Material for the Report,

Blamed and Ashamed,

The Treatment Experiences of Youth with Co-Occurring Substance Abuse and Mental Health Disorders And Their Families

As a public health physician and psychiatrist who has described the development of people with co-occurring mental health and substance abuse disorders over the past twenty years, I was honored to participate in the session, Blamed and Ashamed, at the recent Federation’s Annual Conference. The presentation took place in Washington, D.C. on December 2, 2000. I am pleased to recap my remarks for the published report.

When I first read the draft report of this project I was astonished to find how closely the findings, produced by focus groups of adolescents with co-occurring disorders and their families matched my own work. The material I have gathered from research and clinical experience dovetails perfectly with the findings and recommendations of the focus groups.

What is the big picture?
There are thousands of adolescents and young adults across the United States who, by their behavior, have earned tickets of admission to hospital emergency rooms, homeless shelters, substance abuse treatment programs, psychiatric hospitals, and jails. Many go back and forth in a confusing zigzag, never staying very long in any one place. Despite the best efforts of each agency, not one of them, working alone, can meet the complex needs of these young people. They live with a mixture of mental health problems, alcohol and other drug abuse (AOD) problems, health problems, immaturities, broken relationships with families, disrupted schooling, and behavior that disturbs the community and is often technically criminal.

How many people are affected by co-occurring disorders?
The National Co-Morbidity Survey, headed by Dr. Ronald Kessler in the early 1990’s, indicated that there are about 10 million adults who suffer from at least one mental health and at least one substance abuse disorder. Treatment is often unavailable. When it can be found, it is usually uncoordinated. We need to focus treatment so that it is integrated: humane, family-inclusive, and clinically effective. Treatment of either disorder alone does not work. Treatment integration is essential, because the commonest cause of mental health relapse in this population is continued use of AOD. AND, the commonest cause of relapse to the use of AOD is untreated mental health problems, such as panic-anxiety and depression.
Today, dealing with co-occurring disorders is an every day problem for families, schools, the mental health system, the substance abuse treatment system, the courts and the jails. But it is only recently that the interactive nature of these problems has begun to be recognized.

- In the 1960’s and 1970’s the treating agencies denied that co-occurring mental health and AOD problems existed.

- By the 1980’s there was general acknowledgement that the problem of co-occurring disorders did, indeed, exist.

- By the 1990’s mental health agencies were referring the problem to substance abuse agencies, while substance abuse agencies were referring the problem to mental health agencies. Troubled youth and their families were getting a run-around.

- In this new Millennium we are just beginning to see that providing effective, humane integrated treatment for these interacting disorders is a problem for our whole human service system, for our whole society. We have met the problem, and Pogo says it is all of us.

**What are the problems today?**

- Agencies receive money from separate sources from mental health and substance abuse agencies, at the federal, state, and local levels. In many cases, conditions attached to the spending of these funds makes it difficult or impossible for treatment to be integrated for the individual with co-occurring mental health and AOD problems.

- There are separate agencies for mental health and substance abuse at federal, state, and local levels. Their level of cooperation and collaboration has been poor, and is only now just beginning to improve.

- The different professional jargons in mental health and in substance abuse make it difficult for treating clinicians to communicate with each other. This causes each agency to want to remain separate, and to avoid responsibility for the person with multiple problems.

- Society stigmatizes people with mental health problems. It separately and differently stigmatizes people with alcohol abuse problems. And society’s stigmatization of people with problems with cocaine and marijuana are yet again different. When the person with co-occurring problems gets pushed into the criminal justice system because of ineffective treatment in the community, an additional stigma is tacked
The person who has been marked as a criminal has a greater burden to bear, as s/he struggles to find an honorable place in society.

- Mental health and substance abuse agencies want to do what they know how to do. Their staffs like to do what they were trained to do. Change is difficult.

- As a result of many of the above factors, each agency is likely to reject change because, “We’re always done it this way!” or,

- “We’ve never done it that way.”

**What are administrators doing?**

In government bureaus and at the service agency level, officials responsible for public policy covering mental health and AOD services tend to put forward the following kinds of arguments:

1. “We know that what is being done now doesn’t work,”
2. But let’s not set up a new system for co-occurring disorders,
3. That would be too costly.
4. Don’t ask my agency to take on the task,
5. That would further overburden us, and
6. We are already doing all we can!”

**Who gets hurt by current policies and procedures?**

- Troubled young children who, if their mental health needs are not met promptly and effectively, will probably self-medicate with alcohol and other drugs.

- The majority of emotionally troubled adolescents, because in addition to their mental health problem, they are likely to also have an AOD problem.

- The majority of people with schizophrenia, who also have an AOD problem.

- The majority of people with manic depression, 60% of whom have an AOD problem.

- Perhaps 40% of people now in substance abuse treatment, who are at risk of substance abuse relapse because their mental health problems are not being addressed.

**Who benefits from the current situation?**

The prison–industrial complex, as money from government budgets for health, mental health, social services, and education gets sucked out of those
budgets, to pay for the construction and staffing of more jails and more prisons.
What are the facts? What are the numbers?

1. The mental health treatment system has been radically downsized. In 1955 the nation had 559,000 public mental health hospital beds. By 2000 the nation had only 60,000 beds left.
2. During the past forty years the population of the country has risen by 100,000,000 people.
3. The few remaining beds must serve many more people. That is why it is hard to get anyone into a hospital, and even harder to keep them there for more than a few days.
4. Even if a bed is available, restrictive managed care payments for hospital care makes it virtually impossible for hospitals to keep patients long enough to treat them.
5. We used to have too many beds and over-hospitalization.
6. Now we have too few beds and under-hospitalization.

What has happened to our jail and prison capacity?

- In 1972 the total capacity of all U.S. incarceration facilities – federal, state, and local jails and prisons – was under 200,000.
- In the year 2000 the capacity reached 2,000,000!
- And, they are full:
- Jails are like sports stadiums:
- Build them and they will come!

The National Co-Morbidity Survey, and children:

As noted before, Dr. Kessler's survey gives us our best national data regarding mental health and AOD disorders. The survey data suggests that:

1. Between 8 and 11 million persons in the United States have at least one mental health and at least one substance-related disorder today.
2. The mental disorder developed first in more than 85% of these people.
3. The median age of onset for the mental disorder was 11. That is, of these approximately 10 million people, 5 million developed their mental health problem at age 11 or older, and 5 million developed it at age 11 or younger!
4. The median age of onset for the substance abuse disorder, depending on geography, ethnicity, and gender, was somewhere between 17 and 21 years of age.

What are the implications of these disturbing numbers?

They tell us that co-occurring disorders usually begin in childhood. Whatever the reasons, millions of Americans develop mental health disorders during childhood. The fact that millions go on to develop an AOD disorder some years later – usually substance abuse – suggests that they are self-medicating their depression, anxiety, confusion, disturbing conduct, and so on. Would providing adequate early treatment for these children be an
effective means of substance abuse prevention? It seems likely that if we reached more children with mental health problems early we would do a good deal to reduce problems of AOD. Remember, only one in five children with a mental health disorder gets treated today.

How do the data from the National Co-Morbidity Survey fit with the experience of youth and their families?

Blamed and Ashamed!

There are individuals who have no mental health problem and who become involved with the use of alcohol and drugs, because they want to change the way they feel. These single–disorder individuals start out feeling o.k., but want to feel even better. Then substance abuse and addiction can make them feel much worse.

But for depressed or anxious, shy, fearful, or hyperactive children and adolescents, the motivation for drug use is very different. They are trying to just feel normal.

Mental health symptoms can be temporarily relieved by ‘medicating’ with alcohol, marijuana, or cocaine. However, as drug effects wear off, the post-intoxication rebound tends to worsen the original bad feelings, causing a double motivation to use more and more drugs and alcohol.

The Continuum of Abuse:

The earlier AOD starts, the shorter and faster the road to abuse and dependence:

1. **Experimentation**: Almost all drug abuse begins this way. Young people are curious, feel invulnerable, and just want to see what it’s like.

2. **Recreational AOD**: If experimentation progresses, the young person will be using, with friends, once or twice a week... or every day.

3. **Habitual use**: With continued recreational use, vulnerable individuals, especially those with a mental health problem, increase the amount and frequency of use.

4. **Drug abuse**: When AOD becomes so frequent and important that it interferes with school, family life, and personal development, the person has reached this level.
5. **Drug dependence**: If the situation grows even more serious, the individual’s body craves the drug, and avoidance of the pain of withdrawal becomes an additional motivator for drug use. Now the central focus of the person’s life is the acquisition and use of drugs.
Many people who are familiar with the concept of the Continuum of abuse do not know that the length of time it takes to go from one stage to the next varies with the age of first use.

- Someone who begins experimenting in their twenties may not become dependent until their fifties, if ever.
- Someone who begins recreational use at 16 may become dependent by 20.
- A child, beginning to use drugs at 10 or 11, may become dependent within just two years.

This information has been substantiated in study after study, looking at a wide variety of drugs, from nicotine and alcohol to cocaine. That is why, from a public health and family perspective, we should do everything we can to delay children’s first use of any intoxicating substance, including tobacco.

Do mental health and substance abuse problems in childhood and adolescence affect the maturation of the individual?

We often see that the early development of anxiety, depression, thinking problems, behavior problems, when compounded by early use of drugs and alcohol, interfere with the development of a mature, stable, functional personality and sense of self. I have identified 10 common personality immaturities that may result from childhood and adolescent mental health/AOD problems. Each is normal in a young child:

1. **Low frustration tolerance:** Trouble working hard, and sticking to it, when gratification is not immediate.
2. **Lying to avoid punishment:**
3. **Hostile dependency:** A dependent person, unable to do things on their own, may have trouble developing a confident, independent self. Continued dependency may be expressed as hostility toward the very people whose help they need, such as parents. Hostile dependency, although often directed against others, may really be directed against the self. In extreme cases it can lead to a suicide attempt.
4. **Limit testing:** All children test limits; that is a normal part of childhood. It is a troublesome form of immaturity when it persists into later adolescence and adulthood.
5. **Alexithymia.** Children and older people with this condition are unable to verbalize their feelings effectively. As a consequence, they may act out their feelings, just as young children do. Rather than verbalizing anger, they may strike out physically. Rather than talking about their fears, they may avoid, run away, and hide. Instead of talking about feelings of hopelessness and depression, they may act out by attempting suicide.
People with alexithymia can’t soothe themselves or ask for help. Learning to talk about feelings is a key step in recovery.

6. **Present tense only:** Very young children only live in the present. They do not have a sense of future, cannot anticipate consequences of their own behavior, and have not become able to learn from past experiences. Adolescents who have no clear sense of past and future can repeat the same mistake over and over again.

7. **Rejection sensitivity:** Young children, and many people with co-occurring disorders are so eager to please, have friends, and be accepted, that they may agree to do things that they don’t really want to do. They may seek approval by trying too hard to please. If their efforts fail, they may feel terribly rejected, withdraw, and not try again. They can be very thin-skinned.

8. **Dualistic:** Young children, when they first learn the difference between right and wrong, put every action into one or the other category: Something is either **Right** or **Wrong.** As a consequence, moderation is a problem. A slip – having a glass of wine at a birthday party – may be so **wrong** that they might as well go ahead and get drunk. Dualism can turn a slip into a relapse. Dualistic judgment toward a counselor or a parent can cause condemnation; that person is now useless and hopeless.

**A model for personality development: The Maze**

Everyone’s life consists of an unending sequence of conflicts and problems. The individual whose development goes along a positive track learns, with the help of parents, to climb the steps and enter the maze: It represents the struggle of learning to resolve conflicts and problems. When the person finally makes it out through the maze, no matter how long it takes, there is an increase in maturity and competence. Every time you make it through you have increased your self-esteem and effectiveness.

A troubled youth may drop into the drug intoxication evasion loop, and out of the maze. While in the drug-evasion loop there are many problems and conflicts, nothing gets resolved. Remember, it is the **resolution** of problems and conflicts that leads to maturity.

**The interactivity between mental health problems and substance abuse problems:**

One reason that we cannot treat these problems separately is that they are interactive within the individual. The brain of a person with a mental health problem may be exquisitely sensitive to being disorganized by even tiny amounts of alcohol, marijuana, cocaine, or amphetamines. For all practical purposes, such individuals are ‘allergic’ to drugs, in the sense that a little goes a very long way.
What happens to the social life of the person with co-occurring disorders?
As can be seen from the sociogram, a person’s relationships with others vary in type and intensity:
• At the fifth level of our social network we have acquaintances. They sell us a cup of coffee in the morning, or cash our paycheck at the bank.
• At the fourth level we have casual friends. We do not keep in touch with them on a regular basis, but are glad to see when we cross paths.
• At level three are our good friends. We stay in touch, and they care about us.
• The second circle contains those few friends who are our most trusted intimates. These are the individuals who we know will never intentionally hurt us, and can be counted on to go out of their way to help us if we are in trouble. You are rich if there are three people, other than family members, in your second circle.
• The inner circle shows the private zone. It is shared with no one. The shaded portion refers to the part that is repressed and is not even accessible to the person, while the unshaded portion refers to the part that is suppressed, remembered, but secret; not shared with anyone else.

When someone with co-occurring disorders first comes into treatment, often there is no one in their second circle and few if any in their third circle. Their social network may be nearly empty until we get to the fourth level; casual friends.

The person with mental health and AOD problems may experience their drug of choice as their best friend; it seems to fill the emptiness in their heart gut. Beginning drug abuse treatment, which requires involves abstinence, may lead to feeling much worse. The ‘best friend’ is gone, and the emptiness within is devastating. For this reason, substance abuse programs must address loneliness, sadness, the sense of loss, and the depression that often accompany early recovery. Otherwise, the person may be motivated to leave treatment and rush back to drug or alcohol use, because they cannot bear their depression and loneliness.

**Who says that treatment for co-occurring disorders must be integrated?**

In 1999 the National Institute of Drug Abuse produced a slender but powerful booklet: *Principles of Drug Addiction Treatment*. We do not have space here to list the 13 principles enumerated by NIDA, arising from their vast database of research studies on substance abuse treatment. But item 8 states: “Addicted or drug abusing individuals with co-existing mental disorders should have both disorders treated in an integrated way”.

Item 13 of the booklet is equally important: “Recovery from drug addiction can be a long-term process and frequently requires multiple episodes of treatment”.

**How often is treatment for co-occurring disorders integrated in actual practice?**
Unfortunately, the answer is: **rarely**. Many young people find themselves trapped in a situation in which there is not even integration between mental health inpatient and outpatient treatment. And, after residential substance abuse treatment they may find that their outpatient program is not integrated with the residential program. Worst of all, it is most difficult to find fully integrated treatment, in which one team deals with all the client’s treatment and support needs, and includes the family in the process.

There are three distinct approaches to treating individuals with co-occurring disorders.

- **Sequential treatment**: This is the traditional approach, in which the person is first treated in a mental health or substance abuse agency, and then, presumably after effective treatment has been accomplished, the individual is referred to the other kind of agency. In fact, this doesn’t work. This failed form of treatment, for reasons of tradition, history, and separate funding streams, continues to be common throughout the country.

- **Parallel treatment** treats the person with co-occurring disorders at the same time in two different agencies. If the two agencies attempt to communicate with each other, the treatment is then referred to as **collaborative**.

- **Integrated treatment** provides treatment for the mental health and AOD problems in one place. The treatment team consists of individuals from varied clinical backgrounds who have been cross-trained to work together. The team develops a long-term treatment plan, in which the goals and different modalities of treatment are sequenced: Everything cannot be done at once.

There is considerable controversy among funding, licensing, and treating agencies as to whether or not integrated treatment is really necessary for all but a few people. Agencies prefer parallel or collaborative treatment, because it requires less change. The **Blamed and Ashamed** report which follows makes it clear that adolescents and their families prefer/demand integrated treatment. Thus, we have a conflict between the treating agencies and those they serve.

Five distinct problems have been noted with parallel/collaborative treatment approaches:

1. The young person and their family is caught between the **different treatment philosophies** and values of the mental health and substance abuse agency.
2. It is **difficult if not impossible to coordinate** two different treatment and recovery plans.
3. Treatment is **more expensive** because of duplicated services.
4. Parallel and collaborative treatment **fragments the person**, and is not holistic.
5. Dealing with the **interactivity** of the disorders is virtually impossible when different treatment teams are working with one individual, even if the treaters make a sincere effort to keep in touch with each other.
The tragedy of the current approach:
Shifting young people with co-occurring disorders
into the criminal justice system.

Everyone has to be someplace. When, in today’s society, the public mental hospitals have virtually been shut down, when there is no where else for the person with co-occurring disorders to be, the final ‘three hots and a cot’ are provided by our society in jail.

The best approach to solving the problem of locking up young people with co-occurring disorders in jails and prisons would be
**Prevention, early intervention, and integrated treatment:**
- Offering early treatment for children with mental health problems.
- Offering integrated treatment to adolescents with co-occurring problems.

But we are nowhere near that point today. As a stopgap measure, we should be working now to divert young people, before they get to jail. We have three chances. Diversion can be done at:
- Arrest
- Arraignment
- Sentencing

If diversion-to-treatment has not succeeded in time, and the client ends up in jail, we must insist on
- Treatment during incarceration.

But treatment during incarceration is not enough. Relapse rates are very high if, after treatment in jail has taken place, the individual is released to the street without adequate supervision, support, housing, educational opportunities, and vocational opportunities.

What must be done? A goal for all of us to share:
Our wonderful community, the United States of America, must re-invent itself and its systems of services for every citizen, from the infant to the elderly. We must offer support and treatment to every individual, affording that person the opportunity to succeed to the full extent of her or his efforts and abilities, by providing
- Preventive
- Supportive
- Educational
- Treatment
- Rehabilitative services, and
- By supporting overburdened families, so that the wonders of our technology, our wealth, and our concern for each other benefit all of us.
Bert Pepper, MD
TIE, Inc.