Standards and Guidelines for Early Psychosis Intervention (EPI) Programs

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Standards and Guidelines for Early Psychosis Intervention Programs

QUALIFYING STATEMENT

This document identifies minimum program requirements for evidence-based Early Psychosis Intervention (EPI) programs as well as guidelines to facilitate implementation and ongoing operations of these programs. Successful EPI programs demonstrate improved client outcomes and follow similar standards to those identified in the document, including, for example, low client/staff ratio, use of multidisciplinary teams, specialized assessments and interventions, client and family psycho-education, and staff training on best practices.

The standards and guidelines identified in the document are based on:

- A thorough review of published research evidence
- Examination of existing national and international services
- Direct consultation with experts in the area of early psychosis as well as representatives from the BC Health Authorities, Ministry of Health Services and Ministry of Children and Family Development

The information contained in the document reflects the knowledge and evidence as of the time of its release. As new research gathers, standards and guidelines will need to evolve to ensure clinical practice is based on the best evidence. Efforts for continuing quality improvement, as well as opportunities for knowledge exchange and consultation will be key in ensuring that clinical practices remain current and that clients continue to receive services that result in the best possible outcomes.

Executive Summary

Psychotic episodes are most commonly associated with psychiatric diagnoses such as schizophrenia, schizophreniform disorder, bipolar disorder and major depression (with psychotic features). Their impact on individuals, their families and society is enormous. Such conditions often arise in late adolescence or early adulthood and are associated with decreased quality of life, shortened life expectancy, increased risk of other mental and physical health conditions, and forestalled opportunity for educational, vocational and social advancement. Indeed, the World Health Organization has noted that active psychosis is one of the most disabling of all types of health conditions.

A fundamental principle underlying provision of care for any health condition is that identification, diagnosis and treatment should occur as early as possible to maximize the likelihood that intervention will successfully minimize the burden of suffering, functional decline and societal costs. Unfortunately, this principle has not been applied judiciously in mental health and addictions in general, and with psychotic disorders in particular. Many individuals and their families have been left to languish, relegated to marginal economic, vocational and residential status and have been provided interventions designed to manage the most troublesome symptoms with little expectation of improvement or recovery. This situation is both a result of, and contributes to, the enormous stigma associated with psychosis.

This situation has improved over the last decade as clinicians, people with early psychosis, families, policy-makers and researchers have increasingly embraced Early Psychosis Intervention (EPI) programs. EPI programs, whose effectiveness enjoys ever-increasing empirical support, provide timely recognition and assessment, comprehensive interventions and wide-ranging supports that maintain individual functioning, autonomy and hope through an engaging and respectful approach.

When EPI is done right the results are impressive.

Early psychosis intervention programs have been shown to decrease duration of untreated psychosis, decrease hospitalization, decrease police involvement in admissions, lower medication use, improve functional outcome, lower relapse rates, improve treatment adherence and lead to greater patient satisfaction. These programs have been shown to be cost-effective in other jurisdictions.

EPI has been a welcome counter to the pessimism that has accompanied the onset of a psychotic disorder, as it seeks to dispel myths and prejudices about psychotic disorders while generating realistic hope about the benefits that can result from early treatment. In many ways, EPI has been at the forefront of the system reform needed to improve upon the disappointing outcomes associated with past approaches. EPI programs are specialized and frequently offer a suite of services that may differ in type and intensity from those employed by many existing mental health and addictions services. EPI programs are especially careful to cultivate initial and prolonged engagement of clients and families by pursuing practices that are sensitive to choice, non-stigmatizing and respectful of diversities such as age and culture. In addition to services to individuals and families, EPI programs involve educational and informational activities for the public and health professionals that raise awareness, reduce stigma and facilitate early identification and intervention.

British Columbia was an early supporter of the EPI approach. EPI substantively arrived in British Columbia in 2000 as a result of an inter-ministerial and inter-agency initiative that spurred interest, trained numerous stakeholders and funded a series of pilot projects designed to begin the implementation of EPI clinical services throughout the province. As a result, several EPI programs were established across BC. In 2004, a survey commissioned by the BC Schizophrenia Society revealed considerable variability in the structure, scope and practices of EPI services in British Columbia. One finding that merited consideration was the greater inclusion of best practices by those services designated as EPI programs, compared to those that tried to offer early psychosis services within traditional mental health teams. Programs with mandates that bridged child/youth and adult age ranges appeared most likely to attain greater levels of compliance with recommended clinical guidelines. A follow-up survey (2008) conducted in preparation for the development of the standards and guidelines revealed some improvements but also a number of inadequacies. The findings underscored the need for the establishment of a set of cohesive standards that will ensure that the planning, organization, implementation and evaluation of services are accountable and are conducted in a manner that will provide optimal care to clients and their families. These Standards and Guidelines will allow EPI programs to continue to evolve as a key element in the delivery of mental health and addictions care in British Columbia.

The Standards and Guidelines were developed at the request of the Mental Health and Addictions Branch, Health Authorities Division, British Columbia Ministry of Health Services (MoHS), and the Provincial Psychosis Network supported by the Provincial Health Services Authority (PHSA) to establish a set of standards and guidelines to ensure that all EPI programs in British Columbia provide services that are consistent and adhere to evidence-based best practices. The primary purpose of the document is to make certain that individuals with psychosis (and their families) receive timely, effective and compassionate support through the first years of recovery after the onset of a psychotic disorder. The Standards and Guidelines are specifically directed at those community-based programs operating under the auspices of the current Health Authorities. It is, nevertheless, hoped that programs operated by other government ministries such as the Ministry for Children and Family Development (MCFD) will adopt or adapt these recommendations to their own programs and services.

The standards and guidelines in this document are based on a review of the best existing available research evidence with respect to early psychosis interventions. This includes appraisal of existing standards and guidelines from other national and international jurisdictions as well as consultations with national and international research and clinical experts and informed stakeholders. Existing programs in BC were surveyed and focused discussions were held with relevant ministry representatives and stakeholders. Development of the document was guided throughout by ongoing consultation with an invitational advisory committee composed of researchers, regional representatives, providers and clients/family members.

These Standards and Guidelines are organized along the continuum of care from:

- Recognition (appropriate knowledge of the nature of the problem)
- Access and Intake (timely, barrier-free assessment)
- Required Services (professional skills and programming to provide diagnosis and treatment)
- Program Structure (infrastructure, staffing, education and supervision necessary to maintain the program)
- Quality Improvement (ongoing process and outcome evaluation to ensure adherence to standards and program evolution)

Each of these categories is broken down into specific subsections. These include a:

- Rationale for adoption of the standard
- Statement about the intended outcome of the standard
- Description of the nature and application of the standard
- Minimal, measurable standard set of recommended guidelines for aspirational goals that exceed the minimal standards
- List of key performance indicators for each standard

It is recognized that EPI programs are also part of a larger spectrum of care including, but not limited to, primary medical care, housing and residential services, educational and employment programs, and other mental health and addiction services. Consideration is also given to the fact that there will be variability across the province in how the Standards and Guidelines are applied, particularly between rural and urban programs. A "case study" is provided to illustrate the differences between optimal care and less optimal treatment for persons with psychosis. A resourcing model was also developed to assist in the determination of adequate staffing requirements for urban and rural EPI programs. Finally, the document includes a glossary of terms specific to EPI, a summary of existing national and international standards and guidelines, an abbreviated literature review of important recent developments in the field, a review of the challenges faced by rural communities, the 2008 survey results and a list of key references.

Early Psychosis Intervention programs represent an opportunity for re-establishing hope. They are also at the forefront of the delivery of mental health and addictions services in British Columbia as they thoughtfully reflect the necessity to tailor programs to meet the unique characteristics, needs and potentialities of particular subpopulations. The barriers encountered, lessons learned and successes achieved will guide progress for the future. This document is intended to facilitate and guide that process while providing an evaluative framework. It is important to subject EPI programs to regular empirical scrutiny, since they must be accountable if they are to continue to achieve greater successes and better outcomes for clients, families and society.

Background

The social, economic and clinical merits of providing early identification and intervention in the course of many health conditions and diseases have been endorsed for decades, although adoption has been slow in mental health. Fortunately, recent years have seen a growing interest in Early Psychosis Intervention (EPI). Jurisdictions around the world, including British Columbia, have embraced the opportunity afforded by EPI to combat the professional and societal stigma frequently associated with severe mental disorders, advocate for system reform to better serve individuals and families affected by these disorders and focus efforts on a relatively neglected segment of psychiatric services. The emphasis on early intervention broadens the spectrum of care available and helps address the societal stigma through its educational and early detection strategies.

These Standards and Guidelines reinforce British Columbia's position as a leader across Canada and internationally in advancing clinical services in early psychosis.

Efforts to create capacity and deliver quality EPI programs in British Columbia have been ongoing for a decade. From 1999 through to 2002, the BC Ministry of Health Services and Ministry of Children and Family Development provided the funding for a provincial Early Psychosis Initiative. This was an inter-ministry and inter-agency initiative with partners that included the Ministry of Education, BC Schizophrenia Society and Canadian Mental Health Association. Over the duration of this initiative, regions were provided with the funds, training and tools necessary to provide community early identification education, and several regions were provided with the funds to set up innovative clinical programs. A number of supporting tools were developed by the Ministry of Health, including *Early Psychosis: A Care Guide*, which detailed the range and type of best practices for early psychosis intervention (1).

Over the past decade, there has been considerable growth in the number of EPI programs within BC. In 2004, a cross-sectional survey assessing the state of early psychosis care delivery was undertaken by the British Columbia Schizophrenia Society (BCSS). Responses from the 12 specialized EPI programs indicated great variability in terms of program organization, staffing and the approaches and comprehensiveness of services provided. Across the province, EPI programs performed better on all but one of the indicators employed in the survey, compared to those areas without formal EPI programs.

EPI is a core component of mental health and addictions services and so must be applied in a consistent and optimal manner. A need exists to move beyond the available guidelines for practice and develop minimal standards that will help ensure that the planning, delivery and evaluation of services are undertaken with sufficient care and forethought, so that EPI will continue to evolve and meet the needs of those affected by the onset of psychoses.

The Burden of Psychotic Disorders

Psychotic conditions constitute a major health issue. A person in the midst of a psychotic episode experiences tremendous distress and may engage in actions dangerous to self or others. The burden resulting from psychosis is substantial. The onset of most psychotic disorders in late adolescence severely disrupts the capacity to meet developmental milestones. Social, sexual, academic and vocational pursuits are threatened, as are consolidation of personal independence, identity and values. Family relationships are often severely stressed, and individuals experiencing psychosis are prone to other psychopathologies, victimization, poverty and increased medical problems.

According to the World Health Organization, about 2% of all disability-adjusted life years (i.e., years of "healthy living" lost) are accounted for by schizophrenia and bipolar disorder, and the average life span of those afflicted is decreased by about 10 years (2). About 40% of males and 25% of females with these disorders living in Western nations show persistent moderate to severe disability (3).

Together with the horrific personal costs to individuals and families come immense economic and societal costs. The World Health Organization (WHO) ranks active psychosis as the third most disabling health condition — higher than paraplegia and blindness.

The most common diagnoses associated with psychosis are schizophrenia, schizophreniform disorder, schizoaffective disorder, bipolar disorder and major depression with psychotic features. The use of substances that can induce psychosis has increased significantly in recent years and clinicians are encountering such psychotic presentations in many settings around the world.

Most psychotic disorders tend to follow a relapsing course wherein periods of acute psychosis are preceded by periods of disruption (a 'prodrome') and followed by recovery, deterioration and the subsequent re-emergence of florid psychosis. Conceptualizing the disorder as consisting of these phases suggests that different strategies become appropriate for assessment and treatment at each stage (4).

With respect to outcome, when all psychotic disorders are considered, about half of patients receiving traditional mental health services are considered to have a good outcome after 15 years (schizophrenia 38% versus other psychoses 55%) (5). However, if more stringent criteria are used that exclude patients who had an episode of treatment in the previous two years, showed no symptoms and enjoyed a reasonably high level of functioning, the proportion of recovered patients falls to 16% for those with schizophrenia and 36% for those with other psychoses (5).

These poor outcomes have led many clinicians to fear that a diagnosis of schizophrenia or other psychotic disorders is tantamount to a sentence of deterioration despite therapeutic interventions. Furthermore, many clinicians working in tertiary settings such as psychiatric hospitals or with long-term care community teams work only with individuals suffering from the most extreme forms of these disorders. The research into outcomes was also largely conducted using samples of "chronic" patients. Combined, these factors produce a large degree of pessimism that has been referred to as "therapeutic nihilism" (6). In turn, these attitudes may compromise these individuals' care. Clearly, those affected by psychotic disorders desperately need the attention of research and innovative service delivery models that could improve upon the outcomes achieved over the past century.

The introduction of the atypical antipsychotic medications, a renewed interest in social and psychological processes such as neuropsychological functioning, the ongoing shift to community care, and new psychotherapeutic applications such as cognitive therapy set the stage for a new era of helping those with psychotic disorders. These developments, combined with research into the causes and determinants of the major psychotic disorders produces a new optimism and increased interest in the onset and early stages of psychotic disorders. Newer research indicates that young persons with psychoses often experience significant delays before assessment and treatments begin. Admission and interventions are often experienced as traumatizing, alienating and poorly applied over time (4). Together, these factors have motivated the creation and refinement of service delivery systems around the world, such as the Early Psychosis Prevention and Intervention Centre (EPPIC) program in Melbourne and the International Early Psychosis Association. Despite the research efforts of these programs to use data to refine clinical practice, there remain many areas of clinical care that do not enjoy quality research support. The pioneering innovations made in response to perceived clinical need are being refined and subjected to empirical validation. Thus, although the challenge of early intervention remains a work in progress, the rationale for intervening early, rather than late, retains a compelling logic.

Rationale for Early Psychosis Intervention

Early intervention seeks to improve both short- and long-term outcomes (7, 8). In the shorter term, faster intervention reduces the immediate suffering and danger incurred by the onset of psychosis. Onset typically occurs in late adolescence or early adulthood, causing a major disruption in the ability of individuals with the disorder to meet developmental challenges. Family relationships suffer and parents and siblings experience significant distress (9). Individuals experiencing psychosis are more prone to suicide, depression, aggression, substance abuse, cognitive impairment and anxiety disorders, with these risks highest in the first few years. One in ten people with schizophrenia commits suicide and about two-thirds of suicides occur within the first five years (10).

The link between early intervention and longer term outcomes arises, in part, from the fact that it often takes several years for a person and his or her family to receive proper help after the onset of symptoms of psychosis (11). Lack of awareness of psychotic disorders, ambiguous early symptoms and stigma all contribute to the delay in linking persons with appropriate help. These long durations of untreated psychosis (DUP) are usually associated with slower and less complete recovery, more biological abnormalities, more relapses and poorer long-term outcomes (12, 13, 14). Although the relationship between the duration of untreated psychosis and outcomes awaits further clarification (15), truncating the time to effective treatment is one of several ways to improve long-term outcomes.

The early phase of psychosis is also when deterioration in functions and abilities occurs at the greatest rate. Thus, the early phase may represent a "critical period" for determining long-term outcome (16). It may also represent the time of greatest potential for intervention because course-influencing variables, including patient and family

reactions, develop and are most amenable to positive change during this time (17).

Both short- and long-term outcomes are affected by the relationship between services and clients and families. Currently, most mental health and addictions services are failing youth (i.e. adolescents and young adults) with psychosis. Youth report that mental health and addictions services are stigmatizing, therapeutically pessimistic, and youth insensitive (18). Youth are also frequently unwilling For all psychotic disorders, the better the short-term course, the better the long-term outcome - with the percentage of time spent with psychotic symptoms in the first few years being the best predictor.

to readily accept a medical model of care with which they are unfamiliar. Engagement of youth and their families with services is often compromised, as evidenced by reports from routine service settings that over half of all clients are lost to services within twelve months (19). Youth are also extremely sensitive to the effects of antipsychotic medications, and the appearance of side effects may lead to discontent and non-adherence. Finally, regular mental

health and addictions services generally lack the personnel training and resources necessary to provide the range and intensity of services required for effective early intervention.

To address the unmet need, specialized early psychosis intervention (EPI) programs have been established across many jurisdictions throughout the world, including British Columbia.

Effective early intervention seeks to address the problems by providing services that:

- Are age-appropriate supports that minimize disruption and enable clients to more successfully meet their developmental challenges
- Limit the suffering and possible negative repercussions of psychotic behaviour
- Engage families throughout the course of treatment and provide them with support, education and skills training
- Effectively treat associated problems such as suicidal tendencies, depression, aggression, substance abuse, cognitive impairment and anxiety disorders, rather than simply assuming that these features are secondary phenomena
- Reduce the stigma associated with psychosis
- Improve awareness among the public and professional gatekeepers of symptoms and the need for early treatment
- Reduce the duration of untreated psychosis
- Engage youth and young adults and families in meaningful and collaborative ways
- Base the use of treatments and other procedures on evidence of their usefulness
- Promote recovery, stability, self-determination and personal fulfilment
- Respect and accommodate diversity
- Integrate other service providers into a seamless fabric of support that addresses medical, educational, occupational and social needs

In order to provide these services optimally, EPI caregivers must nurture their willingness to respect clients and work with them in non-traditional ways. This includes remaining sensitive to factors that may hinder successful ongoing treatment, such as negative effects generated by aversive procedures, medication side effects, stigma and other impediments to collaboration. EPI work demands maintaining great sensitivity to youth issues, de-emphasizing diagnosis and emphasizing management of one's life (including symptoms) and promoting choice (such as offering some services in non-stigmatising settings of the client's choice or visiting the homes of clients using an outreach approach).

An impressive and growing body of research shows the effectiveness of EPI when conducted according to the practices and principles described. , Early psychosis programs have been shown to decrease DUP (14, 20) and hospitalization (20, 21, 22), decrease police involvement in admissions (20), lower medication use (21, 22), improve functional outcome (13), lower relapse rates (23), improve treatment adherence (24) and lead to greater patient satisfaction (22). These programs have been shown to be cost-effective in other jurisdictions (25, 26, 27).

BENEFITS OF EARLY PSYCHOSIS INTERVENTION

- Better short- and long-term prognoses
- Increased speed of recovery
- Lower use of hospitalization
- Decreased risk of damaging socio-economic consequences to the individual
- Reduced secondary psychiatric problems (e.g., depression, substance abuse, etc.)
- Minimization of family disruption
- Optimization of personal assets, psychosocial skills, role functions and social/environmental supports

Fundamental Components of Early Psychosis Intervention Services

Effective early psychosis intervention consists of multiple components that progress from recognition and referral, through assessment and treatment, and ultimately, to evaluation. In clinical practice, the focus of early intervention is on the early phases of psychosis.

International interest in early psychosis intervention is growing. There are many well-developed services throughout the world, and new programs are forming. The rapid growth in interest produces the risk of uneven or inadequate practices being provided because of a limited conceptualization of the pertinent issues. The implementation of well-intentioned but piecemeal interventions in the absence of adherence to sound theoretical or evidentiary bases is unlikely to produce the desired results. The evolving research on early psychosis intervention suggests that the interaction between the elements of suite of EPI services is potentially much greater than the sum of its parts. Therefore, it is important both for the integrity of the field and for persons with early psychosis that early intervention is applied comprehensively and in accordance with the identified clinical needs.

There are now a number of published standards and guidelines that outline fundamental principles and best practices of care that apply to all the components of early psychosis intervention (see Appendix I). It is recognized that fundamental components can be incorporated into a variety of models that all retain fidelity to the primary goals and practices. The following figure outlines the fundamental components of early psychosis intervention, and details regarding these components are explained within the standards listed later in this document.

FIGURE 1: FUNDAMENTAL COMPONENTS OF EARLY PSYCHOSIS INTERVENTION

RECOGNITION

Recognizing that a problem exits

- Public awareness education
- Education targeting high-risk groups
- Clinician training
- Gatekeeper training

REFERRAL

Linking individuals to care providers

- Increasing public and professional awareness of available services
- Ready access to services
- Streamlining the referral process

ASSESSMENT AND TREATMENT Optimizing treatment and alliances

- 0 Family involvement
- 0 Comprehensive strategies
- O Biopsychosocial considerations
- Best-practices care
- Normalized recovery context

EVALUATION Continuous quality

improvement

- Measuring individual and program outcomes
- Assessing societal impact
- 0 Research

EPI and the Continuum of Care

People with early psychosis require the same comprehensive continuum of care provided to other client populations served by mental health and addiction services. EPI programs will provide many services and will serve a coordinating function with other appropriate services. An integrated child, youth and adult service continuum is essential for this client population in order to respond to the ages at onset of psychotic disorders.

FIGURE 2: EPI AND THE CONTINUUM OF CARE



Early Psychosis Intervention in British Columbia

Over the past decade, there has been considerable growth in the number of EPI programs within BC. In 2004, a cross-sectional survey assessing the state of early psychosis care delivery was undertaken by the British Columbia Schizophrenia Society (28). The survey was administered to a range of urban and community service providers across the province. Responses were received from 23 communities (representing a response rate of 46%). Twelve communities indicated that they operated specialized early psychosis programs and were examined in greater detail.

Results from the general survey of community services indicated high ratings for accessibility and the training/skill level of practitioners. Most sites reported that appropriate fundamental medical and psychosocial services were being provided (i.e., pharmacotherapy, case management and education for clients/families were virtually universal). However, the amount of time allotted to clinicians to pursue early intervention work was found to be limited. Public education initiatives were ongoing in less than half of the settings and appeared to be particularly lacking among sites where early psychosis clients were seen as a part of routine services. Responses from the 12 specialized EPI programs indicated great variability in terms of structure, staffing, approach and comprehensiveness of services provided. All sites reported that they provided medication management, education to clients/families and individual social interventions. However, only half of the sites reported explicitly following a phase-specific approach to treatment. Levels of outcome evaluation, program evaluation and research activity varied significantly, with only a few programs attaining a high degree of participation in these endeavours. However, despite limitations in the depth and comprehensiveness of services provided, analyses comparing areas with and without designated EPI programs revealed an apparent superiority of specialized programs on several indicators of practice (e.g., accessibility, clinical expertise, continuity of care).

In order to inform the development of EPI standards and guidelines for BC, another survey (adapted from the one used in 2004) was conducted in December 2008. This survey was also administered to a sampling of community EPI service providers throughout urban and rural areas of the province, and provided an updated account of specialized service delivery efforts. Responses revealed a number of program strengths and encouraging patterns of practice. Accessibility was found to be high, as all 15 sites surveyed had adopted inclusive admission criteria (i.e., inclusive of comorbid substance use, affective psychosis) and open referral systems. Significant outreach components for assessment and treatment were also offered by the majority of sites (73% and 80% respectively). Fundamental medical and psychosocial services continued to be well established among sites, as the majority offered psycho-education to clients and families (100%), individual social interventions (100%), medication management (87%), and group interventions (67%).

On the other hand, survey results also highlighted ongoing challenges to the development and maintenance of EPI programming in BC. Qualitative and quantitative responses underscored the need for improved access to specialized services (e.g., housing/residential, recreational/vocational rehabilitation, neuropsychological assessment) and limitations in staffing/program capacity. Problems with continuity of care and integration (e.g., between inpatient and outpatient services, youth and adult services) were also prevalent. Variable levels of program evaluation and research were found (e.g., 7% reported using measures of program accountability, 67% track individual client outcomes, and 33% engage in some form of research activity). Uptake of best practices (such as accessibility, psychiatric service provision, psychosocial intervention, phase-specific intervention and public education) varies widely among both urban and rural programs providing EPI programs in BC. In general, specialized EPI programs demonstrate better uptake of best practices than non-specialized programs. However, limitations in staffing,

resources, and comprehensiveness of services continue to plague even well developed specialized programs. Significant work remains to be done if the benefits of intensive early intervention for this population are to be achieved. Priorities for future development should include standardized assessment, ongoing program evaluation, community-wide education and improving the capacity of EPI-specific programming and resources.

The survey of practices in BC shows great variability in the breadth and intensity with which services are delivered. It highlights the need for programs to develop and implement self-evaluative methods that will ensure fidelity to best practices and quality improvement. The scan also suggests that fiscal and practical constraints often prevent programs from achieving the full range of best practices. When fidelity to EPI practices is compromised, desired outcomes are less likely to be achieved. In turn, doubt concerning the value of the approach may develop, with the attendant risk of resources being re-allocated to other services. Although extensive guidelines exist, the most fundamental practices and services required to claim that an EPI approach is being utilized have not been outlined.

The current document describes standards and guidelines for designated EPI programs in British Columbia. The standards set the minimum requirements for the provision of essential core services to individuals with early psychosis and their families. Recommendations and guidelines for optimal services are also provided. Finally, strategies for implementing EPI in rural and remote areas are outlined, as it is recognized that such regions face additional challenges in providing EPI services.

Overview of the Standards and Guidelines

The primary purpose of the Standards and Guidelines is to ensure timely, effective and compassionate support through the first few years of recovery from the onset of a psychotic disorder.

Accordingly, these Standards and Guidelines outline:

1) The client population for whom EPI is intended

2) The required types and intensity of interventions and services

3) The staffing needed to competently provide the services

4) The liaison activities needed to embody EPI programs within the larger continuum of public and private resources

5) Suggested measures and practices pertinent to the evaluation needed to ensure fidelity, accountability and effectiveness

This document lists minimum standards for ensuring that EPI programs provide services consistent with evidencebased best practices. The minimum standards have been reviewed and approved by the Provincial Mental Health and Addictions Planning Council, which includes representatives from all the health authorities. The approved standards are not expected to have resource implications.

In addition to the minimum standards, the document also contains guidelines that illustrate the differences between minimal and optimal services and provide guidance regarding areas that need to be targeted for further development. These guidelines are therefore aspirational but have the potential to be implemented as standards in the future, if and when resources become available.

Scope

The Standards and Guidelines are intended for use by Health Authorities to develop, implement and evaluate EPI programs.

- The Standards and Guidelines define what is required to designate a service as a specialized EPI program within the jurisdiction of the Health Authorities in BC. It is highly desirable that other jurisdictions providing services to this population, the Ministry of Children and Family Development, for example, also adopt these Standards and Guidelines in order to ensure continuity and consistency of services across the province.
- The intended focus of these Standards and Guidelines is on EPI programs operating in community settings, including the interaction of these programs with inpatient units. However, practices appropriate to hospital and other inpatient settings are not addressed in these Standards and Guidelines.
- This document acknowledges areas in which the minimum standards may differ between rural and urban areas.
- The Standards and Guidelines apply to services for youth and young adults with early psychosis and their families, as this covers the age range in which the onset of psychosis is most likely to occur (i.e., early

adolescence to mid-thirties). "Family" is defined broadly to include both nuclear and extended family members as well as other significant supportive individuals.

- For the purpose of this document, early psychosis includes psychosis associated with affective disorders and non-affective disorders (including schizophrenia spectrum), as well as substance-induced psychotic disorder.
- The Standards and Guidelines are not intended to replace, but rather to complement and augment, existing mental health and addictions policies and procedures where specifically relevant to the provision of care for clients with early psychosis and their families. Existing legislation, such as the Mental Health Act and the Freedom of Information and Protection of Privacy Act, as well as policies and regulations specific to the Health Authorities (with respect to areas such as record-keeping, supervision, rights, consent, complaint mechanisms, etc.), should all be adhered to in addition to the practices outlined herein. EPI programs are conducted in an ethical and professional manner according to standards followed by mental health and addictions programs in BC. Particular attention must be paid to the vulnerability of this population, especially with respect to consent issues, stigma issues, and the sharing of information.

Methodology

These Standards and Guidelines are based on the best available research evidence coupled with input from experts and relevant stakeholders. The principal activities undertaken to support development of the Standards and Guidelines included:

1) A review of existing standards and guidelines documents (see Appendix I for summary)

2) A review of internationally recognized and renowned EPI programs (see Appendix II for summary)

3) A review of the recent scientific literature on early psychosis and the effectiveness of service delivery models and interventions (see Appendix III for summary)

4) A review of the literature on EPI service provision in rural areas (see Appendix IV for summary)

5) An update to the survey of BC EPI programs and the services provided (see Appendix V for summary)

6) Development of and preliminary validation of a model to inform the resourcing required to adequately run an EPI program (see Appendix VI for summary)

7) Consultation with members of an EPI Advisory Committee composed of local EPI experts, representatives from health regions, representatives from other ministries and client/family groups

8) Consultation with the Ministry of Health Services, the Provincial Health Services Authority, the Ministry of Children and Family Development, university-based academics and senior clinicians

Guiding Principles

The following principles pertaining to psychosis and early intervention inform the Standards and Guidelines:

• Care is recovery-oriented

- Care for clients in EPI programs is recovery-oriented and holistic. It extends beyond the reduction
 of symptoms to include enhancement of functioning, personal development and quality of life. The
 pursuit of fulfillment, meaning and happiness is acknowledged and fully supported.
- Clients are supported to assume a stance of active self-management.
- Assessment and treatments are not solely focused on pathology, but rather adopt a strengths-based approach.
- Individuals and families should be engaged in the program as true partners in care
 - Engagement is considered a primary therapeutic goal. Extensive efforts should be made to engage both individuals and families where possible at the time of referral and throughout the course of care. Setting treatment goals and the means of achieving them should be collaborative and ongoing. It is assumed that better engagement will lead to better outcomes, as clients will be more likely to remain in treatment. Clients should have access to the support and skills required to direct their own care to the greatest extent possible.
- Evidence-based practices lead to better outcomes
 - Evidence-based practices undertaken by trained caregivers produce better outcomes. This guide can help educate professionals as to those practices currently believed to be optimal. Practitioners should strive to stay within their competencies, advocate for and receive training where needed, and seek others' expertise through referral and consultation.
- Interventions should be phase- and age-specific
 - There are phases to a psychotic disorder: prodrome, acute, recovery, remission and relapse. Each phase carries implications for assessment, treatment and support. The types of care offered should be appropriate for the individual's age and developmental stage.
- Optimal care consists of integrated biopsychosocial approaches tailored to each individual
 - Psychotic disorders produce pervasive changes in individuals and social networks. Care must encompass the entire spectrum of areas important to an individual's wellbeing rather than focus solely on the signs and symptoms of psychosis. Psychosocial treatments have both direct effects and interactive effects when combined with pharmacological interventions targeting psychosis and associated secondary problems.
- The stress-vulnerability model accounts best for the development of psychosis
 - This model asserts that predisposing factors such as genetic constitution can render an individual susceptible to developing a psychotic disorder. The disorder becomes manifest given sufficient triggering factors. This process can apply to both initial onset and subsequent episodes of psychosis.
- Care should be provided in the most accommodating setting possible
 - The most accommodating setting is one that affords the individual the greatest possible number of personal rights and choices, yet still provides necessary services and safety.

Limitations

Several possible limitations to the outlined Standards and Guidelines should be noted:

1) These Standards and Guidelines reflect the understanding of early psychosis intervention at the time they are being written. Early psychosis intervention is an evolving field and these Standards and Guidelines will require updating as the evidence base expands. It is recommended that these Standards and Guidelines be reviewed and revised, if needed, in three to five years.

2) The practices outlined in these Standards and Guidelines are derived from studies and literature concerning adolescents and young adults with early psychosis. They may not apply to prepubescent children or older adults who may be experiencing psychosis for the first time. They may also not apply to more specific populations such as those presenting with both psychosis and developmental disabilities. There may be specific Aboriginal and other culture-related factors that are not addressed in these Standards and Guidelines.

3) EPI programs operate as one element in the continuum of mental health and addictions services that span individuals, ages and areas. As such, they must interface with services that operate within different jurisdictions, which may present considerable challenges in meeting minimum standards.

4) Psychosis is a state characterized by a loss of contact with reality. It is believed to fall on a continuum rather than representing a discrete phenomenon. Psychosis may be transient or sustained for many years. EPI concerns itself with the assessment of individuals experiencing any form of psychosis, but the ongoing provision of services concerns individuals whose psychosis is a symptom of a psychotic disorder. The Standards and Guidelines cover most psychotic disorders that arise during adolescence and young adulthood, but do not include the treatment of those experiencing psychosis as a transient intoxication (e.g., psychosis associated with the use of hallucinogenic drugs) or as a component of toxicity, traumatic brain injury or dementia.

Layout of Standards and Guidelines

This document is subdivided into five main sections:

- 1) Recognition
- 2) Access and Intake
- 3) Required Services
- 4) Program Structure and Operations
- 5) Quality Improvement

Each section is further divided into subsections that employ the following format:

- A rationale for the standards and guidelines within that subsection
- The intended outcome from the client and family perspective
- A general description elaborating upon the activities and aims of particular program elements
- A list of minimum measurable standards based on the rationale and description
- Guidelines for increasingly comprehensive services that EPI programs should strive to deliver
- A list of key performance indicators related to each standard (which are summarized again at the end of the document)

Derek: Two Possible Journeys

An illustrative case study is included at key points in the document in an attempt to "bring to life" how the Standards and Guidelines are intended to improve the care and the outcomes for individuals with early psychosis and their families.

The case study presents two possible "journeys" that could be taken by an individual after onset of a psychotic disorder. The journey through standard services is portrayed as less optimal than the journey that could be expected to occur with the intervention of an EPI program based on these Standards and Guidelines.

Derek – Background Information

Derek is a Caucasian male from a suburban community in British Columbia. Both he and his older brother had normal births. No developmental problems were noted during his early years. His father, who had a problem with alcohol, was frequently away from the home. Derek's parents divorced when he was 12, and he remained with his mother. Derek's brother remained with his father. Since the divorce, Derek has had very little contact with his brother or father. Throughout his adolescence, Derek lived with his mother, his Indo-Canadian stepfather, and his younger half-sister. Derek's mother experienced a post-partum depression after the birth of his sister, but she had no subsequent episodes.

As a child, Derek was a neat, quiet and polite boy who got along well with peers and adults. He was an average student and was actively involved in school sports. His grades started slipping in Grade 11 after a football injury that required surgery and resulted in several weeks of missed school. Around this time, Derek began to socialize with a different crowd, people who his parents considered "losers". He also started smoking marijuana, drinking (frequently to excess), and experimented with cocaine and ecstasy. He frequently skipped school and barely graduated from Grade 12.

At the age of nineteen, Derek started working in the ordering department of the construction company where his stepfather worked, as his grades were not good enough for him to go to college. Life seemed to be going quite well, as he spent much less time smoking marijuana with his friends and talked about pursuing a trade. Derek also moved into a basement suite of his own, while continuing to visit his family home for meals. Even though he seemed to be less capable than other workers at remembering when to do certain parts of a job, he was liked by his co-workers and worked reasonably well when he was able to settle into familiar tasks. Unfortunately, he was laid off due to a downturn in the housing market and began receiving Employment Insurance benefits.

Derek became increasingly moody and withdrawn during the month after he became unemployed. He spent most of his time alone watching TV and resumed smoking marijuana. His contact with his family became less frequent and he was dishevelled when he came by for a meal or to borrow money. His parents expressed concern for his reduced functioning and encouraged him to resume his previous pride in his appearance and health. His response was to become irritable and angry, and to accuse them of "messing with his life-forces". On one occasion, when his sister told him about a local restaurant that was advertising for a dishwasher, he stormed out of the house leaving a cloud of obscenities and the puzzling comment that she needed to "read between the lines" if she wanted to really know why he did not have a job.

His parents initially attributed these changes to the loss of his job and transition away from high school, expecting it would take a while for Derek to "find his foothold". His stepfather recalled that he had experimented with drugs and alcohol when he was Derek's age, and pointed out that he had turned out all right. However, as his troubling behaviour continued, Derek's parents became increasingly concerned, particularly because Derek was less communicative and sounded "stoned" when they called.

Derek's story continues in the EPI Standards and Guidelines.

Standards and Guidelines

Derek: Two Possible Journeys - Recognition

Optimal Care

Derek's parents saw a program on their community television station about mental health problems among young people. The program talked about how what may seem like normal teen or young adult "phases", such as unexpected or uncharacteristic changes in behaviour, can be the harbinger of more serious concerns. They were concerned about the changes they saw in Derek and made arrangements for him to see their family doctor two days later. Like most youth, Derek rarely had any need to see a physician, and he had never seen the woman who had been their doctor for the last nine years. His mother took him to the appointment and, with Derek's permission, joined part of the session. Derek's mother described some of the changes she had noticed, including his propensity to "sit around all day smoking pot". She was able to provide some documentation from Derek's early medical and school history. During the ensuing interview, Derek's affect was quite blunted, and he expressed little interest in social or recreational activities. He seemed to have a difficult time concentrating and staying involved in the interview and his responses were vague and inconsistent. Derek mentioned that he thought about death sometimes but did not have any intent to kill himself. He denied that anything was wrong with him and suggested that the problem was actually "out there" and they could find the problem if they "actually read the fine print". The family doctor initially thought Derek's presentation was attributable to daily marijuana use, particularly since she could smell it on his clothes. However, as the session continued and Derek continued to behave oddly, she realized something more might be going on. The physician recognized that Derek was exhibiting some features consistent with an emerging psychotic episode. She had recently attended clinical rounds describing the Early Psychosis Program in their region and had her receptionist call the local EPI team before Derek and his mother left the office. She gave Derek the information and set up a time for the team to talk to Derek further.

Less than Optimal Care

Derek's parents became more worried and pleaded with him to see a doctor. He refused to see their family physician but agreed to accept a ride from them to a local walk-in clinic. There was a 45-minute wait -so he left. A few weeks later he returned to the clinic with his mother after his parents agreed they would "lend" him some money. Derek's mother described to the clinic physician some of the changes she had noticed, including his propensity to "sit around all day smoking pot". She was able to provide some documentation from Derek's early medical and school history. During the ensuing interview, the physician noted that Derek's affect was quite blunted and that he expressed little interest in social or recreational activities. He seemed to have a difficult time concentrating and staying involved in the interview. His responses were vague and inconsistent. Derek mentioned that he thought about death sometimes but did not have any intent to kill himself. He denied that anything was wrong with him and suggested that the problem was actually "out there" and they could find the problem if they "actually read the fine print". The family doctor thought Derek's presentation was attributable to daily marijuana use, particularly since she could smell it on his clothes. In addition to his substance abuse, the physician also suspected an emerging depressive disorder and prescribed an antidepressant. She suggested that Derek visit his local mental health team and told him that the contact information was in the phone book.

I. RECOGNITION

A. Community Education – Improving Mental Health and Addictions Literacy

Rationale

Help-seeking and referrals by gatekeepers to treatment services depend upon awareness of the seriousness of mental disorders, the ability to recognize that a serious symptom might be present, and knowledge of the available resources and how to access them. The general public generally have a poor understanding of mental illness, as they: 1) are unable to correctly identify mental disorders, 2) do not understand underlying causal factors, 3) are often reluctant to seek help for mental disorders and 4) are not sure how to help others (29, 30). Additionally, gatekeeper groups (such as school counsellors, police, etc.) and health professionals under-identify the presence of psychosis (31). Educational efforts must increase mental health and addictions literacy, which is defined as the knowledge and skills that enable people to access, understand and apply information related to mental health and addictions. In order to identify psychosis early, education efforts must involve communities, including mental health and addictions service gatekeepers, health care providers, youth and their families.

Intended Outcome

Education improves early identification of psychosis. Early identification reduces duration of untreated psychosis, which leads to better outcomes.

Description

Educational activities to improve recognition of early psychosis are a core component of EPI programs. Adequate time and resources are required to ensure that a sufficiently broad range of education is delivered. Education may be undertaken jointly with other stakeholder or advocacy groups or via linkages with other educational and public awareness initiatives (e.g., Mental Health Week or initiatives under the Provincial Health Literacy Strategy). Rural areas may need to develop regional or sub-regional community education strategies and establish partnerships to engage effectively in community education. Information provided should be population appropriate and culturally appropriate. Education must provide information on how to recognize symptoms of early psychosis, access services, deliver a message of realistic optimism and describe simple appropriate responses. It should include messages targeted to a range of audiences and provide a voice to people who are and have been affected by the problem. Education should support implementation activities (e.g., training), support existing relevant policies and reflect the principles of recovery, empowerment, participation and dignity.

Minimum Standards

- i. Develop a written plan for providing community education, identifying specific targeted groups and the methods and partnerships to be used to deliver education. Educational plans are updated a minimum of every three years.
- ii. Provide targeted education to enhance mental health and addictions literacy among a range of groups including at a minimum youth, gatekeepers, physicians and other health care providers. This education must include information on facilitating the recognition of psychosis and accessing services.

Guidelines

• Target educational activities specifically to multicultural populations as appropriate for the demographics of the catchment area. Disseminate culturally appropriate educational materials and program descriptions in all major languages within the communities served.

- Undertake a wide-reaching public awareness campaign in addition to targeted educational activities within the communities served. This campaign will include information delivered via a variety of media (e.g., posters, brochures, radio, public forums, etc.).
- Link EPI-initiated, physician-focused educational activities with existing educational initiatives such as the Family Physician Guide for Depression, Anxiety Disorders, Early Psychosis and Substance Use Disorder (32) <u>http://www.health.gov.bc.ca/mhd/physicians_guide.html</u>.
- Partner with youth and families to plan and implement educational activities.

- Existence of a written educational plan that is updated a minimum of every three years
- Tracking of educational activities to specified audiences
- Tracking of referral sources (to identify groups to be targeted for education)

B. Battling Stigma

Rationale

Stigma refers to the social unacceptability of having a condition such as a mental disorder. The stigma associated with psychotic disorders is pervasive and is frequently associated with social distancing or outright discrimination. Over 40% of all Canadians would not socialize with a friend with a mental illness and half would not tell friends or co-workers they have a family member suffering from a mental illness (33). Stigma is not unique to the layperson. Studies have shown that health professionals, including mental health and addictions professionals, also stigmatize individuals with mental illness (34). Stigma is thought to be a significant factor in preventing people with mental health problems from seeking help early (35). If services themselves are stigmatizing, then this may also lead to dissatisfaction with services and early disengagement from care (18). The Mental Health Commission of Canada (36) has identified combating stigma in youth with mental illness and the stigma of health professionals as a key priority.

Intended Outcome

Self and societal stigma are diminished. Decreased stigma leads to greater societal respect for diversity, more opportunities for social integration, increased help-seeking and better engagement with services.

Description

EPI service providers must be aware of the far-reaching extent of stigma and discrimination and recognize that mental health and addictions professionals are not immune from holding stigmatizing attitudes. Community education should be designed and delivered to decrease ignorance, misconceptions, prejudice, discrimination and stigma. In addition, all program promotion and services should be developed and delivered in a non-stigmatizing manner – for example, offering services and/or outreach in youth-friendly locations. Input from youth and family members is helpful in ensuring that promotions and services are developed with sensitivity.

Minimum Standards

- i. Ensure that strategies to reduce stigma are incorporated in community education and program development plans. Use empirically-validated approaches where available.
- ii. Implement anti-stigma activities into community education activities (e.g., public forum for dispelling myths about mental disorders).
- iii. Review services for potential to perpetuate stigma, and apply corrective actions.

Guidelines

- Follow comprehensive and empirically-validated approaches for anti-stigma activities.
- Locate the program in a youth-friendly, non-stigmatizing location.
- Seek input from youth and families regularly on program promotion, education and services.
- Incorporate contact with young people who have early psychosis or their families in community education.

- Community education plans and program development plans describe strategies to reduce stigma
- Community education activities contain anti-stigma information
- Client and family surveys about whether any aspect of the program is viewed as stigmatizing

C. Finding Individuals with Early Psychosis

Rationale

Early detection approaches that involve proactively seeking out individuals with early psychosis reduce the duration of untreated psychosis compared to those approaches where services wait passively to receive referrals (35). The ability to find persons with less dramatic psychotic symptomatology is improved when EPI programs respond rapidly with outreach and include psychotic presentations that involve substance use (38).

Intended Outcome

More individuals with emerging or new psychoses and their families are likely to be helped earlier if the program actively seeks to find them rather than awaiting referral from conventional sources.

Description

EPI programs need to include proactive strategies for finding individuals with early psychosis. These strategies should involve mechanisms to ensure ongoing communication and liaison with people and places that may identify or treat individuals with early psychosis (e.g., hospitals, general physicians, private practitioners, forensic services, school counsellors, etc.). Potentially psychotic presentations should not be dismissed as solely due to substances. EPI programs should have the capacity to provide outreach to facilitate rapid screening and engagement with services as appropriate.

Minimum Standards

- i. Identify potential referral sources that require education on identifying potential EPI clients.
- ii. Develop protocols to communicate proactively with service providers and stakeholders about the presence of potential EPI clients (e.g., schools, family practices and hospitals).
- iii. Develop additional protocols for police, ambulance and other crisis intervention services to ensure EPI program linkage to such services.

Guidelines

• Link to other mental health and addictions screening initiatives aimed at other mental health conditions e.g., depression screening may find a person in distress who could be screened further for potential psychosis by EPI.

- Presence of a list of service providers who are contacted regularly by EPI staff seeking persons who would benefit from an assessment
- Updating of the list occurs at least yearly
- Numbers of first-episode clients referred compared to anticipated number of first-episode individuals withir the catchment area (the anticipated rate is approximately 25 new cases per 100,000 persons)

D. Assessment and Monitoring of Persons At Risk for Emerging Psychosis

Rationale

After the screening assessment is completed, some individuals will be found to have clear psychotic symptoms and will be considered appropriate for entry into the program, while others will need to be referred to other services. In addition, there will remain a group of persons with ambiguous presentations – they may be displaying some changes indicative of an incipient psychosis (e.g., subtle cognitive changes, minor perceptual disturbances) or they may be experiencing a general decline in functioning coupled with risk factors for developing psychosis (e.g., family history). Some of these individuals may be thought to be at risk for developing psychosis. To facilitate early detection of psychosis, it will be important to closely assess and monitor this group of individuals. Practitioners in most EPI programs in BC believe they have a responsibility to provide some service to these individuals. Research is underway to determine the risks and benefits of a number of strategies for attempting to thwart any impending psychosis, including strategies based on cognitive therapy (39) and antipsychotics (40, 41). However, it is important to note that even when using the best current research criteria, approximately 60% of all identified at-risk individuals do not make the transition to psychosis within one year (42).

Labelling individuals as at risk for emerging psychosis is associated with the following concerns: 1) research on the effectiveness of interventions is preliminary, 2) interventions such as medications expose individuals to unnecessary risks, 3) there is an unacceptably high rate of false positives, and 4) false labelling of an individual as "pre-psychotic" may lead to fear, increased stigma and the loss of opportunities. Therefore, it is recommended that interventions for these individuals commence with psychosocial strategies to deal with presenting problems such as depressed mood or social problems using cognitive behavioural therapy alone, and that antipsychotic medications should not be used until full threshold psychotic symptoms have been sustained for a week or more, or there is rapid deterioration accompanied by psychotic-like symptoms (42).

Intended Outcome

Individuals deemed to be at risk for emerging psychosis are provided with support and close monitoring. No harm should arise from any interventions that are used in an attempt to thwart a possible psychosis.

Description

It is recommended that EPI programs establish protocols for the identification, monitoring and treatment of that group of individuals who have signs, symptoms and/or risk factors and functional decline that are suggestive of the onset of psychosis but do not clearly exceed the threshold of having entered into a psychotic state. Careful consideration should be given to the vulnerability of these individuals and extensive efforts should be made to avoid any potential harms (e.g., stigmatizing the person, inadvertently increasing stress through discussion of risk, medication side effects, etc.). This is a complex and rapidly evolving area. EPI programs should adopt new developments as they are validated by empirical research. Therefore, programs should review their own practices by examining the indicators they are collecting, and by engaging in ongoing consultation with experts to ensure compatibility of practices with the latest knowledge.

Minimum Standards

No minimum standards have been approved for this section.

Guidelines

- Develop a plan for working with these individuals that outlines how assessment, monitoring and treatment will be provided.
- Monitor these individuals at least once a month for a minimum of six months.
- Provide stress management and treatment of any presenting problems (such as sleep problems, anxiety, mood problems, substance use, interpersonal problems) as needed.
- Avoid the use of antipsychotic medications until full threshold psychotic symptoms have been sustained for a week or more, or there is rapid deterioration accompanied by psychotic-like symptoms.
- Use specialized assessment tools for identifying at-risk clients performed by a clinician trained in the use of these instruments.
- Provide care in a low-stigma setting such as in the person's home or a youth-friendly, community-based setting.

Derek: Two Possible Journeys - Access and Intake

Optimal Care

The intake clinician on duty for the EPI team in Derek's region took the phone call from his family doctor and called Derek at the agreed time. During this conversation, the intake clinician asked questions about Derek's family and whether it would be okay to contact them for some more information and for them to attend an appointment with him. Derek agreed, as he would likely need a ride anyway. The intake clinician suggested an appointment two days later. The intake clinician then proceeded to call Derek's family for collateral information. Derek's mother agreed to attend the appointment with Derek. Derek and his mother were also given the option to meet in a more convenient location, but decided that the EPI office was better for them. With a call from the intake clinician, Derek's physician completed the referral form and faxed over the relevant information.

Less than Optimal Care

Derek returned home from the walk-in clinic and got high. He did not fill the prescription nor did he contact the mental health team. The walk-in clinic contacted him the following week and asked him to come in for a routine follow-up appointment and he complied. The original physician was not available and he saw a locum. The physician, observing that Derek was disheveled, lacking in interest, concentrating poorly and not expressing much emotional intensity, made a referral to a psychiatrist. The appointment with a psychiatrist was made for two months in the future. Presenting problems were described as substance abuse and a depressive disorder. Three days later, when Derek's mother dropped by his apartment with some frozen dinners for him, he initially refused to answer the door. She eventually convinced him to let her in and found him to be very agitated and disoriented, talking about how other people in his apartment complex were opening his mail and spying on him.

Derek's mother looked in the phone book to find a local mental health service. The only number she could find was a Mental Health Information Line that referred her via automated message to a phone number for a "distress line". Feeling frustrated and not knowing what else to do, Derek's mother called 911. The police went to Derek's marijuana-smoke-filled apartment, and found he was abusive, resistant and speaking nonsensically. They suspected this was a probable psychiatric matter and took him to hospital where he was eventually admitted to a psychiatric unit after a five-hour wait. Derek was tentatively diagnosed with a drug-induced psychosis superimposed on an existing major depression and was settled with loxapine. After three days, he appeared much more settled and he was discharged. The sole medication he was prescribed was an antidepressant (citalopram). He was referred to the community mental health team and placed on a waiting list to be seen in two weeks.

II. ACCESS AND INTAKE

A. Target Population

Rationale

Adolescence and young adulthood represent the peak period of onset for psychosis, regardless of race, sex or ethnicity. The onset of psychosis can devastate the functioning and wellbeing of the individual and the family and impede individuals from attaining the developmental milestones that typically await those in late adolescence and early adulthood. Virtually all of the years lost to disability first arising in the adolescent and young adult age group is due to mental disorders. Thus, services should be available that cater specifically to this age range. EPI programs should strive to overcome the difficulties created by the legal (rather than developmental or cultural) distinction of youth versus adult status and develop inclusive services for both (approximately those aged 13-35). All young people with a first episode of psychosis and their families should be eligible for EPI programs. The overwhelming nature of psychotic disorders demands that affected individuals receive specialized and comprehensive service. Other services may be unable to adequately address the needs of this complex population. Therefore, EPI programs should be as inclusive as possible. For example, excluding individuals solely because of involvement with the criminal justice system or the presence of a concurrent disorder or dual diagnosis should not occur.

Intended Outcome

All youth and young adults with a first episode of psychosis, and their families, enter EPI programs.

Description

The age range during which a first episode of psychosis is most likely to occur includes adolescence and young adulthood. Admission criteria to the EPI program include this age range. In cases where different jurisdictions are responsible for a specific section of the age range, the EPI program makes the necessary arrangements for collaboration and service continuity across jurisdictions. Potential EPI clients may have a number of other issues in their lives, including forensic involvement, substance use, developmental disorders and other mental health problems. Given the necessity of treating psychosis appropriately and early, these other issues should not become exclusion criteria for the EPI program. The Health Authority should develop and implement regional policies that support the availability of EPI to a wide range of clients.

Minimum Standards

- Referrals are not rejected solely because of the presence of a co-occurring disorder such as substance abuse or developmental disability or because of involvement with the criminal justice system.
- Referrals are accepted from both hospital and community.
- Services are provided to both adolescents and adults (either directly or through agreements with other jurisdictions (i.e., MCFD)).

Guidelines

• Allow individuals with previous psychotic episodes to enter the program if there has not been an appropriate treatment history and they are in the first five years of illness.

- Tracking of referrals of individuals with co-occurring substance abuse or developmental disability or involvement with the criminal justice system
- Tracking of referrals from hospital versus community sources
- Age range covered by the EPI program

B. Access

Rationale

Delays in accessing services can be created by confusing and complicated referral processes. Individuals with early psychosis typically experience a number of steps before receiving appropriate care (44). One step can potentially be eliminated by accepting referrals from all sources and not requiring a professional referral.

Intended Outcome

Access to the EPI program is simple and open.

Description

Access to the EPI program must be clearly understood in the community. This is facilitated by a single point of contact or phone number advertised throughout the community and written admission criteria that are made available to the public in the communities served. The EPI program is responsive to all referrals. This response may include consultation, information, referral to other services, or an intake interview as appropriate.

Minimum Standards

- i. Develop a single point of contact for each EPI program to accept referrals.
- ii. Ensure that knowledge about the single point of contact is widely disseminated across the area served.
- iii. Accept and process referrals from any source (self, professional, family, friend, etc.).

Guidelines

• Link to other resources (e.g., HealthLinkBC, BC Nurse Line, crisis lines) to direct individuals to the EPI program.

- There is a single point of contact (disseminate information about this point of contact widely)
- Referrals are accepted from any source
- The disposition of all referrals is clearly documented

C. Intake Process

Rationale

Individuals with early psychosis need to receive appropriate treatment as quickly as possible to reduce suffering and danger as well as to decrease the duration of untreated psychosis (DUP). Shorter DUP is associated with better outcomes. Clear and streamlined intake and admissions procedures will ensure that individuals with incipient or recent onset of psychosis receive appropriate screening and enter into services promptly. Rapid response sends a positive message about the service and signals that the referral concerns a serious matter. However, EPI programs do not need to act as emergency services, because: 1) reducing DUP by one or two days does not appear to have a significant effect on longer-term outcomes, and 2) there are a range of emergency services available.

Intended Outcome

Clients and families experience easy and rapid intake into services, minimizing treatment delays. The entry experience facilitates engagement.

Description

In order to ensure that treatment is initiated as soon as possible, the EPI program will respond quickly to all referrals and not maintain a waitlist. Written documentation should include information on demographics, referral source, presenting problems, and reasons for admission or non-admission to the program. The intake process should be easy to navigate and engaging.

Minimum Standards

- i. Provide intake services a minimum of five days a week.
- ii. Respond to a referral the same day as the intake process is operating.
- iii. Ensure the first in-person contact via the intake process occurs within one week after referral when psychosis is suspected.
- iv. Provide an update on the progress of the referral to the referral source within 72 hours after the receipt of the referral.
- v. Perform the intake assessment in the preferred setting of the client and family to facilitate engagement (where practical and safe to do so).
- vi. Encourage the client and family to discuss the description of services provided by the EPI program and to be active partners in the assessment and treatment process.

Guidelines

- Respond to the referral immediately (i.e., the assessment process begins as soon as the referral is received).
- See individuals referred from hospital prior to discharge from hospital.

- Time to respond to referral
- Time to first in-person contact with client (and proportion taking place within one week)
- Client and family questionnaire or interviews asking about satisfaction with the intake process
- Tracking the number of clients and families engaged i.e., the annual proportion of accepted clients who disengaged contrary to the recommendation of the program
Derek: Two Possible Journeys – Assessment and Care Planning

Optimal Care

Derek attended his appointment at the EPI program. His mother accompanied him and, with Derek's permission, participated in the intake process, which took about 90 minutes. Derek met with an EPI clinician, Nancy, who worked exclusively with the EPI program. She informed Derek and his mother that she would be serving as their primary contact with the program. The EPI psychiatrist, Dr. Jeff Johnson, was introduced and jointly conducted the interview/discussion. An extensive personal and family history was taken along with a mental status exam and detailed description of current concerns and behaviours including risk to self or others and substance use. A medical exam was arranged for the next day, which was to include screening for metabolic parameters. Particular attention was given to the presence, severity and duration of both positive and negative signs and symptoms of psychosis. Derek acknowledged that he had some troubling experiences, more specifically a voice he didn't recognize had been telling him for the past few months that he was "worthless" and "stupid" but that he could learn great things if he could figure out how to "read the fine print". These episodes were infrequent and experienced as mostly troubling but also somewhat intriguing. Nancy agreed to call Derek the next day and an appointment was made for Derek and his mother to meet with the EPI team at the start of the next week to discuss the results of the assessment. When they arrived for the appointment, Nancy and Jeff told Derek and his mother that based on the information that they had available to them, they believed that Derek was experiencing a psychotic episode. Derek and his mother were asked about their understanding of psychosis and given the opportunity to ask questions. Derek's mother became quite tearful and attributed his problems to the break-up of the marriage. For his part, Derek became quite anxious and asked if he would have to go to the "nut house". Nancy and Jeff reassured them and acknowledged that they didn't know the exact cause of Derek's episode but they expected that it was likely a function of genetic and psychological factors, which may have been made worse by Derek's marijuana use. They mentioned a number of very helpful medications and psychosocial interventions and expressed optimism that these would likely be effective in helping him recover. They let Derek know that decisions about treatment options and objectives were his and encouraged him to discuss these with his family and come back with further questions. Jeff prescribed a small dose of risperidone (0.5 mg per day) and explained that the medication should help alleviate the voice and some of Derek's other problems. Jeff and Nancy stressed that they would work with Derek and his mother to closely monitor how it was working and whether there were any side effects.

Less than Optimal Care

His mother took Derek to the appointment. He was seen by the intake clinician within the local mental health team that was attached to a medical clinic adjacent to the local hospital. The intake clinician began by asking Derek's mother about whether Derek had been taking his medication since his discharge from hospital. Derek's mother stated that she didn't think he had been taking his medication and left the room in tears when Derek responded with anger, telling her she was "stupid and ganging up on him like everybody else". The intake clinician reviewed Derek's referral form and asked him some questions about his current mood and behaviour, including the frequency of his marijuana use. He was told that he may have schizophrenia but this would need to be confirmed when he met with a psychiatrist at his next appointment. He was also told that his medications would be reviewed at that time and was given a photocopied description of a range of support groups offered by the team for patients with a range of psychiatric problems. He was also given a brochure, "What is Schizophrenia?" to give to his mother.

III. REQUIRED SERVICES

A. Client and Family Empowerment

Rationale

The concept of empowerment arose in reaction to deficiencies in the provision of health care services to those with severe mental disorders. Empowerment is predicated on the principle that persons can gain control over their lives and effectively self-manage their disorders through self-determination, social engagement and developing a sense of personal competence (45). Empowerment refers to the capacity to pursue and fulfill basic human rights, including meaningful participation in society. Empowering clients and families requires that they possess knowledge and abilities and have access to the pursuit of opportunities they consider worthwhile.

Intended Outcome

Clients and families feel empowered through their engagement with EPI services. People with early psychosis can achieve a meaningful and fulfilling life.

Description

EPI programs foster empowerment by providing client-centered care that moves beyond a focus on psychopathology to focusing on strengths and competencies, and by promoting involvement in services planning and delivery. Strategies to foster empowerment include engagement of clients and families as partners in care (e.g., helping choose locations for treatment, choosing targets for intervention), involvement of peers as service providers and advocacy activities. Clients are supported in general self-management skills to improve wellness and build resiliency. Clinicians need to be sensitive to issues of stigma and disenfranchisement and to the social context of clients' lives.

Minimum Standards

- i. Provide clients and families with sufficient information to make informed decisions about participation.
- ii. Encourage clients and families to be partners in planning and carrying out interventions.
- iii. Respect and try to integrate alternative explanatory models into the intervention process.
- iv. Include interventions to facilitate effective self-care.
- v. Inform clients and families of best practices and encourage them to advocate for these if they perceive any aspect of service falls short.
- vi. Provide clients and families with appropriate and confidential opportunities to provide feedback on the quality of care and service delivery (e.g., satisfaction surveys, discharge interviews, etc.).

Guidelines

• Encourage client and family participation in EPI program services (e.g., by providing peer support, participating on an advisory committee, participating in community education, etc.)

KEY PERFORMANCE INDICATORS

• Survey of client and family opinion on the extent to which care is collaborative and fosters selfmanagement

B. Assessment and Care Planning

Rationale

Ongoing accurate assessment helps develop and maintain therapeutic alliance, provides information for diagnosis, guides treatment decisions, monitors changes over time, reveals additional areas in need of attention, and allows for program evaluation and research. Assessment guides the collaborative development of a care plan.

Intended Outcome

Clients and families have care plans to facilitate recovery.

Description

Assessment should be timely, engaging and thorough. The breadth and depth of the assessment process is guided by the level of engagement that has occurred. A thorough assessment ensures collection of collateral information from family, friends, social workers, school, police, or others. Assessments must take into account the client's culture and language and how these affect ability to access and benefit from services. It is preferable to use assessment tools that facilitate and improve collaborative, strengths-based care plan development – for example, the 2-Com (46). A comprehensive EPI assessment includes the following components:

- detailed description of signs and symptoms
- detailed description of substance use
- 0 mental status exam
- o risk of harm to self or others
- o personal history (e.g., developmental, academic, social, medical, etc.)
- o family history (e.g., family history of mental illness, significant family events, etc.)
- o current stressors, coping and social support
- medical examinations including clinical testing for minor physical anomalies suggestive of genetic conditions
- o assessment of client and family strengths
- o client and family goals

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- o role functioning and quality of life
- o clinical formulation and diagnosis
- o estimate of duration of untreated psychosis
- o client and family explanatory model
 - baseline and ongoing assessments of metabolic parameters and motor abnormalities

Care plans should address all facets of recovery, including illness and medication management, employment, family education and social and leisure time. If a person is unable to live independently a referral to an age-appropriate service along the continuum of residential services should be considered (independent living, supported housing, residential care facility). This service should promote independence, be tailored to the person's needs and be part of the care plan. Client and family goals are developed and incorporated into the care plan.

Minimum Standards

- Perform a comprehensive biopsychosocial assessment (including but not limited to the elements described above) within the first few weeks of care. It is recognized that this may be an ongoing process if the client has not yet been fully engaged.
- Conduct and document reassessments of non-historical parameters at least every six months for the first two years (and annually for subsequent years) to permit clinical reformulation and revision of the care plan.
- Develop care plans collaboratively with client and family (when possible) and provide them with a copy of initial and when plans are substantively updated
- Have a vocational and/or educational assessment (where appropriate) conducted by qualified practitioners within three months of entry into the program.

Guidelines

- Have a cognitive assessment (where appropriate) conducted by qualified practitioners within three months of entry into the program.
- Perform brain imaging (e.g., CT scan, MRI) around the time of intake (as deemed appropriate).
- Use psychometrically valid measures of symptom presence and severity
- Perform genetic analysis if justified by the medical examination.

- Documentation that assessments and reassessments are comprehensive and consistent with the time frames of the standards (consider development of a tracking checklist)
- Documentation every six months of whether positive symptoms of psychosis (i.e., delusions, hallucinations or disorganized thinking) are present (consider development of a tracking checklist)
- Client and family sign care plans indicating approval

C. Risk Management

Rationale

Risk management is an essential component of all aspects of mental health and addictions care; however, compared to other psychiatric populations, individuals with psychosis are at the greatest risk for suicide during the first few years of illness (47). Individuals with early psychosis are also at substantial risk for other negative biopsychosocial outcomes (e.g., substance abuse, car accidents, sexually transmitted diseases, violence, victimization and homelessness). Such risks must be assessed systematically and managed on an ongoing basis.

Intended Outcome

Risks to self or others are identified and the potential for harm is minimized.

Description

Risk should be assessed at the time of first contact, upon formal entry into the EPI program and regularly throughout the course of care. Any existing organizational risk management policies must be followed. All staff working with the EPI program and any other care providers, who will have contact with a given client, are alerted to imminent risk of danger to self or others (as per confidentiality requirements). Management of risks should be prompt and aided by the best available practices and procedures including the use of self-management techniques for depression and suicidality. A number of such tools have been developed in BC and are available on the Consortium for Organizational Mental Healthcare website - http://www.comh.ca/resources.

Minimum Standards

- i. Develop a risk management policy and procedures specific to EPI clients, describing appropriate steps to minimize risks.
- ii. Undertake and document individual clinical risk assessments at least every three months.
- Involve the client and family (if possible) in the risk assessment and include their views in the documentation of the risk assessment. If necessary, provide communication to other relevant authorities.

Guidelines

• Hold a multidisciplinary team meeting when a client is deemed at risk for harm to discuss the range of actions available to ensure safety.

- Existence of risk management policy and procedures specific to EPI clients
- Tracking critical incidents including suicides, attempted suicides and harm to others

Derek: Two Possible Journeys – Ongoing Care

Optimal Care

The next week, Derek met again with Nancy and Jeff. Nancy said that she was going to be Derek's case clinician and asked if that was okay. Derek agreed and together they discussed some goals for his involvement in the program. Derek did acknowledge feeling edgy and bored as well as distressed by his auditory experiences. Nancy noted Derek's isolation and lack of structure and they agreed that he would join some recreational programming through the local mental health center. She and Jeff also discussed with Derek his marijuana and alcohol use and the effects it was having on his life. He saw that it was probably holding him back more than it was helping even though it was usually enjoyable, and he stated that he would "cut down" for a while and see how that went. Finally, they discussed medications. Derek indicated that he did not like the risperidone as he was feeling tired and having frequent headaches. Nancy and Jeff agreed these might be side effects but told him that they usually get better and asked if he would try to stick with it for a little longer. Derek was reassured and agreed to continue with the risperidone but said he didn't want to be on pills and would stop if he continued to feel sluggish and have headaches. They agreed to keep monitoring, gave him some information to read, some websites to look at, and arranged for metabolic monitoring.

Over the next few months, Nancy kept in touch with Derek on a weekly basis. She often met him in a local coffee shop and on a couple of occasions, dropped by his apartment. Nancy also met with Derek's mother and stepfather and invited them to a support group for parents and caregivers of persons with psychosis. She worked closely with Derek's local mental health team and arranged for him to join a program focusing on "resiliency and self-care". At one appointment with Derek, Nancy invited the regional concurrent disorders therapist to attend to help go over some of the available options for helping Derek with his continuing excessive marijuana use. Derek decided that he was not prepared to go into a group, but would actively cut down, as he now understood that the marijuana might be part of the problem. Derek was anxious, as his EI was running out, so Nancy helped him obtain some temporary disability assistance to alleviate the burden of paying his bills so that he could concentrate on recovery. Derek did not report any more positive symptoms but did acknowledge still feeling "weird" and anxious around others. He agreed to an increase in medication up to 1 mg of risperidone. This was monitored carefully with the understanding that it would be discontinued or switched if it wasn't helpful. He also worked with Nancy to identify situations that made him feel uncomfortable and developed some techniques to relax and self-calm. Derek also complained that he seemed "stupid" compared to a year earlier, so Nancy arranged for a cognitive assessment from the parttime psychologist with the EPI program. The assessment found that Derek had memory problems for verbal but not visual information, and slightly lower concentration, but that his overall intelligence was normal. The report provided suggestions that were used by Derek and Nancy to help him compensate for his memory problems (e.g., using a day-timer to keep track of his schedule).

Derek: Two Possible Journeys – Ongoing Care

Less than Optimal Care

Derek missed the next few appointments and only attended after a call from the mental health team. After finally meeting with the psychiatrist, Derek was diagnosed with schizophrenia and was asked to come back again to meet with his case manager. After again missing the next appointment with his case manager, Derek finally made an appointment four weeks after his diagnosis. When he arrived, he met with a different staff member, as he was informed his clinician was off on stress leave. Derek was told that the goals of his treatment were to treat his schizophrenia, and he was referred to a "support group" starting in three weeks. He was asked about his medication and, when he admitted that he had stopped taking it due to unpleasant side effects, he was informed that adherence was a condition for ongoing treatment. He was also told that he would need to stop drinking and smoking marijuana and told to attend a Narcotics Anonymous (NA) group that met in a neighbourhood church. Derek was annoyed but did not ask if there was another option. Secretly, Derek was afraid that his money would be cut off if he was seen as not cooperating with the team.

Derek also complained to this case manager that he seemed "stupid" compared to a year earlier. Derek was told that this was probably a result of his marijuana use. The case manager also told Derek that he could apply for Disability payments at the local Ministry of Employment and Income Assistance. Derek needed to pick up the form, bring it back to the psychiatrist so that he could fill it out and then return the form to the ministry office. The next appointment to see the psychiatrist would be in a month.

Following this appointment, Derek filled the prescription for a new medication, olanzapine, but only took it irregularly. There was some reduction in his positive symptoms but he had very unpleasant side effects and complained of feeling "stunned". There was little change in his negative symptoms and his functioning remained very poor. He did check out the NA and support groups but found the other participants to be much older and lower functioning than him. He called them "losers" but actually found the experience to be quite frightening as there was little positive information about recovery or how to manage relapse. Over time, Derek's frustration turned to despondency. When Derek's mother and stepfather asked him how he was doing, he told them he was fine. They still found him to be quite uncommunicative and suspicious but noted that he had gained weight and so presumed he was doing better.

D. Pharmacological Treatment

Rationale

The vast majority of patients with schizophrenia or schizoaffective disorders show a good symptomatic response to antipsychotic medication (48). Most improvement tends to occur within the first six months of treatment (49). Trials lasting shorter periods report response rates of around 60-70% on atypicals (50,51) and about 50% on typical antipsychotics (52,53). Early psychosis clients are typically young and medication-naïve. This tends to render them more sensitive to side effects but also responsive at lower doses of antipsychotic medications (55), and thus lower doses are appropriate (54, 56). Medication should start with a very low dose that is slowly increased until there is a clinically significant response with a minimal level of side effects.

Intended Outcome

Psychotic symptoms are significantly reduced or eliminated by medication. Continuing engagement of the client with pharmacotherapy reduces relapse risk.

Description

All clients should have access to pharmacological treatment prescribed and monitored by a competent provider (e.g., family physician, psychiatrist, nurse practitioner). Ideally, this prescriber is a psychiatrist, and where this is not possible, the program must ensure that the prescriber has adequate training in prescribing antipsychotic medication and in the assessment of psychosis and medication side effects. It is recognized that access is a challenge in rural areas where there may be a shortage of readily available psychiatrists or other competent prescribing professionals. Rural programs are therefore encouraged to utilize a range of options to provide access including the use of outreach psychiatry, telepsychiatry and shared care and collaborative approaches (e.g., Integrated Health Care Networks, local family physicians or nurse practitioners with prescribing privileges).

Prior to prescribing any medication, a client's currently prescribed medication and use of substances will be reviewed. Atypical antipsychotics are preferred over typical antipsychotics because of their more acceptable side effect profile (57).

In order for clients and families to be active partners in pharmacological treatment, they should be knowledgeable about the medication, potential benefits, side effects and risks. The reasons clients may not want to take medication should be explored. Clients should not be refused service because they refuse medication. Complementary forms of care will be provided and the option of pharmacotherapy should continue to be available.

Minimum Standards

- i. Develop a strategy that is consistent with the provincial framework (presently under development) to ensure optimal pharmacological treatment of people with psychosis.
- ii. Ensure all EPI clients have access to a psychiatrist, family physician or nurse practitioner who can prescribe antipsychotics and other medication. If this individual is not a psychiatrist, he or she must have timely access to psychiatric consultation as needed.

Follow pharmacological treatment guidelines for early psychosis (see Appendix 1) including, but not limited to, the following:

iii. Document all pharmacological treatments.

- iv. Avoid the administration of multiple antipsychotics.
- v. Minimize concurrent use of mood stabilizers with antipsychotics unless indicated by the presence of a diagnosed mood episode.
- vi. Consider clozapine if a client does not respond adequately after two adequate trials of antipsychotics, one of which must be an atypical.
- vii. Monitor metabolic changes and other side effects (e.g., sedation, motor effects and decreased sexual ability) per established guidelines. This is the responsibility of the prescribing physician.
- viii. Take proactive steps to prevent the weight gain and metabolic effects that may occur, including the provision of nutritional information and behavioural management.

Guidelines

- Use motivational interviewing or other techniques (including peer support) to enhance adherence among clients who relapse when not taking medications.
- Assess plasma levels where appropriate and available if adherence is questioned.
- Assign a psychiatrist who will be responsible for pharmacological treatments to each client at the time of admission to the EPI program.

- Tracking the percentage of clients in the program for a year or more that are offered clozapine
- Documentation of simultaneous prescription of more than one antipsychotic
- Documentation and assessment of metabolic effects and movement disorders per established protocols

E. Physical Health Care

Rationale

Youth and young adults, compared to younger and older populations, generally have less need to access medical services. As such, they tend to lack familiarity with general physicians and hospitals. However, the onset of a psychotic disorder carries a number of important medical and non-psychiatric ramifications that merit close medical attention. Foremost is the need for monitoring and intervention with respect to metabolic syndromes attributable to the prescription of psychiatric medications (58). Other issues that merit medical attention include substance misuse, tobacco addiction, sexually transmitted diseases, and accidents.

Intended Outcome

Clients' physical needs are responded to appropriately.

Description

All clients receive comprehensive physical examination upon entry into the EPI program and periodically as treatments or new circumstances dictate. EPI programs help coordinate access to physical health specialists such as general physicians, specialist physicians, physiotherapists, nurses, dieticians and other health care providers as needed.

Minimum Standards

- i. Ensure that clients have ongoing access to a primary health care provider (e.g., general physician, nurse practitioner).
- ii. Ensure that all clients receive a comprehensive physical exam at entry and ongoing annual examinations.
- iii. Ensure that clients receive information on the prevention and treatment on any relevant health issues.

Guidelines

- Maintain close contact with the primary health care provider to ensure that all service providers are active constituents of an integrated health care matrix.
- Specialist care should be sought where possible.

- Access to a primary health care provider
- Documentation of comprehensive physical assessment at entry and annually

F. Psychosocial Interventions

Rationale

Psychosocial interventions are key to recovery. A wide variety of psychosocial interventions must be available in order to address the wide-ranging needs of early psychosis clients and their families. Psychoeducation for both clients and families enhances mental health and addictions literacy and improves coping. Psychoeducation leads to improved knowledge, decreased negative symptoms, improved interpersonal skills, decreased relapse rates and shorter hospital stays (59-62). In general, more intensive interventions and involving families in psychoeducation result in significantly better outcomes for both client and family (63-69). Psychoeducation should include strategies for stress management and skills training in a variety of areas (e.g., social skills training, problem solving skills). Relapse prevention involving monitoring for early warning signs, and when signs are detected, the use of supportive problem solving and increases in antipsychotic medication doses, have been found to successfully reduce rates of relapse and rehospitalization (69). For individuals with psychotic disorders, cognitive therapy can be used for: 1) increasing control over and coping with psychotic symptoms (hallucination, delusions, negative symptoms), and 2) treating secondary morbidity (depression, anxiety, adjustment issues, etc.) (70, 71).

Intended Outcome

Client and family wellbeing is increased, symptom and functional outcomes are improved, and relapse rates are decreased.

Description

Psychoeducation should be provided to both the client and family in an interactive format. Psychoeducation should be presented in a manner appropriate to developmental levels and phase of psychosis. It should occur with sensitivity to language preference, explanatory model and spiritual/cultural beliefs. Families will benefit from discussing the stress they are likely to encounter when caring for their family member, thereby improving their ability to cope, to understand the symptoms of psychosis, and to learn how to help the person in recovery. Instrumental supports such as family therapy and respite care should be available. Other psychosocial interventions that should be available may include stress management techniques, problem solving techniques, social skills training and cognitive therapies. All clients should be engaged in health promotion and positive lifestyle activities including those related to diet, exercise, good sleep hygiene and substance use reduction. Relapse prevention plans should be developed collaboratively with the client and family. Many psychoeducational tools are available at the web sites listed in Appendix 2.

Minimum Standards

- i. Ensure clients and families are engaged in individualized and ongoing psychoeducation over a period of at least six months. Psychoeducation should also be reviewed following any relapses.
- ii. Make available a suite of tools and protocols to provide comprehensive and individualized psychoeducation to clients and families.
- iii. Provide interventions designed to improve self-care for both clients and families.
- iv. Provide evidence-based psychological therapies (e.g., cognitive behavioural therapy, interpersonal therapy, family therapy) to treat accompanying distress such as depression, anxiety and relationship problems.
- v. Ensure that each client has a relapse prevention plan in place, provide a written copy to the client and family, and include the plan in the client's chart. Relapse prevention plans are reviewed at least every six months for the first two years (and annually for subsequent years).

Guidelines

- Make psychosocial interventions available in both individual and group formats.
- Make cognitive behavioural therapy available for individuals with persistent psychotic symptoms.
- Make other specialized interventions available for families as needed (e.g., financial assistance, respite service).

- Proportion of clients receiving psychoeducation for at least ten hours over six months
- Proportion of families receiving psychoeducation for at least ten hours over six months
- Relapse prevention plan documented for each client
- Number and types of psychosocial interventions available within a program
- Document rehospitalization rates for each client during the time enrolled in EPI program

G. Facilitating Functional Recovery

Rationale

Psychosis impacts all areas of life, including a person's ability to function. Symptomatic recovery in first-episode psychosis appears to be greater than functional recovery (72-74), so additional efforts and resources are required in order to improve functional outcome. Cognitive functioning is a better predictor than psychiatric symptoms of success in rehabilitation programs and community functioning (75). Peer-based education and support groups provide an opportunity for people to practice social skills and achieve a sense of belonging and social support (76).

Intended Outcome

Clients participate meaningfully in personal, interpersonal, educational and vocational activities.

Description

Psychosocial rehabilitation, the process of restoring community functioning and wellbeing, effects change in social and physical environments and improves coping abilities. Psychosocial rehabilitation promotes recovery, full community integration and improved quality of life for people with mental health conditions. Psychosocial rehabilitation services are collaborative, client-directed, individualized, evidence-based and focus on skill development, accessing resources, and increasing capacity to be satisfied in roles and environments of the client's choice. The main areas of concern include symptom management, social relationships, vocational/educational pursuits, recreation, basic living skills, financial security, health and wellness (nutrition, exercise, sleep, smoking cessation), medical care, housing (safe environments, independent living, supported housing, residential care facility), and community and/or legal resources. Thus, EPI programs need to form partnerships with a wide range of services and supports.

Participation in work or school is informed by assessment, client preference and phase of recovery. Clients are provided with training and support to further enable them to carry out daily living activities and pursue ageappropriate opportunities, if needed. Recreational opportunities should be available to all EPI clients to allow for social interaction and personal enjoyment. In rural areas, peer linking may require creative and diverse strategies (e.g., family-to-family newsletters, secure web-based discussion groups, etc.).

Minimum Standards

- i. Assess and incorporate into the care plan, client and family needs with respect to social relationships, vocational/educational pursuits, recreation, basic living skills, wellness, financial security, health and medical care, parenting, housing (safe environments) and community and/or legal resources.
- ii. Advocate for clients (e.g., entering or returning to work or school, moving into supported or market housing).
- iii. Facilitate peer interaction and peer support for both clients and families.

Guidelines

- Provide specialized psychosocial rehabilitation services (e.g., vocational rehabilitation) as an integrated part of the EPI program.
- Make available interventions to remediate and/or compensate for cognitive problems.

- Make other specialized rehabilitation/supported employment/supported education services available to clients having significant functional difficulties.
- Liaise with educational settings to ensure educational assessments and planning are done to guide re-entry.
- Make available supported housing populated with people of about the same age and at the same stage of recovery.

- The care plan addresses vocational, educational and social/recreational needs
- Proportion of clients entering or returning to work or school per year
- Income status documented every six months
- Housing status documented every six months

Derek: Two Possible Journeys – Transitions

Optimal Care

Over the next year, Derek continued to check in with the EPI team about once a month, where he was reassessed for symptoms, risk of harm and the emergence of additional psychiatric concerns. His general health status was checked with particular attention to his metabolic parameters. He participated in a drop-in group organized by his local mental health team for young men with mental health issues. The group focused on vocational and educational readiness, masculine identity and values, and dealing with the social stigma associated with mental disorders. Derek also attended the EPI psychoeducational group, where he gained new insight into his illness and met others who had dealt with many of the same symptoms and difficulties. Things were going quite well until Derek's parents announced they were retiring and had decided to move to a smaller, more rural community and Nancy told him that she was pregnant and going off on maternity leave in a few months. Derek was very upset and discontinued his medications. He started smoking dope and drinking heavily again and a week later got into an altercation in a local bar. The police took him to the local hospital Emergency Department, where he was stabilized. The hospital contacted the EPI team, who arranged to meet Derek and his family the next day. During this meeting, it was decided that Derek would accompany his parents to their new residence and stay with them for a couple of months until he found a place of his own. The mental health centre in the rural town in which Derek would be living was contacted to facilitate transfer and continuity of care. A teleconference was held between the mental health centre and his current EPI team, along with Derek and his parents. Derek's program and progress were reviewed, documentation was sent and a meeting was set up for two months later when the family was moving. In the interim, Nancy worked with Derek to develop a plan to identify and address any signs of relapse and outline what to do if these occurred. The new community had an EPI program consisting of one clinician with a virtual clinical team and a psychiatrist available via teleconference. Derek was pleased that he quickly developed a good relationship with his new clinician and that she followed the same practices he has experienced before. His understanding of relapse prevention was deepened and she helped him orient to the opportunities available to him in the region.

Less than Optimal Care

Derek attended his next appointment with his case manager and psychiatrist, mostly to fill out the application form for Disability Benefits. His appearance and presentation were deteriorating and he had gained a considerable amount of weight. He stated that he had been taking the olanzapine at least half of the time. On one occasion, he came to the program bruised and bleeding and the staff suspected he had been beaten up in a drug deal that went bad. The staff confronted him with this and Derek became angry and stormed out of the clinic. The next information the program gained was when a staff member heard that Derek had been admitted to an inpatient psychiatric unit after a self-inflicted stab

H. Acute and Inpatient Care

Rationale

Hospitalization for early psychosis clients is often necessary in order to manage acute symptomatology and minimize risk to self or others, however, people may find their initial hospital experience traumatizing (77). Efforts to avoid hospitalization and the use of emergency services can include increasing the intensity of community outpatient care, providing outreach, and even supported housing or residential care. When hospitalization is necessary, efforts should be made to make the experience as positive as possible and link it with the care provided in the community by the EPI program.

Intended Outcome

Client receives coordinated and appropriate care during an acute episode.

Description

EPI programs will take steps to ensure that continuity of care is maintained with hospitals within the catchment area served. If a hospitalization occurs with a person who is not currently enrolled in an EPI program it is important that EPI program staff engage with the person while still in the hospital. In order to accomplish this, protocols must be developed that ensure communication between inpatient units and the EPI program about admission of a potential EPI client. Once contact with the program has been established, EPI staff work with hospital staff to facilitate the delivery of best practices including post-discharge planning. Conversely, any clients requiring hospitalization while in the EPI program will benefit from the support and coordination provided by the EPI program to facilitate an admission. Finally, inappropriate use of emergency services or hospitalization may be avoided altogether for clients receiving community services via the EPI program by increasing frequency of contact, adjusting medication dosages or prescribing additional medications, or maximizing stress management approaches and family support.

Minimum Standards

- i. Develop a protocol involving the hospital and the EPI program that makes the program aware of the admission of any potential early psychosis clients.
- ii. Communicate with inpatient staff about unique treatment planning for clients with early psychosis.
- iii. Make contact with and start to engage potential EPI clients prior to discharge from hospital.

Guidelines

- Provide education to staff on inpatient units and emergency departments on referral criteria and the process of making a referral.
- Offer educational opportunities to inpatient staff on EPI best practices.
- Facilitate the admission process and provide support to the individual when hospitalization is necessary (e.g., being present during the hospital consultation, admission procedures, etc.).
- Provide inpatient care via a specialized unit that is appropriate for youth and young adults and provides care that is consistent with EPI principles and practices.
- Develop capacity for outreach interventions during periods of increased symptomatic acuity, including partnerships with existing services.

- Existence of a referral protocol
- Proportion of individuals identified by the EPI inpatient protocol as potential EPI clients who are engaged prior to discharge

I. Services for Concurrent Substance Use

Rationale

One-year and point-prevalence estimates of comorbid substance abuse in early psychosis range from approximately 20% to 30% (78, 79). The rates of comorbidity in first-episode affective versus nonaffective psychosis appear to be similar (80). In early psychosis, cannabis and alcohol appear to be the two most frequently abused substances (78, 79). The prevalence of stimulant (amphetamines and cocaine) and hallucinogen use is also relatively high, while sedative and opiate use is less common (78, 81). Risk factors for the development of comorbidity include male gender and antisocial behaviour (78, 79). Substance abuse has been associated with an earlier age of onset of psychosis (78, 79, 82). Although substance abuse does not appear to be related to the severity of psychopathology in the early phases of psychosis (78, 83), there is evidence that substance abuse in early psychosis is associated with impairments in functioning, lower quality of life and increased risk of hospital readmission (82). Integrated treatment confers superior benefits compared to other treatment models (84, 85), and the addition of motivational and behavioural interventions could lead to better outcomes (86, 87).

Intended Outcome

Clients have access to services and supports to address the broad spectrum of risks and harms associated with substancuse.

Description

It is desirable that EPI Programs employ a harm reduction rather than an abstinence model (88). Treatment of problematic substance use and psychosis should be integrated to the greatest extent possible. Integrated programs provide treatment for both substance use and mental illness by the same clinician or team of clinicians. This helps to ensure consistency of information and coherency of treatment framework. Integrated programs differ to some degree in the specific treatment components they offer. However, there are many common elements across approaches, including comprehensive assessment, group and individual counselling, education, mediation management, stress management and relapse prevention (86, 89). Clients should be matched to the available substance use service and supports with intensity appropriate to individual needs. When a client's needs change, the intensity of services and supports is adjusted accordingly.

Minimum Standards

No minimum standards have been approved for this section.

Guidelines

- Develop protocols to ensure that clients with problematic substance use issues are accepted into EPI programs.
- Perform a thorough initial assessment and ongoing reassessment of substance use.
- Ensure that all EPI clinicians have training in the assessment and treatment of substance use, including motivational interviewing.
- Provide EPI clinical personnel with access to consultation with a concurrent disorder specialist.

- Develop and document relapse prevention plans specific to any problematic substance use.
- Provide fully integrated treatment for substance use and psychosis.
- Recruit a concurrent disorder specialist as part of the EPI team.
- Make specialized psychosis and substance use group interventions available for clients and families.

J. Discharge Process

Rationale

Discharge and transition to other services within the continuum of should be a systematic and planned process to ensure continuity of care. Due to the nature of the early course of illness, clients and families often benefit from receiving EPI program services for at least three years (23, 90, and 91).

Intended Outcome

Discharge is a planned, non-aversive and individually appropriate process.

Description

If an individual does not engage with the program, this should not automatically lead to discharge. More assertive efforts (e.g., outreach) to engage should be tried and documented.

Prior to discharge, a thorough assessment of needs should inform the choice of service to which the client will be transitioned (if further services are required). The client and family should be involved in developing discharge or transition plans as early on as possible. Files are closed in a timely manner in adherence to the requirements set by the host agency or authority. Discharge may occur earlier than three years if: the client and family refuse services, the client moves to another geographical area outside of the EPI program's catchment area, or EPI programs are no longer appropriate. Clients that have been discharged prior to three years may re-enter the EPI program as deemed appropriate on a case-by-case basis.

The discharge summary should include information on reasons for discharge, diagnosis, current clinical status, treatments provided, progress on treatment goals and follow-up arrangements. It should also include a transition plan if the client requires further services. Existing protocols should be followed or improved to ensure the smooth transfer of EPI clients between services (e.g., Child and Youth Mental Health to Adult Mental Health; EPI to other Mental Health & Addictions Services). The discharge summary should be sent to all relevant health care providers, including the general physician.

Minimum Standards

- i. Ensure a discharge plan is written for each client.
- ii. Develop transitional protocols between the EPI program and other services to ensure continuity of care.
- iii. Establish regional policies that allow files to be closed after a length of time with no contact.

Guidelines

- Hold joint transition sessions until the client and family are engaged with the new treatment providers.
- Hold a discharge conference involving all involved clinical staff prior to the discharge.

- Duration in program for each client
- Existence of transitional protocols
- Existence of a written discharge plan for all clients

V. PROGRAM STRUCTURE AND OPERATIONS

A. Program Organization and Continuum of Care

Rationale

The complexity of providing evidence-based services to early psychosis clients requires a well-organized program. Care for clients and their families includes the coordination of different components of highly individualized services that are phase-specific. The phases of psychosis, ages at onset and concurrent problems dictate that any EPI program must ensure the coordination of services across the continuum of care.

Intended Outcome

Clients and families receive services that are well integrated and coordinated.

Description

EPI programs should have clinical, educational/advocacy and evaluative/research components. EPI programs develop collaborative partnerships with a range of different programs and jurisdictions (e.g., criminal justice system, schools, language services, etc.) to support individuals and families.

Programs may follow a number of different models (see glossary under "program models"). In urban areas, the model would most likely be "hub and spoke" or centralized. In rural areas, the model would most likely be "hub and spoke" or decentralized. Regardless of model, care should be comprehensive, seamless, and not interrupted unnecessarily.

Minimum Standards

- i. Have a written program description for every EPI program that includes statement of purpose, model of service provision, clearly defined inclusion and exclusion criteria, and the range of services provided.
- ii. Assign each client and client family a primary contact at the time of admission to the EPI program. A secondary contact is also identified to provide back-up when the primary contact is unavailable (in urban areas this would be another member of the EPI team, while in rural areas this secondary contact may be another community care provider or service).
- iii. Ensure that outside the EPI program's hours of operation, clients and families have access to (and are informed of) crisis coverage and after-hours services (e.g., after-hours crisis programs, special arrangements with local services, etc.).
- iv. <u>Urban EPI programs</u> must have a coordinator whose role it is to coordinate program operations, guide program development and ensure that evaluation activities are conducted.
- v. <u>Rural EPI programs</u> must have a coordinator whose role is to link EPI service providers across an area or region. The coordinator will guide program development and ensure that evaluation activities are conducted.

Guidelines

• <u>Urban EPI programs</u>: The EPI program has weekly team meetings to review cases per a written schedule established by the program coordinator. These team meetings will involve reviews of new admissions and

new discharges, assessment and treatment planning, termination of services, and discussion of complex cases, including fidelity to treatment plans.

- <u>Rural EPI programs</u>: The rural coordinator should organize weekly teleconference or face-to-face meetings as feasible with all EPI clinicians in the area or region with active caseloads.
- Develop EPI programs according to centralized rather than "hub-and-spoke" models.
- Span the youth and young adult age ranges in a unified single program, thus providing better continuity of care and eliminating the need for transitions across age-related systems.
- Consult with other programs to create a mechanism that allows EPI programs across the province to communicate with each other at least once annually on issues related to program development and new knowledge.

- Written program description exists
- EPI program has identified coordinator
- Documented primary and secondary contact for each client and family

B. Service Intensity

Rationale

EPI involves much more than simply intervening early – phase-appropriate treatments of suitable intensity are required during the first years of illness for improved outcomes. EPI programs must have the capacity to provide intensive services to both clients and families as necessary for a period of at least three years (23, 90, 91). Staffing levels must be adequate in order for clinicians to provide interventions at optimal intensity without becoming overburdened (4).

Intended Outcome

Successful recovery is maximized through the provision of interventions at an optimal level of intensity.

Description

Services are available to clients and families across all phases of recovery or relapse. Poor initial outcomes or relapses should not lead to reassignment of clients to non-EPI programs. Program services should be appropriate to phase of psychosis. Early recovery is typically weeks 3 through 18 and later recovery is months 5 though 12. Typically, later recovery levels of contact continue throughout years two to five except during times of relapse or increased focus on functional recovery (work, school, etc.) in which case greater contact and service intensity is required. Service intensity is increased according to the needs of the client (e.g., more frequent assertive outreach when there is evidence of a relapse). It is recognized that access to a prescribing professional is a challenge in rural areas. Rural programs are therefore encouraged to utilize a range of options to provide access, including the use of outreach psychiatry, telepsychiatry, and shared care with local family physicians or nurse practitioners with prescribing privileges.

Minimum Standards

i. Ensure that contact between the client and family and the primary EPI clinician occurs at the following minimum frequencies during the first year:

	Acute/relapse	Early recovery	Later recovery
Client	1/week	1/week	1/month
Family	1/week	1/month	1/month

ii. Ensure that clients have access to a prescribing professional within 48 hours during the acute phase and within a week if not acute.

Guidelines

- Make EPI programs available to clients and families for a period of <u>at least three years.</u>
- Ensure that clients with acute severe symptoms are seen within one day by a prescribing professional.
- Provide daily contact with clients in an acute state of psychosis while the client resides in the community. When possible, use face-to-face contacts rather than contact via telephone.

- Frequency of clinician contact with <u>clients</u> per year
- Frequency of clinician contact with <u>families</u> per year
- Access to a prescribing professional

C. Staffing Complement

Rationale

EPI clients need a range of interventions that require a multidisciplinary collaborative approach (4, 92). Delivery of optimal care requires adequate staffing. Early psychosis programs frequently cite that the desired clients per clinician/case manager ratio should be in the range of 8:1 to 15:1 (93, 94).

Intended Outcome

Clients and families have the support of a team of professionals with a variety of skills.

Description

EPI programs must have adequate numbers of staff with various competencies (or access to professionals with these competencies) in order to provide the necessary range of interventions and supports to early psychosis clients and families. A resourcing model was created to assist in planning how to adequately staff an EPI program. This model is based on the estimated hours needed per client of clinical staff contact over each phase of recovery. The analysis conceives of clinical services in terms of the clinical personnel needed rather than in terms of case manager to client ratio. This approach allows administrators and planners to integrate a variety of service providers into the program's suite of services rather than relying solely upon case managers to provide all non-medical services.

The model stipulates the intervention intensities required per client over time recognizing there will be variation in service intensity both within and between the treatment courses of individual clients. The service expected of a program across a spectrum of different types of clients is expressed as the average hours needed per client per year multiplied by the estimated incidence and program dropout rates. Simply relying upon a case manager to client ratio does not adequately capture the varying resource requirements as clients move through different phases of recovery or even disengage from the program – therefore the model relies on the number of expected new cases.

Refer to Appendix VI – Resourcing and Service Intensity Analysis – for details of this resourcing model. Note that the model DOES NOT represent "case loads" or case manager to client ratios but is based on the total resources needed to provide the full range of clinical services

The model assumes that that there will be a minimal number, or critical mass, of clients within the catchment area in calculating the minimum required staffing levels. If there are fewer cases, programs should have the staffing complement based on the presumed minimum number of cases that will be enrolled per year. Note that "clinical staff" refers to all professions providing clinical services but excludes program needs for physicians and administrative, educational and supportive personnel. Programs that engage in many educational activities (e.g., community education, public awareness, training conferences and workshops, etc.) will require more resources.

Rural areas may not service the numbers of clients that would warrant the team of specialists that typically exists in urban areas. The lack of specialists encourages the development of generalist practitioners who have access to consultation time with specialists. In rural areas, these staff may be part of a virtual consulting team and need not be located within the same community. Clinical and financial support should be available to allow the clients to travel as needed. Ideally, the person who prescribes medication is a psychiatrist and where not possible, the program must ensure that the prescriber has adequate training in prescribing antipsychotic medication and in the assessment of

psychosis and medication side effects. In addition, the prescriber should have timely access to psychiatric consultation as required (which could be provided via telehealth or outreach).

Minimum Standards

- i. Establish an EPI program coordinator with a mental health and addictions background
- Ensure that adequate staff is in place to carry out the full range of activities provided in an EPI program. Resources must be allocated to clinical services, education/early identification, evaluation and administration.
- iii. <u>Urban EPI programs:</u> An urban EPI program must have psychiatrists involved for psychiatric assessment, to prescribe medication, and to monitor progress and medication side effects.
- iv. <u>Rural EPI programs:</u> A rural EPI program must have access to an individual who can prescribe antipsychotics and other medications.
- v. Ensure that there is sufficient administrative staff in place to support the delivery of clinical services.

Guidelines

- Maximum clinical staff per client ratio of 1 to 20.
- Use the Resourcing and Service Intensity model in Appendix VI to assist in planning additional EPI services in urban and rural areas. The model allows for varying the assumptions (e.g. drop-out rates per year) underlying the calculations. The model DOES NOT represent "case loads" or case manager to client ratios but is based on the total resources needed to provide the full range of clinical services.
- Calculate early psychosis clients as approximately equivalent to four non-early psychosis clients in a standard mental health service for clinicians with mixed caseloads.
- Do not allow EPI clinicians to carry mixed caseloads i.e., all clients will be early psychosis clients.
- Ensure staff possess special expertise in each of the program components, namely, clinical services, education/advocacy and program evaluation/research.
- Create job descriptions for EPI programs that indicate the specific competencies required and do not use generic job descriptions.

- Number of non-physician clinical staff FTEs per 100,000 population
- Multidisciplinary team including prescribing professional (for rural areas this may be a virtual consulting team)

D. Staff Supervision and Education

Rationale

Staff who receive clinical supervision and ongoing training are most successful in providing the range of specialized and complex services required by early psychosis clients. Implementation of best practices has been shown to improve both processes of care and client outcomes.

Intended Outcome Clients and families receive care from competent staff.

Description

Staff can be supported to implement best practices through a variety of mechanisms including supervision, support from colleagues and administrators, small group training sessions, incentives, monitoring and feedback systems, peer supervision and reminders. The coordinator should have training and experience in clinical supervision. Except where there is a revised explicit alternative, the coordinator will be assumed to be the supervisor. Organizational policies and procedures will apply to issues of supervision. Within the broader framework, the EPI program adopts a specific model of supervision and all clinical staff are informed and educated about the goals and process of supervision. Supervision sessions will include case discussion, opportunity to review the supervisee's perceptions of the work, and provision of individualized feedback. Supervision meetings provide an opportunity to revisit the values and ethical standards that guide the program, provide support for EPI clinicians, allow discussion of difficult cases, promote clinician self-care and foster fidelity to best practices.

Minimum Standards

- Provide clinical supervision to each staff member in an individualized manner as frequently as required by the clinician or complexity of the case. EPI programs in <u>rural areas</u> may use teleconferencing or videoconferencing for supervision (as per agency policy and procedures).
- ii. Ensure that all staff receive ongoing training in clinical practice issues, risk assessment and management (i.e., high risk for suicide, self harm and violence), and cultural competency and diversity.
- iii. Ensure that all staff receive ongoing training with respect to current and emerging policies and legislation relevant to persons with psychosis.

Guidelines

- Have new EPI staff mentored by experienced peers.
- Support the development of a regional/provincial "community of practice" for EPI clinicians that will allow for mutual support and information sharing.
- Create professional development plans for all staff that address areas of skill enhancement.
- Hold weekly team meetings or virtual consultations to ensure the provision of component services.
- Develop an annual educational plan based on the identification by the coordinator and staff of training needs and goals.
- <u>Urban programs</u> extend training opportunities to staff associated with EPI programs in rural regions.

- Number of supervision meetings per year
- Tracking the hours and types of training per year

Derek: Two Possible Journeys – Epilogue

Optimal Care

Derek continued to meet with his new EPI team over the next year. The clinician worked with the local GP and the consulting psychiatrist and, with Derek's input, gradually decreased his medication. He regularly attended a social group organized by the EPI program, moved into his own apartment and began helping his stepfather fix up an old barn on their property. He expressed an interest in getting educational upgrading, enrolled in a carpentry program, and began a conversational Spanish course at night. He had met a local girl and had become active in her church. He continued to work with his EPI clinician on maintaining the gains he had made by learning more about psychosis, following through on the relapse prevention plan and working with her to use CBT-based strategies to control the stress he sometimes experienced. After 24 months, Derek was discharged from the EPI program, although he was told that it would remain open to him if he needed it for the next three years. Derek never needed to reengage with the EPI program, but two years later sent the team a letter thanking them for their help and included a picture of his new baby daughter.

Less than Optimal Care

Upon discharge from hospital, Derek never showed up for his appointment with the mental health team. Derek's file at the mental health centre was subsequently closed, because he was not attending appointments. No further outreach was attempted. Derek was an adult so his family was not notified of his lack of attendance or that his file was being closed. Derek's mental health continued to decline and, in addition to marijuana, he began to use crystal meth. He was picked up by the police on one occasion and spent the night in custody but was not charged. Derek was then evicted from his apartment. He had no contact with his family, who had moved to the smaller town chosen for their retirement. He proceeded to stay with "friends" at a local hotel, where he could readily access drugs. Derek ultimately rotated in and out of hospital due to various injuries and incidents, typically being brought in by the police or paramedics. During one hospital stay, Derek was offered stable housing in a group home for addiction issues but was discharged once it was evident that he required mental health services. Derek was referred again to the local mental health centre, but did not attend the appointment.

V. QUALITY IMPROVEMENT

A. Quality Improvement

Rationale

Evaluation and research must be recognized as priorities in order to ensure consistent adherence to best practices, continuously improve care and expand knowledge. Quality improvement systems are important in assuring and continuously improving the quality of EPI programs and their record of achieving best practices and optimal client outcomes. Early psychosis services should consider inclusion of a variety of evaluative methods to help guide refinements in services and care. The use of shared strategies and indicators across services will strengthen evaluation efforts. The development of indicators should include measures of outcome as well as those related to process and implementation. These indicators should be reviewed for their pertinence and efforts should be made to ensure that they are collected in a reliable and valid fashion. Information systems should be built into programs as part of their basic operation. Evaluation should directly assess the routine use of clinical guidelines and inform the teaching of best practices to professionals. The regular monitoring of process and client outcomes identifies opportunities for improving performance (92).

Intended Outcome

The EPI program engages in continuous quality improvement through ongoing systematic evaluation.

Description

Ideally, EPI programs would regularly engage in improvement projects or activities based on evaluations of performance and identified opportunities for improvement. Quality improvement projects should be informed through the regular collection of performance indicators. Client and family input should be sought to guide improvement projects. Feedback on program implementation, operating and evaluation should be obtained from EPI program staff and other appropriate community stakeholders.

Program evaluation includes detailed information on client outcomes, fidelity to the EPI model and best practices, and client and family satisfaction. For any research projects, EPI programs should be governed by and adhere to regional policies for research and ethics approval.

Rural areas may need to develop regional or sub-regional partnerships to guide performance improvement and program evaluation strategies.

Minimum Standards

No minimum standards have been approved for this section.

Guidelines

- Develop and revise annually a performance improvement plan that documents the objectives, methods and timeframes for desired improvements.
- Engage in continuous quality improvement on an ongoing basis and write a comprehensive evaluation report at least every three years.

- Program evaluation report must include both functional and symptomatic outcomes and all of the key performance indicators covered in this document.
- Evaluate outcomes (functional and symptomatic) from clinician, client and family perspectives.
- Assess client and family satisfaction with services during their involvement in the program.
- Undertake a review whenever a critical adverse event occurs (e.g., suicide, seriously aggressive behaviour, or major complaints from staff, client or family members).
- Engage in and publish research to inform the body of literature on early psychosis.
- Expand the list of key performance indicators beyond the indicators listed in this document.
- Use quantifiable measures of symptomatic and functional outcomes for all clients.
- Audit charts and associated documentation routinely for accuracy, comprehensiveness, timeliness and consistency with standards.

B. Key Performance Indicators

This section reviews the key performance indicators listed throughout this document. The purpose of the key performance indicators is to define and measure progress toward achieving the listed minimum standards and other recommended aspects of service.

The key performance indicators provided in this section represent only a partial list. In addition to these indicators, EPI programs are encouraged to devise their own unique list of indicators specific to their program operations, processes of care, and the unique communities in which they operate.

Standards Section	Key Performance Indicators
I. Recognition	
a. Community Education	 Existence of a written educational plan that is updated a minimum of every three years Tracking of educational activities to specified audiences Tracking of referrals sources (to identify groups to be targeted for educational activities)
b. Battling Stigma	 Community education plans and program development plans describe strategies for reducing stigma Community education activities contain anti-stigma information Client and family surveys about whether any aspect of the program was viewed as stigmatizing
c. Finding Individuals with Early Psychosis	 Presence of a list of service providers who are contacted regularly by EPI staff seeking persons who would benefit from an assessment Updating of the list occurs at least yearly Numbers of first-episode clients referred compared to anticipated number of first-episode individuals within the catchment area (the anticipated rate is approximately 25 new cases per 100,000 persons)
II. Access and Intake	
a. Target Population	 Tracking of referrals of individuals with co-occurring substance abuse or developmental disability or involvement with the criminal justice system Tracking of referrals from hospital versus community sources Age range covered by the EPI program
b. Access	 Age range covered by the EPI program There is a single point of contact (disseminate information about this point of contact widely) Referrals are accepted from any source The disposition of all referrals is clearly documented
c. Intake Process	 Time to respond to referral Time to first in-person contact with client (and proportion within one week Client and family questionnaire or interviews asking about satisfaction with intake process Tracking the number of clients and families engaged – i.e., the annual proportion of accepted clients who disengaged contrary to the recommendation of the program
III. Required Services	
a. Client and Family Empowerment	Survey of client and family opinion on the extent to which care is collaborat and fosters self-management
b. Assessment and Care	Documentation that assessments and reassessments are comprehensive and

P	lanning	consistent with the time frames of the standards (consider development of tracking checklist)
		 Documentation every six months of whether positive symptoms of psychosis (i.e., delusions, hallucinations or disorganized thinking) are prese (consider development of a tracking checklist)
		Client and family sign care plans indicating approval
c. R	isk Management	Existence of risk management policy and risk management program specifi EPI clients
		• Tracking critical incidents including suicides, attempted suicides and harm to others
	harmacological `reatment	 Tracking the percentage of clients in the program for a year or more who are offered clozapine
		 Documentation of simultaneous prescription of more than one antipsychot
		 Documentation and assessment of metabolic effects and movement disorder per established protocols
e. Pl	hysical Health Care	Access to a primary health care provider
		• Documentation of comprehensive physical assessment at entry and annually
	sychosocial nterventions	• Proportion of clients receiving psychoeducation for at least 10hours over 6 months
		• Proportion of families receiving psychoeducation for at least10hours over 6 months
		Relapse prevention plan documented for each client
		Number and types of psychosocial interventions available within a program
		Document rehospitalization rates for each client during the time enrolled in EPI
e	acilitating Functional	• The care plan addresses vocational, educational and social/recreational nee
R	lecovery	Proportion of clients entering or returning to work or school per year
		Income status documented every six months
		 Housing status documented every six months
h. A	cute and Inpatient Care	Existence of a referral protocol
		 Proportion of individuals identified by the EPI inpatient protocol as potenticlients who are engaged prior to discharge
i. D	Discharge Process	Duration in program for each client
		Existence of transitional protocols
		Existence of a written discharge plan for all clients
IV. Progra	am Structure, Operations	
	rogram Organization	Written program description exists
ar	nd Continuum of Care	EPI program has identified coordinator
		• Documented primary and secondary contact for each client and family
b. Se	ervice Intensity	Number of clients accepted who stay in the program for two years
		• Frequency of clinician contact with <u>clients</u> per year
		• Frequency of clinician contact with <u>families</u> per year
		- · ·
		 Access to a prescribing professional
c. St	taffing Complement	 Access to a prescribing professional Number of non-physician clinical staff FTEs per 100,000 population
c. St	taffing Complement	
	taffing Complement taff Supervision and	 Number of non-physician clinical staff FTEs per 100,000 population Multidisciplinary team including prescribing professional (for rural areas

Glossary

Affective psychosis – In affective psychosis, psychotic symptoms occur in the context of mania or depression (e.g., Bipolar Disorder and Major Depression with psychotic features). Treatment that addresses both the mood and psychotic symptoms is required.

Antipsychotic medications – Medications used in the treatment of psychosis are generally classified as typical (or first generation) versus atypical (or second generation). Typical antipsychotics (e.g., haloperidol, fluphenazine, chlorpromazine, flupenthixol and loxapine) have been available since the early 1950s and are often associated with motor side effects such as parkinsonism and tardive dyskinesia. Atypical antipsychotics (developed over the past two decades) include medications such as clozapine, risperidone, olanzapine and quetiapine. Although atypical antipsychotics are associated with fewer motor side effects, they are often linked with weight gain and negative sexual side effects.

Assertive Community Treatment (ACT) – A formalized community-based, recovery-oriented, client-centered mental health service delivery model for either urban or rural practice. ACT provides intensive, comprehensive services and facilitates community living, psychosocial rehabilitation and recovery for persons who have severe mental illnesses and/or addictions. These individuals have multiple complex needs with significant functional impairments and are unable to maintain involvement with the traditional mental health and addictions out-patient programs. ACT is distinct from many other mental health service delivery approaches, in that it includes a low client-to-staff ratio, frequent contact, operating after hours and weekends, an integrated multidisciplinary team approach, client-directed delivery of care, assertive outreach and continuous ongoing services to ensure continuity of caregiver.

Assessment – A systematic and ongoing process of evaluating information collected about an individual in order to ascertain his or her diagnosis, individualized needs and desired outcomes of care.

Biopsychosocial approach – An approach to conceptualizing and treating disorders that considers biological, psychological (i.e., thoughts, emotions, behaviours) and social aspects of human functioning.

Cognitive assessment – A specialized form of assessment that involves the formal evaluation of cognitive functioning (e.g., attention, intelligence, learning/memory, language, visual-spatial processing and executive functioning).

Cognitive Behavioural Therapy (CBT) – A psychological treatment that focuses on helping people identify goals, develop problem-solving and coping skills, and modify thinking/behaviour patterns that interfere with functioning.

Continuum of care (also known as continuity of care) – The progression of services received as one moves through the health system. Ideally, the continuum of care promotes early and barrier-free access to necessary mental health services (e.g., primary care, inpatient, outpatient and other community supports) as well as easy transition from service to service as individual needs change.

Duration of untreated psychosis (DUP) – The period between the onset of psychosis and the initiation of adequate treatment.

Early psychosis – The years following the initial emergence of psychotic symptoms (arbitrarily set at approximately five years). It has been argued that this stage may represent a "critical period" during which treatments are most effective in promoting successful recovery.

EPI Clinician – A therapist providing clinical and/or case management services directly to clients in an EPI program.

EPI Coordinator – Professional responsible for the day-to-day management of an EPI program. The EPI Coordinator is also typically responsible for supervising individual EPI team members and ensuring that evidence-based practices and protocols are followed.

Mental Status Exam (MSE) – A specialized procedure used to assess an individual's current mental state (e.g., appearance, behaviour, mood and affect, speech, thought process, thought content, perception, cognition, insight and judgment).

Metabolic monitoring – The use of antipsychotic medications can be associated with weight gain as well as adverse changes in other metabolic parameters (e.g., glucose, cholesterol) that must be monitored regularly.

Mood stabilizers – A class of psychiatric medications used to treat bipolar disorders (i.e., to prevent or treat episodes of mania and depression). Commonly prescribed mood stabilizers include lithium, carbamazepine, valproic acid and lamotrigine.

Multidisciplinary care – A collaborative approach to treatment planning and ongoing care. It involves the liaison and cooperation of varied health professionals to ensure that all relevant treatment methods are incorporated into an individual's care.

Non-affective psychosis – Non-affective psychosis refers to psychotic disorders that are not associated with an underlying mood disorder (e.g., schizophrenia).

Phases of psychosis -

Prodrome – A period of disturbance that represents a deviation from a person's previous experience and behaviour that occurs prior to the onset of psychosis. It can only be diagnosed retrospectively (i.e., after the development of florid features of psychosis). The term has been used to describe the period prior to the first episode of psychosis (initial prodrome) and prior to relapse (relapse prodrome).

Acute – The initial phase of psychosis characterized by the presence of psychotic features such as delusions, hallucinations and/or thought disorder.

Recovery (early/later) –The period following the treatment of acute psychosis, when there is a reduction in symptoms and/or a return to normal levels of

functioning. The early recovery period falls within the first few months after treatment has begun and is typically characterized by some degree of relief from symptoms. Later recovery refers to the subsequent period of time when individuals attempt to make sense of and cope with their experience, prepare for the possibility of relapse, and develop skills that will facilitate their return to normal functioning.

Prolonged recovery –Although recovery may be quick for some individuals, if psychotic symptoms remain (or return), the recovery process is considered to be prolonged.

Program models – There are four primary models of service delivery used in EPI treatment:

Case management – A model in which a single case manager is responsible for [fix indenation] directing the care of an individual, thus providing a continuing relationship between service providers, the patient, and his or her family.

Hub and spoke – Consists of a specialized, central team ("hub") that is responsible for providing program direction, coordination and consultation/supervision, combined with community teams ("spokes") that include clinicians who provide direct treatment services. EPI clinicians are often members of existing general mental health teams.

Centralized – A specialized treatment service consisting of a central, multidisciplinary team in which the majority of staff (and their time) is dedicated to providing EPI services.

Decentralized – A model of care in which no clinical staff are solely responsible for providing early psychosis intervention services.

Psychoeducation – Psychoeducation fosters the knowledge, attitudes, skills and abilities necessary for a person to manage his or her own illness. The overall goal is generally to promote the self-management capacity needed to achieve or recover valued life goals and overall quality of life. Treatment adherence and relapse prevention are often primary targets.

Psychosis – A condition in which there has been some loss of contact with reality. Psychosis can lead to changes in one's thinking, mood, communication, and/or ability to relate with others such that the individual's capacity to deal with reality is impaired. Classic symptoms of psychosis include hallucinations, delusions, disorganized speech, and/or odd behaviours.

Psychotic disorders – Mental disorders characterized by symptoms of psychosis. Although psychotic symptoms may occur in other disorders (e.g., mood disorders), the DSM-IV TR identifies nine formal psychotic disorders: Schizophrenia, Schizophreniform, Schizoaffective Disorder, Delusional Disorder, Brief Psychotic Disorder, Shared Psychotic Disorder, Psychotic Disorder due to a Medical Condition, Substance-Induced Psychotic Disorder, and Psychotic Disorder Not Otherwise Specified.

Relapse – The return of disabling signs and symptoms of psychosis after a period of remission has been achieved.

Remission – A period of significant improvement or recovery from a disorder, which may or may not be permanent.

Rural – Defined by Statistics Canada as geographic areas lying outside of urban regions. From the perspective of health services, rural areas tend to have reduced access to specialist services as well as more limited capacity of existing mental health services.

Self-care (self-management) – Refers to decisions and actions an individual can take to cope with a health problem or to improve his or her health and wellbeing.

Ultra-high risk (UHR) – Individuals deemed to be at incipient (or "ultra-high") risk of developing a psychotic disorder. The Personal Assessment and Crisis Evaluation (PACE) Clinic criteria used to identify UHR states include: individuals between the ages of 14 and 29 years who experience either sub-threshold psychotic symptoms; brief limited intermittent psychotic symptoms; or, have significant trait and state risk factors (i.e., schizotypal personality disorder or a first-degree relative with a psychotic disorder) and have experienced a significant decrease in functioning over the previous year).

Urban – Defined by Statistics Canada as a geographic area with a population of at least 1,000 and no fewer than 400 persons per square kilometre.

Appendices

Appendix I: Summary of Other Published Guidelines and Standards

The following published guidelines and standards were consulted during the process of developing the standards for Early Psychosis Intervention (EPI) programs in British Columbia.

Canadian Guidelines & Standards

EPI Service and Clinical Guidelines (95)

- Adopted provincially by the BC Ministry of Children and Family Development for Child and Youth Mental Health and by the Fraser Health Authority, BC
- Guidelines are considered standards for EPI programs to strive towards
- Available on the following website: <u>http://www.psychosissucks.ca/epi/pdf/ServiceandClinicalGuidelines2006.pdf</u>

Early Psychosis: A Care Guide (1)

- Developed as a part of the British Columbia Early Psychosis Initiative an inter-ministerial project jointly funded by the Ministry of Health Services and the Ministry of Children and Family Development
- Articulates rationale for early intervention and provides guidance for clinical practice in specific aspects of management
- Available on the following website: <u>http://www.health.gov.bc.ca/library/publications/year/2002/EarlyPsychosis_guide.pdf</u>

Guide to Clinical Care for Early Psychosis (92)

• Summarizes current knowledge of early psychosis, guides clinicians in specific aspects of management, encourages the use of appropriate procedures and services, and acts as a planning vehicle to improve service delivery and guide policy

Vancouver Island EPI Program Standards (96)

• Developed for use by EPI programs within the Vancouver Island Health Authority

Policy Framework for Early Intervention in Psychosis (97)

- Developed by the Ontario Working Group to ensure that existing and developing early intervention programs across Ontario are guided by a consistent framework and policy direction
- Available on the following website: <u>http://www.health.gov.on.ca/english/public/pub/ministry_reports/mentalhealth/psychosis.pdf</u>

Nova Scotia Provincial Standards for Early Psychosis (98)

- Adopted by the Nova Scotia Department of Health for use by the Nova Scotia Early Psychosis Program (NSEPP) and an associated network of mental health care professionals located in each district of the province
- Available on the following website: <u>http://earlypsychosis.medicine.dal.ca/services/index.cfm</u>

International Guidelines & Standards

Early Intervention and Recovery for Young People with Early Psychosis: Consensus Statement (88)

- Developed by Bertolote and McGorry on behalf of the World Health Organization and the International Early Psychosis Association (IEPA)
- Articulates the universal principles of early intervention for first-episode psychosis; includes overall strategic recommendations and measured outcomes
- In: British Journal of Psychiatry, 187 (suppl. 48), s116-s119

International Clinical Practice Guidelines for Early Psychosis (99)

- Developed with detailed input from 29 invited international consultants to provide practical guidance to clinicians and researchers
- In: British Journal of Psychiatry, 187 (suppl. 48), s120-s124

Australian Clinical Guidelines for Early Psychosis (100)

- Detailed practical clinical guidelines for early psychosis service developed by the National Early Psychosis Project in Melbourne, Victoria
- Available through the Early Psychosis Prevention and Intervention Centre (EPPIC) (<u>http://www.eppic.org.au/</u>)
- A brief version of these guidelines (EPPIC Short Clinical Guidelines for Early Intervention) is available at the following website: <u>http://www.earlypsychosis.org.nz/eip-aus.htm</u>

The Australian Clinical Guidelines for Early Psychosis - Evidence Map Reference, 2nd edition (43)

- Presented at the 6th International Conference on Early Psychosis, Early Intervention The Next Wave, Melbourne, Australia
- Brief map of evidence-based recommendations for pharmacological and psychosocial interventions for Ultra-High Risk, First Episode, Relapse Prevention, Treatment Resistant and Severe Unremitting Chronic psychotic conditions
New Zealand Early Intervention in Psychosis Guidance Note (101)

- Developed to provide all mental health services in New Zealand with a guide for helping people presenting with a first episode of psychosis
- Available on the following website: <u>http://www.earlypsychosis.org.nz/pdf/nz/Early-Intervention-PsychosisNZ.pdf</u>

Mental Health Policy Implementation Guide – Early Intervention in Psychosis (94)

- Developed by the Department of Health to support the delivery of adult mental health programming across the UK
- Identifies key components and elements of early psychosis intervention as well as service management and operational procedures
- Available on the following website: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4 009350

Clinical Guidelines and Service Frameworks for Early Intervention (102)

- Developed by the Initiative to Reduce Schizophrenia (IRIS) and National Schizophrenia Fellowship (NSF) in the UK
- Intended to guide the development of Early Intervention for Psychosis Services in the West Midlands of the UK and ensure that young people in the early phase of psychosis receive the highest standards of care
- Available through IRIS (http://www.iris-initiative.org.uk/)

Appendix II: Summary of Services Provided by International EPI Programs

Information regarding program characteristics, service delivery, and staffing was collected from a range of local and international EPI programs in order to inform the development of standards for Early Psychosis Intervention (EPI) programs in British Columbia. The following Canadian and international EPI programs were reviewed.

<u>Canada</u>

Fraser South EPI Program

- Type of Service: Outpatient (community-based)
- Location (Catchment): South Fraser Health Region, BC (575,000)
- Website: <u>http://www.psychosissucks.ca/epi/</u>

Vancouver/Richmond EPI Program

- Type of Service: Outpatient, Inpatient (community and hospital-based)
- Location (Catchment): Vancouver and Richmond, BC (752,502)
- Website: <u>http://www.hopevancouver.com/</u>

Vancouver Island EPI Program

- Type of Service: Outpatient, Inpatient (community and hospital-based)
- Location (Catchment): Victoria, BC (730,000)

Calgary Early Psychosis Treatment Service (EPTS)

- Type of Service: Outpatient (hospital-based)
- Location (Catchment): Calgary, AB (954,000)
- Website: <u>http://www.calgaryhealthregion.ca/mh/EPTP/epp/index.htm</u>

Prevention and Early Intervention Program for Psychoses (PEPP) - London

- Type of Service: Integrated Inpatient and Outpatient (university hospital)
- Location (Catchment): London, ON (390,000)
- Website: <u>http://www.pepp.ca/index.html</u>

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

- Type of Service: Integrated Inpatient and Outpatient (university hospital)
- Location (Catchment): Toronto, ON (4,000,000)
- Website: <u>http://www.camh.net/About_CAMH/Guide_to_CAMH/Mental_Health_Programs/Schizophrenia_Prog</u> <u>ram/guide_first_episode_program.html</u>

Nova Scotia Early Psychosis Program (NSEPP)

- Type of Service: Outpatient (hospital-based)
- Location (Catchment): Halifax, NS (850,000)
- Website: <u>http://earlypsychosis.medicine.dal.ca/</u>

<u>Australia</u>

Early Psychosis Prevention and Intervention Centre (EPPIC)

- Type of Service: Outpatient and Inpatient (community and hospital-based)
- Location (Catchment): Melbourne, VIC (850,000)
- Website: <u>www.eppic.org.au</u>

Youth Early Psychosis Program (YEP)

- Type of Service: Outpatient (community-based)
- Location (Catchment): VIC (750,000)

Recovery and Prevention of Psychosis Services (RAPPS)

- Type of Service: Outpatient (community-based)
- Location (Catchment): VIC (750,000)
- Website: <u>http://www.southernhealth.org.au/camhs/rapps.htm</u>

New Zealand

Totara House

- Type of Service: Integrated Inpatient and Outpatient (community and hospital-based)
- Location (Catchment): Christchurch, Canterbury (380,000)
- Website: <u>http://www.cdhb.govt.nz/totara/</u>

<u>UK</u>

Lambeth Early Onset (LEO)

- Type of Service: Outpatient and Inpatient (community and hospital-based)
- Location (Catchment): Lambeth (266,170)
- Website: <u>http://www.mentalhealthcare.org.uk/content/?id=19</u>

Croydon Outreach and Assertive Support Team (COAST)

• Type of Service: Outpatient (community-based)

• Location (Catchment): Croydon (339,500)

Early Treatment and Home-based Outreach Service (ETHOS)

- Type of Service: Outpatient (community-based)
- Location (Catchment): Southwest London (629,000)

Outreach and Support in South London (OASIS)

- Type of Service: Outpatient (community-based)
- Location (Catchment): Lambeth (266,170)
- Website: <u>www.oasislondon.com</u>

Northumberland Early Intervention in Psychosis Service

- Type of Service: Outpatient (community-based)
- Location (Catchment): Northumberland County (310,000)

Appendix III: Summary of Recent Scientific Literature on Early Psychosis

Reviews of the literature on early psychosis intervention have been published previously by the authors in Early Psychosis: A Care Guide (1), Guide to Clinical Care for Early Psychosis (92) and Early Psychosis: A Review of the Treatment Literature (103). For this project, literature searches were conducted for the period since these reviews were performed. Below is a partial list of the key studies and reviews published in the field since 2004. Summaries of each study have been provided.

Early Intervention

Outcome Studies

Specialised care for early psychosis: Symptoms, social functioning and patient satisfaction. (104)

In this randomized controlled trial (N = 140), the authors compared the effects of a specialized early psychosis intervention service (Lambeth Early Onset team) with standard treatment on clinical outcomes, social outcomes and service user satisfaction. Eighteen-month outcomes for patients treated by the early onset team were found to be significantly better in terms of social/vocational functioning, satisfaction with services, quality of life, and medication adherence. Although symptoms improved substantially in both groups over time, no group differences in levels of symptom improvement were found. Overall, the results were taken to indicate the range of benefits attained through the provision of specialist services for people with early psychosis.

The relationship between duration of untreated psychosis and outcome: An eight-year prospective study. (105)

In this prospective, naturalistic study, the influence of duration of untreated psychosis (DUP) on clinical and functional outcomes over the medium-to-long term (8 years after initial treatment) was examined. Multiple linear regression analyses (based on 318 patients) indicated that shorter DUP was moderately correlated with decreased severity of positive symptoms, and enhanced social/occupational functioning and quality of life. The effects of DUP were found to be independent of potentially confounding variables such as gender, age of onset of illness, pre-morbid adjustment, education and duration of prodrome. No association was found between DUP and negative symptoms, as instead, premorbid adjustment was found to be the strongest predictor of this outcome. Clinical and functional outcomes appeared to be particularly poor when DUP exceeded 3 months. These findings support the need for assertive early detection strategies to reduce the risk of short- and long-term negative outcomes among those with an emerging psychotic illness.

The key to reducing duration of untreated first psychosis: Information campaigns. (106)

Using a historical design, the authors compared 2 cohorts of patients with FEP admitted to the TIPS early intervention program – one recruited during a period of intensive information campaigns (ICs) and one recruited after the ICs had stopped. Easy access early detection teams (DTs) were available to both cohorts. During the no-IC period, results (n = 75) indicated that the median DUP increased to 15 weeks (compared to 5 weeks during the IC period; n = 108) and fewer patients overall came to clinical attention through the DTs. Increases in baseline symptoms were also found during the no-IC period (i.e., more positive and total symptoms on the PANSS and poorer ratings of global functioning). The authors concluded that intensive education campaigns targeting the general public, schools, and primary health care providers, combined with low-threshold DTs, constitute key components of successful early detection efforts.

A multisite Canadian study of outcome of first-episode psychosis treated in publicly funded early intervention services. (107)

In this study, the authors evaluated 1-year outcomes in a sample of FEP patients treated at three different publicly funded EI programs in Ontario (2 medium-sized centres and 1 large urban centre). Results (based on a sample of 172 patients across the 3 sites) indicated significant decreases in positive, negative and general symptom outcomes (assessed at 6 months and 1 year) that were independent of ethnicity, education and diagnosis. There was, however, some variability in the degree of positive outcomes observed across the sites with significantly better outcomes found on all symptom measures for the two medium-sized centres when compared with the one large urban centre. Thus, it appears that despite apparent similarities in assessment and treatment protocols, outcomes of early intervention services may be influenced by specific local factors that should be considered when developing models of care.

OPUS Trial

Five-year follow-up of a randomized multicenter trial of intensive early intervention vs. standard treatment for patients with a first episode of psychotic illness. (93)

This study reported the 5-year follow-up results from a randomized, controlled trial comparing 2 years of an intensive early intervention program (OPUS) with standard treatment (community mental health centres) for patients experiencing a FEP. Although the early intervention program demonstrated superior clinical outcomes after 2 years, these positive effects were not sustained to the 5-year follow-up. No significant differences between the groups were found in terms of psychotic or negative symptoms, global functioning, substance abuse, depression, or suicidal behaviour. However, results pertaining to social outcomes did partially favour the intensive early intervention program as patients from the experimental group were living more independently (less use of supported housing) and had spent significantly fewer days in hospital over the 5-year period. The authors emphasized the need for future studies to investigate the outcomes of more prolonged early intervention treatment programs and indentified ways to improve the transition to standard services.

Cost Effectiveness

Impact of a specialized early intervention service for psychotic disorders on patient characteristics, service use, and hospital costs in a defined catchment area. (108)

This study examined the impact of early intervention services on patient characteristics and resource use over the first 2 years of treatment within a defined catchment area in Ontario, Canada. Following the introduction of an early intervention service, the Prevention and Early Intervention Program for Psychosis (PEPP), significant decreases in hospital admissions (both voluntary and involuntary) and ER hospital visits were found. These changes were also associated with significant cost savings (i.e., mean reduction in costs per case of regular hospital bed use and emergency visit).

Reviews

Early intervention for psychosis. (109)

In this Cochrane review, the authors evaluated the effects of early detection, phase-specific treatments and specialized early intervention teams on the treatment of people with prodromal symptoms or FEP. Their extensive search of the literature yielded only seven randomized controlled trials (involving a total of 941 participants) that met criteria for inclusion. Three of these studies were concerned with preventing the onset

of psychosis (among individuals experiencing prodromal symptoms) and four were concerned with improving outcomes among patients with FEP. Most of these studies were found to be underpowered, but, because each study used different interventions or controls, results could not be pooled for meta-analyses. The authors concluded that there was insufficient evidence to draw any definitive conclusions or make recommendations for practice. Given the limited data on the personal and social consequences of providing treatment to people who will not necessarily develop psychosis, they argued that specialized treatment services for people with prodromal symptoms are only justified on an experimental basis. Although there is also little direct evidence supporting early intervention in FEP, the authors argued that because these patients require some form of treatment (and there is a comparable lack of evidence supporting "standard care"), the use of first-episode teams is ethically justified. The authors note that the field of early intervention in psychosis research is growing quickly and that they expect data from a substantial number of trials currently underway to become available within the next few years.

Is early intervention in psychosis effective? (110)

In this paper, the evidence pertaining to the effectiveness of early intervention for psychosis was reviewed. The authors concluded that the evidence on the effectiveness of early intervention programs in reducing the DUP is promising, although limited. They speculated that the fact that existing services primarily intervene when patients present with overt psychosis (as opposed to individuals in the very early stages or at risk) may underlie the lack of strong evidence. With respect to relapse and admission rates, the authors argued that there is preliminary evidence suggesting some advantage of early intervention services over treatment as usual. Additional benefits of early intervention services were highlighted including reductions in suicide attempts among individuals experiencing a first episode of psychosis (FEP) and lower treatment costs (likely due to the reduced expense of inpatient care).

Medication

Early use of clozapine for poorly responding first-episode psychosis. (111)

The authors described the implementation and evaluation of a treatment algorithm standardizing medication management for patients with first-episode schizophrenia. According to the algorithm, patients received two trials with 2 second-generation antipsychotics (olanzapine, quetiapine or risperidone at low, medium and high doses) before receiving a trial of clozapine. Among the 123 first-episode patients treated according to the algorithm, 13 of 23 identified nonresponders agreed to a trial of clozapine. In comparison to a group of 9 patients who refused clozapine (and continued with the same antipsychotic treatment), patients receiving clozapine demonstrated significant decreases in terms of symptomatology and severity of illness. The authors suggested that clozapine may play an important role in the early treatment of patients whose psychotic symptoms do not remit with other second-generation antipsychotics during the initial phase of treatment.

Randomized comparison of olanzapine versus risperidone for the treatment of first-episode schizophrenia: 4-month outcomes. (112)

This randomized study compared 4-month outcomes of patients with first-episode schizophrenia treated with olanzapine versus risperidone. Results (based on 112 patients) revealed no significant differences between the groups in terms of response rates or negative symptom outcomes. In terms of side effects, no differences were found on measures of parkinsonism or akathisia. However, although both medications caused rapid, substantial weight gain, the gain was more pronounced with olanzapine.

Cognitive Behavioural Therapy (CBT)

Cognitive Behaviour Therapy and Early Intervention. (113)

This article reviewed the role of CBT for individuals experiencing a first episode of psychosis and those at clinical high-risk of psychosis. The authors reported that although there are several studies supporting the effectiveness of CBT for psychosis in general, studies focusing on FEP samples are limited and plagued by methodological weaknesses. Preliminary findings were taken to indicate that CBT is an appropriate intervention for individuals with FEP. Results from studies evaluating CBT for those at high risk were found to be particularly encouraging and suggested that treatment with CBT may contribute to improvements in prodromal symptoms.

Acute-phase and 1-year follow-up results of a randomized controlled trial of CBT versus Befriending for first-episode psychosis: the ACE project. (114)

This randomized controlled trial compared the effectiveness of an individual CBT intervention known as Active Cognitive Therapy for Early Psychosis (ACE) with a control condition (Befriending) for patients in the acute phase of their first episode of psychosis. Results (N = 62) indicated that individuals in both groups demonstrated improvements in positive and negative symptoms over time. At mid-treatment, the ACE group outperformed the Befriending group by improving psychosocial functioning. However, by the end of the treatment (and at 1-year follow-up), there were no significant group differences in measures of symptomatology, functioning, or rates of hospital admission. The authors concluded that CBT may accelerate recovery early in the treatment of acute psychosis but that future research is needed to determine whether its positive effects are better sustained over time.

Group cognitive behaviour therapy or social skills training for individuals with a recent onset of psychosis? (115)

In this study, the authors compared the effectiveness of a manualized CBT group intervention with a manualized social skills training group for symptom management among individuals with recent-onset psychosis. A single-blind randomized controlled trial (N = 129) revealed that both interventions resulted in significant decreases in positive and negative symptoms when compared with a wait-list control group. Superior effects for the CBT group were found in terms of post-treatment effects on self-esteem, coping and social support. Lower dropout rates were also reported in the CBT group when compared to the social skills training group. Given that clinicians without significant prior training in CBT or group interventions were used as therapists in this study, the authors also emphasized the feasibility of training mental health workers to administer manualized group interventions.

Substance Abuse

Substance use and abuse in first-episode psychosis: Prevalence before and after early intervention. (116)

The authors examined the impact of early intervention on substance use and abuse among individuals with first-episode psychosis (FEP). At baseline, the prevalence rates for lifetime alcohol and cannabis use among the FEP sample were found to be similar to those of an age-matched sample from the Canadian population. However, significantly higher prevalence rates for lifetime hallucinogen and cocaine use were found among the FEP sample. Prospective analyses (N = 131) revealed that the prevalence of substance use and abuse decreased significantly after 12 months of EI treatment. Thus, preliminary evidence appears to support the effectiveness of EI services for detecting and reducing substance abuse among individuals with FEP.

Randomized controlled trial of a cannabis-focused intervention for young people with first-episode psychosis. (117)

In this study, the investigators evaluated the effectiveness of a cannabis-focused cognitive-behavioural intervention for individuals engaged in FEP treatment services who continued to use cannabis. A single-blind randomized controlled trial compared a specific cannabis-focused intervention (n = 23) with an active control condition involving psycho-education (n = 24). No significant group differences were found, however, both conditions resulted in a significant decrease in cannabis use at the end of treatment (and maintained at 6-month follow-up). Thus, it was argued that beginning with relatively simple, general interventions such as psychoeducation may be warranted when attempting to reduce cannabis use in FEP clients.

Psychotic symptom and cannabis relapse in recent-onset psychosis. (118)

This prospective study examined the influence of cannabis use on psychotic relapse among a sample of individuals with recent-onset psychosis (within 3 years of initial diagnosis). Among a sample of 81 participants (followed for 6 months), more frequent cannabis use was found to be a strong predictor of psychotic relapse (even after controlling for medication adherence, stress and duration of untreated psychosis). Results also suggested a bidirectional relationship between cannabis use and psychosis, as more severe psychotic symptoms were associated with increased risk of cannabis relapse. The findings underscore the importance of targeting cannabis use when treating this population.

<u>High Risk</u>

Outcome Studies

Three-year follow-up of a randomized controlled trial of cognitive therapy for the prevention of psychosis in people at ultra-high risk. (39)

In this randomized controlled trial, cognitive therapy (CT) provided over a 6-month period was compared with monthly monitoring in 58 patients meeting PACE criteria for at-risk mental state. Results indicated some positive benefits of CT over the long term. In particular, receiving CT significantly reduced the likelihood of being prescribed antipsychotic medication during the 3-year follow-up period (after controlling for age, gender, baseline PANSS scores and family history). In addition, when baseline cognitive factors (i.e., maladaptive beliefs targeted during therapy) were controlled for, CT was found to significantly reduce the likelihood of transitioning to psychosis (defined by the PANSS). The authors argued that CT should be offered to people at high risk of psychosis prior to the consideration of antipsychotic medication.

Transition rates from schizotypal disorder to psychotic disorder for first-contact patients included in the OPUS trail: A randomized clinical trial of integrated treatment and standard treatment. (119)

This prospective study investigated whether integrated treatment would reduce or postpone the transition to psychosis among patients diagnosed with schizotypal disorder. A randomized clinical trial compared the effects of a 2-year integrated treatment program (involving monitoring, family involvement, social skills training and the possibility of antipsychotic medication; n = 42) with standard treatment (n = 37). Involvement in the integrated treatment program was found to reduce the risk for transition to a psychotic disorder. At follow-up, significantly fewer patients in the integrated treatment group were diagnosed with a psychotic disorder when compared to those in the standard treatment group (25% and 48% respectively).

Medium term follow-up of randomized controlled trial of interventions for young people at ultra-high risk of psychosis. (120)

In this article, the follow-up results from a randomized controlled trial of treatment comparing a combination of psychological treatment and anti-psychotic medication with supportive therapy in an ultrahigh-risk sample were reported. Three- to four-year follow-up results from 41 participants (69.5% of the original sample) indicated that there were no significant differences in transition rate, symptomatology or functioning between the treatment groups. Benefits of receiving some form of pre-psychotic intervention were indicated in both groups by generally low levels of hospitalization among those who did progress to psychosis. The finding that a significant proportion of participants reported ongoing mild to moderate levels of psychological symptoms and impaired functioning (even when progression to a psychotic episode did not occur) highlights the need for ongoing care among this population.

Review

Prospective investigations of the prodromal state of schizophrenia: Review of studies. (121)

In this paper, the authors provided a comprehensive and extensive review of 23 prospective studies monitoring or intervening in the prodromal phase of FEP. Transition rates among studies defining samples on the basis of "attenuated positive symptoms (APS)", "brief limited psychotic symptoms", or "genetic risk" deterioration" were found to vary substantially (between 9% and 54%). Three randomized controlled trials were reviewed and suggested that specific interventions (psychological and/or psychopharmacological) may reduce transition rates when compared with monitoring and case management alone. However, the authors cautioned against drawing implications for clinical guidelines at this time. They highlight numerous methodological weaknesses among the studies reviewed including small sample sizes and difficulties making cross-study comparisons given variability in selection criteria and heterogeneity of the samples.

Appendix IV: Review of Early Psychosis Intervention in Rural Communities

Service models and needs for early intervention programs in rural areas differ significantly from those in urban areas. A number of issues that are unique to the rural context must be considered when developing or implementing early psychosis intervention programs in rural communities.

Common Program Issues and Challenges:

Geographic and demographic features (122-124)

- Widely dispersed rural communities physical and geographic isolation; low population densities
- Travel: long distances to travel for access to services; lack of public transportation; high cost of travel and inadequate travel allowances; interference by hazardous weather conditions
- Certain interventions (e.g., groups) may be less feasible due to lack of a critical mass of clients, few clients at same stage of illness/treatment, and/or large geographical distances between clients
- Heterogeneity of rural populations (e.g., presence of transient, seasonal workers; Aboriginal populations)

Limited capacity/resources (122, 123)

- Reduced access to specialist services and staff
- Limited capacity of existing services fewer and more thinly spread resources; deficits in vocational, educational, and recreational services; less access to specialist services
- More demands placed on a smaller number of professionals (staff must assume wide-ranging responsibilities)
- Sense of isolation among clinicians many clinicians work alone and independently
- Challenges in the recruitment and retention of trained staff (high staff burnout, turnover and vacancy rates)
- Employment, education and social opportunities may be less available can impede efforts to maintain clients' quality of life

Other Barriers to early identification (123-125)

- Increased stigma surrounding mental health problems and available treatments can lead to reluctance to acknowledge mental health problems and avoidance of appropriate help
- Culture of self-reliance within rural communities used to meeting their own needs without outside help; people may not readily recognize and/or respond to mental health concerns
- Increased tolerance of "eccentricities"
- High rates of alcohol and substance abuse may impede ability to identify individuals with FEP
- Barriers may result in longer durations of untreated psychosis (DUPs) and delayed access to treatment in rural settings

Priorities for EPI Programs in Rural Communities:

Integration of services (123, 124)

- Working within existing structures focus on establishing collaborative relationships with existing primary care services (e.g., GPs) and other key agencies
- Need for greater integration of mental health and drug/alcohol services

Support for clinicians (124)

- Accessible expert consultation and regular clinical supervision (e.g., making using of technology such as telepsychiatry)
- Well-distributed clinical guidelines and protocols (for assessment, treatment, monitoring)

Promoting community awareness/education initiatives (124)

- Build upon strengths of rural communities (e.g., increased social connectedness, presence of informal networks operating within communities)
- Make use of existing community organizations/events in raising awareness (e.g., fairs, festivals, churches, sporting events)

Examples of EPI Programs in Rural Areas:

Southern Area First Episode (SAFE, NSW, Australia) (126-128)

- Has adopted a "specialist-within-generalist team" approach integrates early intervention services with services provided by existing mental health agencies
- All mental health clinicians are trained in EI protocol and procedures based on EPPIC; two clinicians from each team are further trained as specialists to provide EI services and assist other staff
- Supervisory outreach is available by EI specialist psychiatrist
- Training in early identification is provided to all gatekeepers
- Production/dissemination of procedure manuals and resource materials
- All clients are entered into an electronic database that follows them wherever they move within the area (facilitates service continuity); database contains checks and balances to ensure that clinicians are providing the best practice elements of care

Regional Early Intervention in Psychosis Program (REIP, Northeast Ontario) (129)

- Modeled in part after the SAFE program in Australia
- Trained early intervention specialists in each district linked to a regional centre
- Regional coordinator (situated at the regional centre) provides coordination, support, training and consultation to district-based early psychosis services
- The primary function of the REIP program is to support and provide resources for the development of specialized early intervention in psychosis district programs (i.e., disseminates evidence-based best practice guidelines, protocols, resources, common procedural guidelines, specialized training and information to district early intervention in psychosis programs; supports a network for peer consultation, communication and resource sharing for clinicians across the northeast region)
- REIP does not provide direct service to clients, however client care is improved through ongoing clinical supervision and consultation with district-based clinicians throughout the region

Appendix V: Update to the Survey of BC EPI Programs

Introduction

The 2004 report "A Quiet Evolution: Early Psychosis Services in British Columbia" (28) outlined the results of a survey assessing community and hospital-based EPI (Early Psychosis Intervention) programs across BC. At that time, programs varied significantly in terms of staffing, approach and the comprehensiveness of early intervention services provided. The present survey aimed to provide an updated account of specialized EPI programs in BC by examining the state of service delivery and uptake of best practices. The survey was designed to complement the concurrent development of EPI Standards and Guidelines by ensuring that the standards and guidelines included are practical and realistic.

Methods

This report is based on information collected from community EPI program providers in BC. The survey was adapted from the one used in the Quiet Evolution report. Only questions relevant to community (and not inpatient) programs were retained and modified. Information pertaining to program structure and parameters (e.g., service delivery model, accessibility, staffing); service components (e.g., assessments, interventions, education); and research/clinical training was collected.

Surveys were distributed to a sampling of community sites throughout the province and were not intended to provide an all-inclusive representation. Members of the EPI Standards Development Advisory Committee were asked to distribute the survey to sites providing EPI programs within their health regions. Surveys were distributed in late November 2008 and completed/returned by mid-December 2008.

In order to examine uptake of best practices, five key areas addressed in a preliminary draft of the current report ("Standards and Guidelines for Early Psychosis Intervention (EPI) Programs in British Columbia") were selected and then operationalized based on responses to specific survey items. These domains included accessibility (provision of treatment services within one week of intake); psychiatric services (psychiatric involvement and medication management); psychosocial interventions (availability of client/family education, groups, social intervention or CBT); phase-specific intervention (explicitly following a phase-specific approach); and community education (provision of some form of public education). For the purposes of the data analysis, programs responding affirmatively to survey items assessing these areas were considered to have demonstrated a sufficient level of uptake.

Results & Discussion

Surveys were received from 15 sites located throughout urban and rural areas of the province including the Lower Mainland, Vancouver Island, Interior/Kootenays and Central/Northern BC. Among these programs, eight self-identified as being specialized EPI programs. Many of the remaining programs are offering EPI services within the context of existing general community mental health and addictions programs (e.g., Child and Youth Mental Health).

Program Parameters (* = Specialized EPI Program)

Program Name	Predominant Population Served	Program Model	Admission Criteria (length of treated psychosis allowed)	Maximum Length in Program
Lower Mainland				
*Fraser EPI Program	Adult and Child & Youth	Hub and Spoke ¹	FEP ⁴ and/or never treated	2 yrs (extensions possible)
*Vancouver Richmond EPI	Adult and Child & Youth	Centralized ²	Community: FEP and/or never treated; Day Program: w/in 5 yrs of FEP	2 yrs (extensions possible)
Vancouver Island				
*EPI Program – Victoria	Adult	Hub and Spoke	FEP	2-5 yrs
*EPI Program – VIHA Central Island	Adult	Decentralized ³	FEP	None
Campbell River MH & Addiction Services: Early Intervention Youth Transition	Adult	Hub and Spoke	-	None
*On-Board Early Psychosis Program – Duncan	Adult	Hub and Spoke	FEP and/or untreated for up to 5 yrs	5 yrs
Interior/Kootenays				
*EPI - Thompson/ Cariboo/Shuswap	Adult	Centralized	FEP and/or within first few yrs	5 yrs
South Okanagan EPI	Adult and Child & Youth	Centralized	Within 5 yrs of FEP	5 yrs
C&Y Mental Health – Kamloops	Child &Youth	Decentralized	-	None (until recovery or transfer to adult services)
*EPI Program – Peachland, Westbank, Kelowna, Winfield	Adult	Centralized	FEP	5 yrs
C&Y Mental Health – Kelowna	Child &Youth	Decentralized	Flexible	3-5 yrs
C&Y Mental Health – Nelson	Child &Youth	Decentralized	Flexible	None (until recovery or transfer to adult services)

C&Y Mental Health – North	Child &Youth	Decentralized	-	-
Okanagan				
Central/Northern BC				
C&Y Mental Health – Cariboo	Child &Youth	Decentralized	Flexible	1 yr
	einid a roudi	Decentruized	I ICAIDIC	1)1
*Early Intervention Program —	Adult and Child &	Hub and Spoke	FEP	2 yrs (but flexible)
Prince George	Youth			

¹Hub and Spoke – programs with some central staff plus clinicians on teams who also see other types of clients

²Centralized – programs in which the majority of staff (and their time) is dedicated to providing EPI services

³Decentralized – programs in which no staff are solely providing/managing EPI services

⁴FEP – First-Episode Psychosis

EPI Programming Strengths

Survey responses revealed a number of service delivery strengths. All sites appear to be highly inclusive in terms of their admission criteria (i.e., inclusive of comorbid substance use, affective psychosis). They all accept referrals from any source (including self-referrals). Overall, accessibility ratings were found to be high, with the majority indicating either excellent (40%) or good (40%) accessibility.

The majority of sites also reported that they offer substantive outreach components for assessment (73%) and treatment (80%). In terms of fundamental medical and psychosocial service provision, all sites reportedly provide psychoeducation to clients and families as well as individual psychosocial interventions. The majority also offer medication management (87%); CBT for psychosis (67%) and other conditions (80%); and group interventions (67%).

Service Delivery Challenges

The survey results also highlighted significant challenges to the development and maintenance of EPI programming in BC. Qualitative responses suggested that staffing and program capacity concerns are paramount. However, inconsistencies in the data limited the extent to which interpretations could be made regarding the true staffing levels of EPI sites. In some cases, the information provided appeared inconsistent with other data collected (e.g., regarding clinical FTEs, accepted referrals/year), while in other cases, respondents were unable to provide this information at all. This appeared to be particularly problematic among the non-specialized sites (e.g., Child and Youth Mental Health), where it appeared especially difficult to determine the proportion of clinician caseloads consisting of EPI clients.

The unreliability of the staffing/caseload data within the survey further highlights the need for improvements in program monitoring and evaluation. Indeed, only one of sites surveyed reported using measures of program accountability. Engagement in research activities and tracking of individual client outcomes were also less than ideal (33% and 67% respectively). Similarly, use of written protocols for psychosocial interventions was generally low (33%).

Limitations were further highlighted in terms of breadth of EPI service provision. Less than half of the sites surveyed explicitly follow a phase-specific approach (40%). Similarly, the availability of specialized and neuropsychological assessments is variable (60% and 47% respectively). Qualitative responses further indicated the lack of specialized resources for EPI clients (e.g., housing/residential options, after-hours response capacity, recreational/vocational rehabilitation services, access to psychologist).

The majority of sites identified problems with continuity of care (73%). Among those identifying such difficulties, major contributors included clients dropping out (73%) and staff being unable to provide sufficient intensity of contact to properly engage clients (73%). A lack of integration was also identified by respondents as presenting a challenge to service delivery. In particular, limited access to and integration with inpatient treatment as well as the involvement of two ministries (i.e., difficulty bridging from youth to adults services) appear to be problematic.

All sites surveyed accept "at risk" clients and provide them with psychosocial treatment as warranted. However, 53% of sites are currently prescribing antipsychotic medications to a portion of their "at risk" clients, and only 27% are tracking outcomes of these clients.

Uptake of Best Practices

Survey results were also examined from the perspective of best practice uptake. This aim was accomplished by determining whether programs met the identified criteria for accessibility, psychiatric service, psychosocial intervention, phase-specific intervention, and community education.

The following table indicates the number of specialized and non-specialized programs demonstrating uptake of the five key standards.

Number of Key Standards Met (5 in total)	Number of Specialized EPI Programs (8 in total)	Number of Non-specialized Mental Health Programs (7 in total)
5	3	1
4	2	2
3	3	2
2	0	2
1	0	0

Overall, specialized EPI programs demonstrated better uptake of the key standards in comparison to non-specialized programs. More specifically, five (63%) specialized programs demonstrated uptake of at least four of the standards while this appears to be the case for only three (43%) non-specialized programs. However, despite demonstrating superior levels of uptake, specialized EPI programs in BC still have room for improvement as only 3 (38%) met criteria for all five of the minimal standards identified.

Closer examination of the results indicated that most programs are meeting criteria for program accessibility, as 73% of the programs surveyed (six specialized and 5 non-specialized) offer treatment within one week of intake. The majority of programs (87%) provide adequate psychiatric services (eight specialized and 5 non-specialized). Interestingly, the two programs that reported not having dedicated psychiatry coverage were rural, MCFD-funded, Child & Youth Mental Health programs. All programs reported meeting the criterion for the provision of some form

of psychosocial intervention. Only 40% of programs (three specialized and 3 non-specialized) reported explicitly following a phase-specific approach. The lack of phase-specific treatment among non-specialized programs may be due to more limited numbers of EPI-trained staff. However, given that the importance of providing interventions appropriate to the phase of psychosis has been repeatedly highlighted in the literature, it is extremely surprising that only three (38%) of specialized EPI programs currently offer phase-specific interventions. Specialized programs are clearly doing a better job of engaging in community education activities in comparison to the non-specialized programs, as 7 (88%) of the EPI programs reported some form of public education while only 3 (43%) of the non-specialized programs reported the same.

Uptake of best practices appears to vary widely among both urban and rural programs. Thus, being located in an urban centre in BC does not necessarily translate into superior EPI programming. Notably, there are two specialized rural programs and only one urban program that met criteria for all five minimal standards.

Comparisons with the 2004 Quiet Evolution Report

The results from the present survey may be compared with those obtained in 2004 in the Quiet Evolution report to determine whether the extent to which EPI guidelines are being followed has changed across the province.

As in 2004, the vast majority of sites continue to provide fundamental services such as case management, medication management, education, and individual/family psychosocial interventions. Although some improvements have been made in terms of offering more comprehensive services (i.e., increases in the availability of group programming and CBT), the services provided are not necessarily EPI-specific (e.g., as when provided through Child & Youth Mental Health). Unfortunately, the offering of phase-specific services has remained extremely limited across the sites.

In 2004, the integration of psychiatrists into program activities was highly variable with some sites reporting considerable integrated involvement and others operating with no formal affiliation. It appears that some improvement has been made in this regard, as the vast majority of sites surveyed (all except one) have regular access to psychiatric services. However, the extent to which psychiatrists are integrated into the team remains variable – particularly for the rural programs where some sites receive only a couple hours per week of dedicated psychiatric service. Clearly, there continues to be a need for psychiatrists to become better integrated into EPI teams.

In terms of the management of "at risk" clients, more sites are accepting these clients into their programs compared to results from the 2004 survey. The percentage of "at risk" clients being prescribed antipsychotic medication also appears to be increasing – despite the fact that the prescription of antipsychotic medication for individuals considered "at risk" is not supported by the available literature for general clinical practice. Nor is there any indication that those engaging in this practice are scientifically documenting the clinical outcomes, describing monitoring procedures or documenting the ways potential negative effects of this approach are either managed or avoided.

Although the 2004 findings indicated a high number of public education endeavours, this degree of intensity may have been difficult to sustain over time. Despite recognizing the importance of educating public service groups, schools, and gatekeepers, efforts appear to have dwindled somewhat over recent years.

Finally, other domains identified as problematic in 2004, such as continuity of care, integration with inpatient services, and shortages in time and resources, continue to present challenges to service providers in BC.

Summary

As in the 2004 Quiet Evolution report, the results of the present survey are highly dependent on the data available to respondents. In many cases, approximations were used, and as a result, the data provided by some sites may not be considered as credible as the data provided by others. There continues to be a particular lack of clarity regarding the caseloads and referrals received by Child & Youth Mental Health programs that service EPI clients. Although some sites have extensive monitoring and program evaluation strategies in place, the majority appear to have rather limited data systems available to them. As a result, comparisons across sites (and across the two time points) must be interpreted with caution. Clearly, greater attention needs to be paid to the regular collection of data regarding program implementation and evaluation.

Despite methodological limitations, a number of encouraging patterns of practice were revealed, including generally high levels of program accessibility, significant outreach components, and the provision of fundamental medical and psychosocial services – all of which concur with best practices. However, the results also highlighted a number of shortcomings among programs and their approaches. Limitations in staffing, comprehensiveness of service components, and integration/coordination of services are central issues that must be addressed if the benefits of intensive intervention for this population are to be realized. Among the programs (both specialized and non-specialized) that failed to meet the five minimum standards outlined in this report, deficiencies appear to result primarily from limited consideration of phase of psychosis, inadequate psychiatry staffing and restricted community education activities. It does appear that the ability of programs to offer EPI services in accordance with best practices is hindered by significant limitations in staffing and resources.

Priorities for future planning and development initiatives identified by the sites surveyed included: greater standardization with respect to screening, outcome assessment, and program evaluation; increased community-wide education; greater capacity for EPI-specific programming; and more resources (e.g., group treatments, recreational/vocational rehabilitation). Investment in these areas would be in line with best practice guidelines and would help programs produce optimal outcomes.

Appendix VI: Resourcing and Service Intensity Analysis

The potential for substantive benefits because of providing early intervention in psychosis has created interest amongst clinical and administrative stakeholders in enhancing existing mental health and addictions programs by adding EPI services. As laudable as this objective may be, limitations in available funding and the challenges inherent in shifting resources from already burdened existing services may force administrators to consider less than optimal allocation of resources to an EPI program. This risk may be heightened when resource decisions are made by planners and administrators who may be unfamiliar with the rationale for the intensity of services offered to clients and families called for in EPI programs or the paradigmatic differences between existing MH services and EPI. Therefore, a new EPI program may find that the resources it possesses are inadequate, which will limit the range and quality of services delivered, the breadth of the population served or the duration of services before transfer back to regular community programs. Such compromises frequently lead to a program being incapable of following best practices and are likely to yield poorer outcomes that, in turn, force administrators to be reluctant about allocating more monies to a program that has apparently failed to deliver. The approach of asking "what can we do with what we have?" may be particularly dangerous to the integrity of the EPI paradigm, and do a disservice to clients and families. It is therefore strongly recommended that each new service, and especially designated programs, be adequately resourced in order to provide the services needed to achieve the desired outcomes. Such programs must also have the capacity to document those results in order to improve them, share knowledge and justify the expenditures of public funds.

The current development of guidelines and minimal standards has direct implications for resourcing. The greater the sophistication, number and intensity of practices and services provided within a program, the greater the number, type and experience of the professionals involved will have to be. The issue of optimal staffing has not received much empirical examination in the literature. Models of care based on a case manager (typically a psychiatric nurse) and physician that emphasize only pharmacological aspects of care are inadequate to carry out the EPI approach. Rather, a true transdisciplinary biopsychosocial approach is needed. In areas with small numbers of clients, this will need to be achieved by training rather than the assembly of a larger team. In either larger or smaller catchment areas, EPI service planning can benefit from expectations about the number of staff that will be needed to deliver proper EPI care.

The following discussion provides several alternative approaches to determining staffing levels. The focus is on non-physician requirements as a fundamental assumption is that all clients will have access to appropriate pharmacological treatment though a qualified and trained physician.

Finally, preliminary work is presented on a new model being developed based on estimated hours needed per client of clinical staff contact per phase of recovery.

Existing Recommendations for Staffing

Community early psychosis programs frequently cite that the desired clients per clinician/case manager ratio should be about 10:1. The Danish OPUS program employed a ratio of 8:1 (119) while the UK national guidelines seek a ratio of no greater than 15:1 (94). In comparison, adult mental health teams in many urban community settings often report caseloads of greater than 50. A recent British Columbia report noted, "Best practice guidelines recommend caseloads in the range of 30 to 40 per staff member; however case managers carry caseloads of between 50 and 75 clients. ... with these caseloads, genuine case management becomes untenable." (130)

Recent standards for Assertive Community Treatment Teams in BC stipulate ratios of 8-10 clients per FTE (again excluding psychiatry and clerical/administrative staff) (131).

One drawback concerns the use of caseloads as a criterion for determining service planning, as there is variability in the procedures and definitions used to define caseloads. For example, sites may differ on the protocols used to close cases. In some instances, clients seen infrequently or not at all may remain on a clinician's caseload. The use of caseloads also may lead to a restricted conception of how services may be organized and who might deliver needed services. That is, the case management model should not restrict programs from utilizing a variety of service providers within the program. It is unreasonable to expect that each case manager should be providing all elements of care proposed in guidelines. Generalists are not specialists and programs should strive to provide clients with the highest quality care possible. Therefore, it is recommended that the provision of clinical services is conceptualized in terms of the personnel needed (i.e., clinical personnel) rather than from a case manager perspective. This approach allows administrators and planners to integrate a variety of service providers into the program's suite of services rather than relying solely upon case managers to provide all non-medical services. The model described below attempts to explore such an approach.

A Preliminary Needs-Based Resourcing Model

An alternative approach to determining staffing entails examination of the predicted types and amounts of intervention needed per client over differing phases of a psychotic disorder. In essence the basis is not "what can be done with the resources we have?" but "what resources will we need to provide the services clients and families need?" The model described here makes several assumptions; changes in these assumptions will lead to differences in the estimates of staff required. Managers will need to run different versions of the model using the assumptions most appropriate to their needs and circumstances.

The model stipulates the intervention intensities required per client over time. Furthermore, it must be recognized that intensities required differ between clients with different needs (i.e., stage of contact with program, levels of treatment response and impairment). In other words, there will be variation in service intensity both within and between clients. The service expected of a program across a spectrum of different types of clients is expressed as the average hours needed per client per year and multiplied by the estimated incidence and program dropout rates. Finally, an average ratio of direct clinical service to other duties is calculated for clinical staff. In this model it is assumed that one FTE who works 37.5 hours/week will engage in direct clinical service for 17.5 hours per week (46.67%) with the remaining time spent on case planning, documentation, administration, education, consultation, supervision, case co-ordination and travel. Yearly total hours of intervention needed by the anticipated number of service users is divided by average direct service time per staff member (i.e., 17.5 hours per week) to derive staffing levels.

Two scenarios are illustrated. The first provides recommended levels of intensity based on estimates from best practice documents. This example first calculates hours of service needed per client over a three-year period. In order to derive the ratio of FTE clinical staff per client a second set of calculations adopts a program-wide planning perspective by calculating the anticipated number of cases per a given catchment area and then determining the numbers of clinical FTEs required to provide services. The second example analyses the needs of the marginal service frequencies discussed in Standard D – Service Intensity. Each examines non-physician service needs over a three-year period in a community setting. Clinical needs are examined that include all specialized assessments, case management and psychosocial interventions, but do not include program management, secretarial supports, research and physician input. Using a hypothetical client, the hours of services typically employed in the earlier phases including first contact with the program, intake, and clinical work are calculated over the first 4-5 months. The model then shows greater variation depending upon the clients' needs over the remainder of year one and for years

two and three. It is assumed that substance abuse interventions are provided within the allotted hours and that 50% of clients would benefit from vocational rehabilitation services.

Key Assumptions and Conclusions of Resourcing Model

- Approximate incidence rate of 25/100,000 (affective and non-affective psychotic disorders included)
- One FTE who works 37.5 hours/week will engage in direct clinical service for 17.5 hours per week (46.67%)
- Each client has access to each clinician for an average of 47 weeks per year
- Service needs over a three-year period are illustrated
- Program dropout rate is 30% per year and 20% within the first 5 months
- The average client should receive 203 hours direct clinical service over three years
- Each client in the program requires .1045 permanent FTE position or one clinical FTE per 10 expected clients per year
- An urban area such as Vancouver Coastal would need over 10 FTEs (excluding psychiatry, evaluation/research, educator, administrative and management positions)
- Rural areas may need to multiply by 1.25 to attain similar service levels
- Minimal service commitments suggest that each client receive 73 hours of direct clinical service over 3 years
- These minimal service intensities conclude that urban areas hire one FTE clinical staff member for every 26 anticipated clients per year while rural areas need one FTE per 19 anticipated clients

Scenario 1 – Prototypical EPI client

Acute phase (Intake/entry and first 2 weeks in program)	<u>Hours</u>
Screening pre-entry assessment	= 2
Intake assessment (medical, psychiatric, social)	= 2
Acute phase engagement building and assessment'	= 3
Family engagement	= 3

¹ Outreach assessment during acute phase may take several hours longer but it is a preferred practice. The Youth Assessment Team in Melbourne did assessments for 80% of all EPPIC intakes – 40% of assessments were at the person's home and another 20% in a neutral setting. With a catchment area approximately the size of VCH they received 3100 referrals/year of which 950 were possible first episode EPI – of those 956, 587 were assessed and 400 accepted into EPPIC. Similarly, home-based treatment may add several hours to acute phase interventions (EPPIC data shows about 40% never need inpatient care over 18 months).

Case manager/clinician meetings		
(2 times/week at 45 mins each, multiplied by two weeks)	= 3	
Total acute hours	= 14 h	nours
Early Recovery (Weeks 3-18)		
Individual treatment (3 hours every 4 weeks)	= 12	
Education (1 hour biweekly)	= 8	
Group therapies (12 hours in groups) ²	= 4	
Special assessments (psych, voc, OT, etc.)	= 4	
Other (social/educational/vocational)	= 3	
Total early recovery phase	= 31 h	ours
Late Recovery (Months 5-12) avg.	<u>range ir</u>	<u>n hours</u>
Symptom-related treatments (psychosis,		
drugs or other psych problems) (2 hrs/month)	= 16	(8-24)
Education, relapse, recovery (1-3 hrs/month)	= 16	(8-24)
Voc/educational reintegration $(0-2 \text{ hrs week})^3$	= 16	(0-64)
Total late recovery phase average response	= 48 h	ours
Total late recovery hours good response	16	
Total late recovery hours poor response	112	
Total Year 1 (Acute =14 plus Early=31 plus Late=48)	= 93 h	ours
Total year 1 good recovery / low needs	61	
Total year 1 poor recovery/high needs	157	
<u>Year 2-3</u>	<u>avg.</u>	<u>range in hours</u>
Relapse prevention (hrs/year)	= 5	(5-10)
Symptoms	= 15	(5-30)
Vocational/educational	= 10	(5-40)

² Assumes one hour received by a client requires .33 hour of professional time.

³ Factor of .5 applied since preliminary data suggests about 50% of clients in year 1 will require vocational support of this magnitude.

Growth recovery work	= 15 (5-25)
Other	= 10 (0-15)
Total year 2 average response	= 55 hours/year
Total year 2 good response	20 hrs/year
Total year 2 poor response	120 hrs/year
Total year 3 as per year 2	=55 hours/year
Total year 2 good response	20 hrs/year
Total year 2 poor response	120 hrs/year
Total Year 1	93 (61-157)
Total Year 2	55 (20-120)
Total year 3	55 (20-120)
Total years 1-3 per client	203 hours

Discussion

- o The model estimates that the average client receives 203 hours direct clinical service over three years.
- If one FTE = 37.5 hours per week and each client has access to each clinical staff member for an average of 47 weeks per year, then 1387 hours of work per clinician is available. Using the assumption of 46.67% of that time being used for direct clinical services, then each clinician can provide 647 hours of direct service per year or 1943 over 3 years.
- 203 hours per client divided by 1943 =.1045 FTE clinical staff per client. Therefore, each EPI client seen for three years will require .1045 FTE positions. This translates into an approximate ratio of 10 clients per one clinical position. However, this calculation does not account for dropout rates from the program. See Scenario 1 below for a program epidemiologically-based approach to staffing needs that continues to employ the client needs approach.

Scenario 1 - Alternative calculation based on total hours delivered by a whole program

Assuming a program has a 30% dropout rate

Given a catchment size of approximately 650,000

Estimated number of new cases/year = 160

Year 3 operating intensities would include clients at a mix of different phases:

	Hours
Yr 1 clients acute -14 hrs X 160 clients	= 2240
Yr 1 clients early recovery - 31hrs X 80% dropout X 160 clients	= 3968
Yr 1 late recovery – 160 X 70% X 48 hrs	= 5376
Yr 2 -55 hrs X 112 (85%) = 95 clients	= 5225
Yr 3 – 55 hrs X 78 (85%) = 66 clients	= 3630

Total - 20439 hours over 3 years @ 1943 hours per staff member over 3 years = 10.52 FTEs

Discussion

- The program should have approximately one FTE to provide all needed clinical services for every 16 anticipated incident cases.
- Alternatively, planners should consider funding 1.6 clinical FTE positions per 100,000 persons in the catchment area.
- Rural areas applying the adjustment factor of 25% would employ one FTE for every 12 anticipated incident cases and two FTEs per 100,000 persons in the catchment area.

Scenario 2 – Minimal services

The minimal frequencies of contact cited in Standard D suggest that each client and his/her family who stay the full three years and require all six listed services would require a minimum of:

- 1) 37 hours per year of direct service (excluding physicians and administration) in year 1
- 2) 30 hours in years 2 and 3^4
- 3) 12 hours for relapses
- 4) 3 hours intake and screening assessments
- 5) 8 hours specialized assessments (cognitive, vocational, etc.)

6) 20 hours specialized interventions (beyond those covered by the case management, assessment/monitoring and generic interventions delivered in 1 and 2 above and to include CBT for psychotic symptoms, group therapies, vocational interventions, rehabilitation, cognitive adaptation counselling, social rehabilitation, recreation and living skills interventions, etc.)

⁴ The assumption is made that clients are seen monthly for one hour and families are engaged directly for 3 hours per year in years 2 and 3 – relapse are calculated separately.

Total = 110 hours per client over three years. However, this figure should be adjusted to reflect that not all clients would require all services. Adjustments for programmatic planning include the following:

- an annual attrition rate of 30%

- relapse rate of 50%

- 50% utilization rate of specialized assessments – assumes 50% of clients receive such assessments that take 8 hours to complete and disseminate

- 50% of intakes that take 1-2 hours are balanced by the numbers of assessments completed on individuals who do enter into the program yielding no change in the average time of 3 hours

- 25% of clients will receive none of the services listed in 6) above

These adjustments produce the following per client service hours:

- 1) 31
- 2) 14
- 3) 06
- 4) 03
- 5) 04
- 6) 15 Total = 73 hours per client over three years

Discussion

- Assuming that each FTE is able to provide 1943 hours over three years, the ratio of clinical staff to anticipated incident case would be about 26:1.
- This is NOT a standing caseload ration of 26:1. It is the number of FTE positions needed to service the anticipated level of incidence cases in a catchment area.
- Scenario 1 arrived at a ratio of one FTE for every 16 expected cases, while this minimal care analysis suggests one FTE for every 26 expected cases.
- In rural areas, the Scenario 1 analysis yielded one FTE for every 12 incidence cases and one FTE per 19 cases in the minimal care scenario.
- This analysis, like Scenario 1, does not include program needs for personnel to engage in education to facilitate early recognition and referral, administration and management, or research. It does include time needed for a variety of disciplines to provide specialized clinical assistance.
- The assumptions may underestimate the proportions of clients needing specialized interventions and the required intensities of those interventions.

Validation

Validation of the model was attempted by making comparisons to:

- 0 1) actual hours of service provided by an EPI program
- 2) published recommendations for staff/client ratios and reported levels attained in various settings
- 0 3) a resource planning document that also sought to quantify service needs by hours

1) For the first validation effort, data was compiled from service records on the hours employed with four clients of an early psychosis program. Clinical staff rated two clients in the treating program as "good" outcome while the other two were rated as "poor outcome".

The actual hours of service delivered are shown below:

	Client 1 poor	Client 2 good	Client 3 good	Client 4 poor
Year 1	70	55	32	33
Year 2	Transferred	61	58	07
Year 3			51	18

Although preliminary, these data show concordance with the model for at least five of the eight time periods sampled. It should not be presumed that the levels received by the above clients were optimal.

2) The clinician to client ratios derived by the model are consistent with guidelines, national initiatives and research projects. They are also in accordance with actual levels reported in the literature by the more comprehensive programs such as the OPUS project in Denmark.

3) The Australian Tolkien2 project described above recommended that each client receive a minimum of 75 hours of service in the first year of treatment (132). That figure falls between those cited by the model for the first (93 hours) and second year (55 hours). The Tolkien2 model does not distinguish between phases nor does it attempt to consider dropout rates. The table below illustrates the assumption made in the planning scenarios of a 30% attrition rate and the numbers of cases retained in a program over three years.

Table 1 -Standing caseloads per year with 30% annual attrition rate (excludes intake assessments) for cases associated with a 650,000 person catchment area

Year	Year 1 end	Year 2 end	Year 3 end	Year 4
New cases 160	112	78	55	0
160		112	78	55
160			112	78
160				112

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