

Response to the Ontario Government Transformation Agenda

For Developmental Services:

Meeting the Health and Mental Health Needs of Individuals with Developmental Disabilities

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I Introduction

The Ontario Ministry of Community and Social Services (MCSS) transformation goal for developmental services of enhancing the capacity of individuals with developmental disabilities to live more independently in communities across Ontario is consistent with the directions of communities across Canada and in other countries. This goal is based on the fundamental assumption that individuals with developmental disabilities can lead productive and rewarding lives and participate as full citizens in all aspects of society. (Joint Developmental Services Sector Partnership Table, 2004).

To achieve the commitment from all segments of society and the inclusiveness and strong forward-looking and sustainable service system that is envisioned, it is necessary to consider the *health and mental health needs* of individuals with developmental disabilities in a similar fashion to how those needs are considered for all citizens. Currently the basic health and mental health needs of persons with developmental disabilities are not being met and/or the quality of services received is inconsistent across the province. It is to this area that recommendations for a model for health and mental health supports and services are directed in this response.

II The Health and Mental Health Needs of Persons with Developmental Disabilities

1. Health Care

The *true* prevalence (people who might be expected statistically to have a developmental disability) is between 2-3% of the general population (220,000-330,000 individuals in Ontario) (Ouellette-Kuntz et al, 2004). Individuals with developmental disabilities have an increased prevalence of co morbid disabilities and disorders such as physical disabilities (approximately 30%), hearing impairments (approximately 20% but even greater in some groups e.g. Downs syndrome), neurological disorders, primarily epilepsy (approximately 20% overall but increases to 1 in 2 in those with profound disability) and or communication disorders (approximately 30 %). (Ibid). In addition there is an increased prevalence of other related conditions for example:

- In an Ontario study comparing adults with and without developmental disabilities, undiagnosed high blood pressure was found to be more common in the group with developmental disabilities (43.3% compared to 8.3%) (Ibid)
- Dental needs of adults with developmental disabilities are frequently unattended to. In an Ontario study 25% of individuals did not have their dental needs identified. For those whose needs were identified, most were receiving inadequate or inappropriate care. (Ibid) Additionally, the experience of care providers in the specialized dual diagnosis programs of Ontario psychiatric hospitals is that many individuals present to these tertiary services as a result of untreated dental problems.
- A study of practicing community physicians in southwestern Ontario (Gitta & Deagle, 1992) found that neurological disorders (i.e., seizure disorders, cerebral palsy), and hearing and visual impairments were the most commonly reported medical conditions followed by psychiatric conditions which included behavioural problems. Next most common were daily medication issues (i.e., psychotropic medications).
- A study of primary health care and support issues by the Developmental Disabilities Program at the University of Western Ontario (Gitta, 1996-97), found that between the

ages of 14-21 and 55+, 74% to 96% of respondents reported medical problems requiring special attention.

- In a landmark study by Beange et al, (1995) in Sydney, Australia, a stratified random sample of 202 adults with developmental disabilities was compared to health survey information from the general population. An average of 5.4 medical disorders per person were found, half of these had not been detected previously. Compared to the general population data, the study participants were more obese, a large proportion of the females had hypertension (68% of these individuals had not been diagnosed previously) and in 15.5% of the participants, abdominal pain, headache and localized swellings had gone undetected.
- A number of studies have raised concern regarding poor health outcomes leading to a higher mortality rate among people with intellectual disabilities. (Hollins et al, 1998) in a registry study of 2000 people with intellectual disability, followed for eight years in the UK, found the risk of dying before age 50 was 58 times higher than in the general population. Patja et al, (2000) found profound developmental disability implies a 20% reduced life expectancy.
- A study in the Netherlands reported that people with intellectual disabilities were found to be 2.5 times more likely to have diagnosed health problems than patients without developmental disabilities. (Meerding, et al 1998) The population accounted for 8.1% of the total 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 the associated co morbidities.

2. Mental Health Care

In Ontario, dual diagnosis is the term that has been adopted to refer to individuals with developmental disabilities and mental health needs. A conservative estimate of 38% has been used as the prevalence rate for individuals with a dual diagnosis in this province. (Yu & Atkinson,1993). Based on these figures it is estimated that there are between 41,800 and 125,400 individuals with a dual diagnosis in Ontario. However it should be noted that many studies include behavioural and emotional issues as indicators of dual diagnosis as well as mental health needs in their definition of dual diagnosis and prevalence estimates for co morbidity as defined in his manner range from 10-60% of people with a developmental disabilities.

A more recent population based study of teenagers in Ontario provides more exact prevalence data and at the same time reveals a more disturbing picture. All teenagers with developmental disabilities in one geographic area were matched (on age, gender and functioning level) to those with developmental disabilities who also had autism. The overall prevalence of episodic psychiatric disorders (e.g., depression, adjustment, bipolar) in those with co existing autism was found to be 44% compared to 17% in those with developmental disabilities alone, giving an overall prevalence rate of 31%. (Bradley et al 1998). In addition to these episodic psychiatric disorders, 50% of those with developmental disabilities alone and 89% of those with co existing autism has at least one additional non-episodic psychiatric condition (e.g., hyperactivity, impulsivity, anxiety, obsessive behaviours, tics, stereotypies, self injurious behaviours) (Bradley et al 2004a and Bradley et al 2004b). This represents a

very high rate of mental health disorder in youngsters and young adults and especially so in those with co existing autism.

Behavioural and emotional problems can have a significant impact on the individual's quality of life and safety, that of their caregivers, as well as acceptance by society. Such problems are often the primary reason for referral to mental health services. Such difficulties are not infrequently better understood as *communication* or an *indication of underlying problems*, requiring a broad-based approach that incorporates medical, psychosocial and environmental factors into consideration. (Summers et al, 2004; Bradley & Hollins, 2005).

While the prevalence of mental health disorders is greater in the population with developmental disabilities, the diagnosis of mental health difficulties is well known to be problematic (related to confounding health problems, diagnostic overshadowing – [assumption that the presenting problem is due to the developmental disability rather than an underlying health disorder], over-diagnosis of psychosis and under diagnosis of mood and anxiety disorders). This often results in inappropriate treatments (such as polypharmacy), complicating and confounding side effects due to overmedication, frequent contact with police, hospital emergency rooms, and failure in community programs. For example:

- Lunskey et al (2002) in a joint study of rural and urban residential services in Ohio and Toronto reported on the overuse of psychotropic medications to control behaviour. Seventy-nine percent of all clients were prescribed at least one psychotropic or medical medication for this behaviour (and the underlying cause of this behaviour remained unidentified).
- The Gitta study (1996-97) cited a review of London, Ontario Police reports which found that over a one-week period, 14% of all calls related to psychiatric assistance. Out of those 509 calls, 98 (over 19%) were for those with a dual diagnosis.
- Ryan and Sunada (1997) found that approximately 75% of individuals from community settings who were referred for psychiatric evaluation due to behavioral deterioration had at least one medical condition that had been overlooked or under-treated with routine medical care.
- Three different studies, (Howells 1986; Horowitz et al, 2000 and Special Olympics Incorporation Report, March, 2001) reported behavioural expressions of depression such as change in sleep pattern or withdrawal from activities are often missed, therefore left undiagnosed, whereas psychosis is often over diagnosed and as a consequence, people with intellectual disabilities were over-medicated.
- In a study by Kastner et al (2001), 19% of 209 adults with developmental disability, referred for psychiatric and behavioural treatments, had either an unrecognized medical condition or medication side effect, which accounted for behavioural symptoms. Ryan (2001) reported between 70%-85% of nonverbal people with intellectual disabilities referred for psychiatric consultation have one or more untreated, under treated or undiagnosed medical problems influencing behaviour.

III Current Status of Community Health and Mental Health Care For Persons With Developmental Disabilities

Two recent national reports one from the United Kingdom (Valuing People, 2001) and the other from the United States (Closing the Gap: A National Blueprint for improving the Health of individuals with Mental Retardation, 2002) have found that the current situation in those countries is one of a very marginalized population with poor health outcomes and continued difficulties accessing appropriate and timely health care. The situation in Canada and Ontario does not appear any different.

Difficulties in accessing timely and appropriate care has been attributed in part to the limited knowledge, skill and interpretations offered by care providers who have less knowledge regarding the causes of health problems in this population. (Ouellette-Kuntz et al, 2004). Training and education challenges have been enumerated in a number of studies:

1. Health Care:

- The shift in responsibility that occurred in Ontario in the early 1970's from health to social services and from institutional to community care resulted in a significant loss of health knowledge and skilled health professionals and support staff within the institutions. In a 1974 survey across Canada, 74 physicians were found to work full time in institutions for persons with intellectually disabilities. (McCreary , 1974). In a similar survey in 2001, it was difficult to find physicians to complete the questionnaire (Lunsky et al, 2001). Only half of those who did respond to this latter study had received training in their undergraduate medical education and most felt that more training was needed.
- In a 2003 Ontario study parents reported that attitudes and the general level of awareness among health professionals had improved. However they also felt that health professionals required more exposure to persons with developmental disabilities, specific education and acknowledgement regarding the health concerns and special needs of this population. (Ouellette-Kuntz et al, 2004)
- Bradley & Summers (2003) make an interesting point regarding the need to appreciate the concept of critical mass as crucial to the successful and effective training of professionals and development and delivery of services. The authors note that relative to their non-handicapped peers, individuals with developmental disabilities are few in number but have significantly greater health needs. Thus, health care professionals need to be exposed to a sufficiently large number of persons with intellectual disabilities in order to develop knowledge, understanding and expertise in the assessment and treatment of health and mental health difficulties.
- In a Yale university study, it was concluded that health professionals fail to treat individuals with intellectual disabilities because of inadequate training, fear and prejudice and lack of research on the health status and needs of this population. (Horowitz et al, 2000) The US Closing the Gap report notes the need for integrated health promotion in the community, the need for practical and easy to use knowledge and understanding and the need for increased training for health care providers.

- In a study by Piachaud, (1989) it was noted that increased time and adapted procedures are required to complete assessments and treatments of individuals with developmental disabilities. It is generally acknowledged that it takes longer for the psychiatric assessment and treatment of individuals with developmental disabilities than the general population.

2. Mental Health Care

Some progress has occurred in Ontario with regard to addressing the mental health needs of individuals with developmental disabilities. The Joint Policy Guidelines for the Provision of Services to Persons with a Dual Diagnosis (1997), published by the Ministry of Health and Long Term Care (MOHLTC) and MCSS, provided the impetus and framework to support the development of a continuum of community-based supports and services within and across the sectors. The guidelines established a vision of ensuring access *in either/or both* the mental health and developmental services sectors and principles for how this should be achieved. These guidelines, while somewhat dated are still relevant.

Best practice examples of service networks and specialized resources exist in pockets across the province e.g. crisis and safe bed networks funded jointly by MCSS and MOH, and specialized multidisciplinary community mental health teams that integrate developmental and mental health approaches funded by either MCSS or MOH. However there remain gaps and inconsistencies across the province in relation to the implementation of the policy and the availability of local and regional primary, secondary and tertiary mental health services, as well as training and education resources. (Morris 2003).

These apparent successes in mental health care must be viewed with some caution when considering the current situation in the nine Ontario psychiatric hospitals. Lunskey et al (2003) used data generated from the Comprehensive Assessment Projects (CAPs) in the Ontario Provincial Psychiatric and Specialty hospitals to understand the demographic and diagnostic characteristics and clinical support needs of individuals with a dual diagnosis. Key findings included:

- One in five inpatients in the psychiatric facilities have a dual diagnosis.
- The majority of individuals with a dual diagnosis have mild developmental disabilities.
- Most have limited education and were unemployed, two of the most important determinants of mental and physical health.
- Thirty-seven percent of inpatients with a dual diagnosis have been in the hospital for more than 5 years, not because of the severity of their difficulties but because there were no appropriate places for discharge.
- In comparison to those without a dual diagnosis receiving inpatient or outpatient services, the most significant problems for those with a dual diagnosis were in the areas of self-care, aggression and security/management issues.
- In comparison to those without a dual diagnosis, those with a dual diagnosis are equally likely to be diagnosed as psychotic and equally likely to have legal issues.
- Mood and anxiety disorders are not common diagnosis although research would suggest that they are undiagnosed.
- Seven specialized programs serve twenty percent of all inpatients and/or outpatients with a dual diagnosis. Patients in these programs tend to have higher levels of symptom severity, are typically younger, male and have significantly more issues related to aggression.

These findings suggest that attainment of the larger vision of deinstitutionalization and community integration for individuals with developmental disabilities has in fact been more challenging for those with more complex needs.

IV Recommendations for a Provincial Model of Health and Mental Health Care

1. Assumptions

The recent US and UK national reports outline different approaches to addressing the health and mental health needs of individuals with developmental disabilities. As an example, the UK approach has been to plan, and establish over a number of decades a cross sector, multilevel, multidisciplinary infrastructure specifically targeted to support the health and mental health services to this population (Bradley, 2004). This infrastructure includes:

- Professional training organized within Clinical and Academic Centres of Excellence.
- Multidisciplinary developmental disability teams established on a per capita basis.
- Policy documents – the most current one establishes goals, objectives and performance indicators, funding methods as well regional and local structures and task forces to oversee and monitor implementation.
- Clinical guidelines and standards for health and mental health care provision.
- Communication and education strategies e.g. web sites and distance learning.

The experience of these jurisdictions provides a helpful framework. Naturally the approach for Ontario must be based on our own geographic, political, policy and social structures.

The Ontario Transformation Agenda is an opportunity to establish a provincial framework and standards for access to health and mental health services based on a life span, (facilitating transition from child to adulthood) cross sector, holistic (biopsychosocial and multidisciplinary) approach that includes health promotion and prevention strategies. It is proposed that the new policy have as its goal:

- Development of a spectrum of health and mental health related supports and services that are organized as a coordinated and cohesive network including access to primary care (e.g., family medicine, dental care), secondary (e.g., internal medicine for assessment and treatment services, general hospital services and community psychiatric services), and specialized/tertiary level services (e.g., consultation, assessment and treatment of more complex problems provided by professionals with special expertise in developmental disabilities and mental health problems). (Adapted from Bradley & Summers 2003).

It is also proposed that the *service and support assumptions* that have provided the basis for the development of dual diagnosis services since 1997, with some modifications, are applicable to establishing a basis for a provincial model of Health and Mental Health Care for developmental disabilities. These assumptions include:

- In most situations, generic providers in each sector (Developmental/Health/Mental Health) have a role and should continue to have a role in supporting persons with developmental disabilities.
- In more complex situations, additional supports and cross sector team approaches may be needed.

- Specialized services that combine and integrate the expertise of both sectors are required (as an adjunct) for a small but very challenging group.
- Providers are experienced and comfortable working with persons with intellectual disabilities at each level of care.

2. Definition of Specialized Services

Within the transformation agenda, a consistent definition of specialized services will also provide a means of establishing standardized understanding and service development across the province. The Dual Diagnosis Committee of Toronto is in the process of finalizing a short document on proposed characteristics that best define specialized services. This follows a process of reviewing the literature as well as the definitions currently in use by the Ministries of Health and Long Term Care and Community and Social Services. (Flannery, 2004). The committee proposes that a specialized support or service is one that:

- Identifies a specific target population to which their specialized supports are dedicated.
- Has the capacity to mobilize resources and implement supports that reflect complex needs e.g. capacity to increase staff during high need periods, smaller case load ratios, clinical services set up to allow for longer time for assessment and treatment.
- Demonstrates dedicated support to professional training and on going professional development including generalist level training in developmental disabilities, specialist training (e.g., specialist training in dual diagnosis at advanced or specialist level) and on going continuous professional development in developmental disabilities.
- Engages in evidence based clinical practice and the implementation of practice guidelines where available and appropriate in areas of assessment, treatment, support, medications, appropriate professional capacity to meet the needs (e.g., meets population based manpower requirements), accessible educational and clinical resources to staff on day to day basis.

3. Recommendations

Much of what is recommended below has already been outlined by a variety of Ontario authors in a myriad of reports, articles and book chapters previously published. An effort has been made to bring together in a cohesive fashion these various recommendations, and where possible specific references are noted.

Provincial Level

1. Include in the Provincial Transformation policy a vision for addressing the health and mental health needs of persons with developmental disabilities. A proposed vision statement (adapted from the Interministerial Dual Diagnosis Guidelines) is:

“Persons with developmental disabilities and their families/supports will have timely and equitable access to a continuum of health and mental health supports and services within and across sectors that are integrated, coordinated and accessible”.

2. It is recommended that the Provincial Transformation Policy will also:
 - Recognize the need for a continuum of health and mental health services at a primary, secondary and tertiary level.
 - Identify lead government ministries (i.e. MOH, MCSS, Ministry of Education and Training) to develop policies, procedures and performance indicators that ensure clinical excellence and a comprehensive approach to meeting the health and mental health needs of individuals with developmental disabilities.
 - Incorporate collaboration with Community Colleges and Academic Health Science Centres to develop and maintain the necessary infrastructure such as teaching sites, research and program evaluation, interdisciplinary training.
 - Establish population based service targets on a regional and local level e.g. number of specialized multidisciplinary health care teams per population.
 - Establish a target number of trainee graduates for the next decade based on population e.g. number nurses, psychologists, case managers, physicians per population.
 - Identify the need for collaboration with professional licensing and accreditation bodies (e.g. nursing, social work, occupational therapy, medicine, speech and language, psychology) and for advocacy at a national level to include standards of health and mental health care and best practices for persons with developmental disabilities.
 - Establish cross ministry mechanisms to monitor and support implementation of the policy, including the deinstitutionalization of individuals from MCSS Schedule 1 facilities and MOH psychiatric facilities.
 - Establish outcomes in relation to health screening and standardized diagnostic protocols to support primary health care providers. (Ouellette-Kuntz et al, 2004).
 - Commit to the development of appropriate reimbursement structures to permit the required additional time to accurately perform primary, secondary and tertiary assessments, treatments and consultations.
 - Enhance the regional level capacity to undertake human resource planning, education and training.
 - Enhance access to research funds to support building of best practices, outcome evaluation and knowledge transfer.

Regional Level

3. Formal memorandums between the developmental service, community health and mental health providers and identified regional health and mental health clinical Academic Health Science Centers across the province to provide:
 - Specialized community based multidisciplinary assessment, treatment and back up supports related to primary health, mental health, challenging behaviour and specialized services such as to neurology, dentistry, internal medicine, gynecology, psychiatry, etc...
 - Dedicated beds for specialized short and long term care located in the community and in general and psychiatric hospitals to ensure supports and safety for individuals with more challenging needs.

4. Regional cross sector coordinated planning committees that are connected to Community Colleges and Academic Health Science Centres, the regional offices of the appropriate government ministries as well as regional structures such as Local Health Integration Networks and Community Care Access Centres to provide:
 - Collaboration between the MOHLTC psychiatric facilities and MCSS Schedule 1 closure/discharge planning process to ensure integration of two processes that require similar resources and structures while minimizing competition for limited community resources.

Local Level

5. Formal links between generic health services such as primary health care networks, community health centers and Community Care Access Centres and developmental services for day to day care.
6. Community based specialized multidisciplinary teams operating within a biopsychosocial framework with knowledge, skills and specific expertise related to *the health and mental health needs* of persons with developmental disability as well as challenging behaviours to ensure the focus of care remains in the community and integrates developmental, health and mental health approaches.
7. Crisis response and emergency resources to attend to individuals in the community with ready access to a range of time limited options (e.g. flexible funds for developmental, health and mental health resources into the home, community based respite and safe bed options, short-term hospitalization for medical or mental health care).
8. A community-based habilitative support system with the capacity to provide varying degrees of transitional and long term support over a lifetime in recognition of fluctuating needs, relapsing and/or recurrent medical or psychiatric disorders. This would include specialized housing and day programs for those with complex needs such as medically fragile, severe autism and/or challenging behaviours. (Morris, 2003).
9. Intensive case management (with lower case loads) for individuals with more complex needs to support providers and families to negotiate the system e.g. medically fragile, dual diagnosis. (Ibid).

VI Conclusion

Many gains have been made in the last 30 years in relation to the inclusion of individuals with developmental disabilities as citizens in the general community. However these gains are somewhat illusory when the actual health and mental health needs of this population are fully understood. Individuals with developmental disabilities have not had the same access to knowledgeable primary, secondary and specialized health and mental health care provision as the general population. In fact, the studies noted above clearly demonstrate that individuals with developmental disabilities have many health needs that are not met because of the inadequate availability of primary, secondary and specialized health care. These unmet needs often present as “challenging behaviours” and as such these individuals are referred to the mental health sector where the behaviours may be treated as “psychiatric” and the underlying health needs remain unidentified and therefore untreated. In addition individuals with developmental disabilities do also have an increased prevalence of psychiatric disorders and skill is required in teasing out whether these challenging behaviours are due to underlying medical or emotional or psychiatric concerns.

The recommendations proposed by the Ontario Chapter of NADD are broad and extensive in nature in an effort to integrate what we have learned from 30 years of experience in Ontario from deinstitutionalization and community integration as well as from research. The recommendations require a focused commitment across different government ministries, sectors of services and supports, and professional and paraprofessional groups. The opportunity for this discussion is timely. The health of individuals with developmental disabilities depends on it.

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