with developmental disabilities have an increased prevalence of comorbid disabilities and disorders, including hearing, vision, motor impairments, seizures, and other medical and communication difficulties. The resulting need for health care services is demonstrated by the results of a study in the Netherlands. Individuals with mental retardation comprised 8.1% of the total

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health care costs in that country, greater than any other diagnostic group, such as those with schizophrenia, alcohol and drug use and heart disease, due in part to all the comorbidities.⁴

Life-long communication and cognitive disabilities impact negatively on people with developmental disabilities in Ontario and their efforts to access and maintain good health. The experience reported by clients, families and service providers today is that individuals with a dual diagnosis have frequent contacts with numerous providers, experience health disorders that often remain undiagnosed, and are the recipients of uncoordinated services.⁵ For example, health disorders (such as an earache or abscessed tooth) are often attributed to a behaviour disturbance (e.g., self-injurious behaviour) and therefore mistakenly associated with developmental disability. Behavioural expressions of depression such as change in sleep pattern or withdrawal from activities are often missed, therefore left undiagnosed, whereas psychosis is often overdiagnosed and as a consequence, people with developmental disabilities are over-medicated.

Historical Review of Dual Diagnosis in Ontario

The Ontario government policy of deinstitutionalization, adopted in 1973, and the *Developmental Services Act* (1974) shifted the responsibility for individuals with developmental disabilities from the jurisdiction of health to community and social services. This reflected the broader normalization and deinstitutionalization movements that were being led by parent groups in Ontario and around the world and the shift away from an illness service model for individuals with intellectual disabilities. It could be argued that, as a result of this philosophical shift, the quality of life of individuals with a dual diagnosis has been seriously compromised. One reason for this is the closure of 17 institutions operated by MCFCS between 1970 and 2002, which resulted in a significant loss of knowledgeable and skilled professional and support staff. For example, in a 1974 survey across Canada, 74 physicians were found to work full time in institutions for the developmentally disabled.⁶ In a similar survey in 2001 it was difficult to find physicians to complete the questionnaire.⁵ With the de-emphasis on specialized medical care, inadequate supports now exist to meet the medical needs and psychiatric needs of this vulnerable population.

The Joint Policy Guidelines for the Provision of Services to Persons with a Dual Diagnosis (1997), published by the MOHLTC and MCFCS, provided a much needed framework to support the development of a continuum of community-based supports and services within and across the sectors. The Guidelines identified the roles and functions of various components within each sector, including psychiatric and general hospitals and community mental health and developmental service providers.

In a survey conducted by the Ontario Chapter of the National Association of Dual Diagnosis, the effect of the Policy Guidelines were evaluated against targeted outcomes identified by the ministries.⁷ Results indicated that the Guidelines influenced the planning of services and supports through initiation of local and/or regional committees and the development of formal links to local planning (District Health Councils) and funding bodies (Regional Ministry offices). Most committees enhanced cross sector linkages by

being co-chaired by mental health and developmental sector representatives and including membership from health, social service, education, and sometimes families, forensic and colleges/universities. The majority of committees focused their initial activities on joint training initiatives for front line staff in both sectors and implementation of cross sector service protocols.

Where Are We In 2003?

Services designed specifically for individuals with a dual diagnosis are now more evident in Ontario than they were 30 years ago. Networks of services providing crisis and safe bed resources are developing in a few areas of the province. Multidisciplinary specialized dual diagnosis consultation and treatment teams based on integrated mental health and developmental approaches are available in some regions. Generic mental health and developmental services are increasingly providing treatment, case management, housing and day program supports to individuals with a dual diagnosis. MCFCS funding has also recognized the need to invest in individualized approaches, particularly for those leaving the school system.

Current Challenges

We are now also dealing with a different agenda than 30 years ago. Cost savings and measurement of outcomes are more emphasized in current policies, as are issues of improved access and recovery. The focus of the MOHLTC mental health reform policies is on those with *serious mental illness*. Dual Diagnosis is specifically included in this category, however, some mental health providers continue to exclude these individuals for reasons that include lack of a diagnosis, knowledge and/or skill gaps. MCFCS *Making Services Work for People* policy (1997) does not refer to individuals with a dual diagnosis. It focuses services on those *most in need*, therefore limiting investment in health promotion and prevention supports for a very vulnerable population. Families today are the majority of primary caregivers and consistently report difficulties in accessing the supports that they need when they need them.⁸ Long waiting lists (years) in the developmental sector for community-based housing, day and case management supports exist. Staffing of specialized dual diagnosis resources and the developmental sector remains a significant challenge due to serious gaps in formal training and education, lack of a career path for the field and low salary levels. Individuals with a dual diagnosis remain one of the most marginalized groups in our community today.

Summary

There is certainly greater understanding of the required components of the continuum of supports and services today than 30 years ago. There is also stronger recognition that best practice approaches include a continuum of flexible services across the sectors with access to specialist services and supports.⁹ However, we have made only limited progress in ensuring access to services in *either or both* the mental health and developmental services sectors as outlined in the Interministerial Guidelines (1997). To achieve the vision established for Ontario, policy makers, funders and service providers must:

1. Adopt a lifespan approach to planning and service development, with particular attention to the vulnerable transition period of the child to adult systems (ages 16-30). This would occur through (adapted from Dart et al.¹⁰ and King & Barnett¹¹):
 - interministerial structures that are committed to support the implementation of locally accessible best practice approaches;
 - a community-based habilitative support system with the capacity to provide varying degrees of support over lifetimes in recognition of fluctuating needs, relapsing and/or recurrent psychiatric disorders. This would include specialized housing and day programs for those with more challenging needs such as those with Prader-Willi syndrome, autism or offending behaviours;
 - intensive case management (with lower case loads);
 - community-based specialized multi-disciplinary consultation and treatment teams; and
 - dedicated beds within the continuum of community to general and psychiatric hospital services to ensure specialized supports and safety for individuals with more challenging needs.

2. Recognize the specialist health and service needs of persons with a dual diagnosis through (adapted from Lunsky & Bradley¹²):
 - federal and provincial leadership in the development of public policy that ensures access to health care services;
 - federal and provincial leadership and collaboration with Colleges and Academic Health Science Centres to develop and maintain the infrastructure for teaching sites, research and program evaluation; and
 - professional licensing and accreditation bodies (e.g. medical, social work, nursing, occupational therapy, speech and language, psychology) incorporating standards of care for individuals with developmental disabilities.

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⁶ McCreary BD. Full-time medical practitioners in Canadian mental retardation facilities. *Canadian Psychiatric Association Journal* 1974;19:51-53.

⁷ Morris S. Survey results from regional and local committees. *Habilitative Network News, Habilitative Mental Health Resource Network, Fall 2000 Bulletin.*

⁸ Dual Diagnosis Implementation Committee of Toronto, *Action Steps for 2002/2003: Moving Toward the Vision.*

⁹ Smiley E, Cooper SA, Miller SM, Robertson P, Simpson N. Specialist health services for people with intellectual disabilities in Scotland. *Journal of Intellectual Disability* 2002;46:585-595.

¹⁰ Dart L, Gapen B, Morris S. Building responsive service systems. In: Griffiths D, Stavrakaki C, Summers J, editors. *Dual diagnosis: An introduction to the mental health needs of person with developmental disabilities.* Habilitative Mental Health Resource Network, 2002; 283-324.

¹¹ King,R.J, Barnett, R. A tale of two sisters: Quality of life within two systems. *Journal of Developmental Disabilities* 2001;8(1):107-119.

¹² Lunsky Y, Bradley E. Developmental disability training in psychiatry residency programs. *Canadian Journal of Psychiatry* 2001;46: 138-143