

**COMMUNITY NETWORKS OF
SPECIALIZED CARE**

Environmental Scan

**Prepared for the
Hamilton/Niagara and South West Regions
Ministry of Community and Social Service**

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Executive Summary

The Environmental Scan identifies where families of individuals who have a developmental disability and mental health issue(s) and/or challenging behaviour go to receive services and support in the Hamilton/Niagara Region and the South West Region. This study puts the person with a dual diagnosis at the centre of the research. It starts in the local community with families and local DS agencies. It then moves out from there to include Access/Contact agencies and specialized services providers. From there it expands out to key stakeholders and experts in the field. The findings from the Environmental Scan are the result of 19 focus groups; four surveys (family, agency, specialized service provider and Access/Contact agencies); meetings with key stakeholders and discussions with three experts in the field. The process also involved reviewing literature related to challenges within the developmental sector, issues related to dual diagnosis, and the structure and function of networks.

Findings

The structure of the developmental disability service delivery system is made up of families, developmental service agencies, and specialized services providers. At the foundation of the system are families who are taking care of adults with developmental disabilities and dual diagnosis. They provide all of the normal emotional, social and physical supports that any family provides its members. In addition, they must continue to take much of the responsibility for the ongoing protection and security of their family member as they age. The second level consists of community-based organizations providing supports and services to people with developmental disabilities. The primary services include respite; case management; supports for living in the community; social and recreational programs; day activities; employment services; first level assessment and behavioural/emotional support; and residential services. The third level consists of highly specialized services and supports that address the most severe and complex needs of people with developmental disabilities and coexisting mental health and behavioural issues.

It is estimated that approximately 69,400 (2.5%) of the 2,776,149 people living in the Hamilton/Niagara and the South West regions have a developmental disability and of these, 24,000 have a dual diagnosis (35%). These mental health and behavioural problems include (but are not limited to) seizure disorders, dementia, mood and anxiety disorders, sleep disturbances, introversion, over dependence, lack of confidence, poor self-identify, low self-esteem, social isolation, victimization, inappropriate sexual activities, self-abusive behaviours and aggressive tendencies. There are approximately 180 (.75%) individuals whose problems are so severe that they pose a risk to themselves or others in the community.

At the centre of the service delivery system are nine Access/Contact Agencies across the two regions. For the most part Access/Contact agencies provide a central information

and referral function for people with developmental disabilities. The access agency completes an intake process to determine the seriousness of the presenting problem. DS agencies may also contact the Access/Contact agencies when it needs help in dealing with a challenging situation. The Access/Contact agency will refer the family or agency to the appropriate service.

Access/Contact agencies, working with the local DS providers, develop waiting list for services. People can expect to wait anywhere from a few days to many months for service depending on their need and the availability of the service they are seeking. Residential services are by far the most in demand. The ratio is about five to one when compared to the demand for any other service. There is also a high demand for day programs when compared to other non-residential services.

Families report that it is difficult for people who are outside of the developmental services system to receive help. They claim that when there is a crisis there is no where to turn; there are long waiting list for most DS services, emergency rooms are reluctant to take a person with a behavioural problems into their facilities, there are few psychiatrists who provide services to people with dual diagnosis and family physicians provide support but are often not fully informed about the issues facing people with a dual diagnosis.

For the most part agencies report that once a person with a dual diagnosis is part of the developmental service system it is possible to obtain specialized services within the Hamilton/Niagara and South West regions. While waiting times varies across the regions, agencies report that other than crisis services, most other DS specialized services can be obtained.

There are three agencies funded by MCSS providing specialized services in the Hamilton/Niagara Region: Area Resource Team/ Behaviour Therapy Consultation Service; Bethesda Services; and Family Counselling Centre of Brant. Also there is one, Regional Support Associates providing specialized services in the South West Region. Twin Lakes Clinical Services will start providing specialized services in February 2006 and the Area Resource Team will cease providing services at the same time.

Together these agencies provided 3231 people with services in 2004-05. These services included assessment treatment, counselling, consultation, behaviour management and specialized accommodations. The services are provided by behavioural therapists, psychiatrists, psychologists, social workers, speech and language pathologists, physiotherapists, and nurses. Specialized service providers receive referrals from family physicians, DS agencies, Access/Contact agencies, hospitals, mental health agencies, community organizations, school boards, and families and caregivers.

The amount of time a person must wait for specialized services varies across the system. In almost all cases they will receive some preliminary attention. They may be scheduled for a session, but it may take some time for the session to take place given the nature of the problem and the availability of resources. Agencies will provide telephone support or

information if the waiting time persists. The longer people have to wait, the more stress it puts on the caregiver system.

People with a dual diagnosis also have access to mental health services through the Ministry of Health and Long Term Care's (MOHLTC) mental health system. These services, open to all citizens in the province, are intended to meet the needs of people when the local health care system can no longer address their problems. It is estimated that approximately 1,186 people with a dual diagnosis used mental health services in 2004-05 (based on Lunskey et. al. 2003). In principle people with a dual diagnosis have the same rights to mental health services as any other citizen and the system was designed to reflect this belief. However, families, DS agencies and key stakeholders report that people with dual diagnosis do not get equal access. They report that it is difficult to obtain admission into mental health facilities, in part because of the confusion between mental illness and behavioural problems, and in part because of rigidities in the system.

While the specialized service providers funded by MCSS and MOHLTC provide highly skilled experts to deal with the most difficult problems, the community based developmental service (DS) agencies provide the basic services for people with dual diagnosis. They provide social, recreational and emotional support, and programs and services that facilitate people with a dual diagnosis to live in the community.

There are 97 DS Agencies (as defined by transfer payment relationships with MCSS) in the Hamilton/Niagara and South West Regions. These agencies provide a broad range of services that can be categorized into four different types: residential service; day activity and employment programs; respite services; and specialized services. According to MCSS data all of the transfer payment agencies combined provided 22,883 units of service across the two regions in 2004-05. Although a person with a developmental disability may use more than one service, if each unit represents a person then in 2004/05 approximately one third of the 69,400 people with developmental disabilities in Hamilton/Niagara and the South West Regions received services from the DS Sector. The other two thirds of people with a developmental disability cared for themselves or were cared for by their families within the community.

In the Agency Survey the DS agencies described the percent of people with a dual diagnosis they served in each program area. These data were used to estimate that approximately 7566 units of service were delivered to people with a dual diagnosis in 2005-05. From a system perspective it appears that people with a dual diagnosis are receiving slightly more (39%) units of service than would be expected given the prevalence rates in the population. This however is expected since a large portion of the services provided by agencies relate to specialized services. This reinforces the notion that DS agencies provide the primary services for people with a dual diagnosis. They provide the foundation upon which the more specialized services are delivered.

When DS agencies need the services of specialists such as clinicians, psychiatrists, psychologists, physiotherapists, or behaviour therapists to help deal with issues related to

people with dual diagnosis, they seek outside help by either purchasing the services from private practitioners (7%) or engaging the services of a specialized service provider (93%).

DS agencies were asked whether they were able to meet demands for services to people with dual diagnosis in the past year (2004-05). Of the agencies reporting, 62.5% indicate demand exceeds their capacity on a regular basis and 37.5% report demand was a good match for their capacity most of the time. These proportions were stable even when the reporting was divided into: core services, residential services, and highly specialized services and supports. If demand exceeds capacity, agencies say the main causes are: lack of funding, waiting lists, and lack of specialized skilled staff.

In the Family Survey 39% of families caring for someone at home indicate that they are satisfied with the services they receive compared to 71% of families whose family member live in a DS residence. Two thirds of families providing home care report less timely availability of services, more barriers to services, and higher need for additional services. Almost 17% of these families report they never received the services and supports they needed in the past year as contrasted with 3% of families whose family member has residential support.

When asked to identify the gaps and barriers in the system agencies and families report that there is a lack of day programs to keep people with a dual diagnosis engaged in their community as well as recreational programs specifically designed for people with mental health and behavioural issues. Families report they need more respite services both on a regular and an emergency basis. Agencies indicate there is also a lack of specialized respite for crisis situations. Both families and agencies report that there is a lack of transportation (particularly in the rural areas).

Agencies indicate there are gaps in *services* for people with dual diagnosis. There is a lack of crisis services to respond to the needs of people with a dual diagnosis and a lack of trained staff to support people during a crisis. In addition they report there is a lack of psychiatric services for people when they need them and very few communities have specialized residential treatment within the community. At the systemic level there is a lack of collaboration and mutual support in many communities between developmental service agencies and mental health facilities.

In drawing all of the material from the Environmental Scan together the following eight issues were identified by families, agencies, and key stakeholders as the most critical to be resolved.

1. Adults with a dual diagnosis have complex needs.

The needs of adults with a dual diagnosis manifest themselves as ongoing low-level demands, episodic crisis events, and long-term disruptive events. Mental health problems merge with behavioural issues and it is difficult to diagnose and provide effective intervention. Small changes in a person's life and daily routine can have dramatic effects

on their ability to function which make their behaviour and situation unpredictable. All of these issues make it difficult to provide coordinated services.

2. The need for community based support is increasing for adults with a dual diagnosis.

Aging parents have diminishing physical, emotional and sometimes financial ability to continue to provide around the clock care and support for their adult children. Now they worry, for good reason, about what will happen to their adult children when they die. In addition, the Ontario government plans to close the three remaining institutions in the province; the closing of Southwestern Regional Centre in Chatham-Kent will have an impact on the demand for services primarily in that area, but also in the South West Region

3. There is no unified service system for people with dual diagnosis.

The continuum of care and support for these clients and their caregivers comes from diverse policy and program sectors and funding sources. This makes the provision of an effective and responsive continuum of services more complex. The diverse sectors include:

- multiple public sector partners e.g. Ontario Ministries of Community and Social Services (MCSS), Health (MOHLTC), Education, Justice and their transfer payment agencies
- non profit sector services e.g. YWCA residential and recreational programs
- private sector services and supports e.g. psychiatrists, training programs
- other community supports, some supported by community fundraising.

The lack of integration between MCSS developmental services and MOHLTC mental health appears to be the result of misperceptions about each sector's capacity and responsibility. The consequences include: disconnected service provision at the local level; the lack of a long-term shared agenda for sustained, effective care and support; and a lack of a long-term plan for dealing with increased needs.

4. Access to services is variable across the two Regions.

Meeting the needs of people with dual diagnosis depends upon: where they live; the ability of their family to advocate on their behalf; the availability of resources in the community; and the relationship between the developmental services sector, the health sector and other resources sectors.

5. There is a gap between the services provided to children and those provided to adults.

A gap in services is created when a person with a developmental disability moves from having rights to an education as a child to having no rights to services as an adult in the adult system.

6. Developmental services experience many challenges.

Developmental services are functioning at capacity. There is a waiting list for most of the services. At the same time, agencies' ability to deliver effective, timely, and responsive client and family services is at risk. Workers in the field are "tired" in the face of doing more with less, and participating in the development of community service plans, multi year plans and capacity assessments with little follow-up implementation activity to improve outcomes for clients.

7. When a crisis event happens there are few local resources to provide support.

The lack of available continuous, consistent and quality support for many adults in and of itself can provoke unstable client behaviours and crises. Families and providers lament the lack of a "safe space" to diffuse crises episodes for staff, family and client. Emergency psychiatric response is overwhelmed generally, and under trained specifically to respond to the presenting situation and the underlying conditions.

8. The service system does not have an overall strategy for encouraging people into the field.

There is insufficient focus on developmental disability issues in the training and education of professionals. There is no specialty in medicine, nursing, social work or other highly trained disciplines covering the needs of people with dual diagnosis.

Effective recruitment and retention of trained frontline workers is difficult in a environment characterized by declining interest in underpaid and stressful work, lack of cross sector training, diminished access to specialized supports for staff training and mentoring, and client intervention e.g. psychiatry.

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The Environmental Scan

Introduction

The Environmental Scan examines the availability of services for people in the Hamilton/Niagara and South West regions of Ontario who have a dual diagnosis. A dual diagnosis is a developmental disability with a coexisting mental health and/or behavioural issues.

This report presents information provided through surveys of families caring for a person with dual diagnosis; Developmental Service agencies providing services to this population; specialized service providers; mental health organizations; and key stakeholders. It also draws upon Developmental Service data provided by the MCSS for the two regions. The findings relate to four themes: access to specialized services; coordination of services across the system; gaps and barriers to receiving services; and training and human resource development within the sector. The findings highlight the strengths and challenges facing the developmental service system.

The final section of the report sets out key issues facing the system. It summarizes the findings of the Environmental Scan and outlines the challenges that need to be addressed in order to improve accessibility, fairness and sustainability in the developmental services system and support the vision of full inclusion of people with a developmental disability in all areas of society.

Background

In September 2005 the Ministry of Community and Social Service sent out a Request for Proposals (RFP) to explore how to enhance specialized services for adults with a dual diagnosis. The desire to enhance specialized services was a result of the government's announcement in 2004 regarding its commitment to developing a long-term plan to transform Developmental Services in Ontario¹. The RFP called for the development of an Environmental Scan and the creation of a Regional Solutions Report.

The purpose of the Environmental Scan is to identify where the families of individuals who have a developmental disability and mental health issue(s) and/or challenging behaviour go to receive services and support in the Hamilton/Niagara Region and the South West Region. The Environmental Scan will provide an inventory of community-based services and resources that support the functions and objectives of the Community Networks of Specialized Care.

The Environmental Scan will:

¹ *Building the Foundation for the Future: Transforming Developmental Services*

- Identify all specialized resources in the partnering region (e.g., specialized DS agencies and clinical services; generic agencies/hospitals that provide specialized services; crisis services; specialized professionals; academic institutions with professional programs on developmental disabilities and dual diagnosis etc.).
- Identify specialized professionals, their qualifications and clinical approach and any existing relationships, linkages and formal or informal arrangements and agreements between professionals and DS specialized agencies, other DS service providers and generic community resources, including services available in French.
- Identify and describe existing community-based specialized accommodation (e.g., how many, location, short versus long-term, Supported Independent Living etc.).
- Assess community capacity to serve individuals with specialized needs and/or develop service options to meet the needs of individuals moving from facilities into the community, including expertise in the following areas:
 - specialized accommodation (e.g., whether/how mental health, behavioural, and complex medical needs are supported)
 - intensive behavioural/psychological supports and interventions (e.g., staff trained in direct care, chemical and mechanical restraints, rapid response staff on call)
 - clinical health supports and interventions (e.g., daily medical monitoring, interventions that fall under the Regulated Health Professions Act R.S.O. 1991).
- Identify communities' service delivery strengths and gaps in service that will have implications for the provision of specialized services, supports and accommodation.
- Identify any legislative and/or funding barriers that limit the capacity to serve individuals with specialized support needs.
- Prepare a comprehensive report that outlines the findings of the Environmental Scan, and analyzes the strengths and gaps in the system.

Based on findings of the Environmental Scan, the Regional Solution Report will make recommendations and identify strategies that address the issues and resource/service gaps identified in the system.

Methodology

The study begins with the person with a dual diagnosis at the centre of the research. It asks where people with a dual diagnosis find services and what gaps and barriers they face in trying to obtain these services. This means starting in the local community with families and local DS agencies. It then moves out from there to include Access/Contact agencies and specialized services providers. From there it expands out to key stakeholders and experts in the field.

The research focuses on the needs side of the system rather than the service delivery side. This approach resulted in the development of an inventory of issues and challenges rather than an inventory of services. The study provides a view of the problems and issues, gaps and barriers, from the families and local agencies perspective. It offers a client centered understanding of their problems in finding and obtaining specialized services.

The Environmental Scan draws on multiple strategies, and sources of information. Generally, information was gathered and organized for the combined regions of Hamilton/Niagara and the South West. For administrative convenience, each region was divided into 4 areas for setting up focus group and key stakeholder meetings and sending out family and agency surveys. Finally, some families and agencies sent in letters and some agencies sent additional information packages.

A project leadership team was comprised of Ministry of Community and Social Services (MCSS) regional office staff. This Joint Implementation Team (JIT) was responsible for managing the project and providing direction and guidance to the project consultant (See JIT membership, Appendix 1). The following activities were undertaken:

- The literature was reviewed on the issues of developmental disability and dual diagnosis prevalence, related social and health policy formulation, evolution of developmental services in Ontario, and the role and experience of networks as effective change agents for improved human services.
- Families were consulted in two ways. Focus groups of family members were held in each of the eight communities, and families in each area were invited to complete a family survey (Appendix 2). Both initiatives were designed to elicit the families' experiences with services and supports for their family member, the strengths and gaps in services and supports, and what needs to change. The method was designed to protect families' confidentiality. A Family Survey was prepared and five copies were sent, along with stamped self-addressed envelopes to every community Developmental Service agency identified by the MCSS. The agencies were asked to forward the survey to five families who are receiving services or who are on their waiting list to receive services. As well, the agencies were asked to send a focus group invitation prepared by the consultant to three families who receive services, with a response card addressed to the consultant. In this way, the consultant does not know the address or name of the family, and the agency does not know who responded to either invitation. 29 family members participated in the focus groups. One hundred and twenty one families caring for one hundred and thirty three adults with a developmental disability returned a survey. The return rate was higher in the Southwest (65%). Of the 133 people with a developmental disability, approximately 39% live at home with their family, 11% live on their own and the remainder live in other settings (Appendix 3). Almost all families (98%) indicate English is the language they prefer when receiving services.

- Community based Developmental Service (DS) agencies were also consulted in two ways. The Executive Directors or their designate were invited to a focus group in their respective project area, and, asked to complete an agency survey. The purpose of the focus group is to develop a deeper understanding of how agencies serve people with dual diagnosis and behavioural issues; how they connect with Access/Contact agencies and how effective the referral process is. The focus groups also explored how people get connected to specialized services, which services are available in the local area and the barriers that exist to accessing services. The purpose of the DS agency survey was to carry out an in-depth scan of the community's capacity to provide and enhance specialized supports and specialized accommodation available to individuals with a dual diagnosis. The survey asked the agencies to describe the programs and services they offer, the level of effectiveness of each program or service, gaps and barriers the system, access to resources, and the agencies' training needs (Appendix 4). The survey response rate among 96 agencies identified by MCSS was 49% (N=47) (Appendix 5).
- A single meeting was held with the eight CONTACT and ACCESS agencies in the Hamilton/Niagara and Southwest Regions, and subsequently, they were asked to complete a report. The working session was designed to develop a deeper understanding of how people get referred to agencies, programs, services, specialized services and other supports. The discussions explored the process of how people seek services, and how long they wait to receive different types of services and supports. The report they were asked to complete asked for information about the services provided by the Access/Contact agencies, the demand for service, the capacity of their organization to meet this demand, and the gaps and barriers within the existing services.
- Key stakeholders in each of the two Regions were invited to participate in meeting sessions. These stakeholders included representatives from the hospitals, specialized service providers, colleges and universities, police, family physicians, Ministry of Health and Long Term Care, Children's Aid Societies (regarding young adults), Canadian Mental Health Association and experts in the field (Appendix 11). The key stakeholders were asked to discuss the most effective ways of addressing the challenges facing the service system for people with complex needs and dual diagnosis.
- Specialised providers were consulted in two ways. First, there was a meeting for specialized providers from across the two Regions, and subsequently, they received a Specialized Agency Survey electronically (Appendix 10). All of the specialized service providers responded to the survey. The survey was designed to confirm role and function; referral patterns; relationships with DS agencies and related services; and program and service pressure points.

- Three interviews were held with experts in the field: Dr. Benjamin Goldberg, Dr. Dorothy M Griffiths and Dr. Elspeth Bradley in order to assess the challenges and barriers facing the development of services for people with dual diagnosis.
- Finally, a newsletter was developed and three issues were distributed to keep the field abreast of project activities and progress.

Hamilton Niagara and South West Regions

The Regions

The Hamilton/Niagara Region includes four census areas: Brant, Haldiman/Norfolk, Hamilton, and Niagara. While the traveling distances are not as far as in the South West there are still parts of the region that are considered rural and these do not have the benefit of local services. The population was 1,296,551 in 2001 according to Statistics Canada with just over 51% living in Hamilton and 31% in the Niagara area. The region has had a slower population growth rate than the rest of the province. Like the South West it has a larger proportion of seniors and a smaller proportion of immigrants compared with the provincial averages. The unemployment rate and low-income levels are about the same as the rest of the province.

The South West Region includes ten census areas: Bruce, Elgin, Essex, Grey, Huron, Kent, Lambton, Middlesex, Oxford, and Perth. Windsor and London are the two largest urban areas. It is a diverse region with a large land mass and people living in rural areas must travel considerable distances to obtain services. The population was 1,479,598 in 2001 according to Statistics Canada. There has been a slow population growth over the past five years with limited immigration. This area also has a higher than average seniors population compared to the province and a lower than average number of immigrants and visible minorities. While the unemployment rate was similar to the provincial average in 2004, there is a smaller proportion of families with low incomes.

The Developmental Disability Service Delivery System

The basic structure of the developmental disability service delivery system can be divided into three sections (see diagram 1). At the foundation of the system are families who are taking care of adults with developmental disabilities. They provide all of the normal emotional, social and physical supports that any family provides its members. In addition, they must continue to take some of the responsibility for the ongoing protection and security of their family member as they age. There are a number of adults with developmental disabilities who move out of the family home and live on their own. But even these independent people need help in times of a crisis and they often turn to their families as the first level of assistance.

The second level in the delivery system consists of community-based organizations providing supports and services to people with developmental disabilities. These range from DS agencies dedicated to providing service to people with developmental disabilities, to non-specific organizations who accept participants into their programs but who do not provide a dedicated service. Organizations dedicated to meeting the needs of people with developmental disabilities provide a broad range of services including: respite; case management; supports for living in the community; social and recreational programs; day activities; employment services; first level assessment and behavioural/emotional support; and residential services including supported independent

living arrangements, group homes and associate family living. The organizations providing dedicated services are primarily funded by MCSS although they may raise other funds in the community.

The third level consists of highly specialized services and supports that address the most severe and complex needs of people with developmental disabilities. These services are provided by agencies dedicated to working with people with developmental disabilities or by mental health facilities that provide services to the broader community and as part of this process provide services to people with developmental disabilities and mental health problems. The specialized service providers offer assessment; behavioural and emotional support and consultation; psychiatric support; crisis response; treatment; and specialized residential services for people who are at high risk. The third level consists of organizations funded by MCSS and those funded by MOHLTC.



The structure of the developmental disability service delivery system provides a continuum of supports and services for people with developmental disabilities and coexisting mental health and behavioural problems. At one end of the continuum families provide informal social supports, social networks and the resources needed for daily living. The local community provides opportunities for friendship and support and where needed, self-help groups and informal social structures that support people when they have social problems.

As we move along the continuum we find bridging mechanisms that join the family level of support with the agency level. These include social and recreational activities. At the more informal end of these bridging mechanisms, the supports are provided in the community through social networks, at social gatherings and through social clubs. At the more formal level they may be provided by organizations and agencies offering services to a wide range of people including those with a developmental disability.

In the middle of the continuum we find the agencies dedicated to providing services to people with developmental disabilities. As the conditions of the client with a mental health or behaviour problem worsen, the continuum of supports and services responds in different ways. It shifts from providing social, recreational and day activities to providing crisis response, interventions and ongoing support. At the lower end of the treatment continuum the intervention may offer life and social skills or generic counselling. Further up the continuum the interventions may focus on behavioural treatment programs, therapy or pharmacological interventions.

Finally the person may need to be placed within a safe environment for their protection or the protection of others. This may be a secure bed in a specialized service provider's facility or in a mental health facility. Depending upon their needs this may be for a short time or in some cases for long term stay.

Prevalence Rates

Statistics Canada reports that in 2001 (last census) there were approximately 2,776,149 people living in the Hamilton/Niagara and the South West regions. It is estimated that between 2 and 3% of the general population have a developmental disability (Ouellette-Kuntz et al, 2004). This study uses 2.5% (mid-point in the estimates) to estimate the prevalence in the population. This suggests that approximately 69,400 people with a developmental disability are living in the combined regions. The severity of these disabilities ranges from mildly disabled to severely disabled depending upon the level of adaptive skills possessed by the person. These skills include communication, self-care, home living skills, social skills, ability to use community facilities, ability to make life decisions, ability to care for health and safety issues, functional academic skills, leisure skills and work skills.

Number of People with Dual Diagnosis

It is estimated that between 30 and 40% of people with a developmental disability have mental health or behavioural problems (Ouellette-Kuntz et al, 2004, Yu & Atkinson, 1993). This study uses a 35% (mid-point) prevalence rate that suggests that approximately 24,000 people in the regions have a dual diagnosis. These mental health and behavioural problems include (but are not limited to) seizure disorders, dementia, mood and anxiety disorders, sleep disturbances, introversion, over dependence, lack of confidence, poor self-identify, low self-esteem, social isolation, victimization, inappropriate sexual activities, self-abusive behaviours and aggressive tendencies (summarized from Bradley and Burke 2002). As the Task Group of the NADD Ontario Chapter points out, behavioural and emotional problems can have a significant impact on the individual's quality of life and safety; that of their caregivers; as well as acceptance by society (p. 4).

The Ontario Hospital Association estimates that about three-quarters of one percent of the people with a dual diagnosis will have a severe mental health problem (Southwestern Ontario Dual Diagnosis Steering Committee). A severe mental health problem means the person is at risk to either themselves or to someone else in the community. Using this prevalence rate, there are approximately 180 people who have a severe mental health problem at any one time in the Hamilton/Niagara and South West Regions.

Assessing people with a dual diagnosis is very challenging. In many cases underlying mental health problems are masked by behavioural problems. This means that in the assessment process presenting problems are often assumed to be due to the developmental disability rather than an underlying mental health problem (Summers et al, 2004). The Task Group of the NADD Ontario Chapter points out that “this often results in inappropriate treatments (such as polypharmacy), complicating and confounding side effects due to overmedication, frequent contact with police and hospital emergency rooms, and failure in community programs (p. 4).”

People with developmental disabilities and coexisting mental health and/or behavioural problems receive supports and services from many sectors of the social system. These include agencies in the developmental, mental health and health sectors, and community based non-profit organizations. The next section of this report examines the services provided by Access/Contact Agencies in the developmental service sector.

Access/Contact Agencies

There are nine Access/Contact Agencies in the two regions. They are located in Community Living Chatham Kent, Community Living Owen Sound, Windsor-Essex Brokerage for Personal Supports, Community Services Coordination Network in London, Connecting Point and Starting Point in Sarnia, Contact Brant in Brantford, Haldimand-Norfolk REACH in Townsend, Contact Hamilton, and Contact Niagara in St. Catharines. The following material describes the services provided by the Access/Contact agencies.

This material has been drawn from many sources including web pages, annual reports, developmental service plans, data from the agencies, and from focus groups and interviews.

Access and Contact agencies are different in each region and have evolved differently in each community. In some communities all referrals must pass through the agency and in others there is more than one point of entry. The following description is intended to provide an overview of the system in order to identify the common gaps and barriers to service. For the most part Access/Contact agencies provide a central information and referral function for people with developmental disabilities. When a family or person is looking for help they are directed to an access agency that completes an intake process with the person or family to determine whether they need services. They also provide information about services available within the community, and refer people to the most appropriate service. The intake information is forwarded to the DS agencies, avoiding the need for people who are applying for services to provide repeat information.

From the macro perspective Table 1 describes the units of service provided by Access/Contact in 2004-05. These units of services represent the number of times people contacted the agencies looking for assistance for people with developmental disabilities. During discussions with Access/Contact agencies they report that approximately 30% of those seeking services were later determined to have dual diagnosis. Using the assumption that 30% of the people who used Access/Contact services had a dual diagnosis, it is estimated that approximately 1147 people with mental health or behavioural problems contacted the DS system in 2004-05

Table 1 : Care Givers of People with Dual Diagnosis Using Access Mechanisms

	Total	Percent	Dual Diagnosis
Access Mechanism - DS	3825	30	1147

Calculated from information provided by MCSS

Part of the responsibilities of the Access/Contact agencies is determining the level of need of the individual seeking service and to make a referral to the appropriate service provider. This referral is based upon the intake process form that asks for basic demographic information, a description of the circumstances in which the person lives, information about the specific problems they are having and a history of the services they have received. At the end of the intake process the person (or their family) is asked what type of help or support they need. This information is used by the Access/Contact agency to make a preliminary assessment of the level of urgency facing the individual or family. The request for services will be placed into one of three categories: urgent need, medium need or low need. There are a number of factors that determine the level of need. Most important is the level of risk the person represents to themselves or others, next is the living conditions and support the person is receiving at present, and finally how the family or care provider is coping with the situation.

This preliminary assessment provides information to the Access/Contact agency that they share with a DS agency. If there is a service available and the person has a high need, the DS agency will decide whether there is a fit with their programs. At this point an offer will be made. If this offer is accepted by their family, the person will receive the service. If the service is turned down (according to focus group participants this often happens), the family will have to wait for an opening in another service or program.

When services are full the Access/Contact agencies, working with the local DS providers, develop a waiting list for services. The length of time a person can expect to wait for services depends upon their need and the availability of the service they are seeking. Individuals will be informed that they are on a waiting list until services become available. The length of time a person will be on a waiting list varies according to the service that is required and the community in which the person lives. Residential services are by far the most in demand. The ratio is about five to one when compared to the demand for any other service. The waiting lists for supported independent living are the longest, followed by the demand for group home accommodations and a limited demand for associated family living. Focus groups revealed that most families and individuals start by asking for group home support and taking what is available.

There is also a high demand for day programs when compared to other non-residential services. Focus groups report that having something to do during the day is the most important thing for people who are facing mental health and behavioural problems. Parents told numerous stories about their adult child with dual diagnosis walking in circles to fill time or sitting in their rooms staring into space.

Access/Contact agencies report demands for respite, employment services and counselling, but at a much lower level than the need for residential or day programs. In part this reflects the challenges faced by the Developmental Sector. While people with a dual diagnosis need specialized services when things are going wrong or to help them solve challenging problems, they require the basic or core services of supported living and something to do during the day as the foundation of a functioning life. Although providing specialized services is a complex process and requires the skills of highly qualified professionals, it is relatively straightforward. The services can be provided at home, in an agency or in a mental health facility. For the most part they are time specific and have an identifiable goal. What is much more challenging is meeting the basic needs of people with a dual diagnosis. The caregivers, whether they are family members or DS agencies must provide food, accommodation, and support in a stable and secure fashion. Families and DS agencies report that this is very challenging given that any event can cause problems and be upsetting to a person with mental health or behavioural problems. Access/Contact agencies report that the demand for basic services has always been much higher than the demand for specialized services.

Access/Contact agencies report that waiting lists are constantly changing. People needing services come onto the waiting list and go off depending upon changes in their circumstances. A family may be offered a service and turn it down yet still want to remain on the waiting list. The length of time a person is on a waiting list varies by the

urgency of the situation, the demand for the service, and the willingness of the family or individual to accept an alternative program. This leads to different waiting times across programs, agencies, communities and regions. Family members told stories of being on waiting lists for three or four years without any hope of finding a placement. A number of elderly parents are afraid that they will not find a place for their adult child before they die.

There are a number of specific challenges that Access/Contact agencies report in meeting the needs of people with a dual diagnosis. First, it is particularly difficult to meet the needs of people living in rural communities. The further the family is from services the more difficult it is to serve them. They often need help in finding accommodations for when problems emerge or when events evolve to the level where the family can no longer take care of the problems. When these situations arise, the family's isolation becomes a major factor. Transportation can become a problem and if the parents are elderly these conditions are more difficult. Second, meeting the needs of young people in transition between school and work (or other activities) is challenging. The process of transition is stressful and creates conditions that are upsetting to the individual. Families report they go from having support within the educational system to having little or no support within the community. When they approach the Access/Contact agencies for help, they report that there are long waiting periods and little support. This is a very vulnerable time for people with mental health or behavioural problems. They move from a structured life to an unstructured one and families and DS agencies claim there is a need for careful transition planning in order to reduce the likelihood of emotional and behavioural problems.

The refrain most often heard from families, DS agencies and Access/Contact agencies is that services need to be brought to the individual not the individual to the services. Families are most concerned that specialized service providers should be organized to deliver services in the local community wherever possible and that people with a dual diagnosis should not be moved out of the community. The disruption of moving them in and out of the community often undermines the work carried out by the specialized service providers.

Access/Contact agencies say that there is no clear picture of how many people are in the DS system. There is constant movement in and out of different services. There is no annual audit of the number of people being served although there is an audit of the number of units of service that are provided. Since one person may receive more than one service these numbers do not represent individuals. When the Access/Contact agencies were created they did not go back and assess how many people were in the system at that time and although they can report on the number of people who came into the system and were serviced since they started, they are unable to confirm the number of people in the system at present.

In drawing this all together, Access/Contact agencies report that families and individuals with mental health and/or behavioural problems are primarily looking for help in finding

accommodations and day programs. Once they have secured these they go on to seek help with specific problems and they turn to specialized services for help.

Specialized Services in the Developmental Sector

When families and DS Agencies are no longer able to meet the needs of people with a dual diagnosis they call upon specialized service providers in the regions. This section describes the specialized services in the developmental sector available to people with dual diagnosis. These include three agencies providing services in the Hamilton/Niagara Region: Area Resource Team/ Behaviour Therapy Consultation Service; Bethesda Services; and Family Counselling Centre of Brant; and one, Regional Support Associates providing services in the South West Region. Twin Lakes Clinical Services will start providing specialized services in February 2006 and the Area Resource Team will cease providing services at the same time.

The specialized service providers offer assessment, treatment, counselling, consultation, and behaviour management provided by behavioural therapists and occupational therapists, psychiatrists, psychologists, psychometrists, social workers, speech and language pathologists, physiotherapists, nurses, kinesiologists and doctors trained to provide services to people with a developmental disability and mental health and/or behavioural problems. In addition the specialized service providers may offer clinical services, case management, service coordination, specialized community-based accommodation, community outreach, education, training and research focused on adults with a dual diagnosis.

The following provides a general description of the services provided by the four DS specialised service providers in the Hamilton/Niagara South West regions.

The Area Resource Team (ART) serves people 16 years of age and older with a developmental disability and a psychiatric, behavioural, emotional and/or communication problem. Clients must live in Hamilton, Niagara or Brant counties in order to be eligible for these services. The team has members from psychiatry, psychiatric nursing, psychology, behaviour therapy, and speech language pathology and communication disorders. ART is a community-based program in which individuals are seen in their own environment(s). They provide consultation and assessment around psychiatric, psychological, specialized behavioural, communication, and feeding and swallowing issues. ART consults with clients, their families and/or service providers and offers training and in-service education on a variety of topics. They work in conjunction with the Behaviour Therapy Consultation Service (BTCS) in Hamilton.

The Behaviour Therapy Consultation Service is a community-based service for children, adolescents and adults with developmental disabilities and significant behavioural or emotional problems. The team is composed of experienced Behaviour Therapists who work under the direction of a Clinical Psychologist. BTCS provides therapeutic interventions that are person-centred and evidence-based. They use a mediator model to work collaboratively with clients and those who support them, to enhance the client's

quality of life. The service is community-based, with individuals being seen in their own environments, including schools, homes and vocational/residential settings.

Bethesda Services provides a wide range of services and accommodation for people with developmental disabilities. They have residential accommodations in many locations throughout Niagara and are able to provide specialized residential support to high needs adults with mental health and behavioural problems. Bethesda provides 14 short term beds for adults with needs that exceed current caregiver capacity or who are in crisis or need specialized respite. They also have 46 Long Stay beds and provide the same set of services. Supports for both types of beds include 24-hour supervision, assistance with daily living activities, stabilization, assessment, specialized clinical intervention, individualized structured support, caregiver training and transition planning.

The Family Counselling Centre of Brant, Developmental Services division offers behaviour therapy and consultation, case management, family relief services and special services at home for adults with dual diagnosis. The staff and volunteers are committed to the universal acceptance of people with a developmental delay. The staff believes that the organization's mission will be achieved by assisting people with developmental disabilities to grow towards their fullest potential by providing support and access to community services.

Regional Support Associates (RSA) provides specialized services to people with developmental disabilities. The staff have clinical expertise and training in psychology, social work, sociology, nursing and developmental services. Services are offered to the individual, their families and agencies supporting them in their community. RSA provides a range of services to adults with developmental disabilities and dual diagnosis. These services include behavioural interventions, social sexual assessment, supports for abuse survivors, social skills development and a broad range of counselling and assessment services. RSA also partners with community living agencies to provide specialized accommodations. They offer clinical support, training and ongoing monitoring of cases while the residential providers offer accommodation and staff giving direct care. When the individual stabilizes RSA withdraws intense services, as do the residential providers. So, the individual remains in place while the more intense supports are reallocated.

There are three other agencies that provide internal specialized services to people with dual diagnosis. They are the YWCA, Christian Horizons and Choices. Each of these DS agencies employs a behaviour therapist to work with people who have mental health and behavioural problems. When the needs of a person become either too complex or demanding they call on psychiatrists or psychologists from private practice or seek the support of other specialized service providers.

The following table provides a summary of the specialized services provided to people with a dual diagnosis in 2004-05. The services also include core and residential services because some specialized service providers also provide other services.

Table 2: Total Services Delivered by Specialized Service Providers

	ART	BTCT	Bethesda	RSA	Brant	Total
Core Services						
Respite (out of home)			30			30
Respite (in home)					89	89
Behavioural/Emotional support and consultation			52	697	47	796
Case Management					42	42
Social Recreational Supports			42			42
Day Activity/ Employment					15	15
Assessment/Clinical services	29	156	122			307
Residential Services						
Family home/Associate family			15			15
Supported Independent living			2			2
Group home			46			46
Specialized Services						
Specialized community based accommodation			14			14
Assessment/clinical services	36		218	508		762
Crisis Response / Treatment			97			97
Psychiatric Support and Consultation	151			59		210
Psychiatric Nurse	147		93			240
Medical Support and Consultation			5	3		8
Speech and language therapy	72		32			104
Counselling			70	48		118
Sexuality Services				140		140
Family Services				105		105
Special community outreach activities			49			49
Total Services	435	156	887	1560	193	3231

Assessment of Specialized Services

MCSS is in the process of reorganizing the provision of specialized services in the Hamilton/Niagara region. The Area Resource Team will stop providing service in February and a new agency, Twin Lakes, will begin to provide services. There are mixed reviews of this change. Professional educators and health care providers lament the closing of ART. They claim that it is a leader in research and writing about issues related to dual diagnosis and the delivery of specialized service. They go on to note that

members of the ART team have made important contributions to the understanding of the issues facing people with a dual diagnosis and have provided key information on how problems can best be addressed. They claim that ART is well connected to the national and international networks of scholars researching and writing in the field. They also note that ART is connected to a prestigious university and can draw upon the resources of that institution. They point out that ART's connection to the faculty of Health Sciences places them in a position to provide critical information about the needs of people with developmental disabilities and mental health problems to new health care professionals entering the health field.

On the other hand DS agencies report that it takes a long time for ART to deliver services and that they are not responsive to agencies needs. There has been a debate in the community about the merits of ART's services and it has only been recently that MCSS has asked everyone involved for proposals seeking the best way of meeting the needs of people who require specialized services. The submission of these proposals has led to the creation of Twin Lakes Clinical Service.

Agency focus group members and key informants report that the other two specialized service providers, Bethesda and the Family Counselling Centre of Brant have generally provided supportive services. They report that it is not uncommon to have to wait for services but eventually they will receive the support they need. Bethesda has been asked to develop five additional specialized accommodations for the Hamilton/Niagara region.

DS agencies in the South West report that for the most part they are able to obtain the services they need from the Regional Support Associate. There are waiting lists and the services may take longer to arrive than agencies would like, but when they ask for services, agencies can obtain them. DS agencies claim that RSA offers a full range of services that meet the needs of people with dual diagnosis. In order to meet the geographic needs of the communities RSA has offices in Woodstock, London, Walkerton and Chatham.

The Process of Referrals into and out of Specialized Service Agencies

Specialized service providers receive referrals from family physicians, DS agencies, Access/Contact agencies, hospitals, mental health agencies, community organizations, school boards, and families and caregivers. The pattern of referrals is different for each specialized service provider.

ART receives approximately 55% of its referrals from the hospital system and physicians, 40% from community agencies (Contact, developmental and mental health agencies) and the final 5% from families and caregivers.

BTCS receives approximately 40% of its referrals from within the system. These come from Developmental Pediatrics and Rehabilitation as well as the larger Hamilton Health Sciences system. They receive 50% of their referrals from

community developmental service agencies (Community Living Hamilton accounts for 25% of all agency referrals), 7% from Contact Hamilton and 3% from families and caregivers.

Bethesda receives referrals from Children's Aid Societies, APSW, Community Living (9 communities), Good Shepherd, Mainstream, Niagara Support Services, Niagara Catholic School Board, Participation House – Hamilton, and Probation and Court Services. It also takes referrals from individual clients, families and internal referrals from its own programs.

Family Counselling Centre receives 99% of its referrals from Contact Brant and a very small proportion from internal referrals (for Special Services at Home for Adults)

RSA receives referrals from community agencies, family physicians, hospitals, Ontario Works, schools and other social service agencies.

When the Specialized Service providers seek additional support in meeting the needs of people with dual diagnosis they may refer them to other services.

ART claims that if the client does not meet eligibility criteria (age, developmental disability, place of residence), he or she is referred to appropriate services if they exist. For example, clients who are seeking articulation therapy are referred to Community Care Access Centres. Clients with learning disabilities are referred to practitioners with this expertise. Clients with Asperger's disorder (who by definition do not have a developmental disability) are referred to local physicians.

Bethesda has a close working relationship with the Area Resource Team. Their psychiatric nurses make referrals to ART when a psychiatrist is needed to assess and treat an individual. The Bethesda psychiatric nurse remains involved to provide follow-up. A referral may be made when there is a need for a medication review or a client is in a psychiatric crisis. Bethesda's psychiatric nurses also help families and agencies navigate the health system when a crisis bed is needed.

Family Counselling Centre makes referrals to Bethesda for the short-term behavioural unit. Approximately 6 referrals were made to the Area Resource Team for psychiatric consultation. Between 10 and 15 referrals were made to the Canadian Mental Health Association for day programming.

RSA refers those who are eligible for service to other agencies. These agencies develop individual plans for them. The number of these other referrals is not recorded. RSA refers to physicians, adult protective service workers, CSCN (placement), community living agencies (support/placement/work), legal clinics, diversion programs, Developmental Behaviour Management unit St. Josephs Hospital London, dual diagnosis nurses in Windsor & Chatham, Dual Diagnosis

Co-ordinator in Owen Sound, psychiatrists, women's shelters, Children's Aid, CCAC's, and community mental health agencies.

These specialized service providers turn to each other for support and assistance in dealing with complex issues. They are all members of networks across the two regions and they meet to discuss problems and issues. If they are unable to meet all of the needs of a person they will look to other specialized service providers for help.

Waiting Lists

The amount of time a person must wait for specialized services varies across the system. In almost all cases they will receive some preliminary attention, they may be scheduled for a session, but it may take some time for the session to take place given the nature of the problem and the availability of resources. Agencies will provide telephone support or information if the waiting time persists.

At ART clients are placed on a discipline specific waiting list. Referrals for psychiatry are seen by the psychiatric nurse within 2 weeks of receipt of referral for intake and are scheduled for an appointment with one of the 5 ART consulting psychiatrists. Wait times average about 4-6 months and cases are prioritized based on a review of risk factors. Referrals for communication assessments stay on a chronological waiting list until the case can be opened, generally about 6-8 months.

At BTCS clients are placed on a waiting list within 14 days of receipt of referral, and they are and notified verbally and in writing about how long they can expect to wait. The average wait time fluctuates but is generally around 10-12 weeks. The shortest wait time is 2 days and the longest wait time is approximately 12 months. BTCS uses a rating scale to prioritize cases with more serious issues. Some of the factors they take into consideration include: the risk of physical injury to self or others; behaviours jeopardizing community and/or family home placements; behaviours having a negative effect on caregivers; and the person's environment and /or the community at large.

Bethesda places everyone on a waiting list because clinical case loads are high. In 2004/05, they had 347 requests for Outreach Services, and they all were put on a waiting list. The time on the list is determined by the need of the client. If a client is in crisis they will be seen as soon as possible. Bethesda uses a three tiered vetting process. Each Outreach department manages their own wait lists.

Family Counselling Centre's waiting lists are determined in each program area by the availability of resources and the staff's current case load. At the present time there are 5 individuals waiting for behaviour consultation and 32 individuals waiting for case management.

RSA reports that it does not have a waiting list. Referrals are assigned when the appropriate paperwork (i.e., consent, client information packages for assessment

purposes) is received. If the appropriate paperwork has not been received this will delay the referral, hence the wait time. The average wait time from the initial referral call to assignment is 45 days and the average time from the receipt of signed consent to assignment is 15 days. If a referral is of an urgent nature, RSA make exceptions to this process and the referral is immediately brought to the attention of the Director. RSA currently has a database to collect all referral information; this allows the organization to do a broad analysis on specific information related to this referral process.

The waiting time reported by the specialized service providers reflects the comments of the agencies. Their perception is that people must wait to receive specialised service. The waiting period is detrimental to people needing services. The longer they have to wait, the more stress it puts on the caregiver system. Agencies also report there is not an adequate crisis response to very disruptive people with a dual diagnosis. When services are not available in the local area, families and DS agencies sometimes turn to services available out of the community to avoid going on long waiting lists..

Other Specialized Services

There are three other agencies that provide internal specialized services to people with dual diagnosis. This includes the YWCA, Christian Horizons and Choices. Each of these services has employed or contracted with a behaviour therapist to work with people with dual diagnosis. On average these agencies report dedicating approximately 65% of their staff time to providing services to these clients. In addition to having a behaviour therapist these agencies also use the services of psychologists from the private sector as well as a psychiatrist and a speech and language therapist from Area Resource Team.

These agencies report that the availability of a behavioural therapist on staff has greatly reduced the stress of dealing with people with dual diagnosis. The YWCA supported 9 individuals who are dually diagnoses by providing behavioural support in 2004/05. Christian Horizons provided support for 2 individuals identified as sexual offenders and behaviour therapy to 55 others in the Hamilton/Niagara region. They point out that not all of these individuals are officially diagnosed with a mental illness. Choices supported 22 people with dual diagnosis in their residential settings and another 56 people in their core services.

On the one hand, this is an effective use of resources. It allows the agency to deal with issues as they arise. When there is a crisis they can call in the therapist immediately and resolve the issue or make plans for what the staff needs to do. On the other, it limits the availability of these specialized services to other agencies. None of the three agencies shared these resources with other agencies although there was a general willingness to do so if the opportunity arose.

Developmental Services in the Mental Health Sector

People with a dual diagnosis have access to mental health services through the Ministry of Health and Long Term Care's (MOHLTC) mental health system. These services, open to all citizens in the province, are intended to meet the needs of people when the local health care system can no longer address their problems. The mental health care system encompasses a wide variety of programs and services designed to meet local needs. These programs are delivered primarily through hospitals or health clinics. The majority of the programs are designed to serve the most vulnerable and most severely mentally ill.

In the mid 1990s the MOHLTC and the MCSS worked together to develop the "Policy Guidelines for the Provision of Services to Persons with Dual Diagnosis". This document describes a framework for providing community based and specialized supports and services to people with developmental disabilities. The guidelines described the roles for each Ministry.

The MOHLTC is responsible for providing specialized institutional and community based services for assessment, diagnosis, treatment, rehabilitation, continuing psychiatric care, research, training and education. The Ministry provides consultation and education to community mental health, developmental services, general practitioners, and local providers. As well it provides specialized short-term case management to support individuals returning to the community from a health facility.

The MCSS is responsible for community based care for people with developmental disabilities and for promoting cross sector partnerships with mental health services to ensure an appropriate range of services are available to individuals upon discharge from Psychiatric Hospitals. Finally they are expected to participate in education and training initiatives in both the developmental and mental health sectors.

Admissions into hospital mental health units are determined by four factors: medical stability; diagnosis of mental retardation; residence within the catchment area; and a coexisting mental health problem (or psychiatric illness or emotional/behavioural difficulties) or a history of indicators of mental illness. Susan Morris (2005) points out that the terms were left broad in 'order to address the experience by consumers and families of exclusion from the mental health system due to a lack of a "diagnosed" Axis 1 mental illness' (Morris, 2005).

The number of people with a dual diagnosis who used mental health services in 2004 is reported in Table 3. The Table provides a description of the number of patients with mental health issues that were discharged from the hospital. In order to determine the number of these people who had a developmental disability and coexisting mental health problems a prevalence rate of 13% was used (Lunsky et. al. 2003).

Table 3: Percent of Discharged Patients with Dual Diagnosis 2004

	Total Mental Health Patients Discharged from the Hospital	Patients with Dual Diagnosis*
Hamilton/Niagara Region		
The Brantford General Hospital	878	114
St. Joseph's Health Care System Mountain Site	781	102
St. Joseph's Health Care System Hamilton	1,387	180
NHS - Greater Niagara General Hospital	960	125
NHS - St. Catherines General Hospital	838	109
NHS - Welland County General Hospital	786	102
Total	5,630	732
Sout West Region		
Chatham Public General Hospital	475	62
Goderich - Alexandra Marine and General Hospital	449	58
London Health Sciences Centre - University site	2,288	297
St. Joseph's Health Care, London MH	1,121	146
St. Joseph's Health Care, London - St.Thomas	481	63
Grey Bruce Health Services - Owen Sound Site	711	92
Sarnia General Hospital	0	0
Stratford General Hospital	576	75
Windsor Hotel-Dieu Grace Hospital	1,669	217
Windsor Regional Hospital-Western Site	828	108
Woodstock General Hospital	527	69
Total	9,125	1,186

Source: MOHLTC. *Prevalence based on 13% (Lunsky et al 2003)

People with a dual diagnosis go or are taken to one of the psychiatric facilities when they are having problems that cannot be dealt with in the community. These facilities provide a range of in-patient and out-patient mental health services and are meant to be used when a person has a mental health problem. The intent of the Policy Guidelines is to ensure that these public services also meet the needs of people with a dual diagnosis.

The primary challenge for the two Ministries is ensuring that people with a dual diagnosis obtain hospital services when they need them. In principle people with a dual diagnosis have the same rights to mental health services as any other citizen and the system was design to reflect this belief. However, families, DS agencies and key stakeholders report that people with dual diagnosis do not get equal access. They report that it is difficult to obtain admission into mental health facilities, in part because of the confusion between mental illness and behavioural problems, and in part because of rigidities in the system. Diagnostic overshadowing (and the assumption that the presenting problems may be due to the developmental disability rather than an underlying health disorder) can lead to

people not being admitted to mental health facilities. This limits access to health care facilities. While the Policy Guidelines were meant to overcome these barriers they have rigidified the system. Mental health service providers view the developmental sector as having the primary responsibility of taking care of people with behavioural problems and people in the DS sector have come to see the mental health sector as failing to meet the needs of people with a dual diagnosis.

Discussions with key informants and focus group members reveal that the level of services provided in mental health facilities varies across the regions. In the Hamilton/Niagara Region people with a dual diagnosis can be admitted into hospitals in Niagara, St Catharines, Welland and Brantford through the regular admissions process. However there are no specialized nurses or supports for people with dual diagnosis. They are seen by the physician on call and if stable they are sent back home or if not, kept over night. The physician may refer them to Bethesda for assistance or to St. Joseph's Hospital Mountain Health Services in Hamilton. St. Joseph's provides primary psychiatric support for the Region and has a special unit for adults with developmental disabilities. An interdisciplinary team within this unit provides treatment and short-term follow up for individuals with a serious mental illness and developmental disability. This program also provides crisis management supports and medication reviews as well as education to other caregivers, families and community agencies that provide service to this population.

The same variations exist within the South West Region. A number of hospitals will admit patients but have no special supports for adults with dual diagnosis. These include Goderich, Sarnia, Stratford and Woodsock (RSA is located at the Woodstock Hospital). The hospital in Chatham has a half time nurse providing support for people with dual diagnosis. This nurse works with two local psychiatrists. The hospital in Owen Sound has a full time coordinator for dual diagnosis who works with a part-time consulting psychiatrist. She provides an important connection between mental health and developmental services in the local community. Windsor hospital has one dual diagnosis nurse who works with a psychiatrist. The Regional Mental Health Care in London has a Developmental Behavioural Management Program (DBM) with an 18-bed active treatment program for individuals with developmental disabilities. The service provides multi-modal assessments, person-centered care and a multidisciplinary outpatient clinic on site for people with a dual diagnosis. There is also the Southwestern Regional Centre near Blenheim in Chatham-Kent which is a dedicated facility for people with developmental disabilities. This facility is about to be closed as the provincial government phases out institutional services.

Discussions with key stakeholders from within the mental health sector, particularly those from St. Joseph's, Mountain Health Services in Hamilton, Developmental Behavioural Management Program in London and the hospital in Owen Sound, are very open and willing to try new approaches and to develop stronger working relationships with the DS sector. They are willing to enter into discussions and develop team approaches to solving problems, create access mechanisms, and work together to make the system more effective.

Caregivers, whether they are family or an agency, feel the system works if it accepts someone whose behaviour is making it impossible for their caregivers to provide care. When that happens, the health system is viewed as successful. When that does not happen the system is viewed as not working. Families' and agencies' assessments of the health care system depend upon their experience of having someone admitted or not. In the focus groups and surveys people told stories of when the system worked and when it did not. The major theme of these stories was that when someone is accepted into the mental health system the caregivers feel fortunate because it relieves stress in the system. When the person is rejected by the mental health system they are left with nothing to do but take care of the problems themselves leading to frustration and stress in the caregiver.

The health sector has important resources that are needed to deal with people with severe mental health problems. They have the skills and resources to be able to provide service and supports to the neediest people. However, these resources are difficult to obtain. Because they are meant to serve the most severely mentally disturbed clients, the hospitals are reluctant to take anyone who does not meet that criterion. From their perspective, to do so would be a misuse of the resource. When the health care professionals assess a person as having a behavioural problem, not a mental health problem, they believe it is the responsibility of the DS sector to provide the services.

When the mental health sector takes in a client, the person takes up one of the beds in the facility thus limiting the hospital's ability to deal with another person's needs. Once the hospital has resolved the presenting problems it wants the person to be taken back into the DS sector. The person may still have high needs, but not so high that they have to be in a hospital. On the other hand the DS sector is reluctant to take them back into their system because they do not have the resources to deal with the person who they believe can return to dysfunctional behaviour at any time.

This leads to a system malfunction. Hospitals are reluctant to take into care anyone who has a behavioural problem or is not severely mentally ill, and DS agencies are reluctant to take back into care anyone who still has disruptive mental health risks. This leads to an inability in either sector to meet the needs of the other sector.

In an ideal system, a person who becomes severely dysfunctional in the DS sector would be placed in a mental health facility, whether they are cared for by their family or in a DS agency. The mental health facility would then use its resources to stabilize the person and they would be returned to the family or agency. This process would normally take anywhere from a few days to a number of months.

Focus group members describe a much more complex reality. A person with a developmental disability and a dual diagnosis moves in and out of different levels of functionality. Sometimes their behaviour is more difficult to deal with than others. The care givers, either families or DS agencies have difficulty predicting when the behaviour will become so disruptive that the person will need to be hospitalized. When it does happen and they take the person to a hospital, they find that admission depends upon a

number of factors: whether the admitting person believes it is a mental health problem rather than a behavioural problem; whether they have a bed open to receive a new patient; and whether they believe they can return the person to the family or agency at the end of providing assistance. Even if there are beds, it will depend upon how serious the admitting person believes the problem to be. It is not uncommon for a person with a mental health problem to 'settle down' when they are at the hospital waiting room and so the behaviour may seem much less severe. If the person is admitted to the hospital it relieves an enormous pressure for the caregiver. They are reluctant to take the person back into their care if they believe that the conditions have not stabilized or if they fear things will go back to being dysfunctional.

It is clear from the focus group discussions that there are people in the mental health sector who are able to help deal with these systems problems. Focus groups report that special nurses who work in the hospitals can be very supportive when a caregiver is trying to have someone admitted. If the nurse and the caregiver know each other or there is a documented mental health problem, the system works much more successfully. If the nurse has been provided with a plan for how the person will be discharged the hospital is much more willing to admit the person. Nurses are able to make a difficult situation work.

The findings from focus group members in both sectors suggest that to resolve these difficult systemic issues they must be addressed at both the local level and the systems level. At the local level, mental health providers must be more connected to the DS sector and vice versa. There must be a greater understanding on both sides regarding the nature of the problems they are addressing. The mental health care sector must believe that the DS sector is providing all the care they can up to the point they need assistance. At the same time the DS sector must believe that the health care sector will provide assistance when it is needed. The more often the two systems work with each other the more likelihood they will come to understand and trust each other.

The two ministries need to commit to energy to developing a working protocol for the admission of people with developmental disabilities and mental health problems into the health care system.

The Developmental Service Agencies

The developmental service agencies provide the foundation for all services for people with dual diagnosis. They provide social, recreational and emotional support, and programs and services that facilitate people with a dual diagnosis to live in the community. DS agencies provide a broad range of services that can be categorized into four different types: residential service; day activity and employment programs; respite services; and specialized services.

Residential Services helps people with a developmental disability find suitable accommodations and the supports necessary to live in a safe environment. This may

include living on their own or in groups in a home or apartment, with their friends and family, in a lodging home or in a group home. The staff working in residential services provides the social supports needed to ensure that people can live safely and comfortably.

Day Activity and Employment programs support personal and social growth through employment, life skills and social programs. For example community programs may provide opportunities for people to work in supported environments, help them find social and recreational programs that meet their needs, or help them become volunteers in community programs. These programs may provide vocational skills upgrading, academic development, life skills training, interpersonal development and social interaction skills.

Respite care provides short term, temporary, regular or occasional respite care in and out of the family home. It provides an opportunity for caregivers to have time for themselves. This care can be provided in the home or the person with a developmental disability can be taken out of the home allowing the caregiver to be at home alone.

They also provide access to specialized services including assessment and clinical services as well as behavioural and emotional support and consultation. For the most part these services are provided by specialists and experts in the developmental services sector, however, there are situations where an agency may purchase service.

There are 97 Developmental Services Agencies (as defined by a transfer payment relationships with MCSS) in the Hamilton/Niagara and South West Regions providing direct services to people with developmental disabilities (see Appendix 7 for complete list). The following classification is based upon their primary mandate.

Table 4: Organizations* Serving People with Developmental Disabilities

Primary Mandate	Number	%
Community Living organizations	27	28
Developmental supports	25	26
Family and Youth Service	13	14
Residential Services	7	7
Employment Services	4	4
Hospitals	3	3
General Non-profit organizations	17	18
Total	96	100

*Under a Transfer Payment contract
Source: MCSS 2005

According to MCSS data, in 2004-05 all of the transfer payment agencies combined provided 22,883 units of service across the two regions². Table 5 describes the

² Based on information provided by MCSS.

allocation of these units over the four primary activities of DS agencies. The largest proportion consisted of specialized services (59%).

Table 5: Units of Service Provided by DS Agencies

Units of Service	Number	Percent
Residential Services	4156	22
Day Activity/Employment Services	2618	14
Respite Services	989	5
Specialized Services	11295	59
Total Units of Service	19,058	100

Source MCSS, 2005

By combining the Access/Contact units (3825 from Table 1) with the service units from Table 5 (19058) we can estimate the percentage of the population with developmental disabilities that receive services through MCSS. Although a person with a developmental disability may use more than one service, if each unit did represent a person then in 2004/05 approximately one third of the 69,400 people with developmental disabilities in Hamilton/Niagara and the South West Regions received services from the DS Sector.

The other two thirds of people with a developmental disability cared for themselves or were cared for by their families within the community with some support from the DS Sector. Of these families 1845 received Special Service at Home. SSAH makes it possible for families to access funding from the Ministry of Community and Social Services so they can have a worker support their son/daughter in their home or community for a few hours a week. Many DS agencies help families apply to the program as well as administrate approved contracts.

Support to People with Dual Diagnosis

In order to estimate the support provided to people with dual diagnosis, the total units of service as described in the MCSS data was allocated on the basis of the percent of each service reported in the Agency survey as being provided to people with dual diagnosis. For example if the survey reported that 18% of respite services were provided to people with dual diagnosis then 18% of the total units of respite services reported by MCSS was allocated to that group. These percents vary for each type of service and only provide an approximate estimate of how many units of services are delivered to people with a dual diagnosis.

The Agency survey reports that people with dual diagnosis receive approximately 35% of residential services. This coincides with the approximately 35% of people with a development disability who have a dual diagnosis. This means that about the same proportion of people with a dual diagnosis receive residential services as those with developmental disabilities alone. Table 6 describes how these services are distributed over associated living, individual living supports and group living supports.

Table 6: Residential Support for People with Dual Diagnosis

	Total	Percent Attributed	Dual Diagnosis
Associate Living Supports	355	27	96
Individual Living Supports	1744	34	593
Group Living Supports	2057	38	782
Totals	4156	35	1470

Calculated from information provided by MCSS

The Agency Survey reports that families caring for people with dual diagnosis receive about half as much respite services (18%) as those with developmental disabilities alone. It is difficult to determine why fewer people with dual diagnosis than expected would be receiving respite services. It is possible that people with a dual diagnosis receive less because it is more difficult to take them out of the home and so this may reduce the number of families receiving these services.

Table 7: Respite Support for People with Dual Diagnosis

	Total	Percent	Dual Diagnosis
Respite - In Home Supports	5	21	1
Respite -Out of Home Supports	984	18	177
Totals	989	18	178

Calculated from information provided by MCSS

The number of people with a dual diagnosis receiving life skills and employment services is also lower than expected, given population figures. This may be because people with a dual diagnosis are hesitant about seeking these services. It is also possible that the services are not offered at the same rate to people with a dual diagnosis.

Table 8: Life Skills/Employment Services for People with Dual Diagnosis

	Total	Percent	Dual Diagnosis
Foundations	936	23	187
Vocational Supports	560	27	112
Employment Supports (Transition)	1122	27	224
Totals	2618	26	524

Calculated from information provided by MCSS

People with a dual diagnosis used between 25% and 59% of the Specialized Services as reported by the Agency Survey. They are provided with above average services for behaviour intervention, access supports, and video conferencing and below average for assessment and counselling and community supports.

Table 9: Specialized Services for People with Dual Diagnosis

	Total	Percent	Dual Diagnosis
Assessment & Counselling	2554	29	741
Behaviour Intervention	1281	59	751
Access Supports	5625	50	3375
Community Supports	1639	25	410
Video Conferencing*	196	50	118
Totals	11295	43	5394

* Assuming 50% of video conferencing is used for people with dual diagnosis
Calculated from information provided by MCSS

On average 43% of specialized services are directed toward people with dual diagnosis. This reflects the differences in needs between people with dual diagnosis and those with fewer problems.

From a system perspective it appears that people with a dual diagnosis are receiving slightly more (39%) support than would be expected given the prevalence rates in the population. This however is expected since a large portion of the services provided by agencies relate to specialized services. This reinforces the notion that DS agencies provide the primary services for people with a dual diagnosis. They provide the foundation upon which the more specialized services are delivered.

The agencies were asked to describe the level of internal specialized service capacity they have for meeting the needs of people with dual diagnosis. In the Agency survey 66% report that their organization has no specialized services capacity, although they do support adults with a dual diagnosis. For the most part these agencies rely upon help from outside specialized service providers. Twelve percent report that they have begun to develop some specialized programming by targeting a particular need and/or developing the expertise of staff. The remaining twenty two percent reports that they are developing ways to meet the needs of people with dual diagnosis by being able to: respond to a crisis event; provide case management; develop service coordination; and reach out to communities for support and connections.

For the most part DS Agencies focus on providing supports and services to people in their local community (91%). Some of these agencies also report they provide services to their regional area (42%) and a few report they provide a provincial wide response (14%). The numbers are greater than 100% because agencies report on more than one area of program coverage.

Based on the Agency survey results, on average 31% of all the people served by DS agency have mental health or behavioural problems and are deemed to have a dual diagnosis (slightly less than the assumed 35%). This ranges from 26% for people receiving core services, 35% for residential services and 57% for specialized services. The Agency Survey reports that on average 42% of all staff time is dedicated to providing services to people with dual diagnosis. This reflects the differences in needs between people with dual diagnosis and those with fewer problems. The demands on

staff and the differences between people with dual diagnosis and those with fewer problems are even more evident when dedicated staff time is examined in the three areas: core services, residential services, and highly specialized services and supports. This examination shows that an increasing proportion of staff-time is dedicated to dual diagnosis clients with 40.5% for core services, 43.5% for residential services, and 48.7% of agency staff time allocated to highly specialized services and supports.

When DS agencies need the services of specialists such as clinicians, psychiatrists, psychologists, physiotherapists, or behaviour therapists to help deal with issues related to people with dual diagnosis, they seek outside help by either purchasing the services from private practitioners (7%) or engaging the services of a specialized service provider (93%).

The vast majority of agencies report difficulties in obtaining the specialized services they require for people with dual diagnosis. When asked if the DS agency had any difficulty obtaining service from specialists, 88.4% said they did. What is important about this figure is that for the most part the difficulties were in purchasing service privately from psychiatrists and other professionals in the local community. Getting services from the DS sector can take longer than the agency wants but eventually they would get the services they need. But this was not the case when they went looking for services within the private sector. It was difficult to find a psychiatrist in the private sector who would take on a person with a dual diagnosis and there were very few private practitioners who know enough about the needs of people with dual diagnosis to be willing to provide services. Those psychiatrists who do provide services are aging and can no longer meet the demand from the community.

Agencies were asked to describe the nature of the difficulties and report there are long waiting lists, services are not available at the time of a crisis, specialized service providers are slow to respond, and there is a lack of expertise in the local community. Selections of some of the comments are as follows:

- There is limited local access to psychiatric services familiar with the dual diagnosis population.
- Services funded by MOHLTC do not have a mandate to serve people with a behavioural problem.
- There are long waiting lists for psychiatrists in rural areas where transportation is often a barrier to accessing services.
- Most clients do not receive formal assessments or diagnosis. This makes it difficult for them to access services. Obtaining the assessment can be challenging as many people do not have family physicians who can make referrals.

There is a significant positive correlation between the incidence of agencies reporting having difficulties obtaining services from specialists for people with dual diagnosis and their ability to meet demands for service. Thus, 62.5% of agencies that report demand-exceeding capacity on a regular basis also report difficulty in obtaining services

The DS agencies were asked about the number of specialist they use to provide services to people with dual diagnosis. They report that most often they use psychiatrists and behavioural therapists. This is followed by psychologists and further down the scale nurses and speech and language therapists. Table 10 describes the number of agencies that use each professional group.

Table 10: We are interested in the number of specialists who provide services to people with dual diagnosis/behavioural issues. Does your agency employ, purchase or engage any of the following specialists to provide services for people with dual diagnosis/behavioural issues?

Proportion of Agencies Reporting Engaging Services	Percent of Agencies Engaging Specialists
Psychiatrist	62.8
Behaviour therapist	62.8
Psychologist	48.8
Nurse	30.2
Physiotherapist	27.9
Speech and Language therapist	27.9
Social worker	25.6
Clinician	16.3
Case manager	14.0
Other	14.0

* This table reports the percentage of agencies that indicated any purchased or engaged services

* Sample sized used for these calculation n=43

Agencies report that behavioural therapists provide important therapeutic interventions in the developmental sector while psychiatrists provide access to both therapeutic interventions and psychotropic drugs. Psychologists, like behavioural therapists rely exclusively on a social intervention methodology. When all else fails, often the only recourse is to psychotropic medicines and so psychiatrists are important in managing the problems of people with a dual diagnosis.

Strength in the System

Agencies were asked to rank the three services they feel are the most effective in meeting the needs of people with dual diagnosis/behavioural issues. The scores were compiled to create an average score and are reported in Table 11. There are effective activities in all three areas.

The highest ranking activities in core services are ‘Day Activity/Employment’ programs followed relatively closely by ‘Behavioural/Emotional support and consultation’ services and ‘Case Management’. In residential service, ‘Supported Independent living’ scores very highly and ‘Group home’ is also rated as effective. Finally in highly specialized services the agencies rate ‘Crisis Response/Treatment’, ‘Psychiatric Support and Consultation’ and ‘Specialized community based accommodation’ highly.

In the same question the DS agencies were asked to rank the three services they feel are experiencing the greatest systems pressure. For the most part the services that are under the greatest pressure are those that are most important in meeting the needs of people with dual diagnosis. This is a common phenomenon in social services; the most effective services are the most in demand and face the greatest pressure, creating stress throughout the system.

Table 11: Indicate the three services that you feel are currently the most effective in meeting the needs of people with dual diagnosis/behavioural issues. Next indicate the three that are experiencing the greatest systems pressure in terms of gaps between demand and supply for people with dual diagnosis/behavioural issues. Finally, if you had to invest in the services for people with dual diagnosis, how would you spend 100 points for future service enhancement?

Service for people with <u>dual diagnosis/ behavioural issues</u>	Most effective in meeting the needs**	Experiencing the greatest systems pressure**	I would spend my 100 points in the following ways***
Core Services			
Respite (out of home)	0.23	0.35	4.07
Respite (in home)	0.07	0.05	1.86
Behavioural/Emotional support and consultation	0.40	0.12	4.19
Case Management	0.37	0.07	2.79
Social Recreational Supports	0.09	0.05	0.93
Day Activity/ Employment	0.42	0.28	3.88
Assessment/Clinical services	0.26	0.05	1.16
Residential Services			
Family home/Associate family	0.09	0.09	2.91
Supported Independent living	0.70	0.51	9.07
Group home	0.56	0.53	5.74
Highly Specialized Services and Supports			
Specialized community based accommodation	0.35	0.58	14.30
Assessment/clinical services	0.19	0.16	5.23
Crisis Response / Treatment	0.72	1.14	11.98
Psychiatric Support and Consultation	0.47	0.81	14.42
Medical Support and Consultation	0.14	0.09	1.28
Speech and language therapy	0	0.05	0.81
Counseling	0.09	0.12	1.98
Special community outreach activities	0	0.09	0.58
Other (specify)****	0.09	0.14	5.00

* These calculations are based on a sample size of n=43

** These are average scores of an inverted ranking, where 3 is the best, followed by 2, 1, and 0.

***The allocation of 100 points is presented as an average of the spent points where no points allocated is equal to zero.

****Other includes: Psychological Assessment; Staff Training; Provide agencies with funds to purchase services directly; Trained community support workers (2); and APSW.

The last part of the question asked the agencies how they would invest 100 points in the services they feel require future enhancement. Not surprisingly the agencies want to support those areas they rate as the most effective (which also happen to be the ones under the most stress). The highest point allocations in the Highly Specialized Services and Supports category were given to ‘Psychiatric Support and Consultation’ (14.4); followed by ‘Specialized Community Based Accommodation’ (14.3) and ‘Crisis Response/Treatment’ (11.98). The second highest grouping of points went to the Residential Services category with Supported Independent Living and Group Home receiving 9.07 and 5.74 points, respectively. Core Services is the category with relatively lower point allocations; however, the highest points in this category went to ‘Behaviour/Emotional Support and Consultation’ (4.19), ‘Respite (out of home)’ (4.07), and ‘Day Activity/Employment’ (3.88).

It is important to note that the ‘other’ category also received an average score of 5 points for future service enhancements. In the ‘other’ category were: psychological assessment; staff training; providing agencies with funds to purchase services directly; and training community support workers.

The above discussion focuses on how agencies rate three main categories of services meeting the needs of people with dual diagnosis/behavioural issues in the present and moving into the future, while assessing the pressure that these systems are under. DS agencies were also asked to consider and rate the overall effectiveness of the system of services in 8 key areas (based on a 4 point rating scale). The average score is an average of the discrete effectiveness ratings. Generally, the system of services has been rated as fair approaching good in its effectiveness in serving people with dual diagnosis/behaviour issues. For each of the key areas agencies report a minimum score of poor (1) and a maximum score of very good (4).

TABLE 12: THINKING OF THE SYSTEM OF SERVICES FOR PEOPLE WITH DUAL DIAGNOSIS/BEHAVIOURAL ISSUES, RATE THE OVERALL EFFECTIVENESS IN ACCOMPLISHING THE FOLLOWING:

SERVICES FOR PEOPLE WITH DUAL DIAGNOSIS/BEHAVIOURAL ISSUES.	AVERAGE SCORE
Fostering collaborative working relationships between agencies	2.59
Using resources efficiently	2.44
Responding to unique individual needs	2.34
Having a positive impact on people with dual diagnosis	2.24
Identifying and responding to community needs	2.02
Ensuring individuals receive the right services	2.00
Providing services to all people with dual diagnosis	1.66
Ensuring individuals receive services in a timely fashion	1.53
Overall effectiveness	2.05

* AVERAGE OF SCALE SCORE WHERE THE SCALE HAS FOUR OUTCOMES VERY GOOD (4), GOOD (3), FAIR (2), AND POOR (1)

**SAMPLE SIZE N=41

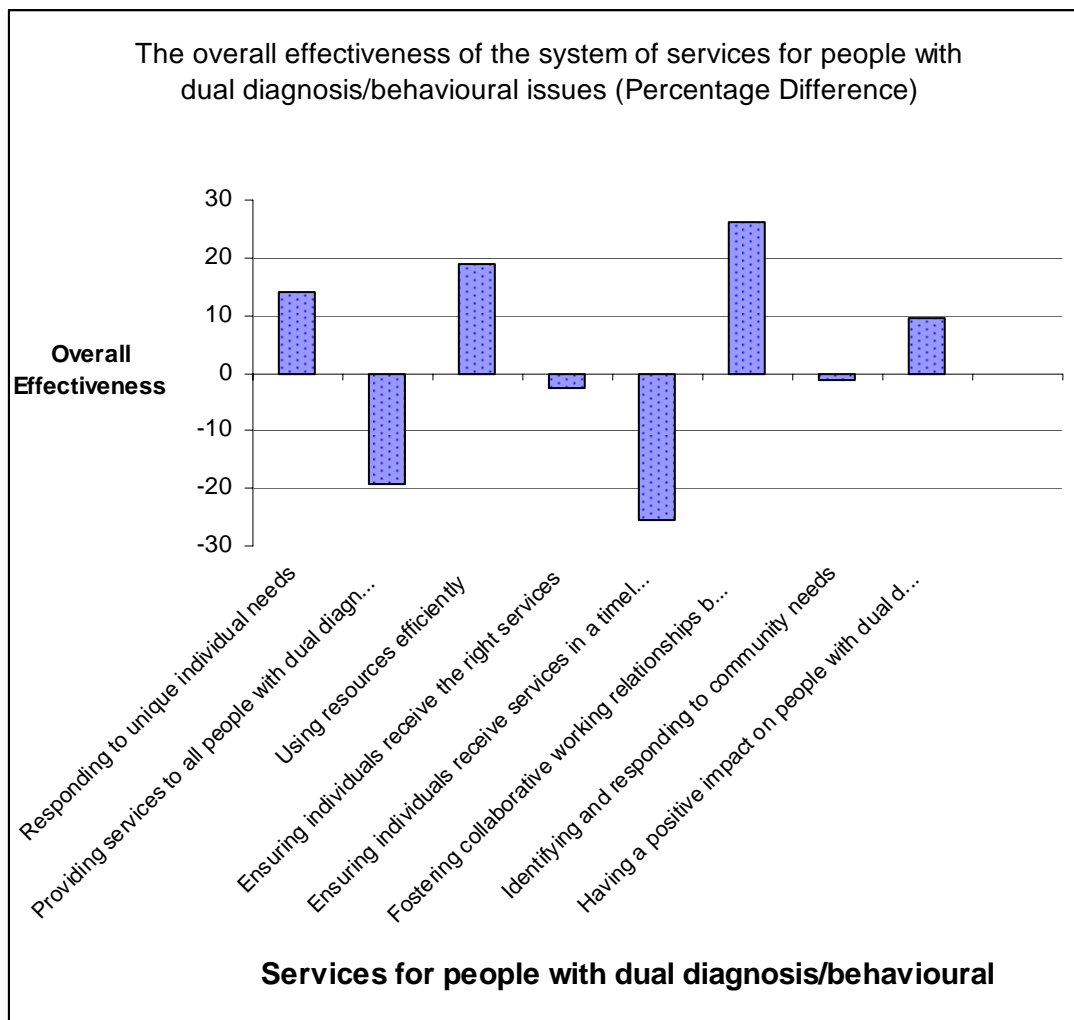
Chart 1 compares average scores for all areas with the average overall effectiveness score. The higher the average scores are, the greater the percentage difference from the overall effectiveness score. In other words, the area ‘fostering collaborative working relationships between agencies’ had an average score across all agencies of 2.59, which is

26.12% above the overall effectiveness score of 2.05. This area was followed by ‘using resources efficiently’ (2.44) and ‘responding to unique individual needs’ (2.34).

The areas with the lowest scores were ‘ensuring individuals receive services in a timely fashion’ (1.53) and ‘providing services to all people with dual diagnosis’ (1.66), which were minus 25.61% and minus 19.1%, respectively, this is below the overall effectiveness average score.

It is interesting to note that areas dealing with providing service in a timely fashion scored generally poorly, while areas focusing on agency relationships, management of resources, and responding to unique needs scored higher - approaching “good”.

Chart 1



The following are some of the explanations that were offered by those agencies that indicated either fair or poor effectiveness. (See Appendix 4 for a list of more comments)

- Only limited resources are available, particularly in specialized supportive housing.
- The system is stretched to the limit so that there are longer waiting times.
- The agencies are all making do with whatever services they can access (whether or not it is the right service).
- They are too busy to look at community needs.
- The system is under resourced; the quality of service is good for those who get it, but not all clients who need services get them.
- Many services are outside our community that means waiting lists and difficulties in accessing them.
- Limited funding and resources make it difficult to meet the clients' needs, RSA provides excellent community based services for people; the local mental health agency provides some clinical services, case management and residential services but it is difficult to access these because of the perception that these services should fall under the developmental sector.
- Lack of resources hampers the ability to provide support; community needs are identified, however, due to resource issues, we are unable to respond.
- There is a lack of community-based knowledge.
- Services are funded collectively, not individually.
- Services are not available to all people especially those in rural locations.
- Waiting lists are too long.
- When supporting someone with a dual diagnosis, the health systems still operate as separate entities as opposed to using a team model.
- There is too much reliance on out of town placements; a lack of crisis response; and a lack of leadership from the planning body
- There is a lack of coordination between the Ministries.
- The number of clients with a dual diagnosis is growing.
- There are strong collegial relationships but there are still territorial divisions even within the Developmental Service sector; there is limited collaboration between Mental Health and Developmental Service.
- The government needs to acknowledge that poor effectiveness is a function of inadequate and inflexible funding.
- Support is crisis driven, with those in crisis getting all available resources, putting others at risk.

DS agencies were asked whether their agency was able to meet demands for services to people with dual diagnosis/behavioural issues in the past year (2004-05). Of the agencies reporting, 62.5% indicate demand exceeds their capacity on a regular basis and 37.5% report demand was a good match for their capacity most of the time. These proportions were stable even when the reporting was divided into: core services, residential services, and highly specialized services and supports. If demand exceeds capacity, agencies say the main causes are: lack of funding, waiting lists, and lack of specialized skilled staff.

It is interesting to note that of the 62.5% reporting that demand exceeds capacity, 39.4% report fair overall effectiveness and 13.1% report poor, as opposed to agencies reporting

demand matched capacity where 23.6% report fair and only 2.63% poor. A more detailed evaluation shows a significant negative correlation between demand exceeding capacity and fair to poor overall effectiveness; this indicates that as agencies are not able to match demand with capacity their rating of the system of services declines.

Overall, 66% of families indicate in the Family survey that their family member usually or always gets services when they need them. However, families caring for someone at home are less satisfied with getting services when they need them. Only 39% of families providing care at home are satisfied, as compared to 71% of families whose family member live in a DS residence. Two thirds of families providing home care report less timely availability of services, more barriers to services, and higher need for additional services. Almost 17% of these families report they never received the services and supports they needed in the past year as contrasted with 3% of families whose family member has residential support.

Supports for Caregivers

The next section shifts focus from services for people with dual diagnosis to their caregivers. DS agencies were asked whether they provide programs and services that support families with an adult member who have a developmental diagnosis. The programs and services offered to family members include: caregiver support groups; support workers and help from attendants; caregiver courses or workshops; outings/picnics; and other programs and services. The other programs and services that agencies specified include: planning and self-advocacy; respite; individualized family support; soft counselling - informal support; coordinating services; day supports; and day programs.

Of the families receiving support, 48% have a family member with a dual diagnosis. This average proportion is substantially higher than the 35% rate for the general population of developmentally disabled. This indicates that families with a member with a dual diagnosis draw on program and services at a higher rate than families with members from the general developmentally disabled population; however, this is not unexpected since these families have greater need for programs and services.

Agencies were also asked to score the programs and services that are most effective in meeting their needs, and assign a score where the greatest system pressure is being experienced. They were then asked to allocate 100 points for future program and service enhancement. The scoring indicates that 44.2% of agencies see support workers and attendants as being most efficient at meeting the needs of these clients; 30.2% of agencies report that this is where the system is under the greatest pressure. Further, this area received the highest point allocation for future enhancement (35.5 points)

TABLE 13: INDICATE THE ONE SERVICE THAT YOU FEEL IS CURRENTLY THE MOST EFFECTIVE IN MEETING THE NEEDS OF FAMILY MEMBERS AND CAREGIVERS OF PEOPLE WITH DUAL DIAGNOSIS/BEHAVIOURAL ISSUES. NEXT INDICATE THE ONE SERVICE THAT IS EXPERIENCING THE GREATEST SYSTEMS PRESSURE IN TERMS OF GAPS BETWEEN DEMAND AND SUPPLY FOR FAMILY MEMBERS. FINALLY, IF YOU HAD TO INVEST IN THE SERVICES FOR FAMILY MEMBERS, HOW WOULD YOU SPEND 100 POINTS FOR FUTURE SERVICE ENHANCEMENT?

PROGRAMS AND SERVICES FOR FAMILY MEMBERS AND CAREGIVERS	THE ONE MOST EFFECTIVE IN MEETING THE NEEDS**	THE ONE EXPERIENCING THE GREATEST SYSTEMS PRESSURE**	I WOULD SPEND MY 100 POINTS IN THE FOLLOWING WAYS (AVERAGE DISTRIBUTION)
CAREGIVER SUPPORT GROUPS	0	11.6	9.1
SUPPORT WORKERS AND HELP FROM ATTENDANTS	44.2	30.2	35.5
CAREGIVER COURSES OR WORKSHOPS	0	9.3	10.7
OUTINGS/PICNICS ETC.	9.3	0	2.0
OTHER	14.0	11.6	15.3

* SAMPLE SIZED USED FOR THESE CALCULATION N=43

**THESE STATISTICS ARE PERCENTAGES

The Agencies describe ‘other’ to include programs and services for family members and caregivers such as: respite; individualized support; psychiatric consultation; crisis response and treatment; mentoring/training from experts in the field; out of home respite; informal support counselling; therapy and intervention; supportive counselling; direct agency funding to purchase unavailable services; community activities during the day; and residential placements. Fourteen percent of agencies score other programs and services as being the most effective at meeting needs, and 11.6% of agencies report that this was receiving the greatest system pressure - leading to these areas receive an average point allocation for future enhancement of 15.3.

Training in the Developmental Services Sector

In this section we shift away from examining how services are provided to explore the training needs identified through the Agency Survey. DS agencies were asked a series of questions about staff training, support for professional development, and their ability to hire educated and trained staff. In providing information the agencies were asked to focus on staff specifically related to people with dual diagnosis. The agencies report that it is difficult to separate training into discreet compartments. For the most part agencies report that training in one area has important implications for all the areas of service.

Of the agencies reporting, 76.7% indicate that they provide staff training within their agency. This includes individualized training relating to specific client needs; having professionals come in and speak with staff; and more generalized training about problems and challenges faced by people with dual diagnosis. More frequently, agencies (83.7%) report that staff goes to other agencies for training. A number of these training sessions are offered by specialized service providers.

The highest proportion of agencies (95.4%) provides staff with support for professional development. For the most part the staff identifies the course or program they want to take and the agency helps to support their attendance. This can include formal courses offered by community colleges or universities; or conferences, workshops and seminars offered by specialized service providers or other community organizations. A number of agencies report more emphasis should be placed on enhancing the professional development of staff through an increase in the training budget.

The situation is not as positive when it comes to hiring staff. The majority of agencies (79.1%) report that they have difficulty hiring or purchasing the services of people with the training and education they require to provide services to people with dual diagnosis/behavioural issues. The following is a list of the challenges they face:

- Frontline staff can be recruited but they are difficult hold onto given the low wages and difficult working conditions.
- There is a high turn over rate for support staff that makes it difficult to maintain a solid core of trained staff.
- There is an overall shortage of part-time staff with training.
- It is difficult to find people with behavioural management experience.
- It is difficult to find college or university educated staff with experience in dealing with clients with a dual diagnosis/ behavioural issues.
- It is difficult to find people with the ability or willingness to work with people with challenging behaviours.

To address these skill shortages within their agencies these organizations have done some of the following:

- developed a model of service and staff training to deal with these issues
- provided core training as well as specialized training in behaviour supports
- worked with colleges and universities to identify people interested in the field
- sent staff to seminars
- used consultants instead of hiring staff

There is a significant correlation between agencies having difficulty hiring trained people and having demands that exceed the agencies' capacity to meet them. It appears that one of the reasons agencies have difficulty meeting demands for service related to people with dual diagnosis is a lack of trained staff.

The majority of agencies (62.8%) identify partnerships with teaching programs that are related to providing services to people with dual diagnosis/behavioural issues. Of these organizations the main relationships identified are 44.2% with student placement and 44.2% with professional development of frontline staff. Between 7% and 18.6% report: staff involvement in data collection and research; staff involvement in teaching; use of research results in client consultation; client consultation; clinical services and 'other'. Other was specified as: partnership with Health Services; the DSW Program Advisory

committee at Fanshaw College; program evaluation by university academic clinicians; partnerships with Regional Support Associates training programs; and connections to the Dual Diagnosis Certificate Course at Brock University.

Educational Opportunities

In the Hamilton/Niagara and South West Region there are three major educational programs for those interested in learning about developmental disabilities. These include the Developmental Disabilities Program at University of Western Ontario; the International Certificate Programme in Dual Diagnosis at Brock University and the Developmental Services Worker Diploma at Fanshaw College. The following provides a brief description of each program.

University of Western Ontario, (London) Developmental Disabilities Division. The overarching goals of the DDD are to attract academic leadership in developmental or intellectual disabilities, to provide a “home” in order to develop and maintain a critical mass of individuals working within the field, and to facilitate the continued development of education, research, and service in developmental disabilities under a single umbrella. The Division has a broad, multidisciplinary orientation, with members being drawn from fields as diverse as medicine (including psychiatry, neurology, and pediatrics), psychology, education, nursing, dentistry, and communication disorders.

Brock University in St. Catharines offers an International Certificate Programme in Dual Diagnosis. The program takes place each summer and is taught by internationally recognized experts in the field of dual diagnosis. There are a variety of courses students take that comprise credit toward a Core-Level Certificate in Habilitative Mental Health. Additional levels of certification in Clinical applications and Leadership and Supervision can be obtained by taking additional courses. This program attracts students from across Canada and the United States.

Fanshaw College offers a Developmental Services Worker Diploma Program. This two year applied training program prepares the graduate to work with people with developmental disabilities at all ages and developmental levels. The program has field practice components in agency settings comprising approximately 50% of the program.

Key informants claim that the interest in studying issues related to developmental disabilities and dual diagnosis has declined in recent years. They believe that this is the result of declining interest in working in the field because of a non-competitive wage structure, difficult working conditions and the opening of many long-term care facilities which have attracted employees. In Ottawa where wages are more competitive there is a much higher interest in the education programs offered in that area.

Family Survey

The final section of the Environmental Scan returns to the family. Families were invited to complete a survey about services and support for adults with dual diagnosis. The purpose of the survey was to find out from families where and how they obtained services for the person they cared for and to ask them to provide feedback about their experiences. DS agencies were asked to distribute the survey to families who were on their waiting lists or were already receiving services. The family member was to return the survey directly to the researchers so that the family was guaranteed anonymity.

One hundred and twenty-one families completed the survey. To begin they were asked what language they preferred to speak when they receive services, 98% said English. The remaining 2% wanted to speak in Mandarin and German.

Families were asked how many adult family members with a developmental disability are in their family. Most families, 95% have only one family member with a developmental disability. The remaining families had between 2 and 4 other people in the family with a developmental disability.

The survey asked where family members lived. Two clear groups emerged: those that live at home with family or live on his/her own and were supported by their family (47.9% of the sample) from now on identified as living at home. The second group lived in accommodations provided by a DS agency (group living, supported independent living, specialized community based accommodation, long term transitional accommodation, short term transitional accommodations, and other) and from now on described as supported living (52.1% of the sample of families). Other includes Home support situation, Institution, and Psychiatric Hospital. Where a person lives turns out to influence how they view the services they receive and how satisfied they are.

Males make up the larger proportion of adults with a developmental disability representing 60.9% of the sample - females made up 39.1%. The average age of adults with a developmental disability was 34.1 years old. Females are on average older than males with their respective average ages being 37.1 and 32.3 years old.

Females and males are quite different with regards to their diagnosis. Families believe that 93.8% of females have mental health problems compared to 84.6% of males. Also, when the family was asked whether their family member has a behavioural problem, families report that 68.6% of females and 86.3% of males have behavioural problems.

When asked if their family member has been diagnosed as having a mental health problem by a professional, 82.0% females and 78.2% of males have. And, when diagnosed by a professional 58.0% of females and 78.5% of males have behavioural problems. Thus, it can be seen that families are reporting higher self-assessed rates of mental health and behavioural problems and relatively lower rates of professionally diagnosed mental health and behavioural problems. Also females generally have higher reported mental health problems and males have higher behavioural problems.

Almost all of the families report having a family physician: 100% for families caring for someone at home and 95% for those in supportive living.

Families were asked about their experience with programs and services for people with a dual diagnosis. When asked did your family member(s) get the services they need when they need them, 55.9% say that yes they always receive or usually receive services when needed; 40.7% report sometimes getting or never getting services when needed; and 3.4% indicate that they did not need services in the past year.

When these numbers were examined according to where the family member lives another story emerges. For those living in supported living, 71.0% report always or usually getting services and 25.8% report sometimes or never getting services. The direction of these proportions change when family members living at home are considered. Only 39.3% of these families report always or usually getting the services they need, and 57.1% report sometimes or never getting the services they need.

Table 14: In the past year, did your family member(s) get the services they needed when they needed them? By Where Family Members Live* (Percentages)

	Family/Own Home	Other*	Total
Yes, Always got services when needed	14.3	35.5	25.4
Yes, Usually got services when needed	25.0	35.5	30.5
Yes, Sometimes got services when needed	37.5	19.4	28.0
Never got services when needed	19.6	6.5	12.7
Did not need services in the past year	3.6	3.2	3.4
Total	47.5	52.5	100
Counts	56	62	118

*Family/Own home implies the family member lives with family or lives on their own. Other includes group living, supported independent living, specialized community based accommodation, transitional accommodation short term, transitional accommodation long term, and other.

Families were also asked to report whether or not their family member(s) face barriers or experience difficulty in accessing services. The possible barriers include language; no services for visually or hearing impaired; culture; transportation; physical accessibility of facilities; fees/costs associated with the service; required service(s) not available; and other barriers. Services not available include, but are not limited to: emergency respite care, accommodation supports, S/L support psychiatrist, adult-day program, lack of transportation, crisis intervention, and mental health services for the aggressive and violent individual.

Of the families that responded to this question, 63.7% report facing barriers to accessing services. When this proportion is examined according to where the family member lives, only 72.4% of those living at home report barriers, compared to 55.8% of those living in supported living. For those living at home the greatest barriers are fees/costs associated

with the service (26.8%); required service(s) not available (35.7%); and other barriers (23.2%). These top three are followed by transportation 21.4% and language 17.9%.

Families with developmentally disabled adults in supported living report a different list of barriers. It is interesting to note that service(s) not available was still top of the list at 21.0%. This was followed by transportation and language barriers (both at 19.4%); other barriers 17.7%; fees/costs associated with the service 6.6%; and both no services for visually or hearing impaired and physical accessibility of facilities at 4.8%. Culture was not reported as a barrier for these people.

Table 15: Does your family member(s) have any difficulty accessing services because of language, cultural or other barriers? By Where Family Members Live* (Proportion reporting barrier)

	Family/Own Home	Other*	Total
Language	17.9	19.4	18.6
No services for visually or hearing impaired	3.6	4.8	4.2
Culture	3.6	0.0	1.7
Transportation	21.4	19.4	20.3
Physical accessibility of facilities	1.8	4.8	3.4
Fees/costs associated with the service	26.8	6.6	16.2
Required service(s) not available.	35.7	21.0	28.0
Other barriers	23.2	17.7	20.3
NO barriers	28.6	45.2	37.3
Total	47.5	52.5	100
Counts	56	62	118

*Family/Own home implies the family member lives with family or lives on their own. Other includes group living, supported independent living, specialized community based accommodation, transitional accommodation short term, transitional accommodation long term, and other.

Families were asked to think about crisis situations and whether their family member(s) receives the required service(s) within a reasonable period of time. Generally, across the families surveyed 49.2% report always or usually receiving services within a reasonable length of time (17.8% always and 31.4% usually); and 36.4% indicate that they sometimes (25.4%) or never (11%) receive services within a reasonable length of time. Of the total, 14.4% report never experiencing a crisis situation.

This general overview misses the detail that only an examination based on where the family member lives can provide. Again, 69.4% of families with developmentally disabled adults living in supported living always or usually get services within a reasonable time - compared to 26.8% of those living at home. Further, 48.8% of those living at home only sometimes or never received the services within a reasonable time; whereas, only 22.6% of family members in supported living feel this way. Thus, family members living at home are less likely to receive services in a reasonable time; however, 21.4% also report never experiencing a crisis situation. Therefore, those family members living in supported living are more likely to experience a crisis (only 8.1% report never experiencing a crisis) but are also more likely to receive care in a reasonable time.

Table 16: Thinking about crisis situations, does your family member(s) get the required service(s) within a reasonable period of time? By Where Family Members Live* (Percentages)

	Family/Own Home	Other*	Total
Yes, Always get services within a reasonable time	5.4	29.0	17.8
Yes, Usually get services within a reasonable time	21.4	40.3	31.4
Yes, Sometimes get services within a reasonable time	32.1	19.4	25.4
Never get services within a reasonable time	16.6	3.2	11.0
Never experienced a crisis situation	21.4	8.1	14.4
Total	47.5	52.5	100
Counts	56	62	118

*Family/Own home implies the family member lives with family or lives on their own. Other includes group living, supported independent living, specialized community based accommodation, transitional accommodation short term, transitional accommodation long term, and other.

When asked how satisfied they were with the services available for their family members 22% reported very satisfied, 24.6% satisfied, 25.4% somewhat satisfied, and 28% not satisfied. When the families were divided by where family members live the results present a contrast. 30.7% of people who live in supported living report being very satisfied, 27.4% satisfied, 29.0% somewhat satisfied, and 12.9% not satisfied. The majority of families are satisfied. This is in contrast to the family members living at home of whom only 12.5% are very satisfied, 21.4% satisfied, 21.4% somewhat satisfied, and 44.6% not satisfied.

Some of the main reasons for the dissatisfaction among families with family members living at home is the time they spend on waiting lists for supported or group home living; the lack of available suitable supportive housing; insufficient weekly relief (respite); shortage of workers to handle workload; crisis precipitated by absence of service; and length of time to get assessment.

Table 17: Are you satisfied with the services available for your family member(s)? By Where Family Members Live* (Percentages)

	Family/Own Home	Other*	Total
Yes, Very satisfied	12.5	30.7	22.0
Yes, Satisfied	21.4	27.4	24.6
Yes, Somewhat satisfied	21.4	29.0	25.4
Not satisfied	44.6	12.9	28.0
Total	47.5	52.5	100
Counts	56	62	118

*Family/Own home implies the family member lives with family or lives on their own. Other includes group living, supported independent living, specialized community based accommodation, transitional accommodation short term, transitional accommodation long term, and other.

The majority of families think there is a need for additional services for their family members with dual diagnosis. Of the families reporting, 69.8% indicate that they need additional services; whereas only 30.3% report they do not. Both families with an adult

child living at home (79%) and families with member(s) in supported living (61%) report a high need for additional services. However, it is interesting to note that families with an adult with developmental disabilities living at home have a 17.7% higher need.

Families indicate that some of the additional services people with dual diagnosis need include but are not limited to: day programs; emergency respite care for times of crisis as well as respite on a regularly scheduled basis; psychiatrists and behavioural treatment; more supported living (especially in rural areas); mentor programs; transportation in rural areas; life skills training; local access to speech therapy & vocabulary development; and more doctors who understand and accept dual diagnosis patients.

The remaining discussion focuses on the families themselves. The issues addressed whether families receive services and supports and what barriers they face in accessing these services. It explores the training, skills support, and additional services that families require.

In general, about half of the families (50.4%) report receiving the services and supports they need when they need them (22.7% always and 27.7% usually receive the services and supports when needed). 42.9% indicate that they either sometimes (30.3%) or never (12.6%) got the services and supports they require when needed. Only 6.7% report that they did not need services or supports.

The higher frequency reporting always or usually getting services and supports is driven by the sample of families with family members in supported living. Of these 68.9% always or usually receive services and only 26.2% sometimes or never. This is in contrast to the families with family members at home that always (12.1%) and usually (19.0%) receive services and supports only 31.0% of the time, and sometimes or never getting services 60.4% of the time. Here again we observe the pattern that people living in the family home are less likely to need services and supports (8.6%); however, when they do need these services or supports they are also less likely to receive them. On the other hand, only 4.9% of families with a family member in supported living did not need services or supports.

Table 18: In the past year, did you get the services and supports you needed when you needed them? By Where Family Members Live* (Percentages)

	Family/Own Home	Other*	Total
Yes, Always got the services and supports when needed	12.1	32.8	22.7
Yes, Usually got the services and supports when needed	19.0	36.1	27.7
Yes, Sometimes got the services and supports when needed	39.7	21.3	30.3
Never got the services and supports when needed	20.7	4.9	12.6
Did not need services and supports	8.6	4.9	6.7
Total	48.7	51.2	100
Counts	58	61	119

*Family/Own home implies the family member lives with family or lives on their own. Other includes group living, supported independent living, specialized community based accommodation, transitional accommodation short term, transitional accommodation long term, and other.

Many families experience barriers accessing services. In general, 46.2% report facing barriers to accessing services. When this estimate is looked at by where the family member lives 58.6% families with members living at home face barriers while only 34.4% of families with family member in supported living face barriers.

The barriers families face which cause difficulty in accessing services include: difficulty getting time off work; language barrier or cultural barrier; hours services are available; transportation; location of the service; fees/costs associated with the service; required service(s) not available; and other barriers. The services that are not available are: supports for families to help them cope with stress; job supports for people with high function; respite; support groups; and psychologists. Other barriers to accessing services include: absence of appropriately trained support staff, lack of communication, lack of support and understanding from employers, respite services, and lack of funding

In summary, it is interesting to note that transportation and location of the service, which are factors that are conceptually linked, create the most difficulty for both groups of families when accessing services. And similarly, language and culture, which are linked, pose the slightest barrier to accessing services.

Table 19: Do you have any difficulty accessing services for yourself because of language, culture or other barriers? By Where Family Members Live* (Percentages)

	Family/Own Home	Other*	Total
Difficulty getting time off work	15.5	6.6	10.9
Language barrier	5.2	1.6	3.4
Culture	3.5	0.0	1.7
Hours services are available	22.4	9.8	16.0
Transportation	27.6	9.8	18.5
Location of the service	25.9	11.5	18.5
Fees/costs associated with the service	19.0	6.6	12.6
Required service(s) not available	19.0	9.8	14.3
Other barriers	19.0	9.8	14.3
NO barriers	41.4	65.6	53.8
Total	48.7	51.2	100
Counts	58	61	119

*Family/Own home implies the family member lives with family or lives on their own. Other includes group living, supported independent living, specialized community based accommodation, transitional accommodation short term, transitional accommodation long term, and other.

Most families report never participating in a caregiver course or a workshop related to their needs (64.1%). This finding is relatively consistent across both groups; 65.5% of families with the family member at home and 62.7% of families with an adult child living in supported living, report not receiving a course or workshop.

Of these families the majority (58.8%) have a need for a course or workshop related to their families' needs. However, this need is stronger among families with an adult child at home (62.1%) than among families with family members in supported living (55.7%).

This may be the case because families with family members at home or living on their own may have less exposure to support staff or trained professionals and thus less of an opportunity for knowledge or skill transfers, which can occur during regular or semi-regular interactions. Thus, this group may have a greater need for such training and skill development to meet their families' needs.

Some of the courses or workshops that families feel would help them manage their situation include courses and workshops on: how to access available services; stress management; and understanding mental illness and how to support people with difficult behaviour; what to do in a crisis; a workshop on how to manage family resources (time & finance management); and how to promote change in government funding.

When asked whether or not they are satisfied with the services available to them as a family member slightly over half (53.1%) report being either somewhat (27%) or not satisfied (26.1%), and 47% report being very satisfied (16.5%) or satisfied (30.4%). Again, breaking the sample into two groups according to where the family member lives is a critical part of this story. For families with a family member in group or supported living 61.4% report being very satisfied or satisfied in contrast to only 32.8% of families with their family member at home or living on their own.

Only 6.9% of families with a family member at home or living on their own report being very satisfied, 25.9% satisfied, 29.3% somewhat satisfied, and 37.9% are not satisfied. This is in contrast to families with a family member in supported living, of which 26.3% are very satisfied, 35.1% are satisfied, 24.6% are somewhat satisfied, and only 14% are not satisfied.

It is not surprising that families with an adult child at home report higher levels of dissatisfaction, since they only sometimes (or never) get the services or supports they require when they need them. They also face more barriers when accessing services, and they need more skills and training to manage their situation effectively.

Families that are only somewhat satisfied or not satisfied have good reason for their dissatisfaction. High levels of stress take a toll on the family. Parents need the relief that respite services provide. Navigating the system is exhausting – families need more support in accessing services. The hours of service do not meet the needs of working parents. There are not enough support groups in rural areas. Waiting lists are too long. Communication is not sufficient to inform caregivers of the availability of services or workshops. And there are too few medical experts that understand dual diagnosis.

So, it is also not surprising that 77.2% of families with a member at home report the need for additional services to help them care for their adult with dual diagnosis - compared to 56.9% of families with a family member in group or supported.

The following is a list of additional services that families require: counselling; more respite; a mentoring program; stress relievers for caregivers; reduction of waiting lists;

training on how to navigate and obtain services; support groups for families; and employment supports.

The survey also asked families what advice they would give to those who plan, organize, and deliver services for people with dual diagnosis. The families believe they should improve: marketing and communication to families so that they are aware of the help and supports that are available to them; funding of day programs and respite care to help reduce the high level of stress among families; the flexibility of things like the hours of service, and individualized supports; merge services so they are centralized under one provider; resources to find, train, and retain qualified dedicated staff and promote consistent of programming; and patience and empathy for the individuals.

Drawing the Environmental Scan Together

The purpose of the Environmental Scan is to identify where the families of individuals who have a developmental disability and mental health issue(s) and/or challenging behaviour go to receive services and support in the Hamilton/Niagara Region and the South West Region. By asking the question in this way the study sought to identify the gaps and barriers faced by families as they looked for services. The investigation has led to an exploration of the waiting lists for services developed by the Access/Contact agencies, a description of the types of services provided by the specialized service providers in the DS sector and in the mental health sector, a discussion of how DS agencies create the foundation for the system of care by providing social, emotional and residential accommodation for people with dual diagnosis and finally to an analysis of the needs of families as expressed in the Family Surveys.

The final section of the Environmental Scan draws together the information in the process of identifying gaps and barriers in the provision of service. It primarily relies on information provided by the agencies in their survey. But it also reports on comments made by members of the focus groups and in the family survey.

Gaps and Barriers

Providers and families were asked in surveys and in focus group meetings, to identify and talk about the gaps and barriers between adults with a dual diagnosis and the specialized services they need. For the most part families and agencies found it difficult to talk about obtaining specialized services without talking about many of the other challenges in the system. This description of the gaps and barriers presents the issues identified by families, agencies and key informants. The challenges identified range from those at a personal level (e.g. distance to service and transportation) to those at a system level (e.g. funding and the relationship between MCSS and the health sector).

Providers and families feel there is a general lack of understanding of the complex needs of adults with a dual diagnosis in the community. For instance, in focus groups, families tell how their friends and relatives have abandoned them because they do not understand

why the family tolerates the bad behaviour of the person with the dual diagnosis. Similarly, families and DS providers find it frustrating when the school system fails to understand the needs of young adults with dual diagnosis and forces them to withdraw from the classroom because of ‘unacceptable’ behaviour. Providers report as well that health and social service professionals are not well trained in dual diagnosis, making it difficult to obtain services. The inability of the community to understand the needs of people with a dual diagnosis leaves families feeling alone and isolated and agencies facing a constant challenge to inform others of the needs of people with a dual diagnosis.

When asked what gaps existed in *programs* for people with dual diagnosis they most often report that there were the following challenges:

- Lack of day programs to keep people with a dual diagnosis engaged in their community
- Lack of recreational programs designed for people with mental health and behavioural issues
- Lack of respite services for families who are providing care at home
 - Families need to be able access these on both a regular and an emergency basis
- Lack of specialized respite for crisis situations
- Lack of transportation (particularly in the rural areas)

A similarly high proportion of agencies indicate there are gaps in *services* for people with dual diagnosis.

- Lack of crisis services to respond to the needs of people with a dual diagnosis
- Lack of trained staff to support people during a crisis
- Lack of psychiatric services for people when they need them
- Lack of specialized residential treatment within the community
- Lack of cooperation from hospitals and the mental health sector

Given these gaps in programs and services, it is not surprising that the vast majority of agencies indicate they would like to strengthen programs or services for people with dual diagnosis that. The following list highlights some of the issues:

- Agencies would like to have funding for additional staffing to engage in ongoing environmental assessments, monitoring and staff feedback.
- Agencies need to increase staffing ratios to allow for greater community integration, for example, many of the clients we support require one-to-one care for community participation, and staffing shortages make this impossible.
- Staff needs more training related to mental health issues, medications, and behavioural supports.
- Agencies want to strengthen contacts with organizations delivering mental health services.
- Agencies would like to develop a case management program specifically to serve clients with a dual diagnosis.

- Agencies would like to offer more for youths making the transition from child to adult, such as training in social skills, anger management, and job-readiness.
- Agencies would like training and funding to provide supports to individuals with sexual deviancy.

Agencies were asked whether or not there are funding barriers that limit their capacity to serve people with dual diagnosis/behavioural issues; there are. The effects of these funding barriers are described generally as follows:

- limited funding for: staff training and development; expansion of services; and higher salaries to retain and recruit experienced staff with the necessary specialized skills
- high turnover in staff which in turn destabilises clients
- lack of group living spaces
- insufficient funding for day programming, access to accessible public transportation, and limited Behaviour Therapy hours
- psychiatrists are not able to accommodate one-to-one requirements needed by some people
- clients with a dual diagnosis need access to housing with a treatment component. The diagnosis of developmental disability inhibits access to appropriate specialized housing offered in the mental health sector.
- Not enough respite services
- staffing ratios need to improve
- The funding between health and social services needs to be reviewed, some people occupy expensive hospital beds for months because resources are not available to provide more suitable and sometimes more economical supports

Finally agencies were asked if there are legislative barriers that limit their capacity to provide support to those in need of specialized services. Legislative barriers are an issue for 34.9% of the agencies responding. The agencies explained the issues as follows:

- silo funding of Health and MCSS prohibit joint initiatives
- labour laws limit staff flexibility
- The Mental Health Sector does not permit individuals diagnosed with both a developmental disability and a mental health issue to access their services.
- Fire code legislation and zoning issues limit capacity in group home and prevent expansion.
- Use of restraint or time-out that may be needed to cope with some individuals is limited by legislation.
- Service and program models all seem to focus on establishing specialized services; for long-term sustainability more efforts need to focus on generic community services.

Language and Cultural Barriers

Providers and families indicate that communication and language problems add to the barriers they face. People with dual diagnosis may be hard of hearing, experience some level of visual impairment, and/or have poorly developed language and communication skills as a function of their personal limitations.

All of the agencies surveyed indicate that English is the only language in which services are offered to people with dual diagnosis. When asked what other communication methods would help them deliver services more effectively, 43% said they need tools and training to help them specifically in communicating with deaf/blind clients and generally to enhance communication with people who are having mental health problems. These include deaf/blind intervener programs, augmentive communication systems and training, and communication techniques for non-verbal clients. Providers also identify a number of things that would help them improve services. These include more staff with sign language training, conversion of material to braille, software for bliss boards, large screen monitors, touch talk equipment, and language interpreters for languages other than French. However, only 20% of families report that language is a barrier for their family member with a dual diagnosis. This may be because 60% of agencies indicate that some of their staff speak languages other than English and French. However, only 2% of the organizations report having material written in languages other than English or French. Language interpreter services are provided by 11.6% of the agencies and 16.3% provide cultural sensitivity training.

When asked whether the agencies offer any services designed to be culturally specific for Aboriginal/First Nations people, 7% report that they offer services to people with dual diagnosis/behavioural issues that respect cultural differences. These agencies describe the services as: day services based in their own community, traditional teaching and or activities that promote First Nations cultural identity; and culturally specific program content. Programs that are culturally sensitive to First Nations issues are provided in areas where there is a high concentration of Aboriginal people with dual diagnosis. Two agencies indicated they are prepared to provide culturally specific services if they are needed.

Summary and Conclusion

While examining the availability and structure of resources and service gaps and barriers we discovered there are many stories of things going well in local situations. In Grey Bruce, local groups have developed an effective way of working together as well as working with the local mental health organization. Regional Support Services provides a number of communities in the South West with important specialized services. In Woodstock the local agency has developed an effective relationship with the Developmental Behavioural Management Program. In Hamilton local groups have created internal resources that help them deal with challenging problems. In Niagara,

local agencies can turn to Bethesda Services for assistance in dealing with difficult issues. Across the both regions, situations that were working well.

However, from a system perspective it appears that the availability of services for people with dual diagnosis has challenging gaps and barriers. While the availability of services and the ability to meet the needs of these people varies across communities and regions, generally DS agencies are not well prepared to deal with the issues presented by people with dual diagnosis and getting services from the mental health system is a challenge in many communities.

Families, DS agencies, specialized service providers and key stakeholders indicate there are a number of challenges facing the system.

From the Family's Perspective

Families are aging and this is putting additional strain on them as care givers

The needs of people with dual diagnosis are episodic and crisis oriented. These people require services ranging from transient to long-term residential care and from minimal to intensive interventions and supports. Sometimes people with dual diagnosis are forced into inappropriate environments because of a lack of appropriate supports and services. The primary need in relation to people with dual diagnosis is for crisis care first, and then for ongoing intervention.

Families outside the system feel deprived and lament the waiting lists. They have difficulty getting services. Even when a crisis happens, families who are outside of the system feel neglected and abandoned by the service providers. Families feel that if their family member does not meet the eligibility criteria for receiving services then even if things change it is difficult to access the system. Families who did not put their children into an agency or institution when they were young are now having difficult getting services or supports for their adult children.

Families fear the use of psychotropic medications. They believe it has negative consequences for the person with a dual diagnosis and that once the person they care for is on the drugs it is very difficult for them to get off.

From the DS Agencies Perspective

While not directly related to issues concerning people with dual diagnosis, general working conditions are affecting the delivery of services. There are low wages compared to similar work outside the DS system, difficult working conditions, stressful periods, high staff turn-over. Training is not keeping pace with changes in the system, and there is a lack of expertise within the agencies.

Most programs that DS Agencies offer have criteria which limit the types of clients they are mandated, funded and equipped to serve. Families have difficulty

understanding and accepting these barriers to service and claim that those who are receiving them are lucky.

The DS Agencies do not have the internal resources to provide an effective crisis response for people with a dual diagnosis. Crisis situations require more staff than is normally available. The lack of flexible capacity hinders agencies when they need to move people out of undesirable circumstances. This increases the likelihood of a crisis event. The system is slow to respond to crisis needs.

When the situation goes beyond the ability of the DS Agency to provide services it is difficult for them to get support from the mental health sector. Most mental health programs do not accept people with 'behavioural' problems and this is compounded by how difficult it is to assess people with dual diagnosis (due to over-shadowing).

Transportation is a major barrier particularly in rural areas.

Agencies face wait times to get assessment, treatment or support from specialized service providers. While this varies considerably across regions and across specialized service providers, the system is generally not able to respond quickly.

Agencies are unable to keep individuals in community as their needs rise.

From the Systems Perspective (key stakeholders)

Professionals and community members lack an understanding of the complex issues concerning dual diagnosis. This leads to reluctance on the part of professionals in education, health, corrections and other community services to provide support for people with a dual diagnosis. The consequence is that since taking responsibility for social, vocational and residential service delivery in 1974, the DS sector has developed resources within the sector to meet the needs of people with a dual diagnosis. At the same time the MCSS has tried to encourage other sectors to provide services to these people.

The mental health system has been the other major provider of services to people with a dual diagnosis. When responsibility for services was shifted to MCSS the health sector acknowledged that they would continue to meet the mental health needs of people with a dual diagnosis. This led to a split in the provision of services. MCSS was responsible for people with developmental disabilities as well as for people with dual diagnosis who were having behavioural problems; while the health sector was responsible for treating the mental health problems of people with dual diagnosis who had a mental health problem.

This led to a fracturing of the service provision. In some communities the fracturing was overcome; it evolved into a functioning system for people with dual diagnosis. Local DS agencies worked well with local mental health agencies

to provide coordinated services. In most communities this did not happen. A more rigid system developed that provides beds to people with narrowly defined developmental disabilities and mental health problems. This led to a lack of coordination and support between the MCSS and health sectors

Key stakeholders claim philosophical differences between the mental health and social services system, resulting in differing programming approaches, prevent coordinated care of this shared client population. Mental health uses a medical model while MCSS uses a service provision model. Mental health focuses on rehabilitation and cure while MCSS focuses on adaptation and functioning independence.

While the primary problems in the system are the lack of coordination and a working relationship between the MCSS and health sector there are challenges with other sectors as well. People in the transition from children's services to the adult service system suffer. There are major dislocations from the school system (where people with developmental disabilities have rights to services) to the community support system (where these same people have entitlements but no rights to services).

Fundamental Issues that Need to be addressed in the Regional Solutions Report

In drawing together the material from the Environmental Scan, eight dominant issues emerge. None of these are new to people who have knowledge of the developmental sector.

1. Adults with a dual diagnosis have complex needs.

The needs of adults with a dual diagnosis manifest themselves as ongoing low-level demands, episodic crisis events, and long-term disruptive events. Mental health problems merge with behavioural issues and it is difficult to diagnose and provide effective intervention. Small changes in a person's life and daily routine can have dramatic effects on their ability to function which make their behaviour and situation unpredictable. All of these issues make it difficult to provide coordinated services.

2. The need for community based support is increasing for adults with a dual diagnosis.

Aging parents have diminishing physical, emotional and sometimes financial ability to continue to provide around the clock care and support for their adult children. Now they worry, for good reason, about what will happen to their adult children when they die. In addition, the Ontario government plans to close the three remaining institutions in the province; the closing of Southwestern Regional Centre in Chatham-Kent will have an impact on the demand for services primarily in that area, but also in the South West Region

3. There is no unified service system for people with dual diagnosis.

The continuum of care and support for these clients and their caregivers comes from diverse policy and program sectors and funding sources. This makes the provision of an effective and responsive continuum of services more complex. The diverse sectors include:

- multiple public sector partners e.g. Ontario Ministries of Community and Social Services (MCSS), Health (MOHLTC), Education, Justice and their transfer payment agencies
- non profit sector services e.g. YWCA residential and recreational programs
- private sector services and supports e.g. psychiatrists, training programs
- other community supports, some supported by community fundraising.

The lack of integration between MCSS developmental services and MOHLTC mental health appears to be the result of misperceptions about each sector's capacity and responsibility. The consequences include: disconnected service provision at the local level; the lack of a long-term shared agenda for sustained, effective care and support; and a lack of a long-term plan for dealing with increased needs.

4. Access to services is variable across the two Regions.

Meeting the needs of people with dual diagnosis depends upon: where they live; the ability of their family to advocate on their behalf; the availability of resources in the community; and the relationship between the developmental services sector, the health sector and other resources sectors.

5. There is a gap between the services provided to children and those provided to adults.

A gap in services is created when a person with a developmental disability moves from having rights to an education as a child to having no rights to services as an adult in the adult system.

6. Developmental services experience many challenges.

Developmental services are functioning at capacity. There is a waiting list for most of the services. At the same time, agencies' ability to deliver effective, timely, and responsive client and family services is at risk. Workers in the field are "tired" in the face of doing more with less, and participating in the development of community service plans, multi year plans and capacity assessments with little follow-up implementation activity to improve outcomes for clients.

7. When a crisis event happens there are few local resources to provide support.

The lack of available continuous, consistent and quality support for many adults in and of itself can provoke unstable client behaviours and crises. Families and providers lament the lack of a "safe space" to diffuse crises episodes for staff, family and client.

Emergency psychiatric response is overwhelmed generally, and under trained specifically to respond to the presenting situation and the underlying conditions.

8. The service system does not have an overall strategy for encouraging people into the field.

There is insufficient focus on developmental disability issues in the training and education of professionals. There is no specialty in medicine, nursing, social work or other highly trained disciplines covering the needs of people with dual diagnosis.

Effective recruitment and retention of trained frontline workers is difficult in a environment characterized by declining interest in underpaid and stressful work, lack of cross sector training, diminished access to specialized supports for staff training and mentoring, and client intervention e.g. psychiatry.

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