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Assessment #7

Changing the Trajectory of a New Generation: Universal Access to Early Psychosis Intervention

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**Seventh in a Series of Ten Briefs Addressing: Bold Approaches for Better
Mental Health Outcomes across the Continuum of Care**

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Changing the Trajectory of a New Generation: Universal Access to Early Psychosis Intervention

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Executive Summary

A growing number of communities across the United States are fundamentally shifting the experiences of young people when psychosis first begins. Rather than a negative spiral of crisis, isolation, disability and social disenfranchisement, Early Psychosis Intervention (EPI) programs support young people and families to access effective care quickly and transition successfully to adult roles. The combination of scientific knowledge, dissemination support, young adult and family voice, and leadership at state, local and national levels has created an unprecedented opportunity for the next generation of youth. By aligning efforts and partnerships toward early identification, developmentally tailored evidence-based support for psychosis recovery, and integrating a Learning Health approach, Early Psychosis Intervention efforts are demonstrating that we can change the storyline of psychosis from one of life-long tragedy to one of hope, recovery, and community engagement.

Individuals with schizophrenia and other psychotic disorders make up a disproportionate share of involuntary hospitalizations, and the time of greatest risk and acuity is in the early stages of illness. Long delays in accessing care for psychosis remain the norm, and most communities lack evidence-based care for this population. While there is a broad societal belief that the teen and young adult years are the healthiest, this time period is also when most serious mental illnesses begin, when people are least likely to be insured, and when they are least likely to access care. The human and financial impact of schizophrenia has been tremendous, with teenagers and young adults dropping out of school, remaining unemployed, marginalized, on life-long disability, and disproportionately in jail, or dying early. Despite the best intentions of mental health professionals, systems often require severe acuity and involuntary entry or established disability to access care. Practitioners may not receive support to provide evidence-based recovery-oriented care. These barriers along with the inherent challenges of psychosis and the transition age perpetuate negative outcomes. Early psychosis intervention provides a transformative paradigm which changes the assumptions and works to provide early, rapid access to specialized, recovery-oriented care.

Since 2014, a critical mass of state and national investment and collaboration has led to rapid expansion of early psychosis programs in the U.S., growing from a small number to the creation of new programs in all states and territories. Early Psychosis Coordinated Specialty Care (CSC) refers to an intensive team-based intervention in the early stage of schizophrenia and other psychotic disorders. The CSC team is responsible for social marketing efforts to identify individuals with psychosis as quickly as possible, and rapid engagement into strengths-based, voluntary, comprehensive treatment. CSC teams emphasize shared decision making and provide specialized psychoeducation and counseling for the individual and family, careful prescribing, crisis response, supported employment and education and gradual transition into ongoing care.

Geographically disparate sites have successfully implemented CSC. State leaders play an important role in tackling the broader systemic issues faced by CSC teams, such as increasing community visibility, financing services, tracking outcomes, overcoming

barriers to access and proactive outreach, and increasing availability of longer-term evidence-based support for mental health, alignment of allied systems, and support for career and independent living. The goal of early identification leads to a stage-wise conceptualization of treatment which offers care when symptoms begin to occur rather than requiring the highest level of acuity or established disability. Recognition and treatment of early symptoms may prevent hospitalizations, suicidality, school and work drop-out, and other negative consequences.

Serious discussion and planning is occurring to envision an “end game” where early psychosis intervention is available to every person in the U.S. The December 2017 Interdepartmental Serious Mental Illness Coordinating Committee’s (ISMICC) recommendations further encouraged all federal departments to work toward a common set of goals of early identification, access, and evidence-based supports for individuals with psychosis and other serious mental illness. Achieving 100 percent access to early psychosis intervention will require strong infrastructure and leadership at the local, state, and national levels. The infrastructure must include social marketing, service fidelity, accurate clinical assessment, ongoing research, workforce development, training and technical assistance, and clinical resources. The ISMICC recommendations, ongoing investment, and the launching of a Learning Health Network by the National Institute of Mental Health promises to bring more rapid and successful adoption while also fueling scientific advancement, interface between science and clinical practice, and outcome-driven program development.

This paper discusses how we can achieve the bold goal of ensuring universal access to early psychosis intervention in every community.

Elias' Story Without Early Psychosis Intervention

Elias is a young man who has a strong network of parents, grandparents, aunts, and uncles, and a supportive religious community at his synagogue. He loves video gaming, fishing, and working on cars, and is a long distance runner. He has not decided what to do when he grows up. He has always been a decent student with passing grades, although he has struggled periodically with depression. His junior year in high school there is a noticeable change. He is no longer doing well in his favorite classes and he seems to have trouble with reading. He is beginning to hear voices other people do not hear, to see color with greater intensity, and to wonder whether, when other students cough, they might be talking about him. He tells his best friend he thinks he may be “going crazy” but his friend laughs it off. Over time, the voices become more intense and it becomes harder to ignore that others are trying to hurt him. He is certain he is being videotaped at home and in class. He drops out of school.

Elias tells his rabbi about his experience, and his rabbi tells his parents. The parents reach out to their insurance company, which refers them to a psychiatrist. They call the psychiatrist, whose next available time for an appointment is in three months. The psychiatrist explains that, because Elias is now 18, he has to make his own appointment and has to choose to come to the clinic. The family tries to convince Elias to go to an appointment, but he is becoming increasingly delusional and not making sense to others. Elias refuses to go and will no longer leave his room. The family calls the local crisis team and is told that when Elias becomes an imminent threat to himself or others they will be able to force him into care. The family continues to try to get help unsuccessfully, and argue frequently. One cold day, Elias leaves the house and ends up hypothermic in a lake. He is picked up by rescue crews and hospitalized on the psychiatric unit involuntarily. He is given a high dose of medication. While he begins to be able to distinguish reality, he remains confused and bothered by the side-effects of the medication. Once he has left the hospital, he refuses to participate in treatment, goes off his medicine—which has caused him to gain twenty pounds--and ends up being arrested for trespassing when he enters a neighbor's house while experiencing a psychotic incident. His parents and grandparents, overwhelmed and distraught, argue frequently over what to do. They turn to the synagogue and to their doctors for help, but no one seems to have answers.

Over the next few years, Elias remains unemployed and out of school. He has a series of legal and involuntary commitment encounters in which he becomes increasingly demoralized, traumatized, and adverse to treatment. His family eventually manages to get him on Supplemental Security Income (SSI) and enrolled with a mental health center. Everyone in the family is grief-stricken over Elias' situation but they are grateful he is alive. He enters a long and slow recovery process in which he is encouraged by peers and mental health professionals who believe in his ability in spite of the systemic obstacles they all face.

Introduction

Although the tremendous costs and severe consequences of schizophrenia are well-documented, delays in access to care (also referred to as duration of untreated psychosis), and treatment which does not reflect current evidence remain the norm in the United States. Starting in 2014, Congress expanded Mental Health Block Grant funding for Early Psychosis CSC programs nationwide, and the 2016 21st Century Cures Act continued that commitment.¹ Commitments by numerous state and national organizations including Congress, the National Institute of Mental Health, the Centers for Medicare and Medicaid (CMS), the Substance Abuse and Mental Health Services Administration through the Community Mental Health Services Block Grant, the National Association of State Mental Health Program Directors, The Robert Wood Johnson Foundation, NAMI, and Mental Health America, among others, has fueled a rapidly growing network of early psychosis intervention programs which attempt to identify individuals who are developing psychosis as quickly as possible, and provide them with evidenced-based treatment. In December 2017, the Interdepartmental Serious Mental Illness Coordinating Committee issued recommendations which explicitly included national dissemination of early psychosis screening and intervention.² The early psychosis intervention movement

¹ See

<https://www.psychiatry.org/File%20Library/Psychiatrists/Advocacy/Federal/Comprehensive-Mental-Health-Reform/APA-Summary-Mental-Health-Reform-Provisions-21st-Century-Cures-Act.pdf> for a summary.

² Focus 2 of the ISMICC Recommendations is entitled *Access and Engagement: Make it Easier to Get Good Care*. Recommendations under that Focus include:

Recommendation 2.6 Prioritize early identification and intervention for children, youth, and young adults.

Focus 3 of the ISMICC Recommendations is entitled *Treatment and Recovery: Close the Gap Between What Works and What is Offered*. Under that Focus,

Recommendation 3.2 Make screening and early intervention among children, youth, transition-age youth, and young adults a national expectation. Develop and implement interdepartmental guidelines for detecting and treating early signs of SED in children and youth, and of SMI in transition-age youth and young adults, in a wide range of settings, including primary care, day care, school- and college-based health clinics, public health clinics, juvenile justice facilities, jails, and emergency departments. In this work, pay special attention to vulnerable populations facing health disparities.

Recommendation 3.3. Make coordinated specialty care for first-episode psychosis available nationwide. Incentivize universal access to coordinated specialty care services in all federal health benefit programs, including Medicaid, Medicare, Department of Defense, the Veterans Administration, and TRICARE. Continue the SAMHSA block grant set-aside requirements and provide guidance to facilitate payment by all public and private insurance programs.

Recommendation 3.5 Implement effective systems of care for children, youth, and transition-age youth throughout the nation. This must include [s]upport [for] national implementation of the SAMHSA System of Care model.

promises to alter the long-term trajectory of young people who develop psychosis in a way that allows young people and their families to continue to live their normal lives and to contribute fully to society. This is in stark contrast to the devastation which has been far too common when appropriate care is not available or provided for individuals experiencing their first episode of psychosis.

Why Early Psychosis Intervention: The Impact of Schizophrenia and Psychosis

Schizophrenia is a neurodevelopmental condition characterized by hallucinations, delusions, thought disorder, and negative symptoms which interfere with the person's ability to engage in normal activities, interact with others, and distinguish what is real from what is not. While schizophrenia affects just under one percent of the population, its onset is common during teenage and young adult years, and the impact both individually and at a societal level has been extreme. Each year in the United States about 100,000 new individuals develop psychosis for the first time (McGrath, *et al.*, 2008; Heinssen *et al.*, 2014). The annual economic cost to the United States was approximately \$155.7 billion in 2013, including \$37.7 billion of direct health care costs, \$9.3 billion of direct non-health care costs, and \$117.3 billion of indirect costs, such as unemployment and the impact of caregiving on productivity (Cloutier *et al.*, 2016). The impact of schizophrenia has caused tremendous public expense, trauma, lifelong unemployment and disability, and early mortality (McGrath *et al.*, 2008). A recent study of commercially insured individuals documented that individuals between the ages of 16 and 30 with a first diagnosis of psychosis are more than eight times more likely to die than the general population within 12 months compared to the general population, and 2.7 times more likely than individuals diagnosed with depression. Deaths resulting from injury or poisoning are particularly high. (Simon *et al.*, 2018).

People who have not experienced psychosis often have difficulty comprehending the extent of disruption and upheaval the condition can cause. The following descriptions illustrate the personal impact of symptoms such as “delusions” and “hallucinations” which might otherwise remain abstract terms for those who have not experienced them:

- *I'd like to say actually that an episode of schizophrenia is like a waking nightmare where you have all the bizarre images, frightening things happening. That's what it feels like, the terror, the confusion, impossible bizarre happenings that don't happen in real life but seem to be happening — happening right now. Only with a nightmare you sit up in bed and open up your eyes and it goes away. And you can't just open your eyes and make a psychotic episode go away.³*

³ From Elyn Sachs, interview with Guy Raz, TED Radio Hour, retrieved from <https://www.npr.org/templates/transcript/transcript.php?storyId=171270996>, 5/2818.

- *We watched helpless as our boy ran around saying he could flip cars over with his mind and fight off aliens coming to get us. We also had to keep redirecting him away from the knives in the kitchen because he wanted to cut out an evil third eye he insisted he had. No amount of reasoning changed the situation. When I finally called the local free psychiatric clinic listed in the phone book, the person on the other end of the phone said we could bring him in for a free evaluation, if he would come willingly. Then he said the famous words repeated to us many times in the coming years, "If he becomes a danger to himself or others, call 911." What a ludicrous statement, I remember thinking at the time; I am not going to call the police on my sweet son. However, a few hours later, that is exactly what I was doing. (Purdy, 2017).*

The onset of schizophrenia is frequently gradual, with “attenuated” or “brief, intermittent” symptoms such as hallucinations or early delusional thought processes which are disturbing but have not yet overcome the individual’s ability to navigate the outside world. At the earliest, or “prodromal” stage of psychosis, cognitive changes in domains such as working memory and information-processing speed commonly affect the person’s ability to do school work or engage in other normal activities. Growing understanding of the onset process has led to the development of structured assessments such as the Structured Interview for Psychosis-Risk Syndrome (SIPS), which can detect some of these early changes before the most acute level of illness occurs (McGlashan, T., Walsh, B., & Woods, S., 2010). As a result of the growing understanding of the early patterns of schizophrenia onset and a growing awareness of the importance of early intervention in serious mental illness, an increasing number of communities are integrating interventions for individuals at “Clinical High Risk” for psychosis.

The following account provides an example of a psychotic prodrome:

- *I had my first severe psychotic episode in early 2010. Two years prior to this my thoughts had began slowing down. Normally, thinking about doing an action and then moving the required body part happened simultaneously. Now there was a gap. I was a radiotherapy student and since operating X-ray machinery requires a smooth flow of decision making and intricate movement. These slow thoughts made me a hazard. Once I gave up my degree, I had nowhere to go during the day and would lie in bed. My general practitioner thought I was depressed and gave me antidepressants. We know now that I wasn’t, and I had prodromal psychosis. Eventually the slow thoughts took over my mind and I began hearing voices that were frightening. (Allen, 2017).*

The first Schizophrenia Patient Outcome Research Team studies documented that less than half of individuals with schizophrenia receive evidence-based care, particularly if they are members of minority groups (Lehman & Steinwachs, 1998). Subsequent reports laid out the evidence for multi-component treatment similar to CSC. (Buchanan *et al.*, 2010, Kreyenbuhl *et al.*, 2010). Many international studies, and most recently the Recovery After an Initial Schizophrenia Episode Early Treatment Program (RAISE-ETP) study, have documented the impact of reducing Duration of Untreated Psychosis (DUP)

on outcomes. The median DUP for RAISE ETP was 74 weeks, and virtually all of the difference between the treatment protocol in RAISE ETP and “treatment as usual” was attributable to those who had shorter durations of untreated illness (Addington, J., *et al.*, 2015). A meta-analysis of randomized studies comparing early psychosis intervention to treatment as usual found consistently better outcomes throughout the duration of treatment for all domains analyzed, including treatment discontinuity, hospitalizations, school and work involvement, and positive and negative symptom severity. (Correll, C., *et al.*, 2018).

Along with the importance of changing the long-term course of schizophrenia, early psychosis programs are able to make inroads into a broader social problem: the lack of access and utilization of health care by adolescents and young adults. Three-fourths of people who experience mental illness experience symptom onset by age 24 (O’Connell, Boat & Warner, 2009) and individuals ages 14 to 24 have been the least likely to access mental health services (Copeland, Shanahan, Davis, Angold & Costello, 2015). In addition, young adults have been much more likely than other individuals at other ages to go uninsured (Sommers *et al.*, 2013).

The Patient Protection and Affordable Care Act included a response to the lack of insurance among young adults by making private insurance available under parental coverage up to age 26, and by extending Medicaid coverage based on income rather than disability (Monaghan, 2014). But even with private insurance, coverage remains an issue as most early psychosis programs currently receive little or no coverage from private insurers. The reasons for this include panel restrictions, clinician licensing requirements, and a lack of alternative payment methods to fund team-based care. In addition, many mental health centers and practitioners do not accept private insurance. Medicaid financing systems may also require or encourage individuals to leave their private coverage in order to access care.

Even when youth and young adults do make it in for medical visits, they routinely encounter medical providers who do not screen for psychosis. When psychosis is identified, there is a lack of a coordinated continuum of care for this age group, which falls between coverage under child and adult services and systems (Davis & Koroloff, 2006). Instead, many young people initially access care through costly and traumatizing hospitalization and criminal justice systems (Institute of Medicine & National Research Council, 2015). In addition to entering and remaining on disability for an entire adult lifetime, studies show that people diagnosed with schizophrenia are dying significantly earlier and often of preventable causes, with a median reduction of life expectancy of 20 years across all age groups (Laursen, Nordentoft, Mortensen, 2014).

Early Intervention Goals

A growing body of international research has demonstrated that intervention in the earliest stage of psychosis can significantly alter short and medium-term outcomes, and longer-term outcomes to a lesser degree (Correll, C., *et al.*, 2018). Early psychosis

intervention does not substitute for effective longer-term care. Early psychosis intervention attempts to build on the large and growing body of. At the systemic level, early psychosis intervention has two primary goals:

- Providing organizations and teams of practitioners with the clinical knowledge, tools and support to respond effectively based on current science, local environment, and individual need.
- Reducing duration of untreated psychosis by facilitating systemic and community identification of psychosis and reducing barriers to care.

Once an infrastructure is established, local teams work closely with decision makers and the community to:

- Identify individuals in the community who are developing a psychotic illness as quickly as possible and proactively engage them in effective, voluntary, recovery-oriented treatment.
- Provide accurate and thorough assessment to ensure appropriate care.
- Collaborate with individuals and families to participate in shared decision-making and empower them to make informed decisions about ongoing care.
- Help the person and family develop knowledge, skills, and relationships which will help them to cope and continue moving forward.
- Reduce the negative impacts of distressing symptoms and side-effects through careful prescribing and other evidence-based treatment strategies.
- Effectively address co-morbid conditions such as mood disorders and substance abuse.
- Support developmental progression in spite of persistent symptoms, including: achievement of key milestones in school, work, and career; fostering a positive sense of identity; and learning adult skills such as decision-making and independent living.
- Provide continuity of care and transitions based on person-centered plans into effective long-term care and support.

Early psychosis intervention teams play a significant role in assessing complex clinical conditions and linking a variety of individuals to appropriate care. A growing number of programs have linked their early psychosis programs to a broader service array for transition-age youth and young adults. It is important to understand that where a broader spectrum of illness is targeted, the focus on proactive engagement and targeted treatment for schizophrenia must be maintained in order to not lose the original and primary purpose of early psychosis intervention. As early psychosis intervention teams include individuals diagnosed with mood disorders or identified as Clinical High Risk for Psychosis through the SIPS in their targeted patient populations, team capacity and treatment practices must be adjusted to address the higher level of incidence and differences in treatment needs.

Coordinated Specialty Care in a Clinical Staging Model

The RAISE studies funded by the National Institute of Mental Health (NIMH) in 2010 to 2014 led to the Coordinated Specialty Care (CSC) concept, which combines widely recognized elements of evidence-based care for psychosis. CSC is provided through intensive local teams which incorporate services for individuals under and over age 18 on a single team. Teams include specialists in psychiatry, mental health therapy and case management, and supported employment and education. Many teams have also integrated peer support, nursing, and occupational therapy. Teams incorporate evidence-based and person-centered shared decision-making, resilience-focused care, substance use disorder treatment, family support and psychoeducation, the prescribing of low-dose medication protocols, and careful medication side-effect monitoring. (Heinssen *et al.*, 2014; Dixon *et al.*, 2018). Table 1 describes the desired outcomes and core elements of CSC.

Table 1. Elements of Coordinated Specialty Care and Desired Outcomes

Outcome	Core Element
Reducing Duration of Untreated Psychosis	Social marketing to encourage identification and help-seeking Integration of early psychosis screening and modification of system workflows Proactive, flexible outreach and elimination of barriers to access Rapid family support and engagement Linkages between early psychosis teams and adult and child crisis systems
Establish and maintain treatment engagement	Persistent outreach Strengths assessment Shared decision-making Strengths-based person-centered treatment planning Peer Support Feedback-informed treatment approaches Family/support system engagement
Accurate diagnosis	Physical assessments Careful attention to differential diagnosis Integration of cultural frameworks and interpretations
Physical safety and well-being	Rapid response Careful risk-assessment including suicidality, symptomology, and environmental concerns Crisis-planning, and linkage to 24-hour crisis services Acute care alternatives Case management to address basic needs Family psychoeducation Relapse prevention-planning
Symptom and side effect relief	Low-dose prescribing and tapering strategies with careful side-effect protocols (reduction where higher doses or medications with metabolic effects are present; gradual increase to minimize side-effects) Alternative therapies including CBTp, mindfulness Individual strategies Learning from peer support Individual and family psychoeducation
Maintain social network and family support; reduce family stress and burden	Integration of families into assessment and treatment-planning Structured family psychoeducation and problem-solving
Maintain school and work progression	Inclusion of supported employment and education specialist(s) on team School and work support following Individual Placement and Support principles modified for developmental appropriateness Support for accommodations Attention to cognitive and sensory issues

Outcome	Core Element
Teaching coping and symptom reduction strategies	Peer Support Attention to and mitigation of trauma Use of healthy lifestyle strategies (daily routine, sleep/wakefulness, social network and goal-directed behaviors, nutrition, substance use reduction), CBTp, mindfulness, emotional regulation, relapse prevention, sensory and cognitive accommodations, Building of a locus of control/identity through strengths and resilience-oriented strategies, shared decision-making
Reducing or preventing substance abuse	Psychoeducation Motivational interviewing using harm-reduction framework Integration of dual diagnosis capacity and inclusion of substance abuse expertise on team Linkage to more intensive levels of care
Reducing metabolic disorder and other health risks	Monitoring of basic health indicators Primary care integration and coordination Encouragement of exercise, nutrition Integration of emerging evidence around non-invasive strategies
Establishment of longer-term supports	Development of comprehensive transition plans Gradual transitions with planned continuity Development of larger infrastructure/ support network for long-term recovery and relapse prevention

The range of services performed by the team, along with the complexity and needs level of individuals with early psychosis, means that an intensive level of care is required that is similar to the standard of Assertive Community Treatment. Psychosis creates significant risk for hospitalization, legal involvement, trauma, and loss of life or injury, and must be treated as an acute condition. Enhanced fee-for-service rates, case rates, bundled service packages, or targeted subsidies are required for these programs to be successful.

In order to prevent severe psychosis and its rapid consequences, CSC teams intentionally seek out individuals in the early stages of illness. Individuals at “Clinical High Risk” for psychosis generally are in distress or having significant consequences already from lower-level symptoms and cognitive changes, and are in need of treatment. Many places, including Australia, Canada, and some states within the U.S. have moved toward a System of Care approach which intentionally works to identify and provide appropriate supports to individuals who may be experiencing such “prodromal” symptoms. Diagnostic uncertainty is common, and service delivery is focused on co-morbid conditions and potential suicidality, support for functioning and social network, and remediation of specific symptoms.

Australian psychiatrist Patrick McGorry has introduced a Clinical Staging model in which recommended treatments vary by the stage of illness. (McGorry *et al.*, 2007). Research has led to several international guidelines recommending the use of Cognitive Behavioral Therapy (CBT), family psychoeducation, and support for functioning for

those at Clinical High Risk of Psychosis, as assessed by a skilled and trained assessor. Low-dose antipsychotic medicine is used only for significant and worsening symptoms. (Addington *et al.*, 2017). Within the United States, a growing number of programs are combining first episode intervention programs with interventions for those at Clinical High Risk for Psychosis. (Sale *et al.*, 2018).

A Vision of Universal Access

The RE-AIM framework provides a way of conceptualizing, as well as monitoring and evaluating the effectiveness of early psychosis dissemination.⁴ Table 2 uses the RE-AIM framework to identify important elements which need to be in place to achieve universal access.

Table 2: Elements Required for Universal Access:

Area	Core Question	Important Elements
Reach	How to reach the target population with the intervention?	Clear diagnostic targets Use of incidence projections in planning and evaluation Effective social marketing methods Adequate social marketing capacity and effort Rural access; telemedicine
Efficacy	Which interventions are most effective	Inclusion of Coordinated Specialty Care components and core practices Ongoing evaluation of evidence base System informed by outcomes and feedback
Adoption	How to develop organizational support to deliver the intervention?	Placement in organizations and departments with well-aligned mission and leadership Alignment to existing priorities (Triple Aim, legal mandates around least restrictive environment, parity/coverage requirement, political priorities) Engagement of current and potential champions in decision-making Integration of constituent voice/lived experience
Implementation	How to ensure the intervention is delivered properly?	Address workforce shortages Establish competence through ongoing workforce development, clinical staff training, and consultation Establish oversight and training infrastructure to address turnover and ensure consistency/service improvement

⁴ More information and planning tools related to RE-AIM can be found at <http://www.re-aim.org/>.

Area	Core Question	Important Elements
		Integration of iterative fidelity review processes and feedback Identification of minimum standards (i.e. intensity, access, etc.)
Maintenance	How is the intervention incorporated so that it is delivered over the long-term?	Work toward parity/coverage across funders Align efforts across systems (child/adult, acute care, school/workforce, independent living supports) Develop diversified funding Establish ongoing Learning Health System

As we approach universal access to early psychosis intervention and thousands of young people graduate from early psychosis intervention programs throughout the country, not only is a significant shift in measurable outcomes from treatment likely to be felt, but a profound shift in culture, community engagement with young adult early psychosis intervention program graduates, and long-term expectations is likely to occur as well. In Oregon, where early psychosis programs have been in place since 2001, there has been a shift in the legislative conversation. Before Oregon’s Early Assessment and Support Alliance (EASA) first began its work, stories of great tragedy were common, including being stranded in crisis without help, or traumatizing and repeated involuntary care. EASA graduates frequently want to mentor others and advocate. Whereas prior to early psychosis intervention, negative horror stories regularly propelled advocates to speak out, advocacy by individuals who have been part of early psychosis intervention programs tends to focus on a desire for others to access care sooner and for services to last longer. It is common for individuals who entered a mental health center years ago to state that they wish such services had been available to them. Early psychosis graduates have already entered research, medicine, occupational therapy, social work, peer support, and law, along with many other fields. They carry with them a grounded understanding of what it means to have access to care and the impact of that access.

It is helpful to envision how things would look different as a result of establishing access to early psychosis intervention. Table 3 attempts to provide a picture of that future.

Table 4: Universal Access to Early Psychosis: What It Looks Like and Its Likely Impact

What Universal Access Looks Like	Impact of Universal Access
<p>REACH:</p> <p>CSC teams are available in all communities with adequate capacity to serve the population</p> <p>Individuals with private insurance, public insurance, and no insurance are accepted without barriers to care</p> <p>Universal insurance coverage for CSC for individuals who have experienced psychosis using alternative payment methods</p> <p>Teams are available to support family members and referents without requiring the person to request care or come to the clinic</p> <p>Telemedicine and tailored strategies are available for rural/frontier areas</p> <p>Adaptations are made as appropriate for culture</p> <p>Widespread, proactive, and effective social marketing is occurring at national, state and local levels</p> <p>Screening and appropriate care is available for individuals with early changes, consistent with psychotic illness; acuity and loss of insight are not required to access care.</p>	<p>Significant reduction of delays into care</p> <p>Everyone able to access care and support when it is needed</p> <p>Problem-solving and proactive outreach available for families and referents versus passive/reactive care</p> <p>People know when and how to get help</p> <p>Less trauma</p> <p>Fewer deaths, hospitalizations, and arrests</p> <p>Individuals more likely to stay in school and work</p>

What Universal Access Looks Like	Impact of Universal Access
<p>EFFECTIVENESS:</p> <p>Early psychosis services closely aligned to evidence from research and feedback</p> <p>Shared decision-making and Peer Support are universal elements of care</p> <p>Dual diagnosis treatment is included within the team</p> <p>Long-term supports consistent with early psychosis team practices</p> <p>Outcomes are reported and integrated into Quality Improvement</p> <p>Learning Health process results in more rapid and complete transfer of knowledge, improved treatment targeting</p>	<p>Better long-term outcomes at system and individual levels</p> <p>Better engagement and accountability</p> <p>Less use of substances</p> <p>Ongoing process of improvement and learning</p>
<p>ADOPTION:</p> <p>Young adult and family leadership and feedback processes guide program development and improvement</p> <p>Senior level support at local, state and national levels within mental health and allied systems</p>	<p>System development and new research directed by both scientific evidence and lived experience perspectives, ensuring relevance</p> <p>Much faster and more complete implementation of changes; more rapid modifications where needed</p>

What Universal Access Looks Like	Impact of Universal Access
<p>IMPLEMENTATION:</p> <p>Clinical teams are supported to develop competence in diagnostic assessment and core evidence-based interventions</p> <p>Culturally tailored interventions address family, school/work, independent living, health</p> <p>Manualized approaches available and supported for all elements of care</p> <p>Ongoing use and refinement of fidelity measures to ensure consistent high quality implementation</p>	<p>Increased overall accuracy of diagnosis</p> <p>Individuals staying on career path, becoming independent, able to participate in long-term program development</p> <p>Family and social network support retained over time</p> <p>People living longer, healthier lives</p> <p>Increased sense of ownership and reduced trauma, negative consequences and perceived coercion</p> <p>Ongoing feedback loops for evaluating quality and identifying needs for training or program development</p>
<p>MAINTENANCE:</p> <p>Ongoing infrastructure ensures training for new staff, ongoing quality-improvement and problem-solving</p> <p>Transitions out of early psychosis intervention programs (including moving across communities) are carefully planned and facilitated with follow-up.</p> <p>Practices within acute and residential supports, school, work, and other allied systems aligned with CSC in System of Care approach (person-centered, trauma-informed, family involvement, careful use of medicine/ side-effects)</p> <p>Comprehensive system of care has consistent philosophy and approach and addresses ongoing comprehensive needs</p>	<p>Expectation of continuity in core elements of CSC, as needed</p> <p>Long-term supports and outcomes monitored and tracked while preserving rapid access for new individuals</p> <p>Easy access to transitions across communities</p>

Getting There: Aligning Efforts Around Learning Health Care

Since 2014, the federal government has prioritized development of early psychosis intervention through a variety of strategies, including funding through the federal mental health block grant and NIMH funds, and coordinated efforts as reflected in the recommendations of the Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC). A national coalition created the Prodrome and Early Psychosis Program Network (PEPPNET)⁵, which brings together organizations and well-established early psychosis programs from throughout the country to foster the momentum of the field. A national process of data harmonization is underway, with the underlying goal of creating a Learning Health Network similar to what has been pursued in cancer and heart disease.

A Learning Health Network occurs when “science, informatics, incentives, and culture are aligned for continuous improvement and innovation...and new knowledge is captured as an integral by-product of the care experience”

Roundtable on Value and Science-Driven Health Care, Institute of Medicine. National Academies Press (US); 2013 (from Vinod Srihari)

Disseminating early psychosis intervention teams to every community in the country is a bold but achievable goal. Beyond this goal, the establishment of a national Learning Health Network approach will allow these programs to integrate the most effective approaches and build regional infrastructures around implementation and service improvement. Groundwork for this network has already begun, with an initial set of core measures identified through the PhenX toolkit⁶, data harmonization efforts beginning on a national level, and an impending NIMH initiative to create a regional Early Intervention Psychosis Network (EPINET)⁷ for sharing data and knowledge across universities, local community programs, and policy forums. EPINET builds on the Institute of Medicine’s framework for Learning Health Care. (Institute of Medicine, 2013). A Learning Health Care System brings together scientists, clinicians and policy makers in a network which shares data, expertise to intentionally address four domains:

- *Science.* Early psychosis intervention has well-established science behind it and is also a rapidly evolving field. Policy-makers and local teams need access to the most current research and training and support to integrate knowledge over time. By pooling data and resources, early psychosis programs can increase

⁵More information about PEPPNET is available at <https://med.stanford.edu/peppnet.html>.

⁶ This process was funded in 2016 by the National Institute of Mental Health. For measures, go to <https://www.phenxtoolkit.org/index.php?pageLink=browse.nimh.epsc>

⁷ See <https://www.nimh.nih.gov/funding/grant-writing-and-application-process/concept-clearances/2015/early-psychosis-intervention-network-epinet-a-learning-healthcare-system-for-early-serious-mental-illness.shtml> for NIMH EPINET Learning Health Care concept.

accountability, identify common areas needing improvement, and more rapidly identify, study, and spread effective innovations.

- *Informatics.* Collection and reporting of real-time intervention demographic, diagnostic, biological, outcome, and fidelity data is a key element of understanding the impact and focusing improvement efforts.
- *Incentives.* Financing and regulatory systems have historically encouraged individuals with psychosis to leave private insurance markets and enter the permanent Social Security Disability system, where they have often stayed for life while remaining unemployed. Creating alternate pathways which support individuals with psychotic illness to obtain evidence-based care while maintaining a normal trajectory of school and employment will require changes to financial incentives for insurance markets, mental health centers, workforce programs, and educational institutions. Data is an important tool in creating this re-alignment.
- *Culture.* Negative assumptions about psychosis outcomes have permeated treatment cultures and broader social contexts, and a significant cultural divide has persisted between research and practice. These negative messages have a significant impact on the identity development of young adults who are finding their way into recovery from psychosis, and they perpetuate discrimination and negative societal expectations. A culture of recovery, learning, and feedback promises to generate a self-perpetuating positive cycle.

Elias' Story With Early Psychosis Intervention

Elias is a high school junior with a supportive family, religious community, and active interests. When he begins having trouble reading, hearing voices, and makes a statement about “going crazy” to his friends, his support network is ready to respond. His high school counselor, rabbi and parents have all been introduced to the early signs and symptoms of psychosis. The parents call their local early psychosis intervention team lead Porsche, who talks to the parents and coaches them about how to respond. Porsche comes to the home, gets to know Elias a little, has him complete a Brief Version Prodromal Questionnaire (PQ-B), and talks to him and his family about the changes they’re experiencing and how those changes are affecting them. She encourages a thorough medical evaluation, and completes a Structured Interview for Prodromal Syndromes (SIPS) assessment tool with Elias. Elias scores as having attenuated psychotic symptoms. Porsche explains that in the developing brain when a person experiences stress there are a variety of things that can happen, and that his experiences are common. She suggests a combination of individual and family psychoeducation, CBT to address the attenuated psychosis, and lifestyle strategies focused on sleep, stress management and maintaining involvement with activities such as fishing and running. She does some additional testing and discovers that he is having difficulty with working memory and is being overwhelmed at a sensory level. This information is shared with the school, which provides additional accommodations under § 504 of the federal Rehabilitation Act of 1973 to allow him to sit in a different place in the classroom, take more frequent breaks,

and spend longer on tests. The early psychosis team does a strengths assessment, and integrates these strengths into treatment.

A year after meeting the early psychosis intervention team, Elias' girlfriend breaks up with him and his auditory hallucinations become more severe and intrusive. He and his parents know what to do. They implement their wellness plan, which includes strategies he has learned, and additional counseling. He decides to try a low dose of antipsychotic, and then tapers off again within the year. Over time, Elias is able to continue in school, becomes an electrician, gets married, and buys his own house. During this time, his family is educated about his condition, he maintains a relapse prevention plan and relationships with mental health professionals, and he volunteers as an advocate for others with similar experiences. He is hospitalized a couple of times over his life when things get worse, but he remains in control of his life with the help of his family and mental health team.

Conclusion

The U.S. is experiencing unprecedented leadership, investment and momentum in early psychosis intervention. State Mental Health Directors have a unique opportunity to capitalize on this momentum to change the long-term trajectory of individuals with schizophrenia and other serious mental illness. Local teams are laying the groundwork, but will need strong state-level participation to ensure that the financing and regulatory environment support a population-based, systemic approach. A Learning Health Network which builds on data, research, and the voice of young adults and family members will be key to achieving 100 percent access to effective early psychosis intervention in the United States.