GUIDANCE MANUAL

# Educating Communities to Identify and Engage Youth in the Early Phases of an Initial Psychosis: *A Manual for Specialty Programs*

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## Introduction

This manual provides program staff with background material, methods and case examples to implement community outreach and education, as developed by the Portland Identification and Early Referral (PIER) program, established in Portland, Maine in 2000. Using a combination of community outreach and education and clinical interventions, the PIER Program:

1) Educates the community, particularly school professionals, mental health clinicians and primary care physicians who are likely to encounter young people in the early stages of psychosis;

2) identifies and equips those groups to identify young people who are displaying early signs of psychosis; and

3) assesses and treats the individual experiencing an initial psychosis.

These same methods of education and outreach are generalizable in that they can be utilized by a wide range of early psychosis intervention programs that might benefit from the experience and lessons learned that have been generated from the successful PIER model.

The manual includes:  theoretical and background material; a description of the outreach and community education model; and a description of methods that have been found to be effective for promoting early and rapid referral of youth and young adults early in the onset of an initial psychotic episode.  It also includes case studies illustrating challenges and opportunities encountered in specific outreach efforts and solutions to unique situations.

Those methods include:

- Developing a plan for community education, including defining the area to be served, estimating opportunities and likely challenges, defining staff roles and leadership, and identifying agencies and constituencies to be contacted and provided with education;

- Establishing a program steering council, to aid in developing awareness and contacts throughout the relevant professional and public sectors in a target community;

- Mapping the specific sectors to be contacted and educated, including—for young people between 12 and 25—a network that primarily includes educational professionals, healthcare providers, friends and family members, mental health clinicians, social and human service providers, community agencies, law enforcement and judicial agencies and multi-cultural groups;

- Developing educational materials for those respective sectors and professional groups;

- Organizing a systematic and ongoing program of outreach and community education;

- Educating professional and public audiences;

- Training community professionals to explain symptoms and treatment options to those experiencing onset;

- Establishing a system of rapid referral for assessment and treatment;

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- Following up on previous educational events and efforts to maintain community knowledge and motivation to refer over time; and
- Initial and repeat evaluations of the community education effort to identify successes, remaining challenges, and the fidelity of the outreach efforts to model criteria

## Background

### THE PROBLEM:  MENTAL ILLNESS AS A MAJOR PUBLIC HEALTH BURDEN

Mental disorders affect over 44 million Americans annually.  The estimated prevalence rate of mental illness is 26.2% for adults (Kessler, Chiu, Demler, & Walters, 2005; Services, 1999).  Over two-thirds of those with a mental disorder also experience some form of disability, which impacts their ability to work and perform the tasks of daily living (Kennedy et al., 1997).  In addition to the human costs, mental disorders exact a large financial toll.  In 2002, the national yearly costs for schizophrenia alone amounted to an estimated $62 billion (Wu, 2005).  Mental disorders also affect children.  In the United States, one in ten children and adolescents suffer from mental illness severe enough to cause some level of impairment (Burns et al., 1995; Shaffer et al., 1996).  Approximately 2.9 million children (5.3%) receive treatment other than or in addition to medication for emotional and behavioral difficulties (Simpson, Cohen, Pastor, & Reuben, 2008).

There are several categories for mental disorders, including anxiety, mood, impulse control, substance abuse, and psychotic disorders.  Within psychotic disorders, specific diagnoses include schizophrenia, bipolar disorder, and major depression.  A psychotic disorder typically emerges gradually over months or years.  Initial signs and symptoms prior to the beginning of active psychosis often include social withdrawal, loss of interest in pleasurable activities, unusual or uncharacteristic behavior, and decline in social, occupational or academic functioning (DHHS, 1999).  Over the past twenty years, research has indicated that there is a pre-psychotic (prodromal, or clinical high-risk) phase for those who develop a psychotic disorder (Falloon, 1992; Hafner et al., 2004; Klosterkotter, Hellmich, Steinmeyer, & Schultze-Lutter, 2001;  McGlashan, 1996).  Improved identification of signs and symptoms characterizing this phase affords new opportunity for earlier intervention and the possibility of significantly improving the longer-term outcome of those experiencing the early signs of onset (Kutash, Duchnowski, & Lynn, 2006).
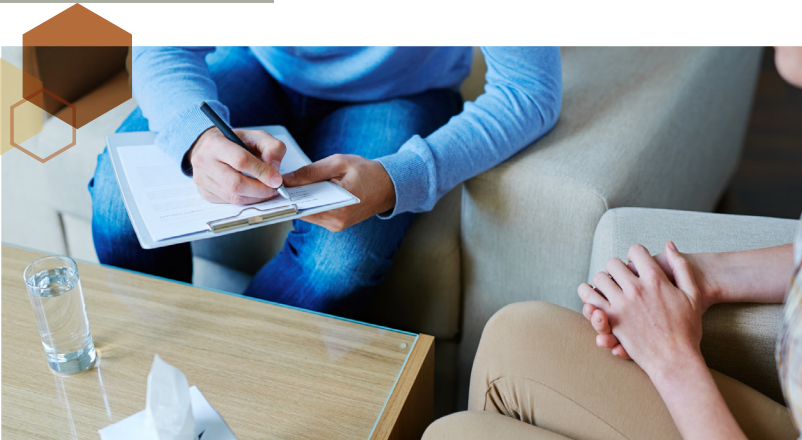
Psychotic disorders can cause severe functional impairment in individuals and significant burden on caretakers and society (McFarlane, Cornblatt, Carter, 2012).  However, the time between first emergence of psychotic symptoms and treatment averages one to two years (Marshall , 2005).  Studies of patients hospitalized for first episode psychosis found that the delay in initiating help was a significant contributor to longer

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duration of untreated psychosis (Chien & Compton, 2008; Kohn et al., 2004). More importantly, the longer the episode proceeds without treatment, individuals with a first psychosis are at high risk for suicide and experience reduced functioning, worsening symptoms, increased isolation, and diminished response to treatment (Bertelsen et al., 2007, 2008; Fusar-Poli et al., 2013; Kelleher, Corcoran, Keeley, et al., 2013; Larsen et al., 2011; Melle et al., 2005). Further, longer duration was strongly associated with more severe symptoms, poor engagement with caretakers and clinicians, and much reduced treatment responsiveness. In a study looking at contacts that led to first episode hospitalization, only 5% of contacts were from primary care providers while 20% were from police (Compton, Esterberg, Druss, Walker, & Kaslow, 2006). In a meta-analysis of pathways to care in first episode psychosis, North American studies found that emergency services were the most common pathway to care, but this portal for access can lead to poor engagement (Anderson , 2010). Roughly half of all those having a new-onset psychosis will be initiated into treatment involuntarily, usually involving police. Surprisingly, those who are in specialty mental health treatment prior to psychosis onset had a longer delay in initiation of adequate treatment than those who seek care after psychosis onset, suggesting that mental health professionals need to be better prepared to identify early warning signs of psychosis and respond appropriately in either providing evidence based care or assuring that their clients receive such care (Norman, Malla, Verdi, Hassall, & Fazekas, 2004).

With treatment at the earliest sign of psychosis, functional outcomes are substantially improved (Fusar-Poli et al., 2013; Haroun, Dunn, Haroun, & Cadenhead, 2005; McFarlane, Cornblatt., Carter, 2012; McGlashan & Johannessen, 1996; McGorry et al., 2002; Nordentoft et al., 2006). Although this early stage may be an optimal time to intervene, the earliest symptoms of psychosis are inherently subtle, subjective, and often overlooked by providers (Norman et al., 2004). These early signs and symptoms are more likely to be recognized by people who have long-term relationships and frequent contact with youth, such as family members, teachers, primary care physicians, pediatricians and community-based mental health providers. Educating these professionals and community members promotes rapid access to treatment for youth whose symptoms signal an initial episode of psychosis and that may otherwise go undetected (Domingues, Alderman, & Cadenhead, 2011; Larsen et al., 2011).



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## COMMUNITY OUTREACH IN MENTAL HEALTH: A BRIEF HISTORY

Historically, the focus of psychiatric and behavioral health services has been on treatment interventions rather than early intervention or indicated (secondary) prevention (Kutash et al., 2006). Early identification and treatment of severe mental illness, specifically psychotic disorders such as schizophrenia, bipolar disorder, and major depression, is a relatively young endeavor for American mental health research and services (McGlashan, 1996). The success of early identification depends on the accurate recognition of the earliest warning signs in a young person by someone in that person's occupational or social network. For young people between 12 and 25, that network primarily includes educational professionals, healthcare providers, friends, family members, and mental health clinicians.

Initial efforts at general and targeted community outreach and education for the purpose of early referral to psychiatric services were initiated outside of the United States (Edwards, Fancey, McGorry, & Jackson, 1994; Falloon, 1992; Joa et al., 2008; Krstev et al., 2004). English, Australian, Danish and Norwegian initiatives identified stakeholders outside of the mental health system who could provide committed participation in the early detection effort. Stakeholders were recognized as people in a unique position, by virtue of their occupation, family relationship or ongoing friendship, to identify young people demonstrating the early mental changes indicating psychosis. Published studies now demonstrate that community members and healthcare professionals can effectively identify and refer those who are manifesting the early signs of a psychotic disorder.

In the United States, until recently there were no similar efforts to implement and investigate the effectiveness of both broad public awareness and targeted community education and outreach for mental health early intervention. Community education and outreach are traditional public health approaches (Luepker, Muarry, Jacobs, & Mittelmark, 1994; Organization, 2004; Thomas, Quinn, Billingsley, & Caldwell, 1994), yet until recently there were no published data on their use or outcomes for the prevention or early intervention of major mental illness in the United States.

When PIER was established, there were no American examples to use as a model for its community outreach for mental health services. Early intervention in the United States was associated with services for children under five (U.S. Department of Education, 2002; Pinto-Martin, Dunkle, Earls, Fliedner, & Landes, 2004). The PIER Program's community outreach and education methods were developed using ideas and strategies from several sources, including public health education, communications, school-based early identification, and the lessons learned by international researchers (Falloon, 1992; Edwards, et al., 1994; Krstey et al., 2004; Joa et al., 2008).

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The PIER Program outreach model can be conceptually described using constructs from two prominent behavioral theories: Theory of Planned Behavior (Ajzen, 1985) and Social Cognitive Theory (Bandura, 1986). The Theory of Planned Behavior states that individual intentions to engage in goal-directed behavior (e.g., making a referral) are predicted by the individual's attitude toward the activity (e.g., positive vs. negative), subjective norms (e.g., whether the individual experiences social pressure to engage in the activity), and behavior control (e.g., whether there are physical, contextual or psychological barriers to the individual's performance of the behavior). Behavior control is conceptually related to Bandura's (Bandura, 1977) notion of self-efficacy; a component in Social Cognitive Theory. The effect of attitudes, subjective norms, and behavior control on actual performance of the behavior is mediated (at least partially) by intention and perceived likelihood of efficacy in achieving a desired end.

*"The PIER Program outreach model aims to alter the knowledge, attitudes and behaviors of those who are in a position to identify young people showing the early warning signs of psychosis.*

Social Cognitive Theory maintains that it is possible to facilitate individual behavior change by modifying an individual's personal and environmental factors to encourage healthful behavior (Maibach & Cotton, 1995). The PIER outreach model seeks to modify environmental factors by making it easy to contact the program. It also focuses on modifying personal factors, by increasing knowledge about the program and promoting the referrer's beliefs that the referral will be efficacious and beneficial to the young person and possibly the referrer. In addressing both the environmental and personal factors, the theory predicts an increased probability of receiving an appropriate referral to the program.

## PORTLAND IDENTIFICATION AND EARLY REFERRAL (PIER): A COMPREHENSIVE EARLY IDENTIFICATION AND TREATMENT SYSTEM

The principles and methods of outreach and engagement utilized by the PIER model provide a sound example of strategies that can be incorporated into other early psychosis intervention programs, serving clinical high risk and/or first episode clients. PIER, located in Portland, Maine, is a treatment and research program that works to:

(a) identify and treat adolescents and young adults very early in a first psychotic episode to offset the development of a severe mental illness, specifically schizophrenia, bipolar disorder or major depression; and

(b) reduce the incidence of major psychotic disorders by early detection and treatment.

Using a combination of community outreach and education and clinical interventions, PIER:

1) Educates the community, particularly school professionals, mental health clinicians and primary care physicians who are likely to encounter young people in the early stages of psychosis;

2) identifies and equips those groups to identify young people who are displaying early signs of psychosis;

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3) evaluates an individual to determine if he/she meets criteria for early psychosis;

4) engages individuals and their families in the treatment process and equips them with the skills to provide the necessary support to prevent worsening and disability;

5) treats those who are at experiencing early psychosis with psychosocial and psychopharmacological interventions with demonstrated efficacy for psychotic disorders; and

6) establishes collaborative networks with other professionals to provide on-going educational, occupational, psychosocial and pharmacological support toward the attainment of appropriate health, educational, vocational, and social developmental milestones.

Many public health initiatives, including tobacco prevention (Curry, Emery, et al., 2007; Curry, Sporer, Pugach, Campbell, & Emery, 2007; Green et al., 2007), safe sexual practices (Coyle, Kirby, Marin, & Gomez, 2004) and alcohol prevention (Perry et al., 1996) target adolescents directly, seeking to influence their knowledge, attitudes and practices. PIER, however, works to change the beliefs and behavior of school and healthcare professionals, as well as adolescents themselves, community members and parents, to prevent/address the most severe and potentially disabling forms of mental illness.  Using existing connections and having a solid understanding of its community resources, PIER gains access to those who interface with adolescents and young adults, particularly school professionals.  In its efforts to create a system of early identifiers for young people at the beginning stages of mental illness, PIER developed a model for community health education that, in contrast to traditional mental health education, strengthens capacity for proactive engagement of key stakeholders in youth mental health.  With the help of personal and professional connections, a compelling message, available resources, and a skilled and dedicated staff, PIER demonstrated that community members can accurately identify young people in the beginning phases of psychotic disorders and successfully refer them to specialized assessment and care.

Community outreach and education has proven to be essential to achieve early intervention on a scale to justify the additional effort and costs.  To that end, PIER staff introduces community organizations to a prevention-oriented approach of early intervention very similar to recent approaches to treatment of cancer and heart disease.  The contrast is with traditional treatment of an established mental illness. If the initial contact and orientation is successful, the next task is to teach those who work with or care for young people about signs of an early psychotic disorder and the process for, and benefits of, making a referral to PIER.  Through frequent and targeted community outreach and education, PIER establishes a network of early referrers, consisting primarily of education, health and mental health care professionals who have been trained by PIER clinical staff.

PIER clinical staff spent much of the first year of operation making onsite visits with those professional groups most likely to observe early symptoms among youth.  Standardized educational material for each professional sector was developed with the assistance of a social marketing and design agency.  Engagement with each referring group

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required different, sometimes multi-pronged, approaches.  In addition to presentations in professionals' offices, large-format professional educational sessions were also held for groups of 50-200 attendees (e.g., grand rounds or meetings of public school professionals).

Two PIER websites were established, one for youth and the general public and one for professionals, so that information was readily available anonymously.

PIER has provided treatment, support, and guidance to over 300 young people between ages 12 and 25 and their families who live in the Greater Portland, Maine area.  Results of the outreach and education program in greater Portland have been promising  (McFarlane et al., 2010; McFarlane et al., 2014b).  To summarize, community outreach from 2000 to 2007 resulted in referral of 780 youths who met demographic criteria, yielding 404 cases that were deemed to be eligible for formal assessment.  After screening by PIER clinicians and rigorous assessment by research interviewers, 37% of those community referrals were found to be at high risk for psychosis, and another 20% had untreated psychosis, yielding a correct-referral efficiency ratio of 57%.  [Note:  PIER serves both clinical high risk clients, as well as those in the very early stage of a first episode.] In addition, community educational presentations were significantly associated with referrals six months later.  Perhaps the most telling result was that half of the referrals, as intended, were from outside the mental health system, and at least half of those were deemed accurate.  Referrals from mental health and other, non-mental-health professionals were equally accurate.  In the end, 75% of the screened referrals were found to already have, or be at risk for, a major psychiatric disorder, and most were treated earlier than would be expected in most American communities.  PIER educated over 7,000 professionals and found a 34% reduction in incidence of first episode for psychosis (McFarlane et al., 2014a).  The approach is limited by its inability to identify young adults who develop early signs and symptoms but are not observed by any of the community outreach key audiences.

### EDIPPP:  A NATIONAL REPLICATION AND DEMONSTRATION

In 2006, the Robert Wood Johnson Foundation (RWJF), seeing PIER as a potential national model for early intervention for severe mental illness, established the Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPP), a six-site replication study of PIER.  EDIPPP replicated PIER's clinical and community outreach components in six cities across the United States:  Portland Identification and Early Referral (PIER), Portland, ME; Early Assessment and Support Team (EAST), Salem, OR; Michigan Prevents Prodromal Progression (M3P), Ypsilanti, MI; Recognition and Prevention (RAP), Queens, NY; Early Detection and Preventive Treatment (EDAPT), Sacramento, CA; and Early Assessment and Resource Linkage for Youth (EARLY), Albuquerque, NM.  EDIPPP tested a preventive intervention (W.R. McFarlane, Cook, et al., 2012) for young people at clinical high-risk for psychosis and very early first episode (onset within 30 days).  Because community outreach is a critical component of the PIER Program's model, PIER provided extensive training and supervision in the community outreach and education model and methods to all EDIPPP sites.  Sites were given regular technical assistance and monitoring to assure fidelity to the model.  For further background on EDIPPP, see ( McFarlane et al., 2010; McFarlane, Cornblatt, & Carter, 2012; McFarlane et al., 2015; McFarlane et al., 2014b).

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EDIPPP provided many examples of community education across a wide and representative sample of the population of the United States, providing both confirmation and guidance for further implementation across the rest of the nation. By design, there was significant variation across sites in geography, demographics, agency affiliation and prior outreach. Defined catchment areas ranged from 4,839 square miles in Oregon to 82 square miles in New York, encompassing a total population of 2,986,646 across all sites, about 1% of the US population (U.S. Census Bureau, 2010a; 2010b). Demographic characteristics for all sites reflected racial and ethnic statistics similar to the United States (U.S. Census Bureau, 2010a; 2010b). Four sites had some prior experience with community education, mostly in connection with early treatment of first-episode psychosis.

The implementation of EDIPPP's community education and referral model required adaptations at each of these six sites to address unique organizational affiliations, geographic, socio-cultural, and environmental characteristics. As in PIER, EDIPPP's outreach and education model intended to generate rapid referrals of youth at clinical high-risk for psychosis by creating a network of professionals and community members trained to identify signs of early psychosis. This systematic approach to outreach included community mapping, establishing a steering council of key community members, developing and delivering outreach messages to target audiences, and evaluating the process (Ruff A., 2012). All six EDIPPP sites followed this stepwise approach regardless of previous outreach experience and received monthly group supervision from EDIPPP senior staff.

Despite their differences, all programs generated a stream of appropriate referrals. During the study (May 2007-May 2010), there were 882 formal presentations to 20,048 attendees and 145 informal presentations to 11,528 attendees. These presentations led to 1,652 referrals. Of those, 520 (31%) were offered in-person orientation. 392 (75%) of those recommended for orientation were assessed and 337 (86%) of those were assigned to a treatment; 205 individuals at high risk for psychosis and 45 early first episode, based on symptom scores (T.H. McGlashan et al., 2003), were assigned to Family-aided Assertive Community Treatment (McFarlane, Cook, et al., 2012); while 87 at lower risk were assigned to community treatment. 69% (n=1132) of those referred to the programs were screened out over the telephone and referred to other providers. The majority of referrals were made by mental health professionals (38%) and parents (37%) (Joly, 2012a; Joly, Elbaum, Mittal, & Pratt, 2010). Qualitative responses from sites suggested that parents typically became aware of the program from school staff, mental health professionals or primary care physicians (Joly et al., 2010). Parents rarely referred their children directly, based on concerns about manifest signs of illness. School-based referrals and medical professionals combined provided an additional 16% of referrals. EDIPPP referrals increased as outreach increased. After the initial outreach effort, the volume of referrals was maintained, even though outreach decreased (Joly, 2012a; Joly et al., 2010). As for

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demographic characteristics of the enrolled participants and EDIPPP catchment areas, ethnicities closely matched race and ethnicity percentages in the United States, suggesting that the sites served a representative diversity of study participants.  EDIPPP enrolled participants were 14% Latino, with the national census at 16% Latino; 62% Caucasian versus 72%.  Rates of clinical high risk cases meeting criteria ranged from 1.5/100,000/ year in New Mexico to 7.2/100,000/year in Maine, averaging 3.5/100,000/year across all sites.  The proportion of those admitted vs. first-episode incidence ranged from 7% to 44% across sites and source of comparison.  By comparison, Nottingham, U.K. incidence rates were 16-21%.  Sites' rates were correlated with duration of outreach and education effort ($r=.84$, $p=.035$) (Lynch et al., 2015).

## Outreach Successes and Challenges

Each site staff had unique experiences with the outreach effort, which are relevant to those implementing a similar program.  EAST's steering council was able to access a wide network of professionals and opportunities for partnering at events where other programs were offering community education.  PIER's steering council was crucial in helping to map community audience groups and in connecting with "gate keepers" for intended audiences, especially among recent immigrants.  EDAPT's steering council provided invaluable guidance on how best to approach some of the cultural communities like the Hmong.  The EARLY program did not ask their steering council to play a more active role in setting up outreach presentations, though they were successful through some of their university's community affiliations.

Regarding catchment areas and their selection, the NY population density was so high that only a few specific and non-contiguous zip codes were included in the catchment area.  As a result of this design, compared to other locations, the NY site had a high volume of telephone referrals that were out of their catchment area (Joly et al., 2010).  EARLY in New Mexico found that presenting to district-wide groups, although efficient, was problematic as some zip codes represented by attendees were not in the catchment area.  Given the expanding size of their treatment team, EARLY's enrollment was staggered by zip codes to eventually include the whole county.  The sites that included the entire county (NM, MI, and OR) had fewer concerns about the catchment restrictions.  EDAPT's initial contact with senior administrators in the Sacramento City Unified School District led to district wide outreach activities, which had a very positive impact on their referral base.  As a result of M3P's outreach in schools, some of the schools and colleges developed their own mental health awareness campaigns.  PIER's greatest area of success was developing a system of regular trainings in all Portland area schools and colleges.  PIER's outreach broadened within the school system as social work and guidance department trainings led to developing a tenth grade health class curriculum, and university health presentations led to resident advisor trainings.  EARLY's initial outreach priority was schools and colleges.  Within the first few months, they had presented to all of the nurses, social workers, school counselors and psychologists in the Albuquerque public schools.  Being a division of University of New Mexico, they had also met with student counseling, campus police, and residence hall directors.  RAP faced unique challenges in school outreach because the NYC Board of Education had restrictive rules about the involvement of outside agencies and research projects.  Thus, conducting outreach events at area schools was difficult,

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but RAP made use of informal networks, mailings, and follow up calls that eventually led to successful school outreach events. However, their inability to do wider school outreach was reflected in a lower rate of school referrals.

Across all these sites, private practice professionals were more difficult to reach without a forum. One successful approach was to offer large scale trainings and conferences, providing continuing education credits. Overall, mental health professionals generated the highest number of referrals across sites and were more likely to make appropriate referrals (Joly et al., 2010). Given the finding that those already in treatment may not be identified rapidly, educating mental health professionals on assessing for early warning signs of psychosis is as necessary as those from outside the mental health field (Norman et al., 2004). Though gaining access to primary care providers (physicians, nurse practitioners and physician's assistants) was a critical part of the strategy, it was a challenge for all sites due to skepticism about the prevalence of psychotic illnesses and limited time available to focus on mental health issues. Surprisingly, hospital affiliations (RAP, PIER) did not facilitate access to primary care providers. PIER found that the most successful approaches included a "lunch-and-learn" to accommodate doctors' schedules, Grand Rounds presentations, and outreach to participants' medical providers. EDAPT clinicians were able to reach family medicine providers and some primary care providers through existing clinical affiliations.

Most sites had enrollment of Latino families that was representative of the catchment area (California had 33% versus 27% in the catchment; New Mexico 53% versus 48%; New York 23% versus 20%. Oregon was the only exception (11% versus 18%). Prior to EDIPPP, UC Davis Medical Center had made efforts to reach underserved cultural communities in Sacramento and had several programs that greatly facilitated outreach to immigrant communities. However, the name recognition of UC Davis, at times, may have hindered outreach to some community providers who were not part of the UC Davis Health System because of an "ivory tower" perception. Albuquerque (and New Mexico, in general) is an ethnic minority-majority state. Many cultures have a different interpretation of the cluster of symptoms that western medicine calls "psychosis." As an example, during a presentation to behavioral health staff at a Native American charter school, the presenters were interrupted as they listed the signs of psychosis by a staff member who said, "You just described a medicine person in my culture." The nature of psychosis, and how it might be interpreted, required cultural sensitivity and a focus on functioning. Staff presented early signs in terms of their impact on work and school like "difficulty speaking or understanding others" or "trouble with reading comprehension and writing." The Michigan staff found that at health fairs with diverse audiences, they were asked to talk more broadly about overall mental health and wellness.

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Consistency of outreach effort resulted in more referrals. Busy educators and treatment providers needed periodic contact from the EDIPPP team to identify early symptoms and make accurate referrals. Maintaining consistent community education was a challenge at all sites, but setting monthly target goals helped. For instance, EARLY stayed in touch with referrers through a quarterly newsletter, periodic emailed program updates, and media coverage.

In summary, EDIPPP was able to replicate earlier results from community-wide outreach to educate key professionals in identifying and referring youth for treatment. School, mental health, and medical practitioners were the critical audiences for community outreach. Six geographically and ethnically diverse sites developed a site-specific plan for outreach, guided and assisted by the EDIPPP senior staff and members of their own steering council.

## Implementing Community Outreach and Education: The Key Methods

The purpose of this section is to describe the implementation methods of the community outreach and education component of PIER (hereafter meaning Psychosis Identification and Early Referral). Again, these same methods might be utilized by diverse early intervention (both clinical high risk and first episode) psychosis programs. **A PIER program defines community outreach and education as any activity designed to inform key audiences about the importance of, and methods for, early detection and intervention of psychosis in adolescents and young adults.** The goals of community outreach and education are to:

1) Decrease barriers to early identification, especially stigma;

2) Provide information about modern concepts of psychotic disorders;

3) Increase understanding of early stages of mental illness and pre-psychotic symptoms;

4) Inform audiences about referral processes and rapid access to treatment; and,

5) Develop relationships with community stakeholders and referrers to build and maintain a network of early identifiers.



The PIER outreach and education model is intended to generate rapid referrals of youth at highest risk or in the earliest stages of onset of psychosis by creating a network of professionals and community members trained to identify signs of early psychosis. This systematic approach to outreach includes community mapping, establishing a steering council of key community members, developing and delivering outreach messages to target audiences, and continuously evaluating the process and its effects (Ruff A., 2012).

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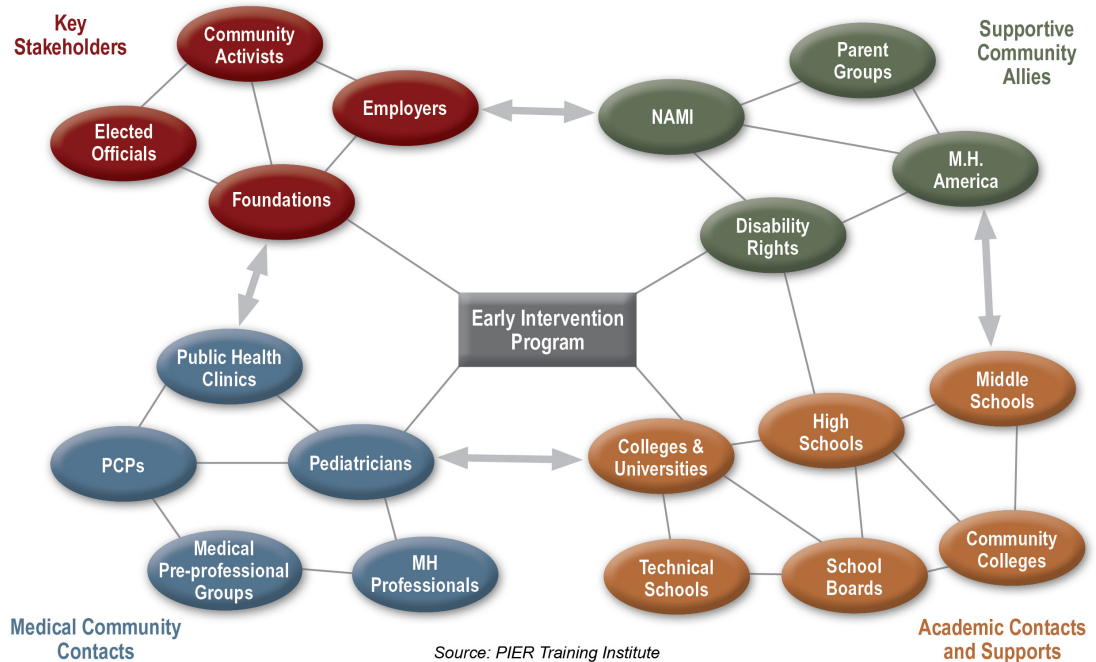
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## ESTABLISHING A STEERING COUNCIL

Before an early intervention program begins its community outreach and education, it convenes a steering council, comprised of community members representing various constituencies, disciplines and interests.  Members include educational professionals (teachers, nurses, social workers, administrators, college health and mental health service providers), primary care and pediatric physicians, community mental health professionals, governmental representatives, parents, and elected officials.  In many communities, it is essential to include leaders and other representatives of the larger minority subgroups.  The purpose of the steering council is to advise the program on the development of outreach messages and materials, and to help identify, prioritize, and engage key audiences.  The steering council is also crucial in connecting program staff with gatekeepers for specific identified audiences.

## DEFINING THE CATCHMENT AREA

Selection of the site's catchment area is based on many factors including:  having a population of 300,000-600,000 people representing the socio-economic and ethnic diversity of the region; school districts contiguous to one another; and geographic areas covered by these clusters located within 20 minutes of the treatment/research facility.  To date, almost all specialty services like PIER have been defined by a political entity, usually a county, a group of counties, a city or a state.  Portland itself was unusual in using a real estate association's definition for a functioning urban area—Greater Portland—which actually consisted of 25 different towns in two counties.

## COMMUNITY MAPPING FOR POTENTIAL AUDIENCES

**Community Mapping Tool**



Source: PIER Training Institute

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The steering council and program staff conduct a community asset mapping process (Fiscus & Flora, 2001; Kretzmann & McKnight, 1993). Through this process, staff and the steering council identify resources and existing relationships, both of which are critical to the success of community outreach and education. As a result of this process, staff typically identify key audiences whose members regularly work with youth and young adults: middle and high school staff; college and university health and mental health services staff; healthcare professionals; mental health professionals; social and human service providers; youth-oriented community agencies; military bases; law enforcement and judicial agencies; multi-cultural groups and their elders; and parents and youth. Wherever possible, the program will develop partnerships with institutions, especially the educational, mental health and general medical communities (because if there are priorities, in most communities it will be these). Thus, working with the school district leadership to promote education of key staff; the health service directors at colleges and universities; large group practices and/ or large medical consortia; as well as the outpatient, inpatient, child and adolescent and crisis service divisions of mental health agencies, will be necessary in most American communities. However, other sectors can be uniquely critical. Identifying and linking to the manifest organizations representing those sectors will often provide some of the most frequent and appropriate referrals, once a collaboration has been established.

## PLANNING AND ORGANIZING OUTREACH

### Outreach Target Audiences

*First Stage*



Source: PIER Training Institute

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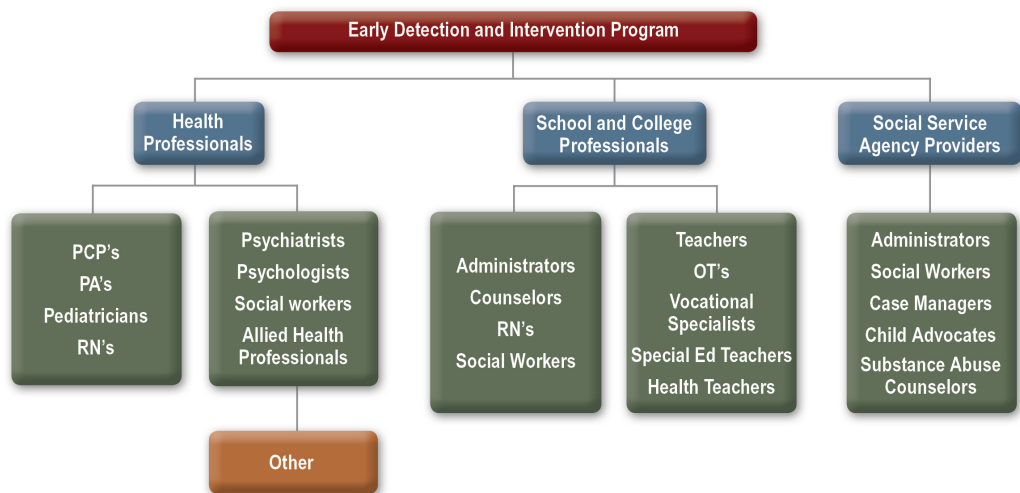
PIER programs develop and follow an outreach plan, established and continually updated by the teams as a whole, but usually spearheaded by a team coordinator who develops materials, identifies targets, schedules presentations, tracks progress and evaluates impact.

Many health and social service programs designate a single staff member to conduct community outreach and education.  However, because this component is central to a PIER program's methods, all program clinical staff members participate in outreach and communication.  With this design, the program's community outreach and education efforts maximize a community's exposure to the clinical staff members who ultimately provide early intervention consultation and treatment services.  This direct linkage of program staff to professionals and community groups working with the affected population greatly increases the likelihood of appropriate referrals.

To facilitate balance of clinical responsibilities and community outreach and education, staff develop a multi-staged approach.  The first stage includes the identification of primary and secondary audiences.  The second stage establishes priorities among those audiences to maximize the number of community members exposed to the education messages, beginning with those most likely to observe the early warning signs in young people, such as high school social workers.  In addition, different staff members provide leadership for different audiences, usually based on professional discipline.  For instance, the social worker meets with school professionals, while the team physician meets with healthcare professionals.  PIER Program staff found that returning annually or biannually to schools, colleges, universities, and medical practices provided the opportunity to train new staff, as well as to provide a "booster" course for existing personnel that included case studies and research updates.

A special circumstance is the community that is largely rural.  As might be expected, geography has several effects on this approach.  When the population is dispersed, a bit of extra effort is required to engage the relevant organizations.  In rural areas, the incidence of onset will be rare, especially because epidemiological research has consistently shown a lower incidence rate in rural settings than in urban.  In most instances, staff will have to travel to the more remote areas and try to coordinate events to efficiently reach the targeted audiences.  The other approach is to do outreach to the relevant rural professionals through existing means, such as regional or state conferences, school district consortia, annual teacher training sessions, pediatric society meetings, therapist conferences and similar venues.

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In most communities, there will be individuals and groups from a wide variety of cultures, including Native American.  In planning outreach and education, it is crucial to have a complete understanding of:  which cultures are represented in the chosen community; what kinds of experiences (positive and negative) those groups have had; who are the natural and/or designated leaders; and a basic understanding of how different cultures view psychosis.  Those views can range extremely widely, from seeing psychosis as a sign of a higher wisdom or special connection to gods, to a sign of marked family shame, prompting the family to hide the individual from anyone outside the family.  Clearly, adapting the outreach plan must address these different understandings.  The key is to involve members of a given culture in the planning process, and, if possible, in the steering council initially, and to have dominant cultural and ethnic groups represented by member of the program staff itself.  Then, outreach planning also needs to take account of the fact that professionals from minority cultures may share beliefs deeply held by that culture, but different from the scientific, biosocial view current in psychiatry.  If the staff is not prepared, contradictions between scientific and religious or cultural beliefs about psychosis and mental illness in general can become apparent in educational presentations, sometimes undermining the acceptance and application of the knowledge being communicated.  It may be a large enough issue that co-presenters from a given culture will need to be recruited and trained, to lend credibility, but also to respect those beliefs.  This kind of cultural adaptation effort will clearly be necessary once the staff begins meeting youth and families during the referral and intake process.  A program needs to develop the highest level of cultural competence and will have to often develop unique and novel ways to reach and educate professional and lay citizens from cultures other than the American mainstream.  While a large and richly informative literature has evolved on this topic, often the best authorities are members of the community that the program is committed to serve.



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## Conducting Outreach

Once the key audiences are identified, PIER staff contact the relevant organizations to offer free professional education sessions. Interest varies widely; some organizations immediately schedule presentations, while others respond only after several calls over many months. Once connections are made, PIER staff give a presentation to the organization's staff about the program mission and rationale, modern concepts of mental illness, the early signs of psychosis, and the referral process. The program staff distribute educational materials, such as bookmarks, booklets and handouts, to participants. Some examples of presentations are available at the NASMHPD website. The figure below provides a basic framework for planning the overall outreach campaign in most American communities.

College health services

Family practitioners

Mental health clinicians

Pediatricians

Military bases and recruiters

School teachers, guidance counselors, nurses, social workers

OUTREACH

Clergy

Employers

Emergency and crisis services

Advertising

General Public

*Source: PIER Training Institute*

Much of the organizing of educational presentations is relatively routine, involving scheduling of program staff in response to acceptance of requests to present to a school, college, physician, agency, therapist or other audiences. However, it has occurred (see Case Studies, below) that an individual in a key role refuses to arrange a presentation to a key professional or lay audience, or there is policy of the organization prohibiting such presentations. This highlights the reality that information spreads in a community through both formal means—explicit education and information sharing, as in the approach described in this manual—and informal, largely by word-of-mouth, in a less organized and systematic manner. Similar changes in health knowledge have occurred through both pathways, perhaps best exemplified, again, by lay knowledge about prevention and treatment of cancer. In early psychosis work, there is a third pathway which may

be necessary and has proven to be quite effective—though more laborious and slower to implement. That is, the program staff use personal connections to colleagues in prospective organizations, providing basic information about what is being offered and a request to invite the staff to present. This may be along discipline lines (e.g., nurses-to-nurses) or to broader audiences (e.g., all professionals in a school system).

In this planning and outreach stage, members of the steering council can be critical, by either convincing reluctant individual officials, or by providing connections to other professionals in key positions in the potential target audience's organization. In some instances, presentations can be arranged through personal or social-organizational connections of staff or administrators. A highly cost-effective method is to offer to present at local or state-wide conferences for relevant professional groups—e.g., pediatric societies; school health and mental health conferences; teacher training conferences at the start of the school year; fraternal and political organizations in the community; cross-religion clerical groups; police training events (CIT), etc. To an extent, the success and particularly the breadth of information distribution will depend on a wide variety of approaches, some formal, some very informal, and some based on professional connections of the staff or steering committee. Ultimately, one key component is the creativity, commitment and persistence of the staff administering the outreach effort.

## PIER COMMUNITY EDUCATION METHODS

The PIER staff develops standard community outreach and education presentations tailored to specific audiences, for instance, school nurses, pediatricians or child psychiatrists. Each presentation includes the following key elements: 1) Modern concepts of psychotic disorders; 2) early stages of mental illness; 3) early signs of psychosis; and 4) instructions on how to make a referral. The multidisciplinary team then delivers those standard presentations. The presentation includes indicators of early psychosis: suspiciousness and paranoid thoughts; altered perceptions; social withdrawal; and cognitive changes, among many others (Fusar-Poli et al., 2013). Some flexibility is encouraged to address each site's geographic and cultural diversity and unique challenges. One of the key points is that psychotic symptoms occur in many disorders, not just schizophrenia. However, they typically indicate that a major mental disorder is emerging and that rapid initiation of treatment—while assessing to determine the most likely diagnosis—is almost always strongly indicated. Educational methods include formal presentations (e.g., educational slides and handouts including early warning signs, de-identified case examples, and referral information) and informal activities (e.g., health fairs, conferences, phone contacts).

In preparing for presentations, a key task is to match the material and message to the mission of the individuals and agencies or organizations to whom you are presenting. The key is to first understand the goals held and difficulties faced by the members of the audiences that are being educated or trained. Then, the task is to emphasize how early intervention not only preserves health and mental health and reduces the community's burden of disease, but also how working with the program staff will help them meet their own goals and reduce the burdens they face daily in their own work. For most new

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programs, a multi-disciplinary early psychosis staff will be able to fine-tune presentations to meet the specific needs and interests of their various disciplines.

For agencies, successful treatment (and even prevention of onset of early psychosis for programs serving clinical high risk groups) will eventually lead to savings in the costs of emergency visits and hospitalizations, as well as reducing the likelihood of staff burn-out and high rates of staff turnover from the frequent crises of those with more chronic illnesses. Working with this stage of illness is inherently less stressful and more gratifying than with later stages.



Educators will be interested in how early identification will improve academic performance, behavior in class and on campus, graduation rates, and avoidance of conflict with parents. In particular, most teachers and principals do not want to be asked to provide any form of psychotherapy, while they usually understand that having an optimal educational plan for each student is the core of their job. Because the PIER model only asks school staff to identify those having an early psychosis, to facilitate referral and engagement with the program team, and then to collaborate to develop a more clinically-sophisticated educational plan, there is an excellent fit with the mission and practices of most schools. Likewise, for colleges, the health service center is usually acutely aware of how common onset of psychosis is during the early months of college. This is an unusually stressful time for most college students, given the acute separation from family and friends and marked increase in academic performance expectations. The college health service system is usually poorly equipped by virtue of limited knowledge and even more limited capacity to address acute onset. Thus, an offer to assist in earlier identification, combined with ready and rapid access to treatment for those who are in an early stage of onset, is usually welcomed and leads to close collaboration with the team. Further, the PIER strategy of treating in place, while working with the institution to temporarily reduce academic demands and social expectations, fits with most universities' policies and efforts for reducing drop-out rates and non-graduation.

For physicians and other primary care practitioners, adolescent mental health issues are usually overwhelming. Over the past decade, many pediatricians report dramatic increases in adolescent and young adult patients with severe psychiatric disorders, but feel poorly equipped to diagnose, let alone treat. Further, they find a dearth of competent services available for referral. Again, the PIER message is that the presenting staff will assist in accurate diagnosis, referral and engagement, while working to coordinate mental and physical health care and treatment with the practitioner to assure best health outcomes. Many physicians also appreciate that the model fosters continuation of doctor-patient relationships while treatment proceeds, to facilitate possible referral back to that physician when treatment is completed.

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For therapists and psychiatrists, there is the issue of psychosis emerging after a young person is accepted for therapy. While it is expected that a review of possible psychotic symptoms occurs during intake assessment, it is rare that therapists would inquire about such symptoms later if they are initially absent. However, for many adolescents and young adults in the highest-risk age range, the presenting problem, especially depression and anxiety, may be the preamble to the onset of psychosis. Psychosis then begins to emerge as therapy attempts to alleviate the presenting syndrome. Thus, when training therapists and psychiatrists, they should be encouraged to be alert for emerging psychosis in youth presenting with other problems, especially if a trend toward deteriorating social and/or occupational functioning is becoming evident. Similarly, it should be emphasized that once such symptoms are detected, referral to an early intervention psychosis program should occur as soon as possible. All too often, such youth will develop serious risks for suicide, as they become aware subjectively of the persistence and increasing severity of their own symptoms, as well as their possible longer-term implications.

The military is another group that often requires a special approach. A military base, on one hand, often can include thousands of young people in the highest age of risk. On the other hand, a military base is largely a closed entity, in which most health issues are addressed by the base physicians and nurses. They are often aware that they do not have the expertise to deal with a potentially serious mental illness, but are also aware that the modern armed services, being all-volunteer, should try to allow all recruits to get treatment and continue with their military service, if at all possible. Somewhat surprisingly, these base services have usually been quite open to education and even referring cases of emerging psychosis out to a PIER-type specialty service. In some cases, the individual may seek out such care, wishing to avoid possible discharge under less than favorable circumstances. In any case the team's outreach and education can be welcomed and useful to the base.

Another key group is the clergy in the community, sometimes represented by a cross-denomination or even cross-religion association. Again, the members of such organizations can be most receptive to information, guidance and specialty services that can complement what they can offer by way of pastoral counselling. Ideally, the pastoral and psychiatric services are coordinated; the presentation explicitly offers that possibility. Many ministers, rabbis, priests and imams are quite interested in differentiating psychotic from profound religious experiences and guiding their parishioners accordingly. Likewise, the PIER team needs guidance, consultation and supportive involvement from religious leaders to engage some youth and/or their families, especially those who interpret psychosis as religious enlightenment.

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The presentations also emphasize that while early identification of developmental and behavioral issues has become common practice within many school settings, early identification of mental health issues in adolescence is often impeded by cultural norms or expectations (Department of Education, 2002; Harrison, 2005). Stigma regarding psychotic disorders remains largely unchanged in population surveys and is a major barrier even to identification, let alone referral for treatment and rehabilitation. This is a persistent and common issue facing community education. It is clear that stigma is almost entirely associated with ignorance about some of the most basic aspects of the severe mental disorders. While most clinicians and administrators using this manual will be aware of the major shift in scientific and biological knowledge about such disorders, among the target audiences that cannot be assumed. Even physicians in practice—pediatricians and family practitioners—will be somewhat surprised to learn of the major cognitive deficits present even prior to onset, as well as the cerebral cortical losses and neurophysiological functional deficiencies that underlay those deficits. Educators are often only as knowledgeable as the general public and, in some cases, may believe negative stereotypes about young people with psychotic symptoms—e.g., that they universally come from "bad" families, that these symptoms are solely caused by substance abuse, that they only occur in youth with low intelligence, and (very commonly) that there is nothing that can be done to avoid onset or work toward recovery.

There is also a common bias that psychosis of any degree is grounds for ejection from school; whereas modern practice is to support the students staying in school with reduced demands. Some educators avoid any issue that might lead to a requirement for special education, which is in some school districts financed solely by the district budget. By contrast, the most common PIER recommendation for early onset supported education is for special accommodations (under Section 504 of the Rehabilitation Act and Title II of the ADA), not special education, especially and specifically not special education classes. These are usually of no or minimal cost to the school. Many universities still require students with even early stages of onset to withdraw, often permanently, whereas the most successful outcome is to treat and support the student in situ, again with a reduced course load, comprehensive treatment and involvement of friends and family to buffer stresses inevitable in the first and last semesters of college.

The overarching message in presentations is that these symptoms indicate a severe, complex, but also very stress-sensitive brain disorder. That is, that the illness is still one that responds to social support, reduced stress, evidence-based therapies and, in most cases, medications, as opposed to long hospitalizations, involuntary care, abandonment of social and occupational activity and giving up hope for recovery. Frequently, the parallels with the older stigma associated with cancer are cited, reminding audiences that stigma can change with knowledge and advances in treatment and prevention. And that the audience itself can assist in that advancement, if its members can learn to identify early psychosis and respond sensitively and quickly by referral to specialty care. Clearly, the presenters need to model not being judgmental about ignorance or negative attitudes on the part of the audience. These attitudes are part of our culture, are often very old and

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deeply held, and may be based in religious belief, while the information that might change those attitudes is not widely known. Fortunately, stigma and its lack of knowledge about mental illness in general, in many parts of the United States, and especially among youth and young adults, appears to be decreasing.

Program staff may also initiate activities to increase general public awareness of the program and its services. These may include movie theater advertisements, arts contests for area high school students, sponsorship of local sports teams, and participation in community health fairs, conferences, talk-shows and other events. Clearly, newspaper advertisements, especially in youth-oriented venues like alternative papers, and high school and college newspapers, can have positive short- and long-term effects on awareness in the younger populations. A website that is graphically designed to appeal to adolescents and young adults should be developed (or a link offered to the NASMHPD website pages on early psychosis) and promoted at all community outreach and education events. This allows visitors to the website to anonymously learn about mental illness and early signs, download all the program's educational handouts, and watch several videos which are available online.

The process of referral is emphasized in educating professionals. For schools, colleges and most other sectors, the basic procedure is that the professional who initially identifies an at-risk youth will first consult, almost always anonymously, with the intake coordinator of the PIER team. If it appears that this is likely a youth who is truly in an early stage of psychosis, a plan is developed for the referring person to inform the youth and the family, while encouraging them to contact the program for an assessment. In schools, this is often the social worker, nurse or guidance counselor. In some cases, the referrer may get permission to have the program team reach out directly to the youth or family. If the referral fails for some reason, program staff can contact the referring professional to decide whether a second attempt should be made. To maximize community health impact, the program should make arrangements for rapid referral of those found not to be eligible by virtue of symptoms below the threshold for early psychosis.

## FOLLOWING UP WITH POTENTIAL IDENTIFIERS

One of the most effective methods for educating community professionals, particularly those not in the mental health field, is to welcome and carefully explore any referrals made for the first time by an individual identifier. This is a perfect opportunity to help him or her fine-tune their knowledge of early signs and symptoms, as well as their skill in discussing with the potential referee and the family the importance and value of accepting and carrying out a referral and assessment. While labor-intensive on the part of the team staff, this work pays major dividends over time, as key professionals in the community

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become both more accurate in identifying and adept in making successful referrals. The team should identify the most optimally placed and disposed professionals in schools, colleges, mental health and social service agencies and among pediatricians and family physicians, to make sure they, in particular, get full support and guidance while making referrals after the initial training. It has been remarkable how accurate, rapid and effective many professionals become over time, given this kind of effort by the team. It also has a remarkably positive effect on the reputation of the program if requests for assistance from these community professionals are addressed quickly and effectively.

The other kind of follow-up involves repeat trainings over longer periods. It is common that in some fields there is high turnover in the very staff who receive the training and are critical to true early identification. This means, for better or worse, that the team will need to re-educate some quarters of the community over again in its first 5 years or so and, in some instances, ongoing after that. In Portland, for instance, the staff repeated trainings in the main high schools and for college RAs as often as every 2-3 years. Over time, it appeared that the junior and high schools had incorporated the knowledge in their health and social service staff, but in some cases, it required further trainings into the second and third 5-year periods. For physicians, this is less an issue, because they interpret the knowledge as part of their continuing education, they tend to retain it and, mostly, they remain in place over many years. Several physicians and primary care practitioners have joined PIER steering councils and even become active in educating their colleagues.

Finally, though it is beyond the scope of this manual, PIER usually coordinates treatment planning with the referring organization, particularly regarding academic and employment support. This is crucial to achieving the best functional outcomes for the youth struggling toward recovery and his or her personal goals. However, these joint efforts solidify both knowledge and skill on the part of the identifying and referring professionals, in the end creating a competent community.



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## Case Examples

The benefit of implementing a comprehensive outreach plan has been well-documented, and is generally considered an integral part of any early intervention program. While the theories and concepts of community outreach have broad appeal to agencies involved in early intervention, the actual implementation can often remain elusive to service providers and administrators alike. The thought of carving out clinical time for outreach education often leads to the following questions and concerns:

> "How can I justify using clinical time for outreach amid billable demands?"
>
> "Do people really want a full outreach presentation when they are busy with other things?"
>
> "Does it make sense to focus on early psychosis when there are so many other aspects of mental health and wellness?
>
> "Do we scare away potential referral sources when we mention the word 'psychosis?'
>
> "My staff hate public speaking, they'll never be interested in doing this. In fact, I'm not sure if I'm comfortable with them being the face of our agency…"
>
> "Isn't a mass email just easier to get referrals going?"

The fact is, currently, almost all mental health agencies are strapped and are forced to make the most of limited resources. So, collectively, we all can and should ask the question: "How can we justify implementing a comprehensive outreach and education program in addition to our clinical demand?" In essence, this question is what underlies each and every concern above. In this section of the manual, we will aim to answer that question directly; and further, we will provide stories and examples from the towns, cities and states that have confronted these questions, taken the risk, and haven't turned back. In the end, the answer should be clear, and a new question will arise: "How can we justify NOT doing outreach in our city/town/state/etc.?"

In the first part of the manual, we reviewed the 7-tiered plan that can maximize success and build in strategies to fine-tune and ensure ongoing impact:

1) Map your community;

2) Establish a Steering Council;

3) Identify key audiences (schools, primary care, community referrals);

4) Develop Messages for Specific Audiences;

5) Train ALL staff;

6) Deliver the messages; and,

7) Evaluate your efforts.

It is in the implementation of these seven outreach processes that the theory and science behind the comprehensive model turns to practice, and, as a result, gets quite interesting, as unique geographic, cultural, socio-economic, political opportunities and barriers come into play. As a practitioner, this is the part of outreach that is the most exciting: where each city/town/state owns a stake in the outcome of not just the early intervention program, but more generally in the wellbeing of young people in their community.

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The PIER Training Institute (PTI) was established to disseminate the methods found to be effective in EDIPPP and previously in Portland. Since 2010, PTI has trained and provided oversight and consultation to many new PIER replication sites. These have included San Diego, Ventura, Imperial, Santa Clara and Contra Costa Counties in California, the State of Delaware, the City of Philadelphia and Weber County, Utah. Some of the key information about these sites is included here as a table. Further, three case studies are presented in detail to illustrate specific issues that were addressed in implementing a community education effort in the respective catchment areas.

What follows are three case examples, ranging from rural, geographically-spread settings, to larger, urban settings, whole counties and states. The model can be expertly adapted to each setting. Information was provided by the PIER Training institute, and/or EDIPPP/ PIER Program direct supervision of the implementation of the full PIER outreach model in their communities. The hope is that these stories will inform and guide their successor programs.

## CASE EXAMPLE 1. FIRST HOPE, CONTRA COSTA COUNTY, CALIFORNIA

In Contra Costa County, California, the First Hope program began in January 2013 as one of the earliest programs to combine California Mental Health Services Act (MHSA) with Federal set-aside funding as part of a county-wide early intervention and prevention effort. Contra Costa had no previous experience with formalized outreach efforts; and as a result, they began with a blank slate for their geographic area. This openness to incorporate a full-fledged outreach model defined their work and helped them to build a foundation that led to the ultimate success of the program.

Initially, First Hope completed extensive outreach planning and material development for a period of 3 months, prior to initiating services. In September 2012, their whole staff participated in a brainstorming "Outreach Mapping" session, in which First Hope exhaustively identified over 100 community contacts that were considered to be high-yield referral sources. Within this initial round of identification, they developed priorities based on methods known to maximize early intervention: schools, primary care practices and community providers. They additionally combined this prioritization with a program-specific goal to reach out to historically underserved populations and Medi-CAL (Medicaid) and uninsured participants. As such, they also included a goal to reach out to clergy, which targets the cultural makeup of their community and prioritizes culturally-based inclusion.

These goals became measurable and achievable by including all staff in the outreach development, and ultimately all staff in the community outreach presentations. Since they trained their staff members in the outreach model, and included all staff in the 'brainstorming session,' they were able to spread out the outreach workload in a manageable way. Armed with a goal of completing one outreach session per staff member per month, they completed 13 presentations prior to the start of referrals; then on average, they completed 3 outreach presentations per month over all. By including all staff, not

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only was it more manageable, but they could target the outreach discipline with the staff member most likely to get those referrals (e.g., clinicians, peers, bicultural perspectives, physicians, administrators, etc.) and/or the staff member most likely to have credibility with the population targeted.

First Hope also emphasized the importance of outreach materials to create an accessible and hopeful presence in the community.  They created bilingual/bicultural outreach brochures and flyers that were community-inclusive, in addition to traditional programmatic brochures targeting professionals, so they could fine-tune the material to their audience. They also created a website, and were careful to track and record their number of "hits," while keeping the information up-to-date, despite staffing and technical expertise challenges that initially slowed the web presence.

The other component that remained strong from the beginning for Contra Costa was their Steering Council.  First Hope assembled an active and supportive steering council from every early on, with several members who championed instituting an early intervention in psychosis program in Contra Costa County before funding was ever approved.  Members ranged from high-level gate-keepers in administrative and oversight positions, to parent advocates with NAMI, and faith-based members that helped broach the cultural divide. Steering council meetings were held weekly, then monthly, then quarterly as the demands shifted during start-up activity.  Meetings were always action-oriented, and involved specific 'asks' and 'requests' above and beyond members' time within the meeting.  Much of the planning focused on promoting connections to target audiences and their respective organizations.  That focus reflected the program aims overall:  to infuse a message of hope with earlier intervention and to engage a network of early identifiers.
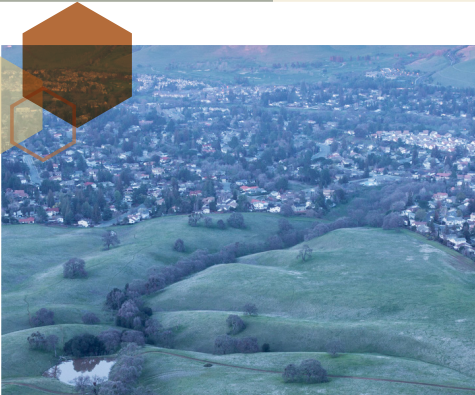
By the end of a two-year period, First Hope exceeded its outreach goals (60% of area primary care clinics, schools/colleges and community referrers) to reach 89% of the school districts, 80% of the colleges, 85% of mental health professionals and 70% of community providers, as well as 73 clergy members, several of whom are actively involved in their steering council.

Their story is one of careful and thorough outreach planning in the initial stage of development.  Currently, First Hope continues the outreach effort with an annual outreach retreat to:  update community mapping; identify barriers and problem-solve solutions; discuss strategies in small steps; and identify quarterly and monthly goals for continued success.  Their steering council remains an active and integral part of their programming, as well.  Over the first 18 months, among 68 enrollees, there were no new psychotic episodes, one psychiatric hospitalization, no suicides or attempts, and two incarcerations.  Average GAF scores went from 41 to 63, 36% were working, and 86% of school-age students were either stable or improving in school functioning (7% were failing, and 7% were not in school).

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## CASE EXAMPLE 2: KICKSTART, SAN DIEGO, CALIFORNIA

In a contrasting demographic setting in California, the Kickstart Program was also one of the earliest programs to use MHSA funding for psychosis early intervention services. Kickstart was in quite a different setting from the program discussed in Case Example #1, with an initial plan to cover referrals from all of San Diego County (including San Diego and South Bay, with a population of over 6 million). Due to the densely-populated urban setting, their implementation of outreach varied somewhat from Contra Costa, with its nearly equal mix of urban, suburban, and rural settings. It illustrates both the need and the ability to adapt the model, while maintaining its overarching values, methods and spirit.

Similarly to First Hope, Kickstart initiated their outreach programming with somewhat of a blank slate. In 2011, motivated individuals within the San Diego professional and county mental health communities sought out the Pier Training Institute and made it their mission to implement PIER in San Diego. Such enthusiasm for early intervention carried through in their program development efforts and initial outreach planning with the community. Kickstart illustrated that by embracing the full outreach model, especially thorough initial planning, they were able to target the early intervention population with a foundation that has led them to become one of the largest such programs in the U.S.

This success was not without barriers along the way. The first apparent barrier was the population size and density of referral area in relation to staffing and their ability to serve the entire county. It became evident in outreach supervision within the first months that—to most effectively develop a strong, engage-able presence in their community—they needed to initially funnel their efforts within a smaller catchment area, and they thus targeted Central and North Central San Diego. They reported that those new boundaries for outreach created a more manageable territory for outreach efforts, as well as clientele intake. Specifically, this move allowed Kickstart to maximize their outreach efforts in a sustainable manner that paved the way for development of strong community alliances and connections. Of note, Kickstart did not opt to only train some staff in outreach to free up clinical hours, as is often the temptation at urban dense sites. Instead, they recognized this barrier and made temporary accommodations to fully implement both clinical and outreach programming simultaneously.
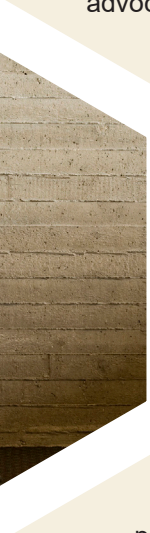
As another method to manage the number of potential referrals, Kickstart targeted their outreach message to develop a network of "gatekeepers" in the community that were well-aware of (and closely-connected to) Kickstart for supervision and consultation. They created a gatekeeper training for professionals in the area, and maintained active relationships with those gatekeepers over time. To keep a balanced focus on the early

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intervention population, they followed the outreach model recommendations to reach out to school districts, community MH clinics and primary medical practices, which in this case was interpreted as including hospital-based medical care. The focus on hospitals for medical outreach was a departure from traditional outreach recommendations to target primary care in order to ensure the earliest intervention possible, and Kickstart was well-aware of this potential risk. As such, they were vigilant in tracking referral sources and continuing to maintain significant (if not heightened) outreach emphasis on the schools and community settings to off-set outreach to the later-stage medical services.

Kickstart faced a second significant barrier: it had difficulty enlisting gatekeepers within the San Diego Unified School District. Resistance was from key officers, apparently due to lack of education and understanding of the program and the community's need. However, current school professionals and the community voiced a need on the campuses to their directors, and slowly they made progress. This is a prime example of the professionals and community members in close contact with vulnerable youth voicing a need, and the administrators either not being responsive or blocking the potential for collaboration, often owing to stigma and/or misinformation. The Kickstart team remained persistent and intentionally altered their approach to focus on educational professionals and colleagues directly. The staff worked to maintain close ties to key professionals and to develop informal gatekeepers from the strength of those maintained relationships. As predicted by the Kickstart team, their progress ultimately flowed upward, as they were able to complete outreach events to school professionals both within the SD Unified Educational District and all area colleges and universities. The key factor was communicating the inherent advantages of early intervention to those educational professionals that were contacted directly, in some cases via personal or social connections. Those professionals then advocated for more formal and much larger educational events.

Lastly, Kickstart wanted to ensure that by building a 'gatekeeper' system of referrals, they were not neglecting the importance of community-based, anti-stigma campaigns that may not yield a high number of referrals, but which are nonetheless extremely valuable in carrying the torch of hopefulness of early intervention. And, in particular, given the perceptions of stigma that they experienced within school district administration, the desire to address mental health stigma in the community held even more heartfelt significance. To turn this motivation into action, Kickstart made a strong effort to be present at a wide range of community events, fairs and conferences, with a low-barrier, accessible approach.

Since the early stages in 2011, Kickstart has expanded budgets, staffing, participants and catchment area and has developed as a leader in the state of California, and nationally. Outcomes have been like those in Portland, EDIPPP and other post-EDIPPP sites in California.

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## CASE EXAMPLE 3:  PIER PROGRAM, PORTLAND, ME:  THEN AND NOW

The PIER program in Portland, ME was the base site for the national EDIPPP project, from which the PIER Training Institute (PTI) grew.  What is of note are:  1) the unique characteristics of the site both in its initial implementation, focused on high-risk youth and in its current orientation, which serves early first episode psychosis, as well; and 2) the impact of uncertain funding and political influences that have consistently required creative thinking, steadfast collaboration, and persistent advocacy for the benefits of early intervention.

PIER grew out of several grants that funded research-based programming for at-risk youth and young adults.  It was in one of the earliest sites in America in 2000.  To be clear, without grant-funded research projects to pave the way for evidence-based practices, the current movement toward early-identification and intervention services would not exist as we now know it.  That said, the varying guidelines from research grant funding led to outreach education barriers that highlight the potential challenges of uncertain funding to EI sites in general.  As such, the PIER effort and ultimate successes carry a resonant and hopeful message for all sites currently doing or planning early intervention amidst economic and political challenges.

From the start of PIER services, outreach education to the targeted referral areas was a priority.  Like the success in both Kickstart and First Hope, efforts were specifically targeted to schools, primary care practices and community mental health providers for primary referrals; as well as stigma-reduction low-threshold community-based outreach, to develop a strong, collaborative, accessible presence in the community.  For the first 6 years of the grant, over 7,000 professionals and students attended 325 events, or roughly one event per week, with training sessions at all area middle, high and post-secondary schools; primary medical practices and medical professional conferences; mental health clinics; and, key community events (for parent groups, police officers, military bases, family law judges, foster care agencies and clergy).  The extensive PIER outreach programming demonstrated that early warning signs of psychosis were able to be accurately identified by non-mental health professionals.  Further, PIER demonstrated that with significant and continued outreach to defined areas over 10 years, the early identifiers in this network were correctly able to identify 2/3 of those expected to have an onset of psychosis.  From a public health perspective, this is significant; and within the community, the knowledge gained appeared to be expanding and persisting.

Nonetheless, in the clinical component of programming, the PIER grant required a random-assignment control group, which maximized the crucial research findings. From an outreach perspective, random assignment was difficult for the community to accept, since some people received the specialized services and others did not.  This distaste was not easily un-done in future outreach efforts.  The clinical team struggled with the balance of the known and necessary research benefit and the difficult implementation of such a model.

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In the next rendition in 2007-2012, EDIPPP continued the extensive outreach programming at the same pace, often with the standard of ensuring biannual, if not annual, outreach events to area schools, medical practices and community providers/personnel. Additionally, the random-control group was removed, replaced by a low risk control group and high risk prodromal and early first episode treatment group. This allowed even earlier intervention, as the low risk group participants were monitored for risk alongside the group that received services. This was a new benefit to the community, and with continued and persistent effort to partner with referral sources, PIER was able to strengthen the community ties vital to outreach and education.



Notably, in both phases of treatment (2000-2012), there existed no specialized first-episode psychosis program in the greater Portland area. By targeting high-risk and very early first-episode youth, and in fact, low-risk youth (control group) in the absence of FEP services, PIER developed a reputation for high-quality grant-funded, services offered to a relatively small population in the midst of a more disabled population that was underserved. Again, the benefits of research-based programming remained undisputed; but, this led to a sense of discrimination when other referrals were turned away, without other specialized services to offer. This was also felt by the treatment team, as well.

Ultimately, this may have been the biggest barrier in implementing a clinically-viable program in the Greater Portland area after research funding ended. As a result, in 2012 services were closed entirely in the area after the grant reached its completion, much to the dismay of the clinical and administrative team, the clinicians and colleagues in early intervention, and the community as a whole. The loss was felt widely.

Nonetheless, the team persisted. PTI continued to train and guide sites throughout the country. PIER staff remained accessible for consult to community members, and opened private practices targeting early intervention. Administrative-level champions of early intervention continued to promote the benefits of early intervention. Op-Eds were published in the local newspapers. The community demanded the return of early intervention. And, in 2014, the state stepped up and restarted services under the mental health block grant for first episode youth (and a separate SAMHSA grant for services for at-risk youth), within a community outpatient clinic, with a clear administrative structure for sustainable evidence-based practices.

Outreach, again, resumed. Mapping and training were completed by all staff for a larger geographic service area and expanded inclusion criteria to provide services for early first episode psychosis, as well as high risk. The PIER program also made itself available to a newly-emerging sister-team that serves later-stage FEP under expanded criteria.

The foundation within the community from 15 years of targeted, specific outreach education in early identification, coupled with the newly-expanded inclusion criteria to serve more people in need, allowed for a renewal of the hopeful message of early

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intervention and accurate, timely referrals. It was clear that the community had been waiting for services that had become valued by the original audiences that received education from the PIER staff.

Despite no longer having the discretionary grant funds that partially supported the PIER program, among other crucial services, there has been heightened support from the community for continued early intervention services. The program is now supported with state general funds and continues to provide services as of this writing. What has emerged is that, even in the midst of uncertain funding, shifting inclusion criteria, changing program elements and geographic catchment areas, the PIER program profile in the community has remained strong. An op-ed appeared in a local newspaper hailing the continuation of the program amidst evident barriers. Furthermore, the state of Maine holds a strategic plan to expand the PIER program, with satellite locations throughout the geographical expanse of the state. If program staff have successfully implemented and maintained a hopeful and strong outreach message in the community, the value of early intervention may well suffice to sustain services through difficult and uncertain times.

As a result of the continued persistence of outreach education, ongoing maintenance of referrals and strong community presence, PIER was able to demonstrate (both within the Portland area, and beyond within all 6 EDIPPP sites across the country) that the use of a defined outreach strategy combined with flexibility and ingenuity, is a feasible and highly effective approach for identifying and providing key treatment and rehabilitation for a highly vulnerable and potentially highly-contributing population of young people.

## SUMMARY

At-risk and first-episode psychosis programs are spreading across the country and world at unforeseen rates, thanks to the growing body of evidence of the effectiveness of early intervention (and newly dedicated funding streams via the MHBG set-aside to support FEP). As this manual illustrates, the key component of developing and maintaining a comprehensive and targeted Outreach Plan is a cornerstone of the foundation for a program to successfully imbed itself into the fabric of the targeted community. In fact, it cannot be emphasized too strongly that early identification completely depends on an educated and responsive professional community both in- and outside the mental health specialty field, to achieve earlier intervention and the major improvement in lives and outcomes that results. By



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adapting traditional psychological theories and employing public health methods, such as asset mapping and stakeholder engagement, PIER, EDIPPP and a large body of international research and experience has demonstrated that the principles of community health education can successfully be applied to secondary and tertiary prevention in mental health. Those public health strategies and methods are effective in identifying and referring a substantial portion of the younger population having an onset of psychosis sufficiently early to markedly affect outcomes. Additionally, PIER has shown that it is possible to engage community members in the identification of adolescents and young adults who are experiencing the early symptoms of a psychotic disorder, and in assuring referral to best practice services for those disorders.

As a result of the continued persistence of outreach education, ongoing maintenance of referrals and strong community presence, PIER was able to demonstrate, within the Portland area, all 6 EDIPPP sites and many others across the country, that use of a defined outreach strategy combined with flexibility and ingenuity, is a feasible and highly effective approach for identifying and providing key treatment and rehabilitation for a highly vulnerable (and potentially highly-contributing) population of young people.

Further consultation and training in the PIER system can be provided by the PIER Training Institute (below). Additional collaborative opportunities exist in resource- and idea-sharing networks such as the International Early Psychosis Association (IEPA) and the Prodromal and Early Psychosis Program Network (PEPPNET) that help to build the efficacy of both early intervention services and outreach and education simultaneously on local, national and worldwide fronts.

Looking to the future, it is likely that to achieve an impact on public health will require the same intensity and duration of educational effort that has been successful in cancer and cardiovascular disease. More widespread progress may also require population-oriented efforts to reduce the continuing stigma associated with mental illness, which is also facilitated by systematic outreach and public education.

For further information and guidance, please see:

www.piertraininginstitute.org

http: //iepa.org.au/

https: //med.stanford.edu/peppnet.html

https: //www.nasmhpd.org/content/early-intervention-psychosis-eip

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