Chapter 9

Building Responsive Service Systems

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Learning Objectives

Readers will be able to:

1. Describe how ideology, culture and philosophy have influenced the development of services and systems for individuals with dual diagnosis;
2. Identify creative ways in which the gaps and barriers in service delivery have been addressed globally, with particular reference to Ontario;
3. Identify strategies for building a community support network and promoting ongoing participation of all stakeholders; and
4. Describe future challenges to bridging service sectors and building service delivery systems.

Introduction

Much work has been done in the past decade that focuses on the context or “system” within which individuals with complex needs are served. What has been learned is that attention to issues in the service delivery system is essential for successful outcomes. This chapter provides an overview of the evolution of this system's focus, and summarizes current thinking regarding effective systems of care for individuals with a dual diagnosis. A review of systems and service models in various jurisdictions provides the context for building systems. Key concepts are defined, service gaps and barriers are identified, the ideal continuum of service is described and, strategies for building networks and partnerships are reviewed. The chapter concludes with a discussion of future challenges.

Historically, services and supports for individuals with a dual diagnosis have been fragmented due to a lack of coordination and communication. One agency or service sector cannot meet all the needs of a person with a dual diagnosis. To be effective, service planning and delivery must be coordinated at the individual (consumer), programme, and system levels. By creating a responsive delivery system, service gaps can be addressed effectively, and in a timely manner. In addition, various community stakeholders can establish formal partnerships, building a community support network that results in better outcomes for individuals who present the most challenging difficulties.

This systemic approach to service planning and delivery promotes an integrated service system for individuals with a dual diagnosis, and in turn, provides a range of comprehensive supports involving a number of service providers and sectors. The goal is to build a *network* based on a continuum of integrated services and supports. Such a network can offer a wide range of options to a consumer, with specific services being provided by agencies working in partnership within the network.

The Context for Building Systems

For purposes of comparison and learning, we have chosen to describe briefly the evolution of service models for persons with a dual diagnosis in other countries and in Canada. This contextual framework is based on the assumption that culture, philosophy and economics influence system development and change. This overview provides a context for what is happening in Ontario. It should also alert us to the future challenges we may face as we better understand the factors impinging on the development of these systems and policies, and their implementation within the community.

The Metro Agencies' Treatment Continuum for Health (MATCH, 1996) document *Creating a Continuum of Supports and Services* describes community and government responses to the needs of persons with a dual diagnosis as dependent upon three broad factors:

- the degree of acknowledgement or denial of developmental disabilities;
- the degree of acknowledgement or denial of mental health needs for individuals with a developmental disability; and
- a community's response to the normalization and social integration movements.

These three factors provide a starting point from which to consider the evolution of services in various countries.

Service system change and development for vulnerable persons with complex needs can arise out of a variety of contexts or trends. Human rights movements, initially focussed on the oppression of specific racial or cultural communities, have often broadened to include other groups of people who are recognized as being marginalized or neglected. Any advocate must first name the group of individuals whose rights are being ignored or abused so that they become visible to mainstream society. By drawing attention to such individuals and the circumstances of their lives, advocacy efforts can then begin to shape the emerging service system on their behalf.

In most countries, the services and community supports for individuals with developmental disability, and people with mental health issues, emerged and grew separately as two discrete areas of concern. The challenge has been to further identify and create an understanding of those individuals with the dual diagnoses of both developmental disability *and* mental health issues. As the knowledge base and understanding of the needs of dually diagnosed individuals grew, along with the recognition that traditional ideologies were not useful in meeting their needs, communities have been challenged to rethink their systems of care in order to provide services to those with the most complex needs. Creating opportunities to learn through research and training, and funding of dedicated clinical resources has emerged in countries where the core values include the creation of a safety net for vulnerable people.

Frequently, the widely held community values that formed the basis for the original advocacy initiative are in conflict with the complex needs presented by people with a dual diagnosis. Jurisdictions that have been more successful in addressing the needs of persons with a dual diagnosis have first had to reexamine their core values as they relate to all persons with special needs. It is important to ensure that the service systems that have been created do not just comply with the policy or ideological framework, but that they operate to actually meet the range of needs for which they are designed. The concepts of normalization and integration as core values surrounding the development of services for individuals with developmental disabilities, therefore, must be massaged to fit the needs of individuals with a dual diagnosis. These factors provide a starting point from which to consider the evolution of services in various countries.

United States

In the United States the *Community Mental Health Retardation Facilities Construction Act* was established in 1963. This formed the origin of the development of systems of care based upon normalization and community integration principles. Social change agendas, founded upon the belief that individuals with a developmental disability should no longer be hidden away in institutions, but rather, included in the life of communities. They resulted in community living alternative care environments, and began the ongoing downsizing of public institutions. However, until the 1990's, many of the individuals with a developmental disability and accompanying mental illness continued to be housed in institutional care settings.

As community integration became the norm for individuals with a developmental disability, legal avenues (e.g., class action suits) were sought to improve the care of those with more complex needs both within institutional facilities and in the community. Despite efforts to ensure that entitlement agendas included those with the most complex needs, access to appropriate, individualized care is still uncertain for individuals with a dual diagnosis, since community agencies serving persons with developmental disabilities continue to screen out the clients with more complex needs. However, efforts are being made to create a diverse array of service options within the community, and in institutional settings that can accommodate those with higher needs.

It is interesting to note that in the United States, the services for persons with a dual diagnosis have emerged primarily out of the service system for mental retardation. This has meant that policy and community initiatives for serving individuals with a dual diagnosis must grapple with how to effectively meet the needs of this group within the context of normalization and community integration values, while, at the same time, recognizing that some individuals do need more intensive and specialized care. Being rooted in the developmental service system also creates challenges for individuals with a dual diagnosis who require access to appropriate mental health services. Menolascino (1994) notes that, despite apparent legislative entitlement to services for persons with a developmental disability, the services that are actually publicly funded are limited. Such examples of conflict arising between values and funding realities appear to be closely related to the fact that other mainstream needs drive political agendas. Conversely, the needs of more vulnerable populations that go beyond safe and protective care models of service, are more difficult to address, since they require the populace to understand complex concepts, and to support a range of service options that may require sophisticated funding structures. The result seems to be what has been called a “cobbled together” funding package (from private insurance, base funding, *Medicaid* and federal grants) to create the individualized services needed.

Sweden

In Sweden, the law clearly articulates that persons with a developmental disability are entitled to the same rights as other members of society (Dosen, 1993). However, by assuming fair and appropriate access to the mental health system for persons with a developmental disability, a service gap has actually been created, in that there is no recognition that specialized services are needed. A well-intentioned commitment to entitlement can effectively become a barrier to the creation of much needed services for those with complex needs. Similar to the challenges faced in the United States, creating specialized services for persons with a dual diagnosis appears to fly in the face of normalization principles upon which all other developmental services are based.

United Kingdom

Alternatively, in the United Kingdom, developmental disability is a psychiatric speciality; hence, a strong clinical base has been created for research and mental health intervention for those with a dual diagnosis. Education and training are enshrined within various professional schools (e.g., psychiatry, nursing). The challenge arises again, however, with the influence of normalization ideology, but in this case, from a different perspective and sector. How should services for persons with a dual diagnosis be organized – within the mainstream of psychiatric services, or as specialized services (i.e., separate from either sector)? How can successful community integration best be supported for people who have very specialized needs?

Italy

In Italy a long-standing influence on the development of services for persons with a dual diagnosis has been a cultural difficulty in accepting the diagnosis of developmental disability. With this as a back-drop to policy and community directions, the shift from institutional care of persons with a developmental disability to community care actually became a shift to family-based care models with minimal organized government-funded supports, and mental health interventions only for those with the most severe needs. In this case, the gap in government-sponsored supports due to a lack of public outcry led to the existence of several private institutions and clinics run by religious organizations (Dosen, 1993).

Other Countries (e.g., Germany, Belgium, Switzerland)

Other countries (e.g., Germany, Belgium, Switzerland, and, to some extent, Canada) until very recently, have failed to integrate in any meaningful way the psychiatric with the developmental or behavioural perspectives. The reasons are varied but some similar themes emerge as follows: benign neglect (usually supported by continued institutional care models); a lack of political will to challenge the extent to which ideologies (e.g., normalization) can actually reduce services for some individuals even though they are intended to provide improved access and support; economic constraints; and/or competing priorities.

The Netherlands

Dosen (1993) notes that in the Netherlands, deinstitutionalization combined with the adoption of normalization principles in the 1970’s, brought attention to the shortage of psychiatric resources for people with a developmental disability. Traditional community psychiatric services were directed towards individuals with higher intellectual levels, many of whom could effectively access services on their own, thus reinforcing the service gap.

Canada (Ontario in particular)

Canada has traditionally had a well-articulated commitment to a publicly funded health care system. Programme delivery responsibilities are assigned to the provinces. Services for individuals with developmental disabilities and mental health needs are designed and delivered on a provincial level, with the result that there is no national vision or approach for persons with a dual diagnosis. Ontario provides a vivid example of the impact of culture, ideology, economic challenges and priorities upon the development of models of care for individuals with a dual diagnosis (Puddephatt & Sussman, 1994).

In the 1800s, institutional care in Ontario was established to shelter and protect both individuals with mental illness and with a developmental disability (both conditions were viewed as untreatable). Later, these same settings were seen as places to keep these “undesirables” from being a “danger” to the rest of society. Also at that time, with the growth in the field of psychiatry and insight-oriented interventions, individuals with a developmental disability were excluded from psychiatric settings because they “drained” resources and services needed for the mentally ill. The resultant facilities for persons with developmental disabilities included those with a dual diagnosis who, because of their behaviours, were often segregated into separate units, and over time were provided with some form of treatment, depending upon the clinical will and interest of the psychiatric resources.

In 1974, the Ontario *Developmental Services Act* moved the responsibility for individuals with a developmental disability from the jurisdiction of the Ministry of Health to the Ministry of Community and Social Services. This served to affirm that individuals with a developmental disability are not “ill”, but rather, are in need of appropriate supports to live as freely as possible and to the best of their abilities. Across Canada, normalization became the philosophy behind significant deinstitutionalization activity. However, typically those individuals with the most challenging behaviours and complex mental health needs continued to be served in the remaining specialized units either within the provincial psychiatric hospitals, or the institutions serving this population.

Similar to other jurisdictions already mentioned, Ontario struggled to create a useful way of understanding and meeting the needs of persons with a dual diagnosis. Defining the problem as “behavioural” or “psychiatric” created a continual shifting back and forth of service responsibility between programmes funded by the Ministry of Health, and services funded by the Ministry of Community and Social Services. This situation was exacerbated by the fact that there was no real knowledge base or expertise that integrated the various professional and community perspectives of the needs and potential for successful intervention. Individuals who were released to the community tended to be referred back and forth between the different service systems, sectors and programmes, while professionals entering either the developmental services or the mental health fields came with no training or experience in serving individuals with dual diagnosis.

In the last ten years, in many areas of Canada, there have been significant changes in the understanding of the needs of persons with a dual diagnosis, both clinically and at the service systems level. In its simplest form, we now recognize the need for a multi-systemic, integrated and comprehensive assessment of the needs of each individual and his/her environment and natural supports. We know also that, based upon this assessment, the components of the individualized service plan must fit together in a way that is flexible, creative, and seamless, virtually eliminating jurisdictional and professional barriers to appropriate service.

Today’s challenge in Ontario is to create a system for serving persons with dual diagnosis based upon a well-documented and agreed-upon vision. In the early 1990's the Ministries of Health and Community and Social Services participated in an Inter-ministerial Dual Diagnosis Initiative. An outcome of this initiative was the development of the *Joint Policy Guidelines for the Provision of Services to Persons with a Dual Diagnosis, 1997*, in which this vision is articulated.

At the regional level, implementation strategies are currently in various stages of development, depending upon local organization and government commitments, competing priorities, and a willingness to work together across system boundaries. For example, in an effort to support the intent of the *Joint Policy Guidelines*, the Ontario Ministry of Health has at various times required its funded providers (e.g., hospitals, community mental health programmes) to describe in their annual operating plans how they intend to address the guidelines. As well, the guidelines have been integrated into the most recent mental health policy framework and implementation plans. The Ministry of Community and Social Services’ *Making Ser-*

vices Work for People policy does not directly reference or include the *Joint Policy Guidelines*. However, at the local community level, the needs of the group of persons with dual diagnosis continue to be highlighted and identified as requiring special cross-sectoral attention. The response to the guidelines at the developmental service provider level is therefore, primarily voluntary in nature, based upon local partnerships that enhance the capacity of the providers to serve individuals with a dual diagnosis by a sharing or exchange of resources. Examples of this are described in more detail below.

Key Concepts in Understanding Service Systems

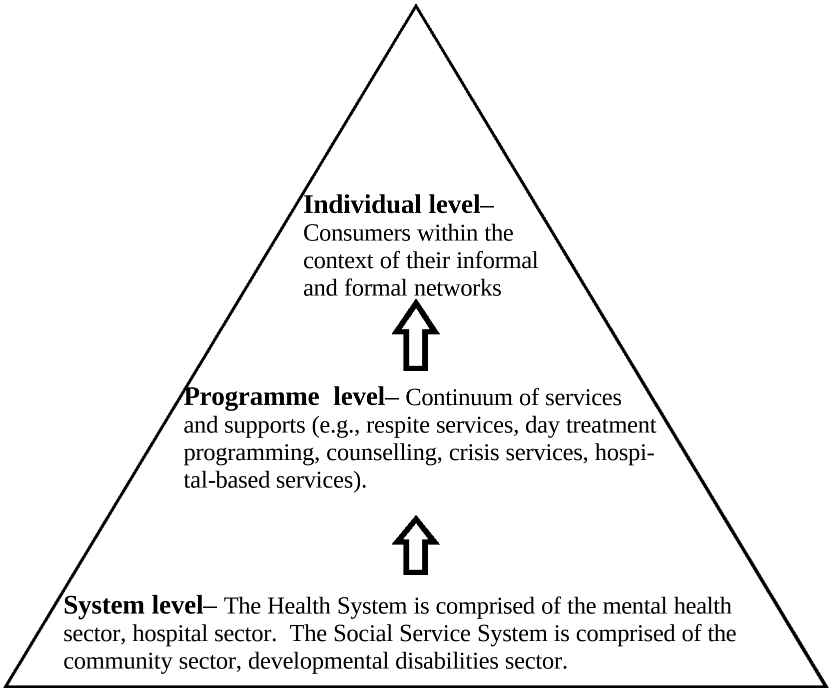
The issues and concepts underpinning responsive service systems for persons with a dual diagnosis must be understood at three levels: individual, programme, and system (see Figure 1). In the following section we discuss each of these levels.

Individual Level

A key feature of successful services for individuals with a dual diagnosis is that each person is viewed within the broader context of his or her environment (McKinnon, 1999). The environmental context includes where the person lives and works, family and friends (informal networks), and services, groups and organizations (formal networks) with which s/he interacts on a daily basis (Trainor , Pomeroy, & Pape, 1993). For individuals who require a range of services and supports, one must use a systemic approach that de-emphasizes the person as 'the problem' and considers the individual within the context of his/her total environment.

It is important to be aware of the quality of the connections an individual may have with the various components of his/her network. Are they strong? Tenuous? Weak? Understanding the impact of these connections, both on the consumer and on the other members of his/her informal and formal networks, is important in assessing the individual's social environment. Understanding the nature of these network transactions allows one to begin thinking about possible points of intervention in terms of strengthening an individual's network of support (Compton & Galoway, 1994). Viewing the person in light of his or her total environment provides a useful framework for identifying how the whole system can be strengthened in order to provide more support to different network components (e.g., family, service providers).

Figure 1– Levels of Support and Services



A person with a dual diagnosis who has a life threatening illness, and who is on probation, may be involved with a number of services that help support the physical, emotional and social aspects of his/her life. These might include specialized services offered through the mental health, developmental, probation and parole, and hospital service sectors. Incorporating this concept of networks with the biopsychosocial approach to assessment and intervention provides the necessary framework for examining how and where supports may work together in a cross-sector fashion, and thus, an integrated plan of care can be developed.

Programme Level

The programme level refers to the actual services that are provided to individuals with a dual diagnosis (e.g., a specific agency providing case management services). Programmes include a range of services drawn from a continuum of supports and services such as respite services, counselling, residential and day programming, and other services (see Figure 1).

The key to providing effective service planning for an individual is to ensure that the services provided are an appropriate match to the person’s needs. Cooperation and coordination between programmes, by sharing information and resources, enhances the ability to meet the unique needs of individuals with a dual diagnosis. Such an approach promotes a more comprehensive service package, avoids duplication of services, and better addresses the gaps which might otherwise exist in a client's plan of care. Similarly, attempts to enhance programmes by adding specialized resources and supports have also provided increased stability and continuity of care. In this way, the continuum of supports and services includes those particular programmes that best meet the needs of the individual, while also supporting all involved with implementing the care plan.

System Level

"System" is a broad term referring to inter-connected parts, which form a complex unity (MATCH, 1996). The major components of a system are called "sectors". For example, the mental health sector (which is comprised of a range of residential, day programme, support and treatment services) is a component of the broader health system. Other sectors within the health system include hospitals and long term care. Similarly, the developmental service sector (also comprised of a range of residential, day programme, support and treatment services) is a component of the broader social service system. Other sectors within the social service system include income maintenance, and child welfare. Given the range and complexity of needs of individuals with a dual diagnosis and their families and caregivers, it is not unusual for various sectors within and across a number of systems to be involved in their care.

Service Gaps and Barriers

From the above discussions regarding the context of service system development, and individual, programme and system level perspectives, one can see how the concept of a continuum of services and supports begins to emerge. Described below is a summary of the gaps and barriers that are often identified by consumers, families and service providers regarding services for individuals with a dual diagnosis.

The Metro Agencies Representatives Council (MARC) report *A Continuum of Service for Persons with a Dual Diagnosis*, June, 1989, is an Ontario report that succinctly summarized seven key service issues or gaps. They are:

1. fragmentation of assessment and treatment;
2. knowledge gaps;
3. failure of existing community support systems to meet the needs of persons with a dual diagnosis;
4. problems with access to mental health services, and lack of resources for discharge from psychiatric units and facilities;
5. mental health services which do exist are only at the most intensive level;
6. lack of specialized treatment and care options for the fragile client; and
7. specialized psychiatric treatment programmes for the developmentally handicapped serve only those in the mild to moderate range of intellectual functioning.

The report also describes common barriers to effective treatment planning, such as the longstanding debate about behavioural vs. psychiatric problems, which can result in the denial of mental health or developmental disability treatment due to causality. Another barrier is the lack of interaction between the staff of the mental health sector and the staff of the developmental service sector; this lack of interaction impedes development of new service responses within the separate sectors.

The Ideal Continuum of Services and Supports

When considering how to build responsive service systems that will effectively address the above gaps and barriers, one has to consider both processes as well as a range of services and supports. This section will examine the service and support elements of the continuum and give examples of creative development within these areas.

For the individual with a dual diagnosis (and his or her family members and caregivers), key service elements along the continuum of supports and services can be divided into three components:

1. Prevention and Early Intervention;
2. Intervention and Treatment; and
3. Long Term Care and Support.

This continuum is fully explained in the document: *Creating A Continuum of Supports and Services: A resource Document* (MATCH, 1996). It represents an ideal model that integrates developmental and mental health perspectives as well as individual, programme and system level approaches.

Following is a summary of these three main components of the continuum, with examples from Ontario and around the world, of how these components have been implemented to address individual, programme and system level gaps and barriers. The examples are not exhaustive, and are provided only to assist the reader in thinking creatively about his or her own experience and local situation. In reflecting on these examples, one cannot over-emphasize the impact of the local culture, philosophy and existing systems. In addition, one must take into consideration that the evolution of the services and systems described is a dynamic and ongoing, ever-changing process.

Prevention and Early Intervention

Prevention and early intervention services and supports focus on the aspects of health that affect the emotional well-being of individuals with a developmental disability. This component includes activities that build on the strengths and positive aspects of the individual, her caregivers and environment. Ensuring access to generic health services for individuals with a dual diagnosis is an example of a preventative and early intervention activity. It also includes anticipating potential crisis situations (e.g., identification of high-risk groups) so that supports and services can be implemented to prevent the escalation of difficulties and longer-term mental health problems.

Early Identification and Prevention *(system level)*

In the United Kingdom, generic and specialized developmental disability services are organized into small geographic units (e.g., 100,000 population). This facilitates early identification and diagnosis through a register of people and their special needs within each area. A range of services (from respite care, in-home support, and community services to specialized services) is accessed through a central point.

Information *(programme level)*

Many dual diagnosis committees have been initiated in Ontario in the last few years. These committees have cross-sector participation, and one of the first activities often identified for joint work involves the dissemination of information and educational booklets or packages.

Support Networks (*individual level*)

In eastern Nebraska, USA, a parent support programme within the developmental service sector offers parents support from other parents by providing such services as programme information and assistance through the initial stages of diagnosis.

Education and Training

Formal educational activities are underway in many locales across Ontario. These include: courses and certificate programmes at various community colleges and universities (*individual level*); internet-based training for medical students (*programme level)*; as well as local, provincial and international workshops and conferences on various aspects of dual diagnosis. An effective *system level* approach in the United Kingdom has been the inclusion of developmental disabilities as a required part of the training for both psychiatrists and nurses.

Intervention and Treatment

Intervention and treatment services and supports attempt to reduce the impact of a condition, and to help the consumer return to his or her previous level of functioning. While the focus in this component is often to address acute needs, it obviously builds upon elements in the prevention and early intervention component. Work done at the intervention and treatment level, such as assessment, will frequently overlap with long term care and support elements. For example, assessment may identify a need for ongoing recreational supports or day programming.

Some programmes in this component have evolved to integrate more than one service element (e.g., crisis services combined with a specialized multidisciplinary assessment and treatment team). The degree to which this integration of services is evolved depends upon various factors including the stage of policy, inter-agency collaboration and service development in a jurisdiction. It should be noted that programmes often start at a relatively simple level. They may offer one or two elements of service (such as case conferencing with various stakeholders from other programmes and sectors, along with the involvement of a specialist), and then evolve to shared ways of working (e.g., protocols for dealing with crisis situations), and sharing of staff to offer services to specialized groups.

Depending on the stage of policy, inter-agency collaboration and service development in a jurisdiction, some programmes have evolved to integrate more than one service element within this component (e.g., crisis services combined with a specialized multidisciplinary assessment and treatment team). It should be noted, however, that often programmes start with what they have. They may offer one or two elements of service (such as case conferencing with various stakeholders from other programmes and sectors).

Specialized Community Services *(programme level)*

Many innovations in service have been initiated in response to the identified needs of clients attending a particular programme or agency. These specialized services have included anger management groups, sexuality programmes, multidisciplinary assessment and treatment, case management, grief counselling and social skills groups being offered by forensic, developmental, mental health, behaviour management or autism services. Examples of this phenomenon abound across Ontario where such programmes are found in developmental service agencies, child and adult mental health services, and community and psychiatric hospitals.

Transitional Day and Residential Programmes *(programme and system levels)*

A programme in eastern Nebraska (ENCOR) provides transitional group home and pre-vocational services to clients with a dual diagnosis and behaviour management problems for a period of six to twelve months. The transitional nature of ENCOR's services allows for the movement of individuals between programmes and sectors, such as from an in-patient or treatment milieu in the mental health sector to a long term care placement in the developmental sector. This model also integrates other elements within the intervention and treatment component, including a range of specialized residential and day community services, to meet the needs of those with more complex behavioural difficulties. It also provides training for psychiatry residents and other professionals.

Intake, Continuum of Crisis Services and Specialized Multidisciplinary Teams *(individual, programme and system levels)*

A lot of attention has been focused in various jurisdictions on specialized crisis and multidisciplinary teams. This has likely occurred in an effort to provide help to individuals with the most complex needs while, at the same time, working with the limited availability of expert resources in areas such as psychiatry, psychology, behaviour therapy, nursing and family or systems work. As a result, a specialized team model has been identified as a key component of various systems: such teams support and build on the strengths of the network of formal and informal service providers working with an individual.

The START programme, located outside of Boston, Massachusetts, is one of the original model services addressing the crisis and specialized multidisciplinary team components of the continuum. It combines 24-hour mobile crisis and respite services with provision of an access point to specialized assessment, treatment, and time-limited inpatient mental health services for individuals with a dual diagnosis. The services are provided by a multidisciplinary team and include psychology, psychiatry and social work (with staff trained at both the Masters and Bachelor degree levels).

Similar to the START model, but with adaptations for the larger urban environment, is the Griffin Community Support Network in Toronto, Ontario. The Griffin Community Support Network was developed to provide a comprehensive response to individuals with a dual diagnosis and their families in crisis situations, and is accessed via city-wide integrated crisis service mobile teams. This network provides community and general hospital safe beds, one-to-one contract workers, and a range of coordinated services (e.g., case management, assessment) through formal cross-sector partnership agreements with over fifty organizations. Services are coordinated for the consumer by a designated agency or agencies, but there is a shared responsibility among members of the network to provide the various treatment and support components.

A recent development is the expansion of the Griffin Community Support Network through integration with the Dual Diagnosis Resource Service. The Resource Service multidisciplinary community team provides specialized assessments, consultation, time-limited treatment, education, training, facilitation services and triage to a specialized inpatient unit. Together with the Support Network, this expanded programme serves as an intake point to a network of services. The goals are to mobilize, strengthen and empower the network, to improve communication, to develop problem-solving strategies, and to increase the supportive capacity of the network for all stakeholders.

Other Treatment and Intervention Models

In British Columbia, four community-based multidisciplinary specialized teams cover specific geographic areas across the province, and are accessed through local mental health centres. Their purpose is to prevent hospitalization, and to work with community caregivers to provide specialized assessment, diagnosis, consultation, treatment, training, back-up support, and mediation between caregivers and systems.

In the United Kingdom, local community mental handicap teams provide back-up to the generic developmental and mental health services. These teams are staffed to provide a range of services, including activities of daily living, behaviour management, family, work, medication consultation and information. They also have a program and system level responsibility for identifying mental health care needs.

In Rochester, New York, crisis intervention, respite care, and clinical assessment and treatment form a continuum of service provided by a multidisciplinary team of specialists in psychiatry, behaviour therapy, and psychology. The team that provides the services is associated both with the university and the developmental service sector.

In Minneapolis/St. Paul, Minnesota, mobile crisis services are integrated across several service sectors. This community based service approach includes access to 90 day respite care, and assessment and treatment services which can provide a range of intervention recommendations in developing a plan of care for a consumer. Staffing of this service constitutes a range of multi-disciplines including psychology, psychiatry, pharmacy, nursing, social work, and behaviour specialists.

Long Term Care and Support

Long term care and support services are required to reduce the level of continuing disability, and to prevent recurrence and relapses over time. As noted above, the services and supports in this component may overlap with those offered within other components of the continuum. Thus, the long term care and support component ultimately reflects the whole system of services, and its capacity to use its resources in a flexible manner.

There are two specific areas that deserve particular focus within this component:

- a range of programmes that meet basic needs such as housing or social recreation; and

- specialized supports and services that meet special and/or chronic needs (e.g., a dual diagnosis day treatment programme within a long term care setting, or a long-term high support living situation in the community).

Range of Case Management/Individual Supports *(individual level)*

In Ontario, there are many examples of how the system has evolved to extend the capacity of each sector to develop informal cross-sector teams around individual cases. For example, staff of a case management or community support service in the developmental service sector, working together with a case management programme in the mental health sector, have successfully expanded the range of options available for maintaining an individual in his or her community.

Medical and Mental Health Follow-up *(individual and programme level)*

Where geography and/or a lack of resources present many challenges, such as in the areas of central and northern Ontario, some psychiatric hospitals have designated staff with specialist knowledge in dual diagnosis (e.g., nursing, behaviour therapy, psychology) to travel to various locales to provide on-site services. These specialists work with local service providers, general practitioners and family members to create a multidisciplinary team providing follow-up and back-up support. In addition to specialized assessment, this arrangement allows for the ongoing monitoring and adjustment of interventions within the individual's home community.

Transitional Programmes and Services *(programme level)*

The ENCOR model described above is one example of a transitional programme. Another example is Home Base in Toronto, a new housing and support service developed to meet the needs of individuals with a dual diagnosis who are also homeless. A five-bed residence for a one-year length of stay is provided to individuals in transition from the shelter system. Linked to the Dual Diagnosis Resource Service and Support Network (previously described), these individuals will benefit from a coordinated system of supports.

A Range of Residential and Day Programmes, Life and Social Skills Training *(individual, programme and system levels)*

The various elements of the long term care and support component described facilitate an individual's successful integration within a community environment. At the same time, the level and nature of integration should be tailored to the needs of the individual (or group of individuals). Within this component, there are a range of services that represent a variety of approaches to integration. For example, in the area of employment, there are instances of work training activities across Ontario occurring in partnership with colleges, universities and private sector businesses.

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Specialized services have also been developed within the long term care and support component of the continuum. Programmes have evolved within the developmental sector to meet the specific long term needs of some individuals. Examples of this can be found in housing programmes where smaller clusters of individuals with higher needs are living together in larger spaces. These arrangements balance individual need by providing a less stressful and safer environment with the goals of community integration and adequate staffing to ensure safety. As a further example, individuals with a history of sexual offences are placed in a specialized home where staff has access to specialists for consultation and support.

An example of a fully integrated community model is found in Italy's 'Open City' (NADD, 1995). Low cost housing is available to both persons with and without disabilities, situated within an existing community. Individuals with disabilities live, work and socialize with all members of the community.

Strategies for Building Community Support Networks and Partnerships

It is important to recognize that no single service or individual alone can achieve the goal of developing a support network, nor can a network be established through any single process or method. Rather, what is needed is an approach that ensures coordination among the various stakeholders. Both formal and informal supports and services must be involved in the development of the network, with formal service agreements signed by network participants outlining the specific services that each will provide. The different services provided by each network member reflect components of the range of resources needed to develop a comprehensive continuum of supports and services as described above. A systemic approach ensures that the essential components of the service continuum are included in the development of the support network. Formal agreements among participants also help to ensure that network members have a vested interest in the success of the network, that they are clear on their roles and responsibilities, and that they are formally recognized as a "network partner" with access to the range of resources provided by the network's continuum of supports and services.

Described below is a range of strategies that can be used when beginning to identify and develop the necessary linkages between community partners that will contribute to the network, and to the development of an integrated continuum of supports and services.

Reframing the Issue: Creating Shared Solutions

Frequently, caregivers and service providers involved with individuals with a dual diagnosis experience a range of concerns and feelings in trying to respond to the complexity of needs such individuals present. At an individual, programme and/or system level, stakeholders often anticipate hearing a blaming message that they are part of the problem. To get beyond these feelings, an approach must be used that promotes the ongoing participation of all the stakeholders. The initial objective is to facilitate an alliance that promotes a non-pejorative, non-judgmental approach, so that a joint process of building solutions together can be developed. Rather than focusing on the stakeholders as contributing to the problems and barriers that exist in providing services, it is important to emphasize that all perspectives are important and unique, and that opportunities exist to use the knowledge, experience and creativity of all stakeholders. Such an approach empowers stakeholders in the decision-making process, and allows them to begin seeing themselves as assets and important participants in providing the various elements needed in the service continuum.

Pacing Change

It is important to recognize that, when working with individuals or families, one must be sensitive to the readiness to change at a programme and systems level, and pace challenges accordingly. Programmes and service sectors often have an investment in maintaining the *status quo* when exploring the possibilities about modifying their services to better accommodate the needs of individuals with a dual diagnosis. This should not necessarily be seen as overt ‘resistance’ to providing service, but may be more of a ‘reluctance’ arising out of ambiguity about how to provide service, and a fear that committing resources differently may result in being totally consumed by the demands of these individuals. One must recognize this reluctance, its reasons, and be sensitive to the need to address people's concerns by beginning where they are in the process and building on the strengths they bring to the table.

Adopting a non-confrontational approach allows stakeholders to feel less vulnerable, thereby reducing their apparent reluctance, and making them more amenable to hearing the possibility of their participation as 'one' component in the development of an integrated continuum of services and supports. An approach that avoids conflict and confrontation, and provides support through access to additional resources (e.g., access to education and training opportunities), encourages stakeholders, and more often leads to their agreement to provide service and to be a network participant.

Engagement Flexibility

The principle of 'engagement flexibility' is critical to engaging community partners in the development of an integrated continuum of support and services. Similar to the strategies often used in providing community outreach to individuals with a dual diagnosis and their families, service providers may need to be engaged in a manner that reaches out and demonstrates genuineness and sensitivity towards their apprehensions about working with these challenging client situations. Service providers are often more willing to commit resources, or to use them differently if their concerns have been openly addressed, and their perspectives have been validated as being important and unique. To encourage such discussions, stakeholders need to feel safe in being open about their issues, particularly if they are addressing areas which may reflect their lack of knowledge or skill level in working with the dual diagnosis population. There are two strategies that can be particularly effective in achieving engagement flexibility: they are forums and facilitation.

Forums

The use of forums can be helpful in engaging partners. Often the simple process of bringing together representatives of various programmes and systems becomes the first step toward the development of more formal linkages. Effective forums are ones that carefully consider their purpose, membership and process.

Forums can be used flexibly and include: individual/case level discussions (e.g., case conferencing); buddy systems — i.e., partnerships between mental health and developmental service providers across sectors (e.g., joint case management); task groups or service and support development committees (e.g., local cross-sector planning and service implementation groups); and formal inter-ministerial linkages at all levels (e.g., Ministries of Health and Community and Social Services as in the MATCH Project, 1996). This range of forums and the mix of participants provide a variety of information, perspectives, knowledge, and strategies, and often lead to creative opportunities to examine how existing resources might be delivered more effectively. Forums also provide an opportunity for stakeholders to work collaboratively to identify service gaps within the continuum, and to begin joint planning on the type of coordinated service system that they want to develop.

In order to promote the ongoing participation of all stakeholders in the development of a coordinated network of supports, the forums must also reflect the components of an integrated continuum of supports and services. That is, the membership in these forums may include a variety of stakeholders who represent a range of services and sectors (e.g., consumer, developmental services, mental health services, health care providers, and correctional services). Naturally, the stakeholders that might be more willing to attend forums are those with a mandate that includes serving individuals with a dual diagnosis. Although many organizations or services may not see the relevance of their involvement in terms of their primary mandates, once at the table, there is usually a recognition of the value of the forum, and an awareness of just how many of their clients do, in fact, have a dual diagnosis.

Again, one key element to success with such forums is a supportive and safe environment in which stakeholders can have an open and honest discussion. In this way, participants are often better able to identify the types of supports and services their organizations might require to be able to respond flexibly to the needs of individuals with dual diagnosis. Through this sharing of experiences, participants begin to recognize that rather than restricting the consumers' right to service, by working together, they will be better able to meet the needs of consumers and their families. Often, these early joint discussions plant the seed for identifying how existing resources might work better together as a network: this can become the basis for forming an integrated continuum of supports and services.

Facilitation

The role of facilitation is to provide leadership and support between and among cross-sector activities that occur at the individual, programme and system levels. The facilitator’s role is to ensure that the engagement of participants is carried out in an objective, flexible manner, and that all perspectives are heard. Also, the presence of a neutral third party can provide mediation and support to the various participants. Depending on the structure and resources of a community, the functions of a facilitator may be performed by one person/agency, or shared among a number of people/agencies. The facilitation role may include:

- **(at the individual level)** ensuring that services for a consumer are both coordinated and integrated between and among services and sectors to support the development of a comprehensive plan of care — including outreach to all relevant stakeholders in the service planning process and in the development of an individual support network;

- **(at the programme level)** seeking and developing formal, interagency, collaborative agreements with relevant stakeholders so that resources are adapted, accessible and coordinated between agencies that serve persons with a dual diagnosis (e.g., mental health programmes, developmental service agencies, probation and parole services); and

- **(at the system level)** identifying and formalizing contractual arrangements with other service delivery sectors that may support the development of an integrated continuum of supports and services (i.e., between children's and/or adult mental health and/or developmental and/or criminal justice and/or addiction sectors) as well as participating in municipal or regional cross-sector planning committees to ensure that the needs of individuals with a dual diagnosis, and service gaps and barriers, are addressed in service planning.

Outreach is also a very important function of the facilitation process. In the discussion above, regarding membership of forums, it was noted that some service providers (particularly those in the generic health and social services sectors) might not initially identify themselves as needing to be part of a process geared to serving individuals with dual diagnosis. Experience has shown that a valuable resource within the continuum may be overlooked or missed if additional outreach attempts are not made to include the more peripheral services or agencies.

It is important that the facilitation process, and/or the facilitator(s) involved in outreach and the development of a network or system design, fully utilize the strategies identified earlier with regard to 'reframing the issue', 'pacing change' and 'engagement flexibility' when building these partnerships. The premise of starting with an agency 'as it is', or being aware that one must be sensitive to pacing engagement efforts to an agency’s readiness to change, have been useful concepts when working with stakeholders who may be reluctant to become involved in the planning and service delivery to the dual diagnosis population. Often, a good starting point in these situations is for the agency to be given an opportunity to identify its experiences and challenges in meeting the needs of individuals with a dual diagnosis. This provides a point from which the facilitator and/or other network members can connect and provide support. The fact that the current network partners feel supported by this initiative, and in turn, extend that feeling to the new member, may result in an agency's willingness to participate. The new member is also allowed to first observe and learn what the potential benefits of membership might be.

Education and Training

A key aspect to the successful development and implementation of an integrated service continuum and support network is the existence of education and training opportunities for service providers at all levels. This is a common element within each of the components of the continuum of services and supports described earlier. It is also the most frequently identified need by family members, individual service providers, and planning groups, and the one programme activity that, if offered, often convinces stakeholders to commit to membership within a network of services.

Education regarding the nature and impact of dual diagnosis assists all stakeholders to identify strengths, recognize difficulties, and deter potential crisis situations. Training sessions must also develop and enhance direct practice skills and allow service providers to try out directly, (with supervision,) different intervention strategies that have been proven successful. In addition, access to ongoing expertise, consultation and support is necessary if stakeholders are to appreciate being part of the network, and to have the sense that they are part of a larger community working together to improve services for individuals with a dual diagnosis. The combination of education (focussed on the theoretical knowledge base) with training (focussed on the practical application of theory and development of skills) is frequently identified as one of the biggest benefits of being a member of a support network.

Frequently, service providers want one 'magical' agency to exist that can provide all of the education, training and consultation support that is required. In reality, in most geographic areas, this type of service does not exist. Most service organizations have their own limitations in what they can provide. What has been learned from various locales and dual diagnosis initiatives is that many of the providers involved in serving this population bring to the continuum of services and supports a piece of expertise that needs to be shared among the members of the network. (For example, a service that works more with the autistic population may have valuable insight into strategies that might work with an individual who has a dual diagnosis with features that reflect an attention deficit disorder.) The important role of specialized services in dual diagnosis education and training is clearly recognized, but our discussion in this section is intended to emphasize the point that stakeholders must be supported and validated for the expertise they may already possess in working with individuals who have a dual diagnosis.

At a staff level, caregivers may not be aware of, or may have minimized, the strengths they actually possess in working with individuals with a dual diagnosis. Within the context of a network of supports, these strengths can be identified and built upon. For example, members of the Griffin Community Support Network have begun to express greater confidence in their ability to work with individuals with a dual diagnosis. They realize that in most situations there are no magical solutions, but that perseverance and patience are often key to success. They also feel supported and encouraged, since they recognize that they are no longer alone in their attempt to serve this population, and are part of a larger continuum which promotes the concept of mutual aid.

To compliment the informal and community based educational initiatives, formal ongoing education and training activities are an equally important strategy for building community capacity. Examples of this have been discussed earlier in terms of university and college-level training**.** The results of such system-level commitments can include established standards of care within professional groups, and the development of advanced practice professionals (MATCH Project, 1996). Furthermore, research activity to identify best practices and outcomes is often a natural outcome of formal educational initiatives.

Future Challenges

In summary, this chapter has discussed the evolution to a system focus in service development for individuals with a dual diagnosis. It also presents the current thinking regarding how responsive systems of care for individuals with a dual diagnosis are built. Clearly, the last ten years in Ontario have been particularly productive in relation to service system development. This is so because of the collaboration that has occurred at the individual, programme and system levels. However, as noted earlier, progress in addressing the gaps and barriers has been, and will continue to be, dependent on how the tensions between values and funding are mediated, on political will, and on the capacity for cross-sector integration and flexibility at an individual, programme and system level. The dynamic nature of these issues means that the more we learn and do, the more we learn that there is more to do. Therefore, what follows is a brief overview of new and continuing challenges that face us in achieving a responsive service system for individuals with a dual diagnosis and their caregivers.

An ideal model of a continuum of supports and services for persons with a dual diagnosis is one that does not create artificial barriers and gaps based upon the age of the individual needing support. Typically, in many countries, the service system is strictly divided between services for children and services for adults, with the result that the knowledge and expertise is clearly split. Consequently, significant service gaps are created between the two service systems as the youth reaches transitional age when children's services end and adult services commence. Proposed solutions include:

- creating a seamless system that has no barriers, wherein specialized services for individuals with a dual diagnosis span the entire age range,

or alternatively,

- developing meaningful linkage and coordination mechanisms across the age jurisdictions that facilitate successful transition from one to the other.

In Ontario, this is a particular concern, since services for children are primarily the responsibility of the Ministry of Community and Social Services, or the Ministry of Education and Training, while the Ministry of Health funds mental health services for adults. Coordination and linkages, therefore, are a particular challenge. Where organizations with specialized service responsibility for individuals with a dual diagnosis exist, it may, therefore, be important for their responsibility to span the age groups, and to be expected to support successful transitions and effective inter-organizational linkages.

It is important that sound service evaluation practices be put in place to inform funders, consumers and service providers of what is working. In this way, learning will guide system and programme design. Development of validated outcome measures related to intervention strategies, along with meaningful consumer feedback data, will further enhance the likelihood that future developments are responsive and effective. Also, it is important to ensure that service providers have ongoing access to learning occurring in other jurisdictions and to information about services for other populations that also require integrated approaches and programme adaptation (e.g., psychogeriatric services). This is another means of ensuring that what we do today doesn't become what we need to undo tomorrow.

Recruitment of professionals, both specialists and advanced specialists, will continue to be a tremendous challenge for at least another decade if action is not taken. In order to address this situation, government leadership and initiatives are required immediately to support the development of formal education and training opportunities. Resource gaps in such fields as psychiatry, family practice, psychology, nursing, social work and generic front-line workers need to be addressed. Salary differentials across the sectors also have significant impact. Without committed resources to funding and human resource development, the capacity, expertise and support needed will continue to be inadequate.

The creation of inter-governmental infrastructures provide opportunities and expectations to plan and organize best practice-policy and service delivery models. For instance, the Ontario Ministry of Health reorganized from a centralized to a regional model, which is consistent with the longstanding regionalization of the Ministry of Community and Social Services. Co-location of regional staff of each Ministry is occurring in some regions which over time, should enhance local planning, service development and cross sector integration.

Furthermore, cross-sector and inter-governmental planning groups at the local and provincial levels must have a mandate that includes reviewing and revising implementation strategies based upon new and emerging community needs and priorities. The Ministry of Community and Social Services is at a key point in the process of implementing its *Making Services Work for People* policy. However, almost consistently across the province, the local discussions have not successfully integrated issues related to serving the dual diagnosis population. At the same time, the Ministry of Health has initiated Mental Health Implementation Task Forces across the province with the mandate of moving forward on the *Making It Happen* policy. Both ministries identify 'coordinated access' in their policies, and the need for cross-sector linkages. This presents an opportunity for dual diagnosis to be placed on the agenda within these separate processes. Additionally, there are natural juncture points for these discussions to “cross the sectors” in relation to mental health mobile crisis services, developmental service case resolution mechanisms, and central information and coordinated access points.

Finally, inter-ministerial provincial commitment is required to ensure development of local continua of service and support with equitable access to specialized services across the province.

Do You Know?

1. The 3 factors that influence dual diagnosis service development
2. The difference between a system and a sector
3. In Ontario, what sectors serve individuals with a dual diagnosis
4. The network of supports and services that can assist an individual with a dual diagnosis
5. Examples within your local community of Prevention and Early Intervention services and supports
6. Two strategies that can be used at the individual level between different community partners that will provide a network of support for an individual who has a dual diagnosis and is on probation for assault

Resources

Creating A Continuum of Supports and Services — A Resource Document, March, 1996: Metro Agencies Treatment Continuum for Mental Health (MATCH) Project

This document provides an overview of the ideal continuum of supports and services for individuals with a dual diagnosis, their families and caregivers. It includes useful tools and additional papers such as a supports and services implementation guide with six stages in the assessment, intervention and treatment planning process, a review of the cross-sector process that provides structure for a shared community change process, a position paper on education highlighting the required attitudes, knowledge and skills, and a framework for an educational continuum.

Available for a small fee from Griffin Centre:
Telephone (416) 222-1153

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