

A Nursing Care Coordination Program for Early Intervention:

A Pilot Case Management Model for First Episode Psychosis in Marin County, California

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Prompt treatment of the acute phase of schizophrenia, also known as first-episode psychosis (FEP), is highly efficacious. According to the Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guidelines Team for the Treatment of Schizophrenia and Related Disorders (RANZCP), prompt treatment results in partial or full remission in nine out of every ten cases (2004, p. 4). Yet, thanks to persisting myths and a disease classification system that tends to delay diagnosis, many clinicians and patients continue to equivocate about early treatment. This results in delays, poor adherence, and correspondingly suboptimal outcomes. Research on the best practice for FEP has been extensive, and numerous randomized controlled trials, meta-analyses, as well as Cochrane reviews have been completed, producing several clinical practice guidelines (CPGs) that more or less agree on what constitute “best practices.” Many of these evidence-based guidelines are simple to carry out, yet are inaccessible to patients in many areas of the United States.

Fortunately for clients in California, voters approved Proposition 63 in 2004, which earmarked revenue from a 1% tax increase on incomes above \$1 million for prevention and early intervention (PEI) programs. As of July 2012, the measure raised \$7.4 billion, of which about \$1.2 billion has been spent on PEI programs over the past five years (Dreier, 2012).

Unfortunately though, the state has not mandated that each PEI program be evaluated on evidence-based outcome measures for early intervention (EI) programs for FEP. Instead, each of California’s counties applies for funding and proposes “how and with what methods it will evaluate its effectiveness and outcomes” (California Mental Health Services Authority

[CMHSA], 2011, p. 26). The result is a hodgepodge of vague outcome measures with only a handful of counties addressing FEP.

Marin County has yet to target FEP in its PEI projects, focusing the bulk of its efforts instead on more general mental health, rather than mental illness issues (Marin County Department of Health & Human Services [MCDHHS], 2012). Marin County's PEI projects, though addressing laudable issues such as parenting challenges, mental health education in underserved areas, and outreach to the Vietnamese community (MCDHHS, 2012), do not have the focus and commitment necessary in providing care that would lead to optimal outcomes for FEP patients.

A number of non-profit organizations in Marin County do provide supportive services for patients who have experienced FEP. These include the Huckleberry Youth Program at the Novato Youth Center, the PATH Program for Transition Age Youth at Bucklew Programs, and the Family Service Agency of Marin. None of these organizations, however, target the prompt assessment and early interventions required to optimize long-term outcomes for patients with FEP. This proposed case management program for FEP seeks to fill this important gap in cost-effective ways that exploit and coordinate the rich resources already available throughout Marin County.

Target Population

The target population for the proposed case management program comprises residents of Marin County between the ages of 13 and 35 who experienced first episode psychosis (FEP) within the past 24 months, and who are specifically *not* at high risk for repeat inpatient readmissions. These individuals will be identified by the community's mental health service providers, such as private practice psychiatrists, the Psychiatric Emergency Service at Marin

General Hospital, as well as families and friends. Once identified, they will enter the program through referral.

The literature has established that FEP occurs most commonly between the ages of 18 and 25 years for men, and between 25 and 35 for women (APA, 2001, p. 307). Based on data provided by the United States Census Bureau (2011), there were 22,515 individuals belonging to these age categories in Marin County in 2010 (p. 12). Applying the prevalence rate of between 0.55% and 1% to this cohort (Srihari et al, 2012, p. 613), and divvying up the new occurrences by year, we predict annual incidences of FEP in Marin County to number between 15 and 25. This estimate excludes the small proportion of individuals who experience FEP at a later age and is thus a conservative one. From this, we project the case load for the proposed case management program to be at about 15 to 25 in the first year, followed by annual increases by about 15 to 25.

Review of Literature

Long-Term Implications for Non-Intervention

The impetus to provide prompt specialized intervention services to individuals experiencing FEP is supported by consensus in the literature that they can lead to better clinical outcomes for a substantial proportion of them (Marshall & Rathbone, 2011, p. 38). This consensus has come about in part because of evidence that has emerged over the past two decades from large-scale, government funded studies in the United States, European countries, Australia, and Japan.

One, a large longitudinal quasi-experimental study entitled Treatment and Intervention in Psychosis (TIPS) found that lower duration of untreated psychosis (5 weeks vs. 16 weeks, $p=0.003$) has significant positive impacts on psychotic symptoms at the one-, two-, five-, and

ten-year periods (ten Velden Hegelstad, et al., p. 374). In the TIPS study, many quality indicators for patients with schizophrenia were found to be significantly better for patients who were enrolled in EI program versus those who were not enrolled, even ten years after the first episode. Most notably, EI patients were more likely than non-EI patients to (a) have fully recovered, defined as having “stable symptomatic remission and intact functional capacity for at least one year” (OR=2.5, $p=0.017$); (b) have full-time employment (OR=3.1, $p=0.007$); and (c) be living independently (OR=0.5, $p=0.027$) (ten Velden Hegelstad, et al., pp. 377-378). ten Velden Hegelstad and her colleagues demonstrated that the ameliorative effects of EI persist even after ten years, with respect to reduced personal suffering, better functioning in society, and in turn, reduced unemployment and cost to society. Another large scale (N=547) five-year longitudinal trial in Denmark, entitled the OPUS Trial, compared intensive early treatment with standard treatment for FEP (Bertelsen, et al., 2009, p. 762). OPUS demonstrated that five years following FEP, individuals who received intensive early treatment were less likely living in supported housing than those who received standard treatment (4% versus 10%, OR=2.3, 95% CI: 1.1-4.8, $p=.02$), and they were, on average, hospitalized for fewer days (149 versus 193 days, difference = 44 days, 95% CI: 0.15-88.12, $p=.05$) (Bertelsen, et al., 2009, p. 762). OPUS further demonstrated that longer durations of untreated psychosis (DUP) (16 weeks versus 5 weeks, $p=0.003$) correlates with increased psychotic and negative symptoms, decreased odds of remission, and smaller social networks (Nordentoft, Jeppesen, Petersen, Bertelsen, & Thorup, 2009, p. S4).

Regardless of clinical outcomes, early intervention and treatment can ameliorate the distress to individuals and their families associated with psychotic symptoms (Johannessen, Friis, & Joa, 2007). Additionally, the risk of suicide can be significantly reduced with appropriate

early intervention (Payne, et al., 2006). Therefore, targeting this population for early intervention is compelling and warranted to decrease both societal cost and human suffering.

What is Schizophrenia?

Schizophrenia is an artificially classified group of debilitating mental disorders that encompasses a heterogeneous constellation of symptomology. Patients often present as floridly psychotic with command auditory hallucinations, but they also may present with persistent catatonia and a flat affect. According to the latest available Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR®), schizophrenia is characterized by the persistent and debilitating experience of *psychosis* for six months or longer, including at least one active psychotic episode that has lasted at least a week (American Psychiatric Association [APA], 2000, p. 298). The most current widely accepted definition of *psychosis* encompasses a divergent array of symptoms, including positive ones, such as delusions, hallucinations, disorganized speech, and disorganized or catatonic behavior; as well as negative ones, such as flattening affect, alogia, and avolition (APA, 2000, p. 297). Psychosis is also widely associated with cognitive abnormalities.

The diagnosis of schizophrenia involves clinical judgment that is subjective and, to some extent, open to interpretation. Manic and major depressive features, if present -- and they frequently are -- are not as prominent as psychotic ones. If such features are considered by the diagnosing clinician to be more significant than the psychotic ones, the patient would instead be diagnosed as having a mood disorder, such as bipolar disorder or major depressive disorder, with psychotic features.

Etiology, Prevalence, and Facts

The causes of schizophrenia remain as yet unknown, although the disease is linked to genetics, perinatal complications, substance abuse, childhood stress, urban lifestyle, and lower socioeconomic status (RANZCP, 2004, pp. 2, 6-7). The worldwide lifetime prevalence is estimated to be between 0.55% and 1% (Srihari, Shah, & Keshavan, 2012, p. 613), and it disproportionately affects males (OR=1.4) and people from disadvantaged backgrounds (RANZCP, 2004, p. 3). For example, Australian indigenous people are 1.9 times more likely to be diagnosed than non-indigenous people (RANZCP, 2004, p. 3). Note that diagnoses are often made in the context of the patients' culture. For example, the Royal Australian and New Zealand College of Psychiatrists warn practitioners that the diagnosis of negative symptoms among indigenous peoples have often been a misattribution of the "corrosive effects of unrelenting social disadvantage" faced by this group (RANZCP, 2004, p. 4).

Due to the heterogeneity of the disorder, varying definitions of the term schizophrenia are used in the literature, with its use much more often found to describe advanced-stage psychosis refractory to treatment than FEP. This "diagnostic artifact" helps perpetuate the pessimistic myth that schizophrenia is difficult or impossible to treat, and thereby undermines the choice to treat early (RANZCP, 2004, pp. 3-4). DSM-IV-TR®'s "six-month" requirement for a diagnosis further discourages early intervention by clinicians (RANZCP, 2004, p. 4).

Several long-term studies have found complete symptomatic remission in 14% to 21% of all patients who experience FEP (ten Velden Hegelstad et al., p. 375). Indeed, more than three quarters of the patients who experience permanent symptomatic remission do so within the first year of the first episode (Srihari et al., 2012, p. 615). Many who experience relapses do so after the first year. About half of all patients experiencing FEP will continue to experience psychotic

symptoms after ten years, of whom about half will exhibit chronic negative symptoms and experience poor outcomes (ten Velden Hegelstad, et al., 2012, p. 374). Symptomatic remission is not to be confused with functional recovery; only less than one-third of FEP patients accomplish employment and/or educational rates that match their gender- and age-matched peers' within the first few years (Srihari et al., 2012, p. 615).

One thing we do know about schizophrenia is that progressive deterioration of the functional and structural parts of the brain commences with the onset of psychotic symptoms (Payne, Malla, Norman, Windell, & Brown, 2006). The declining brain structure is theorized to reduce the neural resources available for adaptive neuroplasticity, and in turn, the brain's responsiveness to treatment (Srihari et al., 2012, p. 616). This theory is supported by findings from brain imaging studies. For example, a two-year randomized control trial demonstrated significant preservation of gray matter among recent onset FEP patients who received cognitive enhancement therapy when compared with those who merely received supportive therapy (Eack et al., 2010, p. 674). Each progressive relapse further dims the prospect of responsiveness to therapy, and indeed complete remission (Wiersma, et al., 1998).

Schizophrenia is associated with nearly all known risk factors for mortality, videlicet, hypertension, diabetes, physical inactivity, obesity, hyperlipidemia, drug abuse, poor adherence, social disadvantage, and smoking (Brown & Mitchell, 2012, p. 843). Quite shockingly, an estimated 45% of all cigarettes sold in the United States are being sold to individuals who are mentally ill (Cather, Barr, & Evins, 2008, p. 70). It is further estimated that 72-90% of individuals with schizophrenia smoke, versus 24% of the general population, and they smoke significantly more (Cather, et al., 2008, p. 71). Consequently, mortality from smoking-related diseases such as lung cancer is up to six times higher among schizophrenia patients when

compared to age-adjusted control groups (Cather, et al., 2008, p. 71). Schizophrenia patients are also much more likely than the general population to abuse substances. For example, it is estimated that among individuals with psychotic disorders, 50% have co-morbid substance use disorder, 25-50% are dependent on alcohol, and 12-35% are dependent on cannabis (Thornton, Baker, Johnson, Kay-Lambkin, & Lewin, 2011, p. 279). Consequently, schizophrenia is associated with significantly increased mortality from all causes excluding suicide (Brown & Mitchell, 2012, p. 845).

Distress Caused by Episodes of Psychosis

Schizophrenia's psychosocial cost is extremely high. Many patients who experience FEP present at the hospital with suicidal or aggressive behaviors, and as such are involuntarily admitted to hospital for a brief time (Mean = 2.93 days) (Payne, Malla, Norman, Windell, & Brown, 2006, p. 42). The latest data suggests that around five percent of people diagnosed with schizophrenia die by suicide (ten Velden Hegelstad et al., p. 374), two-thirds of whom do so within six years of the initial diagnosis (Srihari et al., 2012, p. 614). Schizophrenia is utterly devastating to individuals and their families, as it often first presents during adolescence and early adulthood, thereby disrupting dreams and goals; and causing feelings of confusion, fear, depression, familial disruption, and social isolation (Reed, 2008, p. 85).

Furthermore, each psychotic episode is so distressing that it is tantamount to a traumatic event (Jackson, Knott, Skeate, & Birchwood, 2004). This is particularly true if they are of the paranoid type with persecutory themes, which is the most commonly diagnosed type (Pary, 1993, p. 434).

Because FEP occurs during late adolescence and young adulthood, it disrupts the beginnings of careers and relationships. The result: An estimated 63% to 86% of the patients

remain unemployed and socially impaired ten years after their FEP episodes; and the likelihood for remaining single are seven to ten times greater than the general population (ten Velden Hegelstad, et al., p. 374). The economic cost of schizophrenia is significant, estimated to be \$62.7 billion in the United States in 2002, including \$22.7 billion in direct health care cost and \$32.4 billion in indirect costs, of which \$21.6 billion comprises the cost of increased unemployment (Wu et al., 2005).

Early Intervention – What Is It? What Are Its Goals?

Early intervention (EI) for FEP involves the reduction of duration of untreated psychosis (DUP) and intensive, multifaceted interventions within the first crucial years of the first psychotic episode (Srihari et al., 2012, p. 617). It is extremely effective, with full or partial remission of symptoms being achieved in as many as 90% among those receiving treatment (RANZCP, p. 4). A burgeoning body of high-quality research demonstrates that a negative relationship exists between the DUP and clinical outcomes, thus supporting aggressive interventions during this first stage of schizophrenia. For example, a large historic prospective study by Harrison, et al. (2002) found that the strongest predictor of symptom and disability scores after 15 years was the “percentage of time experiencing psychotic symptoms in the first 2 years” (p. 512).

Early intervention (EI) is disproportionately efficacious because the deterioration of brain function occurs most rapidly within the first two to three years following FEP (Payne, et al., 2006, p. 42). Untreated, such brain function alterations may cause a patient to experience increased durations of psychotic episodes (Wiersma et al., 1998, p. 81), as well as higher risks for chronic negative symptoms and long-term emotional dysfunction. The OPUS Trial found that longer DUP correlates with increased psychotic and negative symptoms, decreased odds of

remission, and smaller social networks (Nordentoft, et al., 2009). Indeed, DUP as low as seven days has been found to negatively impact treatment outcome (Harrigan, McGorry, & Krstev, 2003, p. 97). On the other hand, EI has been found to be associated with higher clinical and functional scores five years following the FEP (Larsen et al., 2011, p. 1461).

The consensus objectives for EI during the FEP phase include building a therapeutic alliance, transmitting hope, providing insight, supporting the patient and their families, reducing psychotic and associated symptoms, managing disordered behavior, attempting to restore prior functional level, and offering treatment in the least coercive setting possible (WGCPGSIPD, 2009, pp. 117-118). Despite the preponderance of evidence in support of early intervention (EI), treatment continues to be delayed by an average of 12 months (Norman & Malla, 2001). This presents an opportunity for a nurse case management program designed to shorten the DUP for patients who experience FEP.

Outpatient care is generally favored over inpatient care. If inpatient care is necessitated, the recommendation is that the facility is unlocked, and that young recent-onset patients be separately housed in early psychosis units, which would “symbolically communicate[] that young people differ in both needs and prognosis from older patients with chronic conditions” (IEPA, 2005, p. s122).

Contrast with Intensive Case Management

EI is not to be confused with another popular psychosocial intervention that has been thoroughly scrutinized in the literature over the past 40 years, intensive case management (ICM). The main difference between the two treatment modalities is that EI is focused on treatment within the early stage of the psychotic disorder, whereas ICM is a treatment modality that is ongoing.

ICM involves allocating dedicated resources from a multidisciplinary team, comprising nurses, social workers, psychiatrists, and others to people with severe mental illness, with low staff-to-patient ratios (Burns, Catty, Dash, Roberts, Lockwood, & Marshall, 2007, p. 1). ICM can be carried out in many permutations. Only one model, assertive community treatment (ACT), has been consistently shown to be effective in reducing hospital readmissions, and even then, *only* among those patients who already use a large amount of inpatient hospital care (Burns, Catty, Dash, Roberts, Lockwood, & Marshall, 2007, p. 1). The practice of ACT involves small case loads (1:10), where ACT team members meet regularly to discuss highly individualized care focused on imparting skills to clients undergoing psychiatric treatment with the goal that they would learn to care for themselves in their communities (Burns, 2010, p. 132). Distinct features of ACT practice include 24-hour access to support, never discharging clients from the program, and strict emphasis on medication adherence (Burns, 2010, p. 132). ACT, particularly if fidelity to the model is high, has been shown to reduce the rate of hospitalization (Dixon, Perkins, & Calmes, 2009, p. 4). ACT has further been shown to improve employment, housing, as well as symptoms, particularly among the homeless population (Bodén, Sundström, Lindström, Wieselgren, and Lindström, 2010, p. 665). One large longitudinal RCT carried out in Denmark involved ACT, psychoeducational family treatment, and social skills training for FEP patients. After two years, the intensive EI group demonstrated significant positive symptom reduction, as measured by their mean differences in Positive and Negative Syndrome Scale (PANSS) scores ($p=0.02$), negative symptom reduction ($p<0.001$), a lower rate of substance abuse, better treatment and medication adherence, and higher satisfaction with their treatment plans (Bertelsen, et al., 2008, p. 763).

On the other hand, many large and credible studies fail to demonstrate ACT's efficacy in reducing hospital utilization, symptoms, and functioning after the intervention has stopped. In a large (n=144) longitudinal study of FEP patients in Sweden, Bodén and his colleagues (2010) found that participating in a modified ACT (mACT) for two years was not associated with improved symptoms or functioning at the five-year follow up point (p. 665). What we do know is that ACT can be helpful if fidelity is high *and* the patient risk for frequent readmission to the hospital is high. In practice, wide variations exist between ACT centers with respect to fidelity, structure, population, and so on. ACT should be reserved for those who are at risk for very high hospital utilization, and it should be implemented with high fidelity to the prescribed model as one of the stated goals. Thus, it would be appropriate to refer patients from EI programs who continue to demonstrate high hospital utilization to ACT programs.

Appropriate Pharmacologic Intervention

There is consensus in the literature that pharmacologic treatments are the cornerstone of FEP, with 60-70% of patients on second-generation antipsychotics (SGAs) and 50% on first-generation antipsychotics (FGAs), showing improvements, mostly within the first six months of treatment (Ehmann, Hanson, Yager, Dalzell, & Gilbert, 2010, p. 44). As to the question of whether to use SGAs or FGAs in first-line therapy, two schools of thought currently exist. The majority of clinicians currently favor the use of SGAs as first-line therapy, since there is considerable evidence showing that SGAs target negative symptoms as well as positive symptoms, whereas FGAs only target positive ones. In a meta-analysis of 124 randomized control trials, Davis, Chen, and Glick (2003) found three FDA-approved SGAs, clozapine, risperidone, and olanzapine, to be more efficacious than the most efficacious FGA, haloperidol (p. 553). Some clinicians who favor SGAs over FGAs as first-line medication argue that FGAs

tend to put patients at risk for extrapyramidal side-effects, even at dosing as low as 1-2mg of haloperidol (IEPA, 2005, p. s122). For these clinicians, the recommended prescription for a patient experiencing FEP is low-dose risperidone (2mg/day) or olanzapine (7.5-10.0 mg/day) (IEPA, 2005, p. s122).

However, recently, two large and comprehensive studies, the Cost Utility of the Latest Antipsychotic Drugs in Schizophrenia Study (CUtLASS), conducted by the British government; and the Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) schizophrenia trial, conducted by the National Institute of Mental Health (NIMH), have challenged this preference. CUtLASS and CATIE independently found FGAs to be just as efficacious as SGAs, with the exception of clozapine, which is more effective than any other medication on the market (Foussias & Remington, 2010, p. 117), but whose harsh side effect profile renders it unsuitable for first-line use. Advocates of FGAs point to SGAs' undesirable side effect profile, which includes hyperlipidemia, weight gain, and diabetes (RANZCP, 2005, p. 9), already scourges of many minority populations in which the diagnosis tends to be overrepresented.

Emergency situations notwithstanding, patients and their families should be consulted in the choice of antipsychotic medication, using interpreters and cultural facilitators if needed and as appropriate (RANZCP, 2005, p. 9). While waiting for antipsychotic medications to show effectiveness, which takes about three weeks, the International Early Psychosis Association (IEPA) recommends "regular and liberal doses of benzodiazepines," presumably to minimize the trauma induced by new-onset hallucination; skilled nursing care; and promoting a safe, non-threatening environment (2005, p. s123).

Whether the selected first line drugs are SGAs or FGAs, the recommended pharmacological intervention for treatment-resistant psychosis is clozapine. Clozapine is not

used as a first-line drug due to high risk for agranulocytosis and seizure, but it should be introduced as soon as two sequential drug trials, each lasting six to eight weeks, fail to produce full remission of positive symptoms or the desired clinical improvement (RANZCP, 2005, p. 9).

Behavioral Weight Management

The RANZCP emphasizes the monitoring and treatment of metabolic syndrome very aggressively, much more so than what this author has observed in the clinical setting within the public mental healthcare domain in San Francisco, California. This recommendation for behavioral weight management is supported by a systematic review of all relevant randomized controlled trials (RCTs) (CEYMH & OYHRC, n.d.).

Prior to commencement of a SGA, the patient's baseline weight, body mass index (BMI), fasting blood glucose (or HbA1c), and serum lipid profile should be measured (Dixon et al., 2009, p. 3). These measurements should then be measured regularly – as frequently as once a month for the first six months, then once every three months afterwards -- as long as the therapy continues (RANZCP, 2005, p. 10). A double-blind RCT of 128 FEP patients receiving olanzapine found adjunctive metformin 750mg/day to be most effective in reducing BMI to desirable levels, followed by lifestyle changes, when compared to placebo (Dixon et al., 2009, p. 3).

Cognitive Behavior Therapy

Several of the most recent CPGs emphasize integrating psychosocial interventions with pharmacologic ones. For example, the RANZCP (2005) considers psychosocial interventions such as cognitive behavior therapy (CBT) to have a “fundamental place in initiating treatment, in providing a humane basis for continuing care, in preventing and resolving secondary consequences of the illness, and in promoting recovery” (p. 18). Indeed, research shows that

CBT can effectively ameliorate positive and negative symptoms, and also improving social functioning (Dixon et al., 2009, p. 4).

One advantage of CBT is that basic techniques can easily and quickly be taught to caregivers as well as nursing staff, and as such, be applied in therapeutic ways on a daily basis (Brabban, Tai, & Turkington, 2009, p. 859). Furthermore, Brabban, Tai, and Turkington (2009) found brief CBT to be effective in reducing overall symptoms as well as increasing insight, especially where the patient is (a) female (OR = 2.39); and (b) has low conviction levels with respect to the delusions (OR = 0.70) (p. 859).

Other Psychosocial Interventions

Medications can rid an adolescent FEP patient of the voices, but they unfortunately cannot help him or her gain employment, make friends, or develop relationships. Thus, in order for the individual to lead a full life, it is important that the approach is multifaceted.

The latest edition of APA's *Practice Guideline for the Treatment of Patients with Schizophrenia*, published in 2004, recommends engagement and collaboration with patients' family members during FEP as well as future episodes (Dixon et al., 2009, p. 4). Systematically providing families with support, education, and access to providers for between six and nine months can help prevent relapse, improve social and vocational outcomes, reduce stress, and enhance the family's ability to cope (Dixon et al., 2009, p. 4).

Relapse Prevention Stage: Assertive Maintenance Treatment

Even after full remission, the RANZCP (2005) recommends an aggressive and holistic approach to relapse prevention, by continuing to actively address the patient's psychological, familial, and vocational needs, as well as monitoring for comorbid syndromes such as substance abuse, depression, anxiety, and post-traumatic stress disorder (p. 20). This recommendation is

based on a systematic review of RCTs. IEPA (2005) suggests that healthcare providers (HCPs) must continue high-quality and intensive biopsychosocial work on the patient during the five years following FEP, since relapse occurs in 80% of these patients during this period (p. s123). Post remission, the goal would be to determine the minimal dose of medication required to minimize the risk for relapse, which could be no medication at all for some patients after one to five years (IEPA, 2005, p. s123). Although this proposed program is not intended to follow clients beyond a two year period, it will emphasize to departing clients the need for maintenance treatment and help them identify resources that would support their continued journeys on the path to recovery.

Estimated Cost of Disease

In dollar terms, the cost of schizophrenia and related illnesses to society is very high. The annual cost of lost workplace productivity, premature mortality, and additional caregiving per patient has been estimated at \$22,032 (Wu et al., 2005, p. 1126). The annual per capita acute inpatient costs (\$1,881), long-term care costs (\$5,422), and schizophrenia-related law enforcement expenditures (\$1,768) are also no small sums (Wu et al., 2005, p. 1126). Over the long run, if this program succeeds in ameliorating patients' independence and functioning, the cost savings to the County of Marin would be substantial.

Proposed Professional Nursing Case Management Practice Model

The literature has established that clients who experience FEP could benefit greatly from participating in a comprehensive, multifaceted intervention program, even if their symptoms have remitted. This proposed Nursing Care Coordination Program for Early Intervention (NCCPEI) recognizes that many aspects of such a program are already available in the community. However, the resources in the current form are fragmented and being provided

piecemeal by multiple agencies. By coordinating the intake, follow-up, data collection, and data sharing processes, the proposed NCCPEI will ensure that more FEP clients would receive evidence-based care by harnessing already available resources in the community.

Functions of the proposed NCCPEI

The mission of the NCCPEI is to coordinate care of all FEP patients in Marin County, using available resources in the community to promote fidelity to best practice guidelines in order to maximize patients functional recoveries over their lifetimes. This involves data sharing, intensive ongoing follow up, data gathering to support research, and a consolidated intake process. To maximize the benefit to this population in this community, the NCCPEI also has an outreach and educational component which will be discussed in detail here. The functions of the NCCPEI are represented pictorially in Appendix A.

Fidelity to evidence-based best practice.

The NCCPEI strives to enhance interventions' fidelity to evidence-based best practice guidelines. This involves complex care within the community requiring care coordination efforts, data sharing, as well as intensive ongoing follow up. While health care providers may be aware of best practices for FEP, they often do not have the wherewithal to coordinate the multi-faceted care involved. The nurse case manager (NCM) fills this crucial gap by guiding the patients, their families, and providers by setting goals, tracking progress, and coordinating the assessments and interventions to be performed along the way.

The NCCPEI coordinates care of the FEP patient with resources that are already available in the community. Such resources include the Huckleberry Youth Programs at the Novato Youth Center, the PATH Program for Transition Age Youth at Buckelew Programs, the Family Service Agency of Marin, as well as the Psychiatric Emergency Services at Marin General Hospital. The

Huckleberry Youth Programs, located in Montecito Shopping Center in San Rafael, provide crucial vocational and psychosocial support to young consumers who experience FEP. Through its subsidiaries, it offers case management, substance abuse counseling, as well as comprehensive health education workshops covering topics such as family dynamics, healthy relationships, self-esteem development, suicide and violence prevention (Huckleberry Youth Programs, 2009). Buckelew's PATH Program for Transition Age Youth, staffed by a case manager, peer mentors, and family advocates, provides 24-hour crisis management, peer mentoring, as well as housing, education, and employment support for young people with mental illnesses (Buckelew Programs, 2012). The Family Service Agency of Marin provides comprehensive therapy interventions for clients and their families for many of schizophrenia's comorbid conditions, such as drug and alcohol addiction, depression and anxiety, stress and trauma, and other issues and conflicts faced by these clients (2012). Finally, the Psychiatric Emergency Services at Marin General Hospital provides round-the-clock crisis stabilization, evaluation, and treatment for psychotic behavior requiring immediate attention (County of Marin, n.d.). The NCCPEI would consolidate the intake processes and coordinate the care provided by these and other outside agencies in order to ensure that each consumer experiencing FEP fully receives the comprehensive and multi-faceted interventions that constitute the best practice based on the latest available evidence.

Criteria for exiting program

Patients can volitionally exit the NCCPEI at any time, and are permitted to actively remain in the program for up to 24 months. With the exception of ACT and medication, no treatment recommendations for FEP lasts more than about a year. For example, the recommendation for CBT is that it "should be approximately 4-9 months in duration" and that

for family intervention should last “at least 6-9 months” (Dixon, et al., 2010, pp. 52-53).

Allowing consumers to remain in the program for only up to 24 months would ensure that the NCCPEI focuses and directs its limited resources at early interventions, where, arguably, they would have the greatest impact. After graduating from the 24-month program, the NCCPEI would point consumers to appropriate agencies that would be most helpful to them.

Notwithstanding the time-based exit criterion, the NCCPEI would attempt to stay in touch with consumers who have graduated from the program in order to continue to assess the long-term efficacy of the NCCPEI.

Supporting Structures and Resources for Implementation

The proposed NCCPEI would rely on collaboration with existing infrastructure available in the community. Because the NCCPEI seeks to lower population-wide long term healthcare costs, as well as costs associated with lost productivity, excessive caregiving, and premature mortality, it is best aligned with an organization that has parallel goals. One such organization Marin County’s Division of Mental Health and Substance Use Services (DMHSUS). The NCCPEI would be incorporated as an extension of Marin County’s DMHSUS and be operated from an office located within Marin County’s DMHSUS itself. The DMHSUS does not currently have an EI program for FEP. DMHSUS can provide the NCCPEI with structure and resources, including consultative services as needed. For example, DMHSUS’s medical staff could provide consultative services to primary care physicians used by the consumers referred by the NCCPEI. The NCCPEI would set aside a budget for consultative services offered by DMHSUS psychiatrists to psychiatric medication prescribers in Marin County who are unfamiliar with FEP best practices.

Another organization that the NCCPEI can collaborate with on the periphery is University of California in San Francisco (UCSF). UCSF would offer support for any research that the NCCPEI chooses to undertake. For example, it has an institutional review board (IRB) and a doctoral program, and could potentially facilitate the sharing of crucial data with the global FEP community with respect to care management best practices of the NCCPEI. One other way that the NCCPEI can collaborate with UCSF is to use UCSF Psychiatric Mental Health Advanced Practice Nursing students to provide cognitive behavioral therapy interventions for NCCPEI clients in Marin County.

Marin County's DMHSUS, UCSF, as well as any other aligning organizations would appreciate that the net cost to them would be zero, because the program would be fully funded by California's Mental Health Services Act of 2004. Indeed, Marin County's DMHSUS can expect to be fully reimbursed for costs such as staffing salaries, rental of office space, the use of the organization's healthcare consultants, costs related to production of health teaching materials, and so forth.

Roles of the Nurse Case Manager

The NCCPEI is led by a full-time Nurse Case Manager (NCM) who should also be a psychiatric mental health advanced practice nurse, and who is well versed with best practice guidelines for FEP. As the leader of the organization, the NCM identifies and builds strong relationships with resources and organizations within the community that have the potential to be supportive of FEP patients' recoveries. In addition to making referrals to these organizations, the NCM will facilitate information sharing among these organizations by coordinating a consolidated intake process. The consolidated intake process would enhance consumer convenience by eliminating duplicative information gathering from them.

On behalf of the NCCPEI, the NCM would build relationships with individuals and organizations from and to whom referrals can be made. They include the Psychiatric Emergency Services at neighboring hospitals, primary healthcare providers, psychiatrists, counselors, school nurses, and youth organizations. The NCM will educate these individuals and organizations about the best practices in FEP, and recommend that they should refer any such patients to the NCCPEI at the earliest opportune time through well-publicized secure web forms, emails, and telephone. After receiving the referral, the NCM would interview the consumer and their family, either in the consumer's home setting, which is preferred, or at the NCCPEI office at DMHSUS. The NCM would teach basic cognitive behavioral therapy skills to the consumer's support group or direct them to appropriate resources. Applying motivational interviewing skills, the NCM would set up suitable family counseling services, vocational services for the patient, and if not already in place, primary care that would address medical issues, such as weight management and smoking cessation; as well as providers that would implement psychotropic medication adjustments. Furthermore, the NCM would encourage and assist in coordinating the use of electronic health records that would enable the seamless and secure sharing of information.

For patients who self-medicate, the NCM would also provide appropriate resources that discourage use, through harm reduction or twelve-steps modalities. Finally, the NCM would systematically follow up on patients and partners alike, by conducting systematic assessments on the fidelity and efficacy of the program. Adjustments to the program would be made, based on the findings.

Because time is of the essence in FEP, it is imperative that referrals be made promptly. The World Health Organization (WHO) recommends that signs and symptoms of psychosis be taught to all fifteen year olds in the community (Bertolote & McGorry, p. s116). The NCM will

help identify resources where such information can be effectively disseminated to this population, as well as to facilitate it. As such, the NCM will arrange for the production of teaching materials to help youth recognize signs and symptoms of psychosis. Such materials should then be disseminated over the internet as well as taught in schools. The NCM must apply teaching skills within the community and the goal is to ensure that signs and symptoms of psychosis are recognized and help is promptly sought.

Why a Nurse Case Manager and not a Licensed Clinical Social Worker?

The functions of a nurse case manager often overlap those of a social worker. In this case, the NCCPEI encompasses many functions that could be performed by either profession. There are, however, several crucial functions that are only within the scope of a psychiatric mental health advanced practice nurse. During the initial assessment, the patient must be clinically assessed for psychotic symptoms as well as the duration of untreated psychosis (DUP) using the PANSS and IRAOS instruments respectively. These clinical assessments must be performed by a trained clinician, such as a psychiatric mental health advanced practice nurse, as opposed to a social worker. Also, during follow up appointments with clients, the clients' mental statuses need to be regularly assessed for recompensation of psychotic symptoms and cognitive functioning. Using a trained nurse clinician for such assessments would be appropriate. As the NCCPEI expands, having a social worker on board would be extremely helpful. The program should start with a NCM for the reasons stated above.

Evaluation

Applying the Donabedian Model, the NCCPEI will be assessed in terms of its structure, process, and outcome.

Evaluative Instruments

Two tools that are used for the evaluation are the Positive and Negative Syndrome Scale (PANSS) and the Short Form 36 Health Survey Questionnaire (SF-36). The PANSS enables the NCCPEI to operationalize the severity of consumers' psychotic disorders by providing a score that represents the severity of the consumer's positive and negative symptoms. It is a standardized 30-item that can be administered by a clinician in about 45 minutes with minimal clinician retraining (Kay, Fiszbein, & Opler, 1987, p. 261). It is a valid tool with impressive α coefficients of .73 and .83 for the positive and negative scales respectively ($p < .001$) (Kay, et al., 1987, p. 266). The SF-36 is a self-administered, 36-question form that takes 5 minutes to complete, and that enables the operationalization of patients' quality of life (QoL) (Brazier, et al., 1992, p. 160). The SF-36 also has high validity (Crombach's $\alpha > 0.85$) and reliability scores (reliability coefficients >0.75), for all but one dimensions, as well as construct validity (Brazier, et al., 1992, p. 162).

Program Evaluation: Structure

The criteria for evaluating the structure of the NCCPEI include relationships with community partners; staffing; educational resources for health teachers, school nurses, and student nurses; as well as enrollment. See Appendix B for a Program Evaluation table with details on these criteria.

The NCCPEI's relationships with community partners are assessed through annual contracts and annual satisfaction surveys, with 2014's goals as follows: 90% contract renewals and mean partner satisfaction score $\geq 85\%$. Indicators for staffing are staff and volunteer satisfaction with their jobs, and staff having appropriate professional licensing or credentials. The outcome measures and instruments for staffing are staff and volunteer retention, employee

feedback surveys, and verification with appropriate credentialing agencies. The 2014 goals for staffing are that 100% of the positions are filled, voluntary turnover of key employees is <20%, and that 100% of staff are properly licensed or credentialed. Another criterion for evaluating structure is the educational resources that is made available to health teachers, school nurses, and student nurses. An indicator for success is that health teachers and school nurses from all high schools in Marin County receive high-quality training and resources. Measures for this success are the informational and production quality of the educational video produced by the NCCPEI, as well as surveys from health teachers and school nurses. The goals for 2014 are that health teachers and school nurses report >85% competence in teaching FEP management, and that 100% of high school students are taught this. The fourth and final criterion for structure is enrollment. The indicators of success in enrollment are a high rate of enrollment and an efficient and effective intake process, as measured by average intake time. Goals for 2014 are an 80% enrollment rate among individuals with FEP, and an intake process that takes an average of <1 hour.

Program Evaluation: Process

The criteria for evaluating the process of the NCCPEI include relationships with community partners; staffing; as well as educational resources for health teachers, school nurses, and student nurses. See Appendix B for a Program Evaluation table with details on these criteria.

Families' access to information, education and other needed support is assessed through data collection and surveys. The goals for 2014 are that (1) families would receive meaningful responses and be linked up with key support systems within one week of identification of their need, and that (2) 90% of families contacted feel respected and valued as partners in care. Client

education is to be assessed using post-tests, with a 90% mean passing rate as the goal for 2014. Client adherence to therapy is to be assessed using surveys of clients and community partners. The goal for 2014 is 90% adherence to medication therapy. Finally, services provided by the NCM are assessed with client satisfaction surveys, with the goal for 2014 being a >80% satisfaction rate.

Program Evaluation: Outcome

The proposed outcome measures for the Case Management Practice Model for FEP are adapted from (a) a consensus statement by the World Health Organization (WHO) and the International Early Psychosis Association (IEPA), and (b) the Prevention and Recovery in Early Psychosis (PREP) program in San Francisco. These specific, measurable goals are:

1. Mean DUP from onset of psychosis for Marin County FEP patients is less than 3 months, as measured by the Interview for the Retrospective Assessment of the Onset of Schizophrenia (IRAOS) (Häfner et al., 1992).
2. Fewer than 25% of Marin County FEP patients are involuntarily hospitalized during the first episode, with an average length of stay of fewer than three days (Bertolote & McGorry, p. s116). Data for rates of involuntary hospitalization of FEP patients and their lengths of stay will be collected from the Psychiatric Emergency Services at Marin General Hospital.
3. The suicide rate for Marin County FEP patients is less than 1% within the first two years (Bertolote & McGorry, p. s116).
4. All 15-year-olds in Marin County, and there are approximately 2,200 of them, receive education on identifying and intervening when they or their peers experience FEP (Bertolote & McGorry, p. s116).

5. One-year after diagnosis, 80% of clients have improved functional abilities and quality of life from the time of intake, as measured by the WHOQoL-BREF (PREP, n.d., p. 4).
6. One-year after diagnosis, 80% of families will report a strengthened relationship with the index client (PREP, p. 4).

Additionally, as part of its outreach effort, the NCCPEI will produce an educational Youtube® video that targets high-school students. The goal for 2014 is for this Youtube® video to have at least 25,000 hits. Finally, data on employment and education rates will be collected for analysis in future years. Refer to Appendix B to see how these evidence-based goals translate to outcome measures in the NCCPEI.

Healthcare Policy Considerations

Voters in California approved Proposition 63 in 2004, henceforth earmarking revenue from a 1% tax increase on incomes greater than \$1 million for prevention and early intervention (PEI) programs. This measure has raised a considerable sum of money: \$7.4 billion as of July 2012, of which \$1.2 billion was spent on PEI programs over the past five years (Dreier, 2012). However, many of the PEI programs address constituents' mental health, instead of urgently needed mental illness needs. Only a handful of California counties' PEI programs address FEP. Marin County has yet to target FEP in its PEI projects, focusing the bulk of its efforts instead on more general mental health, rather than mental illness issues (MCDHHS, 2012). The NCCPEI will help Marin County focus and commit to providing care that would lead to optimal outcomes for FEP patients.

A number of non-profit organizations in Marin County do provide supportive services for patients who have experienced FEP. These include the Huckleberry Youth Program at the Novato Youth Center, the PATH Program for Transition Age Youth at Bucklew Programs, and

the Family Service Agency of Marin. None of these organizations, however, target the prompt assessment and early interventions required to optimize long-term outcomes for patients with FEP. This proposed case management model for FEP seeks to fill this important gap in cost-effective ways that exploit and coordinate the plethora of resources already available in Marin County.

In summary, schizophrenia is a devastating condition which takes an enormous emotional and financial toll on patients, families, and society at large. Fortunately, current research strongly suggests that EI can minimize the long-term costs of the disease, both with respect to human suffering as well as the financial burden imposed. Since a reduced DUP is correlated with better clinical outcomes, aggressive pharmacologic and psychosocial therapies should commence as soon as possible after the first episode of psychotic break. Concurrent CBT is recommended for FEP patients, as are family intervention and vocational training.

Unfortunately, EI is a complex process, involving assistance not just with medications, but also with family counseling, cognitive behavioral therapy, vocational services, as well as good primary healthcare. Many patients and families will not have the wherewithal to navigate the complex treatment modality, even with basic guidance. The proposed NCCPEI will ensure that many more FEP patients, at least in one California county, will receive the multifaceted care needed for the best chances for optimal outcome.

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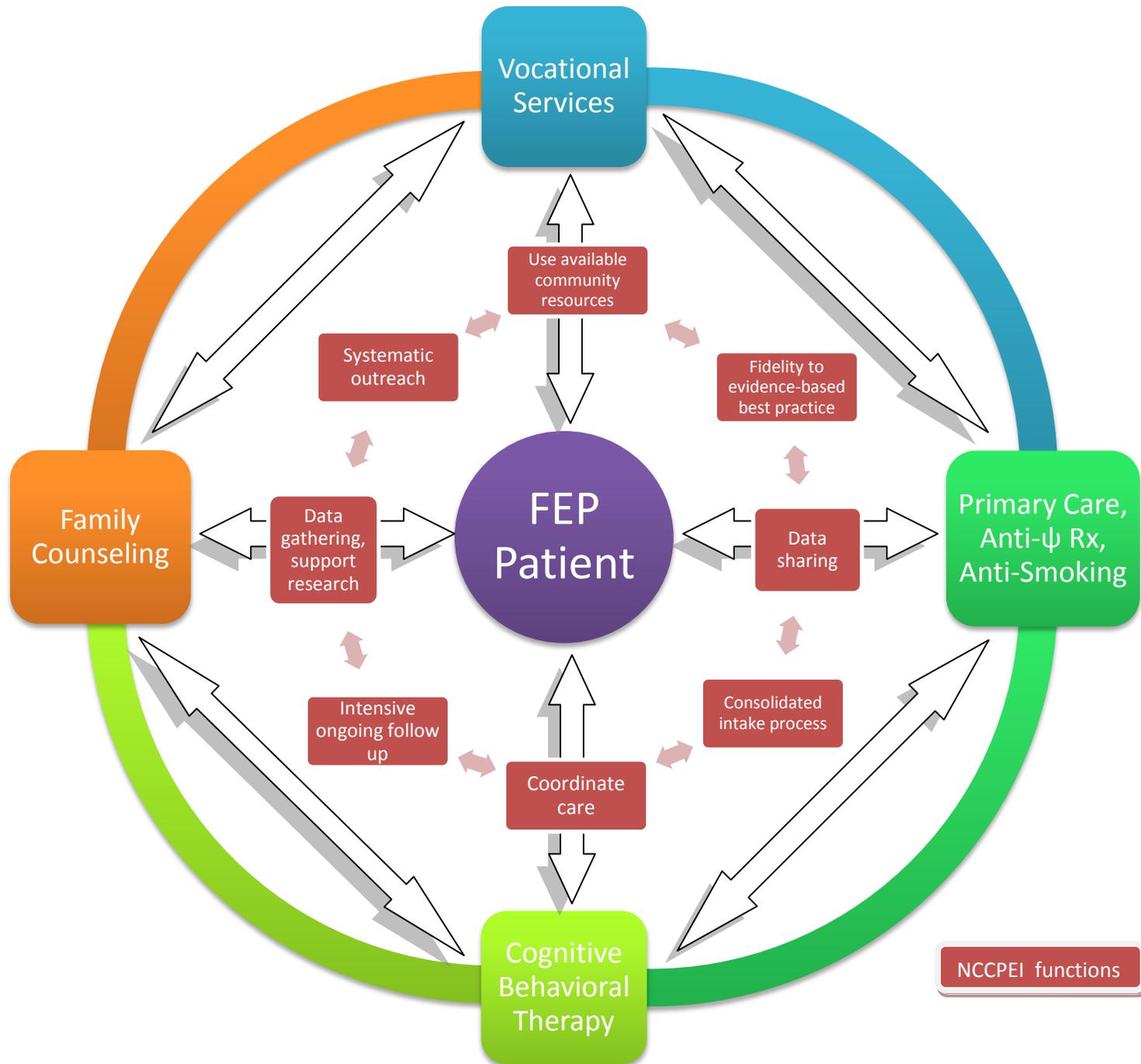
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Appendix A



Appendix B. Outcomes Evaluation Chart

Indicator	Measure / Instrument	2014 Goal	
Structure			
Relationships with community partners	Annual contracts; annual satisfaction survey statuses	Annual contract status; annual satisfaction surveys	90% contract renewals; partner satisfaction scores $\geq 85\%$
Staffing	Staff and volunteer satisfaction / happiness. Staff has appropriate professional licensing and credentials.	Staff retention, including volunteers; employee feedback surveys. Verification with appropriate credentialing agencies.	100% of positions filled; voluntary turnover of key employees $< 20\%$. 100% of staff properly licensed and credentialed.
Educational resources for health teachers, school nurses, and student nurses	Health teachers and school nurses from all high schools in the county receive high-quality training and resources	Educational video information and production quality; Surveys from health teachers and school nurses	Health teachers and school nurses report $> 85\%$ competence in teaching class and 100% of students taught
Enrollment	High rate of enrollment; intake process efficient and effective	Rate of enrollment; intake time data collection	80% enrollment rate; intake process < 1 hour
Process			
Families have excellent access to information, and education and other needed support	Prompt engagement with families / partners in care	Data collection; surveys for family members	Meaningful response to families / key support systems within 1 week; 90% of families feel respected and valued as partners in care
Client education	Each client receives 1:1 education from the NCM	Post-test	$> 90\%$ passing rate
Adherence to therapy	Medication adherence, appointment keeping, treatment adherence	Client surveys; information sharing among community partners	Partner providers report 90% adherence
Services offered by CM and affiliated providers, including CM follow-up	Client satisfaction	Customer satisfaction survey scores	$> 80\%$ satisfaction rate
Outcome (County-wide) (adapted from Bertolote & McGorry, 2005)			
Reduced duration of untreated psychosis	Mean duration of untreated psychosis (DUP) from onset	DUP as measured by the IRAOS	< 90 days
Reduced involuntary hospitalization during first episode	Use of involuntary hospitalization (5150); LOS during FEP	Rate of involuntary hospitalization of patients experiencing FEP at Marin General Hospital	$< 25\%$ involuntary hospitalization; LOS < 3 days
Reduced suicide	Suicide rate within the first 2 years from diagnosis	Suicide rate of cohort	$< 1\%$
Community awareness about the importance and opportunities for earlier detection and improved management of psychosis.	All 15-year-olds understand and are aware of resources to deal with psychosis	NCCPEI's Youtube.com video hits Survey of high school teachers re: number of their students receiving educational training.	Youtube.com video hits reach 25,000 2,000 15-year-olds receive NCM training in 2014.
Affected individuals aspire to healing, recovery, and full participation in society	Long-term employment rate, education rate, satisfaction with life	Employment/ education rates and life satisfaction compared to age- and gender- matched peers at 2-, 5-, and 10- years	Pending data collection, which will begin in 2014.
Quality of life	Improved QoL scores at 1-, 2-, 5-, and 10-years	SF-36 scores	Improved SF-36 score over baseline at 1-year
Symptoms	Improved symptoms at 1-, 2-, 5-, and 10-years	PANSS Score at 1-, 2-, 5-, 10-years	Improved PANSS Scores at 1-year over baseline.

APPENDIX C. Flow Chart for Nursing Care Coordination Program for Early Intervention

