**CANADIAN MENTAL HEALTH ASSOCIATION
ONTARIO DIVISION**


**POSITION PAPER**

**RESPECTING**

# DUAL DIAGNOSIS


**DUAL DIAGNOSIS TASK FORCE
OF THE
PUBLIC POLICY COMMITTEE**

**Chair: Janet Paddison**


**JUNE, 1998**

# EXECUTIVE SUMMARY

There are approximately 80,000 individuals with a developmental disability in Ontario[1], with a significant number living in the community with their families, in group homes, or receiving other residential services. A number of these people also suffer from a mental health problem. We must keep in mind that mental illness in persons with a dual diagnosis has traditionally been under reported because it is often unrecognized, undiagnosed, and untreated. Using a conservative prevalence rate of 30% (some researchers have estimated the incidence of mental illness in a person with a developmental disability to be within the 50-60% range) it can be said that approximately 24,000 individuals in Ontario have a dual diagnosis.

In 1985, approximately 8,000 individuals with a developmental disability lived in institutions and nursing homes. By 1996 this number had been reduced to 2,182 in six Ministry of Community and Social Services (MCSS) institutions[2]. In 1975, 4,600 individuals with developmental disabilities were serviced in community-based settings. By 1995, an estimated 34,000 were receiving community-based supports and services[3].

It has been estimated that a further 978 people with developmental disabilities will have moved from institutions into local communities across Ontario by the year 2,000[4]. Many of these individuals will have complex medical and psychiatric needs and will present a difficult and complex challenge for communities to ensure that the appropriate supports and services are in place. Furthermore, there are many dually diagnosed individuals already residing in communities across Ontario who will continue to require supports and services, furthering the necessity of timely, adequate and appropriate community services for this unique population.

Defining dual diagnosis has been problematic over the years, particularly in terms of having a definition that enabled persons with a developmental disability and a mental illness to access both mental health and developmental services when needed. As such the CMHA, Ontario Division, Dual Diagnosis Task Force supported and proposes the following definition for dual diagnosis[*]:

> **Individuals with a developmental disability and mental health needs**[5].

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[*] In 1990, the interministerial initiative of the Ministries of Health and Community and Social Services used the following definition for Dual Diagnosis: "Individuals who have a diagnosed emotional/psychiatric disturbance as well as a diagnosed developmental disability" However, this definition was problematic in terms of accessing the mental health sector as the individual required a psychiatric diagnosis. Similarly, access to the developmental sector requires a diagnosis of developmental disability. When a consumer does not yet have a diagnosis, it can result in the exclusion of those individuals most in need.

Although this definition is more inclusive, there are still barriers to services that the dually diagnosed commonly are required to overcome.

Individuals with dual diagnosis frequently require services from both the developmental and mental health systems. However, there are few community-based programs providing an appropriate range of supports in Ontario that are comprehensive and integrated between the mental health and developmental services sectors that are fully accessible to the dually diagnosed. Often, individuals with developmental disabilities are excluded from existing generic mental health services for a number of reasons, ranging from exclusionary program admission criteria, misunderstanding the needs of this population, or stigma, to name a few. There may be restrictions on providing services to individuals with severe intellectual impairment, or a lack of expertise in addressing the needs of individuals with dual diagnosis. In recognition of these gaps in mental health services the Ministry of Health (MoH) specifically included dual diagnosis in its definition of priority populations for Mental Health Reform in 1993.

One of the overriding issues facing persons with a dual diagnosis is the lack of information and understanding about the disorder. Service providers and communities are often uninformed and unaware of these issues. This not only can lead to misdiagnosis; it can also lead to the perpetuation of stereotyping as "hard to serve or treat" and increased stigma.

Conceptual and operational differences between the mental health and developmental service sectors and lack of interagency communication, information sharing, and expertise further decreases accessibility to services for the dually diagnosed. All these barriers, and more, demonstrate the need to examine the issues surrounding dual diagnosis and to plan for the elimination of barriers and the creation of a integrated continuum of care for individuals with a dual diagnosis.

Policy directed at developing community-based alternatives to traditional institutional care is now firmly in place in Ontario. Its implementation raises a number of concerns about the size and nature of the dual diagnosis population and effective and appropriate services; issues that are relevant to all sectors of the community including education, social services, health care and law enforcement and to the families of and advocates for disabled persons. It is hoped that this paper will draw attention to the unique needs of persons with a dual diagnosis and the service systems in order that jurisdictions designing services and supports will be able to do so in co-ordinated, timely and responsive manner.

While work has been done in the recognition and understanding of dual diagnosis during the last few years, much still remains to be accomplished. The CMHA, Ontario Division, would like to emphasize the need to maintain this momentum for change. It is imperative that organizations remain committed to attaining the best possible dual diagnosis system possible.

# RECOMMENDATIONS

1. *The CMHA, Ontario Division, should advocate to the Ministry of Community and Social Services and the Ministry of Health that services for persons with a dual diagnosis continue to be given a high priority within and between the mental health and developmental services sectors, including current interministerial initiatives which ensure equity of access to services and programs (Page # 23).*

2. *The CMHA, Ontario Division, should advocate for the development of a co-ordinated and collaborative service system within and between the mental health and developmental services sectors for individuals with a dual diagnosis (Page # 23).*

3. *The CMHA, Ontario Division, should advocate for the removal of barriers that decrease equitable access to services through the development of co-ordinated and collaborative working relationships between the mental health and developmental services sectors (Page # 24).*

4. *The CMHA, Ontario Division, should advocate that a continuum of supports, including social supports, and services for the dually diagnosed be established based on the work developed in the field to date that demonstrates efficient and effective use of resources, and intersector collaboration (Page # 24).*

5. *The CMHA, Ontario Division, should advocate to the Ministry of Health and the Ministry of Community and Social Services that as restructuring in their respective ministries continues, it not be done in isolation of one another and that restructuring include the promotion of interministerial initiatives focussing on the dually diagnosed, clearly define each ministry's role in relation to the service system and provide support to local service providers (Page # 25).*

6. *The CMHA, Ontario Division, should advocate to the Ministry of Health and the Ministry of Community and Social Services that funding be allocated to encourage collaboration between and within the mental health and developmental sectors (Page # 25).*

7. *The CMHA, Ontario Division, should advocate for increased partnerships between dually diagnosed individuals and their families in the policy, planning and implementation of services and programs for the dually diagnosed (Page # 25).*

8. *The CMHA, Ontario Division, should advocate to the Ministry of Community and Social Services and the Ministry of Health that a province-wide public education program focusing on dual diagnosis be developed and implemented (Page # 26).*

*9.  The CMHA, Ontario Division, should advocate for the protection of funding for programs presently based in Provincial Psychiatric Hospitals, the identification, development and implementation of specialized treatment services in the community based on "best practice models" and subjected to rigorous evaluation, and the identification of existing specialized services as resources for other agencies (Page # 26).*

*10. The CMHA, Ontario Division, should advocate for the creation of programs by universities and community colleges, working in partnership with the mental health and developmental sectors to prepare people at all levels with the competencies and skills needed to collaborate, work within and bring the two systems together.  This should include specialized programs that educate and train service providers to understand the unique needs of, and to work directly with the dually diagnosed and their families. (Page # 27).*

*11. The CMHA, Ontario Division, should advocate that exclusionary criteria, including program policies that prevent individuals with a dual diagnosis from accessing existing services be addressed by the mental health and developmental services sectors (Page # 27).*

*12. The CMHA, Ontario Division, should advocate to the Ministry of Community and Social Services and the Ministry of Health that more specialized resources, particularly in terms of staffing, be provided in order to identify and prevent the abuse of dually diagnosed persons in both the institutional and community sectors.  This also includes advocating for resources to serve not only the dually diagnosed who have been abused, but also caregivers and service providers that have abused a dually diagnosed person or have been abused themselves by a dually diagnosed individual (Page #27).*

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## 1.0    INTRODUCTION

As a provider of community-based services, the CMHA, Ontario Division[†], is concerned that persons with both mental health and developmental difficulties are not being served in the most efficient and effective manner possible.  In order to address this concern, the Public Policy Committee of the CMHA, Ontario Division, Board of Directors identified individuals with dual diagnosis as a priority population needing specific attention and better understanding in the social service and mental health systems.  The Public Policy Committee strongly felt that the issues surrounding dual diagnosis[‡] were not merely those of fragmentation of services, but that there are issues *within* and *between* the individual, program and system levels.  A Task Force on Dual Diagnosis was established in order to assist in the development of a CMHA, Ontario Division, position paper and recommendations on dual diagnosis.

The CMHA, Ontario Division, supports the Ministry of Community and Social Services (MCSS), the Ministry of Health (MoH) and the Ministry of the Solicitor General and Correctional Services' direction to help persons with developmental disabilities live in their communities and achieve greater independence.  The goal of community inclusion has been long-standing in both the developmental and mental health sectors in the province of Ontario. It is important that we look at the lessons learned to date as the province proceeds with this strategic direction.

Our organization also supports the recent joint initiative by MCSS and the Ministry of Health in providing guidelines to oversee the planning and implementation of services for the dually diagnosed.  Given that both ministries are undergoing extensive internal and external restructuring at the same time, it is important that both restructuring initiatives are co-ordinated so that implementation of the interministerial initiatives is not compromised.  However, it is important that appropriate and adequate community supports and services are in place in order to successfully realize the goal of community inclusion for people with a dual diagnosis and their families.  It is imperative that restructuring be done in a co-ordinated and timely manner and within the context of restructured local service systems.  A co-ordinated system will enable service providers to more readily exchange information, increase continuity of care and access, permit assessment of needs and outcomes and decrease gaps in service delivery.

In examining dual diagnosis and the issues surrounding it, the CMHA, Ontario Division, acknowledges that individual values and methods of service delivery guide people and systems. It is not our intent to diminish or disaffirm these existing structures, rather, we hope that this document will enable those involved to examine the issues in a neutral manner which will encourage understanding of the nature of dual diagnosis and the importance of an appropriate service delivery and support system.

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[†] The Canadian Mental Health Association, Ontario Division, is an incorporated, registered non-profit charitable organization chartered in 1952.  Approximately 4,000 volunteers are active in direct, board and committee service in a network of 35 Branches located in communities across Ontario.  Ontario Division and Branch services and programs are funded through government grants, local United Ways, and supplementary fund-raising activities.

[‡] In 1993, the Ministry of Health defined the priority population for Mental Health Reform as individuals with serious mental illness/serious mental health problems.  Dual Diagnosis was specifically included in this definition.

## 2.0    BACKGROUND

Prior to 1974, the Ministry of Health funded services for persons with developmental disabilities.

In 1971, the Ministry of Health released <u>Present Arrangements for the Care and Supervision of Mentally Retarded Persons in Ontario</u>, commonly referred to as the Williston Report[6]. This Report represented a shift from the traditional health care model of services to a more community-based approach.

Key points in the Williston Report stressed the need to:

➤ help persons with developmental disabilities in the context of their families, their communities, and their schools; and

➤ enable persons with developmental disabilities to live with their own families during their formative years, and in their own communities as adults.

The <u>Developmental Services Act</u> was passed in 1974 in response to this Report[7]. The Act shifted the responsibility for persons with developmental disabilities from the Ministry of Health to the Ministry of Community and Social Services. Emphasis was placed on the phasing out of institutional-based care and the development of community-based supports.

## 2.1    RECENT ONTARIO GOVERNMENT INITIATIVES

### 2.1.1    Ministry of Community and Social Services

As previously mentioned, the Ministry of Community and Social Services was given sole responsibility to plan for and serve the social, vocational and residential needs of those with developmental disabilities in 1974. Unfortunately, no specific responsibility or mandate was given to the ministry concerning the mental health needs of this population although the ministry took on some of this responsibility by default.

In 1990, the Ministry of Community and Social Services published a document entitled <u>Challenges and Opportunities</u> which detailed a new 7-year plan for persons with developmental disabilities[8]. The plan focused on four service principles:

➤ promotion of independence

➤ protection

➤ individual attention

➤ quality programs.

The 7-year plan encompassed the approximately 80,000 individuals with developmental disabilities living in the community, in institutions and in nursing homes. The major goals were to develop a wide range of community services and community living arrangements for individuals living in MCSS facilities to prepare for deinstitutionalization.

On July 23, 1996, the Minister of Community and Social Services announced a four year plan to close three institutions for the developmentally disabled by March 31, 1999. This four-year plan will move 978 people with developmental disabilities from institutions back into their communities. Additionally, another three institutions are to be downsized by March 31, 2000. It is estimated that approximately 60% of the developmentally disabled population to be deinstitutionalized have a dual diagnosis.

In January, 1997, the Minster of Community and Social Services announced the provision of an additional $15 million to support more services for people with developmental disabilities, specifically geared toward individualized supports for ageing parents caring for their developmentally disabled child at home ($6m); special services at home programming (SSAH) ($5m); and infant development programs ($4m)[9]. Currently, the MCSS spends about $836 million in the developmental services system of which about $650 million goes to community-based service providers through transfer payments[10]. These agencies provide a range of services including case management, group homes, day programs, workshops, respite care, and infant development programs. They provide support to children and adults who live at home with their families, in group homes or other residential-type settings, and adults living on their own or in semi-independent settings.

In July, 1997, the Ministry of Community and Social Services released its restructuring document <u>Making Services Work for People: A new framework for children and for people with developmental disabilities</u>[11]. This document sets out directions for the reshaping of children's and developmental services over the next two years. MCSS area offices have the lead in implementing the Framework, placing implementation challenges at the local level. Of note is that the Framework sets out criteria for local processes, including the requirement that area offices invite involvement from the health and education sectors.

The Framework outlines nine overarching goals for reshaping social services. One of these is that families and individuals will receive a co-ordinated set of services funded by MCSS and other funders at the local level, including the Ministry of Health (health services), the Ministry of Education and Training (school boards), the Ministry of the Solicitor General and Correctional Services, youth justice partners, municipalities, charitable organizations, religious organizations and businesses when necessary[12].

Within the Framework document, the Ministry establishes its commitment to "ensure that essential supports are maintained, services are more integrated, families and individuals receive better care at an earlier stage and consistent core services are provided across Ontario"[13]. There are clear directions for each local community to establish services based on "core functions"

which are the minimum range of ***supports*** that must be available to ensure that individuals and families have access to a consistent range of services. The core functions include *essential* supports[§] and *investment* supports[**] along with reinvestment strategies for increased early intervention, developmental and prevention services. Core functions outline ***who*** will receive services, not how services are currently funded or the functions of existing agencies. Communities will be required to examine and co-ordinate existing services in addition to planning for the future provision of services. It will be important to clarify accountability mechanisms to the consumer/survivor[††] and the funding required to implement the transition of responsibility. Although the new Framework is a model for systems restructuring and not a funding model per se, there is still some concern that the Framework may set into motion the erosion of funding for specialized services that the ministry had traditionally supported and maintained in the past.

Local communities are being encouraged to adopt flexible approaches to change that meet their own needs, and have until April, 1999, to implement a number of modifications in the delivery of services for children and for people with developmental disabilities. Using the ministry's directions concerning core functions, local communities will establish local priorities (what the local community system of services will require in order to provide essential supports), and determine local priorities/needs concerning the identification and establishment of additional investment supports where needed.

Supported employment programs for adults with developmental disabilities are not included in the ministry's Framework at this time. The ministry is planning to review programs and funding for supportive employment, sheltered workshops and life skills as part of its restructuring of employment supports for persons with disabilities and funds for these programs are excluded from the funding envelope covered by the Framework initiative at this time.

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[§] *Essential supports* include mandatory services (required by legislation), and other essential supports to provide safety and security.

[**] *Investment supports* are supports to reduce or eliminate the need for essential supports in the future.

[††] The Ministry of Health adopted the term consumer/survivor during the current reform process and it is the term most often used by those in the community mental health field. This is not a term used, or necessarily understood by those in the developmental sector. It would be beneficial at some point to have a common language in regard to consumers of mental health or social services in order to bridge the two sectors. For the purposes of this document, the term consumer/survivor is used in the context of someone that has or has had mental health problems and has used or is using services in the mental health sector.

In December, 1997 the ministry released the <u>Reinvestment Strategy for Adults with a Developmental Disability</u>[14]. The purpose of the document is to outline reinvestment strategies for local communities that reduce avoidable personal and social costs to families and communities, and financial costs to government that arise when children, youth and adults require long-term or intrusive, expensive services. In conjunction with the Framework document, the purpose of reinvestment is to increase independence of adults with developmental disabilities and their families and to create a care system that is more effective with the same resources.

In the developmental sector, it is expected that services will move away from being organized by program towards services that are individualized and responsive to individuals and their families. Through these policy directions, the ministry is attempting to establish as system of care that will enable persons with developmental disabilities to live independently, which the ministry believes will allow a greater quality of life[‡‡] to be achieved.

The ministry has identified five types of supports for increased reinvestment and six system features. Supports for reinvestment include:

1. Family relief/respite;

2. Communication measures which improve quality of life for non-verbal people;

3. Behavioural supports for marked behavioural problems which improve quality of life for non-verbal people, or for people living at home with families;

4. Preventing abuse by providing information and education about their rights to people with developmental disabilities; and

5. Measures to improve rural transportation for individuals with developmental disabilities.

The six key system features that must be in place in order to be effective in supporting continued independent living, enhanced quality of life and safeguards for persons with developmental disabilities are:

1. Person-centred;

2. Enhanced quality of life;

3. Accessibility;

4. Involvement of parents and families;

5. Community inclusion; and

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[‡‡] Quality of life is defined in the reinvestment document as looking at the whole of a person's life, and assumes that the same factors are important, whether or not a person has a disability.

6. Early introduction of supports.

In summary, core functions as outlined in the Framework document require local MCSS funded systems of services to provide some prevention, early intervention and developmental supports and services. The reinvestment strategy requires an increase in these investment supports and services.

## 2.1.2   Ministry of Health

Prior to 1974, services for persons with developmental disabilities were operated under the Ministry of Health. As previously mentioned, the MCSS was given sole responsibility to plan for and serve the social, vocational and residential needs of those with developmental disabilities in 1974. Unfortunately, no specific responsibility or mandate was given to the MCSS concerning the mental health needs of the dually diagnosed. In recognition of these needs, the Ministry of Health acknowledged its responsibility to the dually diagnosed in its Mental Health Reform policy documents.

In September, 1988, the Ministry of Health released a report entitled Building Community Support for People: A Plan for Mental Health Service in Ontario (commonly referred to as the Graham Report)[15]. The report outlined the philosophy and principles to be used in the development of a comprehensive community-based system of services and supports for people experiencing mental illness and their families. It also recommended a series of steps, which should be taken so that, by 1995, communities across Ontario would have services designed to support people with serious mental illness. The Report suggested 11 essential functions for a comprehensive community mental health system, including, as they appeared in the Report, identification, treatment and crisis support, consultation and co-ordination, residential support, case co-ordination and case management, social support, vocational support, self help/peer support, family support and advocacy. The Graham Report also made 10 specific recommendations, of which number 10 stated that projects should be started to meet the needs of special populations, including those with "mental retardation". The CMHA, Ontario Division, was very actively involved in the development of this Report, and its Board of Directors endorsed the Graham Report in January, 1989.

In June, 1993, "Putting People First: The Reform of Mental Health Services in Ontario was released"[16]. Putting People First established the policy framework for restructuring mental health services in Ontario. The goal of restructuring was to create a balanced and integrated system, which emphasized consumer/survivors as the central focus of the planning and implementation of a comprehensive service delivery system. The document defined a vision, principles and working definitions for mental health service components. Four priorities for community reinvestment were articulated: case management, 24-crisis intervention, housing, and alternative supports planned and run by consumer/survivors and families. Moreover, for the first time, persons with dual diagnosis were identified as a *target population* for Mental Health Reform.

In the fiscal year 1993/94 community, mental health services (excluding those covered by OHIP) received approximately $130 million or 20% of the mental health budget compared to $42.9 million in 1985/86[17]. The Mental Health Reform policy of the ministry proposed to further shift spending from 80% institutional (excluding OHIP) to 60% on community services and 40% to institutions by 2003. In October, 1994, the Minister of Health announced that 20 million new dollars would become part of the base funding for community mental health services geared towards the four priorities as outlined in Putting People First. After a competitive Request for Proposal Process, funds were distributed between 1995 and 1997.

Bill 26, The Savings and Restructuring Act, became law in December, 1995[18]. The legislation gave the provincial government the authority to create the Health Services Restructuring Commission (HSRC), an independent body with a four year mandate to make recommendations concerning the restructuring of Ontario's health care system, and to issue orders for closures of public hospitals. Since beginning its work in 1996, the HSRC has recommended to the Ministry of Health that the Provincial Psychiatric Hospitals in Thunder Bay, London, St. Thomas, and Brockville (and Hamilton as an interim recommendation), be closed, with most inpatients (non forensic) to be transferred to Schedule 1 general hospital psychiatric units. Although most PPHs have served the dually diagnosed in one way or another, only the Brockville, St. Thomas and Penetanguishine Psychiatric Hospitals have specialized dual diagnosis programs for this population and it is unclear what will happen to these programs once restructuring is completed.

Under the current government's fiscal plan, funding for hospitals has been decreased by a total of more than $1.3 billion between 1996 and 1999 (although the 1997/98 reductions have been delayed indefinitely) which has resulted in many bed closures, including those in Provincial Psychiatric Hospitals and General Hospital Psychiatric Units.

The mental health 'system' in Ontario at present might best be characterized as a 'non-system': services are fragmented, with gaps and duplications. Ministry of Health funded mental health services currently include:

➤  Provincial Psychiatric Hospitals;

➤  General Hospital Psychiatric Units;

➤  Homes for Special Care;

➤  Long-Term Care Facilities;

➤  Some Children's Mental Health Centres (most children's mental health services have been funded by the Ministry of Community and Social Services);

➤  Psychiatrists;

➤  General Practitioners;

➤ Community Mental Health Agencies; and

➤ Other community supports such as housing, day and vocational programs and case management services.

Within the Ministry of Health, management of most mental health programs and services has now been consolidated under the Institutional Health and Community Services Group, with the exception of the mental health component of Long-Term Care. Mental health services provided by other Ministries (i.e.: Corrections Canada and the Ontario Ministry of the Solicitor General and Correctional Services, the Ministry of Education and Training and the Ministry of Municipal Affairs and Housing) are still not co-ordinated with those provided by the Ministry of Health.

In late January, 1998, the Minster of Health announced that the Ministry would be conducting a five-week review of the Mental Health Reform process and asked stakeholders to make recommendations as to the manner in which the process should proceed. The results of this review are to be available shortly.

### 2.1.3   Interministerial Collaboration (MCSS & MoH)

In order to work towards the realignment of both ministries to ensure consistent service provision for those persons with a dual diagnosis, it is important to acknowledge that the MoH and MCSS have different approaches and are currently undergoing ministerial reorganization and restructuring. However, it is clear that both ministries must work together and to this end, headway is being made. There has been significant progress over the past few years toward more clearly defined directions for achieving cross-sector and inter-ministry collaboration. In July, 1997, the Ministry of Health and the Ministry of Community and Social Services jointly released the Policy Guideline for the Provision of Services for Persons with a Dual Diagnosis[19]. The new guidelines build on the ministries' past recognition of many shared responsibilities in serving people with dual diagnosis. They realize that a number of system barriers (e.g.: split jurisdictions and responsibilities, lack of specialized supports, and lack of service linkages and co-ordination) prevent people with dual diagnosis from accessing services and support from within or between ministries.

Through a joint and co-ordinated interministerial approach, the guidelines provide direction, assistance for the planning, and delivery of and access to services and supports for persons with a dual diagnosis. The guidelines support ministry restructuring initiatives and focus on persons with a dual diagnosis who are scheduled to move from institutions to the community in both sectors.

The purpose of the guidelines is to:

1. Ensure that persons with a dual diagnosis have access to services in either or both the mental health and developmental service sectors as their needs require; and

2. Provide direction for the planning and delivery of services and supports for individuals with a dual diagnosis[20].

This interministerial approach endeavours to work jointly to ensure simultaneous cross-sector collaboration and accountability at the individual, and program/system/policy levels; collaboration between stakeholders; training and educational opportunities, priorization of unmet service needs, co-ordinated planning and support for the development of regional/district and/or local level specialized supports and to build upon the existing continuum of district services and community supports. The guidelines also recommend that *all* community mental health programs serve consumer/survivors with a dual diagnosis.

The policy guidelines recognize that some specific responsibilities are distinct and some are shared between the two ministries. Roles and functions are identified and both ministries will be responsible to decide how the guidelines will be jointly implemented at the district/area offices and regions in the planning process. Each ministry is undergoing its own restructuring process and it is important to determine how the two will provide services for the dually diagnosed when decisions are being made at the ministerial, district, and local levels. It is essential that decisions are not made in isolation from each other. Implementation plans for the guidelines are to be developed in the near future.

The need for integrated interministerial collaboration, particularly in terms of deinstitutionalization and the developmental sector can be highlighted in lessons to be learned from the Pine Ridge Follow-up Study conducted by the then Ontario Association for the Mentally Retarded and reported in the Habilitative Mental Health Resource Network[21]. This study concluded that Pine Ridge, a MCSS facility closed in 1985, was a good example of what could occur when government and the community work together in a value-based way to provide a new quality of life for persons with developmental disabilities. The study showed that:

*Problems occurred as a result of:*

➤ lack of appropriate, easily accessible and flexible supports at home or work, including professional services as required;

➤ staff who were not trained or were inexperienced in dealing with special behaviours or needs of residents;

➤ lack of a back up resources from local hospitals or other local resources; and

➤ an inappropriate environment[22].

*Success appeared to depend on the following:*

➤ centralized value-based planning (i.e.: quality of life improvements, suitable matching of individuals to their new life space);

➤ comprehensive co-ordination of resources available prior to discharge;

➤ case managers for each individual from planning to placement and follow-up;

➤ resident and family input;

➤ flexible services and supports to accommodate complex needs;

➤ a service plan that involved residential, day and leisure options;

➤ staff training and support services available prior to placement;

➤ an accessible community-based back up unit;

➤ adequate and flexible individual funding;

➤ a commitment to provide resources to prevent placement breakdowns;

➤ a range of community living options; and

➤ commitment[23].

Reform is based on the belief that less reliance on institutions is appropriate and feasible and that resources in the community need to be created and enhanced. Public expectations about the use of institutionalization must be addressed in the reform process to facilitate support and understanding in the shift from institution to community. It is also necessary for the reform process to recognize that there will always be a need for institutions and/or other appropriate levels of support.

**2.1.4    Human Services and Justice Co-ordination Project (HSJCP)**

Although this paper will not deal specifically with forensic issues and concerns, it is nonetheless important to recognize that there are persons with a dual diagnosis in the justice system.

This provincial strategy  is the blueprint for all operational and policy initiatives for people with a mental illness and/or developmental disabilities who come into conflict with the law.  A co-operative effort, the strategy was set up in response to a recognized need to better co-ordinate, resource and plan services for people with clinical needs (including people who are dually diagnosed or developmentally disabled) who come into conflict with the law.

The policy document contains role descriptions of the various ministries in meeting their goals including:

1.    Ministry of the Attorney General concerning the role of Crown Attorneys, defence counsel, the judiciary and Justices of the Peace;

2.    Ministry of Health and the provision of community-based and hospital treatment programs for people with mental illness;

3.    Ministry of the Solicitor General and Correctional Services with attention to police services and care of offenders resident in provincial correctional facilities or through probation/parole stages of sentencing; and

4.    Ministry of Community and Social Services and the provision of a range of services that address the residential, vocational, behavioural, cognitive, community support and family support needs of people with a developmental disability.

District and regional committees are being established to co-ordinate communication, joint problem-solving and planning efforts between health, criminal justice and developmental services organizations within specific communities.  A number of pilot starter sites exist across the province.

In summary, there are a number of governmental initiatives currently taking place that impact on persons with a dual diagnosis.  Hopefully, this momentum will not diminish.  Understanding the needs of the dually diagnosed, and knowing what works effectively with this population may exceed the capacity of the differing sectors working in isolation.  It is extremely important that interministerial initiatives continue (including the HSJCP), that there be linkages between interministerial committees and that the lack of co-ordination of services and complex needs of individuals with a dual diagnosis becomes a high priority within the ministries that serve this population in order to implement policy on dual diagnosis and local initiatives.

We know that individuals with a dual diagnosis and their families require a broad range of combined services and supports in both sectors (MoH and MCSS) and it is on this, and some persistent and problematic issues that impact on the achievement of this continuum, that the Dual Diagnosis Task

Force centres its attention. As such, the Task Force would like to reiterate Metro Agencies Treatment Continuum for Mental Health (MATCH) (1997), philosophy that "in most situations, either sector can and should continue to provide services to a consumer/survivor that has entered their services. However, additional supports and services may be needed to bolster the network around a particular individual and to complement the work in the other sector. For a small number of very challenging individuals, specialized services may be required for consumer/survivors with a dual diagnosis that combine the expertise in both sectors"[24].

## 3.0 LINK BETWEEN MENTAL ILLNESS AND DEVELOPMENTAL DISABILITIES

It is still commonly believed that persons with a developmental disability do not experience the same range of mental health problems as the general population and that they somehow are immune to emotional and psychological problems. This assumption is compounded by the characterization of being worry-free and thus mentally healthy by the popular media and elsewhere. Unfortunately, these assumptions do not stop here. Many still believe that "the severely developmentally disabled [*sic*] have been considered to express no feelings and therefore do not experience emotional stress"[25]. Disturbed behaviours of individuals with developmental disabilities were seen to be either part of the developmental disability or else resulted from 'brain damage' inherent to the condition.

Although mental health problems may present differently in someone with a developmental disability than in a person in the general population and conventional diagnostic methods are difficult to apply without adequate training, recent studies have shown that these individuals do develop all types of psychiatric and behavioural disorders[26]. Prevalence rates indicate that there appears to be a higher correlation between mental health problems/illness and developmental disabilities.

A recent literature review, using a developmental perspective, by Lacharite, Bouter & Proulx (1995), found that as children with developmental disabilities grow older, the co-occurrence of mental health problems increases by approximately 30%[27]. This highlights the presence of a relationship between the age of developmentally disabled persons and the frequency and severity of their mental health problems. It would appear that as developmentally disabled children grow older, there is a greater risk that they will develop a mental illness. Although the whole spectrum of mental health problems seems to be found in children with developmental disabilities, some appear to occur more frequently than others do. Aggression disorders (which may occur out of a lack of resources, etc.), antisocial behaviours and personality disorder are among the types most frequently reported[28].

The availability or unavailability of social supports can have a profound impact on the occurrence and severity of emotional and cognitive problems a developmentally disabled child will develop as they age. In a study by Dunst, Trivette and Cross (1988) quoted in Lacharite, et al., (1995), researchers found that children's behavioural problems increased with age, particularly in the case of children living with parents who had a low level of social support. Children living with socially isolated parents who were not very satisfied with the support they were receiving had a greater risk of developing behavioural problems. The older the children got, the more their behavioural

problems seemed to increase[29]. This study appears to confirm that social supports available to the parents of a child with significant developmental delays has an impact on the child's adjustment. It is essential to look at the supports required, including treatment, for children with developmental disabilities and their families in order to decrease the likelihood and severity of further mental health problems.

In 1996, the Metropolitan Toronto District Health Council's Dual Diagnosis Working Group identified the following factors that may contribute to the high prevalence of mental health problems among those with a developmental disability in terms of frequency and/or severity:

➤ the stress of living in the community;

➤ the absence of services and/or the lack of co-ordination of services;

➤ reduced capacity to withstand the distress of society's excessive demands, constant disapproval and exclusion from normal activities;

➤ inadequate cognitive capacity to resolve emotional conflicts and inadequate attention to emotional states or language (with a failure to develop cognitive and linguistic skills and capacities);

➤ lack of judgement may lead to a greater gullibility, being "led on" into trouble by others;

➤ frequent undiluted sensory and central integrative disorders that hamper appropriate problem solving; and

➤ professional unwillingness to treat mental illness in persons with a developmental disability[30].

Persons with developmental disabilities also have a number of cognitive impairments that affect their perception of their environment. Those with a dual diagnosis are particularly vulnerable to this. The additional mental health problem or emotional component compounds these cognitive difficulties. Given poorly developed coping mechanisms and communications skills, and the stress and frustration often experienced daily, a psychiatric disorder is one of the main causes of secondary disability in the developmentally disabled[31].

While it is commonly understood that psychiatric symptoms can present differently in these individuals, and conventional diagnostic methods are difficult to apply, recent studies have shown that these persons can and do develop all types of psychiatric and behavioural disorders.

## 4.0    PREVALENCE RATES

The developmentally disabled individual experiences the same range of mental health problems as the general population, yet widely differing results across the literature make it difficult to give prevalence rates with any degree of reliability. This is due to past problems with definition, the room for inconsistencies based on categorizations in the Diagnostic and Statistical Manual (DSM IV), lack of suitable diagnostic instruments for persons with a developmental disability, sampling, lack of control

groups, and the lack of differentiation within samples.  However, there does appear to be a general consensus in the literature that:

➤ 1% of the general population have a mild, moderate or severe developmental disability[32].

➤ 30% of all those with a diagnosis of mental retardation (mild, moderate and severe) are believed to have both developmental and mental health problems/illness[33].  We must keep in mind that mental illness in persons with a dual diagnosis has traditionally been under reported because it is often unrecognized, undiagnosed, and untreated.  The 30% rate used here is a conservative figure - some researchers have estimated the incidence of mental illness in a person with a developmental disability to be within the 50-60% range.

➤ There are approximately 80,000 individuals with a developmental disability in Ontario. Given a 30% prevalence rate (see above), it can be said that approximately 24,000 have a developmental disability and mental health needs in Ontario.

➤ It has been felt that we can reasonably assume that the prevalence rate of mental illness in persons with a developmental disability is higher than the prevalence rate for persons without a developmental disability[§§].  It has been reported that 17% of individuals with a developmental disability experience mood disorders as compared to 6% of the normal population[34].  Research also indicates that intellectually disabled persons have a greater tendency to exhibit vulnerable behaviours and signs of psychopathology (cognitive, emotional or behavioural)[35] than do persons in the general population[36].

➤ Approximately 18% of intellectually disabled children suffer, before the age of 12, from significant psychopathology affecting their contact with reality and the pattern of their moods and behavioural problems   For intellectually disabled adolescents, the presence of mental health and behavioural problems increased to 59%[37].  Intellectually disabled children, like adults, seem to be at least twice as much at risk of developing mental health problems as are their counterparts in the general population.

➤ Psychiatric disorder is one of the main causes of secondary disability in the developmentally disabled[38].  Given their already poor coping mechanisms and communications skills, in combination with the stress and frustration they experience daily, the added distress from a psychiatric disorder clearly places these individuals in jeopardy, particularly in regards to treatment, support and access to services.

These figures are clearly astounding and are probably only the 'tip of the iceberg'.  A large number of people with a dual diagnosis are unknown to the system, even now.  Any analysis of prevalence rates must keep this in mind.  Of particular concern, which will be discussed in detail later in the paper, are

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[§§] Individuals with a developmental disability experience the same range of severe and prolonged mental health difficulties, including depression, mood disorders and schizophrenia as the general population, but at much higher rates.

those dually diagnosed individuals who are being supported by ageing parents and have yet to access the system. There are also people with developmental disabilities who have unrecognized symptoms of mental health problems, primarily those affected by depression[39].

## 5.0 PRINCIPLES

Much good work has been done in relation to the development and stating of principles that address the essential needs of a person with a dual diagnosis. Hence, the Task Force felt it was important to re-emphasise work previously completed, in particular those principles that are considered universal and mandatory in nature. The following principles are drawn from a number of sources, including Metro Agencies Treatment Continuum for Mental Health (MATCH) and the joint MoH, and MCSS guidelines document as previously discussed. Please refer to Appendix E for a brief description of how these Principles can be operationalized based on outcome.

1. *The CMHA, Ontario Division, believes that individuals with a dual diagnosis must have equity of access to local broad-based services in the health/mental health and developmental services sectors.*

2. *The CMHA, Ontario Division, believes that specialized dual diagnosis services need to be available to complement and support local broad based mental health and developmental services.*

3. *The CMHA, Ontario Division, believes that co-ordination, integration and continuity are essential within and across the mental health and developmental sectors at an individual, program, and system level.*

4. *The CMHA, Ontario Division, believes that consumer/survivors, families and service providers are integral to the planning and delivery of services and full partnership must be promoted and maintained.*

5. *The CMHA, Ontario Division, believes that the least intrusive services and supports must be available to consumer/survivors and their families.*

6. *The CMHA, Ontario Division, believes that integrated education, training, and research concerning the unique and complex needs of persons with a dual diagnosis is necessary within and between the mental health and developmental service sectors.*

7. *The CMHA, Ontario Division, believes that a full spectrum of consumer/survivor centred, comprehensive and quality services must be developed within the mental health and developmental services sectors for consumer/survivors with dual diagnosis in response to their identified needs.*

# 6.0    IDENTIFYING THE ISSUES

This document includes identification of specific issues, separated into three spheres (system, program, and individual levels) which have impeded the understanding, identification, and implementation of services and supports for persons with a dual diagnosis.  For the purposes of clarity, additional information on each issue can be found in Appendix A.

## 6.1    SYSTEM LEVEL ISSUES

One overriding issue identified by service providers and persons with dual diagnosis and their families is the lack of information and understanding about the disorder and the needs of people who experience both a developmental disability and a mental illness.  Service providers and communities are often uninformed and unaware of the complex problems and issues associated with dual diagnosis.  This can lead to misdiagnosis, perpetuation of stereotyping as "hard to treat or serve" and increased stigma.

### 6.1.1    Stigma

Stigma has been present throughout the evolution of the developmental and mental health fields and the issue must be addressed in order to effectively understand and meet the needs of persons with a dual diagnosis.

The CMHA, Ontario Division, has long been concerned about the stigma associated with mental illness and other forms of disability.  As an organization we are committed to a vision of society "which values human dignity and enhances mental and emotional well being for all"[40].  Intrinsic in this vision is a commitment to addressing stigma and attitudes about mental illness and mental health.

Stigma manifests itself in numerous ways:

- The person with a developmental disability and a mental illness is often viewed as the least desirable consumer/survivor for a mental health professional to work with.

- Overt behavioural expressions of psychiatric distress add even further to the social stigma and rejection that individuals with a dual diagnosis may experience daily.

- The increased risk of this form of stigma may lead to further discrimination in social acceptance and community integration as deinstitutionalization occurs.

- Stigma creates unfair discrimination in terms of housing, jobs, and vocational programs.  The social ramifications are considerable.

- Stigma is one of the largest barriers to people seeking help for a mental illness.

### 6.1.2   Prevention

Mental health promotion, or mental illness prevention, is the least understood and least developed aspect of the mental health field.  What promotes mental health in children, adolescents, and adults, including the developmentally disabled, is often defined in terms of single variables, and not focused on the multiple determinants of health such as employment, well being, resiliency, and support networks and systems.  Each of these elements is also essential to creating and maintaining quality of life.

### 6.1.3   Philosophical Differences

Philosophical differences include:

- Continuing use of the medical model in the mental health field, whereas the use of the medical model in the developmentally disabled field has largely disappeared.

- Both ministries are community-oriented, but generally speaking, there would appear to be two fundamental differences at this time regarding program funding and development: the MCSS is more individual-oriented and the MoH is more program oriented.

- Different service approaches for the two systems.  Generally speaking, for persons with a mental illness, rehabilitation and cure are the primary focus.  This is evidenced through the goal of returning to as near to normal as possible with the assistance of medication and therapy.  On the other hand, for a person with a developmental disability, the emphasis is generally placed on education, adaptive skill training, and behavioural modification with the goal being to lessen the impact of the developmental deficit.

- Conceptual and operational gulfs between the mental health and developmental disability services systems are such that interagency communication is not well established and access to services

across systems is limited. When a person with developmental disabilities and without a prior psychiatric diagnosis experiences a crisis, such gulfs may present a threat to living and working in community settings[41].

The two different services systems have two different goals and disparate views of the purpose of intervention and support. Hence, service delivery systems have had limited success in meeting the needs of persons with a dual diagnosis. It is imperative that the two sectors address the philosophical and service system differences in order to provide a truly comprehensive and effective system that address the needs of the dually diagnosed.

### 6.1.4 Lack of an Integrated and Co-ordinated Service Delivery System

An integrated system for the dually diagnosed would include not only those services and service providers currently working with this population, but also consulting psychiatrists, general and family practice physicians, general hospitals, Schedule 1 facilities, Provincial Psychiatric Hospitals, community based mental health services such as mobile crisis teams and supportive housing, day treatment, recreational and rehabilitation programs working with those programs and service providers in the developmental sector.

Integration means examining and redefining the relationship between all these service providers in order to decrease the difficulties and exclusionary practices between services that negatively impact on the consumer/survivor gaining access to an appropriate service or program; a particularly critical element during periods of crisis. In the current system, few facilities identify persons with dual diagnosis as their primary population. Consequently, when a consumer/survivor is in a developmental setting and develops a psychiatric crisis, staff may not necessarily have the specialized psychiatric or crisis intervention training that is needed.

As clearly as the lack of comprehensive and co-ordinated services for the dually diagnosed has created a dilemma in our mental health and developmental sector systems, it is also clear that there is movement to address this dilemma, and that change is taking place.

### 6.1.5 Ministry Restructuring and its Impact on Persons with a Dual Diagnoses

The restructuring process that impacts on those with dual diagnosis is two-fold. According to MARC (1995), the number of individuals requiring community services in Ontario has recently increased: during the seven year period leading up to March 1994, 1,201 developmentally disabled individuals were moved from institutions to the community under the first operational phase of the Ministry of Community and Social Services 25 Year Plan. The Ministry's long-term aim, as discussed earlier in the paper, is to continue the transfer of individuals from institutions to the community (deinstitutionalization). In the mental health sector, a similar process is underway within the Provincial Psychiatric Hospitals, where many individuals with dual diagnosis have also resided.

As this two-fold process continues, there will be increased pressure on those who work with this population to access a wide range of support services in the community, including secure, affordable and permanent housing - a place to call "one's own".

### 6.1.6   Community Integration/Deinstitutionalization

A policy factor that has significantly influenced the development of services for the dually diagnosed is the emphasis on deinstitutionalization and normalization[42].

In its recently released position paper entitled <u>Deinstitutionalization and Dual Diagnosis,</u> the Habilitative Mental Health Resource Network states that "one sector alone does not have all the expertise and resources to address all the issues and needs of individuals who will be affected by the deinstitutionalization [sic] process"[43].   The Network believes that a new and different approach to deinstitutionalization is required and that this approach must be cross-sectoral in nature.

There are a number of issues concerning deinstitutionalization:

- Individuals with dual diagnosis can be suddenly exposed both to the stresses of modern life and the expectations of socially acceptable behaviour when moved into the community.

- The necessary support system for the dually diagnosed has not yet been fully developed to deal with their unique and specific mental health concerns, and long waiting lists for resources have limited the availability of a whole range of necessary services.

- A person discharged from an institution may not be discharged to his/her home community. Rather, they may reside in the community close to the closed facility for a number of reasons ranging from loss of family members through death, distance and alienation, choice, familiarity with the area that they have resided in, or lack of services elsewhere.  Choice of residence is not always assured.

- When individuals with developmental disabilities experience a behavioural or psychiatric crisis, their community placement may become threatened.

- Persons who continue to live in institutional settings are also more likely to have a dual diagnosis. A study in progress at Rideau Regional Centre found a prevalence rate of 60%[44].  If this is the case, the need for specialized, improved and co-ordinated community services will be even more acute if the focus on moving those now residing in institutions into the community continues. Additionally, if generic mental health care and other services, such as the services available in the psychiatric wards of general and psychiatric hospitals, are to be used as support services for persons with dual diagnosis in the community, these services will need to devote special support service staff to these individuals. Staff will also require relevant information and training to deal with individuals who have a dual diagnosis, particularly those individuals with lesser developmental abilities.

### 6.1.7   Poverty

For many persons with mental health problems, poverty becomes a way of life. Without appropriate income and community support services, people with serious mental health problems are at risk of becoming trapped in the "revolving door syndrome", wherein upon release from hospital, lack of money forces them into substandard housing where their mental health deteriorates and they return to hospital.

Additionally, the Canadian Association for Community Living (CACL) has estimated that 77% of adults with an intellectual disability also live in poverty[45]. Most will continue to live an impoverished life, despite making tremendous progress towards independence and community participation. Statistics Canada data reveals that most adults with an intellectual disability who do not live with their parents exist on incomes of less than $11,000 per year - insufficient to secure even a reasonable quality of life[46]. Those who live in supported independent living situations receive $112.00 per month comfort allowance or $1,344 per year. Based on the above, it is safe to say the persons with a dual diagnosis are a high-risk group for living in poverty.

## 6.2    PROGRAM/SERVICE LEVEL ISSUES

### 6.2.1    Exclusionary Criteria in Service Delivery

Exclusionary criteria practised at the program level are a matter of concern in both the mental health and developmental sectors. Individuals with developmental disabilities may be excluded from existing generic community-based mental health services due to organizational issues (i.e.: restrictions on providing services to individuals with several cognitive or intellectual impairments), or lack of expertise or training in addressing the needs of individuals with dual diagnosis. Belief that individuals with developmental disabilities may not benefit from mental health interventions may also create further exclusionary barriers. The reverse also holds true - individuals with a developmental disability being predominantly serviced in the mental health sector may find it difficult to access services in the developmental sector as the result of similar organizational issues and misconceptions.

### 6.2.2    Identification and Assessment

The details and unique components of any given program will depend on the specific user population, hence the *identification* of persons with a dual diagnosis is of primary importance. Mental illness and developmental disabilities have independent courses, capable of mutually exacerbating the other. Therefore, thorough *assessment* is essential to identification, not only to provide effective and coherent individual services and supports, but also to system planning and service development. Questions about mental health must be part of the intake history of persons who are developmentally disabled, particularly in light of the high prevalence of dual diagnosis. Effective and appropriate identification and assessment tools will help minimize the possibility of misdiagnosis and create more appropriate plans for treatment, support, and services. Correlated with identification and assessment is the necessity of

being able to access assistance or consultations from other specialized fields such as neuropsychology, speech, language, audiology, vision, occupational therapy and mental health to name a few.

### 6.2.3   Misdiagnosis

It is not unusual that an individual who in fact should be considered as dually diagnosed is referred to behaviour management programs, rather than treatments related to mental illness[47]. Under these circumstances, the individual is not given the opportunity to recover because the root of the problem has been undiagnosed and left untreated.

Unfortunately, there is a lack of unique criteria for diagnosing mental illness in persons with a developmental disability, particularly the severely disabled.  Neither the International Classification of Diseases (9th Edition), nor the Diagnostic and Statistical Manual of Mental Disorder (3rd Edition revised and 4th Edition) give any specific definition of dual diagnosis, nor do they refer to diagnostic issues in relation to developmental disability and psychiatric symptoms[48].

### 6.2.4   Lack of Specialized Training

Traditionally, mental health professionals receive limited training regarding persons with developmental disabilities; likewise, individuals working with the developmentally disabled have limited training in mental illness.  The scarcity of staff specifically trained to meet the mental health needs of the developmentally disabled also affects the quality of services offered.

Those working with the dually diagnosed must be trained in dealing effectively with issues related to diagnosis; differentiating mental illness from behaviour problems in persons with a developmental disability; developing comprehensive multidisciplinary/interdisciplinary treatment plans and effective therapeutic approaches.

### 6.3   INDIVIDUAL AND FAMILY LEVEL ISSUES

### 6.3.1   Quality of Life

Quality of live is central to any approach used with dually diagnosed individuals.  Quality of life expectations should be the same for everyone.  The needs of people who are dually diagnosed are the same as for those who are not.  The only difference is that the needs of people with dual diagnosis often become medicalized, and not thought of in terms of well being and quality of life. The underlying issue here is that it is more difficult for persons with a dual diagnosis to access quality of life spheres.  It is important that this is recognized and that both the formal and informal providers of care and services are aware of this.

### 6.3.2   Living with Ageing Parents

Ageing parents with health problems of their own are caring for their dually diagnosed son or daughter in their home because there is often nowhere else to go.  What will happen to these individuals once the

parent dies?  We all know the loss of a parent can be very difficult.  For a dually diagnosed person this can be devastating.  Individuals with disabilities tend to be much more dependent on their parents than others are.  For persons with a dual diagnosis living at home, their parents are not only their caregivers, they are also their advocates, friends, protectors, and more often than not, their lifeline to the outside world.  Losing love, companionship, and protection under these circumstances can be catastrophic.  A vulnerable person may not fully understand what has happened after a parent has died; they may not be able to express their feelings, or even have someone to talk to; they may have little, if anything, to fill the space left by the deceased parent.  (This is also true if the parent needs to leave home for care as well, i.e.: hospital admission or nursing home, etc.)

It has been reported that families who kept their sons and daughters at home and did not place them in an institution are now finding it difficult to gain funding and support for community services.  It is critical, as institutions close, beds in group homes and residential programs grow scarce, and the choice between caring for their offspring inside or outside the home disappears, that resources are made available, in equal manner, to all those who require them.

### 6.3.3   Abuse

Persons with disabilities, including the dually diagnosed, may be at an increased risk for abuse[***] for a number of reasons.  They may have a limited ability to fend off or escape assault; they may have a communication or cognitive impairment that makes it difficult to inform others about abuse; and they may be subject to discriminatory attitudes which lead perpetrators of abuse to believe they are less worthy or deserving of respect[49].  These conditions may also lead to a lack of credibility in relation to the accuser in the courts if an abuse charge is laid.

## 7.0   CONCLUSION

The service delivery system has had limited success in meeting the needs of persons with mental illness and developmental disabilities.  Service for these individuals is complicated by the fact that in Ontario developmental disabilities and mental illness are the responsibility of two distinct systems of care.  It is not unusual to find, for the most part, that consumer/survivors are treated

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[***] Abuse here includes physical, sexual, emotional and financial abuse.

by two dichotomous systems, each setting having its own treatment modality and criteria for admission. Persons with both a developmental disability and a mental illness continue to find themselves being shuttled between two separate and distinct service systems and often "fall through the cracks". Ideally, an integrated system would include the diagnostic, treatment and support needs for both disorders simultaneously.

## 8.0    RECOMMENDATIONS

The Dual Diagnosis Task Force of the CMHA, Ontario Division, Public Policy Committee has developed a list of recommendations intended to address specific issues surrounding dual diagnosis and to provide direction for the CMHA, Ontario Division, to consider the resources and services required to meet the needs of persons with a dual diagnosis in Ontario. As previously mentioned, it is not our intention to disaffirm existing structures and methods of service delivery, rather, we hope that these recommendations will enable those involved to examine the issues and provide a vehicle through which public discussion and policy can continue.

1. *The CMHA, Ontario Division, should advocate to the Ministry of Community and Social Services and the Ministry of Health that services for persons with a dual diagnosis continue to be given a high priority within and between the mental health and developmental services sectors, including current interministerial initiatives which ensure equity of access to services and programs.*

   Persons with dual diagnosis have traditionally been underserved or inadequately served. It is imperative that the current interministerial initiatives concerning dual diagnosis not lose momentum and that we continue to recognize and respond to the unique needs of this population. Equally important is that both ministries ensure equity of access, particularly for families who have kept their sons and daughters at home and are now finding it difficult to gain funding and support for required community services.

2. *The CMHA, Ontario Division, should advocate for the development of a co-ordinated and collaborative service system within and between the mental health and developmental services sectors for individuals with a dual diagnosis.*

   Efforts at co-ordination and collaboration must occur *within* and *between* the mental health and developmental services sectors, not only to increase capacity at all levels, but also to provide appropriate and responsive service delivery and a continuum of care. Services and programs must be available that would concomitantly and collaboratively assist the person with both a mental illness and developmental disability. Attention should be given to strategies that incorporate protocols that integrate treatment and community support, staff

cross-appointments, co-ordination of education, research and training opportunities and information sharing, including information on current programs.

3. *The CMHA, Ontario Division, should advocate for the removal of barriers that decrease equitable access to services through the development of co-ordinated and collaborative working relationships between the mental health and developmental services sectors.*

Collaborative agreements are needed across each region to remove any barriers to equitable access to services (including treatment), such as exclusionary criteria which may prevent people with a dual diagnosis from accessing any of the four key services and supports under Mental Health Reform (crisis intervention, case management, housing supports and consumer/survivor and family initiatives).

4. *The CMHA, Ontario Division, should advocate that a continuum of supports, including social supports, and services for the dually diagnosed be established based on the work developed in the field to date that demonstrates efficient and effective use of resources, and intersector collaboration.*

The MATCH project identified three essential components of a continuum of supports and services. These three components do not stand alone, but overlap and link together: promoting well-being and preventing mental health problems; intervention and treatment; and long-term care and support[50]. Each of these three components must be available in order to provide effective and appropriate services to the dually diagnosed and their families[51].

As noted earlier, the availability or unavailability of social supports can have a profound impact on the occurrence and severity of emotional and cognitive problems a developmentally handicapped child will develop as they age. Children's behavioural problems increase, particularly in the case of children living with parents who had a low level of social support, or have parents who are socially isolated, or parents who were not very satisfied with the support they were receiving. The social supports available to the parents of a child with significant developmental delays have an impact on the child's adjustment. It is essential that the supports required for these children and their families are accessible, appropriate, and co-ordinated in order to ameliorate potential emotional and cognitive problems as the children grow older.

5. *The CMHA, Ontario Division, should advocate to the Ministry of Health and the Ministry of Community and Social Services that as restructuring in their respective ministries continues, it not be done in isolation of one another and that restructuring include the promotion of interministerial initiatives focussing on the dually diagnosed, clearly define each ministry's role in relation to the service system and provide support to local service providers.*

The MoH and MCSS should continue to establish clear roles in terms of the service system for those with dual diagnosis and their families, as well as providing support to local service providers. The need for collaboration at the policy level has become particularly significant within the context of continued deinstitutionalization and devolution of services to the local level. Public expectations about the use of institutionalization must also be addressed in the reform process to facilitate support and understanding in the shift from institution to community. Additionally, it is necessary for the reform process to recognize that there will always be a need for institution-like or protective settings and that some individuals will continue to require this high level of support.

6. *The CMHA, Ontario Division, should advocate to the Ministry of Health and the Ministry of Community and Social Services that funding be allocated to encourage collaboration between and within the mental health and developmental sectors.*

It is imperative that funding for service and training strategies be available to establish integrated networks of mental health and developmental services. Joint ministerial funding must be made available for services for the dually diagnosed and for inclusion in program budgets to purchase flexible supports from other sectors as needed.

7. *The CMHA, Ontario Division, should advocate for increased partnerships between dually diagnosed individuals and their families in the policy, planning and implementation of services and programs for the dually diagnosed.*

It is extremely important for policy makers, planners and service providers to realize that any gains made by a person with a dual diagnosis will not be maintained if the family (where it exists and is believed to be a positive resource) is not involved in the planning and implementation process and is not provided with the supports they need.

8.  *The CMHA, Ontario Division, should advocate to the Ministry of Community and Social Services and the Ministry of Health that a province-wide public education program focusing on dual diagnosis be developed and implemented.*

Public education about mental illness, developmental disabilities and dual diagnosis in particular promotes understanding and addresses the stigma and fear surrounding dual diagnosis.

9.  *The CMHA, Ontario Division, should advocate for the protection of funding for programs presently based in Provincial Psychiatric Hospitals, the identification, development and implementation of specialized treatment services in the community based on "best practice models" and subjected to rigorous evaluation, and the identification of existing specialized services as resources for other agencies.*

Identifying specialized services or the creation of multidisciplinary teams drawing resources from both the mental health and developmental sectors would enable the system to effectively use the resources currently available, enhance program outcomes, and provide staff training and consultation that are geared specifically towards persons with a dual diagnosis.  It must be noted however, that there is a general sense of concern that specialized services for the dually diagnosed, particularly those now housed in Provincial Psychiatric Hospitals slated for closure, will not be transferred, or financially supported in another facility.  As institutions housing these programs close, service gaps will occur and it will take time to develop new community-based programs to support the dually diagnosed.  It is critical that funding for new, community-based programs be available.

Research should not be limited to an evaluation of programs and/or treatments; it should be expanded to include an evaluation at the ministerial level to determine the impact of restructuring and deinstitutionalization.

In order for a truly integrated and comprehensive system to be in place for those working with the dually diagnosed it is also imperative that there be:

- Dissemination and use of best practices;

- Central access to materials, resources, information sharing and expertise;

- Clear linkages to training/education (school and field) at undergraduate and post-graduate levels;

- Continuing education of professionals;

- Staff training within and between community mental health and developmental services sectors; and

- Effective and appropriate identification and assessment tools that will help minimize the possibility of misdiagnosis and that create more suitable plans for treatment, support, and services.

**10. *The CMHA, Ontario Division, should advocate for the creation of programs by universities and community colleges, working in partnership with the mental health and developmental sectors to prepare people at all levels with the competencies and skills needed to collaborate, work within and bring the two systems together. This should include specialized programs that educate and train service providers to understand the unique needs of, and to work directly with the dually diagnosed and their families.***

Training should include, but not be limited to, the recognition and identification of persons with a dual diagnosis, knowledge and understanding of the nature of dual diagnosis and the stigma and fear attached to it, knowledge of mental health and developmental issues, assessment, options for treatment, head injury, ageing and chronic debilitating conditions, existing services and service sectors, and collaborative approaches.

**11. *The CMHA, Ontario Division, should advocate that exclusionary criteria, including program policies that prevent individuals with a dual diagnosis from accessing existing services be addressed by the mental health and developmental services sectors.***

Exclusionary criteria are detrimental and often perceived as punitive. Program policies must be more flexible to accommodate the needs of individuals with a dual diagnosis. Program admission criteria create unfair and unnecessary disadvantages, not only for the consumer/survivor, but also for other service providers trying to find appropriate and timely services for the person with a dual diagnosis.

12. ***The CMHA, Ontario Division, should advocate to the Ministry of Community and Social Services and the Ministry of Health that more specialized resources, particularly in terms of staffing, be provided in order to identify and prevent the abuse of dually diagnosed persons in both the institutional and community sectors. This also includes advocating for resources to serve not only the dually diagnosed who have been abused, but also caregivers and service providers that have abused a dually diagnosed person or have been abused themselves by a dually diagnosed individual.***

It has been estimated that people with disabilities are four to ten times more likely to experience abuse, neglect, or exploitation than other adults[52]. Specific studies have reported high levels of sexual abuse[53], physical assault,[54] and psychological abuse among the disabled. It has also been estimated that 75% of persons who experience abuse have at least one major mental or physical impairment[55].

Sexuality and sexual abuse is an area where persons with a dual diagnosis are particularly at risk – they are estimated to be four times more likely to be sexually abused than non-disabled victims[56]. They often lack an adequate understanding of sexual relationships, including their own sexuality and are less able to discriminate between safe situations and potentially abusive situations. Their prolonged dependency and compliance on families and caretakers is also seen to create a particular vulnerability because this may cause them to unquestionably follow the direction of adults[57].

It is imperative that the issue of abuse be addressed, and that the resources needed to do so are made available.

**APPENDIX A**

# CLARIFICATION OF SELECTED ISSUES

## SYSTEM LEVEL ISSUES

**STIGMA:**

The CMHA, Ontario Division, believes that public education and awareness is a critical element in shifting the beliefs of people and in creating a more accepting community atmosphere.  In general, society devalues persons with disabilities.  Persons with developmental disabilities tend to have a low status in our society because they do not achieve in the areas which are the most highly valued by our society - academics, employment, physical accomplishments, and accumulation of wealth to name a few.

Negative attitudes towards people who experience mental illness or mental health problems are pervasive in our society.  Negative attitudes about mental illness and the individuals who experience it can maginalize and oppress people.  Many people have suggested that the stigma may be more difficult to live with than the mental illness.  Mental illness or mental health problems add significantly to the stigma and rejection those individuals with developmental disabilities may experience in everyday life.  This probably means even further discrimination in social acceptance and community integration.

**PREVENTION:**

Mental health promotion suffers the same stigma as mental illness prevention, with the emphasis on preventing mental disorders rather than on stressing mental and emotional health as a goal for everyone.  Work remains to be done to help the public and service providers to realize the importance of mental health in everyday life and to remove the stigma associated with developmental disabilities and mental illness.

**PHILOSOPHICAL DIFFERENCES:**

Barriers to effective service delivery can stem from philosophical differences between the mental health and social service systems.  Historically, there has been a lack of collaboration and partnerships between the mental health and developmental sectors in working with the dually diagnosed.  This lack of co-ordinated and comprehensive care has come about partly because the mental health and social services systems have differing philosophies, infrastructures, staff training emphases, policies, procedures and funding formulas.

By the 1960's, it was broadly accepted that a developmental disability was a genetically determined condition for which the medical model had little relevance. By contrast, most psychiatrists argue that whatever the genetic component of mental illness, their unique training is vital for alleviating the pain and problems of mental illness. Consequently, conflicts may arise about the responsibility for, and direction of treatment and/or supports, leaving the consumer/survivor and service provider confused or having to choose one over the other.

Two entirely separate service systems, one for persons with developmental disabilities and one for persons with a mental illness, currently exist and provide services for the dually diagnosed. This separation makes it very difficult to access co-ordinated services for the person with a dual diagnosis.

## LACK OF AN INTEGRATED AND CO-ORDINATED SERVICE DELIVERY SYSTEM:

We know that service delivery systems for the dually diagnosed have had limited success in meeting the needs of this unique population. Practitioners within the mental health and developmental sectors have tended to work independently of one another. Each system has its own system of care, or infrastructure, yet they should be highly interrelated.

An approach that concomitantly recognizes and treats dually diagnosed individuals would involve both the developmental and mental health networks via an integrated team, case manager, or other service provider, with each network co-ordinating their approaches at regular intervals. Some aspects of this approach would not require any major alterations in the networks involved. Rather, both developmental staff and mental health staff could learn from each other's expertise and provide the opportunity to design a truly responsive and congruent milieu for treatment and support as required.

The CMHA, Ontario Division, has developed a framework for an accessible, continuous, comprehensive, effective and seamless community mental health system (ACCESS) which will result in better services for persons with mental health problems (See Appendix B). Our organization hopes that ACCESS will be viewed as a resource or tool that can be used by everyone working to support consumer/survivors and their families to further shape, complement or enhance the existing mental health system. It is also hoped that this model of service delivery could be used to provide a framework under which the developmental and mental health sectors can work together to provide effective community mental health services for the dually diagnosed.

## MINISTRY RESTRUCTURING AND ITS IMPACT ON PERSONS WITH A DUAL DIAGNOSIS:

The mental health system in Ontario is undergoing a major reform. The result of this restructuring is meant to shift the system's reliance on institutions to an emphasis on community services and supports. The goal of the current reform is to shift government expenditures from 79% institutional and 21% community services (1993) to 40% institutional and 60% community services by 2003. However, in late January 1998, the Minister of Health announced a five-week review of the Mental Health Reform process in Ontario. The results of this review will be available shortly. Whatever the outcome of the

review, the current and past trend towards deinstitutionalization has left a profound impact on both the mental health and developmental services sectors.

## COMMUNITY INTEGRATION/DEINSTITUTIONALIZATION:

One challenge of deinstitutionalization is that individuals with dual diagnosis can be suddenly exposed both to the stresses of modern life and the expectations of socially acceptable behaviour when moved into the community. Compounding this is that the necessary support system for the dually diagnosed has not yet been fully developed to deal with their unique and specific mental health concerns, and long waiting lists for resources have limited the availability of a whole range of necessary services[58]. MARC (1995), in their Data Collection Report, determined that 2,610 individuals in Toronto were waiting for at least one service as of September 30th, 1994, in the residential, day program or support areas[59]. Additionally choice of residence can be an issue - a person discharged from an institution may not be discharged to his/her home community. Rather, they may reside in the community close to the closed facility for a number of reasons ranging from loss of family members through death, distance and alienation, choice, familiarity with the area that they have resided in, or lack of services elsewhere.

Although progress has been made in the development of community living opportunities for people with developmental disabilities, persons with a dual diagnosis have not been as well served. While in facilities, these individuals were probably receiving the specialized mental health care they needed. However, upon discharge, it was expected that generic or existing services would pick up this responsibility without additional resources. Any new dollars generated from the closure of MCSS facilities were to be directed to community residential and developmentally disabled program care.

A survey concerning the community adjustment of developmentally disabled persons who had spent at least three years in an institution in south-eastern Ontario found the better adjusted consumer/survivors were employed, had a higher level of functioning and, prior to community placement, were rated as having high performance, a high Independent Functioning Index and required a low level of supervision. According to this study, a high proportion of people with a developmental disability who live in the community after having lived in an institution were also found to have significant behavioural/psychiatric problems (about one-third) and health problems (over two-thirds)[60]. Although many of the consumer/survivors in the study had lived for many years in an institution and were, on average, middle-aged with moderate to profound mental retardation, the implications of their difficulty in community integration is alarming, particularly in light of current and future plans for deinstitutionalization and closure of facilities formerly housing these individuals.

Of particular importance is that a range of supportive and specialized services for this population are needed, and will continue to be needed for people in the community who are dually diagnosed. These supports range from high (i.e.: residing in PPHs or residential facilities) to low (i.e.: independent living with case management services). Co-ordinated living and support service arrangements are critical as we continue our advance with the deinstitutionalization process. For those individuals remaining in institutions, this also holds true - they must be able to access appropriate services from both the mental health and developmental services sectors regardless of where they reside.

When individuals with developmental disabilities experience a behavioural or psychiatric crisis, their community placement may become threatened. Some behavioural or psychiatric problems that could be absorbed in institutional settings are often unacceptable and more difficult to treat in community settings. A number of community settings are not currently designed to absorb the level of unsafe behaviour that is demonstrated at times by persons with a dual diagnosis. Consequently, the presence of a dual diagnosis may become a threat to gaining and maintaining community living arrangements, particularly in terms of the least restrictive environment.

Persons who continue to live in institutional settings are also more likely to have a dual diagnosis. A study in progress at Rideau Regional Centre found a prevalence rate of 60%[61]. If this is the case, the need for specialized, improved and co-ordinated community services will be even more acute if the focus on moving those now residing in institutions into the community continues. Additionally, if generic mental health care and other services, such as the services available in the psychiatric wards of general and psychiatric hospitals, are to be used as support services for persons with dual diagnosis in the community, these services will need to devote special support service staff to these individuals. Staff will also require relevant information and training to deal with individuals who have a dual diagnosis, particularly those individuals with lesser developmental abilities.

## PROGRAM/SERVICE LEVEL ISSUES

### EXCLUSIONARY CRITERIA IN SERVICE DELIVERY:

Providers of mental health services need to revisit their eligibility criteria to ensure that there is equitable access for this population. Accessibility is further compromised by service gaps and the complexity of the system itself. The split between the MoH and MCSS has meant that individuals with dual diagnosis can, and often do 'fall through the cracks' between two overburdened systems, neither of which can meet the needs of this population on their own. The current interministerial guidelines may increase accessibility, but, as in the Mental Health Reform process, it may take many years to establish this outcome because of broad-based system complexity and restructuring. It must also be noted that the focus on individualized planning, although optimal, may be prohibitive in some cases.

The prospect of spending valuable time on a consumer/survivor, whose needs are not easily understood, especially when services are subject to fiscal constraints, is not appealing for most service providers; thus, dual diagnosis is often specifically excluded.

**MISDIAGNOSIS:**

As indicated above, there is a continuing misconception in society that certain behaviours demonstrated by a person with a developmental disability are the result of mental retardation, and not the result of a mental health problem.  On the other hand, there are some behaviours that should not be viewed first as resulting from a mental illness, but rather as a symptom of developmental disability.  Because the mental health community tends to see the disability first, mental illness may go undiagnosed; and the person, who in fact is suffering from dual diagnosis, is not given the appropriate and timely interventions required.

A definitive diagnosis may be difficult to attain due to the communicative and cognitive impairments of persons with dual diagnosis.  As reported, these individuals have problems in communication, particularly in relation to speech, hearing, vision, literacy, motor ability, and auditory comprehension. Expression of distress, feelings, and preference is compromised. These difficulties often have a direct impact on the process and outcome of diagnosis and assessments - which in turn effect eligibility for treatment and vocational opportunities.

Lack of treatment, or more frequently under-treatment because of misdiagnosis is a reality for persons with a dual diagnosis.  Important symptoms are often misinterpreted, or unnoticed, or even under-estimated. Under these circumstances, misdiagnosis is a critical issue - resulting in often inappropriate treatment or no treatment at all.  Another factor at play here is that persons with a dual diagnosis may receive treatment for only one disorder depending on which disorder is considered primary or secondary.  If the developmental disability is the primary diagnosis, the person may not receive assistance for their mental illness.  The reverse is also true.

**LACK OF SPECIALIZED TRAINING:**

MARC (1995) highlighted this inadequacy in its review of specialized psychiatric services that are available to address the issue of dual diagnosis.  Compared to programs in the United States and Great Britain it was found that Ontario is significantly lacking in psychiatrists with interest and specialized expertise in dual diagnosis who could give support to the general psychiatrist or family doctor. Additionally, Ontario lacks training programs for social workers, nursing, occupational therapists, psychologists (who may have a legally assigned role in diagnosis) and medical students, both in general medicine and psychiatric curricula that would acquaint them with the complex issues surrounding and needs of a person with a developmental disability and mental health problem[62].

# INDIVIDUAL AND FAMILY LEVEL ISSUES

## QUALITY OF LIFE:

There are many factors that militate against society's ability to work collaboratively with consumer/survivors and family members to assist with achievement of improved quality of life. In the CMHA, Ontario Division's framework document entitled ACCESS: A Framework for a Community Based Mental Health Service System (1998), seven mitigating factors were identified:

➤ the tendency of society and its systems to classify all people who experience significant mental health problems into one homogeneous group with the concurrent assumption that one service delivery approach will suffice for all;

➤ ongoing stigma and fear associated with people with mental health problems which leads to the tendency to create policy and service approaches that seek to control people rather than serve and support them within an atmosphere of respect, dignity and empowerment;

➤ an imprecise awareness of and appreciation for the cyclical nature of mental health problems and the manner in which social and interpersonal factors impact on mental health;

➤ a tendency to ignore the role of social supports, peer supports, and other determinants of health such as decent and affordable housing, employment, adequate income, etc., in the promotion of mental wellness especially among those who are most severely disabled by the mental health problems they experience;

➤ the inability of services, in and of themselves, to deliver the right service/support, at the adequate level, at the right time, in order to adequately respond to changing and complex needs of people with mental health problems;

➤ a lack of integration within the mental health system that would allow for a multidisciplinary or interdisciplinary approach to occur in a planned, integrated and accountable manner; and,

➤ a lack of integration between the mental health system and other health and social systems in order that the overall needs of a person can be addressed in a planned, integrated and accountable fashion[63].

## LIVING WITH AGEING PARENTS:

Many people with dual diagnosis would be completely vulnerable without the support and advocacy of their family and friends. We need to think carefully and face some hard facts about family life and committed relationships when making decisions about, and working with the dually diagnosed and their families including:

➤ Many families and friends are numbed because even the services that are supposed to help are confusing and very hard to get. Information is hard to find.

➤ Families and friends can be neglectful and abusive, particularly when they lack needed support. Families need to learn how to cope.

➤ Many families need the opportunity to plan for the future: "What happens when we no longer can provide for our son or daughter?". A range of appropriate options is required.

➤ Some families are still unknown to the system, are reluctant to become part of the system and only access services in times of crisis.

➤ We need to develop better ways to get information to families in ways that make sense to them.

Families of the dually diagnosed require a comprehensive, timely and co-ordinated support system for themselves as well. Repeated crises and the lack of appropriate, supportive services increase stress, fatigue, and burnout. It is not unusual for families to feel they are 'blamed' for their offspring with a dual diagnosis. They may feel guilty when asking for assistance; feel confused about what, if any, services are available to assist them and their son or daughter; feel anger and disillusionment when assistance is needed but not forthcoming; and feel that they are not 'doing enough' or 'doing it wrong' if their offspring has difficulty becoming normalized or reaching developmental goals that may be impossible.

## ABUSE:

The CMHA, Ontario Division, acknowledges that the abuse of older caregivers and/or parents also occurs by individuals with mental health problems. To this end, a Task Force on Elder Abuse was struck by the CMHA, Ontario Division, Public Policy Committee to examine the issues surrounding the abuse of older adults. The Task Force has found that "with the advent of deinstitutionalization, increasing numbers of consumer/survivors were able to return home after episodes of illness. Further downsizing of hospitals over the years has resulted in more actively ill and/or distressed individuals being cared for at home by family members, usually parents"[64] (taking this a step further, it can be said that the above is also true for the dually diagnosed). The Elder Abuse Task Force also noted that "the mental health system does not recognize the potential for abuse in these situations (caregiver abuse, either to the person with a dual diagnosis or by the dually diagnosed person to the caregiver), perhaps because of the perceived need to promote and implement community-based care and encourage support by well family members". Both family members and others in the community may be vulnerable to abuse by persons with a dual diagnosis, and there is a need for specialized assistance for both clients and families in the community.

**APPENDIX B**

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# APPENDIX C

# GLOSSARY OF TERMS

**ABUSE (Physical, Psychological, Sexual, and Financial)**
Intent of one individual to inappropriately control the behaviour of another through: actual or threatened physical violence (physical abuse); psychological threats, including verbal threats and forced social isolation (psychological abuse); unwanted sexual activity (sexual harassment and/or abuse); improper use or treatment of financial assets, such as fraud, forgery, wrongful use of Power of Attorney, stealing pension cheques (financial abuse).

**ACCESS**
The Ministry of Community and Social Services has defined access as occurring when services are *available* to each community, not that the services are *present* in each community – especially where services are highly specialized or the local population is dispersed.

**ACCESSIBILITY**
Ability of a consumer/survivor to obtain service at the right place and at the right time based on their respective needs. Aspects that should be considered include convenience, providing mobile services, transportation, parking, languages spoken, child minding, etc.

**ADVOCACY**
Representation of individuals who cannot act on their own behalf and/or to help individuals to advocate on their own behalf. This ensures the preservation of the individual's rights and access to the resources that will allow individuals to fulfil their responsibilities and procure services to meet their needs.

**APPROPRIATENESS**
Extent to which a particular procedure, treatment, test or service is effective, clearly indicated, not excessive, adequate in quantity, and provided in the setting best suited to the individual's needs.

**ASSESSMENT**
Process by which strengths, weaknesses, problems, and needs are determined or addressed.

**CAREGIVER**
Family member, client and/or volunteer, or service provider employed by an oganization that provides a service.

**CLIENT**
Any individual, family, group and/or community being served by an organization.

**COLLABORATION**
Work jointly with others; to co-operate with an agency with which one is not immediately connected.

**COMMUNITY-BASED SERVICES**
In the presence of an identified health, mental health or developmental problem, services are provided in the community by local community members (i.e.: peer/self-help), groups (i.e.: planning committees, etc.) or agencies (including hospitals) with a goal to providing services and support for the individual. Community-based services are not defined by 'who' provides the services, rather it is defined by 'where' the service is provided.

**CONSULTATION**
Provision of professional advice on request.


**DEVELOPMENTAL HANDICAP**
A developmental handicap results from a "mental impairment that is present or occurring during a person's formative years that is associated with limitations in adaptive behaviour"[64].

**DUAL DIAGNOSIS**
Individuals with a developmental handicap and mental health needs.

**EMOTIONAL DISTURBANCE**
An emotional disturbance could be characterized by inappropriate responses to the pressures of everyday life, due to inner turmoil and distress[64].

**EFFECTIVENESS**
Successfully achieving or attaining results (outcomes), goals or objectives. It means working on the right things.

**EFFICIENCY**
Refers to how well resources (inputs) are brought together to achieve results (outcomes) with minimal expenditure.

**ESSENTIAL SUPPORTS**
The Ministry of Community and Social Services defines essential supports as including mandatory services (required by legislation: i.e.: child protection and young offenders) and other supports that provide safety and security.

**FAMILY**
Persons with a close relationship to the consumer/survivor, usually, but not always familial. These persons may assume an advocacy role for the client when necessary.

**FAMILY RELIEF/RESPITE**
The Ministry of Community and Social Services defines family relief/respite as referring to alternative care for adults with developmental disabilities which provides family members with short periods without the responsibility of caring for their adult son or daughter.

**HEALTH**
Extent to which an individual or group is able, on the one hand to develop aspirations and satisfy needs and on the other hand, to change or cope with the environment. Health is therefore seen as a resource for everyday life, not the objective of living; it is seen as a positive concept emphasizing social and personal resources, as well as physical capacities.

**HEALTH PROMOTION**
Process that enables people to increase control over, and to improve their health (World Health Organization, 1986). The fundamental conditions and resources for health are peace, shelter, education, food, income, a stable eco-system, sustainable resources, social justice, and equity. Improvement in health requires a secure foundation in these conditions.


**INTEGRATION**

Refers to making 'whole' or complete by adding or bringing together parts.

**INVESTMENT SUPPORTS**
The Ministry of Community and Social Services defines investment supports as those supports that reduce or eliminate the need for essential supports in the future (i.e.: prevention and/or early intervention programs).

**LOCAL SYSTEM OF SERVICES**
The Ministry of Community and Social Services defined a local system of services as the whole of all the services funded by the ministry within a local area. Local processes will have boundaries or catchment areas determined by the ministry's area office. Usually these are a county, regional municipality or northern district. In order for a catchment area to be considered a local system, it must have a sufficient range of services and a sufficient resource base to allow a planning system.

**MENTAL HEALTH**
"The capacity of the individual, the group and the environment to interact with one another in ways that promote subjective well-being, the optimal development and use of mental abilities (cognitive, affective and rational), the achievement of individual and collective goals consistent with justice and the attainment and preservation of conditions of fundamental equality"[64].

**MENTAL HEALTH PROBLEMS**
Mental heath problems exist when there is conflict in the interaction between the individual, the group, and/or the environment. The cause of the conflict may be within the individual (such as mental or physical illness or ineffective coping abilities) or could result from external issues (e.g. societal pressures, oppression, poverty, and family dysfunction)[64].

**MENTAL RETARDATION**
A DSM-IV (Diagnostic and Statistical Manual of Mental Disorders) category defined by three essential criteria:
➤       Significantly subaverage intellectual functioning
➤       Significant limitations in adaptive functioning - at least 2 of the following - communication, self care, home living, social/interpersonal skills, use of community resources, self direction, functional academic skills, work, leisure, health, safety.
➤       Onset before 18 years of age.
Mental retardation is also described based on sub-categories: based on severity of intellectual impairment (mild, moderate, severe, profound).
The term 'mental retardation' is still used for international purposes although rarely used in Ontario where developmental disability is the term normally used.

**NEED**
Physiological, psychological or social requirement of well being. Needs may or may not be perceived or expressed by the person in need.

**NORMALIZATION**
The term refers to providing developmentally handicapped people with an environment that is as close to normal as possible.

**QUALITY OF LIFE**
The Ministry of Community and Social Services defines quality of life as looking at the whole of a person's life, and assumes that the same factors are important, whether or not a person has a disability.

**REHABILITATION**

Dynamic process that allows disabled people to function in their environment at an optimal level. This requires comprehensively planned care and service for the total person.

**SUBSTITUTE CONSENT**
Can otherwise be referred to as "proxy" or "surrogate" consent. Refers to a situation where the individual is mentally incapable of understanding the information needed to make an informed decision regarding service. Consequently, an individual who is authorized under the rules and regulations of provincial/territorial legislation would make service decisions on behalf of the incapable person.

**TEAM**
Small number of people with complementary skills whose functions are interdependent. They work together for a common purpose or result on a short-term or permanent basis.

# APPENDIX D

# ACCESS:  A Framework For A Community Based Mental Health Service System

ACCESS:  A Framework for a Community Based Mental Health Service System (1998) provides a systematic perspective for the development and delivery of mental health care in communities across Ontario.  The operational framework was developed by the CMHA, Provincial Office and its 35 Branches, and we believe that it will be an important resource for everyone working to support consumer/survivors and their families to further shape, complement or enhance existing mental health services and programs.  ACCESS is an acronym for the CMHA's description of an improved mental health system; a system which we believe must be Accessible, Continuous, Comprehensive, Effective and Seamless.  The goal of the ACCESS framework is to ensure that the right service is available to clients at the right time, with the right intensity, in the right place and at the right price.

ACCESS was developed primarily because of the CMHA's concern about the continuing polarization of groups within the mental health field around specific program models.  It is our strongly held view that we need a system-wide operational framework which embraces the full spectrum of services and supports required by consumer/survivors and which facilitates service integration.

ACCESS:  A Framework for a Community Based Mental Health Service System is a theoretical construct for operationalizing a vision of the community mental health system based on CMHA values and principles.  It provides a vision for doing mental health work in the community, which is congruent with existing CMHA policies.  The CMHA, Ontario Division Board holds the copyright for the document.  With the CMHA, Ontario Division's permission, the document may be duplicated for discussion   and implementation by all stakeholders in the mental health system.

The Framework for Support developed by the CMHA, National Office uses the "Community Resource Base" paradigm to describe all of the components important to supporting persons with mental health problems in the community, i.e., consumer/survivor groups; family and friends; mental health services and generic community services.  It also recognizes the importance of fundamental entitlements such as housing, work, education and income. ACCESS:  A Framework for a Community Based Mental Health Service System is intended as an operational framework which is consistent with both the National vision and the Ontario Division vision, principles and policies.

It is believed that ACCESS provides a consistent way of organizing and moving community mental health services forward that will ultimately benefit the consumer/survivors and families who utilize them.

It is expected that ACCESS will provide a framework for the development of an accessible, continuous, comprehensive, effective and seamless community mental health system, which will result in better service for persons with mental health problems.   It is believed that such improvements will be realized by providing the right service at the right time at the right intensity in the right place and at the right price.  ACCESS should be viewed as a resource or tool that can be used by everyone working to support consumer/survivors and their families to further shape, complement or enhance the existing mental health system.

**APPENDIX E**

# OUTCOME STATEMENTS

The outcome statements below are based on CMHA, Ontario Division, Principles concerning Dual Diagnosis as outlined in the Position Paper. These outcome statements have been developed to provide the guidelines for developing, maintaining and implementing a comprehensive system of supports and services for persons with a dual diagnosis. The outcome statements are not mutually exclusive, nor exhaustive in content; rather they are a basis under which future work can be accomplished.

| PRINCIPLE | SYSTEM LEVEL | PROGRAM/SERVICE LEVEL | INDIVIDUAL/FAMILY LEVEL |
|---|---|---|---|
| 1. EQUITY OF ACCESS | Persons with a Dual Diagnosis must have equal access to local broad-based services (basic/generic services) in the health/mental health and developmental sectors. | Service providers are informed and able to access any additional information and any assistance they may need to make appropriate decisions and referrals to provide services within and between the mental health and developmental sectors. | Individuals with a dual diagnosis are provided with services and supports that addresses their unique and complex needs.<br><br>Supports and services are available in a timely and seamless manner and are reflective of the changing needs of the individual requiring the service.<br><br>Procedures for appeal are in place and well articulated. |

| 2. SPECIALIZED DUAL DIAGNOSIS SERVICES | The health, mental health, and developmental needs of the individual are met through integrated approaches across sectors (i.e.: MCSS/HSJCP/MoH) and through specialized services when required. | Case management and consultation services are available within and between the two service sectors through multidisciplinary teams. | Individuals are provided with services designed to meet their needs through multidisciplinary approaches and/or specialized services. |
|---|---|---|---|
| | | Assistance from specialized services is available to provide back up to the generic system, particularly for complex situations. | |
| | | Specialized services are offered at the local or district level depending on community capacity and need. | |
| | A team approach is used in the assessment, planning, and delivery of services where appropriate. | Mechanisms are in place that promote the team approach which promotes consensus, efficient use of resources and provides a process within which stakeholders can reach a common understanding and realistic expectations and goals. | Team approaches are used that include consumer/survivors, families and significant others in the decision-making and individual/group planning process. |

| 3. CO-ORDINATION, INTEGRATION AND CONTINUITY WITHIN AND ACROSS MENTAL HEALTH AND DEVELOPMENTAL SERVICE SECTORS | Decisions regarding local services and supports are maintained or developed based on the size of the community, the catchment area and local capacity to respond to the needs of the dually diagnosed. | Continuum of services and supports are developed at local and district levels through the implementation of daily relationships and clarifying and addressing local specific concerns and needs through the creation of multidisciplinary teams and inter-sector committees. | Supports and services are available for consumer/survivors and their families that are reflective of their needs at the time, including specialized services and/or services from both sectors as required. |
|---|---|---|---|
| | Joint sector planning is critical to ensure effective planning, consensus building, and the identification of gaps. | Community capacity that addresses the needs of persons with dual diagnosis and their families are enhanced through the provision of co-ordinated, integrated and flexible services and supports across the health/mental health and developmental sectors. | Each person will receive personal planning and support that increases independence and is reflective of individual needs. |
| | Co-ordination, integration, and continuity are given a high priority within and across the mental health, justice, and developmental sectors. | | |
| 4. PARTNERSHIP | Consumer/survivors, families, natural supports, and service providers will participate as partners in the planning and delivery of services. | Consumer/survivors, families, natural supports, and service providers will participate as partners in the planning and delivery of services. | Consumer/survivors, families, natural supports, and service providers will participate as partners in the planning and delivery of services. |
| | Planning occurs at all levels including the individual, program, and system levels. | Persons with dual diagnosis and their families must be informed and fully supported in a range of effective and appropriate options within the mental health and developmental services sectors. | |
| | Mechanisms must be in place for ongoing dialogue and feedback at all levels and between all stakeholders. | | |

| | | | |
|---|---|---|---|
| **5. LEAST INTRUSIVE SERVICES AND SUPPORTS** | Supports are tailored to individual needs and are developed to minimize change, which can be difficult for a person with a dual diagnosis.<br><br>Dually diagnosed individuals should be able to live independently as long as this is appropriate and through the use of least intrusive supports and programs. | Full range of residential and non-residential supports is available locally.<br><br>Community consultation is available to care providers, which builds on the consumer/survivor's strengths and skills in their own environment. Services are appropriate to age and handicap. | Recognition that dually diagnosed individuals, their families, and communities have inherent and evolving capacities and strengths, which enhance mental and emotional well being.<br><br>Strengths are recognized and used in the planning and delivery of services.<br><br>Individuals have access to advocates, guardians, and appeal processes to ensure that their concerns are voiced and considered. |
| **6. INTEGRATED EDUCATION TRAINING AND RESEARCH** | Research links to policy and accountability are established and integrated within all components, levels of the planning, and service delivery systems.<br><br>Colleges and Universities establish a research base and curriculum for dual diagnosis. Research into what works and is most cost effective is necessary to provide the foundation for rational, accountable planning and decision-making.<br><br>Public education that addresses stigma and attitudes about dual diagnosis is given a high priority and involves all stakeholders at the direct service, program, and system level. | Training and educational opportunities are available to professionals, paraprofessionals, and caregivers in order to confirm existing skills, develop new skills and knowledge and to increase their education across sectors and the services available for the dually diagnosed.<br><br>Joint cross sector education and training is available.<br><br>Collaborative opportunities are available within and between service sectors (i.e.: workshops, lectures, team meetings, etc.). | Dually diagnosed individuals, their families and significant others are included in giving and receiving training and evaluation of the services provided.<br><br>The results of evaluations by consumer/survivors and families are used in the planning of supports and services. |

| 7. CONSUMER/ SURVIVOR-CENTRED COMPREHENSIVE AND QUALITY SERVICES | Responsive services appropriate to individual, family and system needs are created and/or maintained that demonstrates accountability, quality, and comprehensiveness. | A wide range of residential, supportive living, employment, day program and support services are available to the dually diagnosed living in the community by both service sectors. | The individual can, based on individual capabilities and resources, make program choices. |
|---|---|---|---|
| | | An adequate level of flexible and portable programs and direct care. | Individual program plans are developed with the consumer/survivor and are reflective on each person's unique needs and circumstances. Individual programs must adhere to articulated standards of quality care. |
| | | Appropriate and accountable case management programs are established based on best practice and are effectively managed at the organizational level. | Complaints by consumer/survivors and families are not ignored and a clearly articulated and understood appeals process is in place. |
| | | | Internal accountability mechanisms are in place, which promote safety. |
| | | Outreach is integrated throughout the continuum of supports and services. | Outreach involves all stakeholders including consumer/survivors, families and significant others. |
| | | | Outreach activities are flexible, adaptable and begin with where the stakeholders "are at". |

# TERMS OF REFERENCE

**NAME:**                          **Dual Diagnosis Task Force.**

**AUTHORITY:**

Public Policy Committee of the Canadian Mental Health Association, Ontario Division, Board of Directors.

**PURPOSE:**

To develop a ***position paper*** on dual diagnosis to assist the CMHA, Ontario Division, to respond to issues related to the target population, which will include:

➢       A rationale for the position;

➢       A basis for replies to external requests for CMHA opinion on dual diagnosis;

➢       A foundation for advocacy strategy; and

➢       Recommendations for specific actions that establish policy conditions.

**COMPOSITION:**        See attached Membership List.

**TERM:**                       July 1997 - June 1998.

**CHAIR:**                     Janet Paddison, Member, Public Policy Committee.

**ADMINISTRATION:**  Staffing from Ontario Division (Helen Martin) will be available to:

- Arrange Task Force meeting(s) and/or teleconferences.
- Take and transcribe minutes of meetings and/or teleconferences.
- Distribute meeting packages.
- Develop and write:  a) draft background/issue paper
                      b) Draft position paper

## APPROVAL:

Public Policy Committee of the CMHA, Ontario Division, Board of Directors

## TERMS OF REFERENCE:

- To define and clarify the term dual diagnosis.
- To assess and examine the issues associated with dual diagnosis and the impacts they have on the target population.
- To make recommendations for how the mental health care system could better meet the needs of the target population at a provincial level.

# APPENDIX G

# MEMBERSHIP LIST – DUAL DIAGNOSIS TASK FORCE

**Janet Paddison  (Chair)**

**Public Policy Committee, CMHA, Ontario Division**

**Mark Graham**

**Executive Director, CMHA, Peterborough Branch**

**Don Lethbridge**

**Program Manager, CMHA, Peterborough Branch**

**Susan Morris**

**Ontario Chapter,   National Association of Dual Diagnosis**

**Marty Tannahill**

**Program Director,   Dual Diagnosis Unit, Penetang Mental Health Centre**

**Stephanie Zilinski**

**Policy Consultant,   Ministry of Health,  Mental Health Programs and Services**

**Sheila Munk**

**Policy Analyst,   Ministry of Community and Social Services,   Developmental Services Branch**

**Mark Grant**

**Adult Protective Services Association of Ontario**

**Nancy Stone**

**Past President, Ontario Association for Community Living**

**Dr. Glenna Lawson**

**Director of Adult Programs,  Surrey Place Centre**

**Colin Hamilton**

**Executive Director,  Surex Community Services**

**Cameron Crawford**

**Vice President,  Roeher Institute,  York University**

**Helen Martin, Staff Support**

**Community Mental Health Consultant, CMHA, Ontario Division**