Substance abuse is everywhere, and no one is immune to its effects. Some individuals, however, may be more susceptible than others; this includes people with developmental disabilities. This population, long isolated in institutions, has now moved into the mainstream of society. High numbers of people with developmental disabilities are mildly impaired; they live normal lives, working, marrying, and living in the community, having families. They often “blend in.”

This article will discuss the characteristics and vulnerabilities to substance abuse of people with developmental disabilities, paying particular attention to the complex issues of parenting. It will define and explore developmental disability, offer suggestions for identification and management of people with developmental disabilities, and explore strategies for treatment and intervention.

Definitions

Developmental disabilities are attributable to mental retardation, cerebral palsy, autism or epilepsy. By definition, all developmental disabilities originate before age 18 (in some states, before age 21), are likely to continue indefinitely, and constitute a “substantial disability” to the individual. Significant “functional limitations” exist in several areas of life management, e.g. communication, self care, learning, self direction, capacity for economic self-sufficiency (American Psychological Association, 2000).

About two percent of the population has mental retardation, with many persons having manifestations of other developmental disabilities along with their mental retardation (Murphy, 1998). Most people with this disability were identified early in life; most have received special education services. It is very important to note, however, that 85% of all people with mental retardation are mildly mentally retarded (DSM IV-TR). While they may have functional limitations, these only mildly impair their daily lives.

All states in the United States have some system of service delivery for people with developmental disabilities and their families. The range of services is wide, including early identification and intervention, evaluation and assessment, and on-going practical support. Most systems offer respite service for families, residential and vocational services for consumers, and many other ancillary supports.

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However, many, many people with mental retardation will never come to the attention of any service system, unless and until other life management problems arise.

Life with a developmental disability

Being different is difficult. No one likes to stand out as less capable than their peers. People with lifelong disabilities begin life in a different spot, and spend a lot of energy trying to move off that spot. Sometimes, so much energy is spent trying to appear normal that necessary social, educational and emotional growth is ignored.

As people with developmental disabilities have moved into the mainstream of life, a paradox has arisen. Public awareness of disability (through things as varied as Special Olympics, television portrayals, tax incentives to employers) has opened doors to people who want to be seen as “people first.” The efforts that pave the way to fitting in have also drawn attention. Like most people, individuals with developmental disabilities will state, “I want to be accepted for who I am!” Years of coping with a sometimes hostile, often confusing world, cause changes in the person with a developmental disability. Many try to “cover” or compensate for the disability by pretending to have skills, avoiding challenging situations, or other deceptions. Some will go out of their way to achieve what they believe is “normal” behavior, even if it is illegal or antisocial. In order to meet basic human needs—for companionship, affection, positive regard—some will allow themselves to be exploited or put at risk. Sometimes the need to fit in eclipses good judgment. The paradox is compounded by the reality that the more people enter the mainstream of society, the more they are exposed to its risks.

Recognition and response

In a practical sense, what is required to effectively identify and communicate with people with developmental disabilities? Many will not appear to have a disability; others will have obvious problems, in appearance, clothing or hygiene. Often, the first indication will be problems in speech and communication. Tangential or seemingly irrelevant topics may be introduced and repeated. Sometimes, there is repetition of one subject or idea, seemingly out of context. One of many coping or “covering” mechanisms used is that of stereotypic responses, e.g. saying “I’m fine, I’m cool”, when in fact they are injured or ill. A related factor is using topical jargon or phrases from movies or other pop culture to express themselves. An observer may note memory problems or obvious lack of clarity about time, money, or the basic facts of their lives (e.g., address, phone number). They may act overly friendly, even with strangers. Respect for personal distance or awareness of the finer points of social conduct may not be evident. The common denominator is wanting to be accepted as one of the crowd, not standing out, and going to great lengths to avoid identification as a person with disabilities.

If a disability is seen or suspected, some questions can clarify the situation without unduly drawing attention or causing embarrassment. Non-threatening, open-ended questions, such as “Tell me about your school background, your reading skills, where you live, how you travel around town, who does the cooking where you live?” can give information or hint at areas to explore. Remember that more time will be needed to talk with and serve this group. It may take longer for some to open up or to trust. Others will be very free with personal facts, not always using good judgment about the people with whom they are sharing. It is crucial to avoid labels and not to speak of people as illnesses or conditions. The model of “people first” is apt, e.g. a person who uses a wheelchair, people who have epilepsy, children with autism. Most people with disabilities have made healthy adjustments to their lives and do not see themselves as “suffering from” or “victims of” anything.

Parenting with a developmental disability

One of many ways of fitting in, of having a “normal” life, is to fall in love, marry, and raise a family. Yet, special considerations exist for parents with developmental disabilities. Like most people with a disability, they often are unemployed or underemployed, or live on Social Security disability benefits (Parrish, 2002). About one third of people with developmental disabilities have a co-occurring mental illness, most often depression (Fuller and Sabatino, 1998). Growing up with a disability that sets one apart from peers can create self-esteem and social skills problems. Deficits in problem-solving skills will be part of most cognitive disabilities. These factors, along with others, will complicate parenting and marriage. Difficulties with comprehension can result in ineffective use of contraception, which can result in unplanned pregnancies. Many parents with developmental disability are single parents,
Parenting occurs in the context of the family, community and society. For all parents, regardless of ability, parenting can be stressful, causing feelings of fear, isolation, frustration, and failure. People with disabilities are sometimes reluctant to ask for help with these or other stressors because this draws attention to their limitations. After many years of disappointment and feeling “less than,” becoming a parent can seem like a rare success. Grandparents can become over-involved, controlling too much, usually out of concern for the children of their disabled son or daughter. This could exacerbate problems within the relationships and further undermine the self-esteem of the developmentally disabled parent. Depending on the degree of cognitive limitation, problems with bonding between infant and parent could arise. There may be problems “reading” and interpreting the cues given by the infant. Due to unrealistic expectations about the child or parenting, there may be deep disappointment and higher levels of frustration. Some people with developmental disabilities will have difficulty putting the needs of a child ahead of their own when necessary. Neglect or endangerment of the child may result.

Substance use as an “avenue to self-esteem”

Hand in hand with parenting as a “normalizing” factor, and intimately related to participation in the real world, is the risk of substance abuse, described as an “avenue to self-esteem” to which people with disabilities are more susceptible (Bjorndal, 2001). Using alcohol and other drugs can accomplish two things: it can dull uncomfortable feelings and raise feelings of success, accomplishment and self-worth. Therefore, people with developmental disabilities may be considered more vulnerable to substance abuse due to “inadequate self-regulatory behaviors” and a deep need to fit in (Christian & Poling, 1997).

Early research on prevention of substance abuse identified protective and resiliency factors in all young people. Special social competencies characterize a resilient young person and help protect them from substance abuse (Wemer, 1996). As important as these protective and resiliency factors are, some are closed to people with developmental disabilities or harder for them to achieve. For example, an internal locus of control, competence and personal power is more difficult for a person whose limitations have resulted in others making most major decisions for them. Similarly, having an opportunity to participate in and make a contribution to one’s community may be less possible for a person with disabilities. Being successful at problem-solving and critical thinking will obviously be difficult for people with cognitive problems.

Along with these factors, which, when in place, can “protect” any person, there are others that mitigate against the person with developmental disabilities. “Self-medication” against physical pain, feelings of loss, loneliness, frustration about having disabilities, and possible depression may happen. People with disabilities may think of substance abuse as something they are “allowed” to or “need” to do to cope. Because of the pervasive nature of disability into all aspects of life, adjustment to the condition is a “life-long process” (DeLoach & Greer, 1981). Due to psycho-social deficits implicit in their disability, people with developmental disabilities will be ambivalent about their independence and autonomy (Brady, 1993). They make efforts to fit in, often out of proportion with abilities to control the effects. The fitting in may occur at the local bar, where social expectations shift and alcohol breaks down barriers, and the social approval gained by

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buying drinks for others may be very important. “Intoxication is a great intellectual equalizer” (Wenc, 1980/81). Problems in social, occupational and economic areas may cause stresses that become a rationale for substance use and abuse. The period of normal adolescent rebellion and individuation will be longer and more difficult (Brady, 1993), resulting in more or longer use and experimentation with alcohol and other drugs. The difficulties with abstraction, which characterizes people with cognitive deficits of any kind, will result in problems anticipating the results of their behavior or in delaying use to more appropriate times. The immediate need will predominate. Reluctance to admit a problem and accept another label, a “double-stigma,” may result in not asking for help.

The world in which the person with a developmental disability lives contributes to the risks, often with the best of intentions. Many do not receive even basic drug and alcohol education. Parents, teachers and others “protect” individuals from information. Parents and professionals are unwilling to believe that substance abuse may be present, or fear that confrontation may break an already fragile trust. Fear of a “double stigma” causes reticence also; why burden an already labeled person with another?

People with disabilities may live in families where substance abuse is present, and they may come under pressure to join their parents or siblings in their use. Parents of the developmentally disabled want them to grow up, enjoy family celebrations, and be a part of the family. If this includes alcohol or other drugs, the person with a developmental disability may not be as capable of coping with the effects, may not learn from experience, and may not transfer learning from one situation to another. Some people with developmental disabilities may “use” their disability to avoid the consequences of their substance abuse, attributing slurred speech, clumsiness, etc. to the disability rather than intoxication. Law enforcement staff may willingly accept this rather than attempt to respond to the special needs of the individual.

**Social Skill Building Is Necessary, and Possible, As Responses To Both Parenting And Substance Abuse.** For the Developmentally Disabled, This Will Need To Be Concrete, Practical And Reality Based.

**Convergence and treatment**

How can an already overworked system respond? People with developmental disabilities are more vulnerable to substance abuse, more difficult to identify as needing treatment, and more challenging to treat. If they are also parents, the problems are compounded. However, the underlying issues of learning to parent effectively and learning to abstain from alcohol and other drugs have many commonalities.

Self-esteem is critical. All people have a basic need to be seen as competent, to contribute, and to have some control over their own lives. Parent training or substance abuse treatment programs that recognize this will be off to a good start. An effective program will focus on success, provide opportunity for positive, autonomous choice, and eliminate labels. It is important to recognize that both parenting and substance use may represent efforts to attach to something under the control of the individual—a way of validating connections. In both cases, the treatment/training will require specially trained staff, more frequent opportunities for training, and a longer duration (Annand, 2002).

Social skill building is necessary, and possible, as responses to both parenting and substance abuse. For the developmentally disabled, this will need to be concrete, practical and reality based. Some skills learned will not transfer to other situations or settings. Great care must be taken not to re-traumatize people with disabilities. There is grief and shame in not having achieved success in the world comparable to non-disabled peers (Brady, 1993). For some, these feelings will become intolerable if linked to an exploration of their substance abuse, resulting in rejection of treatment. A group experience where other members may not be sensitive or aware of “disability etiquette” can be painful and cause the person with a disability to flee.

Experts agree that motivation for change must come before efforts to change (Daley and Zuckoff, 1999). Parenting can be a great motivator to shift focus and grapple with a substance abuse problem. Usually, some legal or social consequences identify a problem and a search for help begins. Errors in judgment, impulse control
Lack of Resources to Meet the Need

Throughout the country, few agencies have recognized the needs of those with the coexisting disorders of substance dependence and cognitive disabilities, and fewer still are prepared to address them effectively. In their survey for the National Association for the Dually Diagnosed (NADD) Monograph Series, Sturmey and colleagues (2003) identified less than a dozen treatment programs in the United States for persons with both cognitive disabilities and substance dependence.

Many of the probation/parole officers, mental health professionals, developmental disability workers, alcohol-drug treatment staff, and child protection staff working with persons with both developmental disabilities and substance dependence are doing so without knowing it and without having adequate tools for diagnosing the conditions. Staff members are experiencing persistent frustration, depression, increased sick day use, and other signs of burn out (Annand, 2002; Westermeyer, Kemp, & Nugent, 1996).

In addition, clients are being incarcerated, losing parental rights, and being denied services, including alcohol/drug treatment, because their cognitive impairment prevents them from benefiting. All of this is directly traceable to failure of the various systems to identify the coexisting disorders and the lack of effective strategies for dealing with this population’s needs.

Griffiths, Stavrakaki, and Summers (2002) suggest the prevalence of this population is increasing. They report that Westermeyer, Crosby, and Nugent (1998), after reviewing several indicators of the prevalence of this disorder from people working in the field, determined that 6.2% of clients in two alcohol-drug treatment programs also had developmental disabilities. In 1996, the Rehabilitation Research and Training Center (RRTC) on Drugs and Disability in Dayton, OH, reported that 12.8 percent of vocational rehabilitation consumers, self-identified as having mental retardation, admitted illicit drug use within the past 12 months (RRTC, 1996).

Since traditional wisdom estimates that three percent of the population suffers from mental retardation, a far greater prevalence of alcohol/drug use issues exists among people with developmental disabilities than among the population at large, perhaps as high as twice the prevalence. So clinicians working for programs for those with cognitive disabilities may expect that at least some, and perhaps many, of their clients may have coexisting substance dependence.

Etiology

When persons with developmental disabilities were housed in institutions, or when their freedom of movement was otherwise curtailed, their access to alcohol and drugs was very limited and symptomatic behaviors did not develop. Therefore, the misconception arose that people with cognitive disabilities did not have substance use issues. However, since addiction is a hereditary trait disease (Westermeyer, Kemp, & Nugent, 1996; Cloninger & Li, 1985), those with cognitive disabilities can inherit the disease just like everyone else.

Also, when persons with developmental disabilities are sheltered in early life, they typically begin using later and develop problems sooner after initial use than non-impaired persons (Westermeyer, Kemp, & Nugent, 1996). This invites a conclusion that their problems are attributable to their cognitive disability and may not indicate substance dependence. With the advent of mainstreaming, persons with cognitive disabilities gained access to alcohol and drugs along with their access to housing, employment, etc., and the symptoms of chemical dependence began to appear.

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Problems of Diagnosis

Diagnosis may be difficult. Each discipline tends to see all of the problems a client may have as being related to the issues associated with that discipline. Drug treatment professionals may have a tendency to assume that all the client’s problems are caused by the drug use and attribute cognitive disabilities to resistance or lack of motivation. Mental health practitioners may tend to see the drug use as self-medication of the emotional pain of their mental health condition or miss the drug use entirely under a diagnosis of bi-polar or antisocial personality disorder. Developmental disorders/mental retardation staff may see all the issues as stemming from their client’s cognitive disabilities and never assess for substance use issues. And none of the staff in one discipline may feel or be competent to assess for the other disorders.

Recognizing the difficulty of using mainstream criteria for mental health diagnoses with persons with cognitive impairment, the American Psychiatric Association (APA) and the National Association for the Dually Diagnosed (NADD) will publish *The Diagnostic and Statistical Manual for Mental Disorders in Persons with Intellectual Disabilities (DSM - ID)*. This is an effort by hundreds of professionals from around the world to modify the DSM IV TR criteria to be more effective with persons with cognitive limitations and thereby increase our ability to identify this population.

Methods of Identification

It is important when working with clients, including those who are parents, to gather adequate information to determine if they need assessment for cognitive or alcohol/drug use problems. Information that might indicate the need for cognitive assessment includes:

- Does the parent have any kind of benefits like SSI?
- Does the parent have a case manager? Has he or she ever had one?
- Did the parent have any special classes in school?
- Has the parent ever lived in a hospital or group home?
- Has the parent ever been in Special Olympics?
- Does the parent have any problems reading or writing?

Addiction is a genetic trait disorder that is characterized by compulsive use of a substance. Therefore, some indications of the need for an assessment for substance use issues would include:

- Does the parent have a family history of any substance related disorder?
- Does the parent continue to use while having a problem that could be caused by or could be exacerbated by the use of a substance?
- Does the parent use more than intended or get intoxicated when the goal was to have a beer with a friend?
- Does the parent use after promising not to use?

If the parent uses any mood-altering substance and any of those four indicators is present, an assessment for substance-use disorder is needed.

Non-treatment Interventions

While alcohol-drug treatment programs designed specifically for persons with both cognitive disabilities and substance dependence are rare, there are steps that can be taken to significantly impact the dually diagnosed individual.

Clinicians working with those with both developmental disabilities and substance use disorders can incorporate the following strategies:

- Learn about addiction. Clinicians must become convinced that addiction is a disease and not a stigma, not something to be denied or ignored. They must also be aware that no matter what their specific task or job assignment they may have little success with a client with chemical dependency until the client first becomes abstinent.
- Learn about craving. If clinicians do not understand the phenomena of craving they will unintentionally sabotage their own efforts.
- Understand they are engaging in a process of teaching clients a *routine of living* that will support abstinence and that, because of the difficulty with learning, it will take a long time. They must be prepared to walk through relapses with their clients and use those relapses as learning experiences for themselves and teaching experiences for their clients. They must be patient and persevere.
- Enlist all the family members and professionals already working with the individual to coordinate their support into a *global support team*. In the course of their normal interactions with the client, each member of the team reinforces the idea of abstinence, teaches cause/effect relationships, and encourages the
use of specific tools designed to fit the needs of people with cognitive disabilities.

**Effective tools**

**THE 24-HOUR PLAN**

Each day, the dually diagnosed parent helps to develop a plan of action that he/she will take to stay sober that day. The activities can be divided into three categories: abstinence-permissive activities are those such as going to work or to a movie, which do not necessarily preclude drinking/drug use but certainly allow abstinence. Abstinence-supportive activities are those that are done specifically to stay sober, such as going to an AA/NA meeting. Abstinence-destructive activities include such things as going to visit an alcohol/drug-using friend. It is important to ask a client to include at least one abstinence-supportive and no abstinence-destructive activities in each 24-hour plan. Experience indicates that a client is unlikely to use on a day when he or she has a plan and does at least one thing on the plan.

**RECORDING THE “THINGS THAT HAPPEN TO ME WHEN I DON’T DRINK OR USE”**

As important as it is for clients with dual diagnoses to learn the cause-effect relationship between drinking/drugging and their problems, it is even more important that they learn that there is a direct causal connection between their life’s improvement and their abstinence. The connections will not be automatically clear to them. The improvements will occur slowly and over time, so clients will be prone to see them as accidental or due to other causes. Contrasting the information about the “things that happen to me when I drink and use” with the information collected about the “things that happen to me when I don’t use” will be very beneficial.

When using this information, repetition over time will be required for learning to take place. Because the client with both chemical dependency and cognitive disability has difficulty seeing cause-effect relationships, staff must make those connections for them again and again.

It is important to identify any bad things the dually diagnosed client thinks happen with abstinence. These are likely to be areas where learning new skills will be necessary. For instance, a client may list “I don’t get to hang with my (using) buddies any more” as a negative consequence of abstinence. That client will need time and encouragement to make some sober buddies with whom he/she can spend time.

**RECORDING THE “PEOPLE, PLACES, THINGS AND FEELINGS THAT MAKE ME WANT TO USE”**

Record triggers to relapse, and develop prevention strategies. Again, a narrative approach is helpful—“I was walking to my AA meeting and I ran into my friend Ruth and she offered me a beer, so I drank it and spent the rest of the day getting drunk with her.” Prevention strategies could include: 1) avoiding drinking/using buddies, 2) learning refusal skills, or 3) going to AA meetings with sober friends who can support the dually diagnosed client’s decision to abstain.

**Conclusion**

The coexisting conditions of cognitive disability, mental illness, and alcohol/drug use are not currently being identified with great regularity, and few alcohol-drug treatment programs are specifically designed to meet the needs of this population. There are extremely effective ways of addressing the problem of these coexisting conditions with individuals who have cognitive disabilities.

The development of a global support team can be initiated by any of the many professionals working with a person with both cognitive impairment and chemical use issues. All who have regular contact with the individual can use the non-treatment tools as effective interventions. This can often provide

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FOR YOUR INFORMATION

During the past few months, the AIA Resource Center held 2 national training events:

A WEBCAST ON
Sustaining Your Child and Family Services Organization in Lean Times
(August 5, 2005)

A CONFERENCE ON
Substance Exposed Newborns: Weaving Together Effective Policy & Practice
(October 6-7, 2005)

Although the live events already occurred, it’s not too late for you to retrieve information from the AIA website (http://aia.berkeley.edu).

The sustainability webcast can be accessed in its entirety, along with related handouts, at http://aia.berkeley.edu/training/sustainability/sustainability.html. Featured presentations included the following:

- What Does a Strategic Plan Look Like and How Do You Keep It Relevant?
  Anushka Fernandopulle, Senior Consultant, CompassPoint Nonprofit Services, San Francisco, CA
- Rising Costs - Frozen Bottom Lines
  Barbara Draimin, Executive Director, The Family Center, NY
- Raising More Money: Sustainable Funding for your Mission
  Lynda Bowman, Raising More Money Instructor and Coach

Many handouts and presentation slides from the substance exposed newborn conference are available at http://aia.berkeley.edu/training/2005_conference/archive_2005.html. Also at that sight, you can listen to audio recordings of the keynotes and other general sessions. This includes the following:

- Framing the Policy & Practice Debate on Substance Exposed Newborns
  Barry Lester, Ph.D., Director, Infant Development Center, Women and Infants Hospital, Brown Medical School;
  The Honorable James C. Greenwood, President and CEO, Biotechnology Industries
- Policies & Practices: What’s Happening Around the Country
  Steve Christian, Program Manager, Children and Families Program, National Conference of State Legislatures;
  Nancy Young, Ph.D., Director, National Center on Substance Abuse & Child Welfare;
  Amy Price, M.P.A., Associate Director & Krista Drescher-Burke, M.S.W., Research Assistant,
  National Abandoned Infants Assistance Resource Center
- Working Collaboratively with Substance Users & their Newborns
  Representatives from Arizona, Rhode Island, Washington State, and the metro areas of Albuquerque, New Mexico, and Kansas City, Missouri, briefly described their collaborative efforts to identify and address the needs of substance users and their newborns.
- Preventing Fetal Alcohol Spectrum Disorder: Have We Made Any Progress?
  Kathleen Mitchell, M.H.S., L.C.A.D.C, Vice President and National Spokesperson, National Organization on Fetal Alcohol Syndrome
- Federal Directions in Substance Abuse Treatment & Fetal Alcohol Spectrum Disorders
  Andrew McKehnie, Legislative Aide to Congressman Jim Ramstad, MN
- Future Directions in the Prevention & Treatment of Substance Exposed Newborns
  Ira Chasnoff, M.D., President, Children’s Research Triangle
The overall purpose of the Coordinated Intervention for Women and Children (CIWI) program in New Haven, CT, is to provide comprehensive home- and community-based services to prevent the abandonment of infants and children affected by maternal substance abuse. An intervention team, composed of a clinician and a family support worker, provides child-focused and home-based clinical intervention, prevention and supportive services to substance abusing mothers and their families to ensure the safety and well being of infants and their older siblings as well as the stability of their caretakers. Women using cocaine or heroin are encouraged to enter the program during pregnancy, and the intervention is available for up to eighteen months post-partum.

Many of the clients served by CIWI suffer from both cognitive limitations and substance abuse problems. This article describes the strategies developed by the CIWI program to address the salient issues in working with these parents. A case study is used to illustrate the needs and challenges of this population, as well as the use of interventions that are relationship based, strength based, and family focused, and that provide positive support systems for the family.

Case Study

Ms. S. is one of eight children. Ms. S. always struggled in school. She was tested at some point early on in her academic career and was found to be “Educable Mentally Retarded.” By sixteen, she was pregnant with her first child. Within the next year, Ms. S. found that she was pregnant again. She was seventeen with two children, and high school became more overwhelming and less of a priority to her and her family. Ms. S. never finished high school and never learned to read or write.

Ms. S’s life was marked by violence, drugs, and crime. She developed an addiction to crack/cocaine and spent many years enmeshed in the lifestyle that would lead to her next high. As a cognitively limited person using substances, Ms. S. was taken advantage of on many occasions by those also entrenched in addiction. She would prostitute herself for her drugs, and make choices that would leave her and her children in imminent risk of danger. Ms. S. did not consistently use birth control, and she had six children while she was actively using drugs.

Over the years, Ms. S. and her family were referred to many helping service agencies; however many of them would close her case stating that she was noncompliant with services. Ms. S. was mandated to attend many different treatment facilities to address her drug dependency issues. This included inpatient, residential, and outpatient facilities, and CIWI provided home-based work to help Ms. S. find ways to maintain sobriety and uphold her parenting. Many attempts to engage her were met with resistance and noncompliance. CIWI, like many other agencies, eventually closed her case. After many different attempts to keep Ms. S. and her family together, the Department of Children and Families (DCF) removed her children.

Ms. S. remained in contact with her children and hoped that they all could live together some day. Ms. S. had periods of recovery cycled with periods of relapse. None of the programs she attended seemed to be effective for her. She went to many outpatient programs for substance abuse, where it was reported that she seemed to have very poor insight into her addiction. Finally, after the birth of her sixth child, Ms. S. went to a long-term inpatient treatment facility, which

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provided enough structure to allow her to enter recovery on a long-term basis. When she was discharged, she had custody of her youngest child and her two oldest children. She was working actively with DCF to reunify her whole family.

After the discharge of Ms. S. from her inpatient facility, DCF requested CIWI’s services for a second time. Ms. S. was still struggling in her life and had many concrete needs that had to be addressed. She was living in a high-risk situation in an inadequate apartment. When CIWI was reintroduced to Ms. S., she expressed a need to help her look for appropriate housing.

Ms. S. recently gave birth to her seventh child. She was able to retain her sobriety throughout her pregnancy; this is the first of her seven children who was not born with a positive toxicology. CIWI helped Ms. S. pack her bag for delivery and she was able to talk about all the changes that had occurred in her life. She now realizes that she will always need to work on maintaining her sobriety and building her parental skills, but she has found the support to follow through.

**Lessons Illustrated by the Case**

**RELATIONSHIP-BASED APPROACH**

According to Tymchuk and Keltner (1991), “The ability of parents with learning difficulties to succeed is significantly influenced by the attitude of the helping professionals, family members, and others who make up the family’s support network” (p. 158). This proved true in the case of Ms. S with the assistance, support and patient persistence of the CIWI team.

The Department of Children and Families (DCF), an agency that had been involved in Ms. S.’s life for many years, perceived Ms. S. as noncompliant; she seemed resistant to mandates that were implemented. Ms. S. would be inconsistent with meetings and have an oppositional disposition when confronted by her treatment workers. Similarly, Ms. S. was consistently unavailable to the CIWI team. She would inform the CIWI team that she would be home for her visits, and often was not. She also would easily become overwhelmed with the every day requirements of maintaining her household. Instead of closing her case, however, the CIWI team continued to try to engage Ms. S. and remained flexible in the crucial early stages of this process. By working with Ms. S. and her family in all aspects of their life and remaining consistent throughout the process, the CIWI team was able to gain the trust of Ms. S. and her family.

In the beginning, Ms. S. needed home visits several times per week. It was imperative that the CIWI team begin by addressing the family’s concrete need for housing. CIWI recruited state agencies to address housing; DCF placed Ms. S. and her family on the Section 8 Supportive Housing List, and the Department of Social Services began looking for an appropriate family shelter. CIWI worked with Ms. S. in navigating the systems, thus allowing Ms. S. to have one team who would continually be available to help her with the necessary paperwork and ensure that she had a clear idea of what was happening. By becoming the point persons, the CIWI clinician and family support worker allowed Ms. S. to feel comfortable taking the necessary steps to help her family become more stable.

As DCF began the reunification process for the other children to live with their mother, the CIWI staff spent a great deal of time attending meetings with Ms. S. to guarantee that she understood what was discussed, and what was required of her. As a result, Ms. S. felt that she had support, stating that she had “workers in her life that took the time to listen to her.”

As they began to develop a relationship with Ms. S., the CIWI staff began to better understand some of her underlying issues. During the process of finding Ms. S. stable housing, for instance, it became apparent that Ms. S. was struggling to understand. The CIWI team began to suspect that Ms. S. was cognitively limited. In the beginning, Ms. S. denied any special education services as a child, and never verbally stated knowledge of a cognitive deficit. This is common among people with cognitive limitations, who, to avoid stigmatization, may lie about the fact that they attended special education classes while they were in school.
(Children’s Services Practice Notes, 2004). It is unclear whether Ms. S. was hiding the fact that she received special education or if, in fact, she did not know. However the CIWI team began to ask more specific questions to gain more information. Questions such as, “Were your classes small?” and “Did you stay in one class all day or change classes?” were met with better answers than those that required Ms. S. to be abstract. And the one question that seemed to help Ms. S. identify that she indeed received special education services was “Did you ride to school on the small bus?” With this knowledge, the CIWI team assisted Ms. S. in applying for Social Security Disability Income (SSDI). Receiving SSDI would ensure that Ms. S. would have an income indefinitely.

**CREATING OR EXPANDING POSITIVE SUPPORT SYSTEMS**

One of the necessary steps in remaining in recovery and stabilizing one’s family is finding a support system. For many, the NA and AA meetings become a place where assistance is a constant. However, it seemed difficult for Ms. S. to attend these meetings. Outpatient settings also were traditionally unsuccessful for Ms. S. Thus, CIWI worked with Ms. S. to find a setting where her needs would be specifically addressed, and ultimately recommended an outpatient program that works only with women and has a very structured curriculum. The program created a well thought-out schedule that allowed Ms. S. to understand what was required. Day care also was provided on site, removing any childcare issues that previously were a barrier to attendance. Once Ms. S. was comfortable in her treatment setting, she was able to focus on the work necessary for her to remain in recovery.

While Ms. S. was in treatment, housing remained the primary focus. CIWI worked with Ms. S. to secure her subsidized housing with the State, and make sure that all the necessary paperwork was filed. CIWI attended all the meetings and hearings that were scheduled with Ms. S. to help her to fully understand. Once the Section 8 certificate was awarded to Ms. S., she needed assistance in locating an apartment that could accommodate her large family.

Ms. S. also used the CIWI team to help negotiate terms for her first apartment. Because Ms. S. lived in unstable environments her entire life, she did not know how to talk to landlords and therefore would repeatedly shy away from asking and answering questions. CIWI worked with Ms. S. to coach her into asking appropriate questions. This empowered Ms. S. and created a great sense of independence and accomplishment.

**STRENGTH-BASED APPROACH**

While working with Ms. S. on her concrete needs, CIWI placed equal importance on her recovery. The CIWI team guided Ms. S. through a process of reflection to help her identify the changes she had made and acknowledge the work that went into making those changes. Frequently, the CIWI team prompted Ms. S. to remember that she was continually making the commitment to herself and her children to make daily changes in their lives. Ms. S. worked daily to build new coping skills and to find positive supports in her life that would help her to remain in recovery. Ms. S. learned to remain in the “here and now” and remember her addiction, which was difficult given her cognitive limitations. Ms. S.’s treatment center and home based services collaborated to help her through this process on a daily basis.

**FAMILY-FOCUSED APPROACH**

Intervention with Ms. S. was family focused, which is critical in work with this population. Because parenting typically comes second to a drug addiction, mothers in recovery often experience tremendous guilt and shame regarding their children. Ms. S. was no exception. When she began to talk with her CIWI team about parenting, it became evident that Ms. S. needed guidance in some of the basic skills. Disciplining her children was difficult for her, and she felt that saying “no” to her children was unacceptable. Her CIWI team worked with Ms. S. to help her understand that her children need to have structure in their lives, and that saying “no” does not mean that she does not love them. The CIWI team spent a lot of time helping Ms. S. see that her children’s need for structure is as important as her need for structure in order to maintain her recovery.

Further, by using Ms. S.’s feelings and thoughts about herself, she was able to talk with her team about different ways to create structure for her family. For example, the team helped Ms. S. find a way to tell her children “no” when they asked for money. CIWI made a budget with Ms. S. and the children so they would understand that bills and other responsibilities are a priority before spending money.

*Continued on page 12.*
IDENTIFYING AND ACKNOWLEDGING COGNITIVE LIMITATIONS

Through the process of working with Ms. S., the CIWI team realized that she required repetitive discussions of issues and opportunities to repeat tasks until she could accomplish them. Although Ms. S. had a reputation of being noncompliant and oppositional, an assessment and more comprehensive understanding of her cognitive limitations proved this inaccurate. Ms. S. became very defensive when she was directly confronted prior to her work with CIWI because she did not understand what was happening and did not feel she could trust anyone. Other providers were involved for shorter periods of time, and always left before Ms. S. was able to feel comfortable. By taking the time to address the immediate needs of the client, presenting information in a way that she could understand, and continually proving to Ms. S. that the services were constant, Ms. S. began to feel trust. She then could focus on the necessary work to make her home safe and stable for her and her children.

Conclusion

CIWI has found that mothers who are substance using and cognitively limited have a need for interventions that are relationship- and strength-based and family focused. Further, positive support systems for the family must be created and/or expanded. Long term, home-based support allows mothers, who are otherwise difficult to engage, to build a positive working alliance with providers. Working collaboratively with other agencies to understand the limitations of the mother proves to be an effective tool for teams entering the home. Finally, having a single point person or team, who understands each family’s strengths and limitations and can help them process information coming from many systems and agencies, creates stability for these families.

Currently, Ms. S. is living in her six bedroom apartment, and has become involved in a positive way in her community. Her children are attending school and seem to be doing well. Ms. S. remains actively involved in substance abuse treatment. She has her team to help her in any issue that may arise. Ongoing weekly visits with the family help to ensure that stability is maintained.

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Janice Currier Ezechick, LCSW, Mental Health Program Director for Bridgeport Connecticut Department of Children and Families

REFERENCES


Jerry Annand, MA, Director, Annand Counseling Center, Portland, OR

REFERENCES


The National AIA Resource Center Announces a Publication . . .

Guide to Future Care and Custody Planning for Children
with Recommendations for State Legislation

Parents facing illness, or other events that alter family stability, must make choices about the future care of their children. This monograph examines a variety of approaches to voluntary permanency planning, including innovative tools (e.g., standby guardianship and standby adoption), and offers specific recommendations to advance the development and implementation of these planning tools. Legislators and service providers who want to improve future care and custody planning options for children will find this document to be an essential resource.

To purchase a copy, please contact the Resource Center at 510-643-8390 or aia@berkeley.edu.

More information at http://aia.berkeley.edu
Substance abuse has been a continuing problem in our society for many years, and increasing efforts have been made to identify alternative treatment models for people in different segments of the population. Although there has been some success in this arena, people with disabilities have not always been included in these efforts. This is in spite of a number of research studies finding that people with disabilities may use alcohol and illicit drugs as much as, if not more than, the general population (Moore & Li, 1994; Moore & Li, 1998).

Substance Use and Abuse Among People who have Mental Retardation

The limited research specific to substance abuse and mental retardation indicate that these individuals tend to use alcohol and other drugs less than people in the general population and less than other people with disabilities as well. However, there appear to be greater negative consequences from the same or lesser quantities of alcohol or other drug use when a person with mental retardation does use (Westermeyer, Kemp, & Nugent, 1996; DiNitto & Krishef, 1984). In one of the first longitudinal studies in this area, Westermeyer and colleagues (1988) conducted ethnographic interviews over a five year period with people with mental retardation and found that those individuals with mental retardation who became problem drinkers began their use early, between age 15 and 17, and were more often in the “mild range” of their disability. This phenomenon appears to hold true across various disability categories with those individuals appearing less disabled at greater risk for substance abuse problems, with the exception of people who have experienced traumatic injuries such as brain or spinal cord injuries.

Some of the risk factors for alcohol and other drug abuse for people with mental retardation include the following:

- **Lack of Identification:** This lack of identification can be on the part of the disability professionals and/or on the part of the substance abuse professionals. Individuals who are close to a person with mental retardation are more likely to focus on the disability, missing the warning signs of substance abuse. In the same vein, substance abuse professionals are generally not trained to look for disability and focus solely on potential substance abuse problems. Behaviors often attributed to alcohol or other drug use are attributed to the disability and vice versa. It is more likely for substance abuse problems to remain unidentified in people with mental retardation, and when a person with mental retardation does report to treatment, it is unlikely that any difficulties that occur during treatment will be attributed to the mental retardation.

- **Prescribed Medications:** It is not uncommon for people with mental retardation to take prescribed medications for physical or mental health problems that co-occur. People with disabilities who take multiple medications are more at risk for abusing these medications. In addition, the dangers in using alcohol and other drugs in conjunction with prescribed medications can be easily overlooked, particularly when medical professionals assume that the person with mental retardation does not drink alcohol or use illicit drugs. Any use of alcohol or other drugs may be risky in combination with prescribed medications.

- **Societal Values and Atypical Social Experiences and Opportunities:** Because alcohol is still a common facilitator of social interactions, people with disabilities may have difficulty finding drug-free social alternatives. Some people with mental retardation may attempt to use alcohol as a means...
of “fitting in” with others, particularly if the individual has been isolated from others outside the immediate family. It appears that some people with mental retardation are more likely to learn about alcohol and other drug use from their families rather than from their peers. People with mental retardation who have family members with alcohol and other drug problems tend to have more negative consequences even from only moderate consumption (Westermeyer, Phaobtong, & Neider, 1988).

Physical & Attitudinal Inaccessibility: Some alcohol and other drug treatment programs have not had sufficient experience with people with mental retardation to understand how to make their services fully accessible. Very few professional programs specialize in substance abuse prevention or treatment for people with disabilities, and those that do are unlikely to have specialized services for people with mental retardation. Since treatment programs are not as familiar with disabilities, it is easy for a person’s difficulties to be labeled “uncooperative” or “defiant” when the person simply is unable to function in the same ways as their non-disabled peers.

Entitlement: It is not unusual for family members, friends, and service providers to make extraordinary accommodations for someone with mental retardation, sometimes even believing that a person with mental retardation or other disability is more entitled to use alcohol or other drugs, encouraging substance use as a compensation for the disability (Moore, 1992). For example, some professionals and parents have the attitude “I can’t expect him/her to be responsible; he/she has mental retardation.”

Mental Retardation and Its Impact on Treatment

Mental retardation affects approximately 1% to 3% of the population with the majority falling into the mild range of this disability (American Association on Mental Retardation, 2002). However, some children may be identified as having another disability to avoid the stigma that can be associated with the term “mental retardation,” and many adults with mild mental retardation, in particular those individuals who are able to live independently, can often ignore all labels (The ARC, 2001). Once an individual who has mental retardation or other cognitive disability is out of the school system, the labels related to Special Education are often ignored or forgotten about. Although there certainly can be many positive aspects to this situation, it may create difficulties when people with mental retardation are not identified when they enter a treatment situation.

When individuals with mental retardation enter treatment, a number of factors can impact their progress. These factors include the following:

Memory and information processing difficulties: Individuals with mental retardation don’t understand what treatment is, and they don’t know why they are being assessed. Each concept presented must be broken down into focused smaller steps. In addition, some individuals may have limited attention spans, resulting in the need for shorter sessions and more repetition. Information processing, reading, writing, and interacting with others can create difficulties for them in treatment.

Basic life skills are lacking or missing: Some individuals with mental retardation are unable to attend to their personal needs such as shopping, budgeting money, making appointments, or traveling in their communities. They may not know how to make phone calls independently and may, in essence, be shut off from their communities.

Emotional and behavioral problems are more severe: Some individuals with mental retardation come into a treatment program with histories of mental illness that have never been addressed. In addition, individuals with such disabilities as traumatic brain injury may also have issues with frustration and agitation.

Lack of support from family members: Some families tend to interfere in most aspects of treatment, going beyond what would normally be considered enabling. In other cases, families do not want the consumers to become independent for fear of losing the income that the consumer receives from Social Security or other sources. Individuals with mental retardation may believe that they do not have choices, and that they must abide by the rules instilled by their families. Although consumers of traditional treatment programs

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also experience family and environmental difficulties, the trauma experienced by consumers with disabilities is NOT the same. These consumers face difficult choices because alternative housing, employment, and treatment services are not available.

**Instructional Techniques and Treatment Modifications**

Standard techniques for providing substance abuse treatment activities can work for people with mental retardation or other cognitive disabilities; however, extensive modifications are generally required (Moore & Lorber, 2004). For example, the general technique of working with consumers in a group setting is effective when modified for the particular group members. These modifications may include lessening group time and focusing on one small issue as opposed to allowing each consumer to bring in a topic. Another technique that can be effective is role playing, which when highly structured provides the consumers with the opportunity to obtain realistic experiences to practice what they have learned. Repetition is essential for integration of learning. Concepts need to be repeated in a variety of ways over time. It cannot be assumed that the individuals remember what they have just been taught.

However, a number of traditional treatment techniques appear to be generally ineffective, even with modifications. For example, direct confrontation isn’t as effective with this population. Peer feedback of progress is also largely ineffective, as many of the individuals with mental retardation are unable to comprehend how feedback from peers can be helpful. Abstract concepts, such as chemical dependency as a disease and “higher power” are extremely difficult for them to comprehend even when these concepts are broken down into small components and repeated.

**Identifying Cognitive Impairments in Consumers or Their Parents**

It is not unusual for individuals with mild mental retardation to have adequate social skills and verbal communication skills yet still have difficulty in other areas of their lives such as comprehension, learning, and decision making. Some individuals with this “hidden” condition will go to great lengths to avoid the label of “disabled” or “mentally retarded.” In these cases, professionals in treatment or other social service settings may have difficulty in determining what, if any, adaptations are needed in working with either the consumers or their family members. It may be beneficial for all social service settings to routinely conduct a screening for cognitive impairments when services begin (SAMSHA, 1998).

Whenever possible, family members should be included in treatment. Sometimes the family member will need treatment services directly; at other times, they will need assistance in becoming an appropriate support. The person with mental retardation may have difficulty recognizing his/her functional limitations as well as any problematic use of alcohol and other drugs and/or enabling behavior. Including this individual in all aspects of treatment may provide an empowering way for him/her to recognize problem behavior. The overall key is for this individual to view treatment as a support and not an intrusion into his/her personal life.

When working with children or individuals with disabilities in a treatment setting, it is important to screen for cognitive deficits in parents or guardians. The failure to recognize deficits in family members can lead to interventions that are inappropriate or not likely to succeed. Parents with mental retardation may need separate information sessions or counseling that can occur over a longer period of time and that include more “hands-on” approaches. Parenting classes also may be needed. Additionally, family members will need opportunities to apply the learned information directly to their own situations. This transference is extremely important for consumers.
and their families, and they may need longer periods of aftercare and home visits to ensure that they are in fact making changes in their behaviors.

Generally when looking for mental retardation or cognitive impairment, scrutiny is given to areas of adaptive functioning in the major life activities of self care, receptive and expressive communication, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency (The ARC, 2001). The exploration of these areas can be incorporated into the general intake and assessment process that most programs already have in place. The types of information can be gathered from both the consumer and the consumer’s family as appropriate.

Some general questions to incorporate include the following, which are modified from Treatment Improvement Protocol #29 (SAMSHA, 1998):

- Do you have a disability or have you ever been told that you have a disability?
- Are you currently under the care of a doctor?
- Have you ever received social security or disability benefits?
- Have you ever hit your head hard enough to lose consciousness?
- Were you ever in special classes or tutoring in school?
- How well did you do in school?
- Do you like to read? What do you read and how often?
- Have you ever had problems with the following …
  - remembering things?
  - controlling your temper?
  - following directions?
  - concentrating?
  - getting along with others?
  - keeping track of your money or paying your bills?
  - keeping your home clean?
  - making meals for you and your family?

Ask appropriate follow up questions for any items that were answered in the affirmative. In addition, problems with some self-care tasks may be evident from observation. For example, is the person dressed appropriately for the weather conditions and does the person appear to be well groomed?

These questions just touch on the basic issues that may become apparent more readily to the professionals who generally do not work with people with mental retardation. A referral for additional assessment always should be considered if the individual in question is having difficulty with compliance and with following through on treatment recommendations and the staff suspect that something neurological may be interfering with treatment progress.

**Conclusion**

There is no need for treatment providers or social service professionals to become experts in mental retardation or for professionals who work with people with mental retardation to become experts in substance abuse. However, a general awareness that these two conditions can co-exist and a willingness to make modifications and adaptations to traditional programming will benefit the consumer. Identification and labeling of a cognitive problem is not the goal. Rather, identifying an individual’s level of ability and corresponding strengths will assist in developing a plan of treatment and/or a plan of support for the family. The ability to participate in needed services and to learn self-advocacy skills improves quality of life and community integration.

**REFERENCES**


The Consumer Advocacy Model (CAM) is a standard outpatient chemical dependency program that provides community-based, interdisciplinary treatment services to individuals with a substance use disorder and at least one severe co-existing disability. CAM was developed in 1993 as a replication of the highly innovative and successful TBI Network, a program serving persons with traumatic brain injuries (TBI) which was developed by John Corrigan at The Ohio State University. Since its origins, CAM has been operated by Substance Abuse Resources and Disability Issues (SARDI), a research and training program in the Department of Community Health, Boonshoft School of Medicine at Wright State University in Dayton, Ohio.

Designed to fill a special need in the Dayton area, CAM has a number of unique features. First, CAM frequently receives referrals for individuals who have been in and out of many social service agencies with limited success in their rehabilitation. CAM’s philosophy is to provide less intensity in treatment but for a longer duration of time, so it is common for consumers to stay active and involved with CAM for one year or longer.

CAM has a full inclusion model and uses a comprehensive functional assessment to identify each consumer’s strengths and areas for improvement. Treatment goals are consumer friendly and implemented in a way that provides on-going success. CAM uses a community team approach where all agencies involved with a consumer are involved in treatment, and frequent feedback is provided to the referral source.

Psycho-educational material is presented more repetitiously and in a greater variety of ways than a traditional program, allowing for the material to be understood by consumers with a variety of disabilities. Consumers may attend groups as often as needed to understand the materials that are being presented. Adaptations are frequently made to the standard curricula to meet the individual needs of consumers. Thus, not all participants receive all services or receive services in the same modality. For example, some consumers receive group related materials in individual sessions, and some consumers meet immediately after group with their counselors or case managers to review the information that they just received. This frequent reinforcement assists consumers in remembering the information, and it provides an opportunity for transference of the information to their personal situations. CAM also relies on behavioral interventions more often than cognitive interventions as a primary means of treatment for many consumers.
The importance of case management services for individuals with co-existing disabilities cannot be overstated, and CAM offers a greater amount of these services than most traditional treatment programs. At CAM, the ratio of counselors to case managers is 1:1, whereas in traditional programs the ratio is frequently 4:1 at best. CAM consumers often face many issues around housing and homelessness, literacy, income constraints, and mental health. The ability to provide intensive case management services allows the consumers to address their substance use issues at the same time as other life issues. Perhaps most significantly, CAM assists consumers in becoming advocates for themselves, particularly in the areas addressed through case management services.

Another important facet of CAM is the availability of a vocational specialist who provides a number of important benefits. Individuals with substance abuse problems frequently experience work-related difficulties, and people with other disabilities often face unemployment or underemployment. When disabilities co-exist, employment issues can be even more problematic. The vocational specialist begins to address employment issues early in the treatment process, preparing consumers for returning to work or providing a referral to some type of vocational services in the area. For unemployed consumers, the vocational specialist can begin an exploration of the meaning of work and implications of employment.

Sometimes staff determine that an individual needs a more intensive treatment program. Because CAM only offers outpatient services at this time, an additional referral is needed. One of the most unique aspects of CAM is that, due to the strong support from funding sources and the community referral base, CAM is able to provide simultaneous treatment services to people with disabilities who are involved in treatment at another agency. Both programs are able to provide services and bill as appropriate. This ability benefits a number of consumers who can receive the best level of care while still receiving the specialized services that CAM offers.

The most recent outcome report from CAM showed that 12% of individuals discharged were “much improved,” and another 41% were “improved.” A total of 28% met all of their treatment goals by the time of discharge. In addition, intake CAM reports indicate that generally between 16 – 25% of new referrals are employed. During the most recent reporting period, 25% were employed at intake (11% full time and 14% part time), and by discharge, 35% reported that they were employed with 13% working full time and 22% working part time. An additional 37% were actively seeking employment at their time of discharge.

For more information about CAM, please contact the author, Jo Ann Ford, MRC at jo.ford@wright.edu or CAM’s Clinical Director, Melissa Jones at missy.jones@wright.edu.
problems, being duped by others and other factors result in law enforcement involvement. Often the resulting “nudge from the judge” gets a person with developmental disability into treatment.

There are probably as many ways to approach treatment as there are people needing treatment. However, some basic principals will facilitate treatment for people with developmental disabilities. As noted earlier, sensitive and respectful identification, preferably in a private setting, will set the stage for trust and openness. Extra time with frequent repetition will be needed for all explanations. It is very important to involve the person’s support systems, including family, independent living or group home staff, and social worker (Christian & Poling, 1997). These people will be critical in carryover and follow through support. Adapted materials are available to reduce the need for reading and writing. One of the best is Twelve Ideas for My Improvement, by Alexander Boros. In this booklet, the Twelve Steps of Alcoholics Anonymous are represented pictorially. Additionally, The Twelve Steps Illustrated, published by Alcoholics Anonymous, is available through most local AA community programs. The Hazelden adapted Twelve Steps for Everyone uses simple language and is very accessible.

Treatment programs will need to use concrete, simplified language and directions. Abstract concepts must be made practical and real. For example, abstinence can be redefined as not going to the liquor store, not keeping any money available to buy alcohol, and staying away from certain people. Sobriety can be “one day at a time”, if one day is defined as “see me here tomorrow at this time,” and discussion of what will happen in the meantime is clear.

Jerry Annand, in his book, More than Accommodation: Overcoming Barriers to Effective Treatment of Persons with Both Cognitive Disabilities and Chemical Dependency (2002), outlines a treatment program that is clear, respectful and based on real-life experiences. An early model, The Maine Approach, relies on short term reinforcement for appropriate behavior and involvement in AA (Maine Department of Mental Health and Mental Retardation, 1984). An especially innovative program in Montana (University of Montana, 1989) used non-disabled peers, already in AA, as “buddies” for people with developmental disabilities. These buddies assisted with transportation, remembering meetings, and understanding social and recovery concepts.

CASE EXAMPLE

Doris and her daughter Helen, both women with developmental disabilities, live together and are raising Helen’s daughter. Both use alcohol to excess and have had problems with neighbors due to loud fighting in their apartment. Helen’s daughter has been identified by her teachers and referred to Child Protective Services due to concerns for her health care and hygiene. The local developmental disabilities service system and the Child Protective Services system worked together to fund parenting instruction for Helen, which took place in her home for several hours several times a week. The worker helped arrange medical and dental care for the daughter, and organized menus, a budget, and a house cleaning plan. Another worker facilitated both women’s attendance at a day treatment program for women with alcohol abuse problems. This worker went with them for the intake and assessment interviews, and stayed with them for the first few meetings.

She also assisted in transportation training. At the treatment program, they met other single parents and mother-daughter teams, who supported their recovery. Addressing their depression and isolation as people with developmental disabilities through psychological counseling was also arranged through the parenting instructor. The in-home instruction will continue indefinitely, but hours may be reduced. This family needed support to identify and address their problem, but once this was done, they were very successful.
Another important point in Annand’s book is the need for separate groups. My own experience has been in leading such a group since 1991. We use a simple model with the concepts of “look away, get away, stay away” (avoid, cope, escape), exploring the meaning and application of these concepts weekly. The curriculum is very concrete, uses the consumer’s own life experience, and does not rely on ability to read or write. Annand’s point is that recovery relies on peer support and peers without disabilities may not understand or be a true peer group. In my community, and many others, there are many special interest AA and NA groups, for women, gays and lesbians, people of color, and many others, indicating that many people feel better with known peers. While we have encouraged our consumers to attend AA and NA if they feel comfortable doing so, many have reported that they value the ease of being with others without disabilities. We worry about integration and hope for true inclusion, but our consumers tell us they need the special support.

**Conclusion**

People with disabilities are people first. Life management problems can be compounded by disabilities and service systems need to respond. Fortunately the stigma of having a disability is diminishing, and acceptance is more common. As people with disabilities live, work and recreate in the mainstream, fear and rejection will decrease. We can and do respond to their needs with parent training and substance abuse treatment, among many other things. We have a ways to go, but the journey is underway.

**Ann K. Harris, MFT,**
Program Manager, San Diego Regional Center for the Developmentally Disabled, San Diego, California

**REFERENCES**


University of Montana (1989). Removing Barriers, a Guide to Providing Substance Abuse Services to those with Mental Disability.


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**Congratulations!**  
On October 1, 2005, the following agencies were awarded four-year grants from the U.S. Department of Health and Human Services’ Children’s Bureau under the Abandoned Infants Assistance (AIA) legislation. More information about these and other AIA programs is available at the AIA Resource Center website—http://aia.berkeley.edu.

- Arbor Circle Corporation, Grand Rapids, MI
- Baltimore Pediatric HIV Program, Inc., Baltimore, MD
- Child & Family Tennessee, Knoxville, TN
- County of Santa Cruz, Santa Cruz, CA
- The Health Federation of Philadelphia, Philadelphia, PA
- Latino Family Institute, Inc., West Covina, CA
- Women & Infants Hospital of Rhode Island, Providence, RI
More than Accommodation: Overcoming Barriers to Effective Treatment of Persons with Both Cognitive Disabilities and Chemical Dependency

This “start from scratch” approach is designed to help those suffering from both cognitive disabilities and chemical dependency—the “fall through the cracks” clients who test the patience and resources of overwhelmed providers. This book outlines a new effective treatment approach that focuses on the training of clients with cognitive limitations to develop lifestyles and routines that support abstinence. Cost: $10.95.

J. Annand (2002). Nightwind Publishing, P.O. Box 1143, Beaverton, OR 97075. Ph: (503) 646-3112. Fax: (503) 646-0773. s.annand@gte.net

Substance Use Disorder Treatment for People with Physical & Cognitive Disabilities (TIP 29)

This series provides the substance abuse treatment and related fields with consensus-based, field-reviewed guidelines on substance abuse and people with disabilities. It includes extensive research, numerous resources for further information, and comprehensive references. A related Quick Guide for Administrators is also available. Cost: Free.

Center for Substance Abuse Treatment (CSAT) (2001). Project Officer, CSAT Knowledge Application Program, Division of Services Improvement, SAMHSA, Room 5-1108 1 Choke Cherry Road, Rockville, MD 20857. Christina.Carrier@samhsa.hhs.gov. www.kap.samhsa.gov/general/order.htm.


This guide was written to assist individuals who are supporting parents with cognitive limitations. It provides a conceptual framework, offers supportive strategies in ten areas critical to parenting, and includes additional resources. Cost: $59.50 plus $9.50 shipping & handling.

B. McCusker & B. Irwin (2002). Bernadette Irwin, PACT, 7000 Tudsbury Road Baltimore, MD 21244-2675. Ph: (410) 298-2645. Irwin@Kennedykrieger.org

Learn how Proposed Changes in Social Security will Affect People with Disabilities

This set of seven fact sheets on Social Security and people with disabilities will assist people in understanding what benefits people with disabilities receive from Social Security and the potential impact of privatization. The Consortium of Citizens with Disabilities has put together information “to educate people about the potential devastating effect of major program changes.” Cost: Free.


Twelve Ideas for My Improvement

This booklet is designed for teaching recovery to reading-limited alcoholics. It describes pictorially the Twelve Steps in a simplified male or female version. Cost: $7.00.

SARDI Program, School of Medicine/Wright State University, P.O. Box 927, Dayton, OH 45401. Ph: (937) 775-1484. Fax: (937) 775-1495. http://www.med.wright.edu/citar/sardi/products.html

How to Make a Good Decision CD-ROM Series

This series includes three volumes How to Make a Good Decision in the Community, How to Make a Good Decision at Home, and How to Make a Good Decision in the Workplace or Day Program. They are designed to be used by adults with mental retardation/developmental disability who need concrete help with problem solving and have difficulty with abstract reasoning. They can be used independently, one-on-one with staff, or in groups. Cost: $75 each, or $195 for the series.


Substance Abuse, Disability & Vocational Rehabilitation

This manual, currently used by many state vocational rehabilitation or alcohol and drug treatment programs, includes 9 curriculum modules, case studies, supplements, and guides regarding substance abuse issues designed for rehabilitation counseling programs. Cost: $10.

SARDI Program, School of Medicine/Wright State University, P.O. Box 927, Dayton, OH 45401. Ph: (937) 775-1484. Fax: (937) 775-1495. http://www.med.wright.edu/citar/sardi/products.html

SARDI Training Manual

This manual was developed for anyone interested in learning about or teaching aspects of substance abuse prevention among persons with disabilities. It consists of 9 sections: an overview of substance abuse and disabilities, Americans with disabilities, alcohol and drug use prevention, identification of substance abuse in persons with disabilities, interviewing skills, finding solutions, support groups, connection agencies, and resources. It also includes information on specific disability-related substance abuse risks
and a pharmacology chart listing alcohol-related interactions. Cost: $35.

SARDI Program (1999). SARDI Program, School of Medicine/Wright State University, P.O. Box 927, Dayton, OH 45401. Ph: (937) 775-1484. Fax: (937) 775-1495. www.med.wright.edu/citar/sardi/products.html

The Twelve Steps for Everyone

This classic, 128 page adaptation of the Twelve Steps of Alcoholics Anonymous is a practical, compassionate book that is appropriate for people with developmental disabilities. Although written 30 years ago, it is still used by both lay people and professionals. Cost $11.95 ($10.76 on-line).


Motivating Substance Abusers to Enter Treatment: Working with Family Members

This book presents an empirically based therapy program for the family members or partners of treatment-refusing substance abusers. The author's approach is to teach concerned significant others (CSOs) how to change their own behavior toward their loved ones in order to reward sober behavior, discourage substance use, and ultimately get the substance abuser into treatment. In the process, CSOs also derive therapeutic benefits themselves. Written in an accessible style, the book provides step-by-step instructions for implementing an array of well-tested motivational, behavioral, and cognitive interventions. Cost: $35.00.


The Politics of Disgust: The Public Identity of the Welfare Queen

This book examines the public identity of the so-called welfare queen and its role in hindering democratic deliberation. The author shows how stereotypes and politically motivated misperceptions about race, class and gender were effectively used to instigate a ‘politics of disgust’. Using content analyses of the news media, the 1996 congressional floor debates, historical evidence, and interviews with welfare recipients themselves, she reveals the ongoing role of the ‘politics of disgust’ in welfare policy. Cost: $20.00.


New Advanced Fatherhood Training Curriculum (AFTC)

This new curriculum focuses on best practice and skills needed to engage fathers, particularly those who are resistant or reluctant to get involved with their children. The training package contains a 33-page manual and a 33-minute video featuring differences in fathers’ and mothers’ communication and parenting styles, strategies for engaging and overcoming obstacles to father involvement, case examples identifying specific skills to engage fathers, and a section for administrators on agency policies, competency levels, and research findings that promote father-friendly practice. Cost: $1000.


Helping Bereaved Children: A Handbook for Practitioners

The second edition of this popular casebook and text demonstrates a range of therapeutic approaches and interventions for children who have experienced loss. In-depth case examples, which form the core of the book, are presented in a handy two-column format that provides the reader with the content of the sessions as well as the practitioner’s accompanying thoughts and rationale for intervention. Cost: $22.50.


Family Support Centers - A Program Manager’s Toolkit

Based on 20 years of providing technical assistance, Family Support America has gathered critical questions and a multitude of solutions into a comprehensive reference for family support centers. This ‘technical assistance in a box’ consists of three volumes: Program Planning & Evaluation, Managing Ongoing Operations, and The Power of Partnership. Cost: $78.75.


Assessing Psychological Trauma and PTSD, 2nd Ed

This book reviews current knowledge about trauma assessment and provides up-to-date recommendations for practice. Coverage encompasses the uses of standardized measures, clinical procedures, epidemiological methods, and projective techniques, as well as approaches to evaluating specific survivor populations. Emerging applications of neuromicroimaging and pharmacological probes, legal and forensic issues in assessment, assessment of comorbid PTSD and substance abuse, and effects of trauma on physical health are addressed. Cost: $65.00.


Treating Psychological Trauma & PTSD

Incorporating cutting-edge theory and clinical research, the book provides a crucial reformulation of diagnostic criteria and treatment goals. It then brings together leading treatment experts to describe and illustrate their respective approaches, facilitating the selection and implementation of the most effective interventions for individual patients. Cost: $28.00.


Clinical Work with Substance-Abusing Clients (2nd Edition)

Revised and expanded, this widely adopted test serves as a practical guide to working with substance abusers and their families in a variety of clinical contexts. In this book, expert contributors present widely used assessment and treatment approaches, along with detailed recommendations for intervening with specific substances and meeting the needs of different populations. New chapters in this edition cover motivational techniques, harm reduction, and strategies for working with involuntary clients. Cost: $55.00.


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Foster Care Law: A Primer

Written by two attorneys with substantial experience in child welfare and foster care, the book includes chapters on each group involved in foster care (foster children, foster parents, biological parents, public agencies, and private agencies), detailing their rights, their relationships with each other, and significant legal issues that may affect each group. A final chapter on the court process describes the roles of the participants, the different types of hearings, the extent of judicial power, and the appeal process. A typical case is described to illustrate the timing of some of the events, as well as the possible outcomes. Cost: $30.00.


Don’t Hit My Mommy! A Manual for Child-Parent Psychotherapy with Young Witnesses of Family Violence

This practical handbook offers treatment guidelines to address the behavioral and mental health problems of infants, toddlers, and preschoolers whose most intimate relationships are disrupted by the experience of violence. Practitioners from a variety of disciplines will gain an understanding of the impact of violence and will discover concrete intervention strategies to address the consequences of this experience for young children. Cost: $59.95.


Real Life Heroes: A Life Story for Children

This book presents an innovative, creative arts approach to working with traumatized children, and it provides insightful examples of how parents (birth, foster, and adoptive) can help children become “their own heroes” by providing a safe space to tell their stories and make the burden of past trauma more bearable. A companion volume, Rebuilding Attachments with Traumatized Children: Healing Losses, Violence, Abuse, and Neglect, is a therapeutic guide to helping troubled children move beyond the traumatic experiences that haunt them. Cost: $12.95 for Real Life Heroes; $39.95 for Rebuilding Attachments.


Practice Issues in HIV/AIDS Services: Empowerment Based Models and Program Applications

This book provides a sound framework of intervention practices for case managers and care coordinators to help HIV/AIDS patients live longer and healthier lives. Filled with concrete information and recommendations from practitioners and researchers, it focuses on client-based care that addresses the social and psychological needs of the patient as well as his/her physical and medical requirements. Cost: $34.95.


VIDEOS

Is Love Enough?

This 45 minute documentary film provides a window into the unexplored phenomenon of intellectual disability and caring for children. This film captures the stigmatization associated with intellectual disability and provides perspectives from both children and parents. Cost: $195 (sale); $65 (rental).


Parents with Disabilities: A Fair Chance

This video features six parents with developmental disabilities who talk frankly about their hopes and fears as parents. Organized into six segments, each about eight minutes in length, the program profiles the strengths and limitations of each parent. Cost: $125.00 plus $15.00 for shipping and handling.

MSCD Foundation, Social Work Program, Metropolitan State College of Denver, Campus Box 70, PO Box 173362, Denver, CO 80217. Ph: (303) 556-4464. Fax: (303) 556-5362. www.developmentaldisability.org

Fetal Alcohol Syndrome: Prenatal Drug & Alcohol Use and its Effects

This video discusses the negative impact of drug and alcohol use during pregnancy and the consequences for the unborn child. The program includes a facilitator’s guide and handouts. (13 min) Available in Spanish. Cost: $89.00.


Celebrating Sexuality: Issues, Strategies and Resources related to Individuals with Developmental Disabilities

This two-part webcast presentation provides an overview of specific issues relevant to individuals with developmental disabilities, suggested strategies in addressing these issues, and resources that may be helpful in addressing sexuality issues with this population. The presentation is made by Marilyn Volker, EdD and Martha Sheldon, MSW. Cost: Free on-line.


RELATED WEBSITES

Disability Resources Monthly: www.disabilityresources.org

Hazelden: http://hazelden.org

National Association on Alcohol, Drugs and Disability: www.naadd.org

National Association for the Dually Diagnosed: www.thenadd.org

The Substance Abuse Resources & Disability Issues (SARDI) Program at Wright State University: www.med.wright.edu/citar/sardi
CONFERENCE LISTINGS

Zero to Three 20th National Training Institute
Keeping Babies on the Map: Progressive Policies, Cutting-edge Research and Innovative Practices

This annual training event brings together over 1500 professionals, who focus on early care, health, and education, to advance their learning, interact with top experts in the infant/family field, and connect with a vital network of colleagues from coast-to-coast.

DATE: November 4-6, 2005
LOCATION: Washington, DC
SPONSORING AGENCY: Zero to Three
CONTACT: ZERO TO THREE, National Center for Infants, Toddlers and Families. Ph: (202) 638-1144. www.zerotothree.org

The Many Faces of Adoption Conference

This 13th annual adoption conference brings together adopted people, birth parents, adoptive parents, professionals, and others to find a depth of understanding about issues related to all aspects of adoption.

DATE: November 4-6, 2005
LOCATION: Austin, TX
SPONSORING AGENCY: Adoption Knowledge Affiliates
CONTACT: Adoption Knowledge Affiliates, Ph: (512) 442-8AKA. aka@adoptionknowledge.org. www.adoptionknowledge.org

2nd Annual Western Conference on Addictions

This conference will draw together experts from across the country to discuss the latest research on addiction and treatment interventions.

DATE: November 11-13, 2005
LOCATION: Universal City, CA
SPONSORING AGENCY: UCLA Integrated Substance Abuse Program
CONTACT: http://www.psattc.org/events/11-11-05.html

17th Annual Conference – Federation of Families for Children’s Mental Health

This conference will provide a forum for identifying how families and youth are leading the way to achieve the transformation efforts on behalf of children and youth with mental health needs and their families.

DATE: November 18-20, 2005
LOCATION: Washington, DC
SPONSORING AGENCY: Federation of Families for Children's Mental Health
CONTACT: bcfamily@mindspring.com Ph: (919) 477-3677/ Fax: (919) 477-5902

American Public Health Association 133rd Annual Meeting

This meeting draws thousands of professionals to share successes and failures, discover exceptional best practices, and learn from expert colleagues and the latest research in the field.

DATE: December 10-14, 2005
LOCATION: Philadelphia, PA
SPONSORING AGENCY: American Public Health Association
CONTACT: Ph: (202) 777-2476. anna.keller@apha.org. www.apha.org/meetings/

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National Forum on Child Welfare Workload

The purposes of this national conference are to confront the fact of workload demand as an overwhelming, defining influence on the quality of child welfare practice and decision making, and to launch in some small way a national effort to focus attention on the desperate need for effective workload management.

DATE: December 12-14, 2005
LOCATION: Santa Fe, NM
SPONSORING AGENCY: ACTION for Child Protection
CONTACT: Laura Holder, Ph: 505-345-2500, Fax: 505-345-2626, laura.hughes@actionchildprotection.org, www.actionchildprotection.org

Tenth Annual Conference “Meeting the Challenge: Research In and With Diverse Communities”

The conference will focus on original research that has implications for practice or policy in all substantive social work areas.

DATE: January 12-15, 2006
LOCATION: San Antonio, TX
SPONSORING AGENCY: The Society for Social Work & Research
CONTACT: www.sswr.org/conferences.php

20th Annual San Diego International Conference on Child & Family Maltreatment

This conference focuses on multi-disciplinary, best-practice efforts to prevent or investigate, treat and prosecute child and family maltreatment.

DATE: January 23-27, 2006
LOCATION: San Diego, CA
SPONSORING AGENCY: Chadwick Center for Children & Families
CONTACT: http://www.chadwickcenter.org, Phone: (858) 966-8572/Fax: (858) 966-8018

19th Annual Research Conference—A System of Care for Children’s Mental Health: Expanding the Research Base

This national conference provides a forum for researchers, evaluators, administrators, policy makers, advocates, and family members to explore contemporary, empirical research on systems of care that promote the emotional and behavioral well-being of children and their families.

LOCATION: Tampa, FL
SPONSORING AGENCY: Research and Training Center for Children’s Mental Health
CONTACT: Catherine Newman, Ph: (813) 974-4661, Fax (813) 974-6257, cnewman@fmhi.usf.edu

TRAINING WITHOUT TRAVEL

The 2006 Teleconference Series will include four 90-minute interactive telephone seminars on the following topics:

The impact of prenatal exposure to methamphetamines on infants and young children

HIV disclosure

Parent-child interaction with young children affected by substance abuse

HIV prevention with substance using women

For specific presenters, dates, and other logistical information, go to the AIA Resource Center website at http://aia.berkeley.edu, or contact Kate Spohr at 510-643-8837 or kspohr@berkeley.edu.
## Resources and Publications Available

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