

# YOUTH AT HIGH RISK OF CHEMICAL DEPENDENCE: IDENTIFICATION AND INTERVENTION OPPORTUNITIES FOR THE PSYCHIATRIST

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## EDITOR'S NOTE

Preventive strategies are an inherent part of psychiatric practice. Essentially, in the course of successful psychotherapy, healing is accompanied by the development of coping abilities that will enable a patient to deal with future stress in a healthier and more effective way.

Drug abuse prevention is no exception. This problem has clearly reached epidemic proportions. Epidemiologic studies indicate that there is a *sequence* of drug use among youth, from alcohol and/or cigarettes on to the use of marijuana (called gateway drugs), and thence on to cocaine and other serious substances. The ninth grade, as puberty occurs, is the critical time of onset for gateway experimentation: preventive measures must be in place prior to and at that age.

Youth at high risk of drug abuse share certain personality characteristics: interest in present-tense pleasure; lack of concern for the feelings of others; relative imperviousness to the impact of punishment; frequent and easy lying; and alienation from and antagonism toward adults.

Scare tactics may work well for other youngsters, but not so with those possessing this high risk profile. Among the effective methods used thus far is "peer refusal," i.e. training youngsters in the sixth to tenth grades to say no to drugs offered by peers. Mobilization of caring adults is another approach, encouraging them to learn how to set intelligent limits and institute effective controls and methods of punishment. Most important is an attempt to establish meaningful bonds between youngsters and adults. In the treatment and prevention of adolescent drug abuse, work with family groups is essential.

## Introduction

Whereas alcohol and drug use is common among American teenagers, it is not universal. Some youths, however, are at high risk for drug and alcohol problems, and a new body of clinical and epidemiologic research supports early identification of those high-risk individuals and offers specific interventions. This lesson explores that knowledge and furnishes some suggestions for applying the information to the clinical psychiatric setting.

In order to understand the issue, it is helpful to review the current knowledge about drug use in the United States. Much of that research was recently summarized in the second triennial report to the U.S. Congress from the Secretary of Health and Human Services, entitled *Drug Abuse and Drug Abuse Research*,<sup>1</sup> and some was reported by this author in an earlier lesson in this series.<sup>2</sup>

During the past two decades the United States has experienced an unprecedented increase in the use of illegal drugs. One figure makes that point clear: in 1962, prior to the drug epidemic, only 4% of Americans 18 to 25 years of age had ever used marijuana. By 1979, at the peak of the epidemic, that figure stood at 68%. In 1985, reflecting a recent small but important decline in drug use, the figure was 61%. Nonmedical drug use is usually initiated during the teenage years and rarely after the age of 20. The use of drugs, ranging from alcohol and marijuana to cocaine and PCP, shows peak prevalence between the ages of 18 and 25.

Over the same two-decade span, a corresponding increase occurred in the prevalence of other problem behaviors among youth, including suicide, venereal disease, delinquency, and eating disorders. All those problems of teenagers involve the impulsive pursuit of personal pleasure through behaviors that are in conflict with widely held societal values.

The University of Michigan Survey Research Center annually surveys a large representative sample of U.S. high school seniors. Results from the 1986 sample, the most recent year for which data are available, showed 91% of high school seniors had already used alcohol at least once.<sup>3</sup> Equivalent figures for other drugs were cigarettes, 68%; marijuana, 61%; and cocaine, 17%. Within the 30 days prior to the survey, 65% of the high school seniors had used alcohol, 30% had used cigarettes, 23% had used marijuana, and 6% had used cocaine. That same survey found 37% of high school seniors get drunk at least once every two weeks, with use defined as five or more drinks in a row at one time. Table 1 lists prevalence figures for the most commonly used drugs among high school seniors in the United States.

The high school senior survey includes the age at which youth in the United States typically begin drug use. The most frequent time to initiate cigarette smoking is the sixth grade, and the most frequent time for initiating daily cigarette smoking is the ninth grade, when 5% of the class begins daily smoking. Ninth grade is also the most common age for beginning alcohol consumption (25%), for first drunkenness (19%), and for initiating the use of marijuana (12%). Cocaine use is the exception to the pattern of initial

TABLE 1  
Drug Use Among High School Seniors, 1986

	Lifetime Use	Current Use
The Gateway Drugs		
Alcohol	91	66
Cigarettes	68	30
Marijuana	51	23
Cocaine	17	6
Hallucinogens (including PCP)	12	4
Stimulants	23	6
Sedatives	10	2
Tranquilizers	11	2

Source: National Institute On Drug Abuse, *National Trends in Drug Use and Related Factors Among American High School Students and Young Adults, 1975-1986*; U.S. Department of Health and Human Services, Washington, D.C., 1987.

drug use in junior high school. Its use is most frequently initiated in the 12th grade (5%). Follow-up studies indicate drug and alcohol use that is begun in adolescence often persists for many years.

A related body of research has indicated a sequence of drug use by youth. The sequence begins with alcohol and/or cigarettes and moves on to marijuana. Those three substances—alcohol, cigarettes, and marijuana—are called the gateway drugs because they are often the "gateway" into the drug dependence syndrome.<sup>4</sup> They are perceived by actual and potential drug users as relatively harmless and easily controllable by the user. The younger a person when he or she uses a particular gateway drug, the more likely will be the progression to the next substance in the sequence. Thus youth who begin alcohol use in the seventh grade are more likely to use marijuana than are youth who first use alcohol in the 11th grade. Younger first use of any drug is positively associated with an increased risk of problem-producing use of that drug.<sup>5</sup>

A committee of drug-abuse-prevention experts recently discussed the goal of zero tolerance for youth, and reached consensus that there should be no use whatsoever by youth of drugs or cigarettes.<sup>6</sup> That committee's members were not in unanimous agreement on the goal for the use of alcohol. Some advocated a goal for teenagers of complete abstinence from alcohol, whereas others favored the goal of no excessive use, no problem-producing use, or no use in early adolescence. The gap between achieving any of those goals and the reality of drug and alcohol use reported in the high school senior survey establishes the magnitude of the drug-abuse-prevention challenge.

Two points are particularly relevant to the problem of preventing drug abuse among high-risk youth: since first drug use occurs in early adolescence, any effort designed to stop use of drugs must target youth prior to the sixth or seventh grade; and although large percentages of youth begin drug use during their teenage years, not all do so. Thus, the teenage population comprises both relatively "high-risk" and relatively "low-risk" youth with respect to substance abuse problems.

This lesson focuses on what is known about the youth who are at high risk and on what can be done to reduce that risk. In particular, it deals with the role of the psychiatrist in the process of identification and intervention with high-risk youth.

### The Cardiovascular Disease Model

An appropriate model for substance-abuse prevention is the recent commitment to prevention of cardiovascular disease. In an attempt to reduce the risk for cardiovascular disease, researchers are working rapidly to quantify risk factors and develop specific risk-reducing interventions. Those efforts have focused primarily on health-related behaviors such as smoking, diet, and exercise—life-style factors for the prevention of disease. The life-style patterns contributing to cardiovascular risk, as with drug-abuse risk, are formed at a very young age. Although the rates of cardiovascular disease within the population are high, it is no longer considered reasonable to simply accept them as inevitable.

Use of the model of cardiovascular risk for drug-abuse risk is significant for several reasons. First, it helps establish the legitimacy of the goal of prevention of drug abuse. Second, it conceptualizes the process of risk identification as a health concern, not only a moral or legal matter. The comparison of cardiovascular risk reduction and substance-abuse risk reduction also makes clear that, although primary responsibility rests with the individual and the family, the clinician can play a vital role by helping both the person with the problem behavior and his or her family identify and reduce the risk. In the area of cardiovascular disease as well as in drug abuse, a strong genetic component related to risk is present and is an important added reason to reduce controllable risk factors.

In drug-abuse prevention, as in cardiovascular disease prevention, there is an interaction between individual behaviors on the one hand and social control over behavior on the other. For example, the growing social pressure against cigarette smoking influences many personal decisions by individuals. Making smoking illegal in public places, such as restaurants and airplanes, is understood to be a public health issue, not a moral one.

### Identification of Youth at High Risk

The search for markers of high risk for drug abuse has been carried on for many years, and the resulting body of information shows differences in relative risk for the use of particular substances. For example, those youth at high risk of cigarette smoking are not identical to those at risk for cocaine use. However, the most striking finding of contemporary substance-abuse research is that commonalities for the risk of the various drugs far outnumber differences. That holds true for both legal drugs, such as alcohol and tobacco, and illegal drugs, such as marijuana and cocaine. (The distinction between legal and illegal is tenuous with youth, for whom alcohol and tobacco use is illegal.) Markers of high risk of drug abuse also predict the relative risk of a wide range of problem behaviors of youth, including poor school performance, sexual promiscuity, and eating disorders.<sup>7</sup> Delinquency,

in particular, has been linked to the risk of chemical dependence in youth.<sup>8</sup>

As the drug-abuse epidemic increased over the last two decades, general skepticism about finding clear-cut markers of high risk prevailed. Drug use itself, at least in its early stages, was perceived to be not only increasingly common but even an inevitable part of the adolescent rite of passage. However, as the drug-abuse epidemic has begun to wane, drug use is again being regarded as a serious health problem, and prevention of drug use is regarded as a public health goal.

Many health professionals indicate a surprising contrast in attitude toward cigarette smoking by the young and alcohol use by the same age group. They are in virtually unanimous agreement, for reasons of health, that regular cigarette smoking by young people is unacceptable. It is only slightly less universally recognized that any experimenting with cigarettes by youth is undesirable. Contrast those views on cigarette smoking with the ambivalent attitudes among health professionals about youthful alcohol use. Teenage drinking is tolerated by many physicians working with adolescents. The attitude of many physicians about marijuana and cocaine use among young people falls somewhere between the strongly negative attitude toward cigarette smoking and the accepting attitude toward alcohol use. From a public health standpoint, we should treat alcohol and other drugs as we now treat cigarettes. In this author's view, it means establishing and reinforcing the standard of zero tolerance of cigarette, alcohol, and marijuana use by teenagers. The law establishing 21 as the legal drinking age reinforces that goal.

One recent study that explored the question of relative risk for substance abuse among youth surveyed 10th graders on a wide variety of behaviors, including physical activity, nutrition, stress, and substance use.<sup>9</sup> The variables were grouped into six categories: demographic, psychological, social environmental, behavioral, physical, and substance use. With respect to substance use (cigarette, alcohol, marijuana, cocaine, and other drugs), the authors established six levels of use: (1) those youth abstaining from all substances, (2) those who have experimented with one or more substances at least once in their lives, (3) those who use one or more substances at least once a month but less than once a week, (4) those who use one or more substances at least once a week, (5) those who use one or more substances almost every day, and (6) those who use one or more substances every day.

Using multiple regression analysis, the study showed the strongest single indicator for increased substance use by boys and girls was their friends' marijuana use. Tenth graders who reported their friends did not use marijuana were less likely to use cigarettes, alcohol, marijuana, or other drugs. Youth who said their friends did use marijuana were at a significantly elevated risk of substance use themselves.

Among boys, that risk factor was followed, in order of significance for substance use, by perceived safety of cigarette smoking, poor school performance, parents' education, and the use of diet pills, laxatives,

and diuretics to control weight. Together, those factors accounted for 44% of the variance between the youth who used substances and those who did not.

For girls, friends' marijuana use was also the most powerful predictor of their own substance use. Following in order of importance were poor school performance; self-induced vomiting for weight control; perceived safety of cigarette smoking; use of diet pills, laxatives, or diuretics for weight control; parents' education; perceived adult attitudes about cigarettes; and nonuse of seat belts. Those factors accounted for 53% of the variance for girls in the study. The study's authors concluded, "These findings suggest that for many purposes substance use may be considered a single behavior regardless of the specific substance(s) used and that substance use may exist as part of a syndrome of adolescent problem behaviors."

Other studies show youth who are at high risk of drug abuse share a constellation of personality characteristics, including impulsiveness, pessimism, lack of ambition, and poor work habits. It has also been shown that high-risk youth lie easily, are extroverted, and are often in conflict with adults.<sup>10</sup> Those characteristics bear similarities to the psychopathic personality described by James M. A. Weiss in three earlier lessons in this series.<sup>11-13</sup>

Clinical experience confirms not only are those characteristics predictors of substance abuse but also substance abuse promotes and, in a vicious cycle, deepens them. For many high-risk youth, those personality characteristics are apparent even before puberty. Although no reliable estimates exist for the incidence of high-risk behavior in the United States, my own clinical experience has led me to believe that about 10% of teenagers have such characteristics to a severe degree and an additional 20% have them to a moderate degree. One of the more important findings of the research on high-risk youth is that the bonding of youths to adults is significant to the risk of drug abuse in adolescence. Youth who relate to adults in active, positive ways are less likely to use—and abuse—drugs than are youth who view adults as their enemies and who spend as little time as possible with adults.

It has often been observed that youth with learning disabilities have an elevated risk of drug abuse, and recent research has clarified that complex issue. Learning-disabled youth with good work habits and strong relationships with adults are not at elevated risk of drug abuse, regardless of the severity of their learning disability. On the other hand, learning-disabled youth possessing the high-risk personality characteristics that have been identified are at increased risk of drug and alcohol problems. In other words, the risk of drug abuse is linked to the child's character, not to his or her learning disability.<sup>14</sup>

#### Characteristics of High-Risk Youth

As I work with adolescents in my own practice, I look for the five characteristics for high risk of substance abuse listed below. (1) Interest in present-tense pleasure: high-risk youth value the here-and-now over the rewards of delayed gratification. (2) Lack of empathy: youth who do not care about the feelings of other people are at a higher risk of drug abuse. (3) Lack of sensitivity to punishment: youth

who are responsive to punishment are less likely to be involved with drugs, whereas those relatively impervious to punishment are at higher risk. (4) Easy lying: youth who lie easily, and often, are far more likely to have drug and alcohol problems than are youth who are honest. (5) Distance from and rebellion against adults and others in authority: youth who spend much of their time away from parents and other adults and who have antiauthority values are at increased risk of drug and alcohol problems.

Having identified those character traits of high-risk youth, three points require emphasis. First, rarely are those characteristics either totally present in or totally absent from the personality of any particular teenager. Second, those characteristics tend to diminish after about 16 to 18 years of age (absent perpetuation by frequent drug use). Third, the risk of drug use for an individual is positively related to the extent to which those characteristics are present. Not only does it resemble the profile of the psychopathic character, the list of character traits associated with high risk of drug abuse is also typical of confirmed chemically dependent people of any age. In itself, adolescence, as a phase of the human life cycle, is a risk factor for drug and alcohol problems.

#### Intervention to Reduce the Risk of Substance Abuse

It is useful to know who is at high risk, but what can be done to reduce that risk? It is paradoxical but not accidental that many of the techniques best suited for preventing teenagers from drug and alcohol abuse are relatively less effective with the high-risk population. For example, it is often said that scare tactics do not work with youth when dealing with drug-abuse prevention. That commonly repeated finding is misleading, however. Many youth are, in fact, frightened about the consequences of the use of drugs and alcohol and they respond to scare tactics by not using drugs. Those relatively easily frightened youth are, however, the least in need of such preventive education, since they are the most likely to be concerned about the approval of adults and their own futures. Thus they are relatively less likely to use drugs, even without being confronted by scare tactics. It is the youth who are skeptical—if not hostile—to adults, those who lack empathy and who are not easily influenced by punishment, and those who focus on present-tense rewards who are at high risk of chemical dependence. Scare tactics about drug and alcohol problems are less effective for that latter group because they are not scared.

Drugs and alcohol are especially seductive for rebellious, anti-adult youth who lie easily and who are relatively impervious to the future consequences of their actions. Drug and alcohol use has a payoff in a relatively certain, present-tense "high," whereas problems caused by drug use tend to arise in the future. Drug-caused problems are also unpredictable with respect to any particular user, so youth who are unconcerned about the future and who assume they will do fine no matter what the odds are relatively impervious to the messages of drug-abuse prevention. That is especially true of prevention messages that emphasize risks of drug use, particularly when the risks are, for the individual youth, delayed and/or uncertain.

## Intervention Strategies

A recent report reviewed **three broad categories of interventions** directed towards adolescents at high risk for drug and alcohol use in an effort to reduce the use of drugs: **programs, general efforts, and individual efforts.** Typical of the first approach are smoking-prevention programs conducted in schools, many of which have been shown to be moderately effective. **To reduce the onset of cigarette use through carefully controlled intervention in the 6th to 10th grades, the programs teach youth "peer refusal" techniques and support youth in "saying no" to cigarettes.** Those anti-smoking programs have recently been extended to combat drug and alcohol use with good, but somewhat less impressive, results.

The second type of intervention effort is more general than the highly focused prevention programs described above. Typical are school initiatives such as **eliminating designated smoking areas and tightening rules regarding drug and alcohol use at school and in the home.** Additional approaches are parent-support and "tough love" efforts.

The third type of intervention, individual efforts, demands the **mobilization of caring adults, especially parents and teachers.** In relating to high-risk youth, the caring adults should be clear on their common goal—the young person should grow up to be a healthy, independent adult—and they must take responsibility, even as they bond with the particular high-risk youth. Caring adults should identify drug and alcohol use and intervene so that such use, if it occurs, is detected and an appropriate response is made to discourage any future use. The role for the psychiatrist, who frequently is brought into the picture only after serious problems of school failure and rebellion against parental authority arise, is often vital.

One of the characteristics of high-risk youth is relative imperviousness to punishment, while another is a failure to recognize the future consequences of current behaviors. Those traits make discipline and punishment difficult for both adults and youth. While some might advise abandonment of either punishment or limit-setting, I have found the opposite approach to be more successful. **Punishment for drug and alcohol use and other rule-breaking needs to be swift and sure, but it seldom needs to be severe or prolonged.** The goal of punishment, to help the child regain control of his or her behavior, is best done by moderate, consistent, and evenhanded punishment. The rules and limits must be established and carried out in an environment that **includes discussion of the reasons for punitive action, an explicitly stated commitment by the adults to help the teenager mature into independent adulthood, and a willingness on the part of the parents to submit their rules to outside review if the child feels they are unreasonable.**

Psychiatrists sometimes become part of the family milieu when the youth at high risk is not the problem of central focus, such as occurs when other family members, including siblings or parents, are being seen in the clinical setting. An example is a parent who is in treatment for a drug or—more commonly—an alcohol problem. In that situation, the psychiatrist must act effectively to support the iden-

tification of and intervention with youth in the family who are at high risk of chemical dependence, particularly because of the high risk for drug abuse among teenagers whose parents or siblings have a chemical dependency.

When dealing with a family at high risk, or a particular teenager at high risk, I find it useful to **bring the family together, explain the elements of risk for drug and alcohol problems to them, and offer to work with them to reduce that risk.** I have described elsewhere the basic structure of family life: the family is a team working together to help the child grow up to be a healthy, productive, and independent adult.<sup>4</sup> **The greatest threat to achieving that goal is drug and alcohol use, which, in the long run, threatens the child's independence, even though to some teenagers it may appear to promote it in the short run.**

Teenagers can be helped to recognize their parents are allies (unless, as happens, there is evidence to the contrary) and their potential for lying is a major threat to that vital bond. A phrase I use is, "We are only as sick as our secrets." In fact, the most powerful antidote I can offer to high-risk youth is "ruthless honesty." Teenagers need to understand they can easily determine right from wrong by asking themselves if they can tell those who love them the truth, the whole truth, and nothing but the truth about an action. If they cannot tell the whole truth, they should not do whatever it is they are considering. Lying to parents and adults has become such a common behavior in the teenage culture that it is often assumed, even by mental health professionals, to be part of the teenager's normal efforts to be independent. Lying is both dishonest and immoral. It does not work for the teenager but rather reduces his or her ability to adapt successfully and the parents' and other caring adults' ability to help.

Parents are not always right when it comes to judging their teenager's behavior, but they are more often right about the teen's best interest than the teenager himself or herself, especially if the teenager is one of the high-risk youth this lesson describes. Nevertheless, parents do make mistakes. When the parents and child are in conflict over any particular rule or behavior, I suggest they submit the disagreement to someone they all agree has the child's best interest at heart, such as a grandparent, counselor, or the psychiatrist.

All children—but especially high-risk youth—should **understand the nature of the adult-child relationship.** Being a child carries limits imposed by adults on choices and behaviors and acceptance by the child of adult authority. The teenage years should be considered an advantaged, not a disadvantaged, stage of the human life cycle. Because high-risk youth prize immediate pleasure, even at the expense of their own long-term self-interest, it is often confusing for them.

**Families dealing with high-risk youth need to know whether or not their high-risk teenager is using either drugs or alcohol. I support parents' knowing the truth about their children, including taking urine tests for alcohol and/or drug use whenever a question arises about such use.** Some parents, and many teenagers, see such direct parental action as an undermining

of trust. My experience is exactly the opposite. Parents of high-risk children who trust them about drug and alcohol use without exercising the option of testing them for such use are likely to be unaware of serious problems that can fester and lead to truly devastating results. The psychiatrist can often help the family, including the youth, think about that issue and provide access for the family to drug testing.

The effort to help high-risk youth avoid drug and alcohol problems is most likely to be successful if it is begun before the child enters puberty and the risk of drug and alcohol abuse becomes extreme. **Parents of a high-risk child are often aware of significant differences between the high-risk child and other children, even siblings. Those differences usually manifest themselves at an early age, most often in response to punishment and in a propensity to lie. It is helpful to explain high-risk characteristics to both the parents and children in order to reduce their guilt and confusion. Once they understand they need not feel guilty about them, they can begin to understand the need to work together as a team to overcome the problem created by high-risk characteristics in the same way they would approach any other handicap. On the other hand, if practical understanding is absent, and if the guilt of the parents is supported and even encouraged by the psychiatrist, appropriate prevention and treatment is frustrated.**

It is common to see one high-risk youth in a family with other children who lack that characteristic. On the other hand, all of the children in a particular family can have high-risk characteristics. Families coping with high-risk youth need to understand they will generally be misunderstood by other families who have not coped with that specific problem. It is common for other families to emphasize open and honest communications and trust as the central features of their child-rearing practices and to disparage the mistrust and rigid rules they perceive as characteristic of families coping with high-risk youth.

Families with youth who lack high-risk characteristics are not wrong in their approach to parenting. Their approach works for teenagers who are honest and concerned about the future consequences of their actions, especially when they are positively involved with adults they see as helping them achieve their long-term goals. **The lack of understanding shown by uninvolved people is rarely malicious, but it can add to the confusion and guilt experienced by families coping with high-risk youth. The psychiatrist and parent peer support groups, such as Al Anon, can**

help clarify that issue for the parents and encourage them to take the steps necessary to help their child maximize his or her chances for a good life. For high-risk youth such tough love is often a matter of life and death.

Often the key to real, lasting recovery is participation by the child and the parents in one of the many **self-help groups related to Alcoholics Anonymous, such as Tough Love, Families Anonymous, Al Anon, and Parent Peer Groups.** Talking with others who know firsthand the problems of the high-risk syndrome helps both youth and parents to develop and sustain a sense of purpose and hope. In my experience, Al Anon and Parent Peer Groups are particularly helpful to the parents of high-risk youth.

The characteristics defined as high risk are not unique to the United States and they are not new in the last two decades. **What is new is the powerful social support from the teenager's peer group and others for such impulsive, pleasure-driven behavior and the widespread, easy availability of drugs and alcohol.** Those two elements have put new fuel on old biological fires.

### Summary

High-risk youth possess a combination of related character traits that are similar to psychopathic characteristics, which are an exaggeration of normal adolescent behavior. **The five key features of the high-risk syndrome are impulsive pursuit of instant gratification, lack of concern for the feelings of others, insensitivity to punishment, easy lying, and rebellion against adults in authority.** Those characteristics, which are seldom totally present or totally absent in any one teenager, tend to intensify around 16 to 18 years of age and then diminish with time, unless they are perpetuated by drug and alcohol abuse. The high-risk syndrome is found in all social classes, most often in boys, and while clearly maladaptive, it does not preclude successful adjustment as an adult.

The psychiatrist can support and educate both parents and children about the risks of drug abuse and the goals of drug-abuse prevention: to help the child get through the most vulnerable period, 12 to 20 years of age, free of the use of drugs, including tobacco, alcohol, and marijuana—the gateway drugs. That goal is difficult to achieve, particularly for high-risk youth who need specific, sustained help in surviving and benefiting from the teenage years.

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THESE QUESTIONS ARE TO BE ANSWERED ON THE RESPONSE SHEET MARKED FOR LESSON NO. 8.  
CIRCLE ONLY THE ONE BEST ANSWER.

QUESTIONS BASED ON THIS LESSON:

1. Which of the following statements is correct?
  - A. Alcohol, marijuana, cocaine, and PCP abuse show peak prevalence between ages 18 to 25
  - B. Between 1979 and 1985, a dramatic reduction in drug abuse in the U.S. was observed
  - C. Nonmedical drug use is usually initiated after age 30
  - D. The most frequent time to start daily cigarette smoking is the twelfth grade
  - E. Cocaine use is most commonly initiated in the ninth grade
2. Which of the following statements is correct?
  - A. The strongest single indicator for increased substance use by teenagers is their parents' marijuana use
  - B. A high risk factor for substance use among teenage boys is induced vomiting for weight control
  - C. Poor school performance is a significant risk factor for substance use in teenagers, slightly more so for girls than boys
  - D. Non-use of seat belts was associated with a higher risk of substance use among teenage boys, but not girls
  - E. None of the above
3. Learning disabled youths have an elevated risk of drug abuse:
  - A. Because they all tend to be hedonistic
  - B. Primarily when they lack good work habits and strong relationships with adults
  - C. Because of a disorder in brain chemistry that accounts for their learning disability and also predisposes them to drug abuse
  - D. But only for one drug, PCP
  - E. Only among males

4. Intervention to prevent drug abuse among youth should:
  - A. Not be activated until the twelfth grade, lest students learn about drugs in the effort to warn against them
  - B. Be initiated before youngsters begin drugs (usually in the ninth grade), and integrated with a mobilization of caring adults
  - C. Never use "peer refusal" techniques since these always backfire
  - D. Never go beyond education about the dangers of drug abuse to seek out and modify vulnerable behavior patterns
  - E. All of the above

QUESTION BASED ON PREVIOUS LESSONS:

5. Which of the following statements is/are correct with regard to paranoid symptoms in elderly patients?
  - A. They are never seen in mood disorder states
  - B. Treatment measures are the same regardless of the underlying diagnostic condition
  - C. Reducing anxiety by providing a caring and structured environment can mitigate paranoid features in many patients with underlying organic brain disease
  - D. Trying to establish a very close personal relationship is the best way to approach a delusional paranoid patient
  - E. All of the above

QUESTION BASED ON FUTURE LESSONS:

6. Patients with obsessive compulsive disorder:
  - A. Always have compulsive character structures
  - B. Never complain of ego dystonic symptoms
  - C. Generally tend to be extroverted and very independent
  - D. Usually retain insight into the troublesome, "abnormal," quality of their symptoms in contrast to patients with major psychotic syndromes
  - E. Are identical to those with phobic disorders because avoidance of triggers prevents anxiety

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# Treatment Trends

A NEWSLETTER OF TAYLOR MANOR HOSPITAL

## CONDUCT DISORDERS IN CHILDHOOD AND ADOLESCENCE

Presented by Karen Wells, Ph.D.

Since the late 1960s, there has been considerable research done on conduct disorders in children and adolescents. Emphasis has been on both the factors involved in the etiology of these disorders and the development and evaluation of effective treatment strategies.

DSM-III lists two major categories of aggressive behavior disorders relevant to children and adolescents: conduct disorders and oppositional disorder.

The conduct disorders category includes four subtypes: socialized aggressive, socialized nonaggressive, undersocialized aggressive and undersocialized nonaggressive. Each subtype involves persistent major violations of the rights of other people or of the rules of society and the community. In oppositional disorder, interpersonal social aggression is more implied, with the essential characteristics being stubbornness, argumentativeness, disobedience and violations of minor rules.

Although there are clear differences in intensity and severity of symptoms and long term prognosis, the major categories can all be conceptualized as involved failure to follow interpersonal, societal or community rules.

Unfortunately, there is not a one-to-one correlation between DSM-III categories of aggressive childhood behavior and the dimensions and factors of this behavior found in the empirical literature.

For example, in Quay's 1980 review of studies of children's behavior problems, he found clear empirical evidence for two major categories of aggressive child behavior. The first he called conduct disorder. This factor includes verbal and physical aggression and poor social behavior with adults as well as peers.

The second factor, which Quay called socialized aggressive disorder or subcultural delinquency, emerges mainly in juvenile delinquents or in cases seen in metropolitan area child

guidance clinics.

Achenbach similarly reports two major factors of aggressive child behavior.

*(Continued on page 2)*

This issue of *Treatment Trends* contains another presentation made as part of Taylor Manor Hospital's Continuing Education Lecture Series. Taylor Manor Hospital offers these programs without charge to health care professionals. Regular announcements of upcoming lectures are contained in each *Treatment Trends* issue. See page eight for the current calendar. ■

ior. The one he calls "aggressive" corresponds to Quay's "conduct disorder," and the other, "delinquent," corresponds to Quay's "socialized aggressive."

There is no clear empirical evidence of the existence of a separate, independent syndrome of oppositional behavior which is clearly discriminable from conduct disorders. In most factor analytic studies, oppositional behaviors are carried under a conduct disorder factor. For example, tantrums, stubbornness, disobedience and imperitiveness correlate with and are subsumed by the conduct disorder factor. That factor also includes such behaviors as fighting, destructive and assaultive acting out. It is discriminable from the predelinquent or delinquent factor which includes stealing, truancy and other major community rule violations.

In terms of etiology of the aggressive behavior and prognosis in the effects of treatment, studies show there is a strong resemblance between the pure subtypes of aggressive behavior (conduct disorders) and the aggressive behavior shown by attention deficit disordered children.

Clearly the issue of subtypes of aggressive behavior disorders in children is still open to debate and research. What is not open to debate is the prevalence of conduct disorders in this population.

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*Effective treatment approaches need to be used with conduct disordered children and adolescents since most go on to have serious mental health disorders as adults.*

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Wolfe found that 47% of the two to five year olds in a child outpatient clinic were referred for treatment because of aggressive behavior. The ratio was 65% boys to 35% girls. A study of a group seven years older showed that the prevalence of aggressive behavior had jumped to 74% of that population.

The Rutter study of the total population of the Isle of Wight found that 70% of children with psychiatric disorders of any kind had conduct disorders.

A further concern about conduct disorder is that, in general, these children do not get better. They often carry their problems into adulthood where they worsen.

Several studies support this finding. The Morris study followed patients into adulthood. It showed that 60% had poor social adjustments, 18% committed crimes and 20% went on to schizophrenia. Lee Robins tracked a group, with a beginning diagnosis of delinquent and aggressive antisocial behavior disorder, for 30 years. Almost 40% went on to a diagnosis of sociopathic personality disorder and 30% developed other psychiatric disorders.

Obviously, effective treatment approaches need to be used with conduct disordered children and adolescents since most go on to have serious mental health disorders as adults.

Gerald Patterson is one of the leading researchers of conduct disorders in children and adolescents. He has found that socially aggressive children display a higher rate of negative behavior than normal children. This negative behavior includes ordering other people around, criticizing and humiliating peers and adults, and a general noncompliance with rules and directions. These patients are characterized by their use of a lot of "n't" words: I can't, I won't, you can't make me.

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*Parents of socially aggressive children show a higher rate of criticism, threatening, nagging and attention negative behavior to their children.*

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There are also distinct behavior patterns displayed by the parents of these children that differentiate them from the parents of normal children. Parents of socially aggressive children show a higher rate of criticism, threatening, nagging and attention negative behavior to their children. They also give a much higher rate of bad commands.

There are six generally recognized bad commands. I have added a seventh based on my unit's clinical observation.

Chain commands occur when too many orders are given at one time. For example, "go upstairs, take off your pajamas, get dressed, get your books together, brush your teeth, eat your breakfast, get ready to go to school." Along with behavior problems, these children may have attention, auditory memory, auditory sequencing and auditory processing deficits. A long string of commands cannot be processed. The child simply tunes the parent out.

An interrupted command is one that is given amid a barrage of interrupting verbiage. For example, "put on your raincoat because it is raining outside and you know how you always step in a mud puddle between here and school and you have your best clothes on and you're going to a birthday party and I don't want you getting all wet, etc." By the time the parent stops talking, minutes may have gone by. Chances are that the child or adolescent with a aud-

itory process or auditory memory deficit has already turned off.

Repeated commands are like chain commands except that only one command is continuously repeated. "Hang up your coat. Hang up your coat. Did you hear me say hang up your coat? When are you going to hang up your coat?" What is interesting about this command approach is that just as we all have biological clocks, children also seem to have an internal timing sense. They know their parents' thresholds. So they tune out the first eleven or so command repeats because they know that mom and dad don't really start getting serious until the twelfth or thirteenth time. When parents say that their child doesn't listen, that is a good clue that they are giving too many commands and not following through fast enough with consequences.

Vague commands are just that. "Stop that. Be good. Calm down. Behave yourself. Grow up. Act your age." They don't tell the child what the parent wants him to do. Parent and child may have something quite different in mind.

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*There is no clear empirical evidence of the existence of a separate, independent syndrome of oppositional behavior which is clearly discriminable from conduct disorders.*

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Question commands are misleading. "Why don't you pick up your coat? Don't you think you should be doing your homework? Wouldn't you like to take your bath?" Putting a command in

question form implies that the child has a choice and shares equal power with the parent. Such commands infer that it is just as much up to the child to decide what is going to be done as it is to the parents. The psychological message conveyed is that equal power has been granted.

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*The issue of subtypes of aggressive behavior disorders in children is still open to debate and research. What is not open to debate is the prevalence of conduct disorders in this population*

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Let's commands are often used by parents of small children to trick them into doing something. "Let's go clean up your room," is a typical example. What the parent is implying to the child is that they are going to do a task together. What the parent really means is that he wants the child to do it alone. Often the parent and child will start to do the task together and then the parent will withdraw or, more honestly, sneak out. The child may then erupt into a tantrum feeling that he has been tricked. And he has.

Psycho twister is a bad command category I've added. Twisters convey a very negative psychological message to the child. "If you don't clean up your room, I am going to commit suicide." Such a statement puts the child in charge of the parent's mental health and continued existence. In a divorced family, threatening to send a child to the other parent is a psycho twister that is an obvious threat of abandonment.

Although much of the conduct disorder data leads to the conclusion that poor parent behavior causes poor child behavior, this is not necessarily the case. Direction and causation actually go both ways: poor child behavior feeds back on the parent and elicits poor parenting behavior which then feeds back onto the child eliciting more poor child behavior.

The negative behavior mechanism in this coercive cycle must be clearly understood. Negative reinforcement is not punishment. It refers to the fact that any behavior which removes an aversive event is increased in its probability of occurrence.

In a typical aversive event, the parent gives the child a command. The child's behavior response is to whine and not obey. The parent gives up and withdraws the command. The child is being negatively reinforced for his whining and noncompliance. He learns that if he whines, he won't have to obey.

In the next sequence of events coercion escalates. Mom gives the command, the child whines and non-complis. Mom decides that she is not going to give up so easily this time, so she raises her voice and repeats the command more loudly. The child decides he is not going to give up either, so he whines louder. Finally, mom starts to yell and loudly repeats the command. Then the child complis.

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*Poor child behavior feeds back on the parent and elicits poor parenting behavior which then feeds back onto the child eliciting more poor child behavior.*

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*To treat these children successfully, the behaviors that differentiate this population have to be addressed. A comprehensive treatment plan must include attention to family and parenting factors.*

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In this scenario, child and parent are escalating their coercive interaction. Although one of them eventually wins, both are being negatively reinforced. Negative reinforcement is the most powerful learning process. Behavior is acquired much more quickly and efficiently in this manner than through positive reinforcement and is much more resistant to extinction than that acquired through other methods.

Negative reinforcement is the core of the coercion hypothesis that Patterson has developed to explain how this type of behavior escalates and is maintained in the family. He has found certain global variables within families that are related to aggressive childhood and adolescent behaviors. These he calls family management practices. The absence of such family management practices as family rules of conduct, expressed or implied, and parent monitoring of the child's expectations is related to aggressive behavior.

Patterson also refers to macro social variables which can disrupt family management practices. These include crises such as illness, poverty and marital conflict. While not directly related to family conduct disorder, per se, these social variables do affect the directly related family management practices.

The conclusion drawn from the work of Patterson and others is that to treat these children successfully, the behaviors that differentiate this population have to be addressed. A comprehensive treatment plan must include attention to family and parenting factors.

However, it is important to provide parents with the rationale as to why you are intervening with them so that they will not draw the erroneous conclusion that they are the cause of the problem.

My approach is to tell parents right at the beginning of their child's therapy that "we don't know how this negative interaction pattern got going in your family. What we do know is that right now both parents and child are probably contributing."

"We can and will intervene on the child's level, but you are the ones who have the greatest degree of judgment and responsibility in the family."

Hopefully you have the greatest self control as well. I'm not necessarily implying that your child is not contributing to this too, but you are the quickest, most effective and efficient place for us to intervene. That is why we are going to start with you."

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*Negative reinforcement is the most powerful learning process. Behavior is acquired much more quickly and efficiently through negative than positive reinforcement and is much more resistant to extinction than that acquired through other methods.*

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The approach to adolescents is a bit different in that in behavioral family therapy there is more shared responsibility. Adolescents are usually struggling with a broader range of issues than children. Here, the goal is to bring the family together so that certain basic expectations for the adolescent are addressed and agreed upon. The family also needs to agree upon those areas where the adolescent is free of expectations.

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*In terms of etiology of the aggressive behavior and prognosis in the effects of treatment, studies show there is a strong resemblance between the pure subtypes of aggressive behavior (conduct disorders) and the aggressive behavior shown by attention deficit disorder children.*

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In working with adolescents I often advise them to target behaviors to change in their parents. At the same time I advise parents to define behaviors to change in the adolescent. In this way, the family works out contracts for each other. Often when you invite adolescents into therapy at that level you elicit more cooperation from them than you would receive otherwise.

Parents with very small children are taught how to attend and reward their children's good behavior. We teach them how to ignore poor behavior, deal with clear cut instructions, and follow through with appropriate consequences.

Our studies have shown that through this type of family therapy approach there is positive family change. Parents change their behavior and children show very significant improvement in compliance to instructions, negative behaviors, and their positive relations with other family members. ■

*Karen Wells, Ph.D., Acting Director of Pediatric Psychology & Chief Psychologist for Inpatient Psychiatry, Children's Hospital National Medical Center and Associate Professor of Psychiatry and Behavioral Sciences and of Child Health Development, George Washington University School of Medicine*

*Psychiatric Commentary and References:*

## CONDUCT DISORDERS IN CHILDHOOD AND ADOLESCENCE

*By Bruce T. Taylor, M.D. and Albert A. Kurland, M.D.*

**W**hen the diagnostic evaluation of children who have come in conflict with society is considered—whether or not they have been adjudicated delinquent—it should be remembered that the subcategories of conduct disorder in DSM III originally came from the classification of delinquent youngsters. Moreover, delinquency is a legal term, not a psychiatric term. It designates minors who have been found guilty of transgressions ranging from truancy to homicide. It tells nothing about underlying etiological or psychopathological factors.

The classification of behaviorally disordered children and adolescents according to objectively identifiable descriptive characteristics antedates DSM III by decades. In the early 1940s, Hewitt and Jenkins, studying adjudicated delinquents, attempted to verify the existence of three types of juvenile offenders: socialized, unsocialized aggressive, and overinhibited. Jenkins' initial groupings were not done by statistical method, but by using his clinical judgment guided by his perceived degree of association among selected traits. In the 1960s and 1970s, social scientists such as Quay, using sophisticated multivariate statistical methods

facilitated by computer technology, arrived at categorization of delinquents that were remarkably similar to those of Jenkins and contributed to the DSM III conceptualization and delineation of conduct disorder.

Basically the DSM III in its conceptualization of the conduct disorder viewed this as behavior involving repetitive and persistent patterns of misconduct such as delinquent acts, destructiveness or violations of the rights of others beyond the ordinary mischief and pranks of children and adolescents. Moreover, the conduct disorders could be grouped into (a) an undersocialized group with subtypes, i.e., aggressive

and non-aggressive and (b) a socialized group with two similar subtypes, namely, aggressive and non-aggressive.

The undersocialized subtypes, i.e., aggressive and non-aggressive, fail to form a normal degree of affection, social bond, and empathy with others. Meaningful peer relations are generally absent, and these children and adolescents do not extend themselves to others without obvious and immediate benefit. They are manipulative and callous. They show a lack of concern for others and fail to evidence appropriate feelings of guilt for their actions.

The socialized subtypes manifest social attachment to others, although they may be manipulative and evidence little guilt for actions against persons to whom they are not attached. The aggressive subtypes display repetitive and persistent patterns of aggressive behavior that violate the rights of others through physical violence against other people or thefts involving confrontation with the victim. The non-aggressive subtypes evidence a persistent pattern of violation of a variety of important rules established at home and in school, persistent truancy, substance abuse, persistent lying, running away from home, vandalism and stealing (but without confrontation of a victim).

Numerous explanations have been offered for this behavior. These em-

phasize deprived socioeconomic status, troubled interpersonal relationships in the family, inadequate family discipline in the formative years, and the influences of hereditary and environmental factors. Gender also appears to be a factor in that sociopathic aberrations are more frequently noted in the male and suggestive of other developmental problems such as stuttering and developmental dyslexia. There is also the possibility of actual structural damage to frontal cortex or other brain areas, Pontius (1980).

Lewis (1985) states "a 30 year follow-up study of children evaluated in a child guidance clinic because of antisocial behaviors indicated that their prognosis for successful adult functioning was ominous. As adults only 20 percent were deemed to be well functioning. Although the most common adult diagnosis given to these former patients by the investigators was sociopathic personality, approximately 20 percent were eventually recognized as psychotic. . . . These findings suggest that whatever the underlying psychopathology of antisocial children they are among the most seriously disturbed children who come in contact with the psychiatric system and they are at especially great risk for adult psychiatric illness." ■

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- The editors and authors of Treatment Trends are very interested in having you participate in making this newsletter more responsive. We invite you to send your comments, questions and ideas to: The Editor, Treatment Trends, Dept. of Community Relations, Taylor Manor Hospital, P.O. Box 396, Ellicott City, Md. 21043.*

# Youth Programs

## Case Management with At-Risk Youth

*Hector is a seventeen year old dropout, living on the streets. Barely literate in English and Spanish, he left school two years ago after repeating the ninth grade unsuccessfully. He has never held a steady job and has had several run-ins with the law. He is alternately charming and angry, and not sure what he wants. He needs, at the very least, basic education, skills training, housing assistance, counseling, and a job.*

*Julia is fifteen, a high school sophomore, and several months pregnant. She has gotten along in school, but she only reads at the seventh grade level. She is planning to drop out of school soon and go to work, though her only experience is as a babysitter. She is going to need help staying in school and staying healthy: remedial education, health and day care, career education and some initial work experience.*

Hector and Julia represent a growing challenge for youth practitioners: how to access and manage the increasingly complex set of services needed by at-risk youth. As youth employment and education programs expand their services to those most at risk, they need to coordinate not only employment and training services, but such services as remedial education, family counseling, health, housing, public welfare, and day care. And as the number of organizations involved in serving each youth grows, so do the problems of determining service options, making successful referrals, and tracking client progress over an extended period of time.

For many youth practitioners, the answer to these problems is case management: the use of a broker – the case manager – to help at-risk youth identify, gain timely access to, and successfully complete an individualized set of services provided by a variety of institutions. Case management is not a new idea – social workers and others have made use of it for decades. But it is one that has only begun to be applied in the fields of education and youth employment.

Recently, the Center for Human Resources at Brandeis University was asked to examine case management practices in several fields and to provide some guidance for youth practitioners. What we found was that case management is an

exciting concept. It offers the potential for customized services, coordination, and a coherent, comprehensive approach to the problems of at-risk youth.

But case management is not a magic bullet. The reality is that an effective case management effort is tough and time-consuming to implement. Whatever form it takes (and it takes many forms), case management is more likely to pave the way for valuable, but incremental, improvements in services rather than wholesale change. Moreover, case management is, ultimately, a "political" system. Case management's success depends in large part on the willingness of established institutions to change their traditional ways of doing business.

This article presents some of the basic lessons that we synthesized from our review of case management in employment programs, and in services for teenage parents, the elderly, and the developmentally disabled. Its goal is not to provide a simple, standard case management formula – there is none. But it does attempt to identify some important ingredients for case management and to describe some of the key steps common to case management systems.

### What is Case Management?

One reason why it is difficult to provide a state-of-the-art formula for successful case management is that nobody agrees about what case management actually is.

### In This Issue – Fall 1988

Case Management with At-Risk Youth .....	1
About Case Management .....	2
BEEP Collaborative: A Case Management Partnership for Court-Involved Youth .....	8
Center Notes .....	14

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# About Case Management

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Case management has long been a common tool in fields as diverse as gerontology, mental health, and rehabilitation. But it is just beginning to be applied in the field of youth employment and education. Our interest in it comes from the recognition that, as we serve increasingly disadvantaged youth – that is, youth with a multiplicity of needs – we need to find ways of organizing and implementing more complex sets of services. At the same time, while we are hearing more and more about case management, none of us are any too sure what it really is or how to make it work.

This issue of *Youth Programs* tries to provide some initial answers to those questions. The opening article summarizes some of what we at the Center for Human Resources have learned about case management based on our reading of the published literature and discussions with a number of practitioners. It is very much a preliminary discussion – we are working on a more thorough guide for this Spring. But, we wanted to pass along at least some of what we have already learned about the essential elements of an effective case management system and the key steps in the case management process.

The second article offers a nice counterpoint to the first. It is an interview with Leo Delaney, a Boston-based practitioner who, in 1984, founded a case management program for court-involved youth. Our conversation with Delaney focused on the issue of how you make case management work, and how you create a multi-institutional system that guarantees kids access to services from a variety of agencies when they need them. Delaney's answers come from his experience with one approach – a providers collaborative that developed a common referral system and clear agreements on access to the services of a number of employment, education and social service agencies.

With this issue we also find that we owe our subscribers, some of whom have called looking for our Summer issue, an apology and an explanation. As many of our readers know, this is the first year in which we have tried to publish *Youth Programs* on a quarterly basis. That is quite a challenge, and it has taken us longer than expected to get the hang of it. As a result, this is only the third issue this year – there was no Summer issue.

We do expect that, with practice, we will be issuing *Youth Programs* on a more regular schedule. In the meantime, we want to reassure our subscribers that you will still get a full four issues with your subscription. And if you haven't subscribed to *Youth Programs*, we still hope you will join us by using the return postcard enclosed in this issue. The subscription price is only \$25 for four issues for individuals and \$50 for institutions. For more information, write or call us at the Center's toll-free number: (800) 343-4705.

## Case Management, continued from page 1

After reviewing the literature on the use of case management with the elderly, James Callahan, a Brandeis University policy expert, concluded that it has become "a Rorschach test. Each professional tends to understand case management based on his or her own setting and experience." Others have drawn similar conclusions, commenting that the term is "mired in controversy and confusion" and that "its functions have been interpreted in disparate ways, often making case management a paradoxical assortment of activities...."

**Common Definitions.** Some common themes, however, can be found. One authority, the Joint Commission on Accreditation of Hospitals, defined case management services as "activities aimed at linking the service system with a consumer, and coordinating the various system components to achieve a successful outcome. Case-management is essentially a problem-solving function designed to ensure continuity of services and to overcome systems rigidity, fragmented services, misutilization of certain facilities, and inaccessibility."

A second definition echoes the first: "At the systems level, case management may be defined as a strategy for coordinating the provision of services to clients within that system. At the client level, case-management may be defined as a client-centered, goal-oriented process for assessing the need of an individual for particular services and obtaining those services."

As we reviewed more than a dozen definitions, several consistent ideas emerged. Case management is an approach that seeks to make service delivery:

- Integrated
- Coordinated
- Accountable
- Sequenced
- Sustained
- Client-Centered
- Goal Oriented
- Flexible
- Cost-Effective
- Comprehensive

It can best be appreciated as an opportunity for institutions to link with other institutions in a coordinated fashion that ultimately benefits the client because it:

- incorporates a coherent, sequential, multi-dimensional, problem-solving approach;
- locates the client within a particular "life space" and social framework;



- seeks to stimulate change both within the client and the overall environment of which he or she is a part.

### Why is Case Management Needed?

At-risk youth have needs that are often complex and intertwined. They require help determining which among a variety of services they need, when, and in what order. They require assistance finding and accessing those services, and support to successfully complete those services.

Human service institutions, on the other hand, are often one-dimensional and specialized. They typically offer services that are funded and provided as separate entities: housing is the niche of one agency, education that of another, and job training that of a third.

The result is that there is often a mismatch between the behavior of the helping-professions and the needs of the youth whom those services intend to help. Without case management, interventions are often uncoordinated and scarce resources squandered. A young person can easily fall through the cracks or give up trying to navigate what is, in most locales, a disjointed multi-institutional "non-system." The function of case management is to overcome the mismatch between institutions and client needs and to provide the continuity of services that is critical for at-risk youth.

### Effective Case Management

In order to locate and walk a young person through a sequence of services, the typical case management system has the following components:

- Finding and attracting appropriate clients;
- Intake and assessment;
- Designing a service plan;
- Intervening in the community: brokering, advocating, and linking;
- Implementing and monitoring the service plan;
- Evaluating the effectiveness of case management.

What makes these activities effective, however, is the philosophy or approach that guides them. As we reviewed the literature and talked with practitioners, four major themes stood out as

central to almost every aspect of the case management process:

**Case Management Requires Partnership.** Case management is, first and foremost, a system of partnerships: between case manager and client, and between organizations. In an effective case management system, the case manager works in partnership *with* the client, sharing responsibility, rather than working *on* the client. There is a division, rather than a substitution, of labor. Case management also involves partnerships among institutions. At some level, each must be willing to be flexible and to share access to services or resources. In that context, the case manager works for all the partners, helping institutions access clients, and linking clients with those institutions that offer the services young people need.

**Case Management Must Provide Predictability.** Many disadvantaged youth experience life as a series of random events over which they have little control. Successful case management systems work to rebuild that sense of control and predictability by helping young people to plan, to set goals, and to undertake a systematic process of meeting those goals. Young people learn that they can make choices and that their actions lead directly to concrete outcomes.

**Case Management Demands Accountability.** Client trust and effective coordination rest on the delivery of promised services. For case management to work, clients, case managers, and institutions must be clear about their roles and responsibilities; tasks and associated timelines must be written down; and ambiguity must be replaced by explicit agreements. When accountability is not clear, case management systems break down.

**Case Management Communicates Respect for the Client.** The success of any case management effort depends on the degree to which the young person is engaged in the development and joint ownership of a remediation plan, and has a major stake in insuring its success. A strategy that is imposed with little regard for a client's interests or concerns has little chance to bear fruit. In every aspect of case management, then, the client has to be treated as a mature, responsible adult — not as a number or a child.

### **Making Case Management Work**

These themes set the context for case management and shape much of what takes place in each step of the case management process.

### **Finding and Attracting Appropriate Clients.**

The initial contacts with a case management system are an important opportunity to establish a relationship and set expectations. Predictability and accountability should be hallmarks of those contacts. Potential clients need to be oriented to the purposes and structure of case management, what it can and cannot provide, and what their responsibilities will be. They should clearly understand early on that case managers work in partnership *with* them, not *on* them, and that development of a case management plan may constitute a commitment to long-term services.

Equally important, those initial contacts need to convey an attitude of respect. Case managers and their supporting service providers need to show a genuine feeling of enthusiasm, caring, and dignity to the youths who approach them. This includes initial telephone contacts. No contact with a young person should be conducted in an impersonal, bureaucratic manner: it will only turn that young person off.

Lastly, case management is not for everyone. To be effective, a case management system needs to identify a target population that can benefit from long-term, holistic services, *and* that is amenable to receiving them. The marketing and outreach campaign needs to be clear about what is being offered while highlighting the benefits of a long-term, individualized approach.

**Intake and Assessment.** Intake and assessment should also be caring, professionally-handled experiences that communicate respect to the client.

The enrollment process sets a tone for an ongoing relationship. When the case manager (not a clerical functionary) interviews the client, he or she should retrieve not only the information typically sought in the organization's regular intake process, but also data related to comprehensive, long-term services. This information will contribute to current and later accountability. At the same time, to contribute to the client's sense of predictability and partnership, care must be taken to inform him or her about *why* data is being gathered and how it will be used.

The most effective assessment tool is a series of personal appointments in which the case manager hears, sees, and senses the young person's situation. The case manager can learn

who this person is, what strengths can be worked with, and what vulnerabilities must be compensated for. Interviews should shed light on such questions as:

- What social skills does the client possess? How developed are verbal and expressive capacities? What affect and emotional tone are conveyed? How organized is the client? How does he or she describe problems, possible solutions, and future ambitions?
- What support network already exists? Who within the client's environment can be turned to for help? Are there role models?
- What is the client's school history? What problems crop up and when? Do patterns emerge in the relationship of the client to teachers and school authorities?
- What is the client's employment experience? What issues recur? What vocational interests are expressed? Are the client's expectations realistic?
- What is the client's service history? Is it possible to pick up where a previous service provider left off?

Assessment will probably also involve testing; however, it is important to choose tests capable of generating information that is accurate and that a program will actually use. Many testing instruments exist; however, no one test renders a complete understanding of a client's problems and potentialities. In addition, unless testing is related to real program options and can help determine which options make sense for a client, the entire process becomes a misleading exercise. Respect for the client leads to the rule: "collect all the information you can use, and use all the information you collect."

In sum, the intake and assessment process helps map out the terms of the case manager/client partnership, subject, of course, to revision and renegotiation. But it is equally important to note that, while there are advantages to gathering lots of good data up front, assessment is an ongoing process. The case manager will need to work hard over time to develop a relationship with the client and to continually track his or her progress.

**Designing a Service Plan.** The alliance between case manager and client is intended to bring about change. The case manager works in partnership with the client to develop clear

expectations and set realistic goals. The client's views of what she or he wants must be acknowledged, respected, and then tempered with the case manager's input about reality.

How goals are subsequently translated into changes, through what means, and over what period of time, are issues that are addressed and pinned down in a written service plan. To assure predictability, the case manager needs to explain how one service precedes another, and to help the client sequence each service. Together, they work as partners to formulate a written contract that insures mutual accountability — one that delineates their respective responsibilities and is explicit about the nature of the partnership being agreed to.

An ideal plan includes long-term goals accompanied by short-term objectives that are quickly achievable — the client can experience regular, *predictable* "wins." The plan translates those objectives into the services necessary to achieve them, and identifies organizations or individuals who provide those services.

A well-designed service plan ensures client ownership. Specific, mutually defined tasks, clear timelines, and delineation of mutual roles help the young person feel that it is his or her plan, and that he or she is empowered to carry it out. To reinforce the ownership, predictability and accountability represented by the plan, the case manager should also include dates to review the plan with the client, and a projected date for termination of case-management.

**Intervening in the Community: Brokering, Advocating, and Linking.** For a case manager to make effective referrals, institutions at the receiving end must have slots available on an as-needed basis. They must be willing to grant timely admission to their programs, rather than placing the client on a waiting list. Ideally, the case manager can say: "I need my client enrolled in your program this week," and have it happen. Persuading institutions to do this is not easy.

Agencies providing case management have taken a variety of approaches to the referral process. Some place primary responsibility for identifying and securing services with the case manager, who works to develop needed slots on a case by case basis. Other agencies have organized the referral process more formally by assigning the task to a "resource developer" who secures service slots from agencies in the same manner as job developers have traditionally obtained employment slots from businesses.

Both of these approaches, however, are far

from ideal. Both are essentially piecemeal approaches that do little to encourage institutions to move away from "business as usual." As a result, case managers and "resource developers" continue to face problems securing slots. Both approaches lack predictability (the case manager cannot guarantee a slot to the client) and accountability (agencies are not accountable for failure to provide services). And neither can guarantee respect for the client (institutions have no rules or buy-in related to this aspect of client service). While both approaches place a case manager in charge of identifying and linking together a sequence of services, they offer few tools for assuring the quality of services or that the necessary linkages will actually take place.

The tools needed to assure timely referrals and to institutionalize case management over the long-term are most likely to result from the creation of a formal inter-agency partnership or providers alliance in which member institutions empower case managers to "requisition" slots across institutional boundaries. Formed specifically to enable case managers to arrange fast admission to services for their clients, these collaborations can be organized with clear rules that ensure accountability, communicate respect, and build in predictability. (See the discussion of the Boston Education and Employment Project in this issue for information on one case management alliance.) Collaborations of this type take hard work to develop and maintain. But without the establishment of a network of explicit agreements — partnerships — case management is unlikely to offer significant improvements over the existing service delivery system.

**Implementing and Monitoring the Service Plan.** The partnership between client and case manager continues in accomplishing the terms of the service plan. That process involves a division of labor in which the young person carries his or her weight: showing up for appointments, enduring testing, attending training classes, etc. The case manager provides oversight, ensures coordination and continuity of service, and gives the youth opportunities to show initiative and develop competence. The relationship is dynamic and shifting, sometimes requiring hand-holding, sometimes stern lectures ("tough love"), sometimes nagging, sometimes a gentle push to risk "going it alone" — always based in respect.

A case manager skilled in the use of referral procedures can help a young person become an active partner in his or her own service plan.

After assisting a client to identify the problems he or she faces, translating those problems into service needs, and giving each an appropriate priority, the case manager generates a set of service options from which the client can choose. Before choosing, the case manager and client discuss how each option might meet the client's needs - issues such as the reputation of each agency, their eligibility requirements and fees, the amount of time the client will have to spend in service, and agency locations and proximity to transportation.

Once the client has chosen an option, he or she needs to hear about the referral procedure in simple step-by-step terms. Ideally, the client will then, in the case manager's presence, call a known person at the referral organization and schedule an appointment. In all cases, the client should write down the appointment date, time, contact person's name, and directions to the referral agency. Predictability is the watchword.

The case manager also needs to determine how much additional support the client needs to carry out the referral successfully (transportation, hand-holding, baby-sitting, etc.) and help the client arrange for that support.

To ensure accountability, the case manager usually contacts both the client and the referral agency shortly after the client's appointment to identify what transpired as seen through the eyes of both parties - perceptions often differ. The client and case manager can then determine what the client's next steps are, how the case manager can support their implementation, and whether a revision of the service plan is called for. These tasks are written down and become part of the service plan. Of course, if the client did not attend the appointment as planned, it is through such monitoring that the case manager learns that corrective action is necessary.

After a client has been successfully placed into a program, the case manager monitors the placement to assure that it meets the needs set forth in the service plan. If the client completes a service, he or she can then move on to the next (predicted) aspect of his or her service plan. On the other hand, if the client is unable to achieve his or her goals through the referral, it may be time for the case manager to intervene with the referral agency, or even to review and adjust the service plan.

Accountability and predictability in implementing a service plan also depend on communication among the service providers. As much as possible, there should be regular team meetings, face to face, with the various human service workers associated with each case.

Problems must be worked out, histories shared, expectations established. Team meetings (case conferences) are at the heart of "continuity of care."

Finally, the long-term goal of any service plan should be for a client eventually to no longer need case management. Partnership, predictability, accountability and respect are all aimed at helping young people to complete their service plans, learn how to access other services on their own, and feel ready to handle life without professional intervention: in short, to be ready to break from case management dependence.

**Evaluating the Effectiveness of Case Management.** Case management is expensive and time consuming. It is important, therefore, that its results be evaluated. Some of the questions that need to be asked are:

- Over several years, do the numbers - financial analysis, placements, positive terminations, etc. - bear out what practitioners' gut-level views may have called "success?"
- Have the services and resources to which clients have been referred been appropriate and adequate to meet their needs? Was case management effective at accessing and coordinating those services and resources?
- What has happened to clients one year, and two years, after ceasing case management support? What might have happened if case management had not been provided?
- If evaluation indicates that case management may not have been successful, should it be discontinued, or could some adjustment make it viable?

While these are tough questions, they are critical to understanding if case management is working and whether the effort going into it is ultimately paying off.

### **The Case Manager's Role**

The basic principles of case management point to a multifaceted role for the case manager. In essence, case managers are "jacks of all trades." They stimulate, coordinate, and monitor service delivery so that youth do not fall through cracks. They do whatever is necessary to remove barriers hindering a client's advance towards self-sufficiency.

According to one text, case managers "help clients develop and effectively utilize their own

internal problem solving and coping resources, and facilitate ongoing interactions between resource systems to enable those systems to work together more effectively. Case managers facilitate and improve interaction between staff within resource systems to promote the effective and humane operation of these systems and to make them responsive to client needs. They establish linkages between clients and resource systems, and between resource systems themselves to make them accessible to each other. They develop new resource systems to meet the needs of clients." [Anne Minahan, "Generalists and Specialists in Social Work," *Arete* (Fall, 1976)]

Case managers serve as surrogate parents, role models, counselors, social entrepreneurs, and political advocates. They nag, cajole, prod, and encourage clients. They pressure institutions to act responsibly or lubricate the gears between institutions. They make referrals, and monitor client fit. They deal with the client's family life; work and school; social services and public institutions. They alter client behaviors – strengthening client capacity to exercise self-determination and autonomy.

**Qualifications for Case Managers.** What are the proper qualifications of a case manager? They vary according to the context. A national study examining 140 case managers in six cities, for example, found that roughly a third had less than a college degree, 55% had four years of college and only 15% were master's level. Social work training was typical, but not obligatory. Case managers serving teenage girls often had a nursing background. Ex-gang members sometimes did case management work with gangs. At times, parents served as case managers for developmentally disabled children.

**Disciplined Empathy.** Case management qualifications reflect local environments; nevertheless, some cross-cutting criteria can be identified. For example, effective case managers seem to exhibit what might be called "disciplined empathy." They respect and care about their clients, and can develop partnerships with those clients. They listen to what clients say, read between the lines, and size them up. They can work with the client to develop a service plan, and can have the client "buy in" to it as if it were his or her idea in the first place.

Effective case managers demand accountability from clients. They have a compassionate but

tough-minded understanding of the youth they work with – an ability to develop a therapeutic alliance, and to challenge and confront kids to meet their end of the bargain.

**Partnership Skills.** At the same time, case managers have to have the skills to develop partnerships with institutions. Diplomatic sensitivity is a key trait. Case managers negotiate with bureaucracies for services. To do so well requires adept social skills, and an ability to read institutional cultures. Crossing jurisdictional lines entails a delicate balancing act – doing business on someone else's turf. Out-stationed staff must be able to assert client interests, while being creative and flexible enough to make case management complement the mission of the host.

Being indigenous to, or at least to have a working knowledge of their community can be a plus for a case manager. Being of the same racial or linguistic background as the majority of clients is also desirable. Neither is a precondition.

It also helps if case managers have a human services orientation. They need to adopt a philosophy that barriers to client self-determination are *both* internal and external, and constantly interact. Interventions must aim at changing both the individual and the environment.

**Entrepreneurial Ingenuity.** Finally, case managers should exhibit entrepreneurial ingenuity. Because resources are not immediately accessible, effective case managers need to be able to fashion client support networks from resources under others' control. They need to be able to mediate alliances among competing agencies, establish trust and articulate mutual interests.

**Staff Development Key.** It must be acknowledged, up front, that it is rare for an organization to hire an ideal, ready-to-operate case manager. In fact, it is neither feasible nor desirable that case managers have a standard resume. Rather, good case managers are created. They enter the field with solid "raw material," but it is training that molds them into effective professionals.

The key to that process is on-going staff development that acquaints potential case managers with the multiple elements of good case management, and conveys the capacity to

*continued on page 15*

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*Case Management, continued from page 7*  
design - in partnership with clients - a strategy of predictable remediation and support. Case managers should learn to conceptualize the importance of family, group, community, and social policy as they effect schemes of intervention. They should understand the components of accountability - a good case record, and clear entries for intake, referral, service delivery, termination, and follow-up. Case managers should be able to define and give examples of advocacy techniques. Finally, case managers must grasp the need for partnership - agency coordination and institutional collaboration - and understand the barriers which stand in the way of building such alliances, and how these barriers can be overcome.

### **The Case for Case Management**

In the end, case management cannot be seen as a cure-all for all the problems of serving at-risk youth. It is difficult to implement, time-consuming and resource intensive to operate well, and depends on the willingness of established institutions to change their long-standing ways of doing business.

But case management still has much to offer practitioners serving at-risk youth. When given the care and attention required, a case management approach can provide an essential measure of coordination and support for youth in need of assistance. And as human service professionals confront increasingly complex problems and seek new ways to respond, case management can provide a valuable conceptual framework in which services can be planned and new techniques for bringing those plans into operation.

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*This article draws on research conducted by Andrew Hahn, Paul Aaron and Chris Kingsley at the Center for Human Resources for the New York Community Trust and the Exxon Education Fund. It also builds on the Center's work for the Annie E. Casey Foundation's New Futures initiative. This and additional material form the basis for a forthcoming (Spring, 1989) Center for Human Resources publication on effective case management practices. For more information on that publication, write Chris Kingsley at The Center for Human Resources, The Heller School, Brandeis University, 60 Turner Street, P.O. Box 9110, Waltham, MA 02254-9110.*

*BEEP Collaborative, continued from page 13*  
that kind of time commitment, and it was tough. But, BEEP looked so good, it was such a challenge, and its potential benefits to kids seemed so important, that it was worth the effort. I had a vision of how it should be, and I wanted that vision and dream to be a reality.

Clearly, another important qualification is the ability to be very persuasive. You have to be able to get other people to buy-in to your ideas. You also have to be willing to fight hard. There will be plenty of barriers that hinder collaboration. The leader has to fight many of them. When the heat comes down on you, you have to be able to handle it.

Finally, BEEP may sometimes sound like *my* program. But I hope I've made it clear that a prime qualification is the willingness to transfer ownership to other partners. Although BEEP *started* as my idea, in the end, we all owned it. If you talked to the other agency directors in BEEP, they'd say that it was their program too. There was a lot of pride in what *we* did...you could see that pride of ownership in the council meetings.

**CHR:** What kind of a difference did BEEP make for its clients?

**DELANEY:** Several of the agencies told me that they couldn't have done a good job with court-involved kids were it not for BEEP. They needed the extra support that case management provided.

At the systems end, I think that BEEP's single entry point and case management approach were very important. Tough kids don't go around telling their life histories over and over again. BEEP gave them the opportunity to bare their souls once and only once. I think kids appreciated that and stuck around.

Lastly, we let kids know that they weren't alone, and I think they valued that. They had a caring case manager to talk to. The case manager was theirs - someone they could call to complain to. And when a kid hit a barrier and thought that he or she couldn't continue, the case manager's intervention, and the help that resulted, often made the difference between completing the program or dropping out.

## CASE MANAGEMENT

### I. Definition

As defined in the Regulations [sec.303.6(a)(1)], . . . "case management" means the activities carried out by a case manager to assist and enable a child eligible under this part and the child's family to receive the rights, procedural safeguards, and services that are authorized to be provided under the State's early intervention services.

### II. Steps in the Process

- (1) Coordinating the performance of evaluations and assessments;
- (2) Facilitating and participating in the development, review, and evaluation of individualized family service plans;
- (3) Assisting families in identifying available service providers;
- (4) Coordinating and monitoring the delivery of available services;
- (5) Informing families of the availability of advocacy services;
- (6) Coordinating with medical and health providers; and
- (7) Facilitating the development of a transition plan to pre-school services, if appropriate. [303.6(b)(1-7)]

### III. Discussion

The major task at hand is to promote the effective and efficient organization and utilization of existing resources to assure access to necessary comprehensive services for eligible children and their families, rather than the creation of an entirely new program entity. Given this perspective, the case management system model that is recommended is a community-based transagency model. The essential aspect of this model is that the case manager should be selected on a case-by-case basis from the agency and discipline most appropriate to the child and family's needs. Such a model permits the utilization of both direct service providers as case managers and case management personnel who do not have a direct service role (i.e., a "dedicated" case manager).

Other than being a set of logical steps or activities, as outlined in this document, case management is actually operationalized as a process of interaction with families which assures that a child and family receive needed services in a supportive, effective and efficient manner. Such should go beyond simply a consideration of family needs, into the realm of integrating families into the decision-making process, demonstrating a true "partnership" between professionals and families at all levels of the service delivery system.

#### IV. Recommendations

The following recommendations are organized with regard to the specific case management activities identified in the Federal Regulations [303.6(b)(1-7)]. In addition to these Regulations, these recommendations were developed based upon resource documents developed through the Maryland Infants and Toddlers Program, other state and national resource materials, and upon the expertise of a variety of professionals and parents involved with the Program.

#### ● Coordinating the performance of evaluations and assessments

##### Recommended Responsibilities:

- 1) To assist the family in understanding the process and procedures, including their rights and responsibilities, relevant to the evaluation/assessment process.
- 2) To ensure a timely, comprehensive, multidisciplinary evaluation of the child for the purpose of determining eligibility for early intervention services.
- 3) To ensure that this process includes an assessment of the needs and strengths of the child for the purpose of identifying needed services.
- 4) To ensure that this process includes an assessment of the needs and strengths of the family related to enhancing the child's development for the purpose of identifying needed services[a].

[a] The conduct of family assessment procedures is voluntary on the part of the family.

- 5) To facilitate the movement of the child and family through the evaluation/assessment process, including providing assistance, as needed, in the following areas:
  - (i) completing application/consent procedures;
  - (ii) obtaining copies of existing evaluation/assessment reports, including pertinent medical/health records[b];
  - (iii) scheduling of evaluations/assessments with consideration to the child and family's availability, including the child's sleep/wake and feeding schedule;
  - (iv) arranging transportation;
  - (v) supporting the family in being an active participant in the evaluation/assessment process;
  - (vi) obtaining a copy of desired completed reports from this process.

[b] Parental consent for receiving existing evaluation/assessment information should be obtained immediately in order to avoid duplication.



● Facilitating and participating in the development, review, and evaluation of individualized family service plans

Recommended Responsibilities:

- 1) To assist the family in understanding the process and procedures, including their rights and responsibilities, relevant to the IFSP process.
  - 2) To ensure that a meeting to develop the initial IFSP is conducted within the 45 day time period[a] and that the meeting includes the following participants:
    - (i) the parent(s) of the child and other family members requested by the parent(s);
    - (ii) an advocate or other person as requested by the parent(s);
    - (iii) the case manager;
    - (iv) a person(s) directly involved in the evaluation/assessment process;
    - (v) as appropriate, persons who will be providing early intervention services to the child or family.
- [a] A single time line of 45 days from the time of referral to the "single point of entry" has been established for both completing the evaluation/assessment and conducting the initial IFSP meeting.
- 3) To facilitate the active participation of the family in IFSP process, including providing assistance, as needed in the following areas:
    - (i) obtaining all reports resulting from or related to the evaluation/assessment process;
    - (ii) scheduling of the IFSP and other related meetings (via written notice) dependent on the family's availability;
    - (iii) arranging transportation;
    - (iv) supporting the family in being an active participant in the IFSP process.
    - (v) obtaining a copy of the completed written IFSP.
  - 4) To ensure that the written IFSP is completed consistent with the established format[b], including:
    - (i) medical/health and other non-IFSP services that the child or family needs;
    - (ii) the name of the case manager who will be responsible for the implementation of the IFSP and coordination with other agencies and persons[c-d];
    - (iii) all indicated signatures[e].
- [b] In instances where a child must have both an IFSP and an individualized service plan under another Federal/State program, it should be possible to develop a single document which consolidates both plans provided it is developed in accordance with the requirements under P.L. 99-457.

- [c] The case manager to be responsible for implementing the IFSP may be the interim case manager who was appointed at the time the child was initially referred and who has assisted the family through the evaluation/assessment and IFSP process, or a new case manager more relevant to the child and family's needs, as agreed upon by the family, may be identified.
- [d] The Federal Regulations make it clear that the responsibility for case management be assigned to an "appropriate, qualified public agency employee" (this does not preclude the use of private agencies under contract/agreement with a public agency). Although parents may not be named as "case managers" for their own children, the Regulations recognize that parents (1) are major decision-makers in deciding the extent to which they will participate in, and receive services under the Program, including the selection of a case manager, and (2) must be actively involved in assuring that their eligible children and other family members receive all of the services and protections that they are entitled to under the Program.
- [e] The parents may not sign the IFSP at this time if they choose to further explore service options, or if they have any dispute with the contents of the plan.
- 5) To ensure that a review of the IFSP is conducted every six months or more frequently if conditions warrant, or if the family requests such, in order to determine progress and whether modification of outcomes or services is necessary[f].
- [f] The six month periodic review may be carried out by a meeting or by another means that is acceptable to the parent(s) and other participants.
- 6) To ensure that a formal IFSP review meeting is conducted on at least an annual basis consistent with the provisions in #1, #2 & #3 as stated above[g].
- [g] The requirement for the annual IFSP meeting incorporates the six month periodic review process. Thus, it is necessary to have only one separate periodic review each year (i.e., six months after the initial and subsequent annual IFSP meetings), unless warranted otherwise.
- 7) To monitor compliance with established time lines and other procedural safeguards under the Program.
- 8) To ensure that all appropriate data is transferred to the local data collection system.

● Assisting families in identifying available service providers

Recommended Responsibilities:

- 1) To ensure that the family receives information regarding the availability of service options (i.e., nature of services, eligibility requirements, location, hours, etc.), including services needed that may not be covered under the Program (i.e., non-covered medical/surgical services, equipment/supplies, respite care, etc.).
- 2) To ensure informed decision-making by the family in selecting service options.
- 3) To assist the family in negotiating with service providers regarding the services needed and related financial matters[a], including services that may not be covered under the Program.

[a] This may include assisting in the preparation of eligibility applications or insurance claims.

- 4) To ensure that the family is informed of their rights and responsibilities in regard to specific programs and services.
- 5) To otherwise ensure service utilization, including assisting families, as needed, with scheduling, child care, transportation, etc.

● Coordinating and monitoring the delivery of available services

Recommended Responsibilities:

- 1) To maintain ongoing communication with the family through home visits, office visits, telephone calls and other follow-up activities.
- 2) To maintain contact with and ensure communication among service providers, and between providers and the family.
- 3) To utilize the following information sources in determining that services are being provided in a supportive and coordinated manner, and in assessing child and family progress toward identified outcomes:
  - (i) outcomes and timelines as specified in the IFSP;
  - (ii) parents and other family members as appropriate;
  - (iii) observations of the child;
  - (iv) service providers;
  - (v) written reports.
- 4) To assist the family in monitoring the child's progress, including their maintenance of adequate records.

- 5) To participate in all periodic reviews and the annual IFSP meeting.

● Informing families of the availability of advocacy services

Recommended Responsibilities:

- 1) To assist the family in understanding the general purpose of advocacy services[a].

[a] It should be emphasized that it is the intent of all service providers to be supportive to the family and thus, their advocates in a general sense. However, there may be circumstances in which the family may desire specific advocacy support from outside the service delivery system, including the need for legal representation.

- 2) To assist the family in understanding that an advocate or other such person may attend the IFSP meeting at their request.

- 3) To inform the family of the availability of advocacy services, including specific contact information, when less formal means of dispute resolution with the assistance of the case manager are not successful.

- 4) To explain to the family their right to be accompanied and advised in administrative proceedings, including due process, by counsel, which may be provided by an advocate, and/or by individuals with special knowledge or training with respect to early intervention services[b].

[b] Families may need clarification that the role of the case manager is not one of legal representation.

● Coordinating with medical and health providers

Recommended Responsibilities:

- 1) To ensure that the IFSP provides a comprehensive picture of the child's total service needs, including the need for medical and health services that are not considered early intervention services (i.e., services that are surgical or purely medical in nature, well-child care)[a].

[a] Identifying these services in the IFSP does not impose an obligation to provide the services if they are otherwise not required to be provided as "early intervention services."

- 2) To assist the family, as needed, in securing non-covered medical and health services, including:

(i) determining if there is a public agency (i.e., Medicaid, Children's Medical Services) that could provide financial and other assistance;

(ii) assisting in the preparation of eligibility or insurance claims;

(iii) assisting the family in seeking out and arranging for the child to receive the needed medical and health services.

3) To ensure the coordination of early intervention services with medical and health services[b].

[b] In certain circumstances (i.e., child who is medically fragile), it may be appropriate for the child's medical/health care coordinator to assume the role of case manager for early intervention services. Otherwise, the IFSP case manager should ensure the integration of the medical/health care coordinator into the planning process.

● Facilitating the development of a transition plan to preschool services, if appropriate

Recommended Responsibilities:

1) To ensure provision within the IFSP[a] of steps to be taken to support the transition of the child upon reaching age three to:

(i) preschool services (special education and related services under Part B) to the extent that those services are appropriate; and/or

(ii) other child care, medical/health and social services that may be needed by the child and family.

[a] Transition plans should be addressed within the IFSP at least six months prior to end of the child's eligibility under Part H.

2) To discuss with, and provide training for, parents regarding future placements and other matters related to the child's transition[c].

[c] The family may need assistance regarding the financial aspects of services that will not be an entitlement after transition from Part H.

3) To implement procedures to prepare the child for changes in service delivery, including steps to help the child adjust to, and function in, a new setting;

- 4) To ensure the transmission of information, with formal parental consent, to:
- (i) the local educational agency (i.e., evaluations, assessments, IFSP) if the child is eligible for Part B services; and/or
  - (ii) other child care, medical/health and social service providers, if appropriate.