

Program Policy Framework for Early Intervention in Psychosis

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Introduction

There has been growing world-wide interest in the area of early intervention in psychosis in recent years, and that interest has extended to Ontario as evidenced by the establishment of early intervention programs in the province. These programs reflect an optimism about the outcomes that are possible for people who experience psychosis if appropriate and timely treatment and supports are provided. This program policy framework is intended to provide a guide for new as well as existing programs in Ontario.

The Importance of Comprehensive and Early Intervention

The experience of psychosis¹ has very profound impacts on the individual and their family members and friends. A first episode of psychosis most often occurs in adolescence or early adult life. An experience of psychosis at this stage has great potential to derail educational, work and social goals. A response that specifically considers the key developmental stage of those experiencing an initial episode of psychosis is critical.

Symptoms of psychosis include delusions, hallucinations, disorganized thinking and disorganized or bizarre behaviour. Figure 1 describes the early signs and symptoms of psychosis as well as the phases of first episode psychosis. About 3% of people worldwide will experience at least one episode of psychosis in their lifetime and approximately one in 100 will receive a diagnosis of schizophrenia.² The incidence of first episode psychosis is estimated to be 15-20 cases per 100,000.³ The overwhelming majority of first episodes of psychosis will occur among young people between the ages of 15 and 34.⁴

Intervening in a comprehensive way as quickly as possible following the onset of psychosis is of significant importance. A recent Canadian study found that individuals experiencing psychosis for the first time tried an average of 2.3 times to obtain help and the average length of time that psychosis was untreated was almost two years.⁵ There is evidence that the time period between the onset of psychosis and response with appropriate treatment is important because the longer this delay, known as the “duration of untreated psychosis” (DUP), the poorer the clinical outcomes. Other consequences of delayed treatment that have been identified include: interference with psychological and social development, strain on relationships, loss of family and social supports, distress and increased psychological problems among family members, disruption of study and employment, substance misuse, and increased costs of management.⁶ The economic and societal impact of untreated psychosis should also be considered since potential consequences include homelessness, incarceration and reduced prospects for long-term recovery.

¹ Psychosis is a disorder which affects the brain causing a distortion of, or a loss of contact with, reality. Psychosis is known to accompany several psychiatric diagnoses including schizophrenia, bipolar affective disorder, depression, schizophreniform disorder, delusional disorder and schizo-affective disorder as well as some medical or neurological illnesses. Edwards, G. & McGorry, P.D. (2002). *Implementing Early Intervention in Psychosis: A guide to establishing early psychosis services*. London: Martin Dunitz.

² Milliken, H. (2003). First episode psychosis: What are the signs? *The Canadian Journal of CME*, November, p. 131-136.

³ Lines, E. *An Introduction to Early Psychosis Intervention: Some relevant findings and emerging practices*, retrieved from the world wide web at www.cmha.ca/english/intraevent/about.htm

⁴ It is estimated that there will be 3,430,500 people in Ontario in this age range by 2006. Ontario Ministry of Finance (2002). *Update to Ontario Population Projections 2001-2028*.

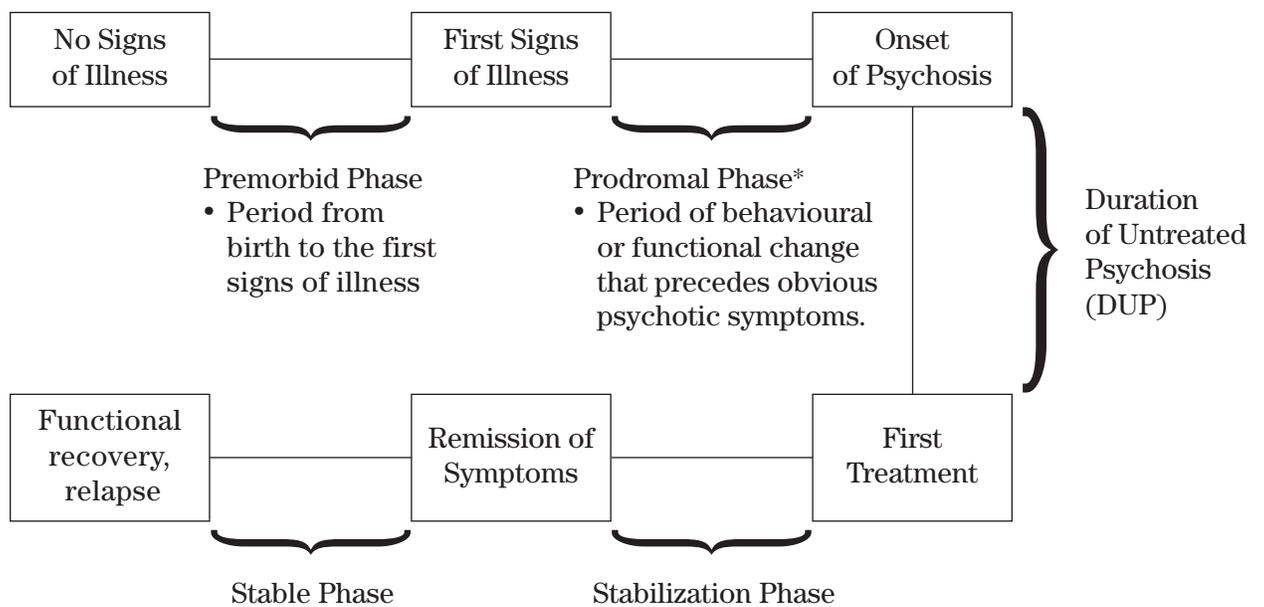
⁵ Addington, J., van Mastrigt, S., Jutchinson, J. and Addington, D. (2002). Pathways to care: help seeking behaviour in first episode psychosis. *Acta Psychiatrica Scandinavica*, 106, 358-364.

⁶ Edwards, J. and McGorry, P.D. (2002). *Implementing Early Intervention in Psychosis: A guide to establishing early psychosis services*. London: Martin Dunitz.

It is also well known that suicide is a major cause of death among young people in general accounting for 24% of all deaths among 15-24 year olds.⁷ Suicide is the leading cause of premature death among people with schizophrenia with between four and 13% committing suicide.⁸ Between 10 and 15% of people with psychosis commit suicide with two thirds of these suicides occurring within the first five years of the illness.⁹ Intervening early and appropriately in psychosis may reduce the risk of suicide since increased risk has been associated with factors such as adolescent onset, co-morbid conditions including substance abuse, fewer treatment opportunities and social supports, feelings of hopelessness, greater deterioration, loss and stigma.¹⁰

While there are many good reasons to ensure a comprehensive and swift response to psychosis, the most compelling is simply to ensure that individuals do not suffer unnecessarily.

Figure 1: Phases of First Episode Psychosis¹¹



* This “prodrome” is usually only identified after psychosis has been diagnosed (McGorry & Edwards (2000), p. 25).

⁷ Health Canada (2002). *A Report on Mental Illnesses in Canada*.

⁸ Sandor, A. (2001). Suicidal ideation and substance misuse in first episode psychosis. *British Journal of Psychiatry*, Rapid response, December.

⁹ Brennan, M. (2002). *Early Intervention in Psychosis: Fellowship Report*. Wakefield and District Health Action Zone.

¹⁰ Beautrais, A.L. (2000). Risk factors for suicide and attempted suicide among young people. *Australian and New Zealand Journal of Psychiatry*, 34, 420-436.

¹¹ Adapted from Milliken, H. (2003). First episode psychosis: What are the signs? *The Canadian Journal of CME*, p. 132.

Context for the Program Policy Framework

Broader Healthcare Directions

This program policy framework for early intervention in psychosis is positioned within the broader health policy context and government directions for healthcare. Ensuring early intervention is available to young people experiencing psychosis is consistent with current emphasis on improved access and wait times, improved health outcomes and planned, enabled and evidence-based care. Enhanced funding for early intervention in psychosis services in Ontario has the potential to provide alternatives to costly and inappropriate inpatient hospital services and to reduce pressure on existing mental health services.

There are also identified opportunities for integration of early intervention activities with broader healthcare initiatives such as primary care.

The goals of primary care reform are:

- 24/7 access in an integrated continuum;
- continuity of care;
- early detection and action;
- better information on needs and outcomes; and
- newer and stronger incentives for providers to participate in primary care approaches.

An environment of reform within both primary care and mental health presents opportunities to consider how the needs of young people who experience psychosis can be addressed in a way that is consistent with priorities and combines the strengths in these two areas.

There is the potential for primary care practitioners in Ontario to play a key role in identifying and engaging young people experiencing psychosis. It is known that most people experiencing mental health problems do not seek professional help and adolescents and young adults are the least likely to use mental health resources.¹² An Ontario study¹³ found that while many people with mental health concerns do not seek help, they do utilize family physicians when dealing with general health concerns. As well, a considerable percentage of those seeking help for mental health issues contact their family physician alone, or in addition to speciality mental health service providers. The primary care practitioner is well positioned to play an important role in the detection of psychosis at an early stage. Of critical importance will be ensuring that they are supported in this role through linkages with the mental health system, or through their involvement in Family Health Teams that may include staff with mental health expertise.

Current mental health policy acknowledges the need for primary / speciality care partnerships linking primary care practitioners with mental health specialists. In Ontario there are currently many shared care arrangements in place whereby psychiatrists support and provide consultation to primary care practitioners serving individuals with mental illness. Existing arrangements of this kind can be utilized effectively in the early detection and referral of individuals experiencing psychosis.

¹² Statistics Canada (2002), Canadian Community Health Survey, Mental Health and Well-being.

¹³ Parikh, S.V., Lin, E. and Lesage, A.D. (1997). Mental health treatment in Ontario: Selected comparisons between primary care and specialty sectors. *Canadian Journal of Psychiatry*, 42, 929-934.

Mental Health Reform

Making it Happen: Implementation Plan for Mental Health Reform, the current policy framework guiding mental health reform in Ontario, provides the overarching framework for the development of a program policy framework for early intervention in psychosis. *Making it Happen* adopts a “levels of need” approach to identifying the range of client needs and the types of services required. First episode in psychosis is identified within the “intensive” level, which includes mental health assessment, treatment and support services which are focused on people with serious mental illness. With a broadened focus that emphasizes early identification, the “first-line” level of need is also applicable. This level includes assessment and treatment provided by frontline healthcare providers who often encounter those experiencing a first episode of psychosis and have a role to play in ensuring appropriate support and referral (See Appendix 1 for more explanation of “levels of need” within *Making it Happen*).

In 1999, nine Mental Health Implementation Task Forces were created in Ontario to develop regional implementation plans for mental health reform consistent with *Making it Happen*. Most Task Forces included the need for early intervention programs within their recommendations. In their final report, the Provincial Forum of Task Force Chairs also identified treatment, education and support for individuals experiencing psychosis and their family members as essential elements of an integrated system of mental health services and recommended the development of a policy framework for first episode psychosis.¹⁴

Need for Policy Direction Specific to Early Intervention in Psychosis

In Ontario, five early intervention in psychosis programs have been established by hospitals located in Toronto, London, Hamilton, Ottawa and Kingston (see Appendix 2 for a description of these programs). Funding announced in 2004 will permit enhanced capacity in the province in the area of early intervention in psychosis services.

Existing programs have developed without the benefit of specific program policy direction. In order to ensure that early intervention programs reflect existing policy direction and are guided by a consistent framework, the ministry undertook a program policy development process. Experience from existing programs and ongoing research evidence provided the basis for the development of the program policy framework for early intervention in psychosis. A literature review and an analysis of early intervention initiatives in other jurisdictions were undertaken to inform the development of the framework (See Appendix 3 for a sampling of key findings from the review).

An external advisory group, the Policy Work Group on Early Intervention in Psychosis, was established to provide advice to the Ministry of Health and Long-Term Care (MOHLTC) on what should be included in the program policy framework for early intervention in psychosis (see Appendices 4a and 4b for Terms of Reference and Membership). This ministry Policy Work Group included representatives from the Ontario Working Group on Early Intervention in Psychosis (OWG) which was formed in 1999 with the goal of partnering with government to improve the early detection and treatment of psychotic illness in the province. The OWG includes representation from the five early intervention programs in operation, organizations involved in developing early intervention programs and others that focus on family supports and public education related to early intervention in psychosis.

¹⁴ *The Time is Now: Themes and Recommendations for Mental Health Reform in Ontario* (2002). Final Report of the Provincial Forum of Mental Health Implementation Task Force Chairs.

Priority Population for the Program Policy Framework

There is considerable variation in who is identified as the priority population for early intervention services both within Canada and in other countries. Three factors account for these differences. Priority populations differ depending on how criteria relating to age, diagnosis and previous treatment are applied.

The priority population for this program policy framework was established based on the experiences of established programs including those in other jurisdictions, recommendations of the Policy Work Group, and on information about who experiences first episode psychosis. The priority population is comprised of individuals between the age of 14 and 35 years old¹⁵ who are experiencing a first episode of psychosis, or who have not received previous treatment for psychosis. This age range for the program policy framework will capture the vast majority of individuals experiencing a first episode of psychosis. While a first episode of psychosis occurs most typically between the ages of 16 and 25, the lower age limit will ensure that those under the age of 16 experiencing psychosis can benefit from services designed specifically to address first episode psychosis. Extension of the upper age limit acknowledges that there may be gender differences in the age of onset of psychosis. For schizophrenia, one of the most common diagnoses associated with psychosis, the age of onset for women is about 4-6 years later than for men.¹⁶ An upper age limit of 35 will ensure that women are not disproportionately excluded from early intervention programs.

Within this framework, it is the experience of psychosis that determines an individual's appropriateness for an early intervention in psychosis program, not any particular diagnosis. This is important since establishing a diagnosis to explain the underlying cause for psychosis may take a considerable length of time.

Those experiencing prodromal symptoms only, without clear symptoms of psychosis are not included within the priority population for the framework because there is currently no adequate evidence for doing so. The point at which intervention is recommended may change as knowledge in this area develops.

Principles

Many of the principles that underlie the program policy framework for early intervention are those that have been identified in *Making it Happen*. Appendix 5 highlights *Making it Happen* principles that also apply to this program policy framework. Additional principles described below have been identified as having a particular relevance to early intervention in psychosis. Taken together, these principles will provide guidance in the planning and development of early intervention programs and should be reflected in all aspects of the delivery of these programs.

¹⁵ There may be a need for some flexibility at the upper and lower ends of the age range depending on differences in available services within local areas for those who do not fall within the priority population definition. As well, it is expected that early intervention programs will provide consultation to those programs serving individuals outside the priority age range.

¹⁶ Seeman, M. V. (2000). Women and Schizophrenia, *Medscape Women's Health* 5(2).

Recovery Focused (See Appendix 6 for additional information on recovery).

A recovery-oriented approach underlies the delivery of treatment and support services.

A recovery-oriented approach emphasizes consumer choice, flexibility in services, individualized supports, and the importance of families, significant others and communities in supporting individuals with mental illness. Such an approach also considers the impact of factors such as poverty, poor housing, unemployment and stigma on people with mental illness. Consistent with a recovery philosophy, early intervention in psychosis programs have a culture of hope and excitement about the possibilities for the future. Such an environment is critical in facilitating individuals' recovery.

Innovative and Appropriate Engagement

Early intervention programs employ innovative and youth-oriented approaches to engaging young people and their families and are willing to try new strategies that may facilitate engagement.

Non-stigmatizing

Services are provided in an environment considered by the individual to be least restrictive, intrusive and stigmatizing. Program staff engage in community activities that are aimed at dispelling myths of mental illness and psychosis.

Collaborative

Consumers, families, family organizations, service providers, government and the community collaborate in creating, delivering, and developing awareness about early intervention in psychosis services.

Empowering

Consumers have the right and responsibility to be involved in decision-making related to treatment and service provision and have access to information and support needed to make informed choices and become active members of the treatment and support team. Family members have the same rights and responsibilities for services provided to them. With consumer consent, family members are also expected to become active participants in the consumer's treatment team.

Education and Support for Families

Education is available in a timely way to support all families of individuals experiencing their first episode of psychosis. Support to families is tailored to meet their changing needs and can be provided independently from the services and supports offered to individuals experiencing psychosis.

Key Objectives

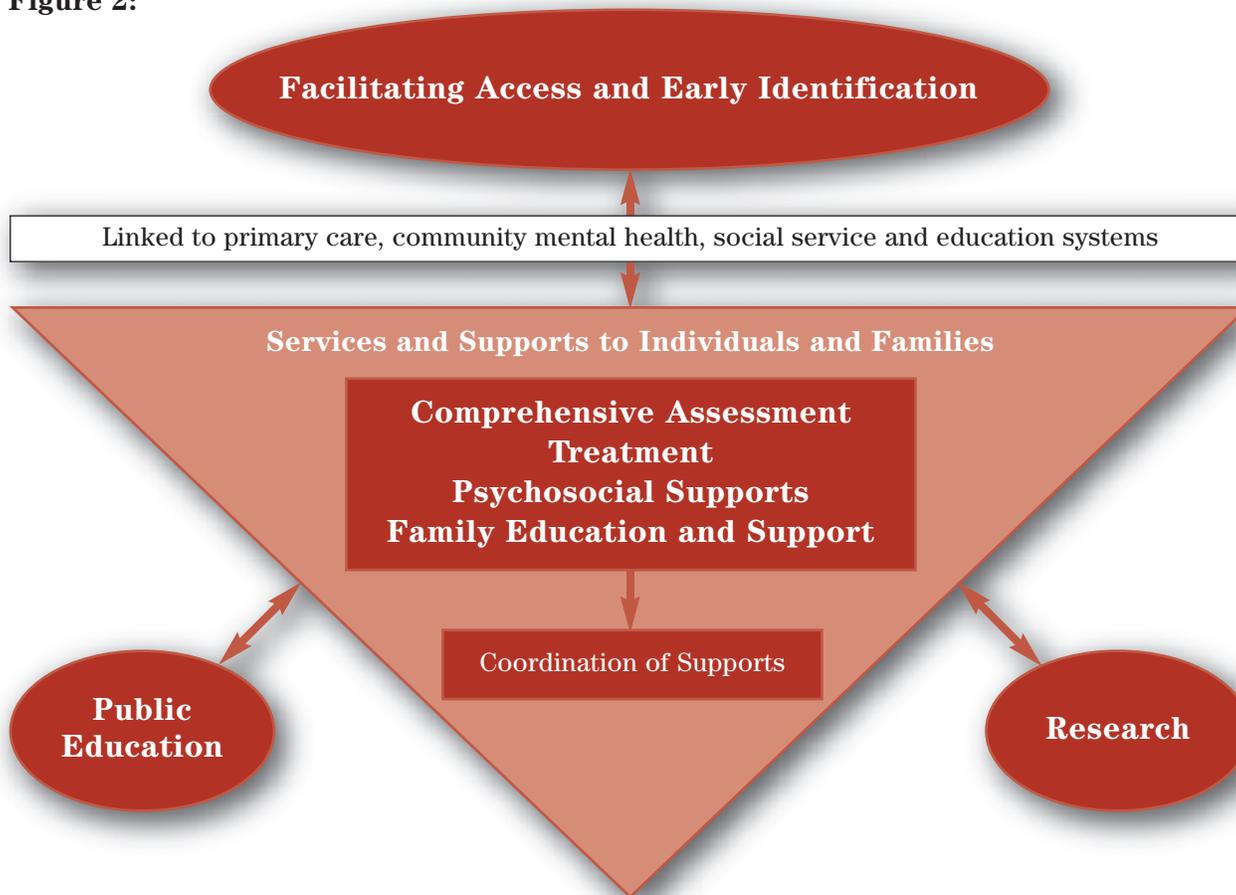
A comprehensive early intervention in psychosis program is focused on achieving the following objectives:

- Reducing the duration of untreated psychosis through early and appropriate detection and response, thereby potentially reducing the severity of the illness.
- Minimizing the disruption in the lives of young people who experience psychosis such that educational, vocational, social and other roles can be maintained.
- Minimizing the societal impact of psychosis including reducing demand in other areas of the mental health, health and social service systems and reducing disruption in the lives of families.

Key Components

Key Components: Program Policy Framework for Early Intervention in Psychosis

Figure 2:



Seven key components of a comprehensive program policy for early intervention:

- Comprehensive Assessment
 - Treatment
 - Psychosocial Supports
 - Family Education and Support
 - Facilitating Access and Early Identification
 - Public Education
 - Research
- Within the triangle are four program components representing the specific services and supports that early intervention in psychosis programs provide to individuals and their families.
 - Outside the triangle are three components representing broader activities that need to be undertaken to help create awareness of early intervention in psychosis programs, facilitate referrals to programs and to ensure that programs are evidence-based.
 - Program components are linked within the framework, ensuring that consumers and family members experience coordinated service.
 - There are also links between program components and the broader system components as each influences and is influenced by, the activities of the other (e.g., early intervention programs inform research and are informed by research findings).

Key Components

The key components describe the services and supports that are needed to establish a comprehensive early intervention in psychosis approach for the province. Achieving the identified objectives requires that individuals and their families have access to these components and that they are delivered in a coordinated way. It also requires that other components are in place that ensure: easy access to needed services, an awareness about psychosis in the community, and a commitment to research that leads to evidence-based practices that can be applied in the field.

The following key components of the program policy framework were developed based on discussions of the Policy Work Group, a review of the early intervention literature and on the experiences of early intervention programs both within and outside Canada.

1. Facilitating Access and Early Identification

The goal of this component is to identify those experiencing psychosis at an early stage and provide help as quickly as possible. A longer-term goal is to increase self and family referrals to early intervention in psychosis programs.

The focus is on educating those individuals who are in positions to identify individuals in need of help and / or in a position to recognize changes in a young person's behaviour. Education regarding early intervention in psychosis may involve formal professional training or may be delivered through workshops and presentations targeted to those working with young people. General information incorporated into the school curriculum or delivered in special workshops and presentations to students is also included.

Education about psychosis and related resources should be available in the wide variety of settings where young people are found, as well as settings where young people experiencing mental health problems or their family members are likely to turn for help. Examples include:

- Primary care practitioners such as family physicians, nurse practitioners, nurses and emergency room staff, who are often the first point of contact especially in rural areas;
- Spiritual / religious leaders, teachers, and guidance counsellors;
- Social service workers and agencies that provide services to youth such as shelters, corrections services, child protection, youth employment and education workers;
- Existing community mental health services in order to assess, identify and appropriately refer individuals; and,
- Workplace-based Employee Assistance Programs (EAPs), managers and human resources personnel.

Of course, parents and other family members are often the first to notice behaviour changes and the symptoms of psychosis and they require information and support to be able to help people to access the treatment they need.

Providing education to those who can act as champions for early intervention in psychosis in local communities is also important. For example, community mental health agencies can play a leadership role by undertaking activities such as community awareness in schools, with youth groups, and with primary care practitioners.

2. Comprehensive Assessment

The goal of the comprehensive assessment is to obtain all the information that is required to develop an appropriate, individualized treatment plan. A comprehensive assessment is undertaken if initial screening indicates that additional assessment is required. An assessment involves:

- a thorough medical / neurological examination;
- a psychiatric assessment including identification of co-morbid disorders (e.g., substance abuse);
- assessment of dimensions of personality as well as functioning in social, family and vocational / educational and other contexts.

The assessment takes into consideration:

- developmental history;
- level of pre-morbid functioning; and,
- input provided by caregivers, family members and others who are in a position to recognize changes in the behaviour of the individual.

During assessment, a therapeutic alliance with the individual and their family is initiated and the individual's and family's goals are identified.

3. Treatment

With treatment, the aim is to effect remission of the psychotic episode thereby improving functioning and quality of life.

Treatment approaches utilized in early intervention programs include some or all of the following:

- medication;
- psychoeducation provided to consumers and the family;
- counselling;
- case management / care coordination;
- cognitive behavioural therapy (CBT);
- substance abuse / use treatment and supports; and,
- crisis intervention.

Physical and psychiatric re-assessment will be undertaken periodically as individuals' needs and / or goals change.

The focus is on providing optimal, comprehensive intervention to individuals experiencing psychosis in an environment that supports their recovery. Specific attention is given to identifying co-morbid disorders (e.g., substance abuse) thereby increasing the effectiveness of treatment. Individuals are supported to learn as much as possible about managing their own illness and symptoms of the illness.

4. Psychosocial Supports

Psychosocial supports are designed to help individuals pursue their life goals. Included are the following types of supports:

- educational / academic;
- vocational / employment;
- housing;
- recreational; and,
- social (e.g., activities focused on spirituality or those centred on the development of skills needed to establish social / intimate relationships); and,
- peer or mentor support / self-help supports.

These supports help individuals achieve self-defined cognitive, vocational, social, educational, emotional and other goals. This may mean re-discovery of goals held prior to the illness or the discovery of new goals.

5. Family Education and Support

Family education and support is intended to assist families understand and cope with their relative's illness, minimize disruption in their lives, and promote families' empowerment, health and recovery. Professionals may provide services and supports to families and / or families may receive support from other families who have experienced similar challenges.

The following services and supports are included within family education and support:

- family education / psychoeducation;
- crisis support and intervention;
- individual counselling;
- family therapy;
- family support groups;
- family "networking" opportunities during social activities;
- consideration of family's physical health;
- multi-family education groups;
- training families to be peer facilitators; and,
- in-home support.

6. Research

The goal of this key component is to develop a capacity to undertake research that furthers our understanding of psychosis and contributes to the development of an evolving set of evidence-based practices. Examples of possible areas of investigation include:

- causes of psychosis;
- treatment approaches associated with better outcomes;
- identification of specific interventions that are more effective under certain circumstances;
- improved understanding of why people drop out of programs;
- the most effective ways of facilitating early detection and intervention; and,
- improved understanding of the value of treatment and supports for consumers and family members.

7. Public Education

The goal of public education is to de-stigmatize the experience of psychosis and mental illness and improve public understanding and perception of psychosis and mental illness (e.g., mental illness as a manageable illness). As well, education initiatives should raise awareness of the importance of intervening early in psychosis resulting in more family, peer and self-referrals to early intervention in psychosis services.

This component involves:

- providing information to the public about psychosis and mental illness by using various forms of media;
- developing and promoting consumer champions and educators; and,
- encouraging the participation of families and their organizations.

Public education initiatives should encourage and foster the idea that individuals with a mental illness are valuable members of all communities who want to feel a sense of belonging to those communities as we all do.

Program Characteristics

While specific programs and services may look different because local needs and existing system configurations vary, there are some key features of services that need to be highlighted given their importance in meeting the needs of people experiencing psychosis.

- First, early intervention services and supports provided to individuals and their families should be consistently available for a period of three years, after which time it is expected that programs will assist individuals to transition to other appropriate services and supports.

It is known that individuals experience the most disability due to the illness within the initial few years after a first episode of psychosis.¹⁷ It is during this time period that interventions are most important because the personal, social and biological factors that influence the course of illness develop in this time period.

Transitioning to other community mental health services, primary care practitioners, community psychiatrists or other supports following participation in the early intervention service should involve appropriate consultation and communication on the part of the early intervention service. As well, there is a need to ensure adequate education of individuals and agencies that will provide follow-up support to those leaving the early intervention service.

- Secondly, home-based treatment may be a very appropriate approach to serving young people experiencing first episode psychosis and may be beneficial because of the potential to provide a less stigmatizing environment.

While access to inpatient beds is sometimes needed in order to meet the needs of individuals experiencing psychosis, most services can be provided in community-based settings.

Decisions to provide home treatment need to be made based on the particular circumstances and include assessment of family, individual and treatment team factors.¹⁸

Where appropriate, outreach to individuals' homes to provide assessment, treatment and supports should be an available option.

¹⁷ Edwards, J. and McGorry, P. D. (2002). *Implementing Early Intervention in Psychosis: A guide to establishing early psychosis services*. London: Martin Dunitz.

¹⁸ Ibid.

System Characteristics

In Ontario, it is unlikely that all early intervention programs will develop in the same way, or be delivered in the same way. While this policy framework describes the key components that should be available to individuals experiencing psychosis and their families across the province, it is acknowledged that the way in which these components are designed and delivered may vary in different communities. Programs suitable in one area may not be practical in another because of demographic and existing service system characteristics.

While services may evolve differently, there is a need work collaboratively with service providers, consumers and families to establish consistency in terms of the services and supports that are available. The Ministry of Health and Long-Term Care (MOHLTC) will be responsible for examining current capacity and determining how best to provide the key components of comprehensive assessment, treatment, psychosocial supports and family education and support to the priority population. Creative approaches that utilize existing early intervention in psychosis programs, community mental health services, primary care resources, educational institutions and health and social services will need to be considered.

Local areas will also develop the capacity to coordinate and share information on local initiatives, identify effective strategies to facilitate access and early identification, co-ordinate training / education, and provide consultation to emerging programs. This may be achieved in different ways depending on how early intervention services evolve in different areas as well as existing service and community characteristics. There will also be programs in some local areas that are appropriately positioned to undertake major research and / or public education initiatives, two other necessary components of a comprehensive approach to early intervention.

Existing early intervention in psychosis programs in Ontario are located in large urban centres and all are affiliated with hospitals. The challenge is to develop programs that will be accessible to all communities in every area of the province and that will provide appropriate direct services and supports as quickly as possible to those who need them. Components of the framework such as public education and research initiatives may be undertaken at the individual early intervention program level where appropriate or at a provincial level and still benefit all local areas.

Experience from other jurisdictions may be useful in determining how early intervention services and supports will be made available in rural settings in Ontario. One such initiative, the Southern Area First Episode (SAFE) Project, has been undertaken in New South Wales, Australia. The approach involves developing specialty capacity within mainstream mental health services. Individuals working within local child / adolescent and adult mental health teams are trained and supervised by established programs to become experts in the identification, assessment and treatment of first episode psychosis.

The use of technology such as video teleconferencing may be particularly useful in ensuring that specialist expertise is available in rural and northern communities, areas that may not otherwise have access to psychiatrists or other early intervention in psychosis expertise available in larger centres.

Interministerial Responsibility

The age range for this policy framework has been determined based on the incidence of first episode psychosis. The framework applies to both adolescents 14-18 years of age as well as adults 19-35 who experience psychosis. Since adolescents and young adults are included in the priority population for the framework, there are implications for the mandates of other ministries. Mechanisms need to be put in place to make early intervention services as seamless as possible for individuals and their families.

Ministry of Children and Youth Services (MCYS)

The MOHLTC and the MCYS will need to determine jointly how best to implement this policy framework given the cross-ministerial implications. Of key importance is how the two ministries will pool their respective expertise so that adolescents who experience psychosis receive the best possible care in the most appropriate setting with the least possible disruption. Those between the ages of 14 and 18 are typically most at risk of not being adequately served by either the children's or adult mental health systems and this segment of the priority population deserves particular attention. Service agreements between MOHLTC and MCYS funded agencies will be required if the youngest segment of the priority population addressed in the framework is to receive the best possible care.

Ministry of Education

Critical to this framework is the need to train teachers, guidance counsellors and other school personnel about psychosis and available local resources that can assist individuals. As well, opportunities to include information about psychosis within school curricula and other forums for educating students should be explored. The MOHLTC and the Ministry of Education should discuss how best to achieve these goals. Community mental health agencies and early intervention programs must work cooperatively with local school boards to provide resources and expertise aimed at enhancing capacity to identify and assist those experiencing an episode of psychosis, and to deliver information on psychosis directly to students.

Ministry of Training, Colleges and Universities (MTCU)

Those who work within post-secondary institutions are identified in this framework as important to the identification of students experiencing psychosis. In order to facilitate early intervention efforts, training and education of these individuals to increase awareness of psychosis is needed. As well, community mental health agencies and early intervention programs should work closely with the college and university systems to incorporate information on the importance of intervening early in psychosis for those in health fields e.g., primary care practitioners and community mental health workers.

Next Steps

Comprehensive early intervention in psychosis programs that are specifically developed to meet the needs of individuals experiencing psychosis and their family members inspire hope in improved outcomes and a better quality of life for those who use them.

Although more research is needed to fully understand all the factors that determine the best possible interventions and the complete impact of intervening early, it is clear that the key components of the approach identified in this policy framework are important in helping individuals gain remission from the symptoms of psychosis and at the same time maintain roles central to their quality of life.

Informed by the work of early intervention programs and with this program policy framework and the *Mental Health Accountability Framework* providing guidance, important next steps include the development of standards for programs, outcome measurement, clinical guidelines and a data collection and evaluation system.

Ensuring that all people who experience psychosis and their family members have access to appropriate early intervention in psychosis services will require collaboration amongst government, service providers, consumers, family members and their organizations and the community. Since the priority population includes adolescents, a cooperative effort is required between the Ministry of Children and Youth Services and the Ministry of Health and Long-Term Care. The initiative also suggests opportunities for collaboration with the ministries of Education and Training, Colleges and Universities. Implementing the key components of the program policy framework will also require strong co-operation both within the mental health sector and between the mental health and general health sectors. Resources exist within many sectors to appropriately address the needs of individuals who experience psychosis and their families. Innovative ways of working together to co-ordinate the most appropriate response in any given community will be required if these needs are to be met.

Appendix 1: Levels of Need¹⁹

These levels focus on the range of clients' needs, which then determine the types of services required. The levels First Line, Intensive and Specialized emphasize a multi-disciplinary, client-centred approach to the delivery of mental health services.

- **First Line:** Refers to prevention, assessment and treatment providers including general practitioners, mental health services, social services, hospital emergency services and hospital primary care clinics;
- **Intensive:** Refers to mental health assessment, treatment and support services which are provided in community or hospital settings and are focused on people with serious mental illness; and
- **Specialized:** Refers to highly specialized mental health programs provided in the community or hospital settings and which focus on serving people with serious mental illness who have complex, rare, and unstable mental disorders. Long-term care is not synonymous with specialized care. Treatment, rehabilitation, and support services are integrated within each program / service type and provided through a multidisciplinary team approach.

¹⁹ *Making it Happen: Operational Framework for the Delivery of Mental Health Services and Supports* (1999) p. 63.

Appendix 2: Ontario Early Intervention in Psychosis Programs

First Episode Psychosis Program (FEPP), Centre for Addiction and Mental Health, Toronto (CAMH)

- CAMH's current early intervention program consists of an 18 bed inpatient unit, an outpatient clinic, the Home Intervention for Psychosis (H.I.P.) team which provides early intervention treatment and support to individuals and their families in their own homes, as well as a satellite clinic located in Mississauga. In September of 2002 the Learning Employment Advocacy Recreation Network (LEARN) was started as a small-scale three-year pilot to provide community-based recovery interventions including social, educational and vocational services.
- The First Episode Family Support and Education Program provides support and education to families of those involved in FEPP.
- FEPP conducts research in the area of first episode in psychosis examining neurological, pharmacological and cognitive aspects as well as the outcomes associated with different treatment approaches.

Prevention and Early Intervention Psychosis Program (PEPP), London Health Sciences Centre, London

- PEPP's early intervention program provides prompt assessment, medical and psychosocial treatment for first episode psychosis. The core of the program is a modified assertive case management service within which the intensity of treatment is modified by the patient's needs, stage of illness and the needs of the family. Patients have ongoing psychiatric follow-up.
- The program is linked with the PEPP Parent Support Group and with a Peer Support Group.
- PEPP undertakes research projects focused on early intervention in psychosis, prognostic indicators and outcome.
- The program maintains an active public outreach strategy involving the local media and schools and is very active in public education in the area of first episode psychosis.

Early Intervention in Psychosis Program, Hamilton Health Sciences Corporation (HHSC), McMaster Site, Hamilton

- HHSC's Psychotic Disorders Team is an interdisciplinary service at the McMaster site that has developed expertise in first onset psychosis.
- The clinical approach includes comprehensive assessment, therapeutic partnership with patients, families and family doctors / nurses, education and support for patients and families, rehabilitation support for recovery, and a shared care after-care program.
- The program has conducted research projects in the areas of program evaluation, family satisfaction, vocational success and a follow-up study of the clinic's long-term after-care program.
- In partnership with the local Schizophrenia Society of Ontario (SSO) chapter the program has established an Early Psychosis Resource Library.

Ottawa First Episode Psychosis Program, Ottawa General Hospital, Ottawa

- Ottawa Hospital's First Episode Psychosis Program consists of a clinic that provides pharmacological treatment, intensive case management, neuropsychological assessment and treatment, day hospital treatment and family and patient education groups.
- The program has also partnered with others in undertaking research focused on early intervention in psychosis.
- Through community outreach and education within the district, the program has established a large referral network. Public education initiatives have also been undertaken through the media and through symposia attended by professionals, consumers and family members.

Kingston Psychosis Prevention and Treatment Program, Hotel Dieu Hospital, Kingston

- Kingston's First Episode Psychosis program is established to provide early intervention in the form of education, assessment and treatment of individuals and their families who are experiencing a first episode of psychosis.
- This program serves as the regional treatment and resource centre to the Southeastern Ontario District.
- Treatment approach is multidisciplinary and is provided to individuals, couples, families or groups.
- The program works closely with the community partners including the local chapter of the Schizophrenia Society to provide public education and organized annual conferences in order to facilitate early detection of psychosis.
- Research into various aspects of First Episode Psychosis and education of trainees from all healthcare disciplines are integral parts of the program.

Appendix 3: A Sampling of Key Research Findings on Early Intervention in Psychosis – From the Literature Review

Area of Interest	Investigator(s)	Findings
Importance of Intervening Early	Norman and Malla (2001)	<ul style="list-style-type: none"> • Most compelling reason to intervene early is to reduce unnecessary suffering associated with delayed treatment.
	Malla et al. (1999)	<ul style="list-style-type: none"> • Those experiencing their first episode of psychosis are more responsive to antipsychotic medication and relatively low doses of medication are needed. • Social supports and insight are intact early on and are important determinants of outcome.
Impact of Early and Comprehensive Intervention	Malla et al. (2002)	<ul style="list-style-type: none"> • Follow-up of 53 individuals with first episode psychosis who participated in a community-oriented treatment program of phase specific medical and psychosocial treatments integrated within an intensive case management model. • Found complete remission of 70%, hospital readmission rate of 20%, highly significant improvement in all dimensions of psychopathology among those who entered treatment within six months of the onset of psychosis, and a longer median duration of untreated psychosis among those who did not experience complete remission.
	McGorry et al. (1996)	<ul style="list-style-type: none"> • Examined outcomes for 51 first episode patients treated in the Early Psychosis Prevention and Intervention Centre (EPPIC) program which emphasizes intervening early, utilizing treatment strategies effective for psychosis and re-integration into the community as soon as possible. • Compared to a historical matched control group that received standard treatment for psychosis, EPPIC patients had fewer hospital admissions, shorter lengths of stay in hospital, lower levels of negative symptoms, lower mean dose of neuroleptic drugs and higher quality of life scores at one year.

Appendix 3: continued

<p>Treatment Outcomes of Reduced Duration of Untreated Psychosis (DUP)</p>	<p>Larsen et al. (2001)</p>	<ul style="list-style-type: none"> • Concluded after a review of the literature that it is still an open question if a reduction in duration of untreated psychosis leads to better outcomes. Found no well designed studies demonstrating this.
	<p>Crow et al. (1986); Erickson et al. (1989); Aguilar et al. (1997)</p>	<ul style="list-style-type: none"> • Shorter DUP may reduce feelings of being personally engulfed by the illness and lessen damage to self-esteem, family relations and other social supports.
	<p>McGlashan (1999)</p>	<ul style="list-style-type: none"> • Causal relationship between longer DUP and poorer long-term outcome has not yet been perfectly established.
	<p>Norman and Malla (2001)</p>	<ul style="list-style-type: none"> • DUP may be related to ease of reducing psychotic symptoms once treatment begins but robustness of these findings needs to be established. • Relationship between reduced DUP and likelihood of relapse (or re-hospitalization) has not been found in four studies that have examined the question (Haas et al, 1998; Linszen et al, 1998; Weirisma et al, 1998; Robinson et al, 1999).

Appendix 3: References

- Aguilar, E. J., Haas, G., Manzanera, F. J., Hernandez, J., Gracia, R., Rodado, M. J. & Keshavan, M. S. (1997). Hopelessness and first episode psychosis: a longitudinal study. *Acta Psychiatrica Scandinavica*, 96, 25-30.
- Crow, T. J., MacMillan, J. F., Johnson, A. L. & Johnstone, E. C. (1986). The Northwick Park Study of first episodes of schizophrenia II. A randomized controlled trial of prophylactic neuroleptic treatment. *British Journal of Psychiatry*, 148, 120-127.
- Erickson, D. H., Beiser, M., Iacono, W. G., Fleming, J. A. E. & Lin, T. (1989). The role of social relationships in the course of first episode schizophrenia and affective psychosis. *American Journal of Psychiatry*, 146, 1456-1461.
- Haas, G. L., Garratt, L. S. & Sweeney, J. A. (1998). Delay to first antipsychotic medication in schizophrenia: impact on symptomatology and clinical course of illness. *Journal of Psychiatric Research*, 32, 151-159.
- Larsen, T.K., Friis, S., Haahr, U. et al. (2001). Early detection and intervention in first-episode schizophrenia: a critical review. *Acta Psychiatrica Scandinavica*, 103, 323-334.
- Linszen, D., Lenior, M., DeHaan, L., Dingemans, P. & Gersons, B. (1998). Early intervention, untreated psychosis and the course of early schizophrenia. *British Journal of Psychiatry*, 172 (suppl. 33), 84-89.
- Malla, A. K., Norman, R., Manchanda, R., McLean, T.S., Harricharan, R., Cortese, L., Townsend, L., Scholten, D.J. (2002). Status of patients with first-episode psychosis after one year of phase-specific community-oriented treatment. *Psychiatric Services*, 53, 458-463.
- Malla, A.K., Norman, R.M.G., Voruganti, L.P. (1999) Improving outcome in schizophrenia: the case for early intervention. *Canadian Medical Association Journal*, 160(6), 843-846.
- McGlashan, T. H. (1999). Duration of untreated psychosis in first episode schizophrenia: master or determinant of course? *Biological Psychiatry*, 48, 899-907.
- McGorry, P.D., Edwards, J., Mihalopoulos, C., Harrigan, S.M., Jackson, H.J. (1996). EPPIC: An evolving system of early detection and optimal management. *Schizophrenia Bulletin*, 22(2), 305-326.
- Norman, R., Malla, A.K. (2001). Duration of untreated psychosis: a critical examination of the concept and its importance. *Psychological Medicine*, 31, 318-400.
- Robinson, D. G., Woerner, M. G., Alvir, J., Ma, J., Bilder, R., Goldman, R., Geisler, S., Koreen, A., Sheitman, B., Chakos, M., Mayerhoff, D. & Lieberman, J. A. (1999). Predictors of relapse following response from a first episode of schizophrenia or schizoaffective disorder. *Archives of General Psychiatry*, 56, 241-247.
- Wiersma, D., Nienhuls, F. J., Slooff, C. J. & Giel, R. (1998). Natural course of schizophrenic disorders: a 15 year follow-up of a Dutch incidence cohort. *Schizophrenia Bulletin*, 24, 75-85

Appendix 4a: Early Intervention in Psychosis Policy Work Group Terms of Reference

Name:

Early Intervention in Psychosis Policy Work Group

Purpose:

This provincial internal / external stakeholder Work Group will provide advice that will assist the Mental Health and Rehabilitation Reform Branch to develop a provincial program policy framework for early intervention in psychosis consistent with the direction outlined in *Making it Happen*.

Rationale:

- In August 1999, the Ministry released *Making it Happen*, the government's plan for reforming the mental health system. This policy document committed the government to further policy work in a number of areas including the development of intensive services for those experiencing a first episode of psychosis.
- For several years, some jurisdictions (UK, Australia, Ontario and BC) have been developing programs to provide early intervention for people experiencing their first episode of psychosis. Evidence points to the importance of early intervention in minimizing the impact of a first episode of psychosis. Early intervention may reduce the long-term impacts of the episode on the individual and the family. It may also reduce the cost of treating and supporting people with a psychotic disorder.
- Ontario's Mental Health Implementation Task Forces have identified the need for early intervention in psychosis programs as a system priority.
- The Provincial Forum of Task Force chairs recognized the importance of programs focused on early intervention in psychosis, to improving the mental health system in Ontario.

Deliverables will include:

- Development of principles for a provincial framework for early intervention in psychosis consistent with the principles outlined in *Making it Happen*.
- Advice on the elements of an early intervention in psychosis policy framework.
- Identification of issues and barriers to the development and implementation of early intervention programs in Ontario (including those related to program definitions) and recommendations for program development.
- Advice on developing mechanisms to monitor and evaluate programs and mechanisms to ensure that programs utilize best practices.

Parameters:

The Work Group is a time-limited group constituted to provide advice to the Ministry of Health and Long-Term Care on a policy framework for early intervention in psychosis.

Reporting Relationship:

The Work Group reports to the Director, Mental Health and Rehabilitation Reform Branch, Ministry of Health and Long-Term Care.

Appendix 4a – *continued*

Composition:

- Membership aims to reflect a range of perspectives and expertise and includes representation from relevant Ministries and from key external partners including:
 - Ontario Working Group on Early Intervention in Psychosis
 - Canadian Mental Health Association (National and Branch Representatives)
 - Research (Hospital for Sick Children)
 - Consumer Representatives
 - Family Outreach and Response Program
 - Prevention and Early Intervention Psychosis Program
 - Early Intervention Program, Hamilton Health Sciences
 - Schizophrenia Society of Ontario
 - Ontario Council of Student Affairs
 - Ministry of Community, Family and Children's Services, Children with Special Needs Branch
 - Ministry of Education, Special Education Branch
 - Ministry of Training, Colleges and Universities, Universities Branch
 - Ministry of Health and Long-Term Care, corporate policy, corporate operations and regional office representation

Role of Members – Committee members are expected to:

- Actively participate in the work of the committee including participation in work groups that may be created from time to time.
- Bring to the table their expertise in providing support to people experiencing a first episode in psychosis and to assist in developing, communicating and promoting the committee's work with their respective constituencies.
- Other key informants with specialized expertise will be invited to meet with the advisory committee as required.

Time Frame:

- Four Work Group Meetings – one in July, one in August, two in September.

Appendix 4b: Early Intervention in Psychosis Policy Work Group Membership

Patrick Keaney

Consumer & Peer Support Worker
Northeast Mental Health Centre

Elaine Crawford

Canadian Mental Health Association
National Office

Maurice Fortin

Canadian Mental Health Association
Thunder Bay Branch

Dr. Bruce Ferguson

Community Health Systems Resource Group
Hospital for Sick Children

Michael Armstrong

Consumer

Ian Chovil

Consumer Consultant
Homewood Health Centre

Heather Hobbs

Early Intervention Program
Hamilton Health Sciences

Dr. Suzanne Archie

Early Intervention Program
Hamilton Health Sciences

Karyn Baker

Family Outreach and Response Program

Rae Johnson

Ontario Council of Student Affairs
Student Crisis Response Program
University of Toronto

John Trainor / Dr. John Sylvestre

Ontario Working Group on Early
Intervention in Psychosis

Dr. Rahul Manchanda

Prevention and Early Intervention Program
for Psychosis (PEPP)
London Health Sciences Centre

Bridget Hough

Schizophrenia Society of Ontario

Catherine Ford / Kathy Glazier

Mental Health and Addiction Branch, MOHLTC

Beth McCarthy-Kent

Mental Health Consultant
North Region, MOHLTC

Eva Vonk

Primary Health Care and Physician Policy
Branch, MOHLTC

Richard Hildreth

Integrated Services for Children, MOHLTC

Wayne Thomas

Special Education Branch
Ministry of Education

Monique Wernham

Universities Branch
Ministry of Training, Colleges and
Universities

Bonnie Myslik

Canadian Mental Health Association
Windsor-Essex County Branch

Staff Support

Lisa McDonald / Beena Azhikannickal
Mental Health and Rehabilitation Reform
Branch, MOHLTC

Appendix 5: *Making it Happen* Principles Applied to Early Intervention in Psychosis Services

- 1) *Consumer at the Centre of the Mental Health System***
Early intervention services demonstrate sensitivity to age, gender, race, culture, ethnicity, First Nations communities, language, gender identity and sexual orientation.
- 2) *Services Tailored to Consumer Needs with a View to Increase Quality of Life***
The provision of early intervention services should take into account the individual's developmental stage.
- 3) *Consumer Choice and Access to Services will be Improved***
Early intervention in psychosis services should be available in all areas of the province of Ontario and services should be able to respond quickly. Individuals should have access to treatment (e.g., medication, cognitive behavioural therapies) and support services regardless of income or geography.
- 4) *Services will be Linked and Coordinated***
Access to early intervention in psychosis services is facilitated through links with other mental health services and services within the more general health and social service sectors. Once individuals gain access to an early intervention program, there is a coordinated approach to the delivery of needed services and supports. Upon leaving an early intervention in psychosis program, individuals are linked to other services and supports in the community as required.
- 5) *Services will be Based on Best Practices***
Early intervention clinicians and service providers implement treatment programs that are based on best practices and evidence-based research. Research in the area of early intervention should inform practice and help encourage innovation. Consumer and family²⁰ – identified outcomes should be the focus of evaluating early intervention programs; evaluation of programs is required to demonstrate that key early intervention components are in place.
- 6) *Mental health funding will continue to be protected and there will be continued investments / reinvestments in mental health services to support mental health reform and increase the overall capacity of the mental health system***
There should be appropriate and ongoing funding of early intervention in psychosis programs.

²⁰ The term “family” is used in this document to describe any person who is identified as such by an adult experiencing a first episode of psychosis. In the case of children, parents or legal guardians are included in the definition of “family”, however, others such as friends may also be included in the definition of family.

Appendix 6: Recovery Philosophy

The advice summarized in this document assumes an understanding of the recovery approach as it pertains to mental health. The concept of recovery should underlie a program policy framework for early intervention in psychosis, and is referred to throughout the document in relation to all aspects of the program policy framework for which advice has been given. A brief description of the recovery philosophy is therefore provided here given the importance of the concept to this program policy framework.

The recovery concept has steadily gained momentum since the 1980's as a result of three main driving forces. First, consumers have provided a conceptual base for the recovery approach in writing of their own experiences. As well, a number of long-term outcome studies suggest that a deteriorating course for serious mental illness is not the norm (e.g., see Harding et al., 1987).²¹ Finally, there is growing recognition of the role that stigma plays in preventing people with mental illness from moving on and achieving quality of life and the recovery approach acknowledges this and incorporates the need to understand the impact of stigma as a central focus.

Anthony (1993)²² states that, "Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of psychiatric disability". Recovery does not mean cure. Recovery can occur even if the person still experiences symptoms of mental illness. Silvestri and Hallwright (2001)²³ note that "The real test for recovery is when the user feels they have recovered, that is, they see themselves as living a quality of life that is not dominated by their past situation or their current symptoms and stresses".

The recovery approach is not tied to any one service model, it can be implemented in a variety of settings and programs. There are, however, implications for programs and services in developing a recovery-oriented approach. There are implications for the role of service providers, the orientation of programs, and the involvement of the broader community in recovery. A recovery approach emphasizes consumer choice, flexibility in services, individualized supports, and the importance of families, significant others and communities in supporting individuals with mental illness. A recovery approach also places emphasis on considering the negative correlates of mental illness such as poverty, stigma, poor housing as well as incorporating wellness promotion, rights advice, and the attainment of basic supports such as income.

²¹ Harding, C.M., Brooks, G.W., Asolaga, T.S, and Breier, A. (1987). The Vermont longitudinal study of persons with serious mental illness. *American Journal of Psychiatry*, 144, 718-726.

²² Anthony, W.A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990's. *Psychosocial Rehabilitation Journal*, 16(4), 11-23.

²³ Silvestri and Hallwright, (2001) The Future Approach for Community Mental Health, in *This is Madness Too*. Llangarron, Ross on Wye.

