# Early Psychosis Intervention Program Standards

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Ministry of Health and Long-Term Care

Copies of this report can be obtained from

Service Ontario, INFOline: 1-866-532-3161

(Toll-free in Ontario only)

TTY 1-800-387-5559. In Toronto, TTY 416-327-4282

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# **Early Psychosis Intervention Program Standards**

## **Preface**

Psychosis is a debilitating condition characterized by delusions, hallucinations, disorganized thinking and/or bizarre behaviour. Symptoms may emerge gradually or abruptly. Psychosis can affect all aspects of life – education, employment, relationships, social functioning, and physical and mental well-being. Psychosis may be caused by a psychiatric disorder, such as schizophrenia or bi-polar disorder. It can also be caused by a other conditions, such as a brain injury or infection, or substance use.

Each year, about 12 out of every 100,000 people in Ontario will experience their first episode of psychosis, and the overwhelming majority of them will be adolescents and young adults between the ages of 14 and 35 (Jablensky, *et al.*, 1992).

#### The Importance of Effective Early Psychosis Intervention

In treating psychosis, it is important for the intervention to be timely, comprehensive and reflect best practice.

Early intervention after onset of psychosis is critical because the delays in treatment, known as the "duration of untreated psychosis" (DUP) are extremely stressful for patients and their families, and may result in poorer clinical outcomes. The first few years of psychosis carry the highest risk of serious physical, social and legal harm (Birchwood, Todd & Jackson, 1998). One in 10 people with psychosis commit suicide: two-thirds of these deaths occur within the first five years of illness. Delayed treatment is likely to lead to problems in 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. The economic and societal impact of untreated psychosis should also be considered since potential consequences include premature death, years of disability, homelessness, incarceration and reduced prospects for long-term recovery.

There is evidence that longer DUP is associated with poorer outcome once treatment is initiated (Marshall *et al.*, 2005; Norman *et al.*, 2005). Intervening early can prevent problems and improve long-term outcomes. When people have access to early treatment and ongoing support, the likelihood of recovery increases significantly.

#### The History of Early Psychosis Intervention in Ontario

Ontario's policy framework for mental health reform, *Making it Happen: Implementation Plan for Mental Health Reform*, published in 1999 identified first episode psychosis as requiring an "intensive" level of care. By January 2003, most of the nine Mental Health Implementation Task Forces created in Ontario identified early intervention programs for psychosis as a priority. The Provincial Forum of Task Force Chairs also identified treatment, education and support for individuals experiencing psychosis and their family as essential elements of an integrated system of mental health services and recommended the Ministry of Health and Long-Term Care develop a policy framework for first episode psychosis.

The Ontario Working Group on Early Intervention in Psychosis ("Ontario Working Group") was formed in 1999 to promote the need for early intervention services and to work with government to make these services a reality. The group was formed with members from three existing clinical programs, family organizations, community mental health agencies, and consumers. The Ministry of Health and Long-Term Care has been involved with the Ontario Working Group from the outset and a cooperative working relationship was established. Since its establishment, the Ontario Working Group has advocated for change, provided educational materials, made funding proposals and developed draft policies.

By 2004, five early psychosis intervention (EPI) programs had been established by hospitals in the province, and other organizations were considering offering similar programs. (Similar programs had also been established in Australia, the United Kingdom and Scandinavia.)

In December 2004, the Ministry of Health and Long-Term Care announced new funding for early psychosis intervention and released the *Program Policy Framework for Early Intervention in Psychosis*, which established the program framework for early psychosis intervention programs for Ontario. The framework for comprehensive early psychosis intervention, which is reproduced in Figure 1 (see below) from the 2004 document, identifies seven key components of early intervention, which were used as the basis for organizing the standards.

Following on this new funding allocation for early psychosis intervention, approximately 30 early intervention programs and allied services have been established in the province. Membership in the Ontario Working Group has increased significantly. With one-time funding from the ministry, the Ontario Working Group has been able to hold provincial conferences, develop a website, and support a range of educational opportunities among programs.

More recently, the Ministry of Child and Youth Services published *A Shared Responsibility: Ontario's Policy Framework for Child and Youth Mental Health* (Nov 2006). This policy recognizes the importance of early intervention with respect to first episode psychosis.

#### **Objectives and Principles**

#### **Objectives**

The objectives of a comprehensive early psychosis intervention program are to:

- reduce the duration of untreated psychosis through early and appropriate detection and response, thereby potentially reducing the severity of the illness
- minimize the disruption in the lives of adolescents and young adults who experience psychosis so they can reintegrate and maintain educational, vocational, social and other roles
- minimize 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

#### **Principles**

Services are client and family centred. Clients are engaged in their own care and treatment. Families are engaged in the client's care as much as possible.

Services are youth friendly, age appropriate and sensitive to gender and culture.

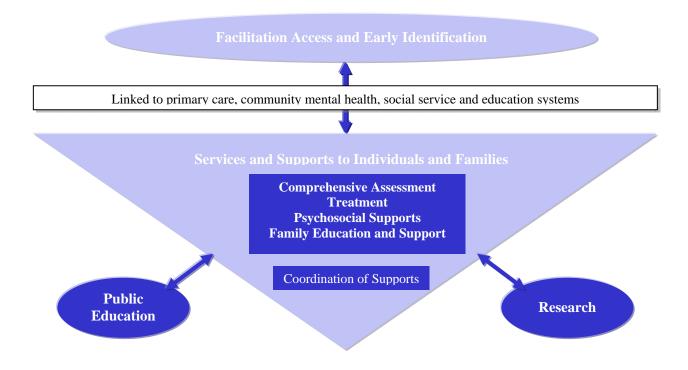
Services support clients in recovering and maintaining age-appropriate social roles (e.g., going to school, maintaining a job).

Services are linked to other services and supports in the community, particularly primary care.

Treatment is provided in the least restrictive and stigmatizing setting. Home-based treatment may be appropriate for adolescents and young adults.

#### **Key Components**

Figure 1: Key Components: Program Policy Framework for Early Intervention in Psychosis



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

- Comprehensive Assessment
- Treatment
- Psychosocial Reports
- Family Education and Support
- Facilitating Access and Early Intervention
- Public Education
- Research
- \*Excerpted from Program Policy Framework for Early Intervention in Psychosis, 2004 (Ontario Ministry of Health and Long-Term Care)

#### About the Standards

#### A Guide to High Quality Services and Supports

#### It is not enough for treatment to be early, it must also be effective.

These standards establish the minimum expectations for all early psychosis intervention programs in Ontario. They are designed to ensure that all Ontarians who meet the criteria for EPI – regardless of where they are treated -- receive comprehensive, high quality, evidence-informed care, treatment and support.

This standards document defines:

- the intended population
- the program length
- the required services
- the intended benefits
- when available, the indicators that will be used to assess whether programs are achieving standards
  (note: the Ministry of Health and Long-Term Care is working with EPI programs and Local Health
  Integration Networks to identify the measures that will be used to measure compliance with the standards)

These initial standards for EPI, which build on guidelines developed by the International Early Psychosis Association Writing Group (IEPAWG, 2005) and by the National Health Service in the United Kingdom (Department of Health, 2005) are based on the best available evidence at this time, and will evolve and be updated based on new knowledge in the field as well as the experience of EPI programs in Ontario.

#### The Structure and Characteristics of EPI Programs in Ontario

#### Ontario's early psychosis intervention programs vary in how they are structured and operate.

Some EPI programs are more centralized, with all skills and services on site; others are a network of different organizations, funded to provide comprehensive first episode psychosis services. Networks work together to meet the needs of people experiencing psychosis. All EPI programs are managed by sponsoring agencies that are accountable to their Board of Directors.

Specific programs and services may be configured differently because local needs and existing services vary. All programs should subscribe to the standards contained in this document.

#### How to Use the Standards

All organizations funded to provide EPI services are accountable for complying with the standards. EPI programs will use these standards as the basis for program planning and evaluation for both stand-alone programs and networks. The ministry and Local Health Integration Networks will develop performance measures based on client outcomes to assess whether EPI programs are providing comprehensive, high quality, evidence-based care based on the standards.

All EPI programs are required to develop policies, procedures and service delivery protocols that reflect the standards. Once policies, procedures and protocols are in place, the EPI programs will: maintain the organizational and service structure required to deliver the services; and provide orientation and training for new staff.

The standards also provide a tool that EPI programs can use to identify any weaknesses in current programs and services, and develop plans to fill any gaps.

#### The Role of the Ministry of Health and Long-Term Care and Local Health Integration Networks

To support consistent, high quality early psychosis intervention, the Ministry of Health and Long-Term Care will, in consultation with the Local Health Integration Networks and the Ontario Working Group:

• develop performance measures for the standards

- review and revise EPI policies and standards based on new knowledge and experience in the field according to best practice
- work with EPI programs to establish a system to monitor and enforce these standards
- work with EPI programs (stand-alone programs and networks), providing information and other resources, to help EPI programs meet the standards
- provide support and advice on data collection
- collect and analyze data, using existing databases, to help monitor and strengthen the programs
- identify opportunities for research to support the development of EPI programs in Ontario

#### Local Health Integration Networks will:

- provide funding for EPI programs
- participate at a provincial level, as appropriate
- foster the development of and support the existence of EPI program networks

## Introduction

#### Eligibility Criteria and Service Type

EPI programs are designed to serve people with psychosis related to serious mental illness, such as schizophrenia, schizoaffective disorder, mood disorder, delusional disorder and bi-polar disorder. According to data from a recent study in three Ontario centres, about 47% of people presenting with first episode psychosis were diagnosed with schizophrenia, 15% with schizophreniform, 12% with schizoaffective disorder and 19% with psychosis related to another cause (Malla, *et al.*, 2007).

Early psychosis intervention programs are intended to serve people between the ages of 14 and 35 who meet the following criteria:

- are experiencing symptoms of a psychotic disorder, and
- have received either no treatment for psychosis or 6 months or less of treatment for psychosis.

Outside the 14 to 35 age range, clients will be assessed on an individual basis and the program will either provide treatment or refer the client to another more appropriate service. Where a particular EPI program does not have a mandate to provide services to children and adolescents, the required service will be provided within the larger Program Network (see Section 12).

Because it takes time to diagnose the underlying cause of psychosis, EPI will provide two types of service:

- 1. Initial assessment and treatment which will be provided to anyone between the ages of 14 and 35 experiencing symptoms of a psychotic disorder. Through that assessment and treatment, the EPI program will determine which clients will benefit from treatment and rehabilitation in the program, and which clients should be referred to other more appropriate services. Individuals who do not have a psychotic disorder should not be admitted to an EPI program.
- 2. *Intensive treatment and rehabilitation services* which will be provided to those individuals who meet the eligibility criteria listed above (i.e., who have been diagnosed with a type of psychosis that can be treated effectively through EPI).

#### **Program Length**

Early psychosis intervention is based on providing intensive services over a limited period of time to help people recover, to remain integrated in the community and, when needed, to reintegrate into the community.

Clients who meet the criteria for an EPI program will be able to receive services for a period of three years. Clients who are stable may graduate from the program earlier; clients who initially have problems engaging and/or becoming stable may require a longer period of treatment.

## 1. Facilitating Access and Early Identification

#### **Background**

For individuals experiencing psychosis for the first time, the mean length of time their psychosis goes untreated for is about one year (Norman, *et al*, 2004). The delay in obtaining treatment – which may result in poorer clinical outcomes – is often due to lack of awareness of the signs and symptoms of psychosis or lack of treatment services.

#### The Importance of Educating Parents, Families, Teachers and Employers

The possibility of a psychotic disorder should be carefully considered in a young person who is becoming more socially withdrawn, performing less well for a sustained period at school or at work, or becoming distressed or agitated yet unable to explain why. 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. Other people who may also notice early signs and symptoms include the young person's friends, teachers, coach or employer.

The most effective way to reach parents, family members, friends, teachers, coaches and employers may be through general public awareness and education programs that work to reduce the stigma associated with mental illness (Larsen *et al.* 2001; Johannessen *et al.* 2001). Stigma often discourages adolescents and young adults from seeking help with a problem, and isolates families who are dealing with psychosis.

The goals of public education initiatives related to psychosis are to:

- make people aware of the signs and symptoms of early psychosis and the importance of early identification and referral
- create a more supportive environment for people with psychosis
- de-stigmatize the experience of psychosis
- reinforce that mental illnesses are treatable conditions

There is potential for EPI programs to collaborate to develop effective public education/awareness materials.

## The Importance of Working with Other Health and Social Service Providers to Create an Early Identification/Rapid Response System

People experiencing signs and symptoms of psychosis often seek help from other service providers, such as primary care providers, school or university health services, youth agencies, community mental health services or other services that have regular contact with adolescents and young adults. Therefore, it is important that these service providers:

- understand the behavourial changes that can occur during adolescence and early adulthood
- are able to recognize the signs and symptoms of psychosis
- have access to valid screening tools for psychosis
- will refer adolescents and young adults (14 to 35 years) who are exhibiting symptoms to the EPI program for assessment

Primary care practitioners can play a key role in identifying and engaging adolescents and young adults experiencing psychosis. Some people seeking help for mental health problems will contact mental health service providers, but most do not. Adolescents and young adults are the least likely to use mental health resources, but they

will go to a family physician for help with general health problems. When family physicians are aware of the signs and symptoms of early psychosis, they are able to make timely appropriate referrals to EPI programs.

EPI programs tend to be small and may not have the capacity to meet all the demand for services in their communities. Some of the Family Health Teams being established across the province will have mental health workers on staff, and may be an effective way to increase early identification and assessment as well as access to appropriate care.

#### **Standards**

- 1.1 EPI programs identify providers and organizations in their communities who are able to assist with early identification of psychosis (see box), help engage clients and make timely referrals for assessment, and be part of an effective early identification/rapid response system.
- 1.2 To promote early identification and referral of people with first episode psychosis, EPI programs support providers and organizations in their communities by:
  - providing initial and ongoing professional education on early psychosis, including signs, symptoms and best practices in screening
  - providing evidence-based screening tools as well as referral pathways for those organizations that do not have the skills to identify signs of psychosis
  - working with members of the early identification (ID) system to ensure people between the ages of 14 and 35 are referred to and access EPI assessment services
  - encouraging them to start the process of engaging the client in his/her own care
  - encouraging schools and community mental health agencies to provide education for youth and families

A community's Early Identification/Rapid Response system for psychosis should include all organizations with the potential to assist in identifying adolescents and young adults (ages 14 to 35) with early signs of psychosis, such as:

- primary care providers, including community health centres, family health teams (FHTs), solo general practitioners and small group practices, public health units
- hospital emergency rooms and other relevant departments
- psychiatrists in private practice
- community mental health agencies
- police, victim services
- mobile crisis teams (where they exist)
- university and community college health services
- high schools
- youth recreational services
- youth help lines
- other organizations working with youth
- rural mental health services
- Schizophrenia Society/Mood Disorders Association and other family organizations
- consumer/survivor groups
- shelters, street services
- landlords/supportive housing
- employee assistance programs and human resource managers
- faith-based organizations.
- 1.3 EPI programs encourage other providers in the early ID/rapid response system to refer clients based on the possibility of psychosis rather than a certain diagnosis of psychosis.
- 1.4 In communities with diverse populations, EPI programs have access to translation/interpretation services.
- 1.5 The EPI program uses various strategies to educate the public and raise awareness of the early signs and symptoms of psychosis, the importance of early identification and referral, and the services available to help, including:
  - distributing brochures, print and internet information
  - developing consumer champions and educators who can speak to groups or be available for interviews
  - encouraging families and their organizations to play an active role in public awareness efforts
- 1.6 EPI programs regularly assess the effectiveness of their education programs and referral pathways. Professional/provider education about early psychosis intervention may involve formal professional training or may be delivered through workshops and presentations targeted to those working with

- adolescents and young adults. Whenever possible, EPI programs should have face-to-face contact with other providers and organizations to reinforce the importance of early identification, of engaging clients early in their own care, and of making timely referrals (i.e., rapid response).
- 1.7 Public education programs should reinforce that people with a mental illness are valuable members of society who belong in their communities. They should also emphasize the non-specific and often subtle nature of early signs of psychotic illness, such as social isolation and anxiety, as well as the potential for people to recover more quickly and more effectively when diagnosed and treated promptly.

## 2. Comprehensive Client Assessment

#### **Background**

A comprehensive assessment is done when, based on initial screening, people appear to meet the criteria for the EPI program. The purpose of the comprehensive assessment is to:

- determine whether the client meets the criteria for the EPI program or requires referral to another service
- begin engaging the client in the assessment process and his/her ongoing care
- obtain the more detailed information required to start developing an individualized treatment plan
- begin building the EPI team that will work with the client

The comprehensive assessment can take place during one meeting with the client (see comment on standard 2.7), or it can require a series of meetings. The length of time required to complete the comprehensive assessment will depend on: the specific assessments required, the professionals who have to be involved, and the time required to engage the client. (Note: It can take six months or longer to engage the client and build a therapeutic relationship.)

Because psychosis has many underlying causes, it can be difficult to develop a definitive diagnosis and determine that the client does meet the criteria for EPI. When the diagnosis is unclear, the client should be treated symptomatically, observed carefully and managed psychosocially until the diagnosis is determined. At that point, the client either remains in the EPI program or is referred to a more appropriate service.

Ideally, EPI assessments are done in a safe, non-stigmatizing, least restrictive setting possible, and clients have a say in where the assessment is done.

#### **Standards**

- 2.1 Clients referred for a comprehensive assessment are contacted by telephone within 72 hours of being referred, and a face-to-face meeting is offered to be held within two weeks. Clients are made aware of crisis and other services such as crisis response teams, which they can use pending their first appointment or if crisis response teams do not exist in the community to the emergency department of the nearest hospital.
- 2.2 Comprehensive assessments are client centred. In keeping with a client and family centred approach, the program strongly encourages client and family involvement in assessment and treatment. Families are involved in the assessment with the client's consent.
- 2.3 The program follows established procedures for communicating with the client and family, which include providing a clear written description of the services the program provides as well as the client's and family's role and responsibilities.

For the purposes of EPI, "family" is defined by the client and may include parents, siblings, friends and/or other people who play a significant role in the client's life.

- 2.4 Comprehensive assessments are done by a practitioner(s) with the following skills/competencies: assessment, communication, cultural competence, treatment, and rehabilitation.
- 2.5 The practitioner(s) doing the assessment have ready access to a psychiatrist.
- During the assessment, the practitioner(s) allow enough time to begin to develop a therapeutic alliance with the individual and family, and identify the person's and the family's goals and aspirations.
- 2.7 A comprehensive assessment includes, as a minimum:
  - engagement with the client

- a history of presenting symptoms, including any recent changes in behaviour
- a risk assessment including risk of harm to self (i.e., suicide) and others
- a psychiatric exam and history, including level of pre-morbid functioning and identification of comorbid disorders (e.g., substance use)
- a physical examination, routine blood work and a neurological screen (according to the Canadian Psychiatric Association guidelines for schizophrenia)
- history of or current involvement with the justice system (e.g., charges pending, on probation)
- a developmental history and assessment of dimensions of personality
- a psychosocial assessment including: social/family functioning, support and resources; living situation; income
- an educational/occupational/vocational assessment
- an assessment of the person's understanding of the episode
- an assessment of any cultural or gender issues (e.g., sexual identity)
- an assessment of information provided by people important to the client (e.g., family, friends)
- 2.8 Assessment findings are shared with the client, and with the family with the client's consent.
- 2.9 Clients who do not meet the criteria for services (e.g., not between the ages of 14 and 35; psychosis caused by a non-psychiatric condition that can be treated medically) are connected to appropriate services, and the program provides support to facilitate the referral.

#### To engage the client one must:

- establish rapport
- engage the whole person
- build trust
- start where the client is
- connect with clients' own goals
- establish a mutual language to describe what is happening
- involve others trusted by your client
- share information, as appropriate, with all concerned
- expect confusion, denial, avoidance, drifting
- relax, stay connected

## 3. Treatment

#### **Background**

Note: if the comprehensive assessment indicates that EPI is not the most appropriate care for a client (given the cause or treatment history of the psychosis), the program will provide initial support and treatment, and link the client with more appropriate services. The following standards are for ongoing treatment of clients who meet the criteria for EPI.

The goals of EPI treatment are to develop and implement a tailor-made, client-centred plan that will:

- help the client manage symptoms
- identify any co-morbid conditions that should be treated (e.g., substance use)
- provide for ongoing risk assessment
- support clients and families in the process of dealing with psychosis
- provide education so clients and, if possible families, can learn to manage the illness and develop coping skills
- focus on recovery

Ideally, treatment should begin before a crisis develops (e.g., self-harm, violence, aggression, substance use, loss of a job) and before the client is hospitalized. In-patient care is less likely to be required when treatment begins early.

#### **Treatment Approaches**

Effective treatment approaches include some or all of the following (Archie *et al.*, 2005; Edwards & McGorry, 2002; Hamilton Wilson, Hobbs & Archie, 2005; Malla *et al.*, 2007; Penn, Waldheter, Perkins, Mueser, & Lieberman, 2005):

- a team approach to case management/care coordination
- ongoing psychiatric/medical assessment and treatment
- client and family education (see Standard #5: Family Education and Support)
- support and counselling (see Standard #4: Psychosocial Support for the Client)
- crisis intervention
- cognitive behaviour therapy (if available)
- supportive psychotherapy (if available)
- relapse prevention

#### Use of Marijuana and Other Substances

use of Marijuaria and Other Substances

#### **Eligibility Criteria for EPI**

People between the ages of 14 and 35 who:

- are experiencing symptoms of psychosis, and
- have received either no treatment or 6 months or less treatment for psychosis

Effective treatment depends on open communication with all those supporting the client's recovery, with the client's consent. These can include:

- the client
- the client's family
- team members
- specialists
- primary care providers
- other service providers
- teachers
- employers

Marijuana use is not benign (Archie *et al.*, 2007; Arseneault, Cannon, Witton, & Murray, 2004). Marijuana can act as a trigger for psychosis – even among people who have no prior history of a disorder. There is an association

between early marijuana use (i.e., at age 12 to 15) and the risk of developing a psychotic illness. Ongoing use of marijuana, other street drugs and alcohol by people with a psychotic illness can make recovery more difficult.

#### Risk of Relapse

There is a high rate of relapse within the first five years after onset of a psychotic disorder. The types of changes in thoughts, feelings and behaviours that clients experience before a relapse vary considerably. To reduce the severity of relapse, clients need individualized relapse prevention plans.

#### **Standards**

#### 3.1 Team Approach/Case Management/Care Coordination

- 3.1.1 Once a client is assessed as meeting the eligibility criteria for ongoing assessment, treatment and support, the program will identify a team responsible for the client's ongoing care that has the skills to:
  - assess, treat and support the person
  - treat and help the client manage common co-morbidities (e.g., substance use, suicidal thoughts, depression)
  - meet the client's psychosocial needs
- 3.1.2 Each client is assigned a lead practitioner from the EPI team who is available to the client from admission to graduation, and responsible for:
  - coordinating the treatment team and treatment process
  - identifying and linking the client to any other services and supports required during the course of care (e.g., primary care, addiction treatment), and ensuring coordination of care
  - attending all client meetings with the psychiatrist (with the client's consent)
  - developing links with the client's primary care provider and helping the client make the transition to the primary care provider when he/she graduates from the EPI program
- 3.1.3 Whenever possible, the client's family is actively involved in the client's treatment (with the client's consent).

For purposes of EPI, "family" is defined by the client and may include parents, siblings, friends and/or other people who play a significant role in the client's life.

- 3.1.4 The program has established mechanisms and protocols to ensure regular, timely, effective communication with clients, families and all those supporting the client's recovery.
- 3.1.5 The client, family and team negotiate and document a comprehensive, individualized, client-centred wellness/recovery plan that includes specific plans for:
  - medical treatment
  - education
  - psychosocial support for the client that addresses all aspects of daily living
  - family support
  - crisis prevention
  - relapse prevention
  - graduation/discharge including any services or supports the client may required after graduation from EPI

- 3.1.6 The initial wellness/recovery plan is developed within four weeks of the first appointment, and is regularly reviewed and updated to reflect the client's and family's changing needs and goals until the client graduates from the program.
- 3.1.7 Programs use proactive outreach strategies (e.g., in-home visits, wherever possible, outreach to families, services provided as part of recreation activities in the community) designed to keep clients engaged in treatment, reduce missed appointments, and minimize the number of clients lost during treatment.

## 3.2 Ongoing Psychiatric/Medical Assessment and Treatment

- 3.2.1 To minimize disruption and anxiety for the client or family, treatment is provided in community settings.
- 3.2.2 Treating symptoms that are affecting client function takes precedence over making a diagnosis.
- 3.2.3 Clients receive periodic physical and psychiatric reassessment, based on their changing needs and/or goals.
- 3.2.4 When clinically indicated, programs use low dose, slow increment anti-psychotic medication as first line therapy to treat psychosis. Medications are administered according to Canadian Psychiatric Association guidelines. When prescribing anti-psychotic medications for clients less than 16 years of age, practitioners seek advice and support from specialists in child and adolescent psychiatry.
- 3.2.5 Informed consent is required for all treatment, including treatment with anti-psychotic medication. Programs have protocols and procedures to ensure that, before beginning treatment with anti-psychotic medications, clients are fully informed about the benefits and risk, and capable of giving informed consent. If clients are not capable of giving informed consent, the team will defer to substitute decisions makers (e.g., parents, guardians) as set out in the *Health Care Consent Act*.
- 3.2.6 Clients taking anti-psychotic medications are monitored closely for side effects (e.g., weight gain, changes in glucose or lipid metabolism, extra pyramidal side effects), and their treatment is adjusted as required. All clients are taught to manage their medications and to self monitor.

## A *recovery-oriented* service provider:

- instills hope
- shares power
- exchanges information
- consults on decisions
- provides choices
- focuses on client strengths

Focusing on recovery means the client is helped to develop a plan for a satisfying and successful life, and is assisted in setting goals in areas that include healthy living, housing, work, education, friendships, spirituality and intimacy. The plan takes into account limitations caused by one's illness as well as one's strengths.

## The Importance of Low Dose, Slow Increment Anti-Psychotic Medication

State-of-the-art treatment for early psychosis (when required) is based on low dose, slow increment anti-psychotic medication as first line therapy. This approach is effective in avoiding side effects and encouraging adherence. Clinicians should follow the clinical treatment guidelines published by the Canadian Psychiatric Association (2005).

- 3.2.7 The team addresses any physical health issues the client has (e.g., co-morbidities) in a timely way either directly or through referrals to other services.
- 3.2.8 The team helps the client and family deal with the impact of psychosis and treatment on other functions (e.g., providing nutrition counselling to counter metabolic disruption and weight gain) either directly or through referral to other services.
- 3.2.9 In-patient treatment is provided only when absolutely necessary. If in-patient care is necessary, it should be provided in age appropriate locations (where available) that support the principles of EPI. The team continues to provide support for the client in the in-patient setting (i.e., in-reach services) and advocates on behalf of the client to ensure he/she receives consistent treatment during the hospital stay.

#### 3.3 Education

- 3.3.1 Programs provide ongoing education tailored to the client's and family's needs.
- 3.3.2 Clients and families are supported to learn as much as possible about:
  - the illness and symptoms
  - the role of treatment, including medications and side effects
  - rights and responsibilities
  - the impact of substance use on psychosis (including marijuana and alcohol use)
  - how to manage the illness in a way that allows the client to function as well as possible with the fewest symptoms
  - stigma associated with mental illness and how to cope with it
  - risk assessment
  - how to sustain recovery and prevent relapses
  - strategies to reintegrate into the community, and return to work and/or school
  - services and supports in the community
- 3.3.3 Programs actively promote a culture of health and wellbeing, and help clients address a broad range of issues, such as weight gain, smoking and other behaviours that affect health. The focus is on improving the client's and family's quality of life.

#### 3.4 Crisis Intervention

3.4.1 Programs have links with community crisis response services (where available) and withdrawal management/substance abuse services as well as develop crisis response protocols for clients with first episode psychosis.

#### 3.5 Relapse Prevention

- 3.5.1 To reduce the need for hospitalization, the lead practitioner, client and family identify the client's early warning signs for relapse as well as strategies the client and family can use to prevent or reduce the severity of a relapse.
- 3.5.2 In the event of a relapse, the program has the capacity and protocols to assess and treat the client quickly.

## 4. Psychosocial Support for the Client

#### **Background**

The goal of EPI programs is to support the rapid reintegration of clients back into and/or to maintain their roles in their communities throughout treatment and recovery. Reintegration occurs most effectively when clients receive treatment and support within their community of choice. Every effort should be made to help the person normalize his or her life and stay or become engaged in school, work (paid or volunteer), recreation and/or religious activities. The longer an adolescent or young adult remains out of school or out of work, the harder it becomes to return to school or gain employment.

Because early psychosis intervention is recovery-focused, it considers the impact of psychosocial factors such as income, housing, and employment on people experiencing psychosis. An unstable living situation and/or lack of income are factors in relapse.

By providing psychosocial supports, early intervention programs promote a culture of hope for the future, and this philosophy is a critical part of supporting the person's recovery. Psychosocial supports help individuals: pursue and achieve self-defined cognitive, vocational, social, educational, emotional and other goals; re-discover goals they had before the illness; or discover new goals.

#### **Standards**

- 4.1 Programs use assertive outreach to actively engage clients.
- 4.2 Programs provide high quality and intensive psychosocial care consistently, assertively and in accordance with best practice throughout the three-year treatment/recovery program. Psychosocial supports include:
  - developing coping and self-help strategies
  - developing resiliency
  - dealing with the symptoms of psychosis
  - activities of daily living
  - educational/academic supports
  - vocational/employment supports
  - housing supports
  - substance abuse supports
  - support in establishing social relationships or connections
  - peer support
  - income support, when necessary
  - recreational supports
- 4.3 Practitioners are knowledgeable about:
  - the client's developmental stage and issues
  - community resources and supports

"Assertive outreach is a way of working with an identified client group of severely mentally ill adults who do not effectively engage with mental health services. The approach is characterized by work with clients in their own environment, wherever that may be. ... In assertive outreach, the worker goes to see the client in his or her environment - be that home, a cafe, a park or in the street – wherever it is most needed and most effective. Housing departments, police stations, social security offices and inpatient units can also be suitable locations for meetings between client and assertive outreach team workers." (The Sainsbury Centre for Mental Health, 2001)

- 4.4 Clients are offered academic or vocational assessment if required within three months of referral to the program.
- 4.5 Programs have formal service agreements (such as a letter of agreement) with education programs, vocational training programs, skills programs, career programs, housing supports and substance abuse treatment services including withdrawal management services.
- 4.6 Programs assertively negotiate/advocate with education, training, skills, housing and other programs to give clients diagnosed with early psychosis priority for service.
- 4.7 The team supports the client in making links with other services, including accompanying the client to community programs as needed.
- 4.8 Programs encourage healthy peer support. They link clients to peer support services in the community. If no such service exists, programs create opportunities for clients to connect with same-age peers.
- 4.9 The team, client and family monitor the client's progress in achieving educational, vocational and other personal goals.
- 4.10 Programs will address the client's emotional, social, developmental, and/or psychological issues related to the illness and their recovery through individual or group counselling.

## 5. Family Education and Support

#### **Background**

When people develop psychosis, their families are intensely affected and will need significant support – regardless of whether the person is living within or outside the home.

See section 2.2 for the definition of "family."

Families also play a key role in assisting with assessment, and in supporting the person through treatment and recovery, and have the important knowledge about the person. When families and friends are actively engaged in the early intervention program, the client's long-term outcomes improve significantly (J. Addington, Collings, McCleery & D. Addington, 2005). The outcome is also better for the family: the family experiences less stress and disruption, is better able to cope with their relative's illness, and is more empowered. Families can also be a significant source of support for other families going through the same experience (Norman, et al., 2008).

Families need education and support to be able to fulfill these roles (Hamilton Wilson, Hobbs & Archie, 1999). Education and support provided by EPI programs, directly or through appropriate referrals, will include:

- involvement in the client's clinical care, with the client's consent
- services for the family itself including psychoeducation, and assistance with income, employment and housing issues for the client
- a proactive approach to connecting families with self-help groups

#### **Standards**

5.1 Programs use assertive outreach to provide support for the family and actively engage the family in the family member's ongoing care (with the client's consent).

See section 4.1 for the definition of "assertive outreach."

- To encourage the family's full engagement, programs provide education about:
  - the illness and symptoms
  - the role of treatment, including medications and side effects
  - acute symptom management, including safety risks
  - rights and responsibilities
  - the impact of substance use on psychosis (including alcohol and marijuana)
  - how to support their family member during treatment and recovery
  - how to help the family member manage the illness
  - stigma associated with mental illness and how to cope with it
  - how to sustain recovery and prevent relapses
  - services and supports in the community
  - acute symptom management, including safety risks
- 5.3 The team assesses and identifies the family's needs, and works with the family to develop a support plan.

- Programs keep the family informed about the young person's progress, and involve the family as often as possible in psychiatric consultations and key treatment meetings (with the client's consent).
- 5.5 The team has at least monthly contact with the family.
- 5.6 The team identifies or develops appropriate opportunities for families to connect with support groups, network with other families, and train to be peer facilitators.
- 5.7 Programs provide ongoing support for families and link them with crisis support and intervention services in the community.
- 5.8 Education and support services for families may be provided by professionals and/or by other families who have experienced similar challenges.

#### **Actively Promoting Family Involvement**

When clients do not consent to having their family involved, programs assertively promote the family's role by explaining that the road to recovery is smoother with family support. If clients still refuse, the team informs the client it will continue to have contact with the family. Although team members will not be able to talk about the young person's care, they can still listen to the family's concerns and provide psychosocial support and education about psychotic disorders.

## 6. Graduation from the Program

#### **Background**

EPI is designed to be an intensive, time-limited service to help adolescents and young adults (ages 14 to 35) experiencing first episode psychosis reintegrate into or maintain their lives while learning how to manage their disorder. Most clients will remain in the program for three years. When they graduate from the program, it is crucial that they be linked to appropriate services to help them avoid crises and reduce the risk of relapse. [See section on Program Length in the Introduction.]

- When clients graduate from the program, they are linked to the least intensive, least intrusive level of care required to meet their ongoing treatment and support needs (e.g., primary/shared care, family health teams, tertiary care, such as ACT teams, and community mental health specialized programs).
- When a client graduates to another level of care, the team continues to be available to consult on his/her care.

## 7. Professional Training and Education

#### **Background**

Effective early intervention for psychosis will require skilled professionals on the EPI team and in other health and social services that play a role in early identification and/or ongoing support in the young person's recovery. Because this is a relatively young field of practice, new knowledge is being developed that must be integrated into practice.

The need for professional training and education was discussed briefly in Standard #1.

#### **Standards**

- 7.1 Programs provide orientation for new staff and ongoing training for teams in principles and best practices in assessment, treatment and support.
- 7.2 Programs provide education for health, social service and education professionals who can play a role in early identification of psychosis, including primary care providers, youth agencies, school and university health services, teachers, coaches and community mental health services (adult, youth and child). Education about early psychosis intervention should include signs and symptoms of psychosis, the use of screening tools, the importance of timely referrals, and the services available in the community.
- 7.3 Programs provide education about psychosis and the impact of both psychotic disorders and their treatment for agencies that provide educational, vocational and other support/recovery services for adolescents and young adults.
- 7.4 Programs provide education for all staff and team members in human rights, the duty to accommodate clients and families with disabilities (e.g., Braille, large print, American Sign Language, etc.) and how to deliver culturally appropriate services.

#### What it takes to work in early intervention programs...

"You need someone who is a good communicator and at ease in relationships, with a relaxed, easy going style and a sense of humour who holds an optimistic, hopeful outlook. It is important to come from value base which respects individuals and their families and culture, and sees people as people struggling to come to terms with the impact of a psychosis."

Dr. Jo Smith, NIMHE/ Rethink Joint National EI Programme Lead, UK

## 8. Research, Program Evaluation and Data Collection

#### **Background**

More information is required to identify and share best practices in EPI programs. Ontario's programs can play a vital role in ensuring the quality and consistency of services across the province and in advancing the field. Programs are expected to monitor and evaluate their services and to collect data that can be used to enhance best practices.

The Ministry of Health and Long-Term Care will work with the programs, Local Health Integration Networks and others to establish performance goals and measures for EPI programs.

- 8.1 Programs have an evaluation plan that includes:
  - a statement of the program's objectives
  - the criteria that will be used to determine whether the objectives were achieved
  - methods for documenting achievements
  - a system of regular review to evaluate the appropriateness of: admissions to the program, treatment plans, and referrals/links to other services
  - a consistent process to assess client and family satisfaction with the program/services.
- 8.2 Programs collect program data as requested by the Ministry of Health and Long-Term Care and/or the Local Health Integration Network that can be used to assess the impact of the program on access to service, hospitalization rates, client and family satisfaction, and longer-term health outcomes (e.g., return to school, gainful employment).

## 9. Client Records

### Background

As with all health programs, it is important to carefully document all treatment and support services provided for clients, as well as the assessment results that are the basis for ongoing treatment, support, education and other plans.

- 9.1 Programs will maintain a complete, accurate, up-to-date record for each client.
- 9.2 All team members will accurately document assessments, the client's wellness/recovery plans, and the nature and extent of services provided in a way that that a person unfamiliar with EPI can easily identify the client's treatment and support needs and services received. EPI networks will develop a mechanism to ensure that all organizations that are part of the network have appropriate access to client records as permitted by legislation.
- 9.3 All records that contain personal health information, as defined in the *Personal Health Information*Protection Act 2004, (PHIPA), including any records it receives about a client, will be maintained in a confidential and secure manner.
- 9.4 The collection, use and disclosure of records of personal health information and access to such records by clients, service-providers and third parties is subject to PHIPA.

# 10. Health Legislation and Complaint Resolution Procedures

#### **Background**

Programs must comply with provincial legislation in respect of health records and consent to treatment. Programs must also work to resolve complaints fairly and efficiently, and have a transparent mechanism to redress complaints.

- 10.1 Team members are knowledgeable about their obligations under the legislation mentioned above and the agency's complaints mechanism.
- Programs have established client and family-friendly policies and procedures for addressing and resolving complaints that are transparent, accessible, confidential, and timely.

## 11. Barrier-Free Services

#### **Background**

Whenever possible, programs should reflect the diversity of the communities they serve, and team members should be aware of cultural factors, such as traditions, customs, attitudes, beliefs and behaviours, that may affect a person's ability to participate in services.

#### **Standards**

- Programs must adhere to the requirements of human rights and accessibility legislation when providing services.
- Programs implement strategies to recruit, retain, and promote a diverse staff who reflect the demographic characteristics of the service area.
- 11.3 Programs offer and provide services in the client's preferred language either directly or using interpreter services at no cost to the client or family. Family and friends should not be used to provide interpretation services (except by request of the client or where interpreter services are not available).
- Programs provide client and family information that is easy to understand, and post signs in the languages commonly used in the service area.
- 11.5 The physical environment and setting must reflect the needs of the client in that it is youth-oriented, family friendly, and stigma-free.
- Any member of the community or a community's Early Identification/Rapid Response System may refer clients to the program. Clients may self-refer. A physician's referral is not required.

See page10 for a description of the community's Early Identification/ Rapid Response System

## 12. Program Networks

#### **Background**

EPI programs vary in size, complexity and program design. The ministry's *Program Policy Framework for Early Intervention in Psychosis* allows for this variety and recognizes that communities can vary considerably across the province. EPI programs have built upon and used services already existing within their communities.

Urban programs, for example, may largely be centralized with a multidisciplinary team that provides for most of the services needed by clients from within the team. Or, an urban program may actually consist of a host of large and small separately funded programs that need to work together to provide the range of services required by the client. EPI programs serving both urban and rural communities may have centralized services for the urban centres, but operate associated offices for rural communities, where these offices provide a smaller range of services. Others EPI urban/rural or rural programs may be more decentralized, with one major provider operating in various locations, but working with other local mental health and social service providers to provide the full range of necessary services. Finally, some EPI programs may be smaller but work with existing community mental health programs largely using a train-the-trainer model and providing consultation and support to these programs in order to meet client needs.

All programs, large or small, urban or rural, centralized or decentralized, will likely need to work with other service providers to make arrangements for those components of a comprehensive service that an individual EPI program is not able to deliver.

- 12.1 The locus of responsibility to meet all the Ministry of Health and Long-Term Care EPI standards rests either with a single agency or program that provides EPI services, or with a "Program Network" of service providers.
- 12. 2 In communities where multiple service providers exist, EPI programs are required to participate in a Program Network. Program Networks must bring the requisite EPI programs together to meet the standards.
- 12. 3 Individual EPI programs are strongly encouraged to sign a written network agreement that states that specifies:
  - that each program will participate in and support the Program Network
  - the role or roles of the participants
  - that individual programs will work together with each other to meet the ministry's standards

## 13. Accountability

#### **Background**

Local Health Integration Networks (LHIN) became responsible for funding adult community mental health services on April 1, 2007. Agencies with EPI programs are accountable to the LHINs.

The Ministry of Health and Long-Term Care establishes requirements for EPI to ensure accountability for both use of public funds and the quality of service delivery.

- 13.1 Sponsoring agencies are required to sign service accountability agreements with the appropriate LHIN and meet LHIN requirements for community mental health programs.
- Programs that experience problems implementing any of the EPI standards should document these problems.
- 13.3 Programs are encouraged to communicate with their Local Health Integration Network if they experience any difficulty meeting any program standards.
- Programs are required to submit regular data reports in accordance with ministry and LHIN requirements. (See Section #8.)

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Ian Chovil, Consumer Consultant, Homewood Health Centre

Maurice Fortin, Executive Director, Canadian Mental Health Association, Thunder Bay Branch

Heather Hobbs, RN Care Coordinator, Cleghorn Early Intervention in Psychosis Program, Hamilton

Gord Langill, Coordinator, Lynx Program, Peterborough

Ursula Lipsky, Family Sector Representative, Schizophrenia Society of Ontario

Joan Nandlal, Manager, Community Support and Research Unit, Community Research, Planning and Evaluation Team, Centre for Addiction and Mental Health

Ross Norman, Professor, Departments of Psychiatry and Epidemiology and Biostatistics, University of Western Ontario; and Prevention and Early Intervention Program for Psychoses, London Health Sciences Centre

Karen O'Connor, Director of Specialized Services, Canadian Mental Health Association, Toronto Branch

Paul Roy, Director, Champlain District First Episode Psychosis Program

John Trainor, Chair, Ontario Working Group on Early Intervention in Psychosis

#### Other individuals:

Suzanne Archie, Clinical Director, Cleghorn Early Intervention in Psychosis Program, Hamilton Jean Bacon, writer

Gretchen Conrad, Psychologist, On Track-First Episode Psychosis Program, The Ottawa Hospital

Ministry of Health and Long-Term Care staff:

Brian Davidson, Manager, Mental Health & Addiction Branch, Community Health Division (CHD)

Sandy Doberstein, Senior Policy Analyst, Mental Health & Rehabilitation Policy Unit, Integrated Policy and Planning Division

Catherine Ford, Sr. Program Analyst, Mental Health & Addiction Branch, CHD; Sr. Policy Advisor, Health Program Policy & Standards Branch, Health System Strategy Division

Rick McInnes, Mental Health Consultant, East Region, Acute Services Division and CHD

Wayne Oake, Manager, Mental Health & Addiction Branch, CHD

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