

**Early Detection & Intervention for the Prevention of Psychosis Program (EDIPPP)  
Talking Points & Responses to Challenging Questions  
June 10, 2009**

**Overview:**

This Talking Points Guide addresses common questions about EDIPPP, and presents a framework for answers we can offer in response. Talking Points are useful in a variety of settings: From preparing for meetings with key audiences, to media interviews, to internal communications needs.

This is a guide only. Talking Points don't cover all the questions or concerns that you may encounter. Nor are they a comprehensive overview of EDIPPP – they represent a starting point for dialogue:

When working with these Talking Points, it is important to ask yourself the following questions:

- **Who** am I communicating with (e.g., policy makers, mental health practitioners, the media, etc.)?
- **What** information is most valued by this audience (e.g., practitioners may be concerned that “intervention” equals medication)?
- **Where** is the conversation taking place (e.g., is it a one-on-one conversation, or a presentation)?
- **When** are you communicating (e.g., is it a response, or a proactive outreach effort)?
- **Why** are you communicating now (e.g., what action do you want as a result of this interaction)?

It is important to localize and personalize these Talking Points. Use the experiences from your site to make your EDIPPP communications effort more personal. For instance:

- Have you received support from local community leaders? Make sure to highlight that fact.
- Does your site have a compelling story that illustrates the need for this service? Make sure that all who can benefit from knowing this story are aware of it.

Ultimately, Talking Points are best used as a resource when communicating about topics such as:

- The need for improved early detection and intervention services in meeting the health needs of adolescents and young adults.
- Key points about building the evidence to direct new thinking and approaches to mental health treatment.

- The broad community benefits that accrue from better, evidence-led early detection and intervention mental health services.
- Why the audience you are communicating with should get behind this program, and advocate on behalf of it.
- The diverse set of mental health needs presented by adolescents and young adults.
- The shortage of adequate early detection and intervention based care that currently exists.
- The need for this new approach, especially in contrast with the chronic lack of focus on, or advocacy for, serious mental illness amongst adolescents to date is great.
- The wide disconnect in attitudes towards mental health treatment, versus those towards physical health where prevention and early detection are well accepted.

## Talking Points:

### **1) *What is the Early Detection & Intervention for the Prevention of Psychosis Program? Why was EDIPPP established?***

- EDIPPP is a research and treatment program focused on gathering the evidence needed to better meet the mental health needs of adolescents and young adults at risk for severe mental illness, before the full expression of that illness.
- EDIPPP recognizes that severe mental illness is a significant problem for many adolescents and seeks to develop effective diagnostic tools and interventions earlier in the life of our youth to minimize its negative impacts.
- Ultimately, EDIPPP was established to reduce the diagnosis of adolescents with severe mental illness - the goal is actually to avoid such a diagnosis altogether.
- Our work is focused on the early emergence of symptoms that indicate the likelihood of future mental illness without intervention. We then work with patients and families to develop interventions that can allow them to achieve their full potential without the trauma, stigma and negative effects of a fully developed illness.
- Every phase of work that EDIPPP programs undertake will inform the activities and approaches employed in subsequent phases, ensuring that the program is constantly improving its efficacy.

### **2) *What approach to care delivery is being promoted by EDIPPP, and practiced by each EDIPPP participating site?***

- In order to collect as much strong evidence as possible, a number of different approaches are being employed by project participants. They all share the ability to be measured and reviewed stringently.
- The program recognizes that no single organization has all the tools and resources needed to help these young adults and their families. EDIPPP develops partnerships with key community groups - schools, community agencies, faith-based groups, families, and others – that can contribute to developing effective, sustainable solutions.
- Treatment tools regularly employed by EDIPPP grantees include family support efforts, and assistance in the areas of education and employment.
- Medication can also be used, in line with clear guidelines and assessment criteria.
- Each site knows that the process of evidence collection, interpretation, application and revision is an ongoing one that will continue as long as there is new evidence to be secured. This model bodes well for the long term success of EDIPPP, given that it implies a process of continual improvement – with the attendant benefits to our society that implies.

- Each site has undergone rigorous review, received approval, and is routinely monitored by its Institutional review board (IRB). The purpose of the IRB is to oversee all research projects to assure that it is ethical, high quality, and protects the rights of participants.
- EDIPPP launched [www.changemymind.org](http://www.changemymind.org) to link mental health professionals and other professionals who interact directly with youth to new research that supports a cutting edge approach that will change the way severe mental illness is addressed—opening the door to evidence that severe mental illness can be stopped in its tracks.

### **3) Can mental health professionals in other communities replicate the EDIPPP approach?**

- As a research and treatment program, EDIPPP sites follow the Portland Identification and Early Referral (PIER) model, which was developed in 2001 in Portland, Maine by Dr. William McFarlane and his multidisciplinary team.
- To increase the likelihood of success, this prescriptive approach integrates outreach education to community stakeholders, family psychoeducation, supported employment, supported education, and medication management if medication is indicated. Specialized training and technical assistance is required to implement the EDIPPP approach.
- Currently, the EDIPPP National Program Office conducts Multifamily Group training for local mental health professionals as one of the key components of the EDIPPP approach.
- Additional training on the EDIPPP approach, including the technical assistance to appropriately implement the model, is in development and will be finalized as the research is completed. The National Program Office can provide any interested professionals additional information on training.

### **4) Why is it important to support the work of EDIPPP?**

- EDIPPP directly benefits society in two broad ways: Supporting the individual so they have more opportunity to achieve their potential and become contributing members of society, and supporting the community so evidence-based services are more available and more effective.
- Locally, communities benefit because youth who participate in early detection and intervention programs are given additional tools to assist them in achieving their potential.
- These adolescents and young adults are empowered to grow up and achieve better employment opportunities for themselves, unencumbered by the deleterious effect of a severe mental illness.
- In addition, communities benefit from any program that works to reduce the stigma attached to issues of mental health, and that encourages more positive interactions with local services.

- For the mental health environment overall, the work of EDIPPP can continue to provide guidance into the best methods of early detection, and the most appropriate, evidence-based approaches to intervention.

**5) *What kinds of severe mental health needs are adolescents and young adults suffering from?***

- Today's youth experience a full range of economic, social, emotional and other pressures, which along with biological factors, can trigger psychosis. However, our resources to detect the emergence of severe mental illness and respond appropriately are not only stagnant, in the current economic environment, they are shrinking.
- In addition, there are a number of biological factors that can lead to the exhibition of symptoms that can lead to severe mental illnesses. Many of these biological factors can go undetected, or can be ascribed to other causes. For this reason alone, research projects such as EDIPPP are important investments in the future of our young adults.
- The major illnesses in which psychosis occurs include Schizophrenia, Bipolar Disorder, Major Depression, and Post-traumatic Stress Disorder, as well as psychosis brought about by substance abuse.
- The National Institute of Mental Health estimates that approximately 2 to 3 percent of youth and young adults develop schizophrenia or a severe psychotic mood disorder, with most cases developing after age 12. An estimated 12 to 15 percent of people who suffer from psychosis commit suicide.

**6) *What are the long term impacts of failing to properly detect and intervene in the development of mental illness for these youth, and for the communities in which they live?***

- For the adolescents, impacts include lower academic achievement, the emergence or escalation of severe behavioral problems – including substance abuse issues, a heightened possibility of mental illness progression, an increased risk of dropping out, and increasing exclusion from the broader community.
- Long term, these young people can face a range of challenges related to the emergence of severe mental health issues – from an ongoing need for care and hospitalization, to reduced job opportunities, to the serious disruption of their families and social environment.
- Many adolescents that develop a serious mental illness end up trapped in a cycle that detracts from their ability to attain a good quality of life, denies them the tools to adequately cope with their condition and places additional burdens on the community to provide what care it can.
- For our communities, the ramifications are serious: an increased burden on the existing health system, the maintenance or growth of a population that is dependant upon our social systems for their survival, a perpetuation of unfair stigmas and labels, and an overall decline in the quality of our communities.

## **7) Who supports/participates in EDIPPP?**

- Launched and funded by the Robert Wood Johnson Foundation, EDIPPP builds on the success of a previous program, the Portland Identification and Early Referral (PIER) program at the Maine Medical Center. This pilot program proved that it is not only possible to identify and treat psychosis early in its development, it is also possible to diagnose youth at risk of psychosis.
- EDIPPP supporters include the National Institute on Mental Health. Thomas Insel, M.D., Director of the National Institute on Mental Health, after a visit to the PIER Program noted that the research is following a “very interesting path to see if we can have a bigger impact on the disease by identifying and treating people much earlier.”
- EDIPPP program sites are in Albuquerque, NM; Davis, CA; Glen Oaks, NY; Portland, ME; Salem, OR; Ypsilanti, MI
- Each site is also a supporter of the program’s goals and approach.

## **Challenging Questions**

EDIPPP can face the same challenges to its efficacy, its purpose and its independence that the mental health profession in general faces. This is not to diminish the power of these challenges, but to illustrate that it is not our role – nor in all likelihood is it a possible goal to achieve – to eliminate all challenges to the development of mental health services.

All we can do is rely on our own experiences and expertise to project the truth about our endeavors.

These challenges include questions such as:

### **1. *Isn't EDIPPP just another excuse to promote the use of medications?***

- EDIPPP is a robust, evidence-led research project. Its goal is to design the best possible early diagnostic and intervention tools. Treatment recommendations are individualized and may or may not include the use of medication.
- The intervention tools regularly employed by EDIPPP grantees include family support efforts, and guidance in the areas of education and workplace training.
- Individuals can receive direct training and support for both their academic and employment needs.
- The broad range of treatment and support options brought to bear, including the use of medication where appropriate can have a powerful impact on the individual's ability to function as part of their community.
- The use of medication is based on well established criteria, and its introduction is dependent on an array of accurate and widely accepted best practices.
- EDIPPP, and its project partners, seek to treat individuals at the very earliest signs of illness. Thus, even when medications are called for, we can often use much lower doses of medications to target specific symptoms and achieve positive outcomes.
- In addition, we monitor medication use and side effects in our all patients very carefully, and adjust our intervention therapies accordingly.

### **2. *Doesn't labeling adolescents as "at risk" or, or "suffering from" severe mental illness become a self-fulfilling prophecy?***

- All mental health professionals are very aware of how sensitive and emotionally fragile young people can be. For that reason, EDIPPP grantees do everything they can to support patients and their families, and maintain their morale.

- At the same time, studies have identified those symptoms that are strong indicators for a major mental illness. We use these indicators to develop treatments that can avoid a diagnosis of mental illness for the adolescents we work with.
- EDIPPP helps adolescents and their families who receive services recognize that early intervention can mean relief from the impacts of symptoms that, up to that point, they didn't understand.
- Individuals being treated are told immediately if they are showing early symptoms indicative of severe mental illness. They are also told that if the full illness can be prevented from developing, it will help them stay in school, maintain relationships, and plan for the future – all of which represent a very positive long-term outlook.
- The goal of this program is to avoid a diagnosis altogether. Our efforts are designed to identify and help young people at risk for psychotic illness, not give them a diagnosis of one.

**3. *How do you help families deal with the stigma of mental illness?***

- The individuals and families who receive care through the EDIPPP initiative are faced with a very tough choice: to go against often entrenched stigma-based attitudes that they themselves may share and work towards a change in thinking; or to continue in silence while early symptoms go untreated, mental illness goes undiagnosed, and lives are disrupted.
- EDIPPP sites partner with a variety of local groups to improve the awareness and understanding communities have of mental illness.
- Through these efforts, and the ongoing efforts of others, our hope is that we can reduce the impact of these stigmas.
- Like physical illness, mental illness can negatively impact the individual, the family, and the community. Helping people see the correlation that severe mental illness has with physical illnesses, such as cancer, can help reduce that stigma.

**4. *There isn't a lot of evidence in the United States that your approach works. Why should we have any faith in your efforts?***

- EDIPPP is, in large measure, an effort to gather and interpret strong evidence, and turn that evidence into robust, replicable treatment options.
- EDIPPP was launched because the evidence for how best to treat adolescents exhibiting early symptoms of severe mental illness was not as available as it needs to be. This evidence EDIPPP is collecting, and rigorously reviewing, is demonstrating that severe mental illness can be slowed or stopped in its tracks.

- Indeed, that is why we combine the active treatment of individuals with the supply of feedback to the EDIPPP initiative. That process allows us to improve our abilities, refine our interventions, and consistently increase the positive outcomes individuals achieve.
- The need to accumulate strong, well-collected evidence is also one of the reasons that EDIPPP is proceeding cautiously, scientifically, and with utmost concern for the wellbeing of the adolescents with deal with.
- Numerous studies undertaken in other countries have indicated the effectiveness of this approach, from Australia to Denmark, projects have concluded that early diagnosis and intervention programs show great potential.

**5. *Psychosis will affect very few adolescents. Why are we diverting finite resources from other, bigger, issues that affect more people?***

- Adolescents treated through EDIPPP exhibit early symptoms of the most severe mental illnesses. The severity of need they exhibit can have a proportionately greater impact on them as individuals, on the families they belong to, the communities they reside in, and the health and social service systems charged with caring for them.
- The evidence being collected has meaningful positive implications for the development of mental health services across the board – especially for our youth.
- By examining the needs and seeking the answers to helping the most severely impacted segment of the adolescent population, we are collecting important information that can inform the diagnostic and intervention services of the mental health field in general, and deliver benefits to everyone.

**6. *There are different philosophies in treatment exhibited by different EDIPPP participants. Aren't these just sites jockeying for the primacy of their own approach?***

- EDIPPP understands that the need to ascertain what works best in a given situation means that a range of approaches is best.
- One of the key aspects to this is the fact that as each approach progresses it feeds information back into EDIPPP, building the evidence that allows us to definitively identify the most effective treatments.
- This approach accelerates the learning and brings us closer, faster, to being able to achieve the goal of eliminating diagnosis of severe mental illness in adolescents.
- EDIPPP's ultimate success is dependent upon scientifically rigorous evidence gathering. This means that only those treatment approaches and philosophies that can deliver successful outcomes are regarded as successful, irrespective of conventional wisdom or preference.

- EDIPPP is not alone in its efforts. Our project is part of a vanguard that is attempting, through a variety of research approaches to deal more effectively with the mental health needs of our young adults, and we recognize that it is by combining our learnings that the most effective approaches will be arrived at.

**7. *You're using kids for experiments and exposing them to the dangers of false positives or misdiagnoses. How can you justify this?***

- EDIPPP is a research-directed initiative, not an experimental program. While we are collecting and reviewing evidence on the effectiveness of a range of treatment options, each option being reviewed is accepted by the mental health community as valid and capable of achieving successful outcomes.
- EDIPPP is a rigorously designed research program. As such, it is exceedingly careful about assessing the mental health states of the individuals taking part.
- In addition, as the research deals with adolescents, and involves their families, additional safeguards have been put in place to ensure that the risks of misdiagnosis are kept as low as possible.
- Prior studies, as well as our own constantly improving assessments, have identified those symptoms that are very strong indicators for a major mental illness. EDIPPP uses these indicators not only to assist in accurate diagnoses and also to develop treatments that can avoid a diagnosis of mental illness for the adolescents we work with.
- We have confidence in the approaches being taken – the question EDIPPP is asking is not whether they work, but which ones work best in which situation.
- All the treatment components being utilized are evidence-based; however, they have not been tested in this kind of systematic way for young people who are symptomatic but not yet ill. That's the evidence gap that EDIPPP seeks to fill.
- EDIPPP is a response to a current and urgent need in mental health care, expressed by practitioners, patients, families and communities. These groups share a driving desire to protect young people from psychotic illness.