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**A Qualitative Examination of Best Practices in the Provision of  
Specialized Mental Health Services to Individuals with a Dual-Diagnosis  
in London and Middlesex County**

**by**

**Tara-Ann C. Glasgow**

Bachelor of Social Work, University of Windsor, 1998

A Thesis  
Submitted to the Faculty of Graduate Studies  
through the School of Social Work  
in Partial Fulfillment of the Requirements for  
the Degree of Master of Social Work at the  
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## ABSTRACT

This study explores the perceptions of prevalence of dually-diagnosed individuals in London/Middlesex County, collaboration between service providers, gaps in service, and models of practice related to best practice literature. Results from a sample of 11 qualitative interviews suggests the following: an abundance of services in the region; limited capacity; lack of service coordination and formal centralized access mechanisms; need for front-line education and cross-training; issues between the Ministries and the LHIN; and unclear roles and expectations between community service providers and inpatient facilities. Key informant's reports of best practices include: person-centred strategies; specialized services; community-based teams of multi-disciplinary staff; flexible service structure; collaboration and coordination in service provision; and sharing of expertise. Implications for social work practice are discussed, as well as a proposed model of treatment and recommendations for future studies.

## DEDICATION

To my parents

Linda M. Swezey & the late John A. Swezey

and

My husband,

Benjamin J. Glasgow

## ACKNOWLEDGEMENTS

This has been a journey like no other. I have learned much from this experience and must acknowledge all my Thesis Advisors that have greatly influenced me during this process. Dr. Bruce Bidgood offered a unique perspective on conducting research and challenged me to find my voice. Dr. Michael J. Holosko inspired me with his zest for qualitative research and the analogies he often used to offer me support. (I am most definitely like a sailboat!) Without the dedication and support of my third Thesis Supervisor, Dr. Irene Carter, I know that the completion of this Master's Degree would not have been possible. (Thank you so much for all your help!) Dr. Carter's devotion and knowledge led to an intellectually challenging and successful academic endeavour.

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## CHAPTER 1: INTRODUCTION

Mental illness has historically been a stigmatizing condition for those afflicted (Cohen, 1989; Everett, Adams, Johnson, Kurzawa, Quigley, & Wright, 2003; Gordon, Tantillo, Feldman, & Perrone, 2004; Mullaly, 2002; Satorius, 2002). Many causes perpetuate stigma in this society. One major cause is the service provider's lack of ability to effectively diagnose, assess and treat individuals with mental illnesses (Simcoe York Dual Diagnosis Education Committee, 2004). The awareness of various new and complex mental health diagnoses compounds this, as many individuals present unique or integrated mental health problems, found in the *Diagnostic & Statistical Manual of Mental Disorders 4<sup>th</sup> Edition (DSM IV)*. Some of the contemporary diagnoses include: borderline personality disorders; dysthymia; concurrent disorders; as well as dual-diagnoses (American Psychiatric Association [APA], 1994).

In the arena of mental health service/care in Ontario, the term 'dual-diagnosis' refers to those who have a concurrent diagnosis of a mental illness and a developmental disability (Owen & MacFarland, 2002) [see Figure 1]. Individuals with multiple diagnoses are subject to even greater stigma as they have two disabilities (Canadian Mental Health Association [CMHA]—Ontario Division, 1998). Historically, during the 1800s, Ontario's public hospitals provided shelter and care for those with developmental and mental disabilities (Dart, Gapen, & Morris, 2002). A century later, treatment was offered by other organizations such as religious orders and other social agencies. These organizations were supported by well-meaning members of society, yet they were also institutionally based (Scheerenberger, 1987). Gradually, a transition to community-based care began in the 1950s. This is largely because psychotropic drugs were introduced and

fueled a movement of deinstitutionalization (Stebbins, 1988). In short, those receptive to drug therapy for controlling symptoms of their illness were able to move into the mainstream of society. Unfortunately, the movement to 'integrate' this population was not as successful as planned (Newman, 1998). Individuals challenged with community living due to a lack of skill or insufficient support services typically were readmitted to institutionalized care (Scheerenberger, 1987). Problems in living such as: deinstitutionalization; difficulty securing safe and suitable housing; poverty; and limited access to mental health services, have further oppressed this population. From a social justice perspective, unless stigma associated for those with a dual-diagnosis is eliminated, this population will continue to be one of the most vulnerable and marginalized groups in society (Johnstone, 2001).

There is a consensus in the literature in addressing the problem of securing safe and acceptable housing. One contributing factor is a growing shortage of affordable rental housing (Goering & Durbin, 1990). The other is an increasing number of individuals living in poverty (Baum & Burnes, 1993; CMHA—Ontario Division, 2008; CMHA—Ontario Division Dual Diagnosis Task Force of the Public Policy Committee, 1998; Surber, Dwyer, Ryan, Goldfinger, & Kelly, 1988). Throughout the literature, studies reference those with dual-diagnoses as suffering from low socioeconomic status, namely those who must rely on public systems for financial security (Ryan, 1993). Despite Canada's universal health care plan and social services system, individuals often do not receive the basic resources and services they need. This can result in a cycle of homelessness and surviving on the streets because of the lack of available funds (Surber et al., 1988). It is important that studies not only focus on the homeless but those at risk

of losing their homes and those in substandard housing (CMHA, 2004). Due to poverty, those discharged from hospital often secure substandard housing which leads to a worsening in their mental health, resulting in readmission to institutionalized care, thus, perpetuating the 'revolving door syndrome' (CMHA, 1998).

Besides issues of housing, the need to improve alternatives to imprisonment for mental health, behavioural and self-harming or other associated crises is paramount. The increasing numbers of those with a dual-diagnosis that are in the criminal justice system is documented. It has been recognized for centuries in the literature that the criminal justice system tends not to respond effectively to those with mental disorders (Heerema, 2005). A greater number of individuals being seen in the streets displaying bizarre or nuisance behaviours is a result of the closures of provincial psychiatric beds and a lack of investment in proper community supports (CMHA, 2007). In combination with society's stigma against those with disabilities and a misperception of violence, more pressure is being put on the justice system by local agencies, families and a variety of professionals. Those living with mental disorders are "more vulnerable to detection and arrest for nuisance offences (e.g., trespassing, disorderly conduct), are more likely to be remanded in custody for these minor offences and to spend disproportionately more time awaiting a sentencing disposition" (CMHA, 2007, p. 1). As part of a solution, the Ministry of Health and Long-Term Care (MOHLTC) has identified mental health diversion and court support programs as an important ingredient in their plan for mental health reform. Diversion provides choices other than imprisonment (i.e., access to community support services, treatment and probation) for minor offences (MOHLTC, 2006a). The premise of this diversion plan is that individuals who receive help for their illness will not become

repeat offenders. Creating mental health courts are also part of this diversion process, whereby dedicated judges, attorneys and court support workers oversee such matters. Cities across Ontario such as Ottawa, Toronto, and Kitchener have already implemented the use of mental health courts. As Heerema (2005) stated, it is impressive that merely a decade ago, none of these courts were reported to exist in North America. In spring 2007, the City of Windsor launched a local mental health court because of the success reported in other regions. With time, it is expected that more mental health courts will be created, thereby improving outcomes for those dually-diagnosed charged with minor offences.

One prevalent theme that occurs in much of the mental health literature relates to those with dual-diagnosis as a population that struggles to gain equal access to even basic services. As those with disabilities are entitled to human rights, denial of access to services for those who may not be a majority is inequitable. Viewing law enforcement services to be of help and support may still be beyond the expectation of many dealing with the daily challenge of dual-diagnosis. Inequality also creates a problem in resource allocation and distribution to target groups or difficult to serve populations as members or clients. Not enough income and denial of access to needed services perpetuates poverty and prevents those with dual-diagnoses from accessing a better quality of life (CMHA—Ontario Division, 1998). The issue of inequality and prejudicial attitudes has been evolving; however, not until the 1970s did researchers believe that it was possible for an individual with developmental disabilities to have a co-occurring mental illness (Bongiorno, 2001). Therefore, the concept of dual-diagnoses is a contemporary and changing area for treatment providers. In regard to mental health services, mental health organizations have tended to exclude those with dual-diagnoses under the assumption

that because of their typically major cognitive impairments, these individuals will not benefit from therapy (Torrey, 1993). In contrast, Woodward (1993) reports that it is well documented in the literature that those with a dual-diagnosis, regardless of the severity of their developmental delay, do benefit from mental health and developmental disability services offered on a concurrent basis. The controversy associated with the efficacy of treatment interventions comes about when new trends in service delivery are being planned but access is prescribed for a selected population, not usually for dual-diagnosis. This adds to the burden of inequality and denial of—or limitations in quality care for dual-diagnosis clients.

In Canada, service delivery for this specific dual-diagnosis population has been assigned to the provinces by the Federal Government. In turn, these provincial programs are often delivered with the absence of a national vision or treatment strategy. Until 1974, the Federal Government assigned developmental disability services and mental health services to the Ministry of Health and Long-Term Care (MOHLTC). The *Developmental Services Act* (1990) created a separation when it came into effect. The Ministry of Community and Social Services (MCSS) was assigned management of developmental disability programs (specifically residential and vocational services) and the Ministry of Health and Long-Term Care (MOHLTC) kept responsibility for mental health services [see Figure 2]. With this fragmented service delivery model which has typically led to inadequate services and a poor quality of life, those with dual-diagnoses have become a vulnerable population as they have tended to fall between the cracks of both systems (VanderSchie-Bezyak, 2003).

Since 1988, the MOHLTC began to view this specific population as a priority, as

shown in their report entitled, *Building Community Support for People: A Plan for Mental Health in Ontario—The Graham Report* (1988). Following this, four major mental health reform reports recognizing the dually-diagnosed have been published—*Putting People First: The Reform of Mental Health Services in Ontario* (1993); *Making it Happen* (1999a, 1999b); *The Time is Now: Themes and Recommendations for Mental Health Reform in Ontario: Final Report of the Provincial Forum of Mental Health Implementation Task Force Chairs* (2002); and *Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada [The Kirby Report]* (2006). In 1997, despite the MOHLTC and the MCSS' joint publication, *Policy Guideline for the Provision of Services for Persons with a Dual Diagnosis*, so far, there has yet to be developed any formal evidence-based care guidelines for this specific population by mental health service providers. This was not as likely as it was once thought as it became the expected practice that those with a dual-diagnosis could be adequately treated using a generic mental health treatment model. However, because of the specific needs and symptoms of this population, a higher degree of intervention remains warranted (Kirby, 2006; MOHLTC, 1993, 1999a, 1999b, 2002; Moss, Emerson, Bouras, & Holland, 1997).

With the Ontario Government's plans for continued mental health reform, established in the early 2000s, rapid and almost daily changes are now occurring that impact service providers and clients. In March 2006, the Ministry of Community and Social Services announced its plan to move ahead with forming four Community Networks of Specialized Care across Ontario. Each network, consisting of professionals such as behavioural therapists, social workers, psychologists, and nurses, will work

collaboratively in assessing, diagnosing, and treating adults with developmental disabilities. These teams will work closely with various community agencies, both from developmental services and the mental health system to improve specialized services for the dual-diagnosis population.

At about the same time, the *Local Health Integration Services Act, 2006* came into effect. This legitimated the Minister of Health and Long-Term Care's announcement of the formation of 14 Local Health Integration Networks (LHINs) across the province of Ontario (MOHLTC, 2006c). Each LHIN is similar to a corporation that has a governing board of directors. While the District Health Councils (DHCs) have been disbanded, the MOHLTC is restructuring and taking on a stewardship role. In the place of the DHCs, a series of geographic planning committees and an advisory committee was appointed by LHIN officials. Since April 2007, each LHIN would be responsible for 100% of their region's healthcare dollars and is now making decisions related to what mental health and addiction services will be offered in each area (MOHLTC, 2006b). This is significant, as Ontario has never had a non-elected body assume control of such funding. Importance continues to be placed on improving service delivery, being patient-centred, providing accountability, quality management and showing favourable outcome measures (MOHLTC, 2006c). Emphasis on the provisions of efficacy and measurable outcomes is influencing agencies to seek and adopt treatment approaches based on so-called 'best practices' research (CMHA, 1998). The scope of best practice literature on treatment models for the dual-diagnosis population has expanded since the turn of the 21<sup>st</sup> century and can now be appraised as 'significant' [author's word]. Examples of such evidenced-informed treatment protocols include: psychiatric care (Bradley & Burke, 2002); bio-

psychosocial approaches to challenging behaviours (Griffiths & Gardener, 2002); person-centred planning (Gahan, Dykstra, & Summers, 2002); psychopharmacology (Stavrakaki, Antochi, Summers, & Adamson, 2002); and substance use treatment (Stavrakaki, 2002).

#### Statement of Purpose and Rationale

As pointed out previously, and summarized in the work of Moss et al. (1997) and VanderSchie-Bezyak (2003), the dual-diagnosis population's needs and problems in living have become increasingly diverse and complex. Currently, this population is one of the most challenging to serve (Bongiorno, 1996). Given the lack of cohesion and integration of best practices in the literature about treatment (National Association of Dual Diagnosis [NADD], 2004), the need for developing a specialized model of care for jurisdictions such as London and Middlesex County has occurred. This study was initially undertaken to help the London and Middlesex Dual-Diagnosis Committee to collect information related to the service provider's perceptions of best practices and the provision of specialized out-patient health services for dual-diagnoses patients in relation to directives from the MOHLTC. It is hoped that lessons learned may extend to other communities over time to the benefit of those living with dual-diagnoses.

The purpose of this study is best captured by the following question: What are the perceptions of service providers regarding best practices for dual-diagnosis clients at the agency, community and inter-organizational levels particularly in London and Middlesex County? Objectives that are of concern to this inquiry are as follows:

- What is the perception of prevalence of dual-diagnosis clients in caseloads of service providers in London and Middlesex County?
- What is the extent of collaboration between community agencies in the provision

of mental health services for clients with a dual-diagnosis?

- What are existing gaps in serving this population in London and Middlesex County?
- What are the perceptions of best practices for this population among service providers in London and Middlesex County?
- What are the current models of care used in London and Middlesex County to treat this population?

Best practices or evidenced-informed practice generally refers to the delivery of treatment based upon information regarding effective practices (Rycroft, Malone, Seers, Titchen, Harvey, Kitson et al., 2004). Before proceeding further, it is important to note that there exists debate in the literature regarding delivering care based upon best practices. The adoption of best practices must be based upon the nature of the evidence and must take into consideration the environment to avoid difficulties in implementation (Grol & Grimshaw, 2003). The research further supports this, noting that there are problems in defining what is sufficient evidence (i.e., research, clinical experience and/or patient experience) and how to use it appropriately (Rycroft et al., 2004). For example, Thompson (2003) notes, experiential knowledge is necessary evidence, but should not be the only evidence considered for treatment planning. For best practices to remain responsive to the needs of the dual-diagnosis population, they must include a broad evidence base with robust findings (Rycroft et al., 2004) and be subject to ongoing critique (Ministry of Health and Long-Term Care, 1999b).

In addition to the purpose of exploring perceptions of best practices, there are several more rationale that inform the conduct of this study. First, this study is timely, as

the Ministry of Community and Social Services announced on September 9, 2004, the three remaining institutions [Rideau, Huronia, & South-western Regional Centres] are closing by March 31, 2009 (Lindgren, 2004). Therefore, expecting the increased need for community based services, service providers in London and Middlesex County are seeking to set up an improved coordinated system for those needing mental health and developmental disability services in their communities. Second, this study will address a gap in knowledge about and understanding of those with dual-diagnoses by providing evidence-informed specific knowledge about out-patient mental health services for such clients. Third, this knowledge-base will be grounded in present-day professional mental health practices and developmental services, as well as scholarly literature. Through, an environmental scan using key informants from various mental health and developmental service organizations throughout London and Middlesex County, this study will tap into the professional practice of mental health teams and professionals. Fourth, based on the process of discovery, relevance of these findings and implications for many community stakeholders may be revealed. It is hoped the findings will benefit the regional community mental health agencies, the social workers they employ, other healthcare providers, and ultimately those with dual-diagnoses. By conducting research with evidenced-informed or best practice guidelines, the findings of this study will likely contribute to addressing this population's service needs and will increase awareness about various treatment choices.

## CHAPTER 2: REVIEW OF THE LITERATURE

This literature review is organized to provide a more comprehensive perspective and to assist in the formation of a solid foundation for determining best practices or evidence-informed out-patient treatment interventions for those dually-diagnosed. Some of the many forms of stigma, isolation and oppression encountered by those with a mental illness will be reviewed. The movement from an institutionalized centralized treatment model to community-based treatment will also be reviewed. Gaining a better understanding of some key issues and circumstances will assist in contextualizing the reality of an individual with a mental illness and provide direction for the most appropriate services for this vulnerable population. Finally, an examination of treatment modalities will be explored as identified in best practices literature.

### Prevalence and Social Stigma

The issue of stigma is ambiguous and endemic to the field of mental health (Corrigan, Watson, & Ottati, 2003). In the past 20 years in Canada, those with a dual-diagnosis have increased in prevalence as this disorder is more frequently recognized (Owen & MacFarland, 2002). Funding through the Canadian Government and current policies have generally assisted this population through supporting deinstitutionalization and encouraging communities of care (Bradley & Burke, 2002): however, this growing population and its specialized treatment needs are exceeding current care resources and arrangements (Joint Developmental Services Sector Partnership Table, 2004). In short, a growing number of people with dual-diagnosis have growing visibility and needs and much work remains to develop a comprehensive infra-structure to support and effectively treat this population.

Mental illness affects people of all ages, races and genders at all socio-economic and educational levels (Canadian Mental Health Association—Ontario Division, 1993). In 2002, the Canadian Community Health Survey was conducted by Statistics Canada and the Canadian Institute for Health Information. This was the first attempt that Canada attempted to acquire national prevalence rates for mental illnesses (Kirby, 2006). Unfortunately, this nationwide survey did not include dual-diagnosis and many other notable disorders such as schizophrenia, psychotic disorders, and personality disorders (Statistics Canada, 2004). A general estimate accepted in the mental health literature reflects that approximately 1 in 5 Canadians will be afflicted by a diagnosable mental illness (Health Canada, 2002, p. 17). Although it is not fully determined what particular brain disorders are related to specific mental illnesses, research indicates that causal factors are related to an intricate combination of genetic, biological, personality and environmental conditions (Health Canada, 2002). Individuals with a mental health disorder are identified and categorized by a diagnosis from a medical doctor or psychologist using criteria found in the *Diagnostic & Statistical Manual of Mental Disorders 4<sup>th</sup> edition [DSM-IV]* (APA, 1994). Each mental disorder is defined as a behavioural or psychological condition of clinical significance that fall into a system of types, categories and modalities.

Systemic oppression of a classification of individuals with disabilities is commonly known as ableism. Thompson (2006) has reported that as a result of stigma, individuals with mental disabilities are subject to ableism, and this is sometimes referred to as 'disableism' (p. 123). *The Surgeon General's 1999 Report on Mental Health* has determined stigma to be "the most formidable obstacle to future progress in the arena of

mental illness and health” (Perlick, 2001, p. 1613). Throughout history, stigma has resulted in “stereotyping, fear, embarrassment, anger and avoidance behaviours” (Health Canada, 2002, p. 21). Due to stigmatization, those with mental illnesses are identified as a vulnerable population (Corrigan et al., 2003) and are among “the most divided and fragmented of all oppressed groups” (Mullaly, 2002, p. 167). Stebbins (1998) associates such oppression with an increased risk of suffering death, pain, and loss of freedom, as well as difficulty in one or more essential areas of functioning (e.g., caring for one’s self, achieving an education, and maintaining a full-time job). The impact of stigma is evident when landlords refuse this population the basic need of accommodation/housing. Mental health professionals unnecessarily hospitalize the vulnerable and marginalized and primary care providers withhold necessary services (Corrigan et al., 2003). Corrigan (1998) reports that this type of prejudice continues to exist as Western culture maintains beliefs that persons with a mental illness are dangerous, incompetent and suffer from a character flaw.

Under the umbrella of critical social theory as theorized by Mullaly (2002), the conflict perspective is representative of this population’s oppression, in that the social problems akin to those experienced by oppression are subject to social structures, processes and practices that tend to favour certain categories in mainstream society (Mullaly, 2002). In addition, those who subject themselves to defining their self-concept through the social context created by the dominant group often suffer from less secure psychological self-concept, in addition to quality of life issues, low self-esteem and lack confidence in their abilities (Kravetz, Faust, & David, 2000; Miles, 1987). Therefore, those who have not placed value upon themselves are at risk of such negative affective

states as frustration, shame and guilt (Corrigan, 2004). In turn, this perpetuates a continuing cycle of stigma and can impede an individual's recovery process (Blankertz, 2001; Markowitz, 1998).

Those with multiple disabilities or diagnoses are subjected to the piling up effect of oppressive situations, and consequently, an even higher level of stigmatization (Centre for Addiction and Mental Health [CAMH], 2005; Corrigan, Thompson, Lambert, Sangster, Noel, & Campbell, 2003; Mullaly, 2002). Those with disabilities are “born with stigma and discrimination, as well as social, educational and economic exclusion” (Samier, 2006, p. A17). Individuals with a dual-diagnosis live in an even greater state of vulnerability to stigma and oppression (Encinares & Golea, 2005). In particular, women with disabilities are at higher risk of violence than women without disabilities (Sobsey, 2000).

Even in the service delivery system, those with a dual-diagnosis are perceived as the least desirable clients (CMHA—Ontario Division, 1998). Although those with disabilities are no longer “warehoused”, they are far from being “assimilated” in today's society (Crawford, 2005, p. E1). In society, personal experiences are often hidden just beneath the cloak of daily life. A concerned parent, Eileen MacMillan, whose daughter, Lois, has lived in an institutionalized setting for the past forty-five years is very concerned about the government's plans to move her daughter into the community. Lois is not able to walk and does not have the ability to verbally express herself or do things that others take for granted, such as blow her nose. Lois' mother believes that the same level of care will not be available in a community-based setting and she feels that society “will not include these unfortunate, vulnerable souls—they will be shunned” (MacMillan,

2004, p. B5). In summary, as reported in the literature, it is evident that those living with a dual-diagnosis are a stigmatized population. In addition, it appears that the very nature of their disabilities further oppress this population.

Another issue of particular importance is the aging population with a dual-diagnosis (Campbell & Herge, 2000). It is not uncommon to have parents in their senior years or siblings caring for a family member with a dual-diagnosis (Salvatori, Tremblay, & Tryssenaar, 2003; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). As aging caregivers lose their ability to adequately care for an aging individual with a dual-diagnosis, they often face social stigma and discrimination in securing an appropriate community placement for their loved one as traditional community services and long-term care facilities are often not designed to accommodate the needs of a dually-diagnosed individual (National Advisory Council on Aging, 2004). As the Canadian population continues to age, this will have an impact on community providers, rest homes and long-term care facilities to make accommodations in service provision to the dually-diagnosed population (Ontario Partnership on Aging and Developmental Disabilities, Transition Task Group, 2005).

Over a decade ago, the prevalence of those with developmental disabilities was estimated to be between 214,386 to 267,983 (0.8% to 1%) of the general Canadian population (National Health and Welfare, 1988). Currently, 899,000 Canadians are identified as having a developmental disability (Canadian Association for Community Living, 2000). Some in the mental health community might comment that these numbers are conservative (Kirby, 2006). The literature reports many challenges in determining the prevalence of individuals with a dual-diagnosis (Oliver, Piachaud, Done, Regan, Cooray,

& Tyrer, 2002). Bongiorno (2001) reports that it was not until the 1970s that researchers believed it was possible for an individual with developmental disabilities to have a co-occurring mental illness. Second, the definitions of dual-diagnosis vary greatly in the mental health literature (CMHA, 1998). Literature reviews conducted by other authors reveal that some researchers have excluded certain psychiatric disorders such as dementia or behavioural disorders, whereas others have included subjects with such diagnoses (CMHA, 1998). As well, diagnostic overshadowing or having a misdiagnosis can be identified within this population (Bradley & Burke, 2002; Fletcher & Poindexter, 1996). All these factors contribute to inaccurate documentation and reporting of dual-diagnosis which weakens the accuracy and reporting of prevalence (Jopp & Keys, 2001). In a meta-analytic study conducted by White, Nichols, Cook, Spengler, Walker, and Look (1995), they report that those with developmental disabilities experience a decrease of 19% in diagnostic accuracy compared to those with a mental illness, who do not have a dual-diagnosis. Since the early 1970s, a general consensus has evolved to reflect the more correct perspective that those with a developmental disability are more likely to suffer from psychiatric difficulties than the general population (Campbell & Malone, 1991; Dosen, 1993; Driessen, DuMoulin, Haveemen, & van Os, 1997; Gustafsson 1997; Hassiotis, 2002; Linaker, 1990; Taylor, 2005; Zbogor, 2002). It is estimated that higher rates of prevalence exist among those with severe or profound developmental disabilities (Cochrane, Goering, Durbin, Buterill, Dumas, & Wasylenki, 2000; Day, 1993), but are often overlooked by clinicians due to the nature of this population's impairments, such as non-verbal communication and low cognition levels (Bradley & Burke, 2002). In Ontario, it is estimated that 2.25% of the population have a developmental disability and

of those, 38% (approximately 93,000 individuals) have a dual-diagnosis (Morris, 2003; Yu & Atkinson, 1993). In reviewing the literature, it is important to note the amount of variance in prevalence rates of the dual-diagnosis population, ranging from 10-60% (Morris, Bradley, Gitta, Nugent, & Summers, 2004). Fletcher and Poindexter (1996) report that the variance attributed to the demographic differences in the groups surveyed also includes the research methodology such as inclusionary or exclusionary criteria and populations selected for study. For example, estimates of prevalence range from as low as 10% (Borthwick-Duffy & Eyman, 1990) to 30% in community populations (Developmental Disabilities Division—University of Western Ontario, 1997) and from 13% (Lunksy, Bradley, Durbin, Koegl, Canrinus, & Goering, 2003) to 60% in institutionalized populations (Cochrane et al., 2000). Variance of percentages may be associated with their location—community or institution—or may reflect the inclusionary and admission criteria, ease of access to diagnostic standards and identification of persons with dual-diagnosis in each setting.

To date, much research with individuals with a dual-diagnosis has focused on different subsets of the population which often makes comparisons across studies difficult (Fletcher & Poindexter, 1996). Fortunately, efforts to increase awareness of the specialized needs in this population as an identifiable cohort have succeeded in recent years and the Canadian Government has placed an emphasis on examining this population more closely (Ministry of Health, 1999a, 1999b). To better understand the plight of these individuals, it is important to note their gradual progression from being ostracized by society locked away in various facilities, to being deinstitutionalized and discharged into the community and the subsequent development of community-

based/out-patient treatment models of today.

#### Deinstitutionalization—The Shift To An Out-Patient Treatment Model

In 1791, when Ontario (Upper Canada) was founded, formal institutions and legislative policy did not exist to treat those with mental illnesses and/or other disabilities. Often these individuals were cared for by family (Grob, 1985), confined to cages, sheds or barns (Johnston, 2000) or “warned out”, resulting in banishment from their communities (Wright, 2006). Due to the lack of public policy until the early 1800s, those with mental disorders who acted out, often found themselves in jail— chained, unkempt and malnourished (Johnston, 2000). After much political struggle, in Upper Canada (now Ontario) in 1839, the *Act to Authorize the Erection of An Asylum Within This Province for the Reception of the Insane and Lunatic Person* was passed. In 1850, Canada’s first asylum was opened in Toronto and consequently was filled to capacity. This led to the passing of the *Act for the Better Management of the Provincial Lunatic Asylum* in 1853 and the formation of branch asylums to handle the overflow of patients.

As biochemical and psychological therapies had not been understood nor available in the treatment protocols through the late 18<sup>th</sup> to early 19<sup>th</sup> century, interventions as isolation and lock-up in shackles, padded cells or cages, to exorcism by the church, low caloric ketogenic diets, laxatives, purges, cold water baths and blood letting (until faint) were tried—often in a trial and error manner or linked to the belief system and biases of the ‘expert’[author’s word] (Grob, 1985; Hunter, Shannon, & Sambrook, 1986, p. 1034). The use of drugs such as morphine, chloroform and ether were popular for sedation and control, not for brain or behavioural rehabilitation (Hunter, Shannon, Sambrook, 1986). Although considered inhumane by our current societal

standards, asylums and their treatment interventions were considered to be progressive for their time and patients were offered a better level of care than most residing in a community setting (McMaster University, 2000). Families often believed their loved one was 'better off' [author's word] in the asylum—a point of view romanticized in fictional western literature of the time.

In the twentieth century, a paradigm shift occurred when mental illnesses were no longer referred to as madness or demonic possession by the medical community, but rather as mental disorder, a condition requiring medical treatment (Stebbins, 1988). With renewed hope that mental disorders could be effectively cured with newer psychiatric interventions such improved medications and behavioural therapies, large medical institutions emerged in North America to house and treat those with mental disorders (Mohr, 1998). As a result of poor success rates, the purpose of providing a higher degree of humane care and psychiatric intervention fell by the wayside and such institutions began to play more of a custodial role as more individuals demonstrated little improvement and continued to require continuous and complex, long-term care (Grob, 1985; Mohr, 1998).

The movement for community-based treatment in North America began in the 1950s and 1960s. This change was in response to a variety of factors most significant of these was economics. Policy-makers had become increasingly aware of the costs, substandard living conditions and declining level of care in psychiatric institutions. More effective psychotropic drugs were discovered and introduced into care regimens. The strategy of providing community-based treatment was determined to be a more economic form of treatment when compared to hospitalization (Stebbins, 1988). During this time,

many psychiatrists embarked upon a movement of redefining their roles in mental health care by departing from psychiatric hospitals and opening community practices for patients (Grob, 1985). As a result of these factors, individuals with various disabilities, including developmental disabilities, were deinstitutionalized, almost en masse, moving back into the community with little or no supports in place. Scheerenberger (1987) reports that the so-called 'normalization movement' which involved de-institutionalizing individuals and [ideally] integrating them into the general population was not as successful as anticipated. Individuals were not able to succeed at rapid immersion into community living and often required frequent re-hospitalization. Families and communities were neither prepared for nor resourced to promote the reintroduction of adults with mental health concerns and/or developmental challenges.

Historic accounts in this particular area attempt to determine whether or not deinstitutionalization was a favourable alternative (Palley & Van Hollen, 2000). The focus of the government has been upon the budgetary cost savings accrued as a result of the transition of individuals from an institution to a community-based setting while societal and professional foci remain on the issue of integration and quality of life for individuals and families in communities throughout Ontario in the twenty-first century (Greenberg, 2004; Kirwan, 1996; MacMillan, 2004; Samler, 2006). Although deinstitutionalization was designed to have as its intention the provision of more humane care, smaller community-based programs have not necessarily been equated with a better level of care (Palley & Van Hollen, 2000). Researchers such as Gibson (1991) contend that those with profound disabilities and the elderly with developmental disabilities are not best served in community-based placements. Bouras, Kon, and Drummond (1993)

examined the outcomes of 71 residents who had been relocated to an urban setting from a large institution in South East England. Observation and assessment of individuals during adaptation to daily life yields meaningful data. One area of concern is challenging behaviours. Challenging behaviours are defined as “behaviours of such an intensity, frequency or duration that the physical safety of the individual or others is likely to be placed in serious jeopardy, or behaviour that disrupts access to and use of ordinary community facilities [e.g., aggression, self-harm]” (Janardhanan et al., 1999, p. 2). Using standardized and reliable measures, Bouras et al. (1993) found no significant differences regarding challenging behaviours (e.g., aggression) and psychiatric diagnosis prior to relocation and 12 months after. However, their findings have clinical significance as they report that relocation was most beneficial for subjects when it was a coordinated and voluntary process designed to foster a better living environment. These findings support the importance of client inclusion in planning and life-directed activities. Stigmatization and being disadvantaged are not to be found congruent with such principles as client-centredness and inclusion (Gilmour & Gravelle, 1998).

When considering past research, one reflects upon researchers in this area, most of whom have studied convenient samples of approximately 100 subjects each and, although acceptable, they could be criticized for the lack of generalizable outcomes when compared to the heterogeneity of the total deinstitutionalized population. Cullen, Whoriskey, Mackenzie, Mitchell, Ralston, Shreeve, and Stanley (1995) conducted a two-year study comparing a group of 100 deinstitutionalized individuals with developmental disabilities to a group who remained institutionalized. Variables such as behavioural management (e.g., adaptive behaviours), quality of life issues (e.g., choice making,

leisure activities, community involvement) and social skills were examined. Benefits to individuals were “generally modest in scale, and are to be found soon after relocation, with no major changes over time thereafter” (Cullen et al., 1995, p. 491). In a similar study, Brook and Bowler (1995), report that there are no significant improvements in an individual’s behaviours as a result of deinstitutionalization; however, clear improvements in the quality of the living environment and an increased standard of living were noted.

Conversely, some literature reports that deinstitutionalized persons experience more health and psychological problems than those who have remained in institutions (Asberg, 1989; Sussman, 1998). A study of 109 individuals conducted by Nottestad and Linaker (1999) report that the deinstitutionalization of those with developmental disabilities has not been effective in solving any of this population’s mental health problems (e.g., symptom management, coping skills). Based upon their findings, they report improvements in leisure time and living conditions, a decrease in the use of mental health services after deinstitutionalization, as well as an increase in the frequency of behavioural disturbances.

Other studies in this area lack control groups (Nottestad & Linaker, 1999) and/or report difficulty determining in-group differences. While accounting for external factors, past and contemporary research fails to address the degree to which community-based services have generated community involvement. These outcomes create research limitations such as the inability to determine the extent to which this population has been successfully integrated into the community (Cullen et al., 1995).

In spite of newer medications that provide the opportunity for those who otherwise may not be stable enough to live in a community-based setting, there is still

much left to explore and address as modern-day institutions continue to be closed due to funding cuts. The reality of the situation is lived by individuals who have been and will potentially be placed in communities without appropriate resources to support them. As there has been no evaluation of the outcomes of change, uncertainty exists with respect to the extent to which the identified population have been or may be successfully integrated into the community. Consequently, policy-makers, researchers and service providers must continue to examine the outcomes and efficacy of services designed to maintain individuals (with mental illness and developmental challenges) in community with or without appropriate out-patient services. Various models of support and intervention have been applied, but little evaluation has been done to date. Evidence-based models must be developed to direct the development and application of best practice guidelines for support of the dual-diagnosis population (Morrison, 2004).

#### An Examination of Various Out-Patient Treatment Modalities

Hassiotis (2002) writes of the Canadian population and notes that adults with a mild to moderate developmental disability have a prevalence rate of 14.4% for mental disorders, similar to that of the general population (Hassiotis, 2002). Of those with dual-diagnosis, 25-50% have problems related to psychiatric health and social service needs (Gravestock, 1999). Marston, Perry, and Roy (1997) contribute to this position by identifying such things as diagnostic overshadowing, non-disruptive symptoms, impaired communication and difficulty regarding accurate assessment and diagnosis of underlying organic brain effects as being characteristic of this population. Jacobson (1997) contends that there is a need to identify improved criteria regarding mental status among individuals with developmental disabilities as well as a need to evaluate the effectiveness

of mental health services related to specific mental conditions among this population.

With clearer diagnoses, treatment modalities may prove to be more efficacious.

In simplified treatment outcome terms, treatment modalities for those with dual-diagnoses have been categorized into two main paradigms. The first broad approach to contemporary care has been pharmacological treatment. This medical orientation emphasizes the importance of medications in treating and managing the conditions and behaviour associated with this population. The three most cited classifications of psychoactive drugs in this category are anticonvulsants, antipsychotics and antidepressants (Lott, McGregor, Engelman, Touchette, Tournay, Sandman et al., 2004). The second paradigm is a specialized therapeutic model, emphasizing interventions from various theoretical frameworks, such as interdisciplinary community treatment, psychotherapy, and cognitive-behavioural interventions (MOHLTC, 1999a, 1999b).

#### *Pharmacological Treatments*

In the practice domain of pharmacology, the use of various psychoactive medications has been evaluated for such drug groups as: 1) antipsychotics (Brylewski, & Duggan, 1999; Citrome, 2002; Janardhanan, Paramala, & Gillian, 1999; Vanden, Vermote, Buttiens, Thiry, Dierick, Geutjens et al., 1993; Williams, Clarke, Bouras, Martin, & Holt, 2000); 2) antidepressants (Manning, 2004; Masi, Marcheschi, & Pfanner, 1997; Sovner, Fox, Lowry, & Lowry, 1993); and, 3) anticonvulsants (Burd, Williams, Klug, Fjelstad, Schimke, & Kerbeshian, 1997). In addition to debates as to which medications are most effective, the prevalence of their negative side effects have also been studied (Gingell & Nadarajah, 1994; Rogers, Karki, Bartlett, & Pocock, 1991; Yousef & Waddington, 1988). The methodologies of these studies vary considerably,

such as small, single system or case studies (Sovner et al., 1993), to naturalistic inquiries (Williams et al., 2000), large population surveys (Lott et al., 2004) and meta-analytic reviews of randomized controlled trials (Brylewski et al., 1999).

When examining best practices or evidence-informed treatments among those with a dual-diagnosis, many studies have related to pharmacology and medication prevalence. Researchers have commonly defined psychoactive medication as either a psychotropic drug or an anticonvulsant (Lott et al., 2004). Psychotropic drugs, specifically antipsychotics were found to be the most commonly prescribed medication for those with a dual-diagnosis (Kiernan, Reeves, & Alborz, 1995; Rinck, 1998; Williams et al., 2000), followed by anticonvulsant medications used for psychotropic purposes (Burd et al., 1997). Linaker (1990) indicates that almost 50% of those institutionalized with mental illnesses and developmental disabilities are prescribed some form of psychoactive medication. Another study from a 1997 U.S. statewide population survey in Oklahoma has found that 22% of adults with developmental disabilities are prescribed antipsychotics, 9.3% anxiolytics and 5.9% anti-depressants (Spreat, Conroy, & Jones, 1997). Kiernan et al. (1995) report that 48.1% of those with developmental disabilities are prescribed neuroleptics. When control measures were implemented in their study, four main variables were found to be significant in determining types of prescriptions provided for this population: a) psychiatric diagnosis, b) place of residence, c) place of origin, and d) severity of challenging behaviour (Kiernan et al., 1995).

#### *Antipsychotic Medications*

Research indicates a high prevalence rate of prescribed antipsychotic drugs in this population (La Malfa, Lassi, Bertelli, & Castellani, 2006; Singh, Matson, Cooper, Dixon,

& Sturmey, 2004; Stolker, Heerdink, Leufkens, Clerkx, & Nolen, 2001). The reasons identified in the literature for prescribing psychotropic drugs were found to be for “modifying behaviour, emotion or cognition” (Burd et al., 1997, p. 488). Prescribing antipsychotics, originally *chlorpromazine*, followed by other similar medications for this population has dated back to the 1950s (Brylewski & Duggan, 1999). These medications were used for two specific purposes with those dually-diagnosed: a) to treat symptoms of mental illness [e.g., psychosis], and b) to limit challenging behaviours (Emerson, 1993; Moss et al., 1997) in non-direct ways (Baumeister, Seven, & King, 1998; Williams et al., 2000). Among this population, specifically challenging behaviours have been the most commonly cited indicators (more so than verbally expressed symptoms) that assist medical and health professionals in determining the effectiveness of medication (Bongiorno, 1996).

The use of antipsychotics in this population continues to be a controversial subject (Hemmings, 2006). There are conflicting orientations regarding whether or not those with dual-diagnoses are at greater risk of developing short and/or long-term medication side effects (Kroese, Dewhurst, & Holmes, 2001; Robertson, Emerson, Gregory, Itatton, Tuner, Kessissoglou et al., 2000). Due to their neurological impairments, Gingell and Nadarajah (1994), Rogers et al. (1991), as well as Yousef and Waddington (1988) suggest that those with developmental disabilities, may be at higher risk of developing movement disorders. Reiss and Aman (1997) report that the evaluation of side effects among this population is not well documented in the literature and due to the nature of their disabilities, individuals diagnosed with a dual-diagnosis may be at greater risk of having certain side effects go undiagnosed, unrecognized and unacknowledged.

Brylewski and Duggan (1999) discuss the ineffectiveness of deriving correct diagnoses from symptom presentation. They also report on the difficulty in correctly describing a specific mental disorder when many individuals are influenced by the severity of the co-existing developmental disability. The same researchers also contend that challenging behaviours, which might be symptomatic of a mental disorder in someone of average intelligence could be explained by other reasons for individuals with developmental disabilities. If a misdiagnosis should occur, the least damaging effect may be an ineffective treatment outcome: however, if a treatment such as a medication is prescribed in error, it may consequently cause significant harm, and/or brain damage by worsening the person's pre-existing condition (Reiss & Aman, 1997). In the community setting, Burd et al. (1997) cite two factors associated with medication use that have placed those with a dual-diagnosis at increased risk of marginalization, stigmatization and vulnerability. These risks due to the inappropriate use of psychoactive medications include; a) general practitioner's inexperience in treating this population, and b) lack of effective monitoring systems that evaluates the use and suitability of medications as compared to those in large institutions (p. 489).

While these are concerns and risks that must be considered, antipsychotics have been found to be effective for acute aggression; however, there is an increased risk of developing extrapyramidal symptoms when used over a long period of time (Janardhanan et al., 1999). These symptoms or side effects are uncomfortable and disruptive to many using this group of medications and include unpleasant sensations, altered fine and gross motor activity, altered gait and slowed responses (Deglin & Vallerand, 2006). With regard to effective medications, the literature has varied drastically in its

recommendations. *Zuclopenthixol* has been reported to be the most effective antipsychotic that has shown significant improvement with regard to long-term behavioural disturbances (Janardhanan et al., 1999). *Risperidone* has also been shown to be effective in some individuals with hostility, aggression, irritability and self-injury (Vanden et al., 1993); as well as *clozapine* (Cohen & Underwood, 1994). In addition to the medication studies above, Kiernan et al. (1995) studied a total of 695 individuals with developmental disabilities. Confirmed psychiatric diagnosis from a doctor, was noted in 13.3% of the sample. The researchers verified that the three most frequently prescribed medications are *chlorpromazine*, *thioridazine* and *haloperidol*.

Isolated medication use can not resolve challenging behaviours. Janardhanan et al. (1999) suggested that best practice guidelines have reflected that challenging behaviours are best treated using a behavioural therapy approach, with use of medication if needed, on a restricted, short-term basis of a few weeks (p. 3). Similarly, Rifkin (2000), states that adequate testing of psychotropic drugs has not taken place and suggests that antipsychotics should be used as a last resort for uncontrollable aggression. The best practice issue however, remains to be that the efficacy of sustainable outcome measures, as per standardized guidelines, have not been consistently reported.

Williams et al. (2000) designed a one-year naturalistic study to determine the clinical effectiveness of atypical antipsychotic drugs in adults with developmental disabilities. The sample was composed of 21 individuals in total, nine males and twelve females. Twelve individuals were prescribed *olanzapine* and nine were prescribed *risperidone*. Williams et al. (2000) report clinical improvement as occurring in 16 of these cases. They conclude that antipsychotics were effective with this population, with

*risperidone* being better tolerated than *olanzapine*. The researchers cautioned that results were not statistically significant due to their small sample size.

In 2002, Citrome explored the advantages of newer antipsychotics and concluded that the newer atypical neuroleptics (e.g., *ziprasidone* and *olanzapine*) are better tolerated in the dually-diagnosed population, especially in cases of acute agitation. When searching research literature for conclusive research outcomes, no clear evidence was found to support the efficacy of newer atypical neuroleptics and antipsychotics as the treatment modality of choice for challenging behaviours. For example, Brylewski and Duggan (1999) attempted to determine the effectiveness of antipsychotic medications with regard to developmental disabilities and challenging behaviours. In their attempt to find high-quality, randomized controlled trials to evaluate, only three studies were successfully identified in this area. Brylewski and Duggan (1999) conclude in their review that there has been no concluding evidence whether or not the use of antipsychotic medications has assisted with management of or reduction in challenging behaviours. As well, other researchers have cited that there is a lack of solid evidence from randomized controlled studies to demonstrate that antipsychotic medications are effective, aside from their overall sedative effects, in reducing challenging behaviours (Aman & Singh, 1991; Singh et al., 2005).

Reiss and Aman (1997) conducted a meta-analysis of clinical efficacy of psychoactive medication with the dually-diagnosed. They invited 115 scientists, practitioners and consumers from 11 countries to be part of a panel to examine best practices and clinical effectiveness related to the use of psychoactive medications specifically with their dually-diagnosed populations. In their report, they comment that

the pharmaceutical industry evaluates the effectiveness of psychotropic medications in adults, predominantly males in all the countries who participated. No particular reference or findings have been reported by any of the scientists concerning the recommended target population that would use these drugs: subjects had not specifically been ones with developmental disabilities. Despite the lack of empirical research regarding the effectiveness of psychotropics among individuals with developmental disabilities or dual-diagnosis, psychotropic medications continue to be prescribed (Reiss & Aman, 1997; Singh et al., 2005).

#### *Antidepressant Medications*

The use of antidepressants is another area that warrants additional research, particularly with regard to diagnostic criteria. Hurley (1989) reports that only dually-diagnosed individuals with higher cognitive functioning can successfully be administered self-report measures that use standard criteria with little adaptation. Those with more severe impairments must be monitored by others with regard to atypical behaviours (e.g., self-injury, aggression) in order to be diagnosed accurately (Hurley, 1989). The same researcher also reports that appetite monitoring is a symptom of key significance when diagnosing mood disorders in the dually-diagnosed population. Rarely has this key observation of efficacy been reported in practice or research.

In addition to diagnostic criteria, researchers have often found it challenging to evaluate the effectiveness of antidepressants in this population. A small study in Italy by Masi et al. (1997) attempted to evaluate the effectiveness and side effects of *paroxetine* among adolescents with a dual-diagnosis, specifically those with a mild developmental disability and major depression. Their uncontrolled study sample was composed of seven

youths, six males and one female. Their average intelligence (I.Q.) was measured at 57. After the nine-week intervention, results from this study reported that although there were generally mild side effects with use of *paroxetine* in a total of seven subjects, four experienced a significant improvement in their symptoms (i.e., inner tension, lassitude, apparent sadness, inability to feel), two experienced moderate improvement and one minimal improvement (Masi et al., 1997). The researchers note that symptoms of reduced appetite, sleep disturbances and a lack of concentration were not significantly improved with the use of *paroxetine*. However, despite the latter findings, there exists evidence from Masi et al. (1997) suggesting that *paroxetine* is an effective medication for those dually-diagnosed with major depression. This study was short in duration and raised many questions regarding the subjects' sensitivity to long-term use of anti-depressants, as well as side effects (specifically seizures) which have been identified to be of increased risk in the dually-diagnosed population (Masi et al., 1997). Aman, White, Vaithiantan, and Teehan (1986) cite that some studies have indicated an increased risk of developing anxiety, irritability and aggressiveness upon taking antidepressants for long-term periods. It is clear that more research is needed in this area with regard to diagnostic criteria and risks of medication use; however, Manning (2004) provides hope as newer antidepressants (i.e., *duloxetine hydrochloride*, *escitalopram*, and *mirtazapine*) offer better safety, decreased side effects and increased effectiveness in treating depressive symptoms.

Some researchers emphasize the need to be aware that depression often manifests itself as self-injury within the dually-diagnosed population (Lowry & Sovner, 1992; Matin & Rundle, 1980; Pirodsky, Gibbs, Hesse, Hsieh, Krause, & Rodriguez, 1985;

Sovner et al., 1993). However, other factors may be responsible for this behaviour. Self-injury is often deemed as a treatment-resistant challenging behaviour, with a prevalence rate of 13-14% among those with severe developmental disabilities (Jacobson, 1982). Sovner et al. (1993) used a two-subject case study design to evaluate the use of *fluoxetine* to treat major depressive symptoms and associated self-injuring behaviours with those having a severe developmental disability. By utilizing a behavioural monitoring tool, they found that self-injurious behaviours were reduced in both cases, as well as many symptoms of depression.

Williams et al. (2000) comment that part of the challenge of conducting randomized controlled trials is related to the heterogeneity of the population as mental disorders are often difficult to diagnose. Compounding this, researchers conducting large meta-analytical reviews, such as Brylewski and Duggan (1999) contend that many studies have failed to report an account of their methodology which has prevented replication of findings. In order to determine the effectiveness of pharmacological interventions, these authors outline three main considerations. These are namely: a) randomized procedures must be used and described in detail, b) demographics on participants must be collected, including severity of the developmental disability, type of mental illness, place of residence, and, c) challenging behaviours and secondary outcomes must be described with respect to short- and long-term outcomes (p. 369).

The literature provides much evidence that the dual-diagnosis population has been overmedicated (Holden & Gitlesen, 2004) and has a history of poly-pharmacy practice (Lott et al., 2004; Stolker et al., 2001). A major theme that has emerged from many best practices studies has related to pharmacological treatment principles with a *less is more*

[italics added] approach (Burd, Fisher, Vesely, Williams, Kerbeshian, & Leech, 1991). The maintenance of an individual on the lowest effective dose of psychoactive medication to facilitate the reduction or the elimination of side effects is currently believed to be the ideal scenario (Bongiorno, 1996). At times, multiple drug use may be appropriate, however the more medication used, the greater the risk of drug interactions and side effects which can create an impairment on cognitive and behavioural skills in the dually-diagnosed (Stolker et al., 2001). Best practice literature indicates that although pharmacological intervention appears to play a significant role in the treatment of the dually-diagnosed, especially when treating various psychiatric disorders, it is only one part in a comprehensive treatment plan (Gorton, 1996). When psychotropic medications are prescribed, the individual must be carefully monitored to ensure the benefits of the medication outweigh the potential risks and side effects (Kroese et al., 2001). Resources such as the *Davis' Drug Guide for Nurses* (2006) and *The Merck Manual of Diagnosis and Therapy* (2006) are available to healthcare professionals to assist in guiding pharmacological treatment. In addition to medical protocols, coordination and effective communication strategies among medical and health professionals, caregivers and clients are vital for successful treatment outcomes (Williams et al., 2000).

#### Specialized Treatment Approaches

Specialized treatment refers to specially developed mental health programs provided in community and/or hospitalized settings that target those whose serious mental illness is complex and often unstable, for example, those developmentally disabled with a mental disorder and aggressive behaviours (Kirby, 2006, p.104). Given the current climate of mental health reform in Ontario, 2008, specialized treatment is no

longer considered long-term institutionalized care, but rather involves rehabilitation and support services that can be provided by interdisciplinary teams to support those living in the community. As the needs of individuals can change, so do the levels of support and services, demanding continuous monitoring and reassessment as part of this treatment orientation for an individual progressing through their recovery (Kirby, 2006).

In the literature, common themes pertaining to out-patient specialized treatment interventions are found to be: 1) models of community-based treatments (Burns & Santos, 1995; Cochrane et al., 2000; Hassiotis, 2002); 2) psychotherapy (Gaedt, 1995; Hurley, Tomasulo, & Pfadt, 1998; Torrey, 1993); 3) cognitive-behavioural therapies (Evans & Moltzen, 2000; Mueser, Corrigan, Hilton, Tanzman, Schaub, Gingerich et al., 2002); and, 4) substance abuse treatments (Degenhardt, 2000; Paxon, 1995). Methodologies also vary with regard to studies examining therapeutic interventions, ranging from qualitative (Gaedt, 1995) to meta-analytical (Mueser et al., 2002) and randomized controlled groups (Marston et al., 1997). In regard to the latter, Oliver et al. (2002) cite difficulty in evaluating treatment interventions using random controlled trials. This is due to factors such as ethical concerns associated with denying a group of individuals needed treatment, flawed methodologies, and limited resources to support such research and unclear assurance that consents are truly informed and comprehended.

Before further examination of various treatment approaches with this population, it is interesting to note that many studies focused on whether or not services are needed or available for those with a dual-diagnosis; however, upon reviewing the literature, very few studies have explored utilization rates. Driessen, DuMoulin, Haveman, and van Os (1997) conducted a study in the Netherlands that examined variables involved in referrals

to psychiatric services and the amount of mental health service utilized amongst those with developmental disabilities. They report that being 24 years of age or older, having a mild form of developmental disability and living alone, were associated with higher utilization rates of psychiatric services. Jacobson (1998) conducted a cross-sectional study of 45,810 adults in New York State and found that almost 25% were diagnosed with a dual-disability. Of those identified as dually-diagnosed, 37% had no contact with a psychologist in the past year and 26% had weekly or more frequent contact. Jacobson (1998) concludes that in general, the severity of an individual's behaviours provided a basis for estimating the frequency of service usage, however there exists much variability. Factors attributed to this difference were identified as "personnel availability, caseloads, resource availability, service locus, identification and referral patterns, eligibility criteria, treatment philosophy, and organizational particulars" (p. 314). Finally, a study from Sweden conducted by Gustafsson (1997) found higher rates of psychiatric services among those in the general population with a mental illness alone, compared to those who were dually-diagnosed. As Gustafsson (1997) surmised, these findings have implied that the level of developmental disability is a key variable and those with more severe developmental disabilities are isolated, therefore, not able to access services independently suggesting that more collaboration among service providers is required to meet the needs of this population.

#### *Community-Based Treatment Interventions*

Community-based treatment is based upon a series of interventions that are simultaneously provided to a client living in a community setting from an array of service providers in the client's social network (Lieberman, Hilty, Drake, & Tsang, 2001). Under

the umbrella of tertiary programming approaches, in response to increasing the collaboration between treatment providers for this population, recommended community-based treatment modalities have been identified as outreach teams, assertive community treatment and case management, and residential care (Cochrane et al., 2000). Studies identify the preferred service delivery model for those dually-diagnosed as a community-based approach with residential supports (Burns & Santos, 1995; Hassiotis, 2002; Philips, Burns, Edgar, Mueser, Linkins, Rosenheck et al., 2001). In addition, a supporting cluster or 'wraparound model', using a strengths-based approach was found to reduce the amount of social isolation and promote empowerment among those with dual-diagnoses (Gilmour & Gravelle, 1998), as well as improving their quality of life in general (Hassiotis, 2002).

The strengths-based approach has been viewed as a paradigm shift in the field of service provision and should be made a priority in practice development (Morgan, 2004). The approach is based upon working in new and creative ways with clients, focusing upon their skills and competencies, as opposed to their limitations (Rapp, 1998). Involving a number of different service providers and supports is integral for success. In the developmental disability field, the wrap-around model is not entirely a new approach. With the emphasis on client empowerment in the mental health field, the philosophy of this model is being recognized as consistent with the MOHLTC's best practice principles regarding client-centredness which promotes a client's choice in service provision and involves family members and other care partners in the treatment plan (Kirby, 2006; MOHLTC, 1999a, 1999b).

As part of community-based treatment goals, the constructive use of leisure time

was identified as being an important component of successful rehabilitation. The use of structured community activities has often resulted in a positive outcome and has decreased the amount of challenging behaviours among this population (Gardner & Sovner, 1994). However, the sample in Nottestad and Linaker's 1999 study was reported to be involved in structured activities for 53.5 hours per week which the researchers conclude was too "tiresome" and may have inadvertently contributed to "an increased frequency of behavioural problems" (p. 528). Also, once deinstitutionalized, the sample experienced a significant decrease in treatment from psychiatrists and psychologists which the researchers surmise was responsible for the notably increase in behavioural disturbances (i.e., attack upon people, disruptive behaviour).

Moss et al. (1997) posit that dually-diagnosed individuals are not best-served solely by the mental health system. There exists much support in the literature regarding the effectiveness of implementing multi-disciplinary assertive community treatment teams to serve the needs of this population (Bond, Drake, Mueser, & Latimer, 2001; Bongiorno, 1996; Hassiotis, 2002; Liberman et al., 2001; Philips et al., 2001). To maximize successful outcomes for community-based living, Hassiotis (2002) reports that it is important to include the promotion of crisis intervention services for this population. In sum, community-based treatment has been the dominant approach since the era of deinstitutionalization and will continue to be effective provided there are proper support services in place (Rosen, Mueser, & Teesson, 2007).

#### *Psychodynamic/Psychotherapeutic Approaches*

Therapeutic approaches in general for mental health clients have undergone dramatic changes over the past several decades. Building upon the principle of recovery, mental

health and well-being has become a goal for everyone, including those with dual-diagnoses (Reiss, 2003). Liberman et al. (2001) define the goal of psychiatric rehabilitation as follows:

To promote the highest possible level of social and vocational functioning and well-being for individuals with severe and persistent mental disorders, so that they may enjoy optimal levels of independence from professional supervision and the least interference from symptoms and neuro-cognitive impairments. An essential aspect of psychiatric rehabilitation is for consumers to set personally relevant life goals, and in this task the involvement of their relatives and other supporters is critical. (p. 1331)

The literature notes that many rehabilitative treatment efforts are being used among the dually-diagnosed population with an emphasis on emotional stability and the development of satisfying personal relationships. Psychosocial treatments have proven effective with the dually-diagnosed (Bond et al., 2001) particularly for those mildly to moderately impaired (Torrey, 1993); however, not much literature exists regarding the efficacy of psychotherapy for this population (Taylor, 2005) likely due to difficulties in communication skills, varying levels of cognitive functioning as well as the possibility of therapist bias (Butz, Bowling, & Bliss, 2000).

Gaedt (1995) promotes the use of psychotherapy with dually-diagnosed persons. Psychotherapy focuses upon the internal or unconscious thoughts and feelings of clients and their developmental processes in assisting them towards the goal of self-actualization. The changing needs of clients, specifically those with dual-diagnoses that have sought treatment, rendered classic psychotherapy ineffective. In response to this, the theoretical bases of this therapy were broadened by including a number of other related theories to gain an understanding of the internal cognitive processes of an individual with a dual-diagnosis, in response to their developmental stage of functioning (Gaedt, 1995).

The literature indicates that the outcomes of psychotherapeutic intervention typically impact positively on a client and their support system, thereby, increasing their quality of life. Torrey (1993) reports that psychotherapy has also been beneficial related to working through issues regarding stigma, independence, feelings of inadequacy and sexual concerns that commonly arise in this population.

Due to the relative effectiveness of psychotherapy with this population, an adjustment in the administration of the technique is required, rather than the abandonment of the treatment altogether (Hurley et al., 1998; Torrey, 1993). Psychotherapy, when modified, is not only beneficial to a client, but also influences the client's emotional environment (Levitas & Gilson, 1989; Whitehouse, Tudway, Look, & Kroese, 2005). In a review of literature conducted by Whitehouse et al. (2005), specific adaptations were examined in using individual psychotherapy with this population. These researchers identified 25 studies, 15 were psychodynamic and 10 were of a related intervention identified as cognitive-behavioural therapy (CBT). Their results indicate a total of 94 specific adaptations, with flexibility in method being the most commonly cited in CBT and considerations for transference and counter-transference related to psychodynamic studies.

Hurley et al. (1998) contribute to the ongoing debate that psycho-therapeutic group interventions are a crucial, yet often overlooked component of treatment for those diagnosed with dual-diagnosis. It has been noted that in practice, therapeutic support groups have been replaced by skills training groups. Hurley et al. (1998) report that the absence of group psychotherapy as a treatment modality limits this population's opportunities for developing self-confidence and mental wellness.

The debate regarding the efficacy of psychotherapeutic intervention with this population dates back between 30 to 60 years (Butz et al., 2000). One explanation for this is related to the continued belief that the dually-diagnosed population lacks the necessary cognitive ability. Also of concern, is the lack of outcome studies in this area (Nezu & Nezu, 1994; Whitehouse et al., 2005), especially randomized control trials (Willner, 2005). However, recent research contributions in this area have appeared promising (Butz et al., 2000) and given the potential treatment beneficence, it is an area worth further exploration.

### *Cognitive-Behavioural Approaches*

Related to psychotherapy under the umbrella of psychodynamic theory is cognitive-behavioural therapy. The literature is sparse in the area of cognitive-behavioural interventions with this population (Hemmings, 2006). Some researchers suggest that the literature has reflected a lack of emphasis on cognitive-behavioural therapy, due to the below-average mental capacities of this client population (Gaedt, 1995; Moss et al., 1997). Cognitive-behavioural therapy focuses upon promoting positive behaviours, sometimes enforced through a system of rewards and punishments, to modify underlying motivations or thought processes that evoke certain negative behaviours (i.e., self-harm, violence, etc.).

A study by Evans and Moltzen (2000) defines best practices as community-based services for those with serious mental illnesses with an emphasis on cognitive-behavioural therapy utilizing six main conceptual themes as follows: a) acceptance, b) creating a positive atmosphere, c) expectations of change, d) responsiveness, e) normalization, and f) education. In a meta-analysis of 40 randomized control studies,

Mueser et al. (2002) discovered that relapse prevention programs reduce symptom relapses and re-hospitalizations. As well, coping skills training that utilizes a cognitive-behavioural approach reduces the severity of psychiatric symptoms in those with developmental disabilities. Similarly, another study with favourable results conducted by Haddock, Lobban, Hatton, and Carson (2004), examined five dually-diagnosed subjects who received an adapted form of cognitive-behavioural therapy. These researchers' findings indicate beneficial outcomes when compared to periods of non-treatment.

As treatment methods are evolving to include a greater degree of client-centred values, the use of traditional therapies such as behavioural modification is also changing. For example, a recent theme that is gaining clinical prominence is positive behaviour support, replacing the older behavioural modification methods. Positive behaviour support focuses on "relationship and instruction" rather than "consequence and punishment" (Bongiorno, 1996, p. 4). Mueser et al. (2002) assert that behavioural interventions are successful in improving medication adherence with this population, which is an important part of their treatment. In addition, interventions based upon best practice guidelines such as being solution-focused, using positive behaviour support measures and strategic family therapies when necessary are recommended (Gilmour & Gravelle, 1998).

Also gaining popularity in treating those with dual-diagnoses is the use of cognitive-behavioural therapy complimented by behavioural assessments. For instance, Marston et al. (1997) note that more emphasis should be placed on behavioural indicators (e.g., aggression, destructiveness, etc.) among this population. Their study contrasts 36 individuals with a developmental disability and depression to 46 non-depressed

individuals with a developmental disability, ensuring that both groups were matched at comparable levels with regard to their varying degrees of cognitive capacity. They conclude that successful identification of depression among those with mild developmental disabilities is attained through standard diagnostic tests and criteria from the *DSM IV*. However, behavioural indicators (notably destructiveness, screaming, and self-injury) were more useful in diagnosing depression in those with moderate and severe developmental disabilities. Conversely, Tsiouris (2001) supports the notion that behavioural indicators should serve as possible signs of depressive symptoms, but should not be considered as a main diagnostic characteristic. Tsiouris (2001) states that due to the additional criteria of *irritable mood* [italics added] in the *DSM-IV*, an accurate diagnosis of major depression can be made for those with severe developmental disabilities (p.118). Although it is not possible to compare the results from the studies identified above due to differing samples and outcome measures, it appears that cognitive-behavioural approaches are very useful with this population with regard to potential diagnostic measures and effective treatment indicators.

#### *Addiction Treatment Approaches*

Another area of intervention with this population relates to addiction treatment. Some research suggests that the prevalence of addiction, particularly alcohol misuse, is lower for those with a dual-diagnosis compared to that of the general population (Christian & Poling, 1997; Huang, 1981; Krishef & DiNitto, 1984). However, the severity of problems for this population is higher when compared to those who were abusing substances without a dual-diagnosis (Degenhardt, 2000). Other studies indicate that the prevalence of problem substance use in the dually-diagnosed population with a

mild to moderate developmental disability is comparable to the general population (Brady, 1993; Philips, 2006). Similarly, Rimmer, Braddock, and Marks (1995) report in their study that those most likely to abuse alcohol have: a mild to moderate disability; greater independence (e.g., lived in a group home); maladaptive health behaviours and; poorer physical health. Given the varied findings from the identified studies, it appears that determining the prevalence of addictions in this population has been problematic.

In 1998, a review of integrated mental health and substance use treatment models was conducted by Drake, Mercer-McFadden, Mueser, McHugo, and Bond. These researchers examined 36 studies, 13 of which used controlled research designs. From this review, promising results have been found for integrated treatment models. Implications for practice reflect the need for programs to be “comprehensive, including assertive outreach, case management, and stage-wise, motivational interventions for substance abuse” (Drake et al., 1998, p. 5). These researchers also indicate the need to create program manuals, utilize outcome measures and to conduct more research using controlled study designs. They also note that there were no studies found in their search for pharmacological treatments (e.g., *disulfiram*, *naltrexone*) for problem substance use in this population.

In 2001, Health Canada published a best practice document entitled, *Concurrent Mental Health and Substance Use Disorders*, yet failed to specifically address assessment and treatment considerations for those with a dual-diagnosis. Although best practice guidelines recognize the importance of harm reduction models in the recovery process (Health Canada, 2001, p.97), an abstinence-based approach has often been recommended for those with a dual diagnosis and a substance use problem (Degenhardt, 2000). After an

initial detoxification program, evidence-based treatment guidelines have recommended social/environmental therapies such as goal setting, skills training with regard to appropriate social skills [e.g., role playing, modeling] (Paxon, 1995), and refusal/communication skills (Monti, Abrams, Kadden, & Cooney, 1989). In addition to this, all forms of psychotherapies, modified accordingly to cognitive ability, have been found effective, including group and family therapies (Stavrakaki, 2002). Furthermore, this author asserts the continuing need for more research in this area as there is limited data available regarding addiction treatment outcomes for this population.

#### Summary of Literature Review

The studies examining specific treatment interventions in this literature review were often non-Canadian and many were composed of small, uncontrolled samples, without repeated measures over time. Hassiotis (2002) reports that evidence regarding best practices for the delivery of mental health services is less advanced despite the increased number of individuals with mental health needs. Oliver et al. (2002) report on difficulties in evaluating treatment interventions by using random controlled trials, due to ethical concerns of denying a group of individuals needed treatment, methodological flaws and limited service capacity to support such research. As those with a dual-diagnosis have been identified as a difficult population to treat (Bongiorno, 1996), there has been an ongoing quest to intervene with a variety of treatment modalities. Upon examining the literature, many discrepancies and gaps have been noted regarding best practices with the dually-diagnosed. Due to differing variables and outcome measures, it is not yet possible to determine which treatment modalities are mutually compatible, desirable and effective or those that are harmful, undesirable and least effective. Through

this study, the area of best practices treatment for the dually-diagnosed population will be examined with the overarching hope that a contribution will be made to the growing philosophy of best practice guidelines and a consensus in this practice area. It is hoped that this study will have much clinical significance as a shift to evidence-based practice will likely lead to improved changes through dissemination of this study's findings by increasing the awareness of access to, variety and quality of efficacious treatment modalities for those with a dual-diagnosis in London and Middlesex County.

## CHAPTER 3: METHODOLOGY

## Research Methods

In research, methodology refers to a certain way of examining social realities (Strauss & Corbin, 1998). Before choosing a particular methodology, I considered different methodological approaches. Neuman (2003) reports there are three approaches to social science research methods namely: positivistic; interpretive; and critical. As I intend to only provide a brief overview, it is important to note that existing research approaches are not limited to the three noted by Neuman (2003). The oldest approach is positivism that evolved during the post-Middle Ages and is the most common approach. The positivistic approach uses deductive logic, focusing on quantitative data collection. Through experiments and statistical analysis, researchers test various hypotheses to arrive at probabilistic causal laws to predict human behaviour. This approach criticizes analyzing people as numbers and questions if generalizations are applicable to real life experience (Neuman, 2003).

Neuman (2003) outlines that interpretivism, the second approach, originated with the German researchers, Max Weber (1864-1920) and Wilhelm Dilthey (1833-1911). The goal of the interpretive approach is to examine the social context which individuals subjectively ascribe meaning and understanding in their natural environment. The interpretivist studies “meaningful social action, not just the external or observable behaviour of people” (Neuman, 2003, p. 76). Positivists regard findings in this approach, as characteristically biased and unscientific. Their analysis differs from those of the Interpretists who rely on facts derived from meanings embedded in specific contexts and therefore are not so precise nor independent of values (Neuman, 2003). Interpretivists, as

well as Positivists, receive criticism for studying the world without intending to evoke change and improving social contexts (Neuman, 2003).

A third approach, critical social science, as reported by Neuman (2003), historically reflects the work of Karl Marx (1818-1883) and Sigmund Freud (1856-1939). This empowering model of research seeks to critique and change social realities of individuals. As an action-oriented approach, it values gained or new knowledge; however, critics view proponents of the interpretive approach as too subjective.

Drisko (1997) reports social work research should be “important, timely and of predictable interest to an audience, and specific research questions should be relevant, illuminating and of practical significance” (p.186). Methodology, as used by social work researchers, reflects two approaches known as positivistic and naturalistic (Rothery, 1993). Positivistic research, as mentioned previously, is recognized as quantitative research supporting a method of problem solving by using numerical data to test a hypothesis (Rothery, 1993). In problem solving, the qualitative method lends itself to discovery, using descriptive data to present findings. Unlike quantitative studies, the researcher does not form any preconceived theories about their findings and builds upon theoretic principles, and patterns of meaning—hermeneutics, as opposed to testing hypotheses. Although debate existed in the past between different methodological approaches (Neuman, 2003), now, social work researchers receive recognition for the strengths and unique qualities each methodology has to offer (Drisko, 1997). As Taylor (1993) states, “... there is no one scientific or empirical method of problem solving, and both naturalistic and positivistic approaches have a solid place in the social work research enterprise” (p.53). For some, triangulation methods (Strauss & Corbin, 1998) facilitates

the application of both approaches within the same study—each method informing the other adding depth and understanding of the outcome findings.

Following the decision to use qualitative methodology, I researched the appropriateness of different methods. Under the umbrella of qualitative research, I noted several methods of analyzing data. Although this is not an exhaustive list of methods, Creswell (1998) summarizes the five main types of qualitative research as follows: a biography; a phenomenological study; an ethnography; a case study; and a grounded theory study. A biographic study refers to the method of a researcher selecting an individual, either living or dead, to examine through archival documents and other records. Popular in the humanities, a biography often highlights the pivotal points in a person's life that has contributed to shaping their existence (Creswell, 1998).

A phenomenological study involves exploration of the meaning of a particular life experience of several individuals. Researchers search for subjects with the experience under investigation and must decide how and in what way they use their personal experiences in the research while striving to harmonize meaning and experiences thorough rigorous analysis (Creswell, 1998). An ethnography involves the study of a particular group's culture over a prolonged period of time through observation and one-on-one interviews. Ethnographies offer an insider's perspective, when one wants to gain knowledge of the experience of a social group. A case study is "the exploration of a 'bounded system' or a case (or multiple cases) over time through detailed, in-depth data collection involving multiple sources of information rich in context" (Creswell, 1998, p. 61). All of these approaches can pose significant challenges to researchers as they require specific skills, must adhere to prescribed protocols and often extensive data collection

(Creswell, 1998).

The final approach, grounded theory, involves several levels of coding procedures to develop findings and theory formation (Drisko, 1997). The researcher must be able to associate the evidence with the theory created, and ensure that it is precise and rigorous in nature (Neuman, 2003). Sociologists Barney Glaser and Anselm Strauss initially founded this approach. Presenting relevant findings to both academic and nonacademic audiences is often the hope of grounded theorists (Strauss & Corbin, 1998). This approach consists of the following three main areas: data [i.e., interviews, documents]; procedures [i.e., coding information] and written and/or verbal reports [i.e., journal articles, books] (Strauss & Corbin, 1998). The purpose of a grounded theory study is to create or uncover new inductive theory about particular situations. Theories are also subject to replication and generalization (Neuman, 2003). The challenges of using this method include: using research objectivity in allowing substantive theory to occur; applying specific steps; determining sufficient data analysis; and theory development (Creswell, 1998).

In selecting a suitable method, I felt it was necessary to capture the complexity of identifying and carrying out evidenced-based practices in the provision of services to the dually-diagnosed population. Given a review of all the types of qualitative research methodologies, it was clear that grounded theory was the best selection due to the nature of this study's research questions and desired timelines. From this approach, I anticipate that theory surrounding the perceptions and delivery of services to the dually-diagnosed population will allow service providers to examine areas that require further attention. Another desired result of this inquiry is to identify best practice guidelines and accommodations to improve outcomes of service for the dually-diagnosed population.

For the data collection, using recommendations from Strauss and Corbin (1998), I determined that a combination of different sources would be best. This study involves collecting data in the following ways: 1) semi-structured key informant interviews [see Appendix E], as explained further on pages 52 through 53; 2) incorporation of relevant program guidelines and Ministry documents; and 3) scholarly literature on best practices. Collecting various sources of data allows for a more in-depth analysis. Typically, findings from such a study are strengthened as further empirical testing of the phenomenon is possible as more associated variables are identified and replicated (Creswell, 1998).

### *Research Questions*

The following research question captures the essence of this study: What are the perceptions of service providers regarding best practices for dual-diagnosis clients at the agency, community and inter-organizational levels in London and Middlesex County?

Objectives related to this inquiry are as follows:

- What is the perception of prevalence of dual-diagnosis clients in caseloads of service providers in London and Middlesex County?
- What is the extent of collaboration between community agencies in the provision of mental health services for clients with a dual-diagnosis?
- What are existing gaps in serving this population in London and Middlesex County?
- What are the perceptions of best practices with this population among service providers in London and Middlesex County?
- What are the current models of care used in London and Middlesex County to

treat this population?

### *The Sample*

Windsor Regional Hospital (WRH) originally encouraged and supported this research, which was part of a larger original study related to the provision of specialized out-patient health services for Windsor-Essex County in 2004. Due to timeframe variations an unfavourable time line evolved and consequently, Windsor Regional Hospital withdrew their support. However, the London and Middlesex County Dual-Diagnosis Committee indicated interest in this inquiry. Therefore, the study was moved to that vicinity. The study is specific to this locale and composed of health service providers from London and Middlesex County. Research Ethics approval was sought and achieved allowing this project to proceed.

The region of London and Middlesex County is located at the forks of the Thames River, halfway between Windsor and Toronto, Ontario. The geographic area of this locality is 2,233.37 square kilometers with a population of 432,451 (Statistics Canada, 2002). This area is home to the University of Western Ontario housing one of the few developmental disabilities divisions within the Department of Psychiatry in Canada. London and Middlesex County is also well known for its state-of-the-art medical facilities and healthcare programs.

Thorough personal contact and snowball techniques, key informants were recruited with help from the Coordinator of the Developmental Disability Division at the University of Western. Volunteer key informants (N=11) selected for interviews were from various collateral agencies (for example, London Community Living, Canadian Mental Health Association, Regional Support Associates, WOTCH Community Mental

Health Services, Strathroy Assertive Community Treatment Team). Key informants met the inclusionary criteria of frontline managers and senior administrators that have been working in London and Middlesex County with this population for at least three years. I began contact with key informants by e-mail and forwarded all relevant documents needed (e.g., Letter of Information, Consent Form) asking them to take part in the study [see Appendixes A & B]. Subsequent contact, included detailed explanation of the purpose of the inquiry. Clarification of mutually convenient interview times were made available as needed. The locations for the semi-structured interviews I arranged were either at the key informant's host organization or another preferred location as specified by the key informant. Each face-to-face interview I conducted was about one-hour in length and I audio-taped responses. Later, an independent party transcribed the audio taped interviews. This particular method of recording responses compensates for the possibility of researcher bias in the collection of data (Lincoln & Guba, 1994) and is a typical strategy for data collection in qualitative research.

#### The Interview Schedule

Interviewing commenced after approval from the London-Middlesex County Dual-Diagnosis Committee [see Appendix C] and final clearance from the University of Windsor Research Ethics Board (REB) received on June 10, 2005 [see Appendix D]. I completed the data collection phase and transcription of interviews by October 2005.

The interview framework used open-ended questions as illustrated in Appendix E. The data collection process is designed to collect both quantitative and qualitative data meeting the definition of a triangulation process (Flick, 2006; Strauss & Corbin, 1998). Key informants were asked about the following:

- their agency's role in the service delivery system (e.g., "Does your organization provide services to clients with dual diagnosis disorders? How many individuals do you serve in programs for clients with dual-diagnosis disorders?");
- beliefs about best practices (e.g., "What do you believe is the ideal/best practices approach to the delivery of services for clients with dual- diagnosis disorders?");
- what role they feel that in-patient facilities should play (e.g., "In addition to inpatient services, what model of treatment do you think in-patient facilities should utilize in the delivery of outpatient/outreach services for these clients?"); and
- their beliefs about organizational collaboration (e.g., "How would you describe the relationship that your organization has with in-patient facilities? What do you believe would be the ideal linkage or interface that your organization should have with in-patient facilities?").

These topics form the main probative questions that reflect the objectives of this study described on pages 50 and 51.

#### Cultural and Third Party Review

In conducting qualitative research, the criterion that Lincoln and Guba (1985) outline for showing trustworthiness contributed to my self-awareness in the data collection phase. An increase in credibility results when a third party provides an internal check on rigor (Lincoln & Guba, 1985). The ethics review boards consulted for this study examined the instrument, before its use. I pre-tested the key informant survey with a previous Thesis Chair before administration to ensure the questions are not only valid, but clear, neutral and open-ended (Grinnell Jr., Rothery, & Thomlison, 1993). As the

survey is merely a semi-structured guide, such pilot testing provided this researcher an opportunity to explore the use of probing questions to maximize the quality and depth of responses from key informants.

Another limitation of particular importance is researcher bias that may transpire due to a researcher's involvement in a study. For example, Tutty, Rothery, and Grinnell (1996) state "...qualitative researchers carry their own cultural assumptions into the field, they risk imposing a foreign frame of reference in interpreting the experience and meanings of the people they study" (p. 18). I provided a cultural review of basic assumptions and expectations, found in the proceeding section. The following comprise my main assumptions about the dual-diagnosis population: they are a stigmatized (Corrigan et al., 2003; Kirby, 2006); they experience discrimination when accessing services and when trying to secure appropriate housing (Kirby, 2006); they fall between the cracks of two provincial Ministries (VanderSchie-Bezyak, 2003); there exists problems with diagnostic accuracy (Bradley & Burke, 2002; Fletcher & Poindexter, 1996); they are lacking adequate primary care (Corrigan et al., 2003); they require accommodations in treatment due to limited cognitive abilities and communication issues (Whitehouse et al., 2005); and, more coordination between service providers is required (MOHLTC, 1999a, 1999b). Becoming more aware of personal thoughts and feelings related to the subject matter ensures I note findings consistent and contrary to my expectations as documented in field notes. In turn, this further reduces the possibility of researcher bias. Clarifying and reaffirming meaning with key informants provides another guard against research bias.

### *Cultural Review*

In qualitative inquiries, the researcher acts in the capacity of an “instrument” (Lincoln & Guba, 1981; McCracken, 1985). This has implications for the observations that take place and the analysis that follows, influenced by the researcher’s thoughts, values, biases and assumptions. It is this reason that a cultural review is an important step in the research to show trustworthiness.

I have been working in the healthcare field for over ten years in a number of roles. I was first witness to the oppression of the population living with dual-diagnosis through my employment with Goodwill Industries where I provided vocational counseling and support. In the emergency department of Hotel-Dieu Grace Hospital, Windsor, Ontario, I was a Crisis Worker for the Community Crisis Centre during the years of 1999-2000 and saw the challenges these individuals experience in obtaining appropriate services. In 1999 I was hired as a case manager for clients with serious mental illnesses at the Canadian Mental Health Association, Windsor-Essex County Branch. In 2006, I moved into the position of Concurrent Disorders Program Leader, providing clinical guidance, education and support to a unit with over sixty case managers. As a result of my experiences in the mental healthcare field, I have had the opportunity to work directly and indirectly with the dually-diagnosed. The variety of roles that I have held provided me with first-hand care-provider experience with the complex issues that must be dealt with and attempts to be managed and overcome by those with a dual-diagnosis.

As documented in the report, *Out of the Shadows At Last—Transforming Mental Health, Mental Illness and Addiction Services in Canada*, Canada lacks nation-wide information on mental illness (Kirby, 2006). Estimates suggest that one in five Canadians

is affected by a mental illness (Health Canada, 2002, p. 17). Despite the knowledge and resources available to our society, those with mental illnesses continue to be stigmatized. A negative emphasis on issues for this population contributes to the stigma. Many know very little about mental illness and what people do know is often not accurate. When the media focuses on negative instances, it may inadvertently exploit this population. Discrimination about employment opportunities and securing satisfactory housing are continuing concerns for those with a dual-diagnosis (Kirby, 2006). Also, reinforced myths add to the stigmatizing experiences (CAMH, 2005; Kirby, 2006).

Involvement with the two systems (the developmental system and the mental health system) adds to their frustrations and they tend to fall through the cracks. At times, added interaction with healthcare and the judicial system adds to the layers of complexity, confusion and frustration for all concerned. Although proposed, in Windsor-Essex County and London and Middlesex County, a formal coordinating body of service providers does not exist (as of 2008) to ensure seamless service delivery. Despite efforts in organizing networks of specialized care through the Ministry of Community and Social Services, it is difficult to surmise if this has made a significant improvement for this population. Sometimes, individuals transfer back and forth between service providers due to ambiguity about their primary diagnosis. As well, often because of difficulty in communication and self-expression, individuals fail to receive an accurate diagnosis. Behavioural disturbances, for example, in those with developmental disabilities are often interpreted as a behaviour problem, when in fact it is a symptom of a mental health issue such as depression as earlier described (Hurley, 1989). This results in inappropriate services and further frustrations.

As documented in the literature, those with dual-diagnoses do not receive sufficient primary care (Kirby, 2006). Although there might exist equal opportunity for medical care, there fails to be equitable access (London Chamber of Commerce, 2007). Further impacting this issue is the lack of family practitioners and psychiatrists in London and Middlesex County, rendering this region severely under-serviced (MOHLTC—Underserviced Area Program, 2004).

Due to cognitive deficits, interventions are customized to client's needs and functioning. It has been my experience as a frontline practitioner, that interacting with this population takes greater skill and effort. For example, communication with this population often consists of simple language, concrete direction and repetition. Workers without proper training may mistake failure in a client's follow-through as treatment incompliance, rather than an issue in understanding or difficulty in learning. As well, greater efforts in coordinating between family members and other service providers are required to ensure quality in service delivery (MOHLTC, 1993, 1999a, 1999b, 2002).

In summary, I am interested in establishing best practice standards for treatment and services for this vulnerable population as I value equitable services designed to meet the holistic aspects of personal well-being. I believe that there should be more cross training and specialized education available to service providers in the community to facilitate appropriate, responsive and effective programming for those with a dual-diagnosis. The stigma this population experiences will hopefully decrease as the level of education in the community increases. As well, I believe that there must be more coordination between service delivery systems, which will eventually improve outcomes for this population attempting to eliminate stigma, prejudice, fear and isolation of the

dually-diagnosed. It is with this cultural context that I undertook this study, attempting to learn more and discover meaning of the needs and life of those with dual-diagnosis and their care providers.

### Contextual and Supporting Data

To understand data in the qualitative context, it is important to gain an understanding of the issues about a community's service delivery system (Posovac & Carey, 2003). For example, this systematic document review differs from a bibliographic review. In finding out the context of what is and what is not possible to offer in mental health services for this population, the researcher reviews relevant documents about specialized mental health delivery in London and Middlesex County. This review considers service provision guidelines found in the following mental health reform reports: *Making It Happen* (MOHLTC, 1999a, 1999b); *The Time is Now: Themes and Recommendations for Mental Health Reform in Ontario: Final Report of the Provincial Forum of Mental Health Implementation Task Force Chairs* (MOHLTC, 2002); and *Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada* (Kirby, 2006) . It also includes other applicable directives from the Ministry of Community and Social Services (MCSS, 1997; MCSS 2006; MCSS, 2007). I asked key informants to identify additional community documents related to the topic of study, incorporated in this review when found suitable; however, key informants did not identify any documents other than the policy documents from the MCSS and MOHLTC. To preserve a current and innovative perspective, I concentrated on best practice examinations of all relevant government documents, professional practice guidelines and academic literature from the past ten years. To ensure a systematic and comprehensive

review, I conducted searches using web-based databases at Windsor Regional Hospital and the University of Windsor (which includes collective holdings of Wayne State University and University of Michigan).

#### Ethical Concerns

Although I set up precautions to safeguard the identity and responses of participants, limitations surfaced. Established measures of keeping confidentiality do not guarantee the anonymity of participants, as their direct quotes and organizational affiliation may appear in the final report to support themes or further explain viewpoints (see Appendixes A & B). I told key informants that they may choose not to answer a question, or withdraw certain information. Also, with organizational affiliations, each participant in the study will review their quotes before inclusion in the final report. By signing the consent form, each participant (or key informant) shows their understanding and acceptance of the conditions related to taking part in this study. I told all key informants that they have the choice of receiving a copy of the final report and any feedback that may be available.

#### The Process of Coding and Developing Themes

Often qualitative researchers conclude their studies by identifying major themes that arise from their data. Others may employ a combination of themes and interpretations in developing theory relevant to the phenomenon studied (Tutty et al., 1996). Creating themes is a continuing process that takes place throughout coding. For example, themes will be under development in this study while creating research questions, conducting key informant interviews, identifying ideas, creating categories and writing code notes. From general patterns in the data, the focus will become more

abstract and by using a constant comparison method, an understanding will develop between the concepts that connect the categories and themes (Tutty et al., 1996). Morse and Field (1995) base theme development on meanings in the data and a true understanding of the phenomena. They suggest that thematic analysis is often difficult as it involves abstract thinking about the representing ideas signaled by the data, rather than concrete examples provided by participants. As theory can be “baffling because it comes in so many forms” (Neuman, 2003, p. 50), creating a strong thematic framework is an important step in research, especially when using themes to develop theories.

Strauss and Corbin (1998) define coding as “the analytic processes through which data are fractured, conceptualized, and integrated to form theory” (p. 3). A microanalysis follows the data collection phase in grounded theory methodology. This is a detailed, combined analysis of line-by-line and sentence analysis of the information gathered to create new ideas or categories. This step uses a combination of open and axial coding. Categories reflect “concepts derived from the data that stand for phenomena” (Strauss & Corbin, 1998, p. 114). Creswell (1998) points out that in open coding, the researcher “forms initial categories of information about the phenomenon being studied by segmenting information” (p. 57). After looking further at the data for properties or subcategories, axial coding, defined as reconstructing the data in a different way, helped in developing central phenomenon and expanding linkages to the subcategories. From this point, implementation of the selective coding process results in theory revision and hypotheses.

Reflecting on the data collected, 30 categories of codes were set aside as being relevant to this study, from which I aligned selected descriptors to each of the five main

research questions to reduce the possibility of biased results about the ideas identified (Williams, Urau, & Grinnell, 1998). This provides a framework to further explore theoretical ideas associated with the pre-determined research questions and categories (Tutty et al., 1996).

The first research question, “What is the perception of prevalence of dual-diagnosis clients in caseloads of service providers in London and Middlesex County?” relates to a special category of codes set aside labeled as (C1) Prevalence.

Categories related to question 2, “What is the extent of collaboration between community agencies in the provision of mental health services for clients with a dual-diagnosis?” includes the following: (C10) Alliances with Other Service Providers; (C28) Sharing Knowledge; (C29) Coordinating Services; and (C30) Advocating for Change.

The categories of codes associated with question 3, “What are existing gaps in serving this population in London and Middlesex County?” includes: (C15) Unaware of Community Resources; (C16) Lack of Expertise; (C17) Stigma; (C18) Issues with Diagnosing Dually-Diagnosed; (C19) Service Gaps; (C20) Accessibility; (C21) Service Capacity; (C22) Issues between Ministries; and (C23) Implications with In-Patient Services.

In response to question 4, “What are the perceptions of best practices with this population among service providers in London and Middlesex County?” the category of codes entitled: (C24) Person-Centred; (C25) Specialized Services; (C26) Community-Based; and (C27) Responsive Services were assigned.

Question 5, “What are the current models of care used in London and Middlesex County to treat this population?” collated into the following categories of codes as

follows: (C2) Housing and Supports; (C3) Social Recreation Programs and Vocational Activities; (C4) System Navigation; (C5) Specialized Programs; (C6) Community Support Services; (C7) Advocacy; (C8) Training/Education; (C9) Special Initiatives; (C11) Primary Care; (C12) Emergency Services; (C13) Information and Referral Services; and (C14) Financial Support Services.

After aligning the categories of codes to the research questions, I reviewed the transcribed interviews again to assist in further refining the development of themes. Themes are abstract concepts used in interpreting categories discovered in the coding process (Williams, Unrau, & Grinnell, 1998). Chapter 4: Findings, provides further detail regarding the formation of themes in this research study.

Qualitative researchers in the field have strongly recommended keeping a journal throughout the research process (Tutty et al., 1996). As noted by Lincoln and Guba (1985), a researcher's journal should contain entries related to the research method selected and notes regarding issues of process and credibility. This strategy allows for an 'audit trail' to ensure that there were no major flaws in the research conducted (Tutty et al., 1996, p. 99). Throughout this process, I have recorded code notes in the form of field memos and diagrams to reflect my analytic thought. This will help later in the generation of theory and contribute to the final analysis (Williams et al., 1998).

#### Concerns and Process Issues in Showing Trustworthiness

All research studies have flaws or limits associated with their respective methods. It is the responsibility of the researcher to limit, or if possible, remove such flaws so as to strengthen the validity of their findings. Patton (2002) contends that there are "no rules for sample size in qualitative inquiry" (p. 244). Thus, recruiting a large, random sample

of the population will not necessarily ensure that data gained reflects the study's research questions. For this particular study, the sample size is small, consisting of eleven interviews. In addition, the sample is not random, but purposeful. The key informants were identified and approached based on their noted credibility and depth of knowledge in this area of study. Partly due to the concerns for the aspects of informed consent and anonymity and the higher ethical obligation of protecting the participants, service recipients were not included in this study. The findings are specific to London and Middlesex County, therefore issues of generalizability exist. In accounting for the limitations mentioned above, I considered the nature and purpose of this exploratory study—to determine best practices for this client population and as a bridge to identifying service delivery gaps in London and Middlesex County.

The instrument is a semi-structured key informant survey that I mostly designed with help from a previous Thesis Chair. The format of the survey uses open-ended questions and is about one-hour in length (see Appendix E). One limit of the instrument is that it does not incorporate the use any standardized scales or tools. To increase the instrument's internal validity, I had the interview framework reviewed by a member of the previous thesis committee and two senior administrators at WRH. Feedback from these experts was integrated into the instrument. Pre-testing the instrument ensures that the questions are clear, to the point, and are not double-barreled or negative (Grinnell Jr. et al., 1993). This principle guided the final interview instrument and the finalized version was applied to all key informants in the second setting. In addition, the interview framework successfully passed all necessary Research Ethics Board (REB) reviews at the time, from both the University of Windsor and Windsor Regional Hospital (WRH). As

the interview framework had been through Ethics Review, the Chair of the London and Middlesex County Dual-Diagnosis Committee did not request an additional Ethics Review and supplied a letter of support for this study on behalf of the committee.

Triangulation is the process of incorporating multiple perspectives to improve the trustworthiness of the research. This study uses two forms of data triangulation. The first form of triangulation involved was in arranging thesis committee members to review the data collection rules, adding validity to the study's findings (Patton, 2002). To further strengthen the study's findings, the key informant's responses will not be the sole source of data used in the study. The second form of data triangulation is conducting a systematic review of best practice literature and relevant government and program documents.

To increase the accuracy of data collection, I audio-recorded the responses of key informants, as opposed to taking detailed field notes. Audio recording during the interview allows the researcher to remain a more attentive listener and focused upon the exchange of information taking place (Patton, 2002). Transcribing the audio-recorded interviews plays a very important role in providing the researcher with raw data for analysis and lessens the likelihood of any errors, omissions, or misinterpretations. Another issue related to researcher bias involves the analysis of the transcribed interviews. Apart from issues related to the accuracy of the raw data, this researcher, using grounded theory techniques (Strauss & Corbin, 1990), must successfully extract themes and patterns from the transcripts. For increasing inter-rater reliability and reducing the probability of coding errors, I coded themes from the transcripts and reviewed them with a member of the thesis committee as suggested by Cooper (1998). As

mentioned previously, I used peer debriefing to further develop insights about the data collection, analysis and implications of the results.

Finally, the second set of limitations that must be considered in the data collection phase of this study includes: random errors about the transient qualities of the key informants; external factors; and administration of the instrument. Key informant transient qualities refer to mood, motivation, and fatigue. External factors refer to physical setting and the presence of a tape recorder. Factors related to administering the instrument include the researcher's behaviour and physical appearance. In accounting for these potential limitations and in an attempt to mitigate their negative effects, I arranged interviews at a key informant's convenience, and at a location of their choice (e.g., key informant's workplace). To avoid researcher and key informant fatigue, I imposed consistent time limits to ensure that interviews did not exceed 1½ hours. I focused on building rapport and remaining observant about the mental, physical, and emotional state of the key informants during the interview process. Accommodations were made for some of the issues such as keeping flexibility whereby interviews needed re-scheduling, changing the order of questions, providing selective feedback, and using probing questions when necessary to gather a higher quality of data. All these variations are considered as acceptable in the qualitative research field (Patton, 2002).

Conducting member checks is the final strategy used in this study to further show trustworthiness. This involves the researcher seeking feedback from the study's participants (Williams et al., 1998). The strength of a study's findings are greatest when participants can provide validation by recognizing and understanding the conclusions made by a researcher, however that is not always the case (Neuman, 2003). The

researcher decides whether to hold or refute their feedback when there is disagreement (Tutty et al., 1996). Seeking feedback validation from key informants until they reflect approval and agreement is one hallmark of trustworthiness.

### Summary of Methodology

Chapter Three presented the interpretative approach used to explore the best practices of mental health services in the dually-diagnosed population. In this approach, there were no preconceived theories. This practical qualitative approach employed research questions and a sample of key informant interviews (N=11) from a cohort of mental health service providers in varying capacities. Each of the participants responded to a semi-structured survey. Consideration of cultural implications involved internal checks and pre-testing of the instrument. A previous internal chair and an external ethics review board reviewed the instrument. I also conducted a personal cultural review to further identify and minimize any risk of researcher bias. Ethical dilemmas considered for this research study included issues of confidentiality. Before the interviews, all participants reviewed and signed consent forms outlining such concerns, rights, and liabilities. I used grounded theory in the coding, where I linked categories to research questions for further analysis. In showing trustworthiness, I used data triangulation by collecting best practice literature, key informant survey responses, member checks and input from the primary and secondary thesis committees. I solely conducted the key informant interviews by using the same semi-structured survey with tape recording process. Later, an independent party transcribed the interviews. All these factors were incorporated to provide a solid foundation supporting the principles of validity and reliability of findings needed in this study.

## CHAPTER 4: FINDINGS

This chapter provides an outline of the following categories of information: 1) a profile of the key informants and 2) results from the semi-structured interview survey. The main themes, sub-themes, and categories of codes represent the results. The use of quotes from key informants explains important points. I intended to link key informant's positions and associated organizations with each quote. Although I received ethical clearance to include affiliations, due to the close-knit nature of the London and Middlesex community and responses of a sensitive nature, my secondary thesis committee advised that this action could have a negative impact. Thus, to reflect the nature of the ethical consent, I decided to report quotes anonymously.

### Key Informant Profile

Fourteen key informants took part in the 11 interviews, as three key informants requested permission to include a colleague. I conducted interviews in London and Middlesex County at each key informant's place of employment. Fifty-seven percent of key informants were from mental health organizations and 43% were from the field of development disabilities. Of the key informants, 36% were male and 64% were female. All key informants, with the exception of one, held management or senior administrative positions. At the request of a key informant that was a manager, one non-management staff person, acting in the role of a coordinator, was included in an interview after I was able to confirm their expertise in the field. Key informants described their formal titles as: Manager, 36%; Coordinator, 29%; Director, 21%; and Supervisor, 7%. I did not seek educational credentials, however, most informants commented on their post-secondary education, their leadership in the community and involvement in local planning and

networking groups. To assure a minimal level of expertise, each key informant confirmed that they had at least three years experience working in the field with the dually-diagnosed population. With regard to ethnicity, none self-identified as a member of any minority group. Informants ranged in estimated ages between 32 years to 58 years and most fell between the ages of 35 and 45 years. In summary, key informants represented well-trained, knowledgeable and seemingly committed members of the selected geographic community who work with clients with a dual-diagnosis. No specific cultural, ethnic or diverse population representatives were identified.

Member checks were another technique of showing trustworthiness in the research process. One key informant declined to respond due to their concern of a negative impact on their community status. Of the fourteen key informants, a total of five submitted detailed feedback. All respondents agreed with my interpretation of the findings and noted that it was reflective of the current state of service provision in London and Middlesex County in 2008.

#### Semi-Structured Interview Findings

In the data analysis, I identified three major themes with 8 sub-themes and 30 categories of codes. The results are presented below using a framework developed by Tutty, Rothery, and Grinnell (1996). Main themes are represented in headings that are centred Times Roman uppercase and lowercase. Sub-themes are represented by headings that are flush left and italicized. Categories of codes are represented by indented headings in italicized text ending with a period.

#### Main Theme 1: Service Delivery

##### *Sub-theme 1: Direct Service Provision*

##### *C 1: Prevalence*

- C 2: Housing and Supports*
- C 3: Social Recreation Programs and Vocational Activities*
- C 4: System Navigation*
- C 5: Specialized Programs*
- C 6: Community Support Services*

*Sub-theme 2: Indirect Service Provision*

- C 7: Advocacy*
- C 8: Training/Education*
- C 9: Special Initiatives*
- C10: Alliances with Other Service Providers*

*Sub-theme 3: Other Community Resources*

- C 11: Primary Care*
- C 12: Emergency Services*
- C 13: Information and Referral Services*
- C 14: Financial Support Services*

**Main Theme 2: Barriers to Mental Health Services**

*Sub-theme 4: Knowledge Gaps*

- C 15: Unaware of Community Resources*
- C 16: Lack of Expertise*
- C 17: Stigma*
- C 18: Issues with Diagnosing Dually-Diagnosed*

*Sub-theme 5: Service Delivery Issues*

- C 19: Service Gaps*
- C 20: Accessibility*
- C 21: Service Capacity*

*Sub-theme 6: Confusing Policies*

- C 22: Issues between Ministries*
- C 23: Implications with In-Patient Services*

**Main theme 3: Identifying Best Practices**

*Sub-theme 7: Identification of Best Practices*

- C 24: Person-Centred*
- C 25: Specialized Services*
- C 26: Community-Based*
- C 27: Responsive Services*

*Sub-theme 8: Collaboration*

- C 28: Sharing Knowledge*
- C 29: Coordinating Services*

*C 30: Advocating for Change*

## Service Delivery

The service delivery system refers to the types of services identified by informants, as offered in the community to those with a dual-diagnosis. This main theme contains three sub-themes and the following respective categories of codes:

*Direct Service Provision*

This sub-theme refers to direct treatment services identified by key informants as offered by either the mental health organizations or developmental disability agencies in the community.

*Prevalence.* The majority of the key informants estimate prevalence of dual-diagnosis ranging from 10% to 50%. Very few are able to provide specific numbers of the clients served with a dual-diagnosis. Prevalence appears to be affected by the degree of disability and whether there is a confirmed diagnosis. Many of the key informants rely upon what best practice literature reports, as illustrated in the following quotation:

I think that we just always go with what the research is getting about 33 and 35% of the [developmentally-delayed] population ... we always just rely on the 33 magical number that seems to be fairly standard for persons with the dual-diagnosis.

Contributing to the issue of determining prevalence are inappropriate assessment tools that rely on self-report measures. Depending on the severity of their disability, individuals with a dual-diagnosis may have little to no ability to speak.

*Housing and Supports.* The literature acknowledges the lack of appropriate housing for this population given two main factors: a growing shortage of affordable rental housing (Goering & Durbin, 1990); and increasing numbers of individuals in poverty (Baum & Burnes, 1993; CMHA, 1998; Surber et al., 1988). Discussion on

various housing services include rehabilitation housing, staffed twenty-four hours continuously a day, to semi-independent group homes and various housing initiatives, located in residential areas subject to case management services. A more severe disability or lack of skill would necessitate a more supportive housing environment such as a 24-hour staffed group home. One key informant suggested a “housing advocate” represents a key ingredient for improved housing services as noted in the following quotation:

... she is connected to most of the housing units in London and she has very good rapport with a lot of our private landlords who support many people on ODSP [Ontario Disability Support Program].

*Social Recreation Programs and Vocational Activities.* Social and vocational activities noted as a part of a person’s treatment plan, identified increased quality of life as an important reason. People with a dual-diagnosis have complex daily needs as expressed in the following quotation:

... typically a person with a dual diagnosis won’t fit into a typical day program. Their needs are too high so in order for us to take these people with the expectation of them fitting into the typical day program it’s not going work, so instead we plan around the whole day 24 hours and we find out what things they enjoy doing and participating in, then, we make sure that we plan accordingly ...

Key informants acknowledge the complexities in customizing social recreation and vocational activities for those with a dual-diagnosis, but remark that it is an important part of community integration.

*System Navigation.* Accessing services in the current health system can be confusing and challenging for those with a dual-diagnosis, as well as their family members. Key informants discuss three ways they help people through the flow of the service system. They identify access to necessary assessments for diagnostic purposes and services as an important item. Creating a coordinated central intake agency for

community-based services coordinated through one organization developed as a response to clients who needed significant services, explained by the following quotation:

... what was happening prior to that which was about six and a half years ago that you would have a client coming out of hospital and you needed them to be hooked up somewhere so you made a referral to WOTCH, you made a referral to CMHA [Canadian Mental Health Association] you made a referral here, you made a referral there, so everybody received to same referral, so it needs to be triaged—almost to find out who'd be more appropriate.

The third area, discharge planning, recognizes the challenge of moving clients from hospital to community. One key informant remarked:

The biggest piece for us is discharge planning, so even though we want them out of hospital and they want them out of hospital quick. That's not how our system works."

*Specialized Programs.* Services developed specifically for clients with a dual-diagnosis included tertiary care, as explained in the following quotation:

... people call us when they are kind of over their head and they can't get a lot of support or aren't getting a diagnosis or developing a treatment plan or strategy around it.

Other programs, not specifically designed for people with a dual-diagnosis, make accommodations for this population. They include Schedule 1 hospital beds, out-patient hospital services, mental health outreach and crisis services, multidisciplinary consultation services, chemical treatment, and developmental disability services. A common thread identified between organizations was an effort to meet the needs of clients that do not necessarily fit the criteria for service provision.

*Community Support Services.* Deinstitutionalization brought an emphasis on community-support services. This category of codes includes various short and long-term case management services with intensive community support services, composed of teams of professionals, as noted in the following quotation:

... we're a service community treatment team and by that we're also a multidisciplinary team that provides an integrated approach to people with mental illness and we also treat people with dual diagnosis and concurrent disorders. We have registered nurses which work with occupational therapists, vocational specialists, therapeutic recreationists. Some teams have addiction specialists and a psychiatrist with our team, and administrative assistant and myself.

On the other end of the continuum, less intensive community support services may not have an extensive team of professionals and may not be long-term. For many, less intensive services are in place on a limited time basis when a need is identified. If the circumstances should change for an individual who has received brief community support services in the past, they often receive priority access to address their issues to likely divert a crisis situation. One key informant described less intensive community support services as follows:

They are a case management team but they don't provide the same integrated treatment focus for service that we do. Theirs is more supporting and helping people to get things put back together if clients tend not to be as ill or complex ...

#### *Indirect Service Provision*

This sub-theme describes providing services to people with a dual-diagnosis in a non-direct way. It pertains more to the nature of relationships agencies have with one another and the work they undertake to ensure quality services for those with a dual-diagnosis.

*Advocacy.* Many key informants spoke of the role they play as advocates for their dually-diagnosed clients. Often it ensures that a client will receive necessary care, financial support or housing. It occurs in macro, mezzo and micro levels of practice.

Comments from one key informant were as follows:

... advocacy around, you know, tenant issues, you know, whatever may come up within a person's life. We're usually the one that's beside them with the doctor or

wherever...

On mezzo levels, advocacy occurs among service providers involved in the care of an individual with a dual-diagnosis. There are many alliances and active committees in that facilitate this in London and Middlesex County. Advocating for clients on a macro level occurs with various provincial committees and most recently with regional Specialized Networks of Care.

*Training/Education.* Improving services for those with a dual-diagnosis entails having professionals educated in knowing how to treat those with dual-diagnoses as well as providing continuing training opportunities. Agencies strive to hold in-service training or provide cross-training for staff, as noted in the following quotation:

The one thing that I see down the road is my staff getting educated from the health sector in everything to do with mental health—and the mental health staff getting educated by my people with regard to developmental disabilities. I think we've started to do that cross training between the two.

There are educational institutions offering programs specific to dual-diagnosis. Key informants also report being involved in the promotion of learning opportunities in this field at colleges and universities as indicated in the following quote.

... we just heard of a new schooling program that in this is from Grey/Bruce that told us... there was actually a course ... to take for dual-diagnosis so that you're educated in both— through a college...that's a huge initiative and we're going to find out more about it so we can bring it to London but you know that is a step in the right direction and it's the first I've heard of that because a lot of us have had either mental health backgrounds or developmental.

Other initiatives include the Ontario Developmental Services Career Connections Grant program which in November 2005, promoted individuals in a specialized service to complete their placements at a specialized developmental services agency (Ministry of Community and Social Services, 2006).

*Special Initiatives.* With an increased emphasis on clients with a dual-diagnosis and their complex needs, both Ministries engaged service providers to find solutions. The Ministry of Community and Social Services set up Specialized Networks of Care to allow service providers to share expertise. Another initiative is the introduction of teleconferencing. This eliminates the need to travel great distances for specialized treatment and keeps individuals in their community of choice. Key informants were very optimistic about future possibilities to improve services through various technological strategies. Since 2007, the Ministry of Health and Long-Term Care has been working on special initiatives, assisting service providers with e-health initiatives to improve the flow of health information.

*Alliances with Other Service Providers.* Organizations work in various capacities with one another in linking dual-diagnosis clients to suitable services. Key informants identified common ways for sharing expertise, such as, case conferences and committee membership. Most alliances identified were voluntary in nature with an absence of formal agreements. The need to bring service providers together in treatment planning is evident. However, it appears that this is an area that may require improvements given the proceeding comment from one key informant:

Every new person that comes along that goes into crisis you know you have to start from the beginning. We have to say, okay, let's talk about this person and bring everybody back, so I think we've a long ways to go.

The Dual-Diagnosis Committee has offered service providers a venue for building alliances as indicated in the following quotation:

Certainly we've tried to work back and forth, transitioning clients that way, and again, we all sit on the same networking committees and that kind of stuff where we can share issues, challenges, and all that as well.

The literature, including best practice recommendations from the Ministry of Health and Long-Term Care have outlined the need for shared service models of care between agencies (MOHLTC, 1999b). This includes cross sector planning and setting up formal service agreements between providers to create a comprehensive continuum of services.

#### *Other Community Services*

*Primary Care.* Most informants identified access to primary care as important. The overt nature of mental and behavioural symptoms often results in neglect of physical health. The following quotation is an example provided by a key informant about accessing primary care for a client displaying problematic behaviours.

... he might be constipated ... if he does become constipated you know ... everything will fall apart and it seems so simple but everything will fall apart. He's not gonna go grocery shopping, he's gonna feel real bloated, he doesn't know what's wrong, he can't communicate obviously .... Another added diagnosis of diabetes or something like that will complicate things for them again.

Key informants are quick to note that special considerations need to be made for those with limited communication as they are often not able to articulate concerns about their health. Commonly, it is behaviour that is uncharacteristic of an individual that indicates a possible mental or physical health issue that needs to be addressed.

*Emergency Services.* Many informants mentioned how they use community emergency services, such as, hospital emergency rooms. These services play a vital role in getting individuals immediate medical care when needed. Other key informants commented on positive relations that exist with local police officers, as pictured in the following quotation.

They've [police department] got a list of our clients—with the clients permission—so that if they get into any difficulties they call us first, you know,

find out what is going on, can you come meet me about Johnny to sort this out for you—get themselves into real trouble, you know, kind of stuff, so we’ve got that going on. It’s very helpful if we’ve had to bring someone into hospital that we were concerned about their safety or ours. The police have been helpful and been very good with us and with our clients....

However, key informants note that their good working relations with local police departments are largely due to the efforts of educating police officers. In addition to this, promoting the use of the mental health court to keep individuals with a dual-diagnosis out of the criminal justice system has also been found helpful.

*Information and Referral Services.* Key informants note that as the service delivery system is often unknown and access can prove challenging, several agencies are taking a lead role in providing information and referral services to clients and their family members. Providing these services has also been helpful for other service providers in the community. One key informant remarked:

We’re considered one of the access points for the community so we have the information referral service—we have referral from anyone, family members, whoever ....

Consistent in the literature, the Ministry of Health and Long-Term Care’s document *Making It Happen Operational Framework for the Delivery of Mental Health Services and Supports* (1999b) recognizes the following: streamlining access to services; less entry points; and centralized information and referral mechanisms.

*Financial Support Services.* Key informants mention the main source of income differs depending on a person’s primary diagnosis. For those with a primary diagnosis of a mental health disorder, they receive financial support through the Ministry of Health and Long-Term Care’s Ontario Disability Support Program (ODSP). For those with a primary diagnosis of a developmental disability, their main source of income comes from

the Ministry of Community and Social Services.

The literature indicates those with dual-diagnoses suffer from low socio-economic status (Ryan, 1993). This population often does not receive the basic resources and services they need (Surber et al., 1988). Due to poverty, often those discharged from hospital secure substandard housing which leads to a deterioration in their mental health, resulting in readmission to institutionalized care, thus perpetuating the 'revolving door syndrome' (CMHA, 1998). The following quotation characterizes the complexity of issues that are often found in this population that have limited incomes:

So you can see that a lot of our time can be spent running around trying to figure out how to help the person whose got some issues ... you know, poverty because they've run themselves in debt and, you know, they don't, may not be able to declare bankruptcy but they, maybe, you know, the homeless have issues—they're on the streets, they're down in the court system ... alcoholism, drug addictions, all of the things that may come into play.

Key informants were also concerned about the potential impact that the Local Health Integration Network (LHIN) would have on funding Ministry of Health and Long-Term Care programs. At the time of this survey, the Ministry of Health and Long-Term Care was still providing funding to service organizations. However, as of April 2007, the responsibility for granting health dollars transferred from the Ministry of Health and Long-Term Care to the Local Health Integration Network (LHIN). Thus, the Ministry of Health and Long-Term Care has assumed a stewardship role, which includes making recommendations to the LHIN and leading special initiatives.

#### Barriers to Mental Health Services

This second main theme identified impeding considerations for clients with a dual-diagnosis. This major theme contains the following sub-themes and associated categories of codes:

### *Knowledge Gaps*

*Unaware of Community Resources.* Many key informants lacked awareness of services available to clients with a dual-diagnosis outside their organizations. One key informant commented, “We have the DBM unit ... quite often... many of the front line staff at the emergency don’t even know what it is.” There is a general awareness for some, but unless the need occurs, service providers are not always current in their knowledge about services available. As stated by one key informant:

Certainly, there’s lots of services available out here and I’m not very well versed in what they all are—we seem to stumble upon things, like by chance, when we get asking, based on client needs and what’s going on.

In another instance the service provider may be aware of a service in the community but does not know the nature of the program’s service capacity, as explained in the following quotation:

I’m like, “Do you realize that there’s a ten year waiting list?” And you talk to them about the system, just to try and educate them a little bit, if they had no clue at all, what the services are actually like in London and Middlesex and you’re trying to work with them. They have a few that have been there done it, but it seems that they don’t talk to each other.

There is concern about the risk of misinformation to clients about available services. As reported in one interview, “We’re being told that many of the clients who come out of Southwest Regional Centre actually receive different information.”

*Lack of Expertise.* All informants reported a lack of expertise in treating clients with a dual-diagnosis, spanning across both the mental health and developmental disabilities fields. For example, key informants identified hospital staff, psychiatrists, clinicians, and rural police officers as having little to no training in dealing with this population. The following informant reported on the impact on people with a dual-

diagnosis, “If you hit that one person who’s uneducated or who does not care you’re going to be told this is a behavior problem and we’re not going to help you.” Key informants note that due to a lack of expertise, clients often do not receive access to the services they need or do not receive treatment to address their issues.

*Stigma.* Key informants reported the issue of stigma and the use of stereotyping are prevalent in this population.

I think often times because they have a diagnosis people feel that they don’t have to explain anything or tell them, they are, they should be treated like everyone else within their rights and if they say, you know, I don’t want to be, please don’t inject me with something I’m not aware, or please don’t you know with the last admission here I was very scared, this is what they did, they tied me to a bed.

The tendency to label individuals by their diagnosis and set them apart in areas of housing placements and services only contributes to discrimination. One informant made the following comment, “... acceptance in the community and the professional services I think were just always noted as being, we could do with more.” In another interview, a key informant recognized the impact of stigma on this population and reported, “... we shouldn’t really label by diagnosis.” Key informants report that more education and training needs to occur to reduce the impact of stigma on this population.

*Issues with Diagnosing Dually-Diagnosed.* In the literature, it was reported that researchers did not think it was possible for those with a developmental disability to have a mental illness until the 1970s (Bongiorno, 2001). Often, it is difficult to get an accurate diagnosis because of a clinician’s lack of expertise, as suggested by the following key informant:

... it’s a little bit harder to get that assessment because, maybe, not a lot of those people are trained to give the assessment with that background already present.

Limited assessment tools contribute to a lack of diagnostic clarity, as explained by the following quote, “It’s difficult ... because there isn’t a lot of tools in the therapeutic background that are developed for individuals with a developmental challenge ....”

Despite common deficits in communication and a need to rely on behaviours to identify mental status, it was stated that, “We know it’s difficult to get accurate assessments, but it’s possible if you adapt it.”

### *Service Delivery Issues*

*Service Gaps.* Although there was reported improvement in services, the majority of key informants discussed at length various areas of provision lacking for clients with a dual-diagnosis, as displayed in the following quotation:

I think it’s in the last five years the services and supports for the dual-diagnosed individual have improved dramatically. I think before they were ... it was sort of not haphazard, people were doing the best that they could but not really getting the services that were required. I think with the mental health and developmental services fields have, now, better understand there is a combination ... there are methods of support for all individuals regardless of whether they’re dual-diagnosis or not.

Informants identified prominent gaps, such as a lack of social recreation and vocational programs, limited clinical and mental health supports, lack of primary care, lack of specialized support, and limited housing choices. In addition to this, many key informants revealed that services are often not available to those with mild disabilities as mentioned in the following quotation:

In London/Middlesex I would say it’s very fragmented and very flawed right now. The fact the people who are receiving service are those that—the seriously mentally ill are receiving it is wonderful, but the fact that those who have moderate mental health issues and are trying to access support and they are falling through all the cracks and there isn’t anything out there is horrendous—you know, if they were able to provide some funding to help crisis a few years later, but if they don’t help these people, then they’re going to be the ones who do have a serious mental health issue in a few years, so provide a little bit of support to

them now, they may not need it later, but in the end they're going to need more. It is evident from the quotation above, that prevention services are also limited. Part of this may be attributed to service capacity issues and due to the way that mental health agencies are funded for specific diagnoses. Key informants further note unmet client needs due to the characteristics of inflexible service provision, service fragmentation and the deinstitutionalizing of clients with a dual-diagnosis.

*Accessibility.* London and Middlesex County in an effort to maintain fair access to services, has developed processes for centralized intake and waiting lists that are managed by a few key agencies in the community. The ability of clients to gain access to service was a major issue related to service provision issues. As suggested in the following quote, many key informants found services provided are based upon priority:

The teams that are there I think are being taxed very heavily. Although they give real positive and effective support, sometimes access can take time, unless it's a crisis.

As well, service agencies use a client's primary diagnosis in deciding eligibility, in absence of examining the appropriateness of their needs, as explained in this quotation:

Years ago people didn't get wrapped up with diagnoses. When somebody came to you they came to you because they needed some support and they needed some help with whatever it might be and then you figured out how to meet that, and now because there's so many people needing help, agencies are getting wrapped up with what's the diagnosis.

From key informants there appears to be a clear direction to base accessibility upon an individual's need for service.

*Service Capacity.* Key informants spoke about the inability to meet the needs of clients due to low capacity, "Right everyone is operating above and beyond their capacity." Most notably, all key informants mentioned the waiting list for suitable

housing. Other conditions affecting service capacity related to the worker's high caseload ratios and limited resources, as noted in the following quotation, "... the issue is you can talk all you want and if you don't have the resources you aren't going to provide the service." This has a direct impact on the quality of service as noted in the following quotation:

... as you know our caseloads are getting bigger and longer like more long-term with people, you know, and then, so it's making it harder to people who are still having ongoing issues that you're still helping them address and then you're getting those in crisis as well. So, it's making it much more difficult ... to have quality in our job for all the people we are working with.

From the reports of key informants, it is evident that the system must be reconfigured to create more capacity, especially if there is no additional funding available for more services.

### *Confusing Policies*

This sub-theme represented the complications that exist in two prominent areas of service provision due to conflicting or unclear policies. Key informants readily identified immediate issues, but often voiced frustration and spoke to the challenges of making changes and improvements.

*Issues between Ministries.* This area refers to confusing policies and the conflicts between the Ministry of Health and Long-Term Care and the Ministry of Community and Social Services. Most key informants noted difficulty in coordination, minimally in one main area. The following quotation pictures this difficulty:

You know originally, it was like, the Ministries would work together and have a separate branch that would work with this, but it never went anywhere, and they still, although they sit at the same table, they still have their same policies and still have their different mandates and guidelines and things. So, although they agreed verbally until they actually start working together employing some dollars on some projects ... they have to work together a little better.

Funding based upon a client's primary diagnosis poses another issue as it appears that a few individuals need a significant amount of community resources, as explained in the following quotation:

The problem is it's on only—3% of the population has a developmental disability, so therefore, only 3% of all those people with a mental illness have a developmental disability. And of that a very small—only 20% to 30% actually have a mental illness, so the number of people presenting to a health program is small compared to the masses that are trying to get help for mental health cases. In developmental services it is quite different because we provide services to individuals with higher needs and this group naturally has a higher need. So what we find is our agency—between 40 to 60% are dually diagnosed. So the volume of people we see is so much higher, the number of people with dual diagnosis, we see them every day, 100s of them ... so I think the challenge for the Ministry of Health is how do you coordinate the approach?

Another key informant commented about the perceived low priority for those with a dual-diagnosis in that there has been a lack of special funding for dual-diagnosis clients. Often service needs are met when agencies' mandates are general enough to offer such services.

*Implications with In-Patient Services.* Relations between community

organizations and local hospitals are also an area affected by confusing policies, as explained in the following quotation:

... there's always a push pull between community and hospital and even between some community agencies. On paper there's a legal or there are signed agreements among the players. In many cases that works extremely well and once in a while like any other, like the family, or like any other organization, once in a while it becomes a tad dysfunctional over certain issues.

Key informants from community and inpatient facilities recognize contributing conditions to this issue that include weak liaisons and lack of discharge planning with follow up. The proceeding quotation captures one informant's perceptions about the nature of the relationship between their organization and the local hospital:

... the liaison piece isn't as strong as it should be and the awareness of the

population probably isn't as strong and who do they call for help and support. We don't have a formal network to do that ... you don't have those relationships in place and as a result you see sort of a compartmental type strategy of treatment going on in the hospital—within the walls.

Other factors key informants cite include differences in professional cultures, consent issues and a lack of expertise that requires a high degree of advocacy to obtain appropriate treatment.

### Identifying Best Practices

The third main theme reflects on practices providing services for clients with a dual-diagnosis. This major theme contains two sub-themes and the following categories of codes.

#### *Identification of Best Practices*

This sub-theme refers to ideas that key informants identified as best practices in the providing services to those with a dual-diagnosis.

*Person-Centred.* Many service providers cited this model of client care as a best practice. The essence of this approach is captured by a key informant's quotation, "... looking at the whole person's life, goals, dreams, aspirations—in a positive sense." Person-centred services go beyond setting goals to meet basic needs as noted in the following quotation:

... looking at the quality of life too. You know when you're setting goals, it's not always just about showering and eating, it's about you know what's their goal in the next year—would they like to go to the Toronto Zoo—did they want to go see a play, what interests them, do they want to take a course—do they want to, you know, work in the café—what is it that they want to do, and then we'll look at those things as well.

Service providers also identify this individualized approach as including a holistic orientation, wrap-around services, flexible support, and services based on needs.

However, getting service providers to agree to support an individual with a dual-diagnosis can be challenging at times as noted in the following quotation:

I believe that the City of London by all means has the skill set, the professionalism, and the services to meet everybody's needs, but it's a matter of getting everyone to play into that and do what they can for the person in need of support. So that's what is ideal or best practice—with everybody willing to say let's do whatever little pieces we can do and maintain their commitment.

*Specialized Services.* Specialized services describe an area specifically designed to meet the needs of clients with a dual-diagnosis. In the 1997 policy document entitled, *Policy Guideline for the Provision of Services for Persons with a Dual Diagnosis (developmental disability/mental health needs)*, because of complex needs, individuals require services from many systems. This is illustrated in the following key informant quotation:

According to best practices, as far as I'm concerned would have to be multi-tiered ... you would have to have health on board and clinical supports in place as well.

Consistent with the afore mentioned document, all key informants agree that this population often needs specialized services that integrate expertise from both ministries. The positive impact of having specialized services was stressed by key informants as illustrated in the following quotation:

... so if you provide an environment that is designed around that person's illness or needs, and then you provide a lot of well trained staff, consistent staff over the course of time, what we're seeing is that a lot of the intensive behavior problems tend to drop off and you see a much more stable path of behaviours.

The success of this treatment approach is strongly linked to the various clinical supports both in-patient and out-patient, which comprise of multidisciplinary staff that have the expertise necessary in treating this population.

*Community-Based.* Key informants recognized case management as an important

role in keeping individuals functioning well in a community setting. Parts of this treatment modality included social recreation planning, community integration, supporting brief hospital stays, and appropriate housing and supports. As one informant noted:

...we firmly believe everyone could be supported in the community. We firmly believe that, and we approve of that. With some of the people we support here have been deemed never able to live in the community are successfully there. There's nobody in my estimation that can't be successfully supported given the right support services.

The Ministry of Health and Long-Term Care also recognizes the benefits of community-based treatment and the need for added resources. As suggested by one key informant, "we'd like to see a split of about 60% being spent in the community and 40% in hospitals", however the reverse of this reflects current funding allocation. Obviously as the deinstitutionalization movement progresses, resources will need to be shifted to meet the demands of those returning to the community.

*Responsive Services.* Key informants noted that services must be responsive to the needs of clients with a dual-diagnosis to be effective. To support best practice, service providers need flexible and satisfactory funding. As one informant remarked:

I think if we're looking at an ideal system, we would have one that has a flexible resource base that could go in and enhance what's available to that person to keep them at home—so they don't have to leave and go to a hospital or go to jail and then go to the hospital and get caught up in that system.

As well, informants highlighted the importance of accessibility to services, in which the process is streamlined and equitable to those seeking services. The impact of not having responsive services is illustrated in the following quotation:

... when you're looking at 10 year waiting lists for group homes, and I think that becomes the issue, and that's where the crisis starts, because you can't really give people what they need when they need it. So they can't leave their homes when

they're no longer able to care for them. It seems to be crisis driven.

Although the Ministry of Health and Long-Term Care has noted these issues, there continues to be a lack of flexibility in resources to make accommodations for those in need.

### *Collaboration*

This sub-theme describes best practices as agencies work together to meet the needs of clients with a dual-diagnosis. The following areas were noted by key informants:

*Sharing Knowledge.* Collaboratively sharing knowledge between agencies received recognition as a best practice. Key informants were able to provide several examples of how sharing knowledge, in the form of cross-training and in-services have played an important part in their agency partnerships. One informant noted the following:

...one thing that I see down the road is my staff getting educated from the health sector in everything to do with mental health—and the mental health staff getting educated by my people with regard to developmental disabilities. I think we've started to do that cross training between the two. We'd like to see a greater enhancement in the cross training.

In addition, key informants recognized consultations for expertise through collaboration with other agencies as important. As one key informant commented:

Certainly the training was needed, it was expensive, didn't know how it was going to make it happen, so, by this way, our team coming out doing the assessments on clients and then providing help to the staff and then helping develop plans, appear to have really worked out well.

All key informants agree the need for sharing knowledge is an important component to increase capacity in the system and leads to a better quality of service for clients with a dual-diagnosis.

*Coordinating Services.* Consistent with best practice guidelines, key informants strive for services that are so well coordinated that they appear seamless to the client.

Such service involves many different forms and levels of collaboration between agencies.

Key informants noted advantages to sharing services, as voiced in the following quotation:

... they [the client] usually belong to one agency that burns out all their resources, moves on to another agency, where that's what we find often, especially for those people, that if we pull together a team and everybody does a piece of it—it works better because you're less likely to burn the team members out.

However, it appears such actions can pose challenges, as illustrated in the following quotation:

We know it can be done. Sometimes it takes a lot of head banging and butting heads with people to get everyone to just put down their barriers and say, look we're all in this together, let's all support each other together, and then we can all rejoice in the success together. It's not a matter of, you know, one person getting the success and saying look what we did, collectively this city should support and work together ...

Most key informants stressed involvement in planning and coordinating services through committee membership where some "... really good stuff happens at those meetings."

Many key informants mentioned the Regional Dual Diagnosis Committee, the local Dual Diagnosis Committee and the Mental Health Alliance. The importance of these committees is reflected in the following quotation:

... as far as dual-diagnosis [local committee] I mean it's great—you are doing this because it is a huge gap and people have recognized that, that's why there is the committee ... that's where we get the opportunity to say—okay where is the gap and what is happening to these clients who are falling through the cracks and how are we going to build a relationship with the other agencies and work closer together.

As there is a limit to available resources, key informants report that this is a prime strategy to address the service needs of the dual-diagnosis population.

*Advocating for Change.* Key informants reference advocacy as another part of collaboration and as a necessity for changes to macro service, as illustrated by one key

informant's quotation:

I think we have a large role in catalyzing change in the region and a number of objectives we lead because we have the ability to do that. Due to the partnerships, because of this region and how we're connected with the USA [United States of America] ... we can lead that sort of change.

Direct services promote change on a mezzo and a micro level, as pictured in the

following quotation:

It was a lot of networking, there was a lot of advocating and it was a lot of getting angry. But honestly, it was a matter of calling up some pretty big powers-that-be and saying—look it, we're getting doors shut on us left-right-and-centre and this kid is in crisis. You know, forget who we are, forget who you are, let's help this kid and that's what happened. So the ability is there, the system just gets in the way.

It is obvious from the accounts of key informants that advocacy will continue to be pivotal in developing services to meet the individual's needs and reduce the amount of stigma associated with having a dual-diagnosis.

### Summary of Findings

Chapter Four presents the profile of key informants from London and Middlesex County and findings gained from the semi-structured interviews. Three main themes with their respective sub-themes listed in parentheses, organize the data. The results include: 1) Service Delivery System (Direct Service Provision, Indirect Service Provision, Other Community Services), 2) Barriers to Mental Health Services (Knowledge Gaps, Service Delivery Issues, Confusing Policies), and, 3) Identifying Best Practices (Identification of Best Practices, Collaboration). Selected quotes from key informants explained ideas in further detail. In total, thirty categories of codes organize data coding and interpretation. Under the main theme of service delivery system many services have been identified in the region. However, a limited number of services are geared toward those with a dual-

diagnosis. Many barriers to service are noted in the second main theme, namely, lack of knowledge, limited expertise, and unclear roles between organizations and government. The final main theme stresses the importance of providing services that address the issues of clients with a dual-diagnosis and the need for organizations to find creative ways to work together to serve this population. Chapter Five presents a detailed analysis and offers further insights into the data provided by key informants.

## CHAPTER 5: DISCUSSION OF THE FINDINGS

Using a grounded theory approach provides a unique opportunity to gain knowledge from the key informants in answering standardized research questions. Using the three main themes and eight sub-themes made it easier to organize the discussion of the findings. Strengthening the validity of the findings is made through referencing the information provided by key informants with best practice literature. Further discussion about the findings contributes to implications about practice and changes that are needed in the service delivery system.

### The Service Delivery System

Key informants discussed many direct and indirect services for those with a dual-diagnosis in London and Middlesex County. Examples of direct services include housing and supports, specialized programs, community support services and emergency services. Indirect services such as advocacy, training and special initiatives are commonly noted. Besides available services for those with a dual-diagnosis, key informants were asked to estimate prevalence rates. Interestingly, they estimate prevalence to range from 10% to 50%. In fact, few are able to provide specific numbers of the clients served with a dual-diagnosis. Barriers pointing to the difficulty in deciding prevalence included inconsistent definitions of dual-diagnosis and the poor quality of epidemiological studies. Key methodological issues that have an impact on the determination of prevalence include: the definitions of learning disabilities and mental health disorders; sufficient sample size; method of identification and assessment; and, the proper use of diagnostic criteria (Smiley, 2005). Several key informants remarked that due to the nature of their disabilities, individuals cannot report their subjective experiences effectively. The

problem lies in that current assessment tools use subjective criteria that inquire about mood, loss of energy and hallucinations (Rifkin, 2000). Based on the findings from researchers including: Fletcher and Poindexter (1996); Jopp and Keys (2001); and Smiley (2005); there is a need to develop more standardized and consistent criteria for identifying those with a dual-diagnosis to get accurate prevalence rates.

The findings present the need to have various adequate housing choices available to those with a dual-diagnosis. Key informants report that it was important to strive for community integration and to have independent housing units or group homes throughout the city as opposed to large apartment complexes that house only those with mental or developmental disabilities. Other factors important for integration are being close to amenities and having access to public transportation. Many key informants reported that agencies have taken the initiative in creating more suitable housing choices for those with a dual-diagnosis. As well, attention must be maintained not only upon the homeless but those at risk of losing their homes and those in substandard housing (CMHA, 2004).

Key informants report that social recreation and vocation activities are important parts in an individual's treatment plan and contribute to a better quality of life. As those with a dual-diagnosis often do not typically adapt well to existing day programs, the need to develop a custom activity plan is essential. Key informants also report that vocational activities may not be the goal for everyone, but for those who secure employment, regardless of what type (i.e., sheltered, gainful), it has been shown to enhance self-esteem and increase confidence. In best practice literature, productive use of leisure time is an important part of successful rehabilitation for those with a dual-diagnosis. As reported by Gardner and Sovner (1994), key informants remark that community activities have

positive outcomes on the population. On a cautionary note, key informants from the developmental disability field advised against over-scheduling which parallels and reinforces the findings from Nottestad and Linaker's 1999 study.

Unlike most communities, London and Middlesex County has a tertiary care facility that provides specialized in-patient treatment to those with a dual-diagnosis. Key informants report that they contact tertiary care frequently for help when getting a diagnosis that is challenging or to help with complex treatment planning (e.g., when stabilization at home is difficult). Given the need, tertiary care facilities have begun offering out-patient support and are linking with specialized community supports to assist with a person's transition back to community. Other services in the area such as Schedule 1 hospital beds, out-patient hospital services, mental health outreach and crisis services, multidisciplinary consultation services, substance use treatment, and developmental disability services, are making efforts to help those with a dual-diagnosis. Similarly, the literature suggests that specialized care should comprise of various services, using different treatment models and should not be equated with a particular location or time frame (MOHLTC, 1999b).

The demand for community-based services is increasing because of the deinstitutionalization movement. Individuals who were once never thought to be suitable for community living are now successful members of society. Intensive services that provide support are often in the form of multidisciplinary teams consisting of—but not limited to—social workers, nurses, developmental workers, personal support workers, occupational therapists, and psychiatrists. Less intensive services provided by multidisciplinary teams can be long-term or short-term, helping individuals only when

necessary. Less intensive services are ideal for those who function well in stabilized environments and do not wish to use more intrusive services. Key informants report the importance of specialized community-based supports such as outreach teams, assertive community treatment (Bond et al., 2001; Bongiorno, 1996; Hassiotis, 2002; Liberman et al., 2001; Philips et al., 2001). Other services mentioned were case management and residential care (Cochrane et al., 2000).

Efforts to speak for the client at local levels is necessary to ensure quality service delivery. Those with a dual-diagnosis are often not good historians because of limited communication skills and cognitive functioning. In response, key informants often need to support their clients on a micro level. Common issues needing advocacy are securing enough financial support, accessing suitable housing and getting necessary treatment (e.g., primary care, psychiatric counseling). Key informants readily identified those with a dual-diagnosis as a vulnerable population in need of advocacy. One key informant provides an example of how stigma impacts this population in the following quotation:

... they [those with a dual-diagnosis] don't have the same social boundaries as we do, but I think the police too need to be sensitive to this because they usually are the victims. This population—they are usually confused by everybody, really, they've been passed around like a hot potato—if they're on the street they're the one ... people will target them for their money, their smokes, or whatever they have.

Taking place on a mezzo level, advocacy is necessary between agencies coordinating services for clients in the form of alliances or partnerships with one another. Advocacy also occurs at the macro level in the form of active provincial committees and lobbying groups. The need for advocacy is clear in the literature, as individuals are vulnerable and do not get their complex care needs addressed (MOHLTC, 1999b). As well, those who advocate at the Ministry level for the dual diagnosis population report success in creating

positive change. The following key informant quotation shows the results of advocacy efforts, “Seven years ago nobody knew what dual-diagnosis was, so we’ve come a long way.” Key informants recognize there are still improvements to be made, but uphold hope as the following quotation explains:

... if you look back on how concurrent disorders with addictions and stuff I’m sure this is where they were 20 years ago ... and look how far we’ve come with them ...

Advocacy efforts have led to both ministries recognizing the need to create special initiatives for aiding this population. The Ministry of Community and Social Services has created Specialized Networks of Care. As well, the Minister of Community and Social Services has approved pilot projects involving video-teleconferencing to allow access to specialized expertise among service providers (Ministry of Community and Social Services, 2006). Video teleconferencing will remove the distance barriers between communities and provide access to specialized services not otherwise available. The Ministry of Health and Long-Term Care has also taken a lead role and has launched many e-health initiatives to improve the flow of patient information between service providers (MOHTLC, 2007).

The two most commonly cited emergency services used by this population are the hospital emergency room and the police. Key informants, as well as the literature, report the importance of providing crisis services for successful outcomes in the community (Hassiotis, 2002). In 2003, the Centre for Addictions and Mental Health (CAMH) produced the document, *Guidelines for Managing the Client with Intellectual Disability in the Emergency Room*. These guidelines provide the emergency room doctor or psychiatrist with necessary information to address to complex medical and mental health

issues of those with a dual-diagnosis. Consistent with the literature, key informants point out that this population is at greater risk for arrest because of nuisance offences (e.g., trespassing, disorderly conduct) (CMHA, 2007). Most key informants report positive relations with their local police departments as suggested by one key informant's comments, "The police have been helpful and been very good with us and with our clients...." Building good relations with local police departments has been instrumental in directing this population to more suitable mental health diversion and court support programs, including mental health courts.

#### Barriers and Issues in Mental Health Services

Key informants report plenty of services available for those with a dual-diagnosis in London and Middlesex County. However, the high volume of those needing service has reduced the capacity of the system. Areas of system strain specifically noted by key informants include: waiting lists for suitable housing and other services; high caseload ratios; and limited resources. Key informants felt that services have improved in the past five years for those with a dual-diagnosis; however, despite improvements in the system, key informants have noted service gaps in the following areas: social recreation and vocational programs; specialized services; mental health supports; primary care; and housing choices. Contributing causes other than a lack of resources are inflexible service provision by organizations, fragmented services and the deinstitutionalizing of clients with a dual-diagnosis.

Key informants report that a high degree of stigma in accessing services occurs for those with a dual-diagnosis. There is consensus among key informants that individuals with disabilities should not be labeled by their diagnosis. Key informants

report the need to treat those with a dual-diagnosis as individuals where there is respect for their fears and treatment concerns. As well, stigma impacts on the quality of care that this population receives and often times, service professionals avoid the individual with a dual-diagnosis as they feel they are too complex to treat. The literature also confirms this notion stating that those with a dual-diagnosis are often perceived as the least desirable clients (CMHA—Ontario Division, 1998). Presenting problem behaviours contributes to stigma experienced by this population. Often these individuals enter the justice system and do not receive necessary treatment to address their issues. Key informants report that specialized treatment is lacking for violent offenders as well as those committing sexual offences.

Key informants note several gaps in the service delivery system. In particular, hospital staff, psychiatrists, clinicians and rural police officers have little to no training in dealing with those with a dual-diagnosis. As this population often has limited communication skills, having emergency doctors rely on self-reporting can be problematic. In response to presenting behaviours, restraints and isolation are often used, or the doctor will send the person home. None of these decisions are appropriate responses to emergency room crises as they do not resolve the issue. Advocacy efforts to educate nurses in Schedule 1 facilities have been made, but failed when the informed and expert mental health nurses resigned or were reassigned to other departments. Although the initiative succeeded in other communities such as Brampton, it did not do well in London and Middlesex County.

In addition to most key informants reporting a shortage of experienced clinicians (i.e., nurses, social workers and psychiatrists), the opinion is that cases are too complex.

Contributing to the lack of expertise, key informants note that limited training exists for doctors and psychiatrists, “like a day or a week ... that doesn’t teach them a lot”. Several colleges and universities are responding to this by including dual-diagnosis training in their curriculum, however, recruiting issues remain. For medical students, dual-diagnosis training is a voluntary four-year subspecialty, which does not appeal to the majority as they concentrate on other compulsory postings.

In a meta-analytic study conducted by White et al. (1995), they report that those with developmental disabilities experience a decrease of 19% in diagnostic accuracy compared to those with a mental illness, but who do not have a dual-diagnosis. Limited expertise and a lack of appropriate assessment tools are two main contributing causes that prevent a timely and accurate diagnosis. Key informants note that many existing assessment tools are not effective with this population, “a lot of the testing material you need to try and adapt because they’re not really designed for this population”. It is often harder to get accurate information to make a proper diagnosis because of limited communication skills. Despite the need for more research, emerging results point to including behavioural assessments for diagnostic purposes.

To maintain fair access to services, London and Middlesex County has developed a centralized intake system managed by a few key agencies in the community. Key informants remarked that because of the limited service capacity and the high volume of those seeking services, those most in need and often in crisis get access to available services. Key informants recognized that basing access on priority is often putting others at risk that could equally benefit from services, but commented that some services are “taxed very heavily”. The other issue of accessibility relates to an individual’s primary

diagnosis. Some services receive funding specifically for those with serious mental illnesses. For example, some supportive housing programs are only for those with a primary diagnosis of a mental disorder (i.e., schizophrenia, bipolar disorder) and excludes those with other disorders such as personality disorders and mild depression. This directly impacts the services available to individuals and influences service provider's views of those in need of services.

Receiving timely services is dependent on how quickly an individual can get a diagnostic assessment. Individuals often experience a delay in processing their referral from a family doctor, as there is not only a shortage of physicians, but psychiatrists as well. As one key informant describes, "it's nearly impossible ... they don't have a psychiatric illness, we can't take them into the service. So that's where the gap falls". Key informant's concerns about the need to improve access are consistent with best practice literature. The Ministry of Health and Long-Term Care has admitted that access to mental health services in Ontario can be "confusing and time-consuming for clients and their families/key supporters" (MOHLTC, 1999b, p.22). Improving access is a priority and the Ministry of Health and Long-Term Care is encouraging communities to reduce the points of entry and to simplify and minimize the assessment protocols (MOHLTC, 1999a, 1999b).

Key informants reported that having limited service capacity contributes to issues of accessibility and can create prominent gaps in service. As one key informant remarked, "...the system is very stretched." This can lead to inadequate service as noted by another key informant, "...a lot of the times now we're just band-aiding the situation." Often because of the volume of referrals, agencies have had to close their intake

departments, as they are not able to provide the extensive services needed by individuals with a dual-diagnosis. Even individuals in crisis during high volume times need to be triaged and may have to wait for service as caseloads can easily reach over 60 individuals per worker. Increasingly complex cases and the occurrence of continuing issues have contributed to the challenge of accepting new clients for services. In sum, key informants' claims of service gaps in the field are consistent with the dual-diagnosis literature. The literature, as well as the Ministry of Health and Long-Term Care, have specifically referenced the existence of service gaps for those with a dual-diagnosis. Due to their complex situations, shared service requirements have been recommended as necessary between local service providers to meet the needs of this population (MOHLTC, 1999b).

On unclear roles and confusing policies, key informants reported issues between the Ministry of Health and Long-Term Care and the Ministry of Community and Social Services. The literature reveals that because of the separation of the Ministries, a fragmented service delivery system has occurred, resulting in those with a dual-diagnosis falling through the cracks of both systems. Key informants voiced frustration over issues of coordination, funding related to primary diagnosis, and the view that those with a dual-diagnosis are not a priority population; however, those with a dual-diagnosis are considered to be vulnerable as they are caught between two Ministries and often times are denied services based on their primary diagnosis. The following quotation expresses the concerns of one key informant:

I know for a fact that there are agencies in the London area that will not accept any referrals for anyone with the dual diagnosis because their Ministry rep told them not to, because of the big fight between the two Ministries ... nobody will even look at them.

Despite a policy document dating back to 1997 entitled, *Policy Guideline for the Provision of Services for Persons with a Dual-Diagnosis (Developmental Disability/Mental Health Needs)* that recognizes responsibilities between the Ministries, little progress has been made. The following key informant comment reflects this position, “I think there are still some issues at the Ministry level, you know ... about who is responsible for what—was it a mental health issue first or is it a developmental disability ... and who funds what?”

As there is continued difficulty in the coordination of services, there is a need for the creation of special initiatives between the Ministries. Besides this, funding continues to be based on a person’s primary diagnosis instead of based on needs. Key informants remark that the above factors perpetuate the belief that services for the dually-diagnosed are a low priority, particularly for the Ministry of Health and Long-Term Care. This opinion is supported as individuals with a dual-diagnosis represent a very small percentage compared to the number of other health issues that share the same funding. In contrast, those with a dual-diagnosis represent a larger cohort/segment under the Ministry of Community and Social Services, yet funds are not allocated for the provision of specialized services for those with a dual-diagnosis in that Ministry either. Both Ministries have recognized the need to revise their policies, but remain guarded. The challenge remains finding a way to move forward without creating a Charter violation or setting a precedent that will negatively impact the rest of health care system.

Confusing policies also pose issues for service providers and in-patient facilities. Common issues are as follows: weak liaisons; lack of discharge planning and follow up; differences in professional cultures; consent issues and; a lack of expertise that often

needs advocacy for admission and/or appropriate treatment. Communication is a key factor in influencing relations with hospital staff. Key informants from community agencies feel that hospital staff are not accustomed to networking with outpatient services. The absence of a formal network poses a problem for those seeking to build healthy working relationships and it is further compromised by hospital staff being frequently reassigned. Emergency physicians are typically contracted per diem or some as locums which can undermine efforts to educate and build good working relations. Another issue related to communication is the difference in professional cultures. The following quotation shows this, “health is a very much more problem-solution oriented group as opposed to the life long support model that developmental services uses...and when you put them in the same room they don’t blend together too well sometimes.”

There also are issues with admission policies and protocol. Community service providers often noted frustration with the process of bringing clients to hospital and being denied admission. Illustrating this is the following comment, “As far as admissions go, you know it’s hit or miss ... I know what’s just behavior and I wouldn’t be wasting my time sitting in emerg if that was the issue”. Key informants revealed that better discharge planning practices are needed as well. Ideally, upon admission, hospital staff and community service providers should be involved with the client in determining a plan for discharge. Key informants state that often times they did not know when a client was being discharged until the very day. Sometimes notification occurs after the fact when the client calls to report that they were released from the hospital. Policies concerning consent issues are another area of concern. With new privacy legislation, the interpretation of who is in the circle of care has differed between hospital staff and

community agencies. The outcome of this confusion may add to the problems of access to service and equitable treatment.

Given these afore mentioned issues, there are efforts underway to bring about changes in the system. Key service providers and the local Dual Diagnosis Committee are planning more frequent meetings to review hospital policies and protocols that promote building linkages and clarify roles. These efforts are consistent with recommendations from best practice literature confirming that both hospital and community programs are equally responsibly in meeting the health needs of clients and should engage one another to enhance skills and develop resources (MOHLTC, 1999b).

#### Identifying and Implementing Best Practices

Person-centredness was the most commonly cited best practice among key informants. The need to help the client holistically was noted in every interview. There is a paradigm shift occurring among service providers where emphasis is now being placed on identifying the personal, holistic needs and preferences of clients. Associated with person-centredness, key informants reported use of the 'wraparound model' which uses a strengths-based approach. A main focus of this approach reported by key informants and the literature is to lessen social isolation and empower those with dual-diagnoses (Gilmour & Gravelle, 1998). This is consistent with the Ministry of Health and Long-Term Care's best practice principles of preserving a client focus and allowing for accommodations in promoting a client's choice in service provision. Wrap-around services involve more than one service provider supporting the varied needs of an individual in the community. However, almost all key informants remarked that getting service providers to agree to supporting an individual with a dual-diagnosis can be

challenging at times because of the complexity of their needs. Individualized care plans that address shifting needs of individuals is a key part of person-centredness and is a best practice among key informants. Flexibility is important in providing quality care. As well, promoting independence wherever possible in a person's life is valuable as noted in the following quotation, "We're flexible in our own lives, be flexible for clients as well..."

In the document, *Policy Guideline for the Provision of Services for Persons with a Dual Diagnosis (developmental disability/mental health needs)*, it is recognized that due to complex needs, individuals require services from many systems. Some may need specialized services that integrate expertise from both Ministries. All key informants note the need for various services. The following quotation explains this view, "According to best practices, as far as I'm concerned it would have to be multi-tiered ... you would have to have health on board and clinical supports in place as well." The positive impact of having specialized services is stressed by key informants as an integral part of successful treatment.

The literature as well as key informants report those with a dual-diagnosis, regardless of the severity of their developmental delay, benefit from mental health and developmental disability services offered on a concurrent basis (Woodward, 1993). One key informant stated, "The most ideal would be having a team of multi-disciplinary people with expertise in all those areas." Consistent with the literature, key informants addressed the shift in traditional behavioural-modification programs being replaced with positive behaviour support or rather the "positive systems approach". Positive behavioural treatment has gained clinical prominence for its effectiveness. Reasons

related to its success are client-centredness, emphasizing coaching and healthy relations as opposed to discipline and an authoritative approach (Bongiorno, 1996).

The literature revealed significant findings related to pharmacological treatment for those with a dual-diagnosis. Psychoactive medications ranging from antidepressants to antipsychotics were presented, however in key informant interviews, pharmacological treatment was not discussed in detail. Research related to the need for specialized services was prominent and consistent with reports from key informants. Consistent with the literature, key informants no longer regard specialized treatment as long-term institutionalized care, but rather a combination of rehabilitative and support services that are often provided by interdisciplinary teams either in hospital or the community. As the needs of individuals can change, so do the levels of support and services, therefore continuous monitoring and reassessment is part of this treatment orientation as an individual progresses through their recovery (Kirby, 2006).

As reported previously, limited literature exists regarding the efficacy of psychotherapy (Taylor, 2005) or cognitive-behavioural approaches (Hemmings, 2006). This is likely due to the lack of communication skills, varying levels of cognitive functioning and the dependence upon a therapist's level of comfort treating this population (Butz et al., 2000). One key informant from the mental health field, as found in the literature, reported that psychotherapy would be very beneficial for this population, but accommodations must often be made (Levitas & Gilson, 1989; Whitehouse et al., 2005). To ensure quality mental health treatment for those with a dual-diagnosis, accommodations are specifically required for testing and treating depression, anxiety and post-traumatic stress (Ryan, 1994). The lack of clinicians willing to provide these

services is concerning. As Hurley et al. (1998) reports, there is a trend where group psychotherapy has been replaced by skill-building groups and in doing so, jeopardizes opportunities for developing self-confidence and mental wellness.

Substance use treatment was another topic found in the literature, but not highlighted by key informants. This is concerning as the literature indicates that the prevalence of substance use in the dually-diagnosed population with a mild to moderate developmental disability is comparable to the general population (Brady, 1993; Philips, 2006). Also, those most likely to abuse alcohol have a mild to moderate disability, greater independence (e.g., lived in a group home); maladaptive health behaviours and poorer physical health (Rimmer et al., 1995). The best practice document entitled, *Concurrent Mental Health and Substance Use Disorders*, failed to specifically address assessment and treatment considerations for those with a dual-diagnosis (Health Canada, 2001). It is evident that this is an area that requires more awareness and research to improve the outcomes for those with a dual-diagnosis (Drake et al., 1998).

Given the deinstitutionalization movement, community-based treatment, especially case management is often a key component to an individual's success in the community. Key informants strongly feel that given the proper supports anyone can be successfully supported in a community-based setting. Components of community-based treatment includes, but is not limited to social recreation planning, community integration efforts, supporting brief hospital stays, and access to appropriate supportive housing. Reports from key informants and the literature indicate the preferred service model to be community-based with a variety of residential supports to choose from (Burns & Santos, 1995; Hassiotis, 2002; Philips et al., 2001). This has been further evidenced by the

Ministry of Health and Long-Term Care shifting its emphasis from hospital-based to community-based support. One piece of community-based treatment that is often overlooked is social recreation programs as stated a key informant, “Social recreation is really, really important. A lot of these clients will isolate if they’re left. It’s an essential part of treatment ....” Even if an individual has a case manager and is quite independent, this does not replace having social activities and building appropriate peer relations. Several key informants mentioned the importance of community integration in this area. Finding activities that clients enjoy in the community may not be typical day-away programs. Key informants from the developmental disability field reported that often times, those with custom social activity schedules are more successful and have a better quality of life.

Another factor in community integration was reported to be appropriate housing and being part of the community. The following key informant quotation further reflects this, “I think it should be in regular residential area just like everybody else.” The majority of key informants felt that housing should be designed on a continuum of support dependent on the life skills of the individual. There would be 24-hour group homes, semi-independent group homes, small integrated settings as well as independent apartment units.

Key informants felt that an essential part of best practice treatment was having services available to the client whenever needed, “Where we’ve created an environment that adapts to the person’s needs we haven’t even needed psychiatric admissions.” Without responsive services, clients often enter crisis states and thus use large quantities of community resources or need to access in-patient treatment to regain stability. It is

known that those with dual-diagnosis may need medical attention for various reasons. As such, key informants report that brief hospital stays are ideal for stabilization and medication adjustments. The following quotation further explains this, “there’s nothing to be gained by taking people out of their homes for long periods of time and then trying to re-integrate them”. The importance of having responsive services is also consistent with best practice literature. The Ministry of Health and Long-Term Care has noted this need and has recommended system redesign based on meeting the needs of clients (MOHLTC, 1999b). Funding is dependent on meeting the following criteria: person-centred treatment planning; common assessment tools and protocols among service providers; and the ability to form partnerships with other agencies with the goal of creating a seamless service delivery system. Despite the Ministry recognizing this need, most of the key informants cite limited resources as impeding consistent services that are responsive to an individual’s needs.

The findings reveal various ways that service providers have collaborated in providing services to those with a dual-diagnosis. However, for sharing knowledge, the following were specifically cited by key informants: shared staff training; special in-services; consultations; and staff cross-training. Several agencies have had staff attend cross-training sessions at partner agencies. This has increased awareness of the issues common to those with a dual-diagnosis and has brought about a better understanding of each agency’s role in the treatment and care of such individuals. Many key informants report an increase in the use of cross-training in the past several years which has been noted as favorable in building comfort levels of service providers from both fields. Arranging consultations with other service providers is noted as another effective way of

sharing knowledge between agencies. It is usually time-limited, on a case-by-case basis and provides the opportunity for skill development and creative treatment planning for complex cases. The other way agencies share knowledge is among their own staff. Often times, agencies look to invest in train-the-trainer education. This enables a core number of staff to develop skills in a particular area and return to the agency to teach their colleagues and other service providers. Two challenges noted in accessing this training are related to limited availability and significant costs.

Key informants remarked that linking services in a way that appears seamless to the client represents a well-coordinated system of services. Such a system not only works from a client-centred orientation, but also benefits agencies where service sharing can prevent depletion of resources when dealing with complex cases. One prominent obstacle identified were the functional barriers that agencies often create with other service providers. Other challenges noted by key informants include the fragmentation of available services and the lack of communication between service providers. Key informants admit that it can be difficult at times, but because of local networking groups, much has been accomplished in the past few years. Key informants also note that sometimes formal service agreements and protocols between agency partners provide improved role clarification and avoidance of agencies creating functional barriers to protect their resources.

It has been known for over a decade that collaboration in service delivery is necessary to support individuals with a dual-diagnosis. Having shared responsibilities between the two Ministries, there continues to be an absence of service linkages within and across the mental health and developmental service areas (Ministry of Health and

Community Social Services, 1997). Partnerships across sectors in the form of policy, planning initiatives and service agreements are key to providing effective support to those with a dual-diagnosis. At the mezzo level, service providers must adopt common assessment tools, cross-training and central access measures. At the micro level, flexible admission criteria and specialized teams of multidisciplinary individuals must be imposed. In May 2005, the Minister of Community and Social Services announced the launch of a special strategy to facilitate more collaboration through Community Networks of Specialized Care. This strategy will provide strategic support and bridge gaps between health, corrections, education sectors and mental health (Ministry of Community and Social Services, 2007). Regional Support Associates (RSA) and Bethesda have taken a lead on this initiative and have launched the Southern Community Network of Specialized Care that will work closely with the local service delivery networks.

From accounts during the key informant interviews, advocacy is still needed to get agencies to “throw down their barriers and say, let’s all give the little bit we can ... then it’s solved—that’s ideal.” Key informants recognize that best practices offer person-centred services, but they recognized the system is not reflective of this and continues to make it difficult to support people. Key informants were clear in communicating the need for promoting system-wide changes for this population. The Ministry of Health and Long-Term Care recognizes this need and supports local planning and network groups to bring forth challenges that impede the health and well-being of those in the community (MOHLTC, 1999b).

### Summary of Discussion of Findings

Chapter Five includes an interpretation of the findings from the semi-structured interviews and references the literature where applicable. An analysis of the findings provides insights on the current service delivery system. The opinions of key informants are illustrated by using relevant quotations. Key informants were found to be very knowledgeable and aware of the status of their services in the community. Despite this awareness, there is still much work to be done in addressing barriers and service gaps. Although London and Middlesex County have many services to offer, such as housing, social recreational programs, specialized services, community support services, the capacity of these services is limited. Much effort has been placed on building linkages which is evidenced by the number of local networking groups in the area. According to key informants, this has been of great benefit to have key service providers around the same table. The addition of Specialized Networks of Care brings hope of improved relations between the Ministries, as well as service provider's relations with in-patient facilities. Chapter Six offers a summary of previous chapters and implications for social work practice.

## CHAPTER 6: SYNOPSIS

This chapter provides a summary of previous chapters and several implications for advanced generalist social work practice. These implications are based on the responses from key informants, with my experience and interpretation of services needed for those with a dual-diagnosis. Best practice literature supports all the implications discussed. Implementing best practices at the community level is contextualized through the experience of the key informants. A summary of the member checks provides a current perspective in response to interpreting findings and an update about the present system of services for those with a dual-diagnosis. Closing remarks and commentary about the need for more research presents opportunities for future studies.

Chapter One presents an outline of the available services for those with a dual-diagnosis. Stigma continues to be a main cause that impedes access to mental health services and other necessary services. A major consideration is the lack of consensus about defining 'dual-diagnosis'. As well, unclear funding guidelines exist between the various Ministries and the LHIN. This in turn creates many trickle-down issues for this vulnerable population who fall through the cracks between Ministries' jurisdictions.

There continues to be a lack of a Federal strategy to address the service needs of those with a dual-diagnosis in Canada. A literature review in Chapter Two explores the implications of the deinstitutionalization movement which drives the need for extra funding in out-patient services to promote successful community integration. Various out-patient interventions such as pharmacological treatment, specialized services, and addiction treatment are discussed.

Chapter Three outlines the key concepts related to methodological issues. As this

is a qualitative study, the utility of choosing grounded theory methodology is discussed. Research questions are revealed and a description of the sample and location for key informant interviews is outlined. Ethical concerns are presented and the process of coding and developing themes is defined. To reduce researcher bias, a cultural review is related in which the researcher explores personal views and experience working with those having a dual-diagnosis. To ensure that the research questions are addressed through the key informant interviews, relevant categories of codes were aligned with each corresponding question. Considerations for increasing trustworthiness include the use of member checks and cross-referencing the literature. As well, outlining limitations of this study aids and strengthens the findings.

Results from key informant interviews are presented in Chapter Four using three main themes as follows: Service Delivery; Barriers to Mental Health Services and; Identifying Best Practices. The three main themes are further divided into 8 sub-themes and 30 categories of codes. There is much consensus between the best practice literature and the findings from interviews with key informants. However, there are prominent gaps in research particularly around pharmacological interventions, psychotherapeutic strategies and other cognitive-behavioural strategies.

Member checks with key informants helped to increase the trustworthiness in interpreting the findings. I received a total of six responses, in which one key informant declined, perceiving that it would be inappropriate to comment given their high level position within the community. Of the five individuals willing to provide their comments, all agreed with my interpretation of the findings and found the challenges and issues to be reflective of the current climate. Several issues resonated with the key informants, most

notably, the need to develop coordinated access and service provision. As well, increasing expertise through cross-training and education is also a priority. It appears that smaller organizations and groups continue working together at a grass roots level to adapt the system locally in response to the absence of larger systemic changes.

A discussion of the findings is presented in Chapter Five. Despite having many services in London and Middlesex County, the service delivery system as a whole is lacking in many critical areas. There is a serious need for primary care and physicians/psychiatrists trained in better practices and treating those with a dual-diagnosis. As agency resources allocated for those with a dual-diagnosis are limited, access and coordination of services are the most prominent challenge for providers. Although improvements have been made, the relations between hospital and community service providers remain unclear. The Ministries and the LHIN continue to negotiate funding arrangements and strive to develop special initiatives to best address the needs of those with a dual-diagnosis. Key informants readily identified best practices in service provision which emphasizes person-centred strategies, specialized services and community based treatment.

#### Implications for Social Work Practice in Mental Health Services

Advanced generalist practitioners in the field of social work must promote social justice by removing the barriers created by stigma associated with this vulnerable population. Social workers need to continue to advocate for treatment and services based on need, instead of diagnosis. Advanced generalist social work practitioners must also support the use of best practice psychotherapeutic interventions. As key informants noted, there is significant need for providing trauma counseling to those with a dual-

diagnosis. An active role is necessary for developing proper assessment tools and tailoring traditional treatment accommodations to meet the personalized, holistic, and unique needs of this population. Advanced generalist practitioners must recognize the importance of preventive services. These services are important components to build sustainability in the system and to improve capacity. Concentrated efforts on macro levels to influence policies regarding funding and treatment need to continue. The service system must work to meet the needs of an individual, opposed to having the individual try to fit into the system of available services. Only then will a client-centred approach be achieved and result in a client's needs being fully met.

As advanced generalist practitioners promote a holistic, client-centred approach, it was surprising to note that several major trends identified in the literature were not noted in the field of practice. One area relates to not being aware of the prevalence of those with dual-diagnosis on service provider caseloads. This may directly impact the quality of treatment planning and future allocation of resources for services. There were limited reports among key informants about the inclusion of family and care partners in treatment, despite this being referenced as a best practice in the literature. This study also reveals an absence of discussion related to the use of psychotropic medications and problem substance use treatment. It is unclear whether these treatments are perceived as a best practice by social workers and warrants future research. Other possible reasons could include educational training and the role assumed by social workers among allied health professionals in the field. Although some practices are beyond the scope of the social work profession (e.g., prescribing medication), it is critical that advanced generalist practitioners empower themselves to become knowledgeable about other treatments and

address them in their holistic care plans to promote better outcomes for the dually-diagnosed population.

This study has implications for future educational opportunities (e.g., courses, workshops, 'lunch & learn' sessions, etc.) as there is a need to share knowledge about the challenges experienced by the dually-diagnosed population. Through awareness and understanding, stigma can be eliminated allowing the inclusion of those with a dual-diagnosis in society. Education should not be limited to social work practitioners, but should include interdisciplinary health professionals (e.g., nurses, psychologists, developmental service workers, social service workers, etc.). Education must address the fact that the dual-diagnosis population may be subjected to additional stigma due to other factors such as their gender, class, race, ethnicity and sexual orientation (Corrigan et al., 2003). Providing professionals with the knowledge and necessary skills to conduct an intersectional analysis ensures that appropriate and culturally-sensitive services are implemented for those with a dual-diagnosis.

#### An Out-Patient Dual-Diagnosis Treatment Model

Many supportive services are necessary for an effective out-patient treatment model for individuals with a dual-diagnosis. Components that comprise this model of care are from best practice literature and information from key informants [see Figure 3]. These parts include: expertise and training in treating dual-diagnosis; appropriate housing and supports; specialized mental health services; and social recreation activities/vocational opportunities. Life and social skills training, community services, and linkages between service provider organizations are also included in this model. Advocacy to promote social justice, effective government and agency policies as well as

research in treatment for dual-diagnosis are important parts. Components such as income support, community services and advocacy are the building blocks or rather the basic needs of individuals. One is no more important than the other, as the absence of any part will not fully support the needs of an individual. This simplified model shows that without all these parts in place, a solid foundation on which to deliver effective treatment and support is not possible.

#### Concluding Remarks and the Need for Additional Research

The findings suggest that carrying out best practices must be a strategic process and can be challenging when there is limited capacity in the system. As well, some best practices are not global and do not translate well from one community to another. This is a key element that each community must address if the needs of those with a dual-diagnosis are ever to be met.

Several subsets of the dual-diagnosis population have been identified to be beyond the scope of this research study. The need to conduct research on the transition of individuals living with elderly parents to an alternate level of care (i.e., rest home, long-term care) was commonly cited among key informants. Violent offenders in the justice system are another subset identified by key informants who often do not have access to suitable services. Key informants also report that a model needs to be identified for those with severe behavioural issues that address states of aggression and assault as well as problem drug and alcohol use.

More research is needed to address the issue of diagnostic issues which include definitions and types of dual-diagnosis and assessment tools. Adaptations to current treatment strategies, such as psychotherapeutic approaches and cognitive-behavioural

methods must also be explored to better match the needs of this population. As there were many inconsistencies in pharmacological treatments, more studies are required to examine the benefits and limitations of various medications within this population.

The responses from key informants in this study confirmed and added to existing literature about the identification and service provision of specialized mental health services to individuals with a dual-diagnosis. Therefore, this study was successful in addressing its research questions and has added to the body of knowledge regarding best practices in the field of dual-diagnosis.

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## Appendix A—Letter of Information

**UNIVERSITY OF WINDSOR**  
**LETTER OF INFORMATION**

**An Examination of Best Practices in the Provision of Specialized Mental Health Services to  
Individuals with a Dual-Diagnosis in London/Middlesex County**

**PURPOSE OF THE STUDY**

Ms. Tara-Ann Glasgow (MSW candidate) under the direction of her Thesis Chair, Dr. Michael J. Holosko (Professor) of the University of Windsor's Social Work Department is seeking information regarding the implementation of directives from the Ministry of Health and Long-Term Care (MOHLTC) with respect to the development of an array of interventive initiatives in the provision of specialized mental health services for those with a dual-diagnosis in London/Middlesex County.

**PROCEDURES****METHOD**

The study involves a multi-method or combined design. The principal data collection strategies will include: a review of relevant program documents, bibliographic research (literature review on best practices in mental health) and semi-structured interviews with key informants from key collateral organizations.

**Key Informant Interviews:**

A representative from the University of Western Developmental Disabilities Division has identified a number of key collateral organizations, including specific informants, in the provision of mental health services to those with a dual-diagnosis in London/Middlesex County. Key informants will be recruited by Ms. Glasgow and she will also initiate subsequent contacts to provide a further explanation of the purpose of the inquiry and arrangement of interview times and locations. The proposed location(s) for the conduct of the semi-structured interviews is the key informant's host organization.

Each informant will be requested to participate in a semi-structured interview designed to collect both quantitative and qualitative data on the specialized mental health domain prescribed by the MOHLTC. Each interview will be conducted in-person by Ms. Glasgow. The content of each interview will be audio recorded and chronicled in detailed field notes which will later be transcribed for analysis. These data will be stored, under lock-and-key in a secure location for the duration of the investigation and subsequently destroyed. Access to the data will be confined exclusively to the members of the Thesis Committee.

The data from the key informant interviews will be thematically analysed and the results reported in aggregate fashion. Direct quotes from individual interviews will be used to illustrate key concepts and themes. *Individual participants will, however, only be identified through their organizational affiliation. Given that many key informants are well known to the community, this means that the anonymity of participants and the confidentiality of their responses may only be partial and subject to extrapolation by the reading audience.* Each informant, therefore, will be given an opportunity to review any of their direct quotes which are being targeted for inclusion in the final document to ensure that they are suitable for public consumption. A summary of the results of the research will be available to all interested.

Note: Prior to the interview, the participation of all key informants will be based upon informed consent. Each key informant will be asked to sign a consent form signifying their understanding and acceptance of the conditions of participation. The proposed informed consent procedures have been reviewed by the Ethics Committee of the University of Windsor.

**As a participant in this inquiry, each key informant will be expected to:**

- 1) review the study's "Letter of Information";
- 2) provide written consent signifying agreement to participate in the inquiry;
- 3) participate in a semi-structured key informant interview of approximately one hour duration, to be conducted face-to-face, by Ms. Glasgow at a mutually agreed upon location;
- 4) review any direct quotes by the informant which are targeted for inclusion in the final report;

\*\* Note: Each key informant will be provided with a copy of the final report upon request

### **POTENTIAL RISKS AND DISCOMFORTS**

Your participation in this study is completely voluntary. You have the right to withdraw from the study at any point of time without any form of negative consequence.

The only known risk/discomfort of the inquiry resides in the fact that key informants may be identifiable through their organizational affiliation. Direct quotes from key informants will be used to illustrate key concepts and themes derived from the inquiry. Therefore, the source of key informant narratives may be extrapolated by the reading audience. Key informants will be given the opportunity to review any direct quotes targeted for inclusion in the final report.

There are no other known risks associated with participation in this inquiry.

### **POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

The current investigation is intended to provide state-of-the-art knowledge about the best practices in the delivery of specialized mental health services to those with a dual-diagnosis, which is grounded in contemporary professional and academic knowledge as well as the service delivery context of London/Middlesex as identified by key informants from collateral organizations in the mental health care system. The study will also contribute to the knowledge base of the mental health field through the dissemination the results of the inquiry in scholarly academic forums (i.e. conferences, journals).

The inquiry will also serve as an opportunity for one graduate student, Ms. Tara-Ann Glasgow, to learn, first-hand, the conduct of applied social welfare research. She will use the data from the inquiry to complete her thesis requirements of the Masters of Social Work Program.

### **PAYMENT FOR PARTICIPATION**

Subjects will not receive any remuneration for their participation in this study.

### **CONFIDENTIALITY**

Please refer to the section titled '*Potential Risks and Discomforts*' regarding issues of confidentiality.

### **PARTICIPATION AND WITHDRAWAL**

**You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind.** You may exercise the option of removing your data from the study. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

### **RIGHTS OF RESEARCH SUBJECTS**

**You may withdraw your consent at any time and discontinue participation without penalty.** This study has been reviewed and received ethics clearance through the University of Windsor Research Ethics Board. If you have questions regarding your rights as a research subject, contact:

**Research Ethics Co-ordinator  
University of Windsor  
Windsor, Ontario  
N9B 3P4**

**Telephone: 519-253-3000, # 3916  
E-mail: [ethics@uwindsor.ca](mailto:ethics@uwindsor.ca)**

## Appendix B–Consent Form

## UNIVERSITY OF WINDSOR

<b>CONSENT FORM</b>
---------------------

**CONSENT TO PARTICIPATE IN RESEARCH**

**An Examination of Best Practices in the Provision of Specialized Mental Health Services to Individuals with a Dual-Diagnosis in London/Middlesex County**

**You are asked to participate in a research study conducted by Ms. Tara-Ann Glasgow (MSW candidate) and Dr. Michael Holosko (Professor) from the Department of Social Work at the University of Windsor.**

**If you have any questions or concerns about the research, please feel to contact Dr. Michael Holosko by e-mail: holosko@uwindsor.ca**

**PURPOSE OF THE STUDY**

Ms. Tara-Ann Glasgow (MSW candidate) under the direction of her Thesis Chair, Dr. Michael J. Holosko, B.A., M.S.W., Ph.D. (Professor) of the University of Windsor's Social Work Department is seeking information regarding the implementation of directives from the Ministry of Health and Long-Term Care (MOHLTC) with respect to the development of an array of interventive initiatives in the provision of specialized mental health services for those with a dual-diagnosis in London/Middlesex County.

**PROCEDURES****METHOD**

The study involves a multi-method or combined design. The principal data collection strategies will include: a review of relevant program documents, bibliographic research (literature review on best practices in mental health) and semi-structured interviews with key informants from key collateral organizations.

**Key Informant Interviews:**

A representative from the University of Western Developmental Disabilities Division has identified a number of key collateral organizations, including specific informants, in the provision of mental health services to those with a dual-diagnosis in London/Middlesex County. Key informants will be recruited by Ms. Glasgow and she will also initiate subsequent contacts to provide a further explanation of the purpose of the inquiry and arrangement of interview times and locations. The proposed location(s) for the conduct of the semi-structured interviews is the key informant's host organization.

Each informant will be requested to participate in a semi-structured interview designed to collect both quantitative and qualitative data on the specialized mental health domain prescribed by the MOHLTC. Each interview will be conducted in-person by Ms. Glasgow. The content of each interview will be audio recorded and chronicled in detailed field notes which will later be transcribed for analysis. These data will be stored, under lock-and-key in a secure location for the duration of the investigation and subsequently destroyed. Access to the data will be confined exclusively to the members of the Thesis Committee.

The data from the key informant interviews will be thematically analysed and the results reported in aggregate fashion. Direct quotes from individual interviews will be used to illustrate key concepts and themes. *Individual participants will, however, only be identified through their organizational affiliation. Given that many key informants are well known to the community, this*

*means that the anonymity of participants and the confidentiality of their responses may only be partial and subject to extrapolation by the reading audience.* Each informant, therefore, will be given an opportunity to review any of their direct quotes which are being targeted for inclusion in the final report to ensure that they are suitable for public consumption. A summary of the results of the research will be available to all interested.

Prior to the interview, the participation of all key informants will be based upon informed consent. Each key informant will be asked to sign a consent form signifying their understanding and acceptance of the conditions of participation. The proposed informed consent procedures have been reviewed by the Ethics Committee of the University of Windsor.

**As a participant in this inquiry, each key informant will be expected to:**

- 1) review the study's "Letter of Information";
- 2) provide written consent signifying agreement to participate in the inquiry;
- 3) participate in a semi-structured key informant interview of approximately one hour duration, to be conducted face-to-face, by Ms. Glasgow at a mutually agreed upon location;
- 4) review any direct quotes by the informant which are targeted for inclusion in the final report;

**\*\* Note:** Each key informant will be provided with a copy of the final report upon request

**POTENTIAL RISKS AND DISCOMFORTS**

Your participation in this study is completely voluntary. You have the right to withdraw from the study at any point of time without any form of negative consequence.

The only known risk/discomfort of the inquiry resides in the fact that key informants may be identifiable through their organizational affiliation. Direct quotes from key informants will be used to illustrate key concepts and themes derived from the inquiry. Therefore, the source of key informant narratives may be extrapolated by the reading audience. Key informants will be given the opportunity to review any direct quotes targeted for inclusion in the final report.

There are no other known risks associated with participation in this inquiry.

**POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

The current investigation is intended to provide state-of-the-art knowledge about the best practices in the delivery of specialized mental health services to those with a dual-diagnosis, which is grounded in contemporary professional and academic knowledge as well as the service delivery context of London/Middlesex as identified by key informants from collateral organizations in the mental health care system. The study will also contribute to the knowledge base of the mental health field through the dissemination the results of the inquiry in scholarly academic forums (i.e. conferences, journals).

The inquiry will also serve as an opportunity for one graduate student, Ms. Tara-Ann Glasgow, to learn, first-hand, the conduct of applied social welfare research. She will use the data from the inquiry to complete her thesis requirements of the Masters of Social Work Program.

**PAYMENT FOR PARTICIPATION**

Subjects will not receive any remuneration for their participation in this study.

**CONFIDENTIALITY**

Please refer to the section titled '*Potential Risks and Discomforts*' regarding issues of confidentiality.

**PARTICIPATION AND WITHDRAWAL**

**You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind.** You may exercise the option of removing your data from the study. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

**RIGHTS OF RESEARCH SUBJECTS**

**You may withdraw your consent at any time and discontinue participation without penalty.** This study has been reviewed and received ethics clearance through the University of Windsor Research Ethics Board. If you have questions regarding your rights as a research subject, contact:

**Research Ethics Co-ordinator  
University of Windsor  
Windsor, Ontario  
N9B 3P4**

**Telephone: 519-253-3000, # 3916  
E-mail: ethics@uwindsor.ca**

**SIGNATURE OF RESEARCH SUBJECT/LEGAL REPRESENTATIVE**

**I understand the information provided for the study "*An Examination of Best Practices in the Provision of Specialized Mental Health Services to Individuals with a Dual-Diagnosis in London/Middlesex County*" as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.**

\_\_\_\_\_  
Name of Subject (*please print*)

\_\_\_\_\_  
Signature of Subject

\_\_\_\_\_  
Date

**SIGNATURE OF INVESTIGATOR**

**In my judgement, the subject is voluntarily and knowingly giving informed consent to participate in this research study.**

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Date

Appendix C–Letter of Approval London/Middlesex Dual-Diagnosis Group



**Community  
Living London**

Working Together to Achieve  
the Inclusion of People with  
an Intellectual Disability

---

Dr. Pierre J. Boulos  
Interim Chair  
University of Windsor  
Research Ethics Board  
Lambton Tower room # 8115  
Windsor, Ontario  
N9B 3P4

Wednesday, June 01, 2005

Dear Dr. Boulos:

**RE: Glasgow, Tara-Ann**

I am writing this letter to inform you that on behalf of the London/Middlesex Dual-Diagnosis Group, we are aware that Ms. Tara-Ann Glasgow, in pursuit of her Master's of Social Work Degree, will be conducting her study entitled "An Examination of Best Practices in the Provision of Specialized Mental Health Services to Individuals with a Dual-Diagnosis in London/Middlesex County".

It is our understanding that she will be selecting key informants from various local organizations for her data collection phase. We support Ms. Glasgow's study and believe that her research findings will be helpful to our community service providers.

If you should have any further questions or concerns, please do not hesitate to contact me at (519) 886-3000.

Sincerely,

Ms. Michelle Palmer  
Chair  
London/Middlesex Dual-Diagnosis Group

Cc: T.A. Glasgow

190 Adelaide Street South, London, Ontario N5Z 3L1

A Member of United Way of London & Middlesex  
Tel: (519) 686-3000 Fax: (519) 686-5490  
Website: <http://www.cfl.on.ca>

## Appendix D- Letter of Approval University of Windsor REB

Page 1 of 1

**From:** boulos@uwindsor.ca  
**Subject:** REB Clearance RTR (Final) - Glasgow (Sweezey)  
**Date:** Fri, 10 Jun 2005 09:53:19 -0400  
**To:** sweezey@webmail1.uwindsor.ca  
**Cc:** holosko@uwindsor.ca, lbunn@uwindsor.ca

Dear Tara-Ann

This is to inform you that your Request to Revise your research project, "**An Examination Best Practices in the Provision of Specialized Mental Health Services to Individuals with a Dual-Diagnosis in London/Middlesex County,**" has been given final clearance by the Research Ethics Board of the University of Windsor. The clearance has been given in the context of the information provided in your application, the subsequent revisions, the subsequent request, and the subsequent receipt of the letter from the London and Middlesex Dual Diagnosis Committees.

Please note that the conditions stipulated in the original clearance apply with respect to this revision. If a formal letter stipulating this clearance is needed, please let me know.

Best wishes for your research,

Dr. Pierre J. Boulos, Interim Chair  
 U of W Research Ethics Board  
 Lecturer, School of Computer Science  
 University of Windsor  
 Windsor, Ont. N9B 3P4  
 Room: 8115 Lambton Tower  
 519.253.3000 ext. 3767  
 E- mail: boulos@uwindsor.ca  
 Course Related E-mail: boulos@cs.uwindsor.ca  
 web: [http:// www.uwindsor.ca/boulos](http://www.uwindsor.ca/boulos)

## Appendix E–Semi-Structured Interview Framework

## An Examination of Best Practices in the Provision of Specialized Mental Health Services to Individuals with a Dual-Diagnosis in London/Middlesex County

### Semi-Structured Interview Framework

---

**Preface:**

Have you had the opportunity to review the purpose of the inquiry and the prescribed practices to ensure the ethical conduct of research with human subjects?

Do you have any questions about the purpose of the study or the proposed procedures?

**Have key informant sign the consent form signifying their understanding of the study and their willingness to participate and acceptance of the ethical procedures.**

Inquire whether there are any questions about the context of the inquiry.

---

**General Introductory Question:**

What role does your organization play in the provision of specialized mental health services to residents of London and Middlesex County?

---

**Section 1: Dual-Diagnosis**

Do you believe that you are knowledgeable about services for clients with dual diagnoses in London & Middlesex County? **If no, proceed to next section.**

- 1) Does your organization provide services to clients with a dual diagnosis? [*Do you have program descriptions or brochures?*]
- 2) How many individuals do you serve in programs for clients with dual diagnoses? [*Do you have any service delivery statistics?*]
- 3) How would you describe the current system for delivering services to clients with a dual diagnosis in London/Middlesex County. [*Strengths, Weaknesses, Opportunities, Limitations*]
- 4) What do you believe is the ideal/best practices approach to the delivery of services for clients with a dual diagnosis [*Where did you get this view? References? Literature?*]
- 5) Are there any other issues you would like to mention about services for clients with a dual diagnosis?

**Section 2: Community Capacity**

All key informants to complete the following questions.

- 6) How would you describe the current capacity of London/Middlesex County to deliver specialized mental health services the identified population in this survey? [*Strengths, Weaknesses*]
- 7) What do you believe is the ideal model/best practices for delivery of specialized mental health in London/Middlesex County? [*Are there any constraints, limitations which would prevent the achievements of this idea?*]
- 8) What model of treatment should in-patient facilities utilize in enhancing the community's capacity to deliver specialized mental health services in London/Middlesex County?

**Section 3: Interface/Linkages**

All key informants to complete the following questions.

- 9) How would you describe the nature of the relationships between mental health agencies in London/Middlesex County? [*Strengths, Weaknesses*]
- 10) What do you believe is the ideal model/best practices for the relationship between mental health agencies in London/Middlesex County? [*i.e. Cooperation, Communication, Coordination, Integration*]
- 11) How would you describe the relationship that your organization has with in-patient facilities?
- 12) What do you believe would be the ideal linkage or interface that your organization should have with in-patient facilities?
- 13) What changes do you believe need to occur to make this shift?

**Section 4: Debriefing**

All key informants to complete the following questions.

- 14) Do you have any additional comments regarding 'best practices' in specialized mental health services?
- 15) Are you interested in receiving a copy of the final report?

**Thank you for your cooperation in this effort to provide information to improve specialized mental health services in London/Middlesex County.**

## Appendix F—Glossary of Terms

*Best Practices*—The definition of this term utilized in the *Making It Happen. Operational Framework for the Delivery of Mental Health Services and Supports* (1999) is “... activities and programs that are in keeping with the best possible evidence about what works. Best practice models influence policy and direction at both the service system level and the service delivery level” (p. 61). Best practices are typically derived from empirical evidence about the phenomena. To remain effective, these practices must continually be critiqued to address gaps in service as this population’s needs change over time.

*Better Practices*—This term is relatively new to the healthcare services field and is often used in place of *best practices* to address the evolving nature of effective services for a population with changing needs. Quality of service and continuous evaluation are key components of this concept.

*Collaboration*—To “work jointly with others; to co-operate with an agency with which one is not immediately connected” (Canadian Mental Health Association- Ontario Division, Dual Diagnosis Task Force of the Public Policy Committee, 1998, p. 40).

*Community-Based Services*—This term defined by the Canadian Mental Health Association—Ontario Division, Dual Diagnosis Task Force of the Public Policy Committee (1998) is;

... in the presence of an identified health, mental health or developmental problem, services are provided in the community by local community members ... groups ... 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. (p. 40)

*Developmental Disability*—This term, used in Canada has been deemed more

universal and less oppressive than similar terms as *intellectual disability* or *mental retardation* used more commonly in the United States of America and *learning disabled* that is often used in the United Kingdom.

*DSM-IV*—This term stands for the *Diagnostic & Statistical Manual of Mental Disorders 4<sup>th</sup> edition*, published by the American Psychiatric Association. This provides guidelines and functions as a tool in diagnosing, studying and treating individuals with various mental disorders.

*Dual-Diagnosis*—This term is used to describe an individual with “mental retardation” (APA, 1994) and a mental disorder.

*Evidence-Based (or Evidence-Informed) Practices*—This term is often used interchangeably with better practices to reflect empirical evidence about a phenomenon. It promotes the most effective interventions and recognizes that client needs will change over time, as will treatment protocols. Quality of service and continuous evaluation are key components of this concept.

*Key Informants*—Taken to mean in this study, service providers of those with dual-diagnoses in London and Middlesex County. These service providers are composed of various front-line staff, middle managers and upper-level managers that have practiced in the dual-diagnoses field for a period of at least 3 years.

*Mental Illness or Mental Disorder*—These terms are often used interchangeably. Each mental disorder is defined as a behavioural or psychological condition of clinical significance and is coded on Axis I and II of the *DSM-IV*. Disorders typical of Axis I include mood disorders, anxiety disorders, and schizophrenia. Mental conditions included in Axis II are mainly related to various personality disorders (e.g., paranoid, borderline,

obsessive-compulsive, etc.).

*Mental Retardation*—This term in the *DSM-IV* is defined by the following three criteria:

- A) Significant sub-average intellectual functioning: An I.Q. of approximately 70 or below on an individually administered I.Q. test (for infants, a clinical judgment of significantly sub-average intellectual functioning).
- B) Concurrent deficits or impairments in present adaptive functioning (i.e., the person's effectiveness in meeting the standards expected for his or her age by his or her cultural group) in at least two of the following areas: communication, self-care, home-living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety.
- C) The onset is before age 18 years. (*DSM-IV*, 1994, p. 50)

The *DSM-IV* then further specifies the severity of the developmental disability as follows:

*Mild Mental Retardation*—I.Q. level 50-55 to approximately 70

*Moderate Mental Retardation*—I.Q. level 35-40 to 50-55

*Severe Mental Retardation*—I.Q. level 20-25 to 35-40

*Profound Mental Retardation*—I.Q. level below 20 or 25

*Mental Retardation, Severity Unspecified*—when there is a strong presumption of mental retardation but the person's intelligence is untestable by standard tests (e.g., for individuals too impaired or uncooperative, or with infants). (*DSM-IV*, 1994, p. 50-51)

*Specialized Services*—This term defined by the Ministry of Health and

Long-Term Care (1999a) refers to;

... treatment provided by specifically trained professionals to persons with serious, complex, and/or rare mental disorders whose service requirements cannot be met in the first line or intensive levels of service. Specialized services include special intensive programs both episodic and long-term rehabilitative care for people with severe and chronic symptoms. It includes outpatient, outreach and consultative services. (p. 41)

*Treatment Modalities*—This term is best defined by the Ministry of Health and

Long-Term Care (1999b) as “those interventions directed toward assessing, alleviating, reducing or managing the symptoms of an illness or disorder, or symptoms resulting from the trauma of abuse” (p. 65).

FIGURE CAPTIONS

Figure 1. A visual representation of the combination of two types of disabilities that comprise what is termed a 'dual-diagnosis' in Ontario.

Figure 2. Ministry funding responsibilities for those with a dual-diagnosis, prior to April 1, 2007 (Simcoe York Dual Diagnosis Education Committee, 2004).

Figure 3. Various components of an out-patient treatment model for those with a dual-diagnosis (see pages 117 and 118 for further explanation).

FIGURE 1

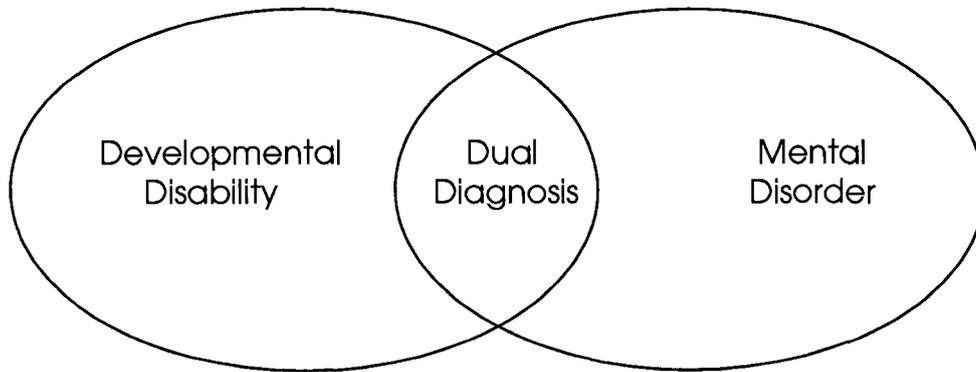


FIGURE 2

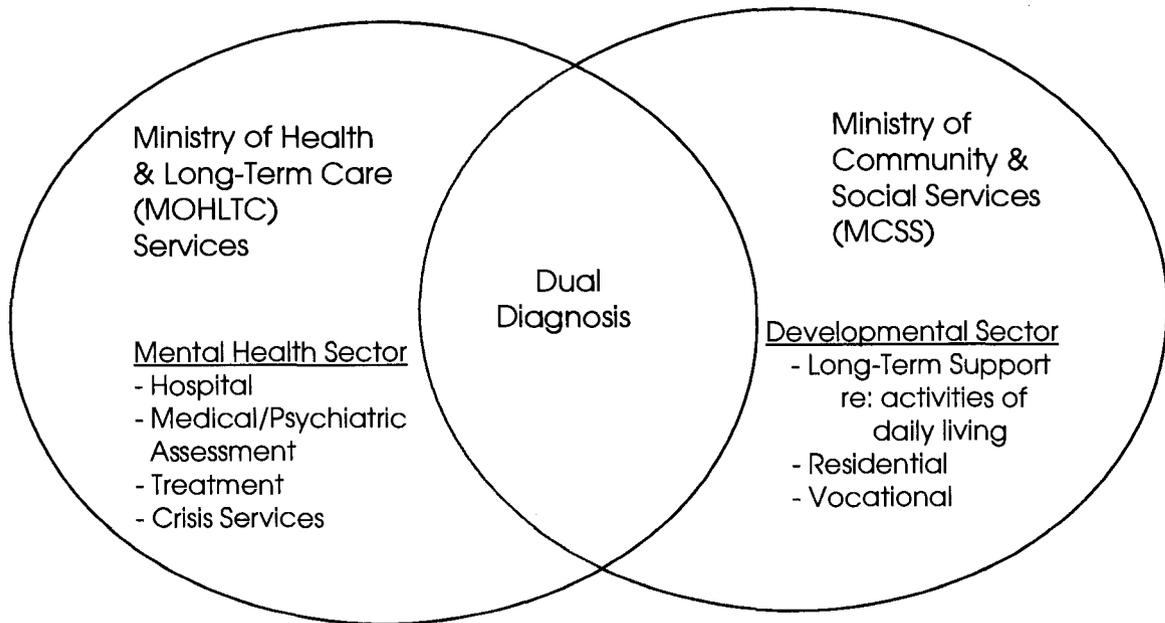
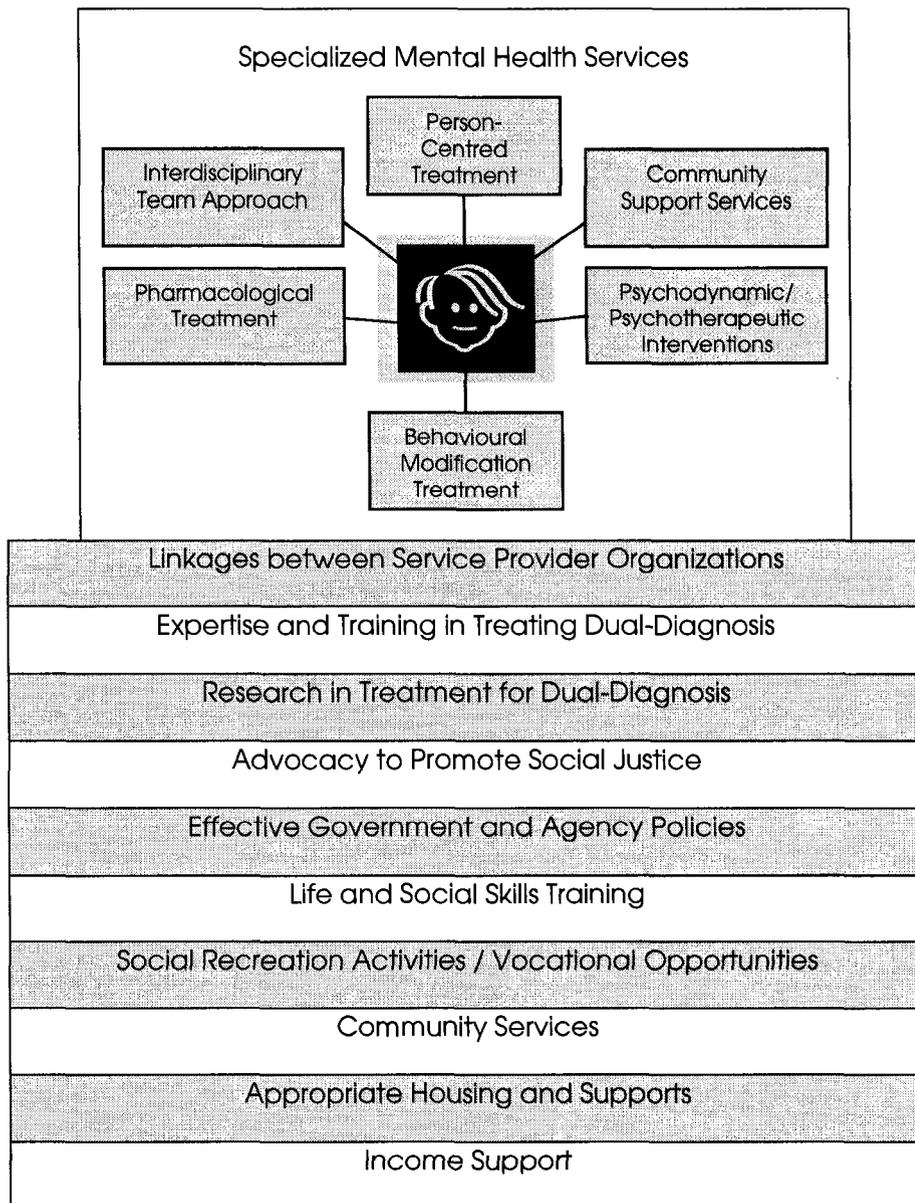


FIGURE 3



### VITA AUCTORIS

Tara-Ann Catherine Glasgow was born in Montreal, Quebec. She graduated from Vincent Massey Secondary School in 1994. From there she went on to the University of Windsor where she obtained a Bachelor of Social Work degree in 1998. For the past ten years, she has worked in a variety of capacities in the mental health field. Currently, she is the Policy, Ethics and Research Manager at the Erie St. Clair Community Care Access Centre. She is a candidate for the Master's degree in Social Work at the University of Windsor and will graduate in the Summer of 2008.