

## **CHAPTER VIII**

# **FIRST ONSET OF SERIOUS MENTAL ILLNESS AND/OR PSYCHOSIS IN TRANSITION AGED YOUTH (TAY)**

*“The soul would have no rainbow if the eyes had no tears.”*

- **MINQUASS TRIBE**

## CHAPTER VIII

### First Onset of Serious Mental Illness and/or Psychosis in Transition Age Youth (TAY)

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#### **PURPOSE:**

1. How research is used to frame the sub topic
2. Issues and challenges/background
3. Target audience

## **A) INTRODUCTION**

Young individuals who experience their first episode of psychosis may have previously received diagnoses such as depressive disorder, anxiety disorder or ADHD, and may have previously been prescribed medications. (Meyer et al 2005). Although psychosis is a core symptom of schizophrenia, it is also a symptom of other disorders with first onset of severe symptoms in adolescence.

Many disorders besides schizophrenia include psychotic symptoms. Psychosis may occur during intoxication with or withdrawal from numerous medications and street drugs, and it may be associated with a medical illness. Brief psychotic disorder may be present during overwhelming stress. Psychiatric disorders with psychosis, other than schizophrenia, include schizophreniform disorder, schizoaffective disorder, major depression and bipolar disorder.

In this chapter, the term “First Onset” is used in a broader sense than “first break” schizophrenia. It applies to the point at which a youngster, or those around him, realize that he is experiencing serious symptoms of a mental disorder.

### **1. EPIDEMIOLOGY OF ONSET OF SEVERE MENTAL ILLNESS (SMI) AND PSYCHOTIC SYMPTOMS IN LATE ADOLESCENCE**

It has long been known that many psychiatric disorders unfold developmentally in adolescence (Roberts, et al 1998). The prevalence of severe depression, schizophrenia and bipolar disorder totals about 3% in the population. The first onset of schizophrenia and bipolar disorder, sometimes heralded by a psychotic episode termed “first break”, typically occurs in late adolescence and early adulthood. Psychotic symptoms may also be a manifestation of posttraumatic stress disorder (PTSD), acute or arising from early developmental trauma, reactivated in response to adolescent pressures.

### **2. “MULTIPLE HIT” MODEL**

The “Multiple Hit” model has been proposed to explain how cumulative factors may lead to eruption of severe symptoms during the challenging period when a young person navigates from adolescence to adulthood (Eyler et al 2000). These factors include: (1) genetic vulnerability (temperament and risk of temperament mismatch with parents or potentiation of vulnerability because of shared traits with parents), plus (2) developmental stress, plus (3) traumatic experiences (Rosenberg et al 2007), plus (4) inadequate early prevention, recognition and treatment.

### **3. VULNERABILITY OF TRANSITION AGE YOUTH (TAY) TO FIRST ONSET SMI**

Vulnerability of Transition Age Youth is higher because they may (1) lack family support (2) suffer continuing psychosocial stress, (3) live in situations that expose them to risk of substance abuse, (4) lack health care coverage (Aarons et al 2008), or (5) lack adequate access to high-quality or evidence-based psychiatric care. All these risk factors are exacerbated if there is also substance use.

#### **4. IMPORTANCE OF EARLY RECOGNITION**

Early recognition of emerging mental disorders and optimum treatment of existing mental disorders will maximize opportunities for TAY to stay on track to meet the developmentally appropriate challenges of their age group: to complete education, to engage in productive work, and to develop peer and intimate relationships. Consideration of the individual's developmental stage, and the stage of development of their disorder, is necessary to inform the choice of treatment.

#### **5. EARLY ONSET SCHIZOPHRENIA SPECTRUM**

For youth whose psychosis is a part of early onset schizophrenia spectrum disorder (EOSS) early identification and treatment is very important. (Frazier et al 2007, Imran & Clark 2008).

### **B) DEVELOPMENTAL CONSIDERATIONS**

#### **1. NORMAL DEVELOPMENT**

Adolescence and early adulthood is a time of rapid behavioral, social, emotional and neurological development and consolidation. Self-regulation and personal capacities develop throughout the life span. These can be roughly organized into the domains of attention, executive function, control of impulses, mood/anxiety, and capacity for relationships. These capacities are shaped and modified by the ways in which the individual has adapted, and continues to adapt, to his/her life experiences or the psychosocial environment and possible traumatic experiences. TABLE 1, The TAY Mental Health Overview, presents an overview of these domains and shows the continuum for each domain from strengths through problems potentially reaching a degree that meets criteria for an Axis 1 diagnosis.

The brain reorganization normally occurring during adolescence, involving both pruning of neurons and formation of new connections, influences each of these domains. Cognitive capacities: attention, executive function, become more sophisticated and efficient, so the concrete thinking of the child is succeeded by the abstract thinking of the adolescent and adult. This helps modulate control of impulses, as the individual becomes capable of more reflective thought and becomes cognizant of his context and the effects of his actions on others. The intensity of moods may increase, and so may anxiety, as the adolescent undergoes physical and social changes, but at the same time, if he can build on positive experiences during childhood, capacity to tolerate intense emotions and moods matures, and confidence may increase as the adolescent widens his experiences. His capacity for relationships deepens as he brings strengths from the other domains to a wider range of relationships beyond the family and classroom. Neuro-developmental changes underlying this optimum normal growth have been extensively described (Cicchetti & Curtis 2006).

#### **2. DEVELOPMENT UNDER STRESS**

However, not all youngsters are fortunate. Many contend with the effects of blighted attachments, troubled relationships, psychosocial stress, and trauma, misfortunes that may leave them with "unfinished business" in the development of their personal

capacities. TAY who have suffered disruptions in their families, who may have lived in the foster care system, or who may have experienced developmental trauma, are at increased risk. Emerging patterns or problems that are sub-clinical may stay “below the radar” too long, and opportunities for preventive intervention lost. A displaced or misplaced youngster may have Trouble of Unknown Origin, rather than an obvious diagnosis, or may have received various diagnoses at different crisis points when mental health consultation was obtained. TABLE 1 presents an approach to assist systematically considering each developmental domain, not only so as not to miss one area of difficulty because another seems salient, but also so as to identify strengths. This could be used by providers and by TAY in collaborative treatment planning (see below). This approach is recommended because many TAY are developmentally capable of being medically literate and beginning to manage their own health and mental health. It is consistent with a practice approach to empower TAY to recognize and self-identify challenges and strengths, addressing stigma, engagement, social context

### **3. HOW DOES SEVERE EMOTIONAL DISTURBANCE (SED) OR SEVERE MENTAL ILLNESS (SMI) JEOPARDIZE NORMAL DEVELOPMENT?**

Examples are given for Schizophrenia, Bipolar affective disorder, Major Depressive Disorder, and PTSD.

#### **a) SCHIZOPHRENIA**

Onset of schizophrenia before age 18 occurs in approximately 0.5 % of adolescents; onset before 13 occurs in only .002 %. (Frazier et al 2007). Younger onset is associated with worse symptoms and greater functional and social impairment, including social, academic and behavioral problems, aggression and legal problems, previous hospitalization and suicide attempts.

Prodromal schizophrenia is a recognized pattern; risk factors include specific problems with verbal and visual knowledge acquisition, reasoning and conceptualization, as well as developmental lag in attention, problem-solving working memory and processing speed (Reichenberg et al 2010).

Prodromal signs of schizophrenia include social isolation, decline in school functioning, inattention, unusual perceptual experiences such as illusions, unusual beliefs, disorganized thought process and flat affect. Although typical age of onset of schizophrenia is during the late teens and early twenties, prodromal symptoms have been identified in younger teens. The progression may be (a) episodic, without deficits between episodes, (b) episodic with inter-episode deficits, or (c) steady deterioration. Of these, (b) is the most common pattern.

The prodromal stage of schizophrenia has been shown (see Kumra 2008 for a brief review), to be associated with cortical grey matter loss. There is emerging evidence that early treatment with antipsychotic medications may offer neuroprotection, and that vigorous social support also slows the erosion of age-appropriate capacities. The NIH study of childhood schizophrenia has provided evidence that it is biologically continuous with schizophrenia of later onset (Nicholson & Rapoport (2000), although there are certain clinical differences; for example boys show more delayed milestones and motor abnormalities, suggesting more blatantly disrupted earlier development. This could be due to more environmental or genetic liability.

TABLE 2 demonstrates some differences observed in individuals with early versus later onset (Eyler & Jeste 2000). These studies suggest that late onset may be a less severe form of the disorder, and argues for a diathesis-stress model that proposes a genetic vulnerability combined with environmental insult, (such as obstetric complications), with onset triggered by maturational changes or life events that stress a developmentally damaged brain through “multiple hits”. Both individuals with childhood onset and those with later onset schizophrenia have developmental defects (Feinberg 1983), but later onset may be due to fewer “hits,” or environmental risk factors or to more protective features.

Frazier et al (2007) described clinical features of children 8-19 with early onset schizophrenia as part of the Treatment of Early Onset of Schizophrenia Spectrum disorders (TEOSS), a multi-site NIMH-funded study of 119 youths with schizophrenia, schizoaffective disorder or schizophreniform disorder. The majority had IQ scores at or below average. They had received other diagnoses before SSD was diagnosed, including ADHD (28%), mood disorders (25%), anxiety disorders (19%) and conduct or oppositional defiant disorders (16%). Most resided with their families, but 7% lived in group homes or residential care. A history of aggression and legal problems was present for 25% and of suicide attempts for 15%. The careful histories obtained for children in this study showed that by preschool parents and teachers were concerned that something was wrong, and by school age, the children had obvious social, behavioral and attention impairments. In the TEOSS study, both youth with schizophrenia (SZ) and schizoaffective disorder (SA) had significant deficits in intellectual and academic achievement skills, but, except for spelling, which was worse in those with SZ, there were no differences between SZ and SA on any of the battery of neuropsychological tests (Hooper et al 2010).

Schizophrenia is a disorder not only of cognitive, but also of emotional processing (Carter 2006). There is growing evidence of overlap between schizophrenia, schizoaffective disorder and bipolar disorder, especially from longitudinal national registry data (Laursen, Agerbo & Pedersen 2009). This challenges the strictly categorical approach of both DSM-IV and ICD-10 classification systems (Jabben et al 2009).

## **b) MOOD DISORDERS**

Major Depressive Disorder and Bipolar Disorder Major Depressive Disorder (MDD) has long been known to occur during childhood and adolescents, and may be associated with psychotic periods (see Geller and Luby 1997 for a review). Developmentally, MDD causes youth to miss out on developmentally appropriate experiences, derails them academically, disrupts peer relationships, and erodes self esteem. Evidence-based treatments, especially cognitive-behavioral therapy (CBT), have been demonstrated to be effective; several psychotropic medications are approved for use in children (APA working group 2006); psycho-education is essential to assist family support. Early treatment is thus developmentally appropriate

- i. **BIPOLAR DISORDER (BP):** As compared with adults, children and youth with bipolar disorder (BP) have more frequent changes in symptoms from “highs” (mania) to “lows” (depression), and a fluctuating course with a range

of symptom severity from sub-syndromal to mood syndromes that meet full DSM-IV TR criteria (Birmaher & Axelson (2006). Longitudinal follow-up study shows that 40% have symptoms during 75% of a 4-year follow-up period, and 16% had psychotic symptoms during 17% of the follow-up period (Birmaher et al 2009)

Onset of BP may be heralded by irritability. This, and the pattern of episodes of mood symptoms predicts later development of mania or associated ADHD and major depressive disorder (MDD) (Liebenluft, Thompson & Rappoport 2007). Episodic hypersensitivity, lability of mood, and anger dyscontrol, as well as subtle affective symptoms of bipolar disorder occur much earlier than age 18, which is the average age of onset of Bipolar disorder (for a review, see Knapp & Mastergeorge 2009). As in schizophrenia, individuals with more severe psychotic symptoms also have more neuro-cognitive impairment (Habben et al 2009). Earlier onset is associated with higher depression symptoms over 20 years in participants in the NIMH Collaborative Depression Study (Coryell et al 2009).

Youngsters with earlier onset, sub-syndromal mood symptoms, longer duration of illness, more rapid mood fluctuation, psychosis, co-morbid disorders, low socioeconomic status and family psychopathology seem to have worse outcomes over time. Children and adolescents with BP may have high rates of hospitalizations, suicidal behaviors, psychosis, and substance abuse, as well as family and legal problems, and poor psychosocial functioning. Early intervention may slow the onset for bipolar disorder Chang and Micklowitz (2007) Therefore, early recognition and treatment of BP is of utmost importance.

#### **c) POST-TRAUMATIC STRESS DISORDER (PTSD)**

Risk factors for PTSD (Brewin 2000) include those that many TAY may currently have or previously have had, such as childhood abuse, previous trauma, family history of psychiatric disorder, lack of social supports and other adverse factors. Many TAY have experienced childhood trauma, which is long been known (e.g. Perry 1995) to jeopardize self-regulation through multiple neuro-developmental impacts (see Knapp & Mastergeorge 2009 for review). The clinical manifestations of posttraumatic stress disorder are very diverse, and may mimic or predispose to other psychiatric diagnoses. Children and adolescents with posttraumatic stress disorder may miss out on age-appropriate interpersonal experiences because of either avoidance or counter-phobic recklessness or reenactment resulting from their PTSD.

### **4. RISK, PREVENTION & SCREENING**

#### **a) RISK**

Which TAY are at greatest risk for developing serious psychiatric disorders? Clinical observation has established links between childhood adversity and adult mental illness, particularly mood disorders (Lu et al 2008). Epidemiologic studies show that some youth may be at higher risk for a first psychotic break. First episodes

are more likely to occur in young males, those with prior treatment for depression, anxiety or attention deficit disorder. Young people with a history of violence and aggression homelessness, and small supportive social networks, a first degree relative with a history of psychosis are also at higher risk. Specifically, schizophrenia risk factors include schizophrenia in first-degree relatives, viral exposure or malnutrition in the womb, life stress, childhood trauma or abuse, older paternal age. (<http://www.mayoclinic.com/health/paranoid-schizophrenia>).

## **b) PREVENTION**

Prevention may occur at many levels on a continuum. This continuum has been described as Primary, Secondary and Tertiary, or as Universal, Selective, and Indicated. A typology of prevention is shown in FIGURE 1. Universal prevention refers to reducing risk and enhancing resilience factors at a population level; selective prevention refers to early identification of at-risk individuals so as to provide them with interventions that prevent them from developing disease, and indicated prevention refers to treatment that reduces the risk that a disease or disorder will worsen or develop complications

## **c) SCREENING (EARLY RECOGNITION)**

The importance of early recognition of signs of impending psychosis reinforces the need to educate people who may come in contact with troubled youth. The ability to distinguish between adolescent angst and mental illness requires specialized understanding and training.

Screening instruments for clinicians to identify those youth with at-risk mental states have been particularly useful. The CAARMS (Comprehensive Assessment of At Risk Mental States) (Yung et al 2005), developed at the Personal Assessment and Crisis Evaluation (PACE) clinic (Yung et al 2007) in Australia, and the SIPS (Structure Interview for Prodromal States) developed at Yale (Miller et al 2004) help clinician assess and evaluate the individual's information. Applied in the North American Prodrome Longitudinal Study, these screening tools robustly distinguish youth who go on to develop schizophrenia from a normal comparison group and from those with family high risk or schizotypal personality disorder (Woods et al 2009).

## **C) CLINICAL PERSPECTIVE: THE EXPERIENCE OF TAY**

This section describes the experience of first onset of major mental disorder for TAY through a case history and summary of a TAY discussion group.

Pitfalls in early recognition may include ascribing problems to situational or life stress and not recognizing the psychiatric symptoms, recognizing symptoms but ascribing them to substance abuse or developmentally appropriate denial, as adolescents perceive themselves as invulnerable and are strongly motivated to be "ok" instead of impaired.

### **1. THE STORY OF ONE TAY**

Missed cues and lost opportunities for intervention are common themes in the histories of youth with first break psychosis. Here is an example of a youth referred to the Transition Age Team (TAT) in Alameda County.

Twenty one year old Troy had had a psychiatric hospitalization a 5150 hold after he was found disheveled, wandering the streets, and responding to internal voices. His difficulties began in eleventh grade when his grades began declining and he lost interest in school or sports. Before that, he had been a good student, played basketball and enjoyed a group of friends. His parents also divorced at that time. His mother sent him to live with his father hoping a change of school and environment would spark his interest. At the new school Troy made few friends and began experimenting with drugs. He refused school-based counseling services at school. His belligerence and hostility finally drove his father to ask him to leave his home. He was homeless for several months before being picked up by the police.

Troy's family, school, and peers had missed potential warning signs of mental illness. They had interpreted his behavior to be adolescent rebellion, substance abuse and a lack of ambition for his future. How might Troy's story have had a different ending? New information on early identification and intervention in first break psychosis offers hope for preventing long term consequences of untreated mental illness.

Clinical signs of an impending first psychotic break are often mis-attributed (as in Troy's case) to adolescent belief in their invulnerability, to depression, to stress, to anxiety, or to substance use/abuse. All of these issues are part of the picture as the young person begins to experience impending psychosis, but together, they don't account for psychosis.

## 2. WHAT THEY HAVE TO SAY

A group interview for young people who had experience a First Break Psychosis\*

**Question: What would have help when you started to experience problems?**

**Answers:**

-“If teacher of school counselors had tried to talk to me instead of assuming that I was angry or just messed up. They needed to ask me what was going on. If they could have pulled me aside and asked me some questions.”

-“Confidentiality is really important. A private space to talk with four walls not out in the open like a patio.”

-“If teachers or police could inform us at school and if people knew the symptoms of drug use and what schizophrenia is, kids would think twice about using drugs.”

-“Understanding schizophrenia...nobody was around to inform me.”

-“Someone to explain what was happening to my parents. When we heard the word schizophrenia it felt so hopeless. My mom thought I was never going to be what she had hoped.”

**Q: When people get diagnosed there can be anger or stigma attached to it. What would have helped?**

**Answers:**

- “I was very disoriented. I did not know how to deal with it.”

-“Companionship would help- peer support from people who have been in the

same place as me.”

**Question: What event led to your mental health issues?**

**Answer:**

-“I was smoking marijuana. Friends asked me to smoke. It was free. Alcohol and hard drugs cost money. I thought marijuana’s not bad. It’s the weakest drug. Why not? Everyone was doing it. I felt immune to it. I didn’t think of the consequences. DARE didn’t really focus on marijuana only on the hard drugs. Smoking was a way to escape feelings of loss, being alone, being sent away all the time no family to talk to. I haven’t been to other cities because of the hospitals. I didn’t want to deal with those things.”

**Question: What are some other things that would have been helpful to you?**

**Answers:**

-“Have people I could talk to who really understand what is going on.”

-“Have things to read explaining and identifying what was happening. –“Have classes in school that can teach these things, the effects of drug use and different symptoms.”

-“Have some one come in and speak in the classroom.”

-“Educate the parents about what is happening to us.”

-“Tell people when they need treatment.”

-“Understanding how communities in the Bay Area perceive mental health differently.” (Staff)

**Question: Where do we find young people who are likely to be affected?**

**Answers:**

-“Outcasts, in high schools people who are hanging out by themselves.”

“It would be good to have programs in diverse semi-serious environments like Youth Uprising (a youth development center in Oakland.

*\*This group was held at a STARS Transition Age Youth Program (San Leandro) December 17, 2007. Three young people attended; two young men and a young woman all African-American, and all who had had a hospitalization and now were in an outpatient treatment at STARS. Three STARS staff members also attended.*

## **D) TREATMENT**

### **1. THE IMPORTANCE OF TREATMENT**

Duration of Untreated Psychosis (DUR), the period between onset of psychotic symptoms to first treatment is, on average 18-24 months (Buckley, Correll & Miller 2007), but individuals do worse the longer their symptoms are untreated, and this clinical worsening is, for schizophrenic individuals, associated with loss of brain matter.

Differential diagnosis of psychosis in adolescents encompasses mood disorders, brief psychotic disorders, conduct and emotional disorders, dissociative disorders, organic conditions, pervasive developmental disorders, schizophrenia and schizoaffective disorders, and substance abuse psychosis. A careful history is necessary to make a correct diagnosis, because treatment differs for these conditions. Practical guides to assessment and management are available (e.g. Imran & Clark 2008, Clark & Unruh 2009)

## **2. TREATMENT PLANNING**

Treatment planning must begin with accurate diagnosis. As depicted on TABLE 1, there is a continuum from normal variation, through problematic adjustments or adaptations, to emerging psychopathology, with symptoms that meet criteria for a psychiatric diagnosis. A thorough history and use of standardized screening and assessment measures will allow the clinician to discriminate serious symptoms from behaviors and reactions that the TAY may have developed to adapt to his or her life experiences.

Healthy social emotional and behavioral development occurs in these domains: (1) thinking (cognition, language), (2) attention and executive functions (3) self-regulation and control of impulses, (4) modulation of mood and anxiety (5) capacity for relationships. In each of these 5 domains, children and adolescents develop in the context of their environment, especially the interpersonal environment of their closest relationships. Understanding the nature of those relationships is crucial to evaluating for TAY, their risk, and their resilience.

It has been well established that when relationships are troubled or toxic, or when the child is exposed to trauma, children may develop problems or symptoms in any or all of the 5 domains; many TAY have suffered neglect, trauma, out-of-home placement, disruption of important relationships.

## **3. PHARMACOLOGICAL TREATMENT OF SCHIZOPHRENIA AND BIPOLAR DISORDER**

It is beyond the scope of this chapter to address treatment of schizophrenia (2196 references on NIH Library of Medicine) and other psychotic disorders (955 references) with antipsychotic medication. Very briefly, antipsychotic medications have been shown to be effective in reducing positive symptoms (exaggerations and distortions of perception and thinking e.g. hallucinations, delusions). First Generation antipsychotic medications (FGA) such as Chlorpromazine (Thorazine) or Haloperidol (Haldol) established this efficacy. However, adverse effects (side effects) are significant, particularly sedation, parkinsonian movements, tardive dyskinesia and metabolic changes leading to serious weight gain. Moreover, their effect on negative symptoms is minimal. Negative symptoms are inability to show interest in people and the world, to feel pleasure, to act spontaneously, inexpressive face or monotone/monosyllabic speech; these symptoms that seriously compromise a person's ability to live independently, hold a job, have personal relationships and manage everyday social situations.

Development of Second Generation antipsychotics (SGA), also known as Atypical antipsychotics, such as risperidone (Risperdal), olanzapine (Zyprexa), quetiapine (Seroquel), aripiprazole (Abilify), ziprasidone (Geodon) and clozapine (Clozaril), aimed to provide better relief of positive, negative, and depressive symptoms with fewer adverse effects. A meta-analysis of 150 double-blind studies with 21533 participants showed that, although SGAs differ in many properties, overall they were not more effective than FGAs for negative symptoms, but also overall have generally similar adverse effects (Leucht et al 2009). However many "efficacy" trials were sponsored by pharmaceutical companies, and most are short-term, and include only selected patients. These facts, and the far higher cost of SGAs, led to a debate about their merits. For this reason, two large pragmatic double-blind clinical trials, with no industry sponsorship, broad patient inclusion criteria, and long follow-up were undertaken: the Clinical Antipsychotic Trials

of Intervention Effectiveness (CATIE – 1493 participants) and the Cost Utility of the Latest Antipsychotic drugs in Schizophrenia Study (CUtLASS – 277 participants). CATIE and CUtLASS findings indicate that SGAs do not live up to previous expectations, but SGAs did produce better subjective effects for patients and lower incidence of tardive dyskinesia (Naber & Lambert 2009).

No single antipsychotic medication is best for all persons with schizophrenia, as individual responses differ markedly, so treatment must be individualized and a multitude of options for antipsychotic medications is needed. Even for effective medications, non-adherence to medication jeopardizes recovery. Gilmer et al (2004) found that adherence to treatment with antipsychotic medications was lower for schizophrenic individuals who were: less than thirty, female, non-Latino whites, had a substance use disorder, and homeless.

#### **4. PSYCHOSOCIAL TREATMENTS**

##### **a) EARLY TREATMENT**

Early treatment programs for youth thought to have an At-Risk Mental State (ARMS) are founded on the building of a relationship of trust. If further symptoms develop, the established trusting relationship with a caring and trained adult (or peer) can prevent hospitalization or reduce the length of stay, and enhance treatment for co-morbid symptoms such as depression and anxiety (Phillips et al 2005). Comprehensive programs for youth with first episode breaks would include a community education campaign, specialized training to recognize early warning signs to those likely to be in contact with youth and early treatment programs working with both youth and families.

For TAY, selective prevention of conditions associated with psychosis faces a particular challenge: the very pattern of symptoms and social functioning associated with a developing psychosis interferes with the individual, and those near him/her, being aware that the problem is developing. Yet the relationship of Duration of Untreated Psychosis (DUP) to outcome is strongest in the earlier months of psychosis. This has strong implications for how early intervention should be targeted (Drake et al 2000). Longer duration of untreated illness is associated with worse outcomes. The average time from onset of psychotic symptoms to first receiving treatment is 18-24 months, and the individual's functional impairment increases the longer the psychosis has gone untreated. (Buckley, Correll & Miller 2007), and early treatment improves chances of improved cognitive functioning and reduces recurrences of psychotic symptoms (Lewis et al 2005).

While positive symptoms may be reduced by antipsychotic medications, negative symptoms require education, behavioral training, psychotherapy, and help with housing, employment and family relationships. Behavioral approaches improve social skills such as how to make requests, express feelings, and adjust facial expression and voice. Cognitive therapy, specifically cognitive rehabilitation, remediation or enhancement, improves confusion, self-defeating thoughts, and withdrawn behavior that arises from the person's fear of exposing their limitations.

Although treatment of psychosis most commonly includes medications, it should be emphasized that medication alone is never enough, that psycho-education about the

underlying condition is essential, and that a recovery approaches is required to produce sustainable change. Some argue that psychosocial intervention produces better outcomes than medication (e.g. Irwin 2004), and avoids the adverse effects of medications. A subgroup of individuals with schizophrenia, not treated with medication, have been shown to have periods of recovery and better global function over 15 year follow-up (Harrow & Jobe 2007), but these are persons with better developmental achievements, more internal locus of control, and higher self-esteem. Cognitive behavioral therapy has also been shown to be effective for treatment of schizophrenia (Turkington, Kingdon & Chadwick 2003).

Treatment of psychosis arising from other conditions than schizophrenia is a large topic beyond the scope of this chapter; suffice it to say that multiple non-pharmacologica treatment approaches have evidence for efficacy for Bipolar disorder, Major Depressive Disorder and PTSD. Thus there is no one-size-fits-all treatment.

#### **b) FAMILY INVOLVEMENT IN THE TREATMENT PROCESS**

Whenever possible, the family should be involved in the treatment process. Family involvement with almost-grown children after the age of 18 is the rule rather than the exception in our society, for numerous economic and cultural reasons. The family's involvement should be tailored to the TAY developmental level, and work with families should consider the family's relationships and history of involvement and should build upon their strengths. This will include psycho-education to increase the family's awareness of symptoms, and treatments for SMI and/or psychosis. Family therapy helps individuals with schizophrenia and their families avoid angry confrontations or harmful emotional distancing. TAY without involved family are at particular risk, and need a more comprehensive treatment plan.

#### **5. COMBINED TREATMENT APPROACHES: EARLY INTERVENTION WITH MEDICATION AND PSYCHOSOCIAL TREATMENT**

Recent studies support early detection and treatment to prevent the actual psychotic break or mitigate the long-term sequelae of chronic schizophrenic illness. Studies done in Australia, England, and the US (McClashan & Johannessen 1996) conclude that the goal of early intervention is to improve outcomes by promoting the fullest possible recovery and thus reduce long term disability and the costs – both human and economic - associated with psychotic illness. Growing evidence that early intervention changes the trajectory of illness after the first episode of psychosis has prompted the Robert Wood Johnson foundation to invest \$12.4 million in the “Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPP).” Replication grants have been awarded, with the original Portland (Maine) program Portland Identification and Early Referral (PIER) serving as the main site. These programs reach out to the communities in which young people live to educate teachers, social workers, doctors, nurses, students, parents, clergy, and police officers about early signs of psychotic illness, so that young adults who are at risk of mental states (ARMS) can be identified and proper treatment started. Treatment components include ongoing evidence-based psychosocial support and education, and counseling for youth and their families. A course of medication may be started, if agreed to by TAY, and support may be provided for treatment adherence.

One EDIPPP site in California is The Early Diagnosis and Preventative Treatment of Psychotic Illness (EDAPT) clinic at the University of California Davis. Outreach identifies ultra-high risk youth and those with a “first episode.”

#### Ultra-High Risk Youth

- Attenuated positive symptoms state: onset or worsening in the past year of (a) paranoid, grandiose, or referential ideas but without full conviction (b) perceptual disturbances but without certainty of an external source, or (c) vague, circumstantial or tangential communication that is coherent and structured under redirection.
- Brief Intermittent Psychotic Symptom State: Onset in the last month of transient hallucinations, delusions, and/or thought disorder, lasting less than one hour/day
- Genetic Risk and Deterioration State: a decline of 30% or more on the GAF in the past 12 months AND patient either (a) has first-degree relative with schizophrenia or (b) meets criteria for schizotypal personality disorder.

Offer an array of treatments including medication management, individual and group therapy, multifamily support group and advocacy (school, vocational insurance and disability)

First Episode treatment issues: Diagnostic uncertainty, symptom based treatment, side effects. Denial of illness, non compliance. Depression, suicidality, Family support, “re-entry” socialization, stress, advocacy, Individualized pathways to recovery, value of peer groups.

Adapted from UC DAVIS EDAPT

[www.naccho.org/events/asthonaccho2008/upload/-NEW1-CARTER.pdf](http://www.naccho.org/events/asthonaccho2008/upload/-NEW1-CARTER.pdf)

Another program using the multipronged approach is the PREP ( Prevention and Recovery of Early Psychosis) program in San Francisco and Alameda County. This program is a collaboration of UCSF( University of San Francisco) for training, Mental Health Association of Alameda County for outreach and education, Family Services of San Francisco and in Alameda East Bay Community Recovery Project for clinical services and co-occurring disorder services.

Recognizing that genetic risk factors, sub-threshold psychosis and functional decline predict 20-40% conversion rate to full syndrome schizophrenia, ultra-high risk youth are identified and enrolled in a comprehensive multidisciplinary treatment program that is family-focused, offer rapid response and extensive medical and psychiatric assessment,

In addition to outreach, this program includes the following elements:

- i. Careful diagnostic assessment SIPS (Structured Interview for Prodromal States) plus active diagnosis and co-morbid diagnoses.
- ii. Targeted pharmacological therapies
- iii. PIER model multifamily psycho-education and support groups.

## E) COMMUNITY OUTREACH

### 1. THE CASE FOR INVOLVING THE COMMUNITY IN EARLY RECOGNITION AND TREATMENT

Community outreach is a critical component of an effective effort to improve the lives of TAY facing mental illnesses. There are multiple and compelling goals for a community outreach campaign. In order to offer meaningful access to early identification services it is important to reduce stigma and discrimination regarding mental illness. The campaign can provide user-friendly, clear information and education to patient and family members. In addition treatment access tools can be extended to the community of consumers, family members, teachers, youth workers and police, making the support of youth at-risk both a priority and a genuine possibility.

Increasing community awareness is important to decrease stigmatization regarding psychosis and to improve access to treatment and community support. Evidence that shorter DUP is associated with less loss of function (Marshall, Lewis, Lockwood et al 2005) and that early treatment improves outcomes (e.g. Drake et al 2000, Marshall et al 2005), should compel communities to take measures so that all parents, teachers, youth workers and criminal justice employees should know how to make effective referrals. To de-stigmatize mental illness, referrals to services should be considered as a positive response to problematic adolescent behavior, not a last resort.

Country-wide public awareness campaigns to address the need for understanding of first episode psychosis have been used in England, Australia and Canada. These campaigns had the combined goals of community education and easy access to first onset program. In addition, anti-stigma campaigns led by consumers to reach out to families are a major component of the program in Canada led by NAMI (National Alliance on Mental Illness). Their website offers information on schizophrenia (causes, current treatment, and the use of medications). The NAMI website also addresses myths about schizophrenia. Consumer choice is the message for TAY and families. The website also lists access to peer support groups for parents of psychosis sufferers (PSPOPS) [www.psychosissupport.com](http://www.psychosissupport.com).

Identification of members of the community to be targeted by public education campaigns include those people who would be in contact with youth when they first are experiencing symptoms: teachers, physicians, social workers, counselors, police, clergy and most importantly parents. The model in England targeted general practitioners with an educational intervention included focus groups and a video role-play of mental health situations. In Norway, after an educational intervention targeted at health professionals, schools and the general population, two early detection intervention teams (TIPS) were integrated into health outpatient clinics. The TIPS team also visited each high school in the country twice during each semester. As a result, the duration of untreated psychosis (DUP) was reduced from 114 weeks before the campaign started to 26 weeks during the intervention ([www.preventmentalillness.com](http://www.preventmentalillness.com)).

In the United States, the PIERS program in Portland Maine initially reached out to pediatricians, parents and school personnel in a specific community. Family psycho-education is a major component of the Maine PIERS program a major component.

Families meet for 90 minutes every two weeks with a clinician to discuss the nature of the illness and practical ways to create a supportive environment. They learn from each other how to deal with the stress and conflict of living with a family member with mental illness. Studies have shown communication is improved and often the need for hospitalization is averted. Stressors are dealt with in a matter-of-fact non-blaming manner. On the PIER website the message is continually “Hope with Early Intervention.” [www.preventmentalillness.org/images/pdfs/overview\\_pier.pdf](http://www.preventmentalillness.org/images/pdfs/overview_pier.pdf).

## **2. RESILIENCY AND HARM REDUCTION**

Resilience is defined as the “the ability to recover quickly from illness, change, or misfortune.” Individuals’ resiliency to overcome adversity depends on protective factors that person’s life, particularly in their relationships. Bernard (1997) and Krovetz (1999) describe features of a positive community and school environment, communities that assist youth to establish positive relationships, develop strong problem solving skills, cultivate positive self-identity and autonomy and build a sense of purpose. A resilient community would build a caring environment, positive expectations and expect participation.

As discussed earlier, TAY request safe places both to access treatment and continue to feel part of a peer group. It is important to help TAY to achieve continued progression during a period of their life when development is rapid, despite cognitive or emotional symptoms.

Attention is now being paid to the need for program models that address co-occurring mental health and substance abuse. Specialized programs for TAY are rare and they are expected to conform to adult models. For example, harm reduction works developmentally for TAY far better than abstinence only programming. NAMI has championed the need for a Recovery Model which focuses on consumer choice and the belief that people can survive mental illness and go on to live productive happy lives.

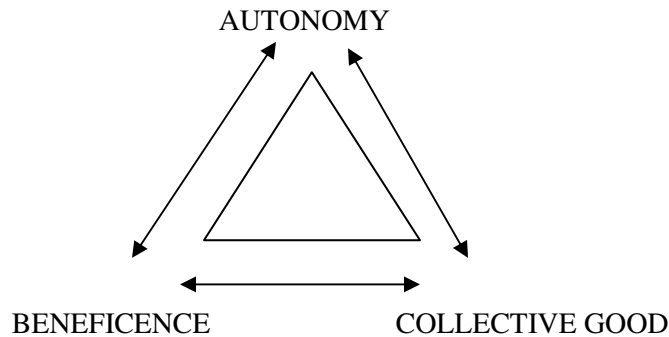
In California, the Recovery Model is a basic principle for the Mental Health Services Act (MHSA). Recovery principles are required by consumer employment and the hiring of peers as mentors in each of the MHSA full-partnership programs. County Behavioral Health providers are being educated and encouraged to include consumers as staff, volunteers and on oversight boards.

Program models such as TIP (Transition to Independence Program) identify youth early and provide necessary interventions to help restore them to their healthiest level of functioning. The TIP model involves youth aged 14-25, their families and other key individuals, in a process to assist moving toward self-sufficiency and successful achievement of their goals related to their education, employment and career, living situation, and personal wellbeing and effectiveness in the community (Clark & Davis 2000). This has been replicated in multiple counties in California for Transition Age Youth (TAY).

## **F) Ethical Issues in Decision-Making During Late Adolescence and Early Adulthood**

### **1. THE BIOETHICAL TRIAD**

The bioethical triad identifies the need to evaluate balance between the three arms of autonomy, beneficence and collective good:



- i. **Autonomy** refers to the individual's right to decide about his own care. This includes Patients' Rights.
- ii. **Beneficence** refers to the provider's need to ensure that the person receives the best care. Implementation might tilt toward prescribing psychotropic medication with strong psychosocial component
- iii. **The Collective Good** refers to the need to apportion limited treatment resources equitably, and to protect society from the threats of an individual's illness (e.g. contagion, immunizations, involuntary treatment for violent symptoms). Implementation might lead to an argument for medications-only treatment, on the basis that it is less costly than psychosocial or community-based treatments.

Any of these arms in the bioethical triad may (or maybe must) be in conflict with the others; some examples are offered: Autonomy may conflict with Beneficence in the situation where an individual with disabling positive psychotic symptoms refuses to take medication, and Beneficence may conflict with Autonomy if the physician or psychotherapist imposes a treatment against the individual's will. Beneficence may conflict with the Collective Good when prescribing physicians select costly new medications that are no more effective than their generic or affordable alternatives.

The classical tensions of the bioethical triad are heightened in treatment planning for TAY, as TAY may still be cognitively immature, which underlies and complicates the fact that cognitive impairment from the mental disorder may preclude rational decisions. TAY emerging from the foster care system may lack family support, and their experience with blighted or toxic relationships in their biological families may have left lasting problems with trust. TAY with families may experience conflict with them about treatment. TAY who are severely debilitated by their mental illness may be under conservatorship, and the conservator must be included in the treatment alliance and treatment planning.

## 2. SHARED DECISION-MAKING

Shared-decision making incorporates decision-making processes of both the patient and the provider. This is currently the forefront of the National Institute of Mental Health (NIMH) agenda to improve mental health interventions and services. A model of patient

decision making links “micro” variables at the patient level to “macro” variables at the service level. The NIMH prospective agenda for incorporating new decision-making concepts in ongoing mental health research includes (a) improved measures of decision-making processes for particular study populations, (b) testing decision aids in effectiveness research, and (c) improving, understanding and incorporating preference concepts in intervention designs. This is consistent with the MHSA essential element of a client/family driven mental health system for older adults, adults and transition age youth and family driven system of care for children and youth.

## **G) Conclusion**

Adults often miss or misinterpret early signs of mental illness in youth. In addition, many adolescents feel a strong sense of invulnerability, making appropriate services and treatment difficult. If we de-stigmatize mental illness by educating communities about both the warning signs of psychosis in youth and the documented benefit of early identification and the response, the duration of untreated psychosis can be shortened. The urgency of intervening early to shorten the duration of untreated psychosis (DUP) is now recognized. Intervention programs are designed to shorten the period of DUP.

The challenges of psychosis among youth are tremendous for the young person, his/her family, their support network and the system. However, these are promising times. New strategies and technologies for consumer and family education and empowerment exist and have proven effective. New evidence-based technologies for early identification of risk and transfer to effective treatments are available. A realization that effective treatment includes psychosocial components and patient/family participation in care plans has gained acceptance.

We recognize the importance of providing TAY with the best the field has to offer (Imran & Clark 2008). This includes use of standardized, best practice assessment tools (such as SIPS) as described in the Robert Wood Johnson EDIPPP programs below, combined with a bio-psycho-social model to determine client needs and factors that constitute obstacles or serve as resources. Following assessment for those TAY at risk for mental illness, clinical services should be offered. In addition, support groups for families (family psycho-education) should be offered to help families understand what their youth is experiencing and how to help.

Critics of the current mental health system say interventions are reactive, focused on problems, a “fail-first system” no proactive. Resiliency experts recommend an environment that would foster mental health and wellness. The early identification and engagement in treatment described here are an appropriate alternative to these concerns and are supported by data noted above. For a recent summary Clark HE & Unruh DK (2009) Transition of Youth and Young Adults with Emotional or Behavioral Difficulties: an Evidence-supported Handbook. Adds information about improving prevention, policy, funding and sustainability of practice.

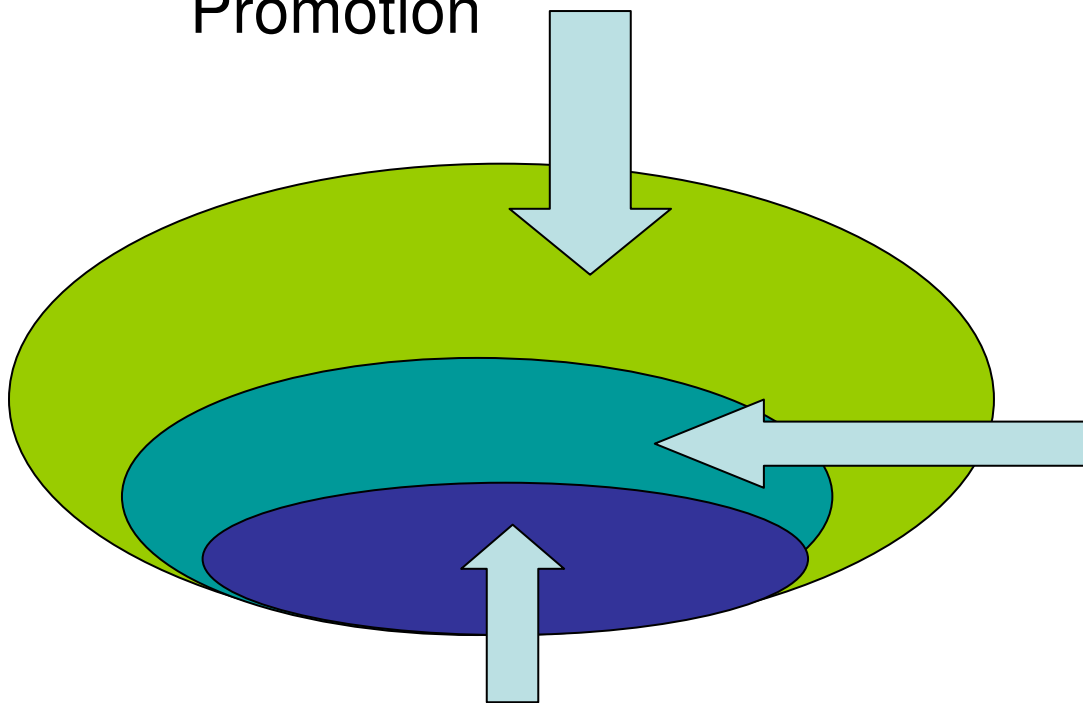
The California Mental Health Services Act (MHSA) delineates five essential elements: a client/family driven mental health system for older adults, adults, transition age youth, and family driven system of care for children and youth; a wellness focus, which includes the concepts of recovery and resilience; an integrated service experience for clients and their families with the mental health system; and cultural competence with community collaboration. MHSA funding offers exciting opportunities to transform systems for TAY experiencing first onset mental illness with psychosis, including MHSA Early Intervention

funding to support campaigns to increase public awareness and education. Anti-stigma and discrimination associated with psychosis led by NAMI and similar organizations will champion consumer choice and attack myths associated with the hopelessness of psychosis. Involving families in treatment from the very beginning will help to create supportive environments that may eliminate the need debilitating remissions (*recurrences*) and hospitalizations.

The problem is real, the solutions are equally real and supported by the data The remaining challenge is leadership. Are we willing to do what is necessary, what is possible and what is required of a civil society? Together; youth, families, advocates and behavioral health leaders can end the notion that first episode is a lifetime mental illness.

**FIGURE 1**  
**The Typology of Prevention**

**UNIVERSAL:** - e.g. Screening, Case management, Parenting Education, Promotion



**SELECTIVE:**  
e.g. Risk-specific assessment, preventive intervention

**INDICATED:** e.g. Diagnostic Assessment, Direct Infant or early childhood services

**TABLE 1: TAY MENTAL HEALTH OVERVIEW**

Adapted From Knapp P & Laraque D and AAP Mental Health Task Force 2006

Domain	Strength	Expectable function	Problem	Possible DX (DSM-IV or DSM-PC)
Developmental Progress	Precocious	Age-appropriate	Lagging, inconsistent or immature	Delay or deviant development, specific developmental disorder (e.g. ASD)
<b>AREA OF SELF-REGULATION - PERSONAL CAPACITIES</b>				
Cognition, Language	Intelligent, verbal	Able to perform & express self	Language delay	DD, LD, language disorder
Attention, executive function	Abilities to concentrate, learn	Able & eager to learn	Distractible, impersistent, forgetful, inconsistent etc	SCHIZOPHRENIA Attention Deficit/ Hyperactivity Disorder
Control of impulses		Individual able to manage his strong urges or feelings	Impulsive, reckless, frequent accidents, aggressive etc	Conduct Disorder Antisocial Personality disorder
Mood/ Anxiety	Mature ability to express and understand feelings.	Good range and modulation of moods. Anxiety is reasonable in response to stress	Persistent sadness, mood lability or over-reaction to events. XS worrying, fears	Major Depressive D/O, Bipolar Affective D/O Anxiety Disorders
Capacity for Relationships	Strong, intense and well-modulated interactions	Warm, reciprocal, shows empathy	Isolated, avoidant, lack of empathy, cruel etc.	Adolescent::emerging personality disorder
<b>LIFE EXPERIENCES</b>				
Psychosocial environment	Nurturing environment, strong family and community support systems	Safe, “adequate” environment	Exposure to community violence, Unstable home, homelessness, Foster care	Social problems (V60.9 (housing, economic); V63.9 ...)
Traumatic Experiences	Resilience, without symptoms	Resilience, with some symptoms	Significant behavioral & emotional symptoms related to past traumas	PTSD – DSM-IV

**TABLE 2: EARLY ONSET AND LATE ONSET SCHIZOPHRENIA**

Clinical/psychosocial	
SIMILARITIES between late and early onset schizophrenia	DIFFERENCES: Late onset schizophrenia has:
Overall degree of psychopathology	Preponderance of women
Severity of positive symptoms	Less severe negative symptoms
Family history of schizophrenia	Disorganized subtype rare
Qualitative response to neuroleptics	Lower daily neuroleptic dose
Early childhood maladjustment	Better psychosocial functioning in early adulthood
Constitutional sensory impairment	
Quality of well-being	
Minor physical anomalies	
Increased mortality	
Neuropsychological	
SIMILARITIES between late and early onset schizophrenia	DIFFERENCES: Late onset schizophrenia has:
Overall pattern of neuropsychological impairment	Milder impairment in learning, retrieval, and abstraction/cognitive flexibility
	Less disturbance of semantic network
psychophysiological	
SIMILARITIES between late and early onset schizophrenia	DIFFERENCES: Late onset schizophrenia has:
	Longer latency of N400 congruity effect
	Normal P300 amplitude
Neuroanatomic	
SIMILARITIES between late and early onset schizophrenia	DIFFERENCES: Late onset schizophrenia has:
Degree of nonspecific structural brain abnormalities (ventricular enlargement, white matter hyper-intensities)	Larger thalamus

ADAPTED FROM:

Eyler LE, Zorilla LT, Jeste DV: Late –Onset Schizophrenia: New Insights into Disease Etiology. IN Rapoport, JL: Childhood onset of “Adult” Psychopathology American Psychiatric Publications Inc. Washington DC 2000 pp 149-166.

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