

**The
Empowering Families
Program**

'To break down the barriers'

An Overview

By

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Author and Facilitator

QUESTION:

How can we the parents, carers and significant others, of people with mental health, substance abuse or co-occurring disorders become part of the recovery process? What is our role? Surely not to simply stand back and hope that a treatment or medication is the total solution to the problem? We all know we can play a part.....but what part is that and how can we transcend our fear and despair to bring hope and joy back into our lives?

ANSWER:

The Empowering Families Program is an evidenced based psycho-educational* program designed to help parents, carers and significant others learn to respond appropriately to the needs and behaviours of family members with co-occurring substance abuse and mental health disorders, and build stronger relationships with them. It is also a coping skills training program, consumer driven, which helps families learn to cope more effectively to support their consumer to learn to self-manage their illness and work toward their recovery.

THE RESULTS HAVE BEEN AWESOME!

*A definition of psychoeducation on a Web site devoted to patients with psychiatric disorders and their families reads as follows:

Psychoeducation is the education of a person in subject areas that serve the goals of treatment and rehabilitation. Psychoeducation involves teaching people about their problem, how to treat it, and how to recognize signs of relapse so that they can get necessary treatment before their difficulty worsens or occurs again. Family psychoeducation includes teaching coping strategies and problemsolving skills to families, friends, and/or caregivers to help them deal more effectively with the individual (PsychoEducation, 2003).

Program History

My son began experimenting with marijuana then other drugs at an early age. Along with peer pressure to do so, he said they made him feel good. He used those drugs much the same way we all use drugs today – to mask his feelings. They were his medication to escape the problems, fears and pain that he was experiencing yet couldn't discuss with anyone.

Over time as his usage increased, he became dependant on them to cope with everyday life – thus depleting his capacity to live life without them. Depression set in and so began a cycle of self-destruction, which culminated in a suicide pact with his girlfriend.

(Today this scenario is finally being acknowledged as coming under the one umbrella – Mental Health.)

Police informed me in the early hours of the morning of that event and that tragically his girlfriend's attempt had been successful. My son was in the intensive care unit of a NSW hospital and thankfully, was expected to survive albeit with numerous disabilities.

I transferred him to the local hospital where upon being admitted, he was placed under the care of a 'Plastic Surgeon'!

In time, he was fortunate enough to find a wonderful rehabilitation centre called 'Mirikai' a place where people would *listen* and help him make sense of his behaviours and beliefs, teach him new communication skills and strategies to cope more effectively with life issues and guide him to re-build his life and his life story. It was his first port of call in a very long journey towards his recovery.

I was not so fortunate. My gut wrenching experiences were still tormenting me. I cried a lot. Felt hopeless most days and hoped like hell that my son would find the strength to want to live! Unbelievably to me, help for me was nowhere to be found and yet I was his prime carer!

It is now ten years ago that with the help of Mary Alcorn from 'Mirikai' I established the first support group in the Gold Coast area.

Mary Alcorn is the Executive Director of the Gold Coast Drug Council. She has worked tirelessly and effectively for greater funding, development and facilities for drug-affected people (often experiencing dual diagnosis) on the Gold Coast. Winner of the Australia Day Award in 2002 Mary Alcorn continues her fight today.

Initially it provided an outlet for families and carers to meet to express their feelings, talk about the problems they were encountering and hopefully find some solutions which might help them cope more effectively. This worked in the short term, but it didn't provide us with the ongoing skills to help us solve our problems in the long term, nor did it help us to gain the skills required to support our loved one's in their recovery.

2001 saw the birth of The Empowering Families Program – a psycho-educational program for parents, carers and significant others – a program for families compiled by families.

TODAY, THIS PROGRAM IS RECOGNISED AS A MAJOR SOURCE OF INFORMATION WHICH SUPPORTS THE RECOVERY PROCESS OF PARENTS, CARERS, SIGNIFICANT OTHER AND THE CONSUMERS THEMSELVES.

IT HAS ACHIEVED OUTSTANDING RESULTS AS AN INTERVENTION, PREVENTION AND RECOVERY SUPPORT TOOL.

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**Blamed and Ashamed: The Treatment Experiences of Youth
With Co-occurring Substance Abuse and Mental Health Disorders
and Their Families**

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1. INTRODUCTION

The unbelievable technological and scientific advancements we have made throughout the past 30 years have been astounding. We've split the atom, we've spliced the gene and we've

roamed Tranquillity Base – we've reached for the stars and never have we been so close to having them in our grasp. The changes have been astounding.

However, one clear result of these changes is that we now live in a society where **NOT** living in the nuclear family is now mainstream – whether that means you live alone, in a blended family, as a single parent, in a group household or child-free with your de facto. Indeed it is more than likely that during your lifetime you will experience living in a number of these contexts.

In the past divorce was an unusual and shameful anomaly, whereas today it heralds a rapid and profound transformation in the structure of families, in which members are both acquired and lost, where children and financial support move between households, and where there are new and complicated changes wrought to the structure of kinship relations.

Today many of the ideals previous generations have held dear are being challenged and the (patriarchal) authoritarianism that marked the way people raised children as recently as 40 years ago is slowly but surely being replaced by an emphasis on **intimacy**.

How people **relate**, what they expect from marriage, parenthood and their personal aspirations – are all dramatically different from the generations before them. Where once roles were clear, and patterns of behaviour and expectations were settled and agreed upon, now most of us must find new norms and new philosophies to make sense of our lives.

This interpersonal gap is now one of the major social problems of our troubled society.



Introduce mental health or substance abuse issues into this scenario and daily life can become a nightmare!

1. OUR YOUTH ARE IN CRISIS!

Today, there are thousands of adolescents and young adults across Australia who, by their reactive actions, 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 problems, health problems, immaturities, broken relationships with families, disrupted schooling, and behaviour that disturbs the community and is often technically criminal.

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.

The commonest cause of mental health relapse in this population is continued use of alcohol and other drug abuse. AND, the commonest cause of relapse to the use of alcohol and other drug abuse is untreated mental health problems, such as panic-anxiety and depression.

Families, regardless of their specific characteristics, are a permanent part of a young adult's life while services and providers come and go. Youth and their families rarely see eye-to-eye at the crisis point when they first enter services; however, most young adults return to their families and communities after treatment and unless they find the appropriate support, they will quickly relapse.

Families are at the very centre of care.

Families represent one of Australia's most under-recognized sources of power that can transform mental health care.

Families often are the strongest advocates for youth and their staunchest supporters. More than anyone else, families understand that each child possesses unique strengths and abilities.

It is these traits that can be the foundation of their incredible personal growth—socially, emotionally, and educationally.

2. THE FAMILY'S DILEMMA

Families become accustomed to interacting a certain way and when that pattern is broken, there is usually upset of varying degrees. They often respond with a knee jerk reaction in these difficult situations – based on long established habits combined with the passing mood of the moment. When challenged, they experience separateness, disconnectedness from those around them – a feeling of 'you or me' – a sense that there is not enough for both of us, and if one person is right, then the other person must be wrong. Often they have not taken even a moment to consider what is the best approach in the circumstances.

With limited access to information and support, many families attempt to control the situation by either wrapping their loved one in cotton wool and doing everything for them, or using 'power over' tactics in an attempt to force conformity to their 'beliefs' about how 'their family' members 'should' or 'ought' to behave.

Over time their loved one may experience 'hostile dependency' or 'co-dependency' as a result of the family's efforts to control the situation, and often feels unable to do things on their own, or may have trouble developing a confident, independent self. This continued dependency may be expressed as hostility toward the very people whose help they need and although it may be directed at significant others it may really be directed against the self. In extreme cases it can lead to a suicide attempt.

A major barrier experienced by many families is the belief that they have bent over backwards to accommodate the needs of their child, parent or sibling to the point where they themselves are experiencing massive stress, anxiety and grief at not being able to 'fix' the 'problem'.

THE FAMILY IS IN CRISIS.

This program encourages family members to look at their family system, expectations, beliefs, behaviours and communication style so that they can reflect on the impact this may be having on their relationships with the people they love and value most in their lives – the one's they are trying so desperately to save or change.

3. THE EMPOWERING FAMILIES PROGRAM

In any family crisis it's so easy to forget that our personal relationships are our most precious resource for coping with life in unstable and uncertain times. What we most need is each other. When changes in society and health issues threaten to isolate us and rob us of the time we need for maintaining and nurturing our relationships, the big challenge is to become **more effective communicators**.

Today, more than ever, most people long to share what really matters – the tender, shy, reluctant feelings, the sensitive, fragile, intense disclosures. Although most

people yearn for warm, positive, meaningful relatedness to others, many seem unable to experience it.

Having effective relationships that meet our needs requires us to be willing to learn and change the way we relate to become more effective communicators.

- **The Program provides clear, concrete guidance to families** to enrich their relationships whilst focusing on building mutual understanding and trust – even expressing love in situations where that love is sometimes difficult to convey.
- **It promotes harmony, cooperation, sharing and a reverence for life.**
- **It encourages healthy communication** with the important people in their lives, and focuses on valuing and loving them more.
- **It's a program about listening more and being respectful of others feelings.**
- It encourages participants **to take responsibility for their own actions and reactions** to the events occurring in their life and developing the strength and resilience to set limits or boundaries around their own behaviours
- **It empowers families to begin the process of empowering others**
- And **it has guided many out of reactive behaviours** such as unnecessary enabling and confrontations, self-righteousness and aggressive beliefs to re-uniting with their loved one by developing thinking habits and behaviours which are more constructive and more creative than the ones they had been using.
- **Empowering Families to break down the barriers is a voyage of 'discovery'** and presents a new way to understand our most crucial relationships: with parents and children, with friends and co-workers, and most importantly, to reconnect with our deepest sense of self. With this increased knowledge and awareness –
- **The Family becomes the catalyst for personal growth in others through developing greater resiliency in their own lives.**
- **It's a simple program that has achieved some powerfully huge outcomes!**

4. DEVELOPING THE STRATEGIES – SOCIAL PROBLEM SOLVING SKILLS TRAINING

The Empowering Families Program supports the transition from an illness focused model of support to a more holistic approach to our problems. Beginning with a series of continuous small steps, transformation is meant to identify, leverage, and even create new underlying principles for the way things are done. With transformation, new sources of power emerge. Transformation is ultimately about newness—about pushing the boundaries...about new values, new attitudes, and new beliefs. It is about creating something new within the existing paradigm. It is a readiness to change, and a willingness to risk that compels the pace, scope and character of transformation.

The ultimate goal of this program is to support that change —the transformation— towards a more holistic approach to our problems.

From a position of listening and changing the agenda in the conversation, families can focus on developing strategies, which increase their social problem solving skills capacity – increasing their resiliency and enabling them to re-unite and re-establish their family unit and 'values'.

These cognitive skills include sensitivity to interpersonal problems;

- **The ability to choose the desired outcome of a social exchange**
(means-end thinking);
- **Considering the likely outcomes of ones' actions**
(consequential thinking); and
- **Generating different ways to achieve the desired outcome**
(alternative thinking)

Other Training Included in the Empowering Families Program include:

- **Lateral thinking**
(to teach creative problem solving),
- **Critical Thinking**
(to teach logical reasoning),
- **Value Education**
(to teach values and concern for others),
- **Assertiveness training**
(to teach non-aggressive, socially appropriate ways to obtain desired outcomes),
- **Negotiation Skills Training,**
(to teach win-win outcomes),
- **Interpersonal Cognitive Problem Solving**
(to teach thinking skills for solving interpersonal problems),
- **Social Perspective Training**
(to teach how to recognize and understand other people's feelings),
- **Role Playing and Modelling**
(demonstration and practice of effective and acceptable interpersonal behaviour).

Through a number of training techniques which include; modelling, role-play and discussion, and most importantly - self-instructional training, The Empowering Families Program includes all of the above.

5. REAPING THE BENEFITS

This program has helped thousands of families to:

- ◆ Stop blaming themselves for their child's illness.
- ◆ Understand the many life experiences which influence/impact on their child's life.
- ◆ Learn more about mental health, addictions, rehabilitation and the recovery process.
- ◆ Become more aware of their actions and reactions to 'others' behaviours.
- ◆ Communicate more effectively and honestly with their child.
- ◆ Base their value on who they are, not what they are or what they have.
- ◆ Value themselves for the miracle they are.
- ◆ Teach their children how to 'value' themselves.
- ◆ Empower other members of the family to take responsibility for their lives.

It empowers families to:

- ◆ Develop strategies that create positive changes in family behaviours.
- ◆ Re-write their 'life story'; of 'who' they are, and what they want out of life.
- ◆ Empower their loved ones.
- ◆ Re-unite the family unit.
- ◆ 'Minimize' the lapse/relapse potential of their loved one in recovery.
- ◆ Prevent younger siblings taking up substance use.
- ◆ Communicate more honestly and openly.
- ◆ Live a more balanced life!

Families learn to:

- ◆ Communicate more effectively to resolve issues and strengthen their relationships.
- ◆ Develop a greater understanding of the needs that drive people's behaviours.
- ◆ Nurture and develop their personal relationships with their family and children.
- ◆ Identify and deal with their own and others 'trigger' points.
- ◆ Develop skills which sustain their own change processes towards self empowerment.
- ◆ Effectively support their loved one towards their recovery.
- ◆ Discover the Freedom of Choice.
- ◆ Be more in control of their life!

IT'S ALL ABOUT RELATIONSHIPS!

6. REDUCING THE TRAUMA – REBUILDING HEALTHY RELATIONSHIPS

The prevalence of trauma experienced by Australian families wrought by the changes in our society presents us with an incredible challenge. It affects persons of every gender, race, age, and economic class.

A child doesn't have to suffer trauma physically to experience its effects. Witnessing trauma can hurt as deeply as any blow. A teenager seeing his friends fall victim to street violence, a young girl watching her mother being abused repeatedly, a small child overwhelmed by the loss or absence of a parent—each experience can cause acute traumatic stress in a child.

Alas, today's parents, carers and significant others, at some stage of their lives, have experienced this traumatic stress themselves. Developing the skills to address their pain is in itself, 'empowering'. They then become the 'teachers' and 'mentors' of our children and our future generations. **The process of self-empowerment and cycle of change - begins.**

THIS PROGRAM IS EFFECTIVE FOR ANY AGE GROUP.

7. THE FOCUS:

➤ Re-ignite the flame of 'Hope'

I believe that 'hope' plays a very integral part in the work I do. Too often, the people I serve are short on hope. Yet, hope can be as important as any medication. A powerful yet delicate concept, hope helps people prevail in the face of an illness.

Hope is the catalyst that can start a positive chain reaction to help a consumer, incrementally, cope with life's challenges...to build resilience...to facilitate recovery. Hope is an essential ingredient of recovery!

Uniting isolated family members into supportive partnerships is the key to building resilience and facilitating recovery for our precious children ... opening the door to a new world of ideas, opportunities, and hope for them.

Our ability to create a recovery focused system hinges on 'The Family's' ability to break down the "silo" mentality and draw strength from each other's progress. Perhaps the most important thing graduates of this program do is to continue to inspire others with the idea that recovery is a real possibility. The ripple effects are incredibly powerful!

They keep spreading the word...people can recover...people do recover. When we all accept recovery as the common, recognized outcome of mental health services, the stigma and discrimination surrounding mental illnesses will be reduced, reinforcing the **hope** in recovery for every person with a mental or substance use disorder.

There is a growing evidence base that supports the concept of recovery. A number of long term studies conducted in countries around the globe—including the United States, Japan, Switzerland and Germany—reveal significant or complete recovery of persons diagnosed with major mental illnesses...a testimony that people can...that people do, recover.

➤ Building 'Resiliency'

From early childhood until death, mental health is the springboard of thinking and communication skills, learning, emotional growth, resilience, and self-esteem. These are the ingredients of each individual's successful contribution to community and society.

Each major transition in our lives can make us more vulnerable to a mental disorder. Marriage, divorce and retirement are life-altering transitions in our lives. So is re-entry into the community after military service, incarceration, or institutionalization. Consequently, any experience that undermines the sound mental health of an individual can prevent them from attaining their full potential and leading a full life in their communities.

A mother can find the joy of birth darkened by post-partum depression. A consumer released into the community without adequate social supports can experience relapse. Each transition, however, also presents us with opportunities to develop greater resilience. We gain strength, courage, and confidence every time we confront our personal challenges. We can say to ourselves, **"I overcame this hurdle. I can handle the next thing that comes along."**

The term “resilience” has its origins in physics and architecture. To be “resilient” means that a building material, such as tempered steel, has the ability to withstand stress. We have adapted this same term to describe a person’s ability to face the challenges of life.

Resilience often is defined as “the ability of a person to spring back from and successfully adapt to adversity.” Just like tempered steel, it means that a person can withstand stress. Resilience is the reason why one abused child grows into a mature and successful adult while another abused child develops chronic depression. It’s the reason why one combat veteran develops debilitating post-traumatic stress disorder while another veteran goes on to become President of a large corporation.

The most intriguing aspect of resilience is that it can be developed. We can teach these skills to our children; we can learn them as adults.

➤ **Aiming for ‘Recovery’**

What does recovery mean and what expectations do we hold for it?

In the mental health arena, recovery is about individuals taking control of their own lives and not having others determine their care or treatment. It describes the process by which an individual comes to terms with his or her disability and learns how to cope. ***Recovery does not imply a cure, but a lifelong process.***

Recovery refers to the process by which people are able to live, work, learn, and participate fully in their communities. For some individuals, recovery will be the ability to live a fulfilling and productive life despite a disability. For others, recovery will be a reduction or complete remission of symptoms. For many, recovery simply means being able to help make important decisions affecting one’s own life.

This definition is based on several fundamental principles. Recovery is a process that builds on the strengths of each individual. It is nonlinear and self-directed. It is holistic and person-centered, and it involves personal and community respect, responsibility, and hope. The process of recovery empowers consumers to make decisions that impact their lives. It recognizes the valued role of consumers in supporting and encouraging others as they continue their own journey toward recovery.

We must believe that every person’s journey to recovery is unique. We must believe that recovery is the expectation, not the exception.

8. WHY DO PEOPLE COME TO THE EMPOWERING FAMILIES PROGRAM?

I posed this question to one of my groups. Listed are some of their answers.

☺ **I** want to help myself to understand problems with depression and addiction and help my family to communicate better. To face problems head on and to have the strength to admit my past problems and family problems.

☺ **I** have a 16yr old son that is acting out. It is a big wake up call to me because I didn’t think he would do any of the things he is doing. I am scared to death that it will get worse. He actually frightens me. I don’t know how to talk to or even approach him. Some days he is the little boy I knew, and then other days I don’t even know him. I’m scared I’m going to lose him. He is not living up to my expectations, and he doesn’t take my advice. Basically, he is breaking out and I don’t like it!

☺ I want to change my behaviour with those I love. To change my words when I feel the need to address issues of concern. I want to feel more OK about myself. I want to improve my relationship with my 2 children especially my daughter. I want to feel equipped to handle situations with young people that I might come across. I want a better relationship with my partner. In general I want to be more 'cruisy' and not get upset with day-to-day issues. I want good business relationships and I want to value others more and learn to appreciate me also.

☺ I need to help myself to help my son. I need to find more strength and courage and stop using my fears when relating to my children. I need to love unconditionally and stop reacting in a way that is going to make myself sick. I need to trust that my son knows what he is doing and where he is going and to cut that umbilical cord, stop treating him like a child and don't – don't accept him treating me like a doormat.

☺ Learn to communicate more effectively. Personal development – new skills. Meet new people and to be part of a supportive group. To be a better father to my children and to learn how to understand young people (teenagers)

☺ I've fallen back into old behaviours and allowed my daughter to take control of my feelings. I need a top up of what I gained in self-esteem from my time with this program a couple of years ago. Initially I thought I was coming here to learn how to help my eldest son with 'his' problems. It didn't take me long to realize that 'I' have problems which have been nearly 55 years in the making. I've learned about some 'erroneous' zones that I'm still discovering in my attitudes, ideas, mindsets and thinking. I'm learning to sort out things that concern me so that I can recognize and deal with issues that are mine and let others work out the issues that are their problems. I am learning to choose how I will react, feel, think and act in response to the many and various situations that confront most of us in our busy lives. I am learning that I can choose to be happy no matter what is going on around me. I'm learning that I can be the person I want to be without expecting (insisting) that others do things my way. It's not easy, but I feel good.

9. WHAT DO PARTICIPANTS HOPE THE PROGRAM WILL HELP THEM TO ACHIEVE?

☺ This program is helping and has been a lifeline in helping me own my own problems and so control my anger. It has helped me greatly with my depression (have gone off medication) and helps me with my self-esteem.

☺ I want to listen to my son and let go of my expectations of him. I need to learn to talk to him on his level and retrain myself to become a better mother. I don't want to lose him before it's time. I just need help. I need answers.

☺ Peace of mind. Happy relationships with all my loved ones and an acceptance of my mother as I don't feel valued for who I am by her. I want to gain a greater understanding of why young people do drugs and develop a better way to talk to young people I may become involved with. More love all around.

☺ I'm looking to develop more self-confidence and the strength to make the right decisions for all concerned and greater courage to take the steps. I need answers!!

☺ **Serenity** – a fulfilled life by having the power to communicate with other people and family in an honest, open way and to be ‘who’ I really am.

☺ I’m hoping to gain insight – and ways I can change my life to have more meaningful relationships.

☺ I dearly hope this program will assist me to learn the right behaviours to hand over my fears, to accept my sons for what they are (although I would pray and wish that they could be drug-free) I need help!

☺ I’m looking to have a better relationship with my family – mainly one son. I want to be able to give myself a protective layer and to accept my son has to accept the consequences of his behaviour in order to learn. I want to enjoy everyday and not be so consumed or obsessed with things going on that I can’t control but have to step back from and to stop letting people push my buttons!

☺ I want to further communication skills and improve my knowledge of how to communicate better. To be able to receive support – emotional, and thereby I will be able to continually support my son in his emotional development. Being a part of this group I receive validation of being valued, respected and loved.

☺ I’m anticipating that as I practice the things I’m learning they’ll eventually become habitual and replace the bad old habits that I’ve had most of my life. I want to learn to ‘automatically’ respond to those around me by Listening (and really hearing) what they’re trying to say to me. Then I want to learn to really empathize (put myself in their shoes) with how they’re feeling. Then I want to ask what ‘they’re’ going to do about it (sending the message that I’m confident they’ll work it out) Finally, I want to detach from the situation (let go, not because I don’t care, but because I do) because it really is not my problem or problems. I want to become the kind of person who keeps calm and happy in all situations because I’ve learned to choose to react in those ways. I am determined to show gratitude for all that I have, even when I’m sad because it is my choice to make!

10. RESPONSES TO THE 1 DAY WORKSHOP AT THE SUNSHINE COAST 2004

- Thank you for an open door of many wonderful & positive opportunities
- Great discernment for carers and life & capabilities of the consumer.
- Congratulations in doing this work shop. I’m sure one can only benefit from this program as it is making one aware of our ‘life’ choices. Self challenging
- This is a valuable tool for communication both personally and professionally. Thank you very much for an inspiring day.
- A great workshop. I have learnt a lot today. I fully recommend this workshop to anyone. It was well presented and really informative. Congratulations on a job well done.
- I have learnt so much for myself. Thank you so much. I will do my best to follow these things.

- I loved and appreciated the whole day. I felt that the main thing I'm working on immediately is more emphasis on my son's good points instead of seeing what I perceive as his bad behaviour. Thanks heaps. Loved your humour!
- A very valuable learning presentation. My daughter (eldest) was 31 on Friday 29th This week I apologised for my failures, advised her that she is an adult and controls herself yet I will help if asked and that I love her and her younger sister (10) very much. I am still and will continue to learn. Congratulations.
- Thank you very much. I enjoyed it. A timely reminder of good strategies and introduction to some new ones.
- My daughter was diagnosed at 16-19. Now 40. Wish I had looked for help earlier. My relationship with her has been damaged because of today's topic. Maybe other friendships also. I will write her a letter of apology today. I have grown personally today. Thank you Sue.
- I will go home with an open mind and greater understanding of my role. Thank you.

11. THE EXPERTS HAVE THEIR SAY

2000 - Kath

When your family is thrown into a conflict, the likes of which you have never experienced, it is difficult to explain your despair even to your dearest family or friend. You have problems grasping reality yourself. You may not fully understand your problem.

Faced with such a situation we have only our personal resources to draw upon, and often our lack of knowledge is our own enemy.

More often than not our love of our person in strife and our reaction to their behaviour and the well-meant but inappropriate handling of our relationship exacerbate the problem. You know that a loved one is in deep trouble and after having tried everything within the realms of your personal power to solve or alleviate the problem and failed; you are faced with total desperation.

At this time it is crucial that you speak with people who have experience of your particular problem, people who have knowledge of strategies that you can employ to guide you through this turbulent time. You need guiding because often these strategies are foreign to you. We all have deeply embedded ideals of how relationships 'should' be and how families 'ought' to behave and to challenge all that you 'know' takes courage and work and guidance.

Sue offers this help to families, from the knowledge gained from her personal experience. She gives the direction and hope, which from a personal perspective was not to be found elsewhere. When every avenue is exhausted and you have repeatedly been informed by countless

professional people that your loved one in strife can only be helped if they volunteer themselves, and you have realized that this is not going to be the situation, you feel frustrated and totally helpless.

I feel blessed that I was directed to Sue Koningen's program and cannot stress enough the benefits we gained as a family in conflict through my attendance.

Thank you Sue.

Kath

2005 – Jan

Sue, my dear, you are quite the most inspiring presenter and facilitator I have ever had the pleasure of listening to.

During the period that I have attended your course on Empowering Families, I have laughed, I have cried, I have been shocked, embarrassed, appalled by some of the things I have done, and encouraged to realise that whilst for most of us, all of my actions were considered normal, because that was the way we were taught to be, but that there is a more effective way to behave.

Thank you for introducing us to a better, more positive way to live our relationships, where we each take responsibility for our own thoughts and actions, and we each give other people the respect that enables them to take responsibility for theirs.

Thank you for helping me re-discovers the essence of my beloved son James, who seemed to have drifted almost out of reach. Thank you for helping me realise that your programme works for every other aspect of my life too.

Thank you for the love, thank you for the laughter.

Jan Kealton

2005 - Murielle

After many years spent under the misconception that loving support and repeated rescue would enable my son to overcome his problems with addiction to alcohol, I sought the help of Sue Koningen to find a way to deal with 'my' problem.

The principles of Sue's program have given me the understanding that my actions, advice and expectations were misguided. Putting these principles into practice has enabled my son to find some independence and responsibility and has enabled me to see it is imperative for him to overcome 'his' problems in his own way. I now believe our journey of recovery and reconciliation has begun.

Sue's program is a life saver for parents and children struggling to find a better way.

With my heartfelt gratitude,
Murielle.

2005 - Irena

Dear Sue,

I would like to share with you, how your program 'Empowering Families' continues to improve our lives [my life and my sons]

When 2 years ago, my 23 old son was thinking of suicide after smoking cannabis for about 3 years, I was beside myself watching him going through so much pain and difficulties while he was trying to get out of the rut!!!! He was getting more and more depressed and being less and less capable of working things out for him self!!!

He was living interstate and he was in contact with me on regular basis, indirectly looking for help as he did not want to talk to anyone else about his feelings. I knew I needed help, to be able to be of some assistance to him, because whatever I was doing wasn't changing anything!

I kept on looking until I found your program.

My son started to feel the positive effects of the small changes I started to make in communicating with him, in the first week of me attending your program!!!!!!!!!!!! And I know this for sure, because he told me, he felt a little happier straight away!!!!!!!!!!!!!!!!!!!!!! What a relief that was!!!!!!!!!!!!!!!!!!!!!! And the positive effects slowly but surely continued.

He stopped smoking cannabis almost a year ago!!!!!!!!!!!!!!!!!!!!!!

I know that by me changing myself gradually with the material from your program, he is continuing to improve his self-worth with his own material, learning to take responsibility for whatever happens in his life, continues learning about his reactions and is able to turn negative feelings to positive ones. He is feeling better about himself and is more in control of his own life now!!

It certainly is a long journey, but it is working unlike anything else I tried. Our relationship is improving all the time. We are able to discuss and communicate about almost anything that is happening in our separate lives and help each other learn to be less and less effected by unpleasant life events that we do not have control over. We are learning to have happier and a less stressful life on daily bases.

His psychological state and outlook on life is incredibly different to one year ago, and the changes I made with your help, encouraged my son to start learning about himself and to understand himself better on a continuous basis.

As far I'm concern your program improves not only the lives of our troubled children, but our lives as well, and relationships with every one around us. Thank you very, very much Sue.

2005 - Alex

Who would have thought it could be so difficult to have a successful relationship with your own child? Not me. I loved him and "love is all you need" isn't it? Well no, love is not all you need. As well as love you need knowledge. Knowledge of a technique or method that will let you see how destructive many of your actions, comments and attitudes are, even though they come from a basis of love.

Sue Koningen's detailed and insightful understanding of this subject has given me that knowledge essential to turn our relationship around and after applying it for only a few months the result is that my son and I feel much better about ourselves and each other.

Our relationship now has a positive future.

Thank you Sue.

Sincerely,
Alex.

2005 - Yvonne

Sue

I would like to let you know what I have learnt attending your 2 hour weekly meetings.

Firstly, I feel an inner sense of peace, I have never felt. By this I mean I no longer respond in a non-thinking manner. By taking time to respond to people's requests, comments, judgements, commands etc. etc. means that I think before responding, giving me time to be in control of my reactions/responses.

No longer putting blame on to others shoulders, but trying to weigh up both sides of a discussion/disagreement in a manner where hopefully there is no loser, just two people trying

to get the best outcome from any two way conversation. Immediate, thoughtless blameful responses cause too much anger, frustration and heartache and communication breakdown.

That is my number one asset gained.

My daughter and my son have said I've changed. I know I have. We spend more quality time together because we want to, not have to.

People are now let make their own decisions without forceful views and opinions from each other. That's a great step forward. Now we try and focus on being contented within ourselves, not trying to force others to feel how we want them to feel, but accepting how they feel and showing understanding and compassion towards them, however they feel.

Listening.

I can actually hear people when I listen to them. How fulfilling this is. Stop and listen. Switching off to other tasks and taking time to listen. How much more people want to share their time and thoughts with you when you actually listen and hear them. What a great sense of satisfaction that gives both parties. But mostly, taking a step backwards and letting them handle their own predicaments and not letting my fear of their failures or getting into dangerous situations, stop them living their lives. Of course I still feel fear for them over certain situations, but letting them solve their own problems is making them into more responsible and caring people.

Taking a step back has opened my eyes to their great ways they have of handling their own situations. I can now try and get on with my life.

I'm starting to feel hopeful towards the future. (Empowered.)

Thank you Sue.

Dear Sue,

I wrote my son another letter, (thanks to your reminder and workshop) accompanied by an A4 collection of some photographs of him ranging from 2months old, 3 yrs, 9 yrs and 19 yrs. I told him this was the richness and fullness of how I perceived him and asked for his help to remind me in an appropriate way if I overstepped his boundaries and did the 'Mum thing'.

I received a great response via a phone call from him.

He said that he was going to put the letter on the wall along side the A4 copy of photos as a reminder that when he reacts like an angry bear being poked with a stick (his definition) to what I am saying, he will remember who he is and who I am and will do his best to point out the problem and remind me in an appropriate way.

He said that he could understand how it must be pretty painful dealing with the angry bear. In the past his reaction was to abuse and to hang up on me, leaving me hurt, angry and confused.

I told him I loved his analogy about the bear.

We talked about the photos and his early childhood, and we finished our phone call with him thanking me for making him feel so special and that he was going to ring his Dad to see if they could establish some sort of relationship.

So darling Sue another goodie, thank you!

12. ENDORSEMENTS

1999 – Dr Graham Sivyer

One of the greatest fears we face as parents is the premature death of our child.

Be it death through illness, suicide, a motor-vehicle crash or some other trauma, this fear remains often dormant in our subconscious mind.

The fear that we may lose our child to drugs is particularly prominent in our society. This fear is enhanced by the media and also by our politicians. They tell us that there is an ongoing “war against drugs.” (Sadly, the lines become blurred and at times this war becomes a war against our own children.)

When we discover our child is using illicit drugs what can be done? Where can one get help? To whom can we turn?

When I became medical officer to the Detoxification unit at the Gold Coast Hospital in the 1980's I discovered that I needed a lot of assistance to help my patients. There were very few medical experts in the field of addiction.

In time I found that a wealth of information and expertise was present within the community of recovering alcoholics and addicts and those members of their family who had also suffered.

Sue Koningen is one such expert. Since 1995, Sue has assisted over 700 families.

Parents and relatives of drug affected children referred from Fairhaven Salvation Army and Mirakai on the Gold Coast have also benefited.

Sue has the understanding and the practical knowledge gained by walking the long and arduous path of personal suffering. “Empowering Families” is a map of this pathway.

Sue's program is designed to give insight into the destructive behaviour that we as parents demonstrate to our children. It explains and clarifies the paradox “to help another you first must help yourself.”

"Empowering Families" illustrates how to re-establish and maintain communication. It describes boundaries and the formulae for setting boundaries so that you are able to effectively indicate your dislike for certain destructive behaviours whilst still communicating your love.

By confronting and overcoming her own fear, Sue has provided a means for others to walk this path with safety, reassurance and compassion.

I commend to you "Empowering Families" by Sue Koningen.

Dr Graham Sivyver. MBBS (hons) Dip. RACOG FRACGP AMSAD (cert)

2005 – Amanda Blacklock

Dear Sue,

I am writing to you to express my sincere appreciation for the workshop you presented 'Empowering Families' to an audience of families and carers who are impacted by Mental Illness in the Toowoomba District.

Personally I enjoyed your sensitivity and honesty in the assessment of the families' situation, whilst always offering a hopeful possible outcome for all. Importantly you encouraged the group to take great care of themselves and learn a mental release from problems, enjoy every day and continue to cultivate a sense of humour. Your workshop encouraged families and carers to develop meaningful friendships with their loved one whilst seeking independence from the issue of inappropriate responsibility.

For your information I have the results from evaluation sheets which are indeed pleasing.

Workshop was attended by 22 participants. On completion of workshop an evaluation Questionnaire was filled out by participants using Likerg scale rated 1-4, from Strongly Disagree to Strongly Agree (4 being the highest). **Overall, 96% of respondents rated 3 or higher**, 45% put a response of 4 and 49% put a response of 3.

Sue, I cannot help but admire your obvious enthusiasm for this issue. I must admit though I am particularly drawn to the more personal notation such as the impact on your strategies to your relationship with your son.

Sue, once again thank you for your workshop and looking forward to future opportunities to work together in the near future.

Kindest regards and best wishes

**Amanda Blacklock
Social Worker
Adult Mental Health Unit
Toowoomba Base Hospital**

13. CONCLUSION

Today, hundreds of families (including their consumers) are in recovery because of this program. Over two thousand of them were involved with the research and development of its birth and many more in its continued rebirth. No doubt even more have benefited because of its ripple effect. **Each and every one of them are the Co-Authors of this program.**

The consumers' ages range from seven to fifty years. Some had been diagnosed with a mental illness and/or addictions - others not. **One thing I can be sure of is that they were all a member of a family which loved them dearly and wanted to support them to make a difference in their lives.**

With little support or guidance to increase their knowledge and awareness of their role in the recovery process, it's difficult for parents, carers and significant others to see how often their reactionary behaviours have become just as addictive and chaotic as any other addiction. And just as destructive. I know mine were - despite coming from a place of love.

I understand that the issues are incredibly complex but that's what we have been researching and addressing for the past ten years!

Most come along wanting a quick 'fix' for their problems and are rather taken aback to find that I encourage them to 'put down their magnifying glasses and pick up a mirror' to find the solutions to their problems.

Once they step out of their reactionary 'cycle' and begin to understand what it is that is causing them to react the way they do, they can begin the process of healing and learning healthier ways to communicate and restore their relationship.

With a more balanced and appropriately supportive home life the journey of reconciliation and recovery can begin.

Today, the joy of my life is out there 'strutting his stuff' on his journey of recovery. He is magnificent. Each day I see enormous growth in his self-esteem and ability to address the problems life deals him. He is my champion of champions and my greatest teacher.

I believe the information presented in this overview is an enormous breakthrough in the way we view and treat the growing numbers of young people and their families experiencing co-occurring substance abuse and mental health disorders – and so is this program.

14. PRICE STRUCTURE AND BOOKING DETAILS

Originally designed to be presented as a two hour weekly session for a ten week period, it can also be presented as a Workshop, Week-End Retreat or Series of Seminars.

Prices start from \$500.00 for a 4 hour workshop (maximum 30 participants)
to \$5,000.00 for the full 20 hour program (maximum 30 participants)
(Exclusive of GST and where necessary travel & accommodation costs)
Perhaps a 4 day seminar would best suit your needs?

Help your families become a part of the recovery process. They are our biggest asset in combating this phenomenon.

If you would like to discuss this program further with me or make a booking - my contact details are as follows:

SUE KONINGEN
2/40 Government Road
Labrador Qld 4215

Phone: (07) 5537 9697 Mobile: 0412 732 717

Email: suekoningen@bigpond.com ABN 286 12173235

15. RESEARCH ATTACHMENT

Blamed and Ashamed: The Treatment Experiences of Youth With Co-occurring Substance Abuse and Mental Health Disorders and Their Families

Federation of Families for Children's Mental Health and Keys for Networking, Inc.

October 2000

Funded by the Child, Adolescent and Family Branch in the Federal Center for Mental Health Services, Substance Abuse and Mental Health Services Administration

Acknowledgements

We are deeply indebted to the youth and their families who shared intimate details of their lives so the rest of us would really understand their experiences. We also appreciate the cooperation of the Federation's state organizations and chapters for their ongoing support and a their assistance in recruiting individuals to participate in the focus groups.

The youth researchers, the Federation of Families for Children's Mental Health, and Keys for Networking, Inc. wish to acknowledge Dr. Nelba Chavez, Administrator of the Substance Abuse and Mental Health Services Administration. Her encouragement, leadership, and support made this work possible. We thank you for listening.

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Letter From The Federation of Families for Children's Mental Health

Dear Readers:

It has been both an honor and an adventure for the Federation of Families for Children's Mental Health to conduct this study with Keys for Networking, Inc., our statewide organization in Kansas, and a team of outstanding youth researchers. This was a unique project in which youth took the lead and adults provided training and technical support. This fine product is a tribute to the resilience, creativity, energy, and intelligence of the young men and women with co-occurring mental health and substance abuse disorders who designed the study and did the work. *Blamed and Ashamed* is a wake-up call to everyone concerned with improving services for children and youth who have both substance abuse and mental health problems.

We appreciate the cooperation of the Federation state organizations and chapters throughout the country for their assistance in recruiting individuals to participate in the focus groups. Mostly we are deeply indebted to the youth and their families who shared intimate details of their lives so the rest of us would really understand their experience. We are conscious of their trusting us to use their stories with respect and compassion.

Blamed and Ashamed was presented as a performance by some of the researchers at the Federation's Annual Conference in December of 2000. Dr. Bert Pepper, a member of the SAMHSA Advisory Council and an acknowledged expert on youth with co-occurring disorders, provided background information on this problem and commentary on our findings. His valuable remarks are appended to our report. We appreciate Dr. Pepper's validation of our work and his support of our recommendations.

We also gratefully acknowledge Dr. Nelba Chavez, Administrator of the Substance Abuse and Mental Health Services Administration at the time this study was conducted. Her encouragement, leadership, and financial support made this work possible. We thank you for listening.

Sincerely,
Barbara Huff, Executive Director
Federation of Families for Children's Mental Health

Executive Summary

This report presents the findings of a two-year project intended to document and summarize the experiences of youth with co-occurring mental health and substance abuse problems and their families. The purposes of this study were to offer youth and their families the opportunity to reflect on and give voice to their experiences, to identify their successes and concerns, and to formulate recommendations so that a national audience might learn from their experience and improve services. The work was funded by the Substance Abuse and Mental Health Services Administration (SAMHSA) in the U.S. Department of Health and Human Services and conducted by two family-run organizations—the Federation of Families for Children's Mental Health, Alexandria, Virginia, and Keys for Networking, Inc., Topeka, Kansas.

A unique and key feature of the study was the high ownership of youth throughout the process. Their control over the study led to a strong sense of power which was key to establishing the trust and comfort necessary for participants to think deeply about and honestly share details and feelings about experiences that were very personal—even painful.

Between 1997 and 1999, over 150 people from California, Georgia, Illinois, Kansas, Maine, New Mexico, Virginia, West Virginia, and the Washington, DC, area were interviewed or participated in focus groups. They represent a cross-section of youth with co-occurring mental health and substance abuse problems and their families. Youth participating were from every ethnic group and socio-economic status and ranged in age from 13 to 28. They all shared the experience of having resided in both mental health and substance abuse treatment facilities. Focus groups for youth and parents were held separately. Once the focus groups were completed, audiotapes were transcribed and a meeting was held in Kansas City to review and analyze the raw data. The Federation of Families for Children's Mental Health and Keys for Networking, Inc., wrote the final report.

The findings of this study are powerful. Tragically, youth with co-occurring mental health and substance abuse disorders and their families rarely get the kind of help they need at the time they need it. Services and supports are fragmented, isolated, and rigid. These negative experiences, however, direct us to the changes that are necessary to get better outcomes. Peer-to-peer support for both youth and families, really accurate and useful information for both youth and families, and combined treatment that includes families are necessary. And mostly, youth and their families want to be heard and respected. They want a say in deciding what services and supports they will receive as well as where and how they will be provided.

The report's recommendations are framed in the spirit of promoting positive change. They focus on how treatment, services, and supports for youth with co-occurring substance abuse and mental health disorders and their families are:

- thought about
- designed

- provided
- evaluated

The report's recommendations are intended to stimulate everyone who has an interest in this subject to reflect deeply about what can be done to improve practices and outcomes. Any change process occurs when individuals take responsibility and start to do things differently. Therefore, the recommendations are directed at providers, families, and youth. But they could be applied to a wide variety of individuals, as well as programs and systems. In addition, the report offers SAMHSA suggestions for activities to fund that would begin to address the key information and service needs identified by this study.

Recommendations for Providers

Listen carefully and attentively and treat youth and families with respect and dignity.

- Rely on them to guide you in understanding who they are, what they can do, and what problems they are facing.
- Use what you hear to reach your decisions and make your recommendations.

Involve youth.

- Actively engage youth in designing and evaluating programs.
- Offer youth access to information, and a voice in the decisions which get made about their treatment.
- Create opportunities for youth to help others in treatment and afterwards.
- Create options for youth to use their experience and turn it into positive growth. Help them reclaim self-esteem.

Make sure families are included. Invite them into the treatment process.

- Provide whole family treatment throughout the length of time the youth is in residential treatment to strengthen the bonds that get broken when children are not living at home.
- Provide or link the family to services after the youth returns home from treatment.
- Help parents understand the treatment process and help them learn how to notice their child's progress as well as signs of relapse.
- Extend treatment to parents as well as youth.
- Work with families to help them set realistic boundaries and enforce the rules they can live with.

Offer services and programs that deal with youth in an individualized way and treat each youth as a total person, and include the whole family in the healing process.

- Offer choices and include information about the benefits and risks associated with each one.
- Promote family-child interaction as core to treatment.
- Focus on the length of time the youth needs treatment instead of the length of time a family is able to pay for services or their insurance is willing to cover it.
- Combine substance abuse and mental health treatment—only focus on one before the other if the drug use is so serious that youth cannot function.

Deliver usable and helpful information on illness, treatment, after care, and funding to youth as well as to parents.

- Have friendly staff available to answer questions at convenient times so families can ask their questions.

- Provide easy access to information.
- Develop information specific to "what to do if/when my child relapses" so parents, paraprofessionals, and clergy listen and help youth without treating them as failures.
- Educate youth and parents on the effects and appropriate recommended dosage for prescription and nonprescription drugs.
- Include fathers, especially; develop programs to inform and support fathers.
- Educate parents about the symptoms of abuse and the effects of drugs so they can provide information to their children and so they will recognize regression when it occurs.

Develop public awareness of mental health issues and positive models of treatment to disseminate in schools, to families, and through youth groups.

- Develop and disseminate press releases showing good-looking role models taking prescription medication for mental health needs.

Recommendations for Family Members

Get involved and stay involved.

- Listen to what your child is saying. See it from their point of view. Walk a moment in their shoes.
- Address substance abuse and mental health issues with your child at the same time. Insist that treatment programs address both. Know the treatment program, visit the program, and visit your child. Be there and be there often.
- Support your child in treatment and "hear" what he/she has to say about all his/her problems.
- Praise your son or daughter for making progress and watch for signs of regression—but remember regression is part of recovery.
- Participate in evaluating the program as well as your child's treatment.

Educate, educate, educate.

- Tell other parents about mental health/substance abuse issues and treatment.
- Offer what you know to other families who need your support and can benefit from your experience.
- Offer your child access to information, and ensure that he/she has a voice in the decisions made about treatment issues.
- Respect your child's and your own openness and readiness for disclosure.
- Read everything and ask for more.
- Ask other parents who have been through this. They know.

Recommendations for Youth

Speak up and be heard.

- Speak out about getting better: what is helping you and what you need to make progress.
- Ask your parents to be part of your treatment. Ask them to learn about the "treatment."

Get reliable information and share what you know.

- Educate yourself on what prompts regression; know your own weaknesses.
- Know whom you can ask for help.
- Ask to mentor or help other young people with problems. They can benefit from what you have learned and what you have accomplished.
- Offer your expertise to treatment programs and share your observations with staff.

Recommendations for SAMHSA

Provide peer support

- Fund peer-to-peer youth outreach and network development.
- Fund family-to-family outreach and peer support activities.

Facilitate information dissemination

- Fund a multi-stakeholder process to identify information that is critically needed by youth and families.
- Fund family-run organizations to disseminate information in usable formats and use strategies that will get it to the people who need it most.

Support collaboration and integrated treatment

- Fund a multi-stakeholder process to promote collaboration between the substance abuse and mental health systems, agencies, and providers.
- Fund a multi-stakeholder process to develop and disseminate guidelines for providers to ensure services for youth with co-occurring mental health and substance abuse disorders are fully integrated and effective.

Blamed and Ashamed: The Treatment Experiences of Youth With Co-occurring Substance Abuse and Mental Health Disorders and Their Families

Introduction

This report presents the findings of a two-year project intended to document and summarize the experiences of youth with co-occurring mental health and substance abuse problems and their families. The purposes of this study were to offer youth and their families the opportunity to reflect on and give voice to their experiences, to identify their successes and concerns, and to formulate recommendations so that a national audience might learn from their experience and improve services. The work was funded by the Substance Abuse and Mental Health Services Administration in the U.S. Department of Health and Human Services and conducted by two family-run organizations — the Federation of Families for Children's Mental Health, Alexandria, Virginia and Keys for Networking, Inc., Topeka, Kansas.

A unique and key feature of the study was the high ownership of youth throughout. Their control over the study led to a strong sense of ownership which was key to establishing the trust and comfort necessary for participants to think deeply about and honestly share details and feelings about experiences that were very personal — even painful.

It was a new experience for youth to do this kind of work and they needed substantial training and support from more experienced adults to carry it out. Throughout the project, both the youth researchers and the family members assisting them had to work through the tensions inherent in their different perspectives and develop relationships which, in essence, transformed the traditional ways adults and youth relate to each other. The youth were really in charge. They learned how to exercise this new authority judiciously and understand the consequence of their decisions. The adults were really not in charge. They learned how to guide youth by providing training and support without the adults having the 'last say' about how the study would proceed.

A team of youth trained to be researchers designed the questions. They carried out the focus groups and interviews, and they analyzed the data. Keys for Networking, Inc., and the Federation of Families for Children's Mental Health provided support, training, and guidance, and compiled the information the youth had collected. The youth on this research team came from all over the country and did much of their work together via telephone conference calls facilitated by a researcher hired to teach them. Family-run organizations from around the country that are focused on advocacy for children with emotional and behavioral issues assisted by setting up focus groups and arranging interviews so youth could collect data from their states.

In the course of doing this study, both the youth and their parents voiced many stressful, painful, and very personal experiences related to the topic of addressing the needs of youth with co-occurring substance abuse and mental health problems and their families. The recommendations made as a result of these disclosures cut across class, race, and cultures and are much more than a simple critique of services. They point the way for policy makers and practitioners who are committed to achieving better outcomes in the future.

The youth and families who participated in or worked on this study took a risk when exposing themselves with their public testimony. Some youth and their parents were sharing their experiences with each other for the first time during this process. Everyone who took these risks did so because they wanted to help shape public policy and improve both the mental health and substance abuse service delivery systems for youth and their families. In Kansas City, small groups of youth and family members met and discussed the raw material

separately. The responses and conclusions of each group were shared in a manner that protected the identity of the individuals. In other words, parents could not tell which comments or experiences their own children and youth had contributed and youth could not tell what their own family members had said.

We learned much. Tragically, youth with co-occurring mental health and substance abuse disorders and their families rarely get the kind of help they need at the time they need it. Services and supports are fragmented, isolated, and rigid. Peer-to-peer support for both youth and families, really accurate and useful information for both youth and families, and combined treatment that includes families is called for. And mostly, youth and their families want to be heard and respected. They want a say in deciding what services and supports they will receive as well as where and how the services and supports will be provided.

Blamed and Ashamed: The Treatment Experiences of Youth With Co-occurring Substance Abuse and Mental Health Disorders and Their Families

How the Study Was Conducted

The study included a series of activities aimed at: (1) improving the understanding of the needs of youth with co-occurring mental health and substance abuse disorders and their families; and (2) providing policy makers and service providers with better information on how to respond to the needs of these youth and their families.

Participants

Between 1997 and 1999, over 150 people from California, Georgia, Illinois, Kansas, Maine, New Mexico, Virginia, West Virginia, and the Washington, DC, area were interviewed or participated in focus groups. They represent a cross-section of youth with co-occurring mental health and substance abuse problems and their families. Youth participating were from every ethnic group and socio-economic status and ranged in age from 13 to 28. They all shared the experience of having resided in both mental health and substance abuse treatment facilities. Focus groups for youth and parents were held separately.

Formulating The Questions

The team of youth researchers began with a series of interstate conference calls to design the study process and develop questions. Dr. Melissa Nolte, an independent evaluator and qualitative researcher whose specialty is participatory evaluation, worked with the youth researchers. Six conference calls were held with 10 youth and 6 adults to decide how to do the study, what to ask, and how to ask the questions. Questions were phrased differently for youth and for their parents in order to capture their different perspectives. Yet, the questions for both groups addressed the same broad areas of experience and explored the same three themes.

- What really worked to help you?
- How were your (or your child's) substance abuse and/or mental health issues addressed in the different treatment centers?
- What would you change?

Once the questions were developed, pilot focus groups were held under the supervision of Dr. Nolte and Dr. Jane Adams, Executive Director of Keys for Networking, Inc. Audiotapes of the pilot focus groups were reviewed and critiqued by the youth research team.

Training youth on interviewing and focus group techniques

Drs. Nolte and Adams provided training in conducting focus groups, eliciting group responses, and recording information. Ten youth (from Illinois, Kansas, Montana, Ohio, New York, and Virginia) participated in the focus group training. The training covered six areas:

- Each question was reviewed and its rationale discussed including examples of

"good" answers to each question and questions to use as probes for additional information.

- Instructions were given to manage the logistics including arriving early, arranging seating, handing out questions, locating restrooms, and other comforts for participants. Procedures were established to go over all the questions first, then solicit answers. Everyone was to be asked to answer; if they elected to pass, the interviewer was to go back to them.
- Confidentiality procedures were provided and discussed. Names would not be used (unless participants specifically requested) and data would be gathered so parents would be unable to identify responses from their own child.
- Managing problems arising from participant discussion and procedures to refer people to professionals were detailed.
- Instructions for telling participants how data was to be used were reviewed, including how they could request a copy of the final report.
- Instruction on the use of tape recorders was provided, including when to turn it on or off if participants requested to go 'off the record.'

Each youth trained as a focus group leader was provided with a focus group kit that included everything needed to conduct the focus group and record the data. The kit included:

- Rules for conducting the focus group.
- Sign up sheets, which were mailed back to Keys for Networking, Inc., so participants could get paid.
- Audio tapes and tape recorder.
- Letter to give to agencies, families, and youth to recruit participants and explain the project.
- Permission and consent forms with directions on how to get these completed.
- Confidentiality statements and directions for obtaining informed consent.
- Self-evaluation form for the focus group leader.
- Postage to mail everything back to Keys for Networking, Inc.

Gathering Data

Family-run organizations across the U.S. were invited to assist the youth researchers identify participants and convene focus groups of youth and family members who had the experience of both substance abuse and mental health residential treatments. Trained youth interviewers from this project facilitated the focus groups with the support of staff from Keys for Networking, Inc., and the local family-run organizations. There were 10 participants in each focus group; one third were groups of parents and family members and two thirds were groups of youth. The youth researchers actually conducted a total of 15 focus groups, held in California, Georgia, Illinois, Kansas, Maine, New Mexico, Virginia, West Virginia, and the Washington, DC, area. Data from four focus groups was discarded because the individuals participating in the focus groups did not meet the criterion of having both a substance abuse problem and a mental health disorder.¹ In addition to the focus groups, Keys for Networking, Inc., mailed questionnaires to ten parents who couldn't attend the focus groups themselves but who were willing to participate because their own child had been in a focus group. The questionnaires addressed the same issues that were discussed in the focus groups. Keys for Networking, Inc., received six completed questionnaires. These responses were added to the data from the focus groups.

Recording Responses

All the focus group sessions were audio taped. The tapes were transcribed by Dr. Nolte who helped youth researchers at Keys for Networking, Inc., compile all the raw data into lists of responses for each of the questions. Youth and parent responses were compiled separately. Duplicated items were combined.

Analyzing the Data

The research team felt strongly about who was qualified to analyze the data. They did not want to have some 'outsider' or a person removed from the data analyze it. It was, therefore, decided to hold a conference to examine the data looking for common and recurring themes. The meeting was held in Kansas City in October 1999. Twenty-nine individuals met for two days to review the information that had been collected, make sense of it, and develop recommendations.

The participants in the Kansas City meeting were carefully selected in order to ensure that there was a real 'member check.' Individuals were selected because they had firsthand experience with co-occurring mental health and substance abuse disorders and were astute and courageous enough to speak openly and frankly about it. In addition to this expertise, participant parents and youth were selected to ensure: (1) geographic distribution and representation from the sites where the focus groups were held; (2) social and economic mix; and (3) racial and cultural diversity. Youth participants were both in school and out. Some were living with families and some were not. Some of the young people had children of their own and some didn't. Some of the youth had been incarcerated. Parent participants included an adoptive mother who is a schoolteacher, a husband and wife who are cooks, a mother who works for a national policy organization, and a mother who directs a state agency.

The group consisted of 12 youth and 17 adults. Among the youth, four had conducted focus groups and three had been participants. Among the adults, nine served as workgroup leaders, facilitators, recorders, and logistical support during the meeting. There were five parents (including three who had participated in focus groups), and three adults with the experience, training, or skills to provide support and structure for youth when the going got tough for any of them. These three individuals were available round the clock.

Before getting started, this group acknowledged that everyone had strong emotions associated with the subject and that both youth and parents were anxious about talking about it in front of each other. The working conference, therefore, opened with low stress activities to help everyone get acquainted, build trust, and express anxieties and expectations. Youth and parents anonymously posted brief descriptions of their hopes and fears related to sharing this very personal information. These descriptions are summarized below to illustrate the range of emotions associated with the topic. These feelings are likely to be present in any setting with youth and their families where co-occurring mental health and substance abuse disorders are discussed.

Hopes

I hope to:

- Keep an open mind about others' experiences
- Hear others' experiences
- Touch others with my experiences
- Start something constructive for my life
- Help others feel free to express themselves
- Have a real and profound effect on services for children,

youth and families

- Improve services for other young people who need assistance in dealing with substance abuse and mental health
- Affect policies and make the process smoother for other youth facing substance abuse and mental health issues

Fears

I'm afraid:

- Of coming forward with all the hurts I've experienced
- I will be judged
- I will be embarrassed, frustrated, or say the wrong thing
- I will not touch everyone here. I'm afraid of hurting someone's feelings.

¹ Since participants in the focus groups were recruited by other individuals, agencies, and organizations, the focus group leaders did not necessarily know in advance who was attending. This left open the possibility that some participants would not have co-occurring disorders and the experience of residential treatment.

Blamed and Ashamed: The Treatment Experiences of Youth With Co-occurring Substance Abuse and Mental Health Disorders and Their Families

The Questions

1. [Where would you go to get information about substance abuse and mental health services?](#)

2. [How would you want information distributed to the community \(schools, justice department, etc.\) about substance abuse or mental health issues?](#)
3. [How has your substance abuse and mental health affected your family and everyday living?](#)
4. [Describe your substance abuse and mental health services. What could have made those services better?](#)
5. [What was the first residential treatment session you received like? How did you want it to be?](#)
6. [How could the initial residential treatment interview have been changed?](#)
7. [What kind of residential treatments have you received for your substance abuse and mental health issues? How were your substance abuse and mental health treatments combined? How would you combine them if they weren't?](#)
8. [Do you feel that your substance abuse led to your mental health problems or vice versa?](#)
9. [What was your aftercare program like? What did you need for a stronger aftercare program?](#)
10. [What was more important to focus on when you started your treatment, substance abuse or mental health issues?](#)
11. [How did you get into treatment? How did you want to get there?](#)
12. [What decisions would you have liked to have made about your treatment that were different from the choices you were given?](#)
13. [How were your parents' views on your treatment needs different from your own?](#)
14. [Which are you more comfortable with, telling people that you have a substance abuse problem or that you have a mental health problem?](#)
15. [If you were to relapse, whom would you tell and why?](#)
16. [Did they allow you/invite you to evaluate the services you received?](#)

Responses to Questions

There were hundreds of pages of transcripts from the focus groups and interviews. All were chock full of powerful statements about individual experiences yet each had features in common with many others. The responses to the questions are summarized below and illustrated with quotations from the transcripts.

Where would you go to get information about substance abuse and mental health services?	
Youth	Parents
<p>Youth identified many sources where they would seek information. These included professionals or service programs such as school counselors, Narcotics Anonymous, or community mental health centers as well as family members and friends. A few did not know where they would go. In choosing where to go, knowing that the source had experience with the issues and was reliable and trustworthy was important.</p> <p><i>"I'd go to a friend, or someone with experience, a peer. I'd go to a counselor at school."</i></p> <p><i>"I need someone I can go to as an older role model, someone I can trust, a 'peer advocate' or someone who has been through this."</i></p>	<p>Parents did not know where to go other than to agencies and programs that provide substance abuse treatment or mental health services. However, they said the information they got did not help them recognize their son or daughter was in trouble and needing help.</p> <p><i>"There was essentially no information before our child went to treatment."</i></p> <p><i>"I looked at church, youth groups, recreational centers, movies, television, and treatment centers for the right information—nothing fit our situation."</i></p>
How would you want information distributed to the community (schools, justice department, etc.) about substance abuse or mental health issues?	

Youth	Parents
<p>All youth thought other youth were the best source of information and suggested ways their personal strengths and talents could be used to distribute information (i.e., public speaking, writing poetry, rapping, youth crisis and warm lines). They advised that brochures, tapes, public service announcement, and such should be up to date and 'real.' They stated that word of mouth, preferably from peers, is effective and suggested door-to-door campaigns and personal testimony at rallies and school meetings.</p> <p><i>"I think they just have to listen to my story. I can give a lot of information because it's real. I lost everything and have all these health problems that follow and all that kind of stuff."</i></p> <p><i>"I think they should offer information about symptoms, services, and programs everywhere, so we can't, our parents can't miss it and will have it when we need it."</i></p>	<p>Parents thought parents who have been through it should educate other parents.</p> <p><i>"There needs to be a group of us, of us normal parents, who have children who were in trouble so we can relate to each other and so we can go out and tell other parents they are not alone."</i></p> <p>About half of them also thought the schools have a role to play and suggested using "parents who have recovering kids to talk to other parents" during drug awareness week and other school based opportunities for parents to share information. They also recommended:</p> <p><i>"Classroom resource guides so teachers can incorporate discussions."</i></p> <p><i>"Internet, school-based health and mental health centers, youth ministries, and parent hotlines and information centers."</i></p>

How has your substance abuse and mental health affected your family and everyday living?

Youth	Parents
<p>Youth experiences varied. Most reported that family life was really bad when they were using drugs.</p> <p><i>"It basically tore the family apart."</i></p> <p><i>"It's crazy around the house like she doesn't trust me with anything."</i></p> <p><i>"I'm fighting hurt feelings. My family turned their backs on me. They gave up on me because of ignorance, pain, and frustration. I am angry about that."</i></p> <p><i>"I just kind of quit everything."</i></p> <p>Some of these young people also acknowledged that their parents' efforts at supervision didn't work.</p> <p><i>"They tried locking me up in the house to keep me away from guys, keep me off the streets. It didn't work, it made me madder, made me run away."</i></p> <p><i>"She wants to keep me off the streets and it don't help. I just keep doing it cuz the weed has control over me right now and I don't listen."</i></p> <p><i>"They're trying to help me out, you know. I respect that, but it's my life."</i></p> <p>Some youth described parental indifference to their substance abuse or complicity with it.</p>	<p>Parents universally reported dramatic changes in their family and in relationships with their son or daughter.</p> <p><i>"Ripped it apart."</i></p> <p><i>"It changes your whole life, it really does. It changes how you talk to people, who you associate with, what you do, what plans you make, and what plans you don't make."</i></p> <p><i>"The house is chaotic all the time. We have no life."</i></p> <p><i>"It changes every aspect of your life, emotionally, financially, mentally. We're all so busy with my daughter and running her here and there. There's no time and no money left."</i></p> <p>Some parents stated that their child's substance abuse was actually a symptom of other serious problems in the family and that highlighting the drug problems got them to recognize they all needed help.</p> <p><i>"I can't say that she tore up the family, but she made the loudest noise and so we started getting some help."</i></p> <p>Many parents noted the change in their own social lives.</p> <p><i>"Because you don't know what's going to</i></p>

<p><i>"My dad does it too and it's ok as long as I do what I gotta do, he don't really care."</i> <i>"I'm around it every day, since my mom's boyfriend is always getting high downstairs. She doesn't really care because she knows that he gives it to me and my friends sometimes."</i></p> <p>Youth also expressed specific concern about the impact on schoolwork and especially on younger siblings.</p> <p><i>"It affected our family in huge ways. I am the bad apple. My mom vows that I will spoil my brothers and sisters. I have."</i></p> <p>The few youth who felt there was little or no impact on their family attributed it to their family not knowing about their problem. Youth felt punished and abandoned when they were sent away. They felt "put away" as if they didn't belong anymore.</p>	<p><i>happen tonight, you don't socialize. You don't have friends over, you don't go other places."</i></p> <p>Many also talked about added activities and time-consuming responsibilities.</p> <p><i>"Balancing caring for the family, caring for this child, and protecting other children from getting it is hard."</i> <i>"There are meetings four nights a week. We eat dinner at eleven o'clock at night."</i></p> <p>Parents described deterioration in relationships with their children.</p> <p><i>"I just couldn't trust him anymore, for anything. He would lie about the stupidest things, whether he actually brushed his teeth or not. But it seems to be very, very important for him to be able to be in control."</i></p> <p>Parents recognized the conflict between letting their son or daughter take responsibility for their behavior and doing all they could to support their recovery.</p> <p><i>"Protecting vs. letting her take responsibility is a push and pull thing."</i> <i>"You try and make it work for them, which we're not supposed to do, I know. But we're the moms. You do what you've got to do to protect them."</i> <i>"I know my daughter has to do it on her own, but she's my kid and I've gone this far to keep her alive. It's hard to just back off."</i></p> <p>Parents also mentioned that the financial drain, the stigma and shame "were transferred to the whole family."</p>
<p>Describe your substance abuse and mental health services. What could have made those services better?</p>	
<p>Youth</p>	<p>Parents</p>
<p>The youth talked mostly about their experiences with counseling—individual and group or family sessions. Their descriptions of these sessions were very powerful and also very negative. Youth felt ‘talked-at’ ignored, ‘set-up,’ blamed, and disempowered by counselors. Generally it was not helpful.</p> <p><i>"It really sucked!"</i></p>	<p>Parents described substance abuse and mental health treatment programs as oriented toward treatment for adults. No program successfully involved families in their son's or daughter's treatment.</p> <p><i>"The adult substance abuse system is not prepared to deal with interested or involved parents, let alone parent</i></p>

"The counselor made it seem like 'Oh it's all your fault. You're the one starting the problem with your father'."

"All I know is I didn't like it. My mom and me just sat there fighting the whole time."

"If your parents were to talk to them beforehand then they make it seem like everything is against you. It kind of felt like being set up."

"They talked to me for like a half hour and then the other half hour they talked to my mom and that didn't work for me because my mom would have a different story than I would. So we need to be in the same room so like we could talk and she could listen and understand."

"I guess he was scared of my dad, cuz every time my dad would jump in, he would let my dad take over and say whatever he want. He just had everybody in there and it didn't work. Everybody would talk at the same time; no one would listen to each other. He didn't have control of none of us."

"They'll do a family session and they'll have everyone go against me. That's actually a terrible way to counsel somebody. It makes it seem like you're stupid or you're bad."

Youth stated that they wanted counselors who listened to them, who could see their strengths, who were not judgmental, and who could advise them about strategies for getting along with parents or working on their problems.

"I wanted to be listened to. I needed support. I wanted someone who would hear both sides, mine and my parents'."

"The thing you don't want, at first, is to change. You want them to work with you and point out the good points, maybe even be on your side."

"I wanted the first session to be where it was just me and him, he would ask me questions, I would tell him how it went. He could like maybe tell me how I could talk to my parents, or whatever."

"I needed individual and family counseling to help me explore my problems. Then I needed help working them through with the family."

One Youth described a drug abuse class, which

advocates. Adult substance abuse treatments see parents who are involved as 'enablers.'"

"Pure AA systems make individual(s) responsible for actions and consequences. Young people need support from the family to put it together. We need help to figure this out."

Parents also objected to the separation of services by the substance abuse and mental health systems.

"Substance abuse and mental health need to be addressed as equally important, inextricably linked. Treatment centers don't see them as linked due to system division."

"We were told we'd have to enroll our son in one program, finish that, and then send him away to treatment. Our son was away for two years and he did not come home recovered from mental illness or substance abuse. He was a stranger to us."

Parents talked about their need for information: to know about treatments, to know what works, to be involved in planning the treatment for their child, to be included, to learn new ways to relate to a family, to know the signs of relapse, to set boundaries.

"They treated me like an interloper. They made me feel like it was my fault."

"They didn't even talk to us until our insurance ran out. Then he was all ours."

<p>she attended for one day.</p> <p><i>"It was mostly police stuff like what would be different kinds of arrest and what would be a felony and all that stuff about what would happen. It worked but I really didn't want to go."</i></p> <p>Another described an anger management program.</p> <p><i>"It was boring though, like an hour and half and I took like ten lessons but I didn't learn anything."</i></p>	
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What was the first residential treatment session you received like? How did you want it to be?

Youth	Parents
<p>Youth emphasized the importance of neutrality and strength. They want treatment staff to be fair, focus on the positives (rather than the negatives which was the general rule), and be strong enough to keep all sorts of personalities in balance.</p> <p><i>"Whoever is facilitating needs to be someone with a strong personality and 'neutral' and not give in to the aggressive person in the family."</i></p> <p><i>"I want them to make me feel like a person, and not look down on me. It is such a negative thing and so much focus on the negative aspects."</i></p> <p>Young people also want the atmosphere to be more welcoming and personal and they want their families to participate.</p> <p><i>"Youth should be allowed to take someone they are comfortable with to the first session."</i></p> <p><i>"I was able to continue counseling and therapy that fit my needs. However, my family did not continue their therapy. So it didn't work in the end."</i></p>	<p>Parents stated that the whole family needs help and it is insufficient to focus solely on one individual—even though that individual may have very great needs.</p> <p><i>"While the youth is in treatment, the family should be getting special counseling, then everyone should be brought together in joint counseling. It all works hand-in-hand."</i></p> <p><i>"Family must participate because family is affected. There needs to be something set up for the youth to go into right after treatment."</i></p> <p>Parents also recognize that they need help in understanding the treatment.</p> <p><i>"Parents need to know how to work with their kids and understand them at their level and understand the treatment."</i></p> <p>As much as parents are committed to full family involvement, they also recognize that sometimes their sons and daughters need some private space.</p> <p><i>"Allow youth to express issues privately so treatment is more effective in addressing the issues."</i></p>

How could the initial residential treatment interview have been changed?

Youth	Parents
<p>Youth tended to describe their first interviews as a formal event with a professional asking a lot of questions or someone filling in forms that had to be signed. They would have preferred situations that were more personal.</p> <p><i>"I felt intimidated, bombarded with repeated questions by the interviewer."</i></p> <p><i>"I would have [preferred going] one on one with someone closer to my own age."</i></p>	<p>Parents characterized half of their initial interviews as positive and half as negative. They tended to evaluate the initial interview in terms of how the interviewer approached their son or daughter and/or how truthfully their son or daughter responded.</p> <p><i>"[My daughter] just danced in circles with them—didn't give them any information, so they didn't focus on what they needed to</i></p>

<p><i>"I got tired of all the questions." "They didn't ask me how I felt about being there or if I wanted to be there."</i></p> <p>Young people want to be treated with respect and dignity.</p> <p><i>"I'd like to be treated like a person not just a case or money. Start with sensitivity, try and get to know us. Be friendly and help." "I was strip searched, psychoanalyzed, and had to take too many tests, too many questions. I want to be treated like a human being."</i></p>	<p><i>do." "I was very impressed with him [the interviewer] because he talked on my son's level. He wasn't judgmental or anything. My son really related to him."</i></p> <p>Parents admitted that they were 'on guard' during the intake, fearing they would be blamed or their child would not be admitted if they gave 'wrong' answers.</p> <p><i>"My input was based on the agency's perception of me as a parent. I was afraid they would say it was my fault." "Our input was driven by the need to get the child in treatment and safety rather than our real issues. Treatment occurred before they even talked to us."</i></p> <p>Parents would have liked the initial interview to be less formal, establish communication, and focus on the real issues that brought them to the facility in the first place.</p> <p><i>"The interview needs to be more focused on the youth's needs at the time, instead of just admitting to the treatment program."</i></p>
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What kind of residential treatments have you received for your substance abuse and mental health issues? How were your substance abuse and mental health treatments combined? How would you combine them if they weren't?

Youth	Parents
<p>Youth see the inter-relationship between mental health problems and substance abuse. They reported that substance abuse treatment without mental health treatment doesn't work. They recommend getting off drugs and combining medication and working on the "real issues." They value programs that help them find out who they are.</p> <p><i>"They worked mainly on substance abuse and I think they should split the time between mental health and substance abuse because I really honestly don't know anyone who has a substance abuse problem who doesn't have a mental problem." "I'd first get you off of drugs and then try to</i></p>	<p>Parents stated that their children needed to be treated holistically as teenagers yet they described a variety of treatment patterns—some separate and some combined. These included counseling, groups, Alcoholics Anonymous, self-medication, inpatient treatment, day programs, private psychologists, and aftercare. Parents talked about the confusion of service fragmentation and how often it was their own efforts that resulted in combining treatment. Yet, they get no credit and much blame.</p> <p><i>"We need programs that deal with our child as a whole." "It was our responsibility as family members to put the two together, substance</i></p>

<p>figure out what you were covering up with your using and go from there."</p> <p>"I didn't want to hear from someone else, who I was. They basically help you understand. They really got me to look at myself. The treatment I received was pretty sufficient for both mental health issues and substance abuse."</p> <p>"When you're in [substance abuse] treatment you should work on also mental health issues because a lot of your mental health issues have to do with drugs."</p> <p>Some youth mentioned that lack of family participation was a problem.</p> <p><i>"When I was ordered to treatment, I was forced to get services. My parents were not."</i></p> <p><i>"When it was over, I was sent back to an unhealthy environment, back with parents who sometimes use, back with parents who knew nothing about how to help me."</i></p>	<p><i>abuse and mental health. No one even offered to help us sort this out."</i></p> <p><i>"We need access to funding streams that allow us to get services in both areas. We don't know when substance abuse is a problem or is the problem mental health? How are we supposed to know!"</i></p> <p>All the parents mentioned the lack of family participation.</p>
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Do you feel that your substance abuse led to your mental health problems or vice versa?

Youth	Parents
<p>All youth stated that their mental health or emotional problems existed before they got involved with drugs or alcohol.</p> <p><i>"Ineffective interventions with my mental health symptoms resulted in my substance abuse."</i></p> <p><i>"My depression led me to using drugs to try and work my way out of it."</i></p> <p><i>"I used substances to forget my problems."</i></p> <p>Some also recognized that substance abuse exacerbated their mental health problems or brought on new ones.</p> <p><i>"My emotional feelings led to my drug use, but drug use led to a lot of mental health problems down the road, so it's like that vicious cycle they talk about; one thing leads to another."</i></p> <p><i>"My substance abuse fed my mental health problems and made them much worse than they actually were."</i></p>	<p>Parents generally felt the underlying mental health problems, largely untreated or ineffectively treated, led their child to substance abuse. They saw substance abuse as a form of escape from mental health problems their sons and daughters did not understand. They chided the substance abuse system for refusing to deal with mental health issues.</p> <p><i>"Untreated mental health problems led to my child's substance abuse."</i></p> <p><i>"No one at substance abuse even asked about mental illness."</i></p>

What was your aftercare program like? What did you need for a stronger aftercare program?

Youth	Parents
<p>About a third had no aftercare program. Comments from those who did were generally positive but for some, "It was the same—I hate</p>	<p>Parents stated that they did not know what aftercare was. They said there was no such program and described concerns about getting</p>

<p>going." What works seems to be an individualized approach.</p> <p><i>"They sent a letter in the mail directly to me rather than my dad or mom, which made me somewhat important. The fact that it was personalized was really cool. Or for that matter, they actually cared enough to write a letter back."</i></p> <p><i>"What I personally do, I go to aftercare once a week, I go to a brief one every day. And I have a sponsor who I talked to everyday on the phone and all my friends are clean and they're from my home group."</i></p> <p><i>"The sessions were all right, at least this time. The counselor said, 'Well, you know you got a real bad temper, your father has a bad temper, your sister has a bad temper. I guess it just runs in the family.' Nothing would have made them better really, me and my dad just never talk."</i></p> <p><i>"What I needed, they gave me, they gave me a psychiatrist. I just wish that he would talk longer, that's all. He just asks me common questions about how school is and things like that cause he's on a tight schedule, cause he always synchronizes his watch whenever I speak to him."</i></p> <p>Youth recommendations for stronger aftercare include more opportunities to make 'clean' friends and to "discuss stuff" related to their treatment. They also suggested younger staff and people they could feel comfortable with and trust.</p> <p><i>"I got to two to four meetings a week, and just going once to aftercare is not enough."</i></p> <p><i>"It's easier to talk to people who are around your age."</i></p> <p><i>"Reliable peer or case management would help."</i></p> <p>Youth also mentioned that they needed help from their families to get to aftercare services and this was sometimes difficult.</p>	<p>aftercare started but generally were pleased with the services once they began.</p> <p><i>"Until I find the right one, I'm just kind of holding my breath that she can maintain long enough to get started."</i></p> <p>They mentioned making new friends and having 'clean' fun as being important for their son or daughter.</p> <p><i>"It's helping more than an intensive program. It's getting them involved with people who've been through the program and who are wanting to stay clean. Because that's the most important thing; they're going to have to have new friends."</i></p> <p><i>"Just the camaraderie seems to be helping more than anything."</i></p> <p><i>"I'm not sitting in front of a counselor pouring out my guts, I can go have fun."</i></p> <p>In addition, parents mentioned long waiting periods, little or no connection between residential treatment and aftercare, and the adult treatment model that puts full responsibility on the youth and excludes the family as being obstacles to overcome.</p> <p><i>"Young people are expected to take full responsibility for themselves. I feel that the service model needs to be revised to support the youth in making aftercare a success."</i></p> <p><i>"The parent as participant—family involvement—is not considered favorable in aftercare. Youth need support until they can do it on their own. They are not yet adults."</i></p>
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What was more important to focus on when you started your treatment, substance abuse or mental health issues?	
Youth	Parents
<p>Youth were fairly evenly split on whether their mental health or substance abuse issues were more important to focus on at the start of treatment. Those who favored treatment for their substance abuse problems focused on the</p>	<p>Parents had difficulty choosing one problem over the other and for the most part described how they interacted and both needed to be addressed.</p> <p><i>"I kind of thought they went hand in hand, that as they worked on his substance abuse,</i></p>

<p>physical danger they were in or their lack of awareness of their mental health problems.</p> <p><i>"If I didn't get off drugs the right way, I was gonna die."</i></p> <p><i>"I wasn't aware of my emotional problems or anything."</i></p> <p><i>"Sometimes it's just overwhelming and you feel like you're just on the verge to do something that might damage you or the others around you."</i></p> <p>Those who favored treatment for mental health issues attributed their problems to their family background or going "through a stage."</p>	<p><i>they also worked on his mental health side to understand why he's abusing and how to quit abusing."</i></p> <p>About half the parents stated that their child's mental health issues were neglected.</p> <p><i>"I felt like they focused more on the substance abuse, which was a severe problem, but I don't think there was enough focus on the mental health issues, to be honest."</i></p> <p><i>"She's got a lot of anger issues and I just wish they would have worked more on that."</i></p> <p>At the same time, they saw that substance abuse had to be brought under control in order for their son or daughter to make progress with the underlying mental health issues.</p> <p><i>"She has emotional problems but they couldn't be addressed until she wasn't on drugs and she was on drugs because she had emotional problems. Keeping her structured and in one place was able at least to keep her clean long enough to get to some of the problems."</i></p>
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How did you get into treatment? How did you want to get there?

Youth	Parents
<p>The vast majority of youth were forced into treatment by their parents or a court. They all wished they had gone into treatment voluntarily. However, they acknowledged that they were resisting treatment at the time.</p> <p><i>"At the time I didn't want to get there but since I had to go I wish I could have made the decision on my own to go."</i></p> <p><i>"My mom kept referring and I kept putting it off and finally she had me arrested as a runaway."</i></p> <p><i>"Once I got in the group and learned about why I had problems, I wished I had gone on my own. Being forced into it was a good thing for me."</i></p> <p><i>"I would have wanted it to be that they were acting upon first detection of behavior they couldn't understand."</i></p> <p><i>"I wanted to get into treatment on my own, but I didn't. I wanted to go get help with assistance from someone close to me, like my mother. She is always there for me."</i></p>	<p>Parents reported three ways their sons and daughters got into treatment: 1) voluntarily (which rarely happened); 2) enrolled by parents; or 3) involuntarily through the courts or social services (sometimes because parents called the police). All parents would have liked their child to enter treatment voluntarily. In addition, parents reported that they did not have sufficient information to recognize or understand the depth of their son's or daughter's problems which made it easy to conceal until they did something that caught the attention of some outside agency (such as the police).</p> <p><i>"I had no information about how to identify the symptoms of substance abuse. I didn't know there was a problem. When I did get suspicious, there was not enough information to handle the problem. I didn't know what to do or where to go!"</i></p> <p>Consistently, all parents indicated that they would have liked their child to voluntarily enter treatment.</p>

What decisions would you have liked to have made about your treatment that were different from the choices you were given?

Youth	Parents
<p>The underlying theme in all the youth responses was having choices and having a say in decisions.</p> <p><i>"There was never an alternative or a choice. Just do it."</i></p> <p><i>"I wanted to be a participant in the decision process for my own treatment. My parents, probation officer, etc., made all the important decisions. This caused me to go into the program with a negative outlook."</i></p> <p>Youth would have liked to choose where they were going to receive treatment and to have a say about the length of their stay and have more information and preparation for transitions and entering new programs.</p> <p><i>"I would say the decisions I would have liked to have made were all done before I got to treatment."</i></p> <p><i>"I would have liked to choose to go somewhere else or had outpatient treatment."</i></p> <p><i>"It was difficult to deal with a different group of people from different areas. There should be more preparation for that."</i></p> <p>Being able decide about taking medication was very important to youth.</p> <p><i>"I would rather have been given a choice of whether to take medication or not, but no ultimatum, no alternative, they don't even tell that if you don't take it you get restrained."</i></p> <p><i>"If I didn't take, then I'd get restrained. They treated people like crazed dogs or animals. They give you no choice."</i></p> <p>They would also have liked more contact with their families.</p> <p><i>"My parents could not be involved because of the structure of the treatment. I was told this was my problem."</i></p> <p><i>"Families needed to be involved, because once I was treated I returned to my family."</i></p>	<p>The underlying theme in all the parent responses was having choices and having a say in decisions. Most of the parents felt they had not been given any choice of program—this decision was made by some agency with authority (social services or a court). Those who had a choice of program found it difficult to find reliable information about something that was likely to work for their family.</p> <p><i>"System information was driven by the provider's needs and not the youth's or family's needs."</i></p> <p>One parent suggested that choices might not have been a good idea because they were so overwhelmed and could not have made one.</p>

How were your parents' views on your treatment needs different from your own?

Youth	Parents
<p>Youth reported that they did not see eye-to-eye with their parents—especially at first.</p>	<p>Parents reported that they did not see eye-to-eye with their sons and daughters—especially at first.</p>

<p><i>"She was more for it and I wasn't, see."</i> <i>"My parents took my treatment a lot more serious than me and I'm grateful for that because I probably wouldn't be clean if they hadn't."</i></p> <p>Youth also described their parents as having expectations that were unrealistic or being over controlling.</p> <p><i>"My parents thought that as soon as I came out I had to be this new person and it obviously never worked. By the end of the last treatment center, I was ready to make a change and my parents really supported it."</i> <i>"I can't even go outside and smoke a cigarette without them asking where I'm going, what I'm doing. There's like, no trust."</i> <i>"Every time I needed money or something else it was always up to them to get it. So it just caused big problems."</i></p> <p>Youth described their parents isolating them as 'the' problem and denying that there was a family issue to deal with. Involved and supportive families were valued and contributed to the youth's progress and recovery.</p> <p><i>"My mom and me agreed on everything, and that was one of the biggest factors in getting through my treatment. It helps when someone agrees with your views."</i> <i>"Family support is a strong issue, and they have to be involved in the treatment."</i> <i>"There should be some information for the parents to encourage them to want to be involved. If the child gives up, the parent or support needs to want it for them. It's sad to see the parent give up."</i></p>	<p><i>"In the beginning I think she had an attitude, then she realized that she had to cooperate to get through the program and she accepted it."</i> <i>"I, of course, wanted something that could save my child, so our views were very different. I was willing to make her do anything. She was willing to get out of doing anything and that's kind of where we were."</i> <i>"My daughter thought it [treatment] was way too long. I thought it [treatment] was way too short."</i> <i>"I was there to break down what was wrong, what was going on in order to figure out how to not have it happen any more. He was of the frame of mind that he didn't want to be there, nothing was wrong and he most certainly didn't want me in his face."</i></p> <p>Parents described how the treatment separated them from their son or daughter and failed to effectively involve the family.</p> <p><i>"There was no attempt to involve family, which created a sense of isolation."</i> <i>"The program needs to help resolve parent conflict and heal the family."</i></p>
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<p>Which are you more comfortable with, telling people that you have a substance abuse problem or that you have a mental health problem?</p>	
<p>Youth</p> <p>Youth were universally more comfortable telling people about substance abuse problems. They felt that there is a general understanding of substance abuse and alcoholism but there is limited understanding and great stigma associated with mental health problems.</p> <p><i>"More people understand what using drugs is about . . . it is more common than mental health issues."</i></p>	<p>Parents</p> <p>Parents said they too were more comfortable talking about substance abuse problems. Most said they would let their children take the lead.</p> <p><i>"I just have a handful of people that I talk about it with, because she is so complicated."</i></p> <p>Many parents expressed an active desire to talk about both mental health and substance abuse as a way to educate others. All the parents were</p>

<p><i>"They hear better if you say, 'I'm a weed head; I'm stuck on weed', than 'there's something wrong with my head; I'm going crazy'."</i></p> <p><i>"I'm not really comfortable telling people any of those things because to me, people stereotype and put people down if they have a problem."</i></p> <p>In some cases the youth reported that they did not understand their mental health problems well enough to explain them to others.</p> <p><i>"Substance abuse would be what I would talk about because I really don't understand why I'm depressed."</i></p> <p>Youth who were comfortable talking about mental health issues were getting effective treatment for their problem.</p> <p><i>"First I would only talk about mental health. But I'm pretty open. I feel I can talk about it because it's part of my life. I feel I'm getting help with it, so it doesn't need to be hidden."</i></p>	<p>willing to reach out to other families to share.</p> <p><i>"I don't have a problem telling anybody anything because I'm proud of what he did [in treatment] and I would like to be an advocate to parents; you know, 'Don't do what I did'."</i></p> <p>Parents also mentioned that confidentiality and legal issues sometimes made it difficult to talk openly. However, they felt it was a family decision—typically led by their son or daughter—whether or not any of them would speak publicly about their experience.</p> <p><i>"The issue is if the child is comfortable with talking about it, it becomes more comfortable for the family."</i></p>
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If you were to relapse, whom would you tell and why?

Youth	Parents
<p>Most youth reported they would go to family members or supportive and understanding friends. The words they used to describe the individual they would seek out showed they recognized the family members who can be trusted to offer help and support without judgement. They emphasized trust.</p> <p><i>"It is very important to trust who you are talking to: peer advocates, case managers, and counselors."</i></p> <p><i>"If I was real worried about it I'd tell my mom because I know that she would help me come up with some ideas of things I could do."</i></p> <p><i>"My best friend, because he would be supportive of me . . . he wouldn't look down on me."</i></p> <p><i>"My grandma, because that's the only person who really be trying to help me instead of going behind my back. She be trying to help me, get me to the hospital or something."</i></p> <p>Youth also would seek out others who shared their experience and had constructive advice about making positive change.</p>	<p>Parents almost universally said they would go to a professional—typically someone with whom they and their child already had a positive and trusting relationship. Parents were looking for advice and guidance about what they were "supposed to do first to make this curable and fix this?"</p> <p><i>"I knew Shane was a professional that would know what to do, and I knew that he understood her too."</i></p> <p>A few parents would go to close friends mostly for "emotional support." One parent was very clear about whom NOT to tell.</p> <p><i>"I would not tell my husband's parents. They are very closed-minded about what you can do to help."</i></p> <p>But some families were at a loss as to where to turn.</p> <p><i>"How do you connect with a community based service when there is no continuing care and no one to talk to?"</i></p>

<p><i>"I would tell my best friend because he's been through treatment and he knows what I've been through and where I'm coming from."</i></p> <p><i>"I would tell my mom because she would do something and she's gone through this with me and all that."</i></p>	
<p>Were you allowed/invited to evaluate the services you received?</p>	
<p>Youth</p>	<p>Parents</p>
<p>Never</p>	<p>Never</p>

Blamed and Ashamed: The Treatment Experiences of Youth With Co-occurring Substance Abuse and Mental Health Disorders and Their Families

What We Learned—Conclusions

None of the youth or parents involved in this process had ever been invited, until now, to evaluate the worth of services they did or did not receive. Nor had they ever been asked to make any recommendations for future services. The participants in the Kansas City conference took time to carefully review and reflect on the data before identifying several key themes.

All the youth and family members were severely blamed and shamed by providers and systems when they needed nonjudgmental recognition of their struggle to find caring help and support. Both youth and their parents pointed out that blaming one another hurts deeply and contributes to the complex array of problems they face (i.e., anger, hurt, frustration, lack of services and support, isolation, disappointment, conflict, etc.). Youth and their families want and need providers, programs, and systems that focus on and reinforce the positive and stress the use of their strengths to overcome or remediate their problems.

Youth with co-occurring substance abuse and mental health disorders and their families need and want to be treated with dignity, respect, honesty, and fairness. They want a voice in making decisions about their care and treatment—whether or not to take medications, where to go for treatment, whom to talk with, and how long treatment should last. Many youth want to get better but react strongly to the inhumane way in which they feel they are treated. They become resistant to participation or, at best, they ‘fake-it’ to get through a program. The result is release from treatment (after the standard period of time) without any real change—often resulting in a relapse. Indeed, recovery begins after youth and families themselves choose to change their behavior and engage in treatment activities or access programs and services that meet their needs.

Co-occurring substance abuse and mental health disorders are inseparable problems and cannot be effectively addressed in isolation from each other. The current categorical distinctions reflected in the funding streams and administrative structures for physical and

mental health services, substance abuse services, social and family services, educational services, and legal services have prevented youth and their families from obtaining the kind of comprehensive and integrated treatment they need. Complex physical, psychological, social, economic, and environmental factors contribute to the substance abuse among youth with mental health problems. All these factors must be considered in order to individually design treatments, services, and supports that will be effective for any particular young person and his or her family.

Co-occurring substance abuse and mental health disorders affect the entire family and cannot be effectively addressed without including everyone who plays a key role in the child's life. Conversely, values and attitudes about mental health and substance abuse as well as behaviors and relationships among family members influence how youth and their families seek help and respond to services. The culture and beliefs as well as the strengths and problems within a family must be taken into consideration and should drive the design of intensive treatment and after care services.

Families, regardless of their specific characteristics, are a permanent part of a child's life while services and providers come and go. While youth and their families rarely see eye-to-eye at the crisis point when they first enter services; however, most youth return to their families and communities after treatment. Unless they find improvement, they will quickly relapse. Bonds of affection and trust between youth and families are weakened when they are separated during residential treatment. Families need help to maintain relationships with a young person who is temporarily not living at home and to create the supportive and structured environment a youth needs to continue or complete his/her recovery during aftercare.

Youth often experience serious legal trouble before treatment for co-occurring substance abuse and mental health disorders become available. This is too late. Early warning signs go unnoticed or are deliberately ignored, leading to escalation in destructive behaviors. Co-occurring substance abuse and mental health disorders, when ineffectively treated, create great stress in the family; escalate conflicts among parents, children, and siblings; and impair a family's ability to intervene appropriately or effectively.

Currently treatment programs for substance abuse and mental health disorders are based on an adult model. The principles upon which they are built are inappropriate for adolescents who are not developmentally ready to take the level of personal responsibility required. Furthermore, adult models intentionally exclude families from treatment planning, implementation, or aftercare. Youth with co-occurring substance abuse and mental health problems cannot, and should not, be totally independent of their families. They are not finished 'growing up' and have not learned all they need to know about choosing friends, finding and keeping a job, getting to meetings, and accessing services. Without family involvement and family support (emotional and financial), most youth cannot follow through with the requirements of a treatment or aftercare program.

There is a tragic lack of helpful information about substance abuse and mental health disorders, accompanied by a widespread stigma, prejudice, and misinformation about the disorders. Youth and families from all walks of life need and want access to reliable, straightforward, and current information about early warning signs and symptoms. They want and need effective treatments, access to services, and coping skills training. Youth who are in recovery from co-occurring substance abuse and mental health disorders and their families have been the best source of information and support for others who are facing these problems. Youth and family outreach and support from peers are greatly needed and sadly lacking. Peer-to-peer networks for youth should be developed and operated by and for the youth themselves.

Blamed and Ashamed: The Treatment Experiences of Youth With Co-occurring Substance Abuse and Mental Health Disorders and Their Families

Recommendations

Our recommendations are framed in the spirit of promoting positive change in how treatment, services, and supports for youth with co-occurring substance abuse and mental health disorders and their families are designed, provided, and evaluated. The recommendations are derived from what we have learned, and we hope they will stimulate everyone who has an interest in this subject to reflect deeply about what can be done to improve practice and outcomes. Change occurs only when individuals take responsibility and begin to do things differently. Our recommendations are directed at all those involved—providers, families, youth, and treatment systems. In addition, we offer the Substance Abuse and Mental Health Services Administration (SAMHSA) our suggestions for activities to fund that would begin to address the recommendations and needs identified by this study.

Recommendations for Providers

Listen carefully and attentively and treat youth and families with respect and dignity.

- Rely on them to guide you in understanding who they are, what they can do, and what problems they are facing.
- Use what you hear to reach your decisions and make your recommendations.

Involve youth.

- Actively engage youth in designing and evaluating programs.
- Offer youth access to information, and a voice in their treatment decisions.
- Create opportunities for youth to help others in treatment and aftercare (mentoring).
- Create opportunities for youth to use their experience and turn it into positive growth. Help them reclaim self-esteem.

Make sure families are included. Invite them into the treatment process.

- Provide whole family treatment throughout the length of time the youth is in residential treatment to strengthen the bonds that are broken when children are not living at home.
- Provide or link the family to services when the youth returns home from treatment.

- Help parents understand the treatment process and help them learn how to notice their child's progress as well as signs of relapse.
- Extend treatment to parents as well as youth.
- Work with families to help them set realistic boundaries and enforce the rules they can live with successfully.

Offer services and programs that deal with youth in an individualized way and treat each youth as a total person. Include the whole family in the healing process.

- Offer choices and include information about the benefits and risks associated with treatment options.
- Promote family-child interaction as core to treatment.
- Focus on the length of time the youth needs treatment instead of the length of time a family is able to pay for services or their insurance is willing to cover it.
- Combine substance abuse and mental health treatment—only focus on one before the other if the drug use is so serious that youth cannot function.

Deliver usable and helpful information on illness, treatment, after care, and funding to youth as well as to parents.

- Have friendly staff available to answer the families questions at convenient times.
- Provide easy access to information.
- Develop information specific to "what to do if/when my child relapses" so parents, paraprofessionals, and clergy listen and help children without treating them as failures.
- Educate youth and parents on the effects and appropriate recommended dosage for prescription and nonprescription drugs.
- Include fathers, especially. Develop programs that inform and support fathers.
- Educate parents about the symptoms of abuse and the effects of drug abuse so they can provide information to their children and so they will recognize regression when it occurs.

Develop public awareness of mental health issues and positive models of treatment to disseminate in schools, to families, and through youth groups.

- Develop and disseminate press releases showing positive role models taking prescription medication for mental health needs.

Recommendations for Family Members

Get involved and stay involved.

- Listen to what your child is saying. See it from his/her point of view, and try to walk a moment in his/her shoes.
- Address substance abuse and mental health issues with your child at the same time. Insist that treatment programs address both. Know the treatment program, visit the program, and visit your child. Be there, and be there often.
- Support your child in treatment and "hear" what he/she has to say about all problems.
- Praise your son or daughter for making progress and watch for signs of regression, but remember regression is part of recovery.
- Participate in evaluating the program as well as your child's treatment.

Educate, educate, educate.

- Tell other parents about mental health/substance abuse issues and treatment.

- Offer what you know to other families who need your support and can benefit from your experience.
- Offer your child access to information and ensure that he/she has a voice in the decisions that get made about treatment issues.
- Respect your child's and your own openness and readiness for disclosure.
- Read everything you're given and ask for more.
- Ask other parents who have been through this. They know.

Recommendations for Youth

Speak up and be heard.

- Speak out about getting better—what is helping you and what you need to make progress.
- Ask your parents to be part of your treatment. Ask them to learn about the "treatment."

Get reliable information and share what you know.

- Educate yourself on what prompts regression. Know your own weaknesses.
- Know whom you can ask for help.
- Ask to mentor or help other young people with problems. They can benefit from what you have learned and what you have accomplished.
- Offer your expertise to treatment programs and share your observations with staff.

Recommendations for SAMHSA

Provide peer support

- Fund peer-to-peer youth outreach and network development.
- Fund family-to-family outreach and peer support activities.

Facilitate information dissemination

- Fund a multi-stakeholder process to identify information that is critically needed by youth and families.
- Fund family-run organizations to disseminate information in usable formats and use strategies that will get it to the people who need it most.

Support collaboration and integrated treatment

- Fund a multi-stakeholder process to promote collaboration between the substance abuse and mental health systems, agencies, and providers.
- Fund a multi-stakeholder process to develop and disseminate guidelines for providers to ensure services for youth with co-occurring mental health and substance abuse disorders are fully integrated and effective.

Blamed and Ashamed: The Treatment Experiences of Youth With Co-occurring Substance Abuse and Mental Health Disorders and Their Families

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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 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 1990s, 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 alcohol and other drug abuse. AND, the commonest cause of relapse to the use of alcohol and other drug abuse 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 1960s and 1970s the treating agencies denied that co-occurring mental health and alcohol and other drug abuse problems existed.
- By the 1980s there was general acknowledgement that the problem of co-occurring disorders did, indeed, exist.

- By the 1990s 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 runaround.
- 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 alcohol and other drug abuse 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 on. 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've 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 alcohol and other drug abuse services tend to put forward the following kinds of arguments:

- "We know that what is being done now doesn't work."
- "But let's not set up a new system for co-occurring disorders."
- "That would be too costly."
- "Don't ask my agency to take on the task."
- "That would further overburden us." *and*
- "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 selfmedicate 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 alcohol and other drug abuse problem.

- The majority of people with schizophrenia, who also have an alcohol and other drug abuse problem.
- The majority of people with manic depression, 60% of whom have an alcohol and other drug abuse 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?

- 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
- During the past forty years the population of the country has risen by 100,000,000 people.
- 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.
- 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.
- We used to have too many beds and over-hospitalization: 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 alcohol and other drug abuse disorders. The survey data suggests that:

- Between 8 and 11 million persons in the United States have at least one mental health and at least one substance-related disorder today.
- The mental disorder developed first in more than 85% of these people.
- 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!
- 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 alcohol and other drug abuse disorder some years later—usually substance abuse—suggests that they are selfmedicating 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 alcohol and other drug abuse. Remember, only one in five children with a mental health disorder gets treated today.

Blamed and Ashamed: The Treatment Experiences of Youth With Co-occurring Substance Abuse and Mental Health Disorders and Their Families

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 alcohol and other drug abuse starts, the shorter and faster the road to abuse and dependence:

- **Experimentation:** Almost all drug abuse begins this way. Young people are curious, feel invulnerable, and just want to see what it's like.
- **Recreational alcohol and other drug abuse:** If experimentation progresses, the young person will be using, with friends, once or twice a week...or every day.
- **Habitual use:** With continued recreational use, vulnerable individuals, especially those with a mental health problem, increase the amount and frequency of use.
- **Drug abuse:** When alcohol and other drug abuse becomes so frequent and important that it interferes with school, family life, and personal development, the person has reached this level.
- **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 several common personality immaturities that may result from childhood and adolescent mental health/alcohol and other drug abuse problems. Each is normal in a young child:

- **Low frustration tolerance:** Trouble working hard, and sticking to it, when gratification is not immediate.
- **Lying to avoid punishment.**
- **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.
- **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.
- **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.
- **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.
- **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.
- **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 ([Figure 4](#)), 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 them 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 alcohol and other drug abuse problems may experience their drug of choice as their best friend; it seems to fill the emptiness in their heart. Beginning drug abuse treatment, which requires or 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 alcohol and other drug abuse 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 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:

- The young person and their family is caught between the different treatment philosophies and values of the mental health and substance abuse agency.
- It is difficult if not impossible to coordinate two different treatment and recovery plans.
- Treatment is more expensive because of duplicated services.
- Parallel and collaborative treatment fragments the person and is not holistic.
- 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 nowhere 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. We must provide preventive, supportive, educational treatment and rehabilitative services. We must also support overburdened families, so that the wonders of our technology, our wealth, and our concern for each other benefit all of us.