

## Delaware CORE: Early Psychosis Prevention in the First State

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As few as 1 in 10 or as many as 1 in 4 adolescents experience at least one psychotic symptom in their lifetime.<sup>1</sup> Fortunately, for most, “hearing things” or “odd beliefs” are transitory events, often triggered by a medical condition or drug use. For a small percentage, however, these symptoms constitute the early signs of a developing disorder. Lifetime prevalence for psychotic disorders depends on how broadly they are defined. Schizophrenia and Schizophreniform are the disorders most commonly associated with psychosis and affect approximately 1% of the population<sup>2</sup> with an annual incidence of 10-20 per 100,000.<sup>3</sup> Prevalence increases (2-3%) when other non-affective disorders are included (e.g., brief psychosis, delusional disorder, and psychosis not otherwise specified (NOS)) and grow to 3-5% when affective disorders with psychotic features are added to the count.<sup>4</sup>

Most psychotic disorders onset between the ages of 15 and 35.<sup>5</sup> Their onset and course are typically broken in 3 phases: prodrome, episode and recovery. In “prodrome” (phase 1), symptoms are mild to moderate and seen by the individual as errors of perception or interpretation. The prodrome often marks the onset or worsening of symptoms, as well as declines in cognitive, social or occupational functioning.<sup>2</sup> In the “episode” (phase 2), positive symptoms, such as delusions, paranoia, or hallucination overwhelm the individual’s world view to the extent that she or he grows accepting of these new idiographic thoughts or perceptions with growing conviction. Episodes are associated with observable (i.e., with MRIs or PET scans) neuroanatomical changes and further loss of functioning.<sup>6</sup> Hospitalization and antipsychotics for reducing the intensity of symptoms are usually required to end an episode. In “recovery” (phase 3), affected individuals and their families deal with the residual deficits that originated during the prodrome and worsened during the episode. This phase is often prolonged and usually requires as many as 6 to 24 months before an individual has sufficient energy and recovered functioning to return to routine life.<sup>6</sup>

While this conceptualization of psychotic process is commonly shared, its implications for treatment are not. Clinical researchers disagree about when and in what phase to intervene. Most agree that treatment should follow as close on the heels of an episode as possible, the better to reduce debilitating positive symptoms (e.g., delusions, paranoia, hallucinations).<sup>7</sup> Consequently, most early intervention programs in the United States target first episode psychosis (FEP). By contrast, researchers strongly disagree about whether to introduce secondary preventive strategies during the prodrome. Opponents of secondary prevention argue that current assessment

batteries only predict about 1 in 3 cases of true developing psychosis and that this high “false positive” rate should prohibit professionals from unnecessarily stigmatizing people who will probably never convert.<sup>8</sup> Proponents argue back that neglecting the one third who do convert has dire consequences. Schizophrenia is the eighth leading cause of disability in people 15-44<sup>9</sup> and evidence suggests that early intervention to address negative symptoms and functional deficits during the prodrome can reduce the risk of conversion (i.e., to psychosis). For those that do convert, prodromal intervention accelerates remission and reduces the risk of brain abnormalities and neurobiological changes.<sup>8</sup> As for the high false positive rate, proponents observe that subthreshold prodromal symptoms are sufficiently disabling, in and of themselves, to warrant effective intervention.<sup>8</sup>

This article describes the rationale and implementation strategy behind Delaware’s plan to develop a system of care for transitional age youth (ages 12-25) experiencing FEP or prodromal symptoms. The program is titled Community Outreach, Referral and Early Intervention or Delaware CORE ([www.delawarecore.com](http://www.delawarecore.com)). What follows is a description of federal funding, the service model, a brief account of some lessons learned during implementation, some administrative challenges, and plans for future evaluation.

## Funding

In 2014, the Substance Abuse and Mental Health Services Administration (SAMHSA) launched two initiatives that focus on the mental health needs of transitional age youth.

**SAMHSA NITT HT Grant Program:** In the wake of the Sandy Hook shootings in 2012, the Obama administration issued a 2013 proposal to reduce gun violence that included a directive to increase access to mental health and substance abuse services. SAMHSA seized on that directive in 2014 with a new program entitled Now Is the Time - Healthy Transitions (NITT-HT: [www.whitehouse.gov/issues/preventing-gun-violence](http://www.whitehouse.gov/issues/preventing-gun-violence)).

NITT-HT called upon states and the indigenous territories to expand and improve their systems for transitional age youth with, or at risk of having, serious mental illness. In response, Delaware proposed a statewide program for 16-25 year olds with early psychosis. The response was, in part, driven by visits recently paid by William McFarlane, MD to Delaware to discuss local implementation of an evidence-based model he had developed entitled the Portland Identification and Early Referral program (PIER).

PIER had been recently replicated on a national sample of early FEP and clinically high-risk prodromal cases.<sup>10</sup> Delaware’s proposal led to a 5-year \$5 million award.

**Mental Health Block Grant Set-Aside:** Also in 2014, congress passed legislation requiring states to set aside 5% (increased to 10% in 2015) of their annual SAMHSA mental health block grant dispensation to fund evidence based services for youth and young adults with FEP. The legislation was, in part, a response to recent findings by the National Institutes of Health that coordinated specialty care (CSC) for serious mental illness was a cost-effective treatment approach that could be transferred to community-based settings ([www.medicaid.gov/federal-policy-guidance/downloads/cIB-10-16-2015.pdf](http://www.medicaid.gov/federal-policy-guidance/downloads/cIB-10-16-2015.pdf)). Delaware seized upon this new opportunity to broaden its projected age-range for FEP participants being served from 16-25 to 12-25.

## The Service Model

### Description of PIER

PIER is grounded in a biosocial understanding of psychosis wherein vulnerabilities developing early in life (e.g., in utero, perinatal, early childhood) are manifested under stressful conditions and the neuroanatomical changes that come with young adulthood. PIER roundly rejects the now outdated premise that schizophrenia is a failure to connect with a primary caregiver, but confirms that optimizing the home environment after the onset of symptoms can reduce stress, and delay or prevent the exacerbation or onset of symptoms. Family environments that do not catastrophize and blame, and instead maintain calm, and share the burden of caring for a member with illness are the ones most conducive to recovery.<sup>6</sup>

Much of PIER's therapeutic weight rests on the keystone of the multifamily group. This foundational component dates back to research conducted in hospitals in the 1980s and 1990s showing that people with schizophrenia experience greater clinical improvement when they and their families are randomized to multifamily as opposed to single family therapy.<sup>6</sup> McFarlane suggests that multifamily groups may offer a greater diversity of peers from which to choose, identify, problem solve and share resources. He also suggested that being in therapy with families struggling "in the same boat" promotes family-to-family learning, either directly (e.g., one mother advises another) or indirectly (e.g., one mother observes another). Finally, the multifamily group provides needed support and understanding for the isolated caregiver that is solely responsible for the care of a disabled relative.<sup>6</sup>

Another innovative aspect of PIER, embraced by Delaware, is the model's inclusion of the prodrome as a viable target for secondary prevention. McFarlane and his team began exploring the use of multifamily groups with prodromal cases in 2001.<sup>10</sup> By that time, a growing number of randomized controls had shown that a variety of early interventions were not only preventing the onset of FEP but also accelerating recovery for clients that did have an episode.<sup>11</sup> For identifying the prodrome, PIER comes equipped with an assessment called the structured Interview for Psychosis-Risk Syndromes (SIPS)<sup>12</sup> designed to identify individuals with a 30-35% chance of converting to FEP within 2 years.<sup>8</sup> It also includes guidelines for choosing medications that are symptom-focused, and least associated with stigma, and side effects.<sup>6</sup>

Most families referred to Delaware CORE receive services in the following order: (a) prescreen, (b) assessment, (c) "joining sessions" in the home to introduce the social worker, team and program, (d) family psychoeducation meetings to learn about serious mental illness and staying healthy, and finally (e) a multifamily group that provides ongoing support and opportunities for collective problem solving. Psychiatric consultation, occupational therapy and supported education and employment are also available on an as-need basis. Typical lengths-of-stay in Delaware CORE run from 6 months to 2 years.

The following case example, based on a client admitted to Delaware CORE, helps to demonstrate how these six components are typically delivered.

### Case Example

Prescreen: In late February, Delaware CORE received a referral from a counselor at a local high school about a student who had been experiencing blackouts for no apparent medical reason. After getting signed permission to contact the referral's mother, a social worker conducted a

phone screen two days later. Doing the phone screen, the mother reported changes in the way her 17-year-old son was “hearing things, expresses his emotions, his sense of touch.” She also disclosed that her son had some mental health history, was diagnosed with Asperger’s Syndrome years ago, and currently took medication for anxiety.

Prescreening did not rule out early prodromal symptoms or FEP. Thus, an assessment was scheduled for the following week.

**Assessment:** One week after the prescreen, the social worker drove to the family’s home and administered the Structured Interview for Psychosis Syndrome (SIPS). The worker first interviewed the mother to get an overall picture of her son’s history (i.e., development, clinical history, family background) and status. The worker learned that the son was living with her, his stepfather and two stepsiblings; and that both resident parents had been diagnosed with Bipolar Disorder.

Next, the worker met alone with the son to ask questions about symptoms of psychosis and the recency and frequency of endorsed symptoms. The young man confirmed that he had experienced periodic blackouts in recent months. He also endorsed seeing shadows out of the corners of his eyes, hearing ringing in his ears, and hearing his name called when no one was around. These perceptual distortions had worsened in the past year and were beginning to affect his grades and interest in friends and family.

After administration of the SIPS, the social worker told the family that she needed to talk to her clinical team before deciding whether the young man was eligible for CORE. When she tentatively scheduled some in-home meetings with the family over the next month, the mother cautioned that, if admitted, she did not want strange people showing up at her door. The worker reassured her that visits by other team members would be planned with her ahead of time.

That week, the social worker presented the SIPS results to the team, which decided that the young man was eligible. Based on the SIPS scores for each positive symptom, the team agreed that the referral met criteria for Attenuated Psychosis Syndrome.<sup>13</sup> The advanced psychiatric nurse practitioner recommended a clinical interview to review the Asperger’s diagnosis and current symptoms of anxiety and mild psychosis. The occupational therapist recommended testing to account for the recent drop in grades and gauge the need for school accommodations. Team consensus was to give the family a few months of individual sessions (3-5 meetings) to stabilize before inviting them to a multifamily group.

**Joining Sessions:** Over the next several months, the social worker met with the family to build an alliance and prepare for the multifamily group. These initial meetings uncovered significant family stress and frequent arguing – partially triggered by the son’s failing grades. To make matters worse, the participant’s biological father died suddenly from a heart attack within the first two months of meeting. News of his father’s death temporarily worsened symptoms and raised the frequency of blackouts. The social worker engaged the occupational therapist and educational consultant to help seek accommodations from the school, engaged the youth in grief counseling and continued to track for signs of lingering traumatic stress. By week 10 (session 5), the family’s stress level had reduced and they were ready to join a multi-family group.

**Family Psychoeducation and Multifamily Group:** In the first two meetings, the client’s mother and stepfather learned that psychosis symptoms are caused by changes in the brain that weaken a person’s ability to filter distractions from without (e.g., neighboring conversations) or within

(e.g., thoughts). Although the stepfather stopped attending after psychoeducation, the mother and son continued in multifamily groups where they heard about other families having to advocate at school or take steps to calm things down at home.

Outcome: By the end of August, the social worker reassessed the client and discovered that he had no blackouts in the past month, and that audio and visual hallucinations were less frequent. In addition, the participant was using an agenda and deep breathing to help organize and reduce anxiety and stress in school. He had a renewed interest in football and a new girlfriend. The parents reported less stress, fewer big arguments, and more open dialogue about each other's feelings and "what was really going on." The social worker brought this progress report back to the team, which in turn recommended that the family stay involved with the multifamily group for a few months to see if improvements continued into the school year.

## **Implementation and Lessons Learned**

### **Infrastructure**

Implementation of PIER began on October 1, 2014. By July 15, 2015, administration had produced a basic infrastructure— including finalized contracts for a Project Director, Youth Coordinator, a host agency for the PIER program (i.e., Psychotherapeutic Services of Delaware Inc.: PSI: [www.psychotherapeuticservices.com](http://www.psychotherapeuticservices.com)) and a third party evaluator (Center for Education, Training and Community Collaboration, University of Delaware: C-TECC: [www.ctecc.net](http://www.ctecc.net)). Meanwhile, PSI hired its clinical staff to match, as closely as possible, PIER's prescription of one clinical team per catchment area of 300,000 people. In its original test trials, PIER defined a "clinical team" as three half-time professionals (i.e., a psychiatrist, occupational therapist and educational/vocational specialist) and two full-time social workers. Full compliance with this prescription would have ultimately exceeded Delaware's budget. Thus a compromise was struck whereby one team would cover the more populous but less geographically spread New Castle County (549,684 people) and the second team the less populous but wider Kent and Sussex Counties (376,605 people) (2010 Census). Two halftime equivalents (the .5 FTE occupational therapist and .5 FTE education-vocational consultant) were merged across teams into full time positions, and offices space was identified for administrative, clinical and evaluative staff.

### **Outreach**

In the first year of field implementation (year 2 of grant), Delaware CORE imposed several constraints on outreach to insure that information was reaching intended audiences. On PIER's recommendation, the project focused its initial attention on schools and doctors' offices in order to reach the general population of youth with early psychosis. While clinical staff were trained to deliver a standardized presentation on basic symptomology (e.g., delusions, hallucinations), administrators compiled a database to systematize the scheduling of events and avoid double booking.

A second constraint was imposed to direct help to the most underserved or underresourced parts of Delaware. Teams were instructed to limit the scope of year 1 outreach to the poorest zip codes in Wilmington's inner city (19801, 19802) and all zip codes in Sussex County. Early data from PSI's electronic health record found these constraints effective in most cases. In the first seven months of implementation (July, 2015 to February, 2016), clinicians completed 313 outreach

events, mostly personal contacts, one-to-one conversations, or literature e-drops with a few presentations. One third (33.9%) of these events occurred in schools, colleges or universities, one quarter (26.2%) in medical clinics, and only a sixth (16.9%) in mental health agencies or facilities. Regional constraints were less effective. While a majority (63.6%) of the events took place in Sussex, very few occurred in downtown Wilmington (5.8%).

The poor showing for inner-city outreach, combined with a second observation from the same dataset that audiences across the state were tending to be white and middle-aged, inspired steps to strengthen outreach to the city's minority communities. With supplementary funds from SAMHSA, Delaware CORE engaged young African American leaders and a Latino community center to develop YouTube trailers promoting the importance of good mental health and advertise Delaware CORE to a young minority audience. Spanish translations of outreach materials (e.g., pamphlet, referral form) were also improved [note: translation of the project website [www.DelawareCore.com](http://www.DelawareCore.com) is still pending].

## Assessment

As previously stated, implementation of the PIER model presumes that clinicians will administer the Structured Interview for Psychosis-Risk Syndromes (SIPS) at intake. The SIPS takes approximately 2-4 hours to administer, assesses for the presence and severity of 5 positive symptoms (i.e., unusual thoughts, suspiciousness, grandiosity, perceptual problems, and disorganization), and includes items for negative, disorganizing and general symptoms. A scored summary of positive symptoms determines whether profiles fall within the normal, at-risk (prodromal), or psychotic range.<sup>12</sup>

Hardcopies of the SIPS are proprietary and may only be administered by a clinician that is trained and certified under the authority of the PRIME Psychosis Prodrome Research Clinic at Yale University. All present and past clinicians in Delaware CORE have been trained and certified by Barbara Walsh Ph.D., one of the original SIPS developers. Clinical teams have since participated in bi-weekly or monthly consultation with Dr. Walsh.

One of the most frequently discussed topics in consultation has been the use of language when reporting results to families. On the advice of Dr. Walsh, clinicians for Delaware CORE have tended to move away from words like "psychosis" or "mental illness" when first sharing SIPS results with families. Increasingly, the staff use clients' own language when introducing thought problems (e.g., "you said you go blank in the middle of a conversation.") or focuses attention on the impact symptoms have on school, work or social activities. When the topic of "psychosis" is discussed, it is heavily qualified as an umbrella term that describes very different people with very different symptoms and very different levels of functioning. With prodromal cases, clinicians are especially careful to distinguish being "at risk for" from "destined for" psychosis, and stress the probability that prodromal clients may never have an episode.

A few other details about Delaware's assessment protocol are worth mentioning. First, all referrals to the program are prescreened to rule out cases that either have no history of psychotic symptoms, or one that is chronic. Second, all referrals admitted to the program receive, in addition to the SIPS, a psychiatric clinical interview, a career interest inventory, and a short battery of tests administered by the occupational therapist.

It should finally be noted that Delaware CORE made a conscious decision not to exclude cases of affective psychosis. "Affective psychosis" describes individuals with symptoms of psychosis

that co-occur with changes in mood. Much of the evidence supporting early intervention with FEP is based on samples that selectively exclude this subgroup. However, results from a multisite effectiveness study found PIER effective with a sample that did not screen out affective problems. Since the goal of the project was to replicate PIER's earlier successes and because it was considered unethical to withhold service from a group that had empirically benefited from said service, these cases were enrolled.

## **Treatment**

The Delaware teams began PIER training in May of 2015 and has since participated in ongoing monthly or bimonthly consultations calls. The teams have thus far admitted 40 participants (35 active; 5 discharged). Admissions have an average age of 18.6 (SD=2.39) and are predominantly male (71%) and racially mixed (54% Caucasian; 39% African American; 7% Native American). One of eight (12%) are Latino, and roughly two-thirds (63%) are working or in school full or part time. At the time of writing, Delaware CORE has delivered 121 joining sessions, 11 family psychoeducation meetings, and 14 multifamily group sessions. The program has a multifamily group in each of the three counties and two new groups are starting up in November.

Current n-size is not enough to assess outcomes and some parts of the evaluation (e.g., model fidelity) are still in the planning phase. A protocol for rating model fidelity is still in the planning phase. Nevertheless, some anecdotal lessons have been learned in the first year of implementation.

### **1. Outreach takes time and money**

Outreach is not optional, but essential to the mission of engaging young people in the early stages of their illness. Fear, isolation, stigma, and poor access to services are some of the reasons why individuals wait years before getting into treatment after an episode. In order to shorten the duration of untreated psychosis or prevent/delay it from happening in the first place, it is necessary to educate the general public and not just mental health professionals. Creating an informed public and broadly based referral network takes many hours and outreach is not a recoverable service under Medicaid. Therefore, Delaware CORE has to expand outreach to funders, donors and third party payers.

### **2. Clinicians have to learn the treatment model at their own pace**

In "real world" community mental health clinics, clinicians have limited exposure to evidence-based practices (EBP), and even less to their systematic implementation. In PIER, clinicians are expected to attend didactic training, participate in two years of consultation, and submit videotaped sessions for expert review. For some, Delaware CORE has been their first experience with a prescriptive model, and for a few, the level of scrutiny has been initially uncomfortable. One aspect of the model, namely "team decision making" has been especially challenging for clinicians that have either worked alone or autonomously as members of a group practice. Coming to appreciate different points of view as parts of an integrated clinical picture has been a process. One strategy that has proven useful is to have senior and supervising clinicians learn PIER alongside supervisees in order to model that the components are feasible, mistakes are inevitable, and accepting criticism is an essential part of learning.

### ***3. Some families need time to stabilize***

Some families come to Delaware CORE on the heels of a crisis or hospitalization, or amidst a family debate about the perceived needs of an affected member. Clinicians may add joining sessions for these families in order to assist with the immediate crisis or help the family access needed services (e.g., a father is preoccupied with an immigration issue, and needs access to legal help before he can focus on mental health issues). However, program staff also have to set limits when providing impromptu case management services. To some extent, assistance with food, housing, financial or legal issues falls under the treatment goal of reducing family stress, but such assistance must never supplant the clinician's primary purpose of assessing the referred individual and engaging the family into treatment.

### ***4. Be careful with stigmatizing labels***

Clinicians attending case review hear words like “prodromal,” “psychosis,” “bipolar disorder” and “serious mental illness” on a daily basis. This overexposure runs the risk of desensitizing staff to the fear and stigma that most people associate with such terms. An error clinicians commonly make with their first PIER cases is to introduce the word “psychosis” before the family has fully comprehended the severity of symptoms. For prodromal clients especially, more experienced clinicians use a family's own language when describing assessment results. They may wait until the first family psychoeducation meeting to process words like “psychosis” and “bipolar”, first by asking families what these words mean to them, and then deconstructing and demystifying them, while also debunking false myths, and providing evidence that people with diagnoses can continue to pursue goals and lead their lives.

### ***5. All staff member should be taught to run a Family Psychoeducation group***

A complete understanding of PIER family psychoeducational materials is a prerequisite for anyone working for Delaware CORE. Some clinicians join the project with limited knowledge about serious mental illness. These materials provide a knowledge base that is commonly understood by teams and can be accurately and reliably shared with project participants. Every person working for Delaware CORE is expected to become capable of running a family psychoeducational group.

### ***6. Use plain language when providing information about psychosis***

A common criticism from families attending family psychoeducation is that information is often presented in professional jargon that is inaccessible to most people. As a result, the project has recently exchanged all of its original educational materials for new slides and handouts produced by PIER and written in plain language with concrete examples. A slide that used to read, “Research shows that the duration of untreated psychosis correlates with increased problems with cognitive functioning,” now reads “Getting help early helps you get back to functioning well.” The new materials not only give generic definition of symptoms, but also provide visual representations, quoted examples from de-identified clients, and the concept of continuum (e.g., normal: “I could play for the Knicks someday” to delusional: “I’m playing at Madison Square Garden tonight”).



### **7. Groups require considerable logistic support**

When Delaware first submitted its NITT-HT application, the authors assumed that managing groups would require less time than seeing families individually. This assumption did not consider what is required to start a group (e.g., locating, scheduling, and motivating participation) and maintain it (e.g., reminders, food, technical support, addressing poor attendance). As Delaware CORE enters its second year of implementation, the teams are exploring avenues for ways to make group management more time efficient (e.g., a logistics coordinator).

### **8. Not all families want treatment at first**

Some of the issues that multifamily groups are designed to address (e.g., stigma, misinformation poor social support, isolation) may also impede some families from enrolling in the program. One case example helps to illustrate. A teenage boy was referred to the program due to subtle, potentially prodromal, signs of a problem. The social worker learned that the boy's father had severe Schizophrenic and ultimately committed suicide. The teenager's uncles, traumatized by their brother's death, are convinced that history is repeating itself and that the young nephew is doomed to suffer the same fate. The social worker tries to educate them about early intervention and prevention, but the family is resigned.

Not all families are ready to immediately engage into treatment. In such cases, clinicians may resort to motivational interviewing, or ask for permission to check in periodically and assess for changes in symptoms or new developments in the family.

### **9. Consider the cultural composition of groups when building a staff**

Racial, cultural, or ethnic matching (i.e., between therapists and clients) is a known predictor for treatment retention. It is possible that mismatching may partially explain Delaware CORE's difficulty with starting its first multifamily group in central Wilmington. Members of a focus group, convened in the early planning stages of Delaware CORE, expressed feeling misunderstood by white, suburban clinicians in the past that seemed educated, but lacked any lived experience as a resident in a stressed urban environment. Nearly all of the clinicians working for Delaware CORE currently describe themselves as White or Latino. This is a problem for zip codes 19801 and 19802, which are 79% African American. Thus, the project continues to try building new alliances with the African American community, and of course, to hire and promote a staff that is racially and ethnically diverse.

### **10. Problem solving in multifamily group is not always about mental illness:**

While family psychoeducation focuses heavily on early psychosis and its management, multifamily groups may explore issues that, at first, do not seem unrelated. Group topics may range from finances to sleep hygiene to time management; and problem solving may be done on behalf of an undiagnosed family member. Staff has come to appreciate that this broad application of the problem-solving method is therapeutically beneficial to the group as a whole. Broad application helps normalize problem solving as a useful way to reduce stress for the whole family, and gives group members that do not have diagnoses an opportunity to model problem solving for members that do.

## **Administrative Challenges**

Long-term sustainability of Delaware CORE poses two main challenges for the State's mental health system as a whole. First, the age range of the intended population (12-25) requires simultaneous operation in two discrete systems of care; and second, third party payers do not cover some components.

Two systems – one population: Delaware is one of only four states in the U.S. that maintain separate systems-of-care for people over the age of 17 (i.e., Delaware Division of Substance Abuse and Mental: DSAMH), and those less than 18 years old (i.e., Delaware Division of Prevention and Behavioral Health Services: DPBHS). Because the mean age for prodromal onset of the prodrome is 16 years (McFarlane, 2002) and because recovery from a treatment episode can last anywhere from 6 to 24 months, a considerable number of Delaware Core's child participants eventually "age into" Delaware's adult care system. Thus, DPBHS and DSAMH have embarked on a series of measures to coordinate transition care across systems.

Most important, the divisions sought out a common contractor for the delivery of PIER so that participants stay with their assigned treatment team for the duration of enrollment. Other bridge building measures include monthly meetings, joint representation on the oversight committee, sharing of case and service utilization data, and united representation before third party payers.

Incomplete coverage: Some crucial components of the PIER model are not covered under Medicaid. Specifically, outreach is classified as a preventive activity and educational/vocational consultation is an uncertified service. DPBHS and DSAMH are reviewing various options for sustaining these parts of the PIER model, such as aligning them with services that are already covered, blending or braiding funding sources, or applying for a Medicaid waiver that would grant coverage to these services as essential parts of the service model.

For this latter option, Psychotherapeutic Services Inc. (PSI), has agreed to more than the usual amount of scrutiny and data collection so that cost of delivering PIER can be broken down into a fee-for-service model and data points can be identified for use in future fidelity checks. In the past year, the agency has launched a reporting system that provides regular status on service delivery (e.g., community outreach, number and type of sessions) and operates through the agency's electronic health record.

## **Evaluation**

Delaware CORE has the potential to impact public mental health in Delaware on multiple levels. First and foremost, the youths served could make significant gains in symptom reduction, functioning, mood, relationships, and social support; participation also aims to decrease feelings of stigmatization that often impede treatment access and progress. Outreach efforts can yield results not only in terms of identifying youths in need of care, but also raising awareness and reducing stigma. Reducing stigma in both the affected families and the community is a large goal to help facilitate early identification and treatment access for those in need. In addition, the impact on the broader system is promising. For example, as hospitalization rates for psychosis decrease, substantial costs savings could be realized and valuable healthcare resources freed up for other uses.

While positive impacts cannot be understated, projects like Delaware CORE are vulnerable to a variety of long-term implementation problems. Stakeholders and policy-makers may fail to

recognize or may undervalue the emerging system changes. This may limit or completely block support for sustained services. Conversely, stakeholders may overestimate or inflate the project's effects as a flawless success or cure-all. Thus, without evidence that is accurate and carefully communicated to stakeholders, projects like Delaware CORE simply fade away.

These potential pitfalls can be addressed with close monitoring and impact (i.e., outcome-oriented) evaluation at each level. In terms of monitoring, evaluation efforts that track client demographics, outreach locations and participation, and flow through the system can identify disparities in implementation, help streamline intake and referral systems, and document strategies that possible warrant expansion. Outcome-oriented evaluation can operationalize success around those areas deemed most important to stakeholders and families.

The objectives and indicators of CORE evaluation were developed in partnership with several key stakeholders including Suicide Prevention Coalition, Mental Health Association of Delaware, National Alliance on Mental Illness, State of Delaware Health and Social Services Department, and multiple mental health centers and schools. The details are included here with the important note that the dynamic needs of the project may lead to minor changes as implementation progresses.

## **Procedures**

Consistent with its dual role as monitor and outcomes assessor, the Center for Training, Evaluation and Community Collaboration (C-TECC) is charged with measuring, analyzing, and reporting success in the following areas: 1) community awareness of prodrome and FEP presentation, 2) effectiveness of state-wide recruitment, 3) screening of referred individuals in a timely and efficient manner for entry into the program, 4) delivery of evidenced-based treatment (i.e., PIER Model) to those in need, 5) effectiveness of treatment delivery on youth mental health and functional outcomes, 6) representative race/ethnicity recruitment, enrollment, treatment outcomes, and identification of disparities, and 7) keys to sustainability and public health impact.

These overall evaluation aims are divided into four areas: Outreach, Assessment, Treatment, and

## **Public Health.**

### **Outreach**

The effectiveness of outreach will have a trickle-down effect on Delaware CORE's prevention efforts by impacting the climate of mental health discussion (i.e., level of stigma) and referral process. Outreach activities, such as the number of events held, number of attendees, demographics of attendees, and types of event venues are monitored on an ongoing basis. Basic descriptive statistics and frequency graphs provide valuable, immediate numerical and visual information that describe community audiences. Data serves as a feedback loop to the outreach team to recalibrate and optimize outreach efforts. For instance, indications that target audiences are not being reached or a certain demographic is over represented may change advertising and/or where events are held (see above in Implementation and lessons learned: Outreach).

### **Assessment**

Recruitment data, including who is referred, who qualifies, and which diagnoses/symptoms are represented, constitute an intermediate process that informs outreach and results of treatment.

The number and type of referrals provide direct feedback on outreach efforts; low numbers or inappropriate referrals may indicate ineffective communication. Referrals also are mapped across the state to determine accurate distribution according to population. Demographics will be examined for race and ethnicity patterns to help diminish the potential for disparate access to treatment. Identifying youth who are referred can also provide data on community needs (e.g., mean age, primary concerns, functional impairments) and can describe who CORE is serving.

Program eligibility is determined according to the results of the Structured Interview for Prodromal Syndromes (SIPS). Data from this instrument will not only discriminate who is eligible for the study (e.g., a prodromal symptoms versus FEP diagnosis), but also provide a measure of symptom severity. Descriptively, symptom and diagnostic data can inform at what stage in the disease model youth are being identified and seeking treatment. Treatment results may also depend on diagnosis or symptom severity, and thus be used to posit some groups as better responders to treatment.

## **Treatment**

Treatment evaluation is centered around impact (i.e., Are participating youth better at the end of the program?) Assessment for improvement will target: symptom reduction, social functioning, social support, occupational/academic functioning, and stigmatizing feelings about one's emotional health. Participants are assessed on these variables prior to entering treatment (i.e., baseline), every six-months during treatment, at discharge, and six-months post-discharge. Intent-to-treat analyses, which include all eligible participants irrespective of participants' program completion status, will serve as a conservative approach to testing program effectiveness. Linear Mixed Effects (LME) models change over time while accounting for biases in data due to clustering (e.g., data from the same person). LME will estimate change in data from baseline to end of treatment. Differences between data at end of treatment and six-months post-discharge will determine maintenance of (potential) improvements. Effect sizes will indicate how large of a change occurred. These results will be compared to similar studies evaluating PIER and large-scale prevention studies.

A number of factors will be explored that might impact treatment trajectories and outcome. As mentioned before, initial diagnostic status may affect response to treatment. Other areas of functioning may predict treatment response, such as estimated measure of executive functioning (i.e., measure of planning, inhibition, decision-making). Additionally, demographic factors, such as age and race/ethnicity, and treatment engagement, such as attendance and treatment completion, may also impact treatment response. Thus, all of these factors will be explored as covariates or potential moderators of treatment.

Another important measure of treatment success is treatment acceptability. Youth are asked to report on their perception of care while in treatment. Perception of care may relate to treatment outcomes, but also has importance independently. Poor treatment acceptability may help explain poor engagement, or impact the larger system acceptance.

## **Public Health**

Two types of data will explore Delaware CORE's impact on public health. On an individual level, session data will reveal the burden on providers, and illuminate the demand for psychiatric care. National estimates of burden of care can be compared statistically to estimated costs of

Delaware CORE. On a larger scale, data from local hospitals will be examined from years prior to Delaware CORE implementation and years during implementation for changes in hospital admittance for early onset psychosis. Analyses will aim to replicate findings from a similar study using the PIER model.<sup>6</sup>

## Summary

Delaware CORE has the potential to reduce personal and familial distress and improve social and occupational wellbeing for the more than three thousand youth and young adults in the state living with a psychotic disorder. The program is based on the Maine Medical Center's PIER model, which has been successfully replicated in a 6-site nationwide effectiveness study. Delaware CORE is entering its second year of implementation with 36 families enrolled and support groups in every county. Significant challenges remain. The program is still trying to gain a foothold in Wilmington's inner city, and a plan will eventually be needed to sustain parts of the program that are not covered by insurance. Future evaluations by the University of Delaware will report on the outreach effort, service utilization, treatment outcomes, and public benefits associated with the program (e.g., reduced hospitalizations).

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