The purpose of this article is to illustrate the need to assess substance use and misuse when working with people, especially adolescents and young adults, with mental retardation (MR), in order to facilitate better psychosocial and occupational outcomes. Empirical evidence supports the need for substance use assessment. Directions for future research are offered.

INTRODUCTION

The majority of youth with MR are now included in “regular” classroom settings because of the major legislative changes that began in the early 1970’s. Therefore, youth with MR now face the same challenges and opportunities, and socialize in similar environments, as youth without MR. These changes greatly increase the probability that youth with MR, especially youth within the mild to moderate range of functioning, will encounter social situations that involve experimentation with legal and illegal substances. Notably, epidemiological data indicate that adolescence and young adulthood represent the developmental periods when experimentation with substances is most prevalent in the general population, reaching rates of almost 50%. Since youth with MR are now included in “regular” classroom and social settings, and the prevalence rate of substance use is high during adolescence, the probability is increased that youth with MR will encounter opportunities to use cigarettes, alcohol and other substances. Currently, there is little information available regarding risk factors for substance misuse in youth with MR. Additional information would be useful in developing prevention and intervention plans specifically for youth with MR.

Extant data suggest youth with MR have access to, and engage in, use and misuse of legal and illegal substances. Of particular interest, the results of one investigation suggest people with MR may experience more severe consequences from ingesting smaller amounts of alcohol than would be demonstrated by peers in the general population. However, the available research has significant methodological shortcomings, including loosely defined definitions and categories of “disability” that often group severe behavioral problems, developmental disabilities, and learning disabilities together. Clearly defined criteria for disability status or functional limitations are also missing. Therefore, it is not possible to ascertain behaviors or emotional response patterns that may be indicative of risk for substance use and misuse specific to youth with MR.

When comparing the documented research on youth without cognitive impairments and substance related behaviors, it becomes evident that little information is available regarding drinking patterns or motivations for drinking, or use of other substances, specifically related to youth with MR. The existing gaps in the current knowledge base contradict the ongoing efforts aimed at promoting healthy development in people with MR. However, there are substantial data available related to risk for substance misuse and abuse in the general population that may expedite our understanding of substance use and misuse in youth with MR. A discussion of these data follows.
RISK FACTORS FOR SUBSTANCE ABUSE AND MENTAL RETARDATION

In the broadest sense, the concept of risk means an increased probability for acquiring a disease. Research related to risk for substance abuse has evolved over the past 30 years to substantially advance current knowledge of the etiological and epidemiological factors related to the initiation, escalation, and maintenance of substance misuse and abuse. Overall, these efforts have illuminated current understanding of the role that individual and environmental factors play in contributing to a person’s vulnerability for substance misuse. The risk factors specific to early substance use and misuse common to youth with and without developmental disability include the following: family history of substance abuse, prenatal exposure to alcohol, difficult temperament, psychiatric disability, and peer-group socialization processes.

INDIVIDUAL FACTORS

FAMILY HISTORY FOR SUBSTANCE DEPENDENCE

Empirical findings support a strong relationship between family history of substance abuse and early onset of substance misuse in biological male offspring. The critical underlying mechanisms remain unknown, as there is evidence supporting genetic, biochemical, and environmental contributions. Additionally, research indicates that multiple mechanisms may operate in each of the above areas making accurate identification of a specific, precipitating mechanism difficult.

To date, the majority of empirical research on intergenerational transmission of substance abuse has examined transmission through paternal bloodlines. As a result, the majority of knowledge on intergenerational transmission of substance abuse is based on male data, although research on maternal substance use is beginning to emerge. The existing data indicate that intergenerational transmission of substance abuse through paternal bloodlines usually occurs when the father is substance dependent or has a family history for substance dependence. Moreover, the data suggest transmission may be mediated through modeling behaviors related to substance use, difficult parent-child interactions, and deficits in parenting practices.

The research findings also support secondary paths to substance misuse in children with a positive family history for substance abuse. Conflicted parent-child relationships often promote feelings of alienation in children. Sometimes children may begin to engage in deviant behaviors as a direct response or reaction to the conflicted parental relationship. However, the data also indicate that children may compensate by developing strong affiliations with deviant peer groups. The research indicates these peer groups model and promote antisocial behaviors, including substance use and abuse.

There is less documentation on the effects of family history of substance abuse on the maternal side. The majority of research on maternal substance abuse has been on Fetal Alcohol Syndrome (FAS). FAS occurs when alcohol is ingested in large amounts during pregnancy and is the most common preventable cause of MR in the United States. Substance abuse problems in children with FAS have not been extensively researched. The issue is further complicated because children with FAS vary in their clinical presentation, which is contingent on the amount and timing of substance use during the pregnancy, making detection and follow-up of children with FAS difficult. In addition, the variability in presentation precludes identifying a threshold level of prenatal substance use that is specifically linked with FAS as compared to the milder, other alcohol-related, neuropsychiatric disorders (ARND).

Findings from a recent longitudinal investigation illustrate the need to monitor substance use in youth with MR that is linked with FAS. Specifically, the data reveal that maternal use of alcohol in any amount affects fetal development. The women in this study all drank moderate amounts of alcohol while pregnant. Investigators initiated contact with 439 families at the time of the child’s birth, and followed these families for 14 years. Findings from the most recent follow-up indicate that alcohol use during pregnancy is a more significant predictor of adolescent alcohol use and related problems than a positive family history for substance abuse. Although the cognitive status of the biological offspring was not reported in this study, these data have important implications for children with MR since MR is one of the core
symptoms of children with FAS and children with ARND.

“Risk pathways” for substance misuse and abuse have not been explored in youth with MR or related developmental disorders. Little documentation is available related to the substance use histories, or current parental drinking patterns of families who have a child with MR, even in cases where the child’s cognitive impairment is linked with prenatal exposure to alcohol. Further, the existing research examining paternal and maternal transmission does not provide enough descriptive information to determine if any of the biological offspring who participated in the research had MR, either as a consequence of prenatal exposure to alcohol or some other event that occurred during pregnancy. Despite the absence of information in the existing data, recent empirical findings related to maternal alcohol use during pregnancy provide compelling evidence to explore risk for substance misuse and abuse in youth with MR.2

Temperament

There is evidence that individuals with a “difficult temperament” (often characterized by difficulties with executive cognitive functioning, including planning, attention, abstract reasoning, judgment, self-monitoring, and behavioral self-regulation13) are at significantly higher risk for the early onset of substance misuse and its related problems.3,4,13,29,34 Overall, these data suggest that children with a difficult temperament may encounter poor acceptance in an adaptive peer environment because of their antagonistic interpersonal style.13 These children often end up associating with other peers who are having difficulty negotiating the social environment and who engage in antisocial behavior patterns.34 The antisocial behaviors that frequently characterize these groups result from poor social decision-making skills, manifested by unsafe sex and other high-risk behaviors, such as substance misuse, driving while intoxicated, vandalism, physical violence, and precocious sexual activity. Moreover, these behaviors are often considered the “norm” within the deviant peer group. Consequently, the deviant peer group often provides an environment where poor emotional regulation and incompetent problem-solving strategies are modeled and accepted.34 Importantly, if the adolescent is feeling alienated from the family of origin, the deviant peer group might provide a replacement, or “adolescent family” whose approval and acceptance are highly valued.

Information related to temperament in people with MR converges in part from two areas of related research: social information processing14,17,24,31,35 and self-regulation.11,22,36 Difficulties in social information processing experienced by children with MR often manifest in the form of anger and argumentativeness, increasing the risk of being ostracized and avoided by peers.33,35 Similarly, the available research examining emotional and behavioral regulation in children with MR indicates children with problems in these areas can appear aggressive.11,32,36

Extant data also reveal children with MR may have difficulties negotiating peer group entry,36 regulating negative affect,36 interpreting social cues,14,17,24,35 and correctly identifying emotional expression.14,17,24,35 Further, people with MR may have a greater tendency to interpret ambiguous social cues as hostile and potentially threatening.16,19,27 Notably, there are data suggesting young adults with mild and moderate MR demonstrate a significant and qualitatively different underlying trait structure of facial expression when compared with young adults without MR.17

Cumulatively, these data suggest that children with MR may have problems gaining acceptance into an adaptive peer environment because of their unusual interpersonal style, which might be considered odd or unfamiliar to peers. However, it is not clear that these children will experience pathways to problem behavior patterns similar to non-retarded or neurotypical youth. These children might not experience difficulties with their parents, because their parents might attribute their antagonistic nature to MR rather than the child’s temperament, which could affect the parental response to the child, as well as the child’s response to their peer group. The effects of parental responses to negative behaviors in children with MR could have positive or negative effects, but it is not researched or documented. It should also be noted that parental acceptance does not preclude involvement with a dysfunctional peer group. When trying to negotiate membership in a peer group at school, children with MR might be pushed to the more “antisocial” group because of general response style and base rate of general peer rejection. The existing data suggest the need for further investigation in this area.
Psychiatric Disorder

Evidence indicates adolescents without MR who have a psychiatric disorder engage in early substance misuse at rates higher than peers without mental illness. The data also indicate that gender- and age-related differences may exist, precluding any uniform description of individual or environmental characteristics that contribute to the initiation of substance misuse in this population. In both males and females disruptive and depressive behaviors predict early onset and high rates of substance abuse. Interestingly, disruptive behavior disorders are more predictive of early onset substance misuse and abuse than a family history for substance abuse, with males experiencing more conduct-disorder-type symptoms than females. Lastly, disruptive behaviors and early substance use predict marijuana use in later adolescence.

Psychiatric disorder in people with MR has been well documented, with the majority of reports indicating significantly higher prevalence rates than in the general population. Prevalence rates of comorbid psychiatric disorder for people with MR range between 10% and 80% compared to the general population where rates range between 10% and 20%. Variability in reported prevalence rates reflects methodological and historical problems. However, available data indicate that people with MR frequently experience mood disorders, psychotic disorders, attention deficit disorder with hyperactivity, severe behavior disorders, personality disorders, and anxiety disorders. These disorders, especially behavior disorders and certain personality disorders, have been demonstrated to contribute to the early onset of substance abuse in those individuals without MR.

Environmental Factors

Peer Domain

Investigations of peer group effects on risk for substance abuse show that involvement in a deviant peer group is one of the strongest predictors of early initiation of substance use. Deviant peer groups make substances available, and provide reinforcement for deviant behavior. Also, adolescents in the “deviant group” usually have low skill levels that are often very similar to the “rejected” youth’s skill level, making membership in a delinquent group more comfortable than group membership with more socially adept youth where the lack of social skills may be more pronounced and uncomfortable.

Importantly, recent data indicate that problems with social competency are the strongest predictors of cigarette, alcohol, and drug use even in the presence of a psychiatric disorder. Further, social impairment was the sole predictor of conduct disorder, which subsequently predicted alcohol dependence, and in the presence of low socioeconomic status, significantly predicted alcohol and drug dependence. These findings illustrate the power of social competency and the attendant protective influence exerted by involvement with a socially-appropriate peer group. These data also provide an example of how social competency can transcend the social stigma that frequently accompanies a psychiatric disorder and illustrate the important role of peer group associations in the early onset of substance misuse even in the presence of a significant disability.

Psychosocial research examining long-term adaptation finds that people with MR experience difficulty in the peer domain throughout the lifespan. During childhood and adolescence, the “rejected-neglected” response from peers is common in social interactions. Such avoidance, which is often non-contingent on specific behavior, can be very confusing for young adolescents with cognitive impairments. Research examining adult adjustment suggests this problem is not limited to childhood, but continues after high school when the person is living in the community. The data also indicate that one of the primary reasons that adults with MR have difficulties in employment settings, often resulting in termination, are interpersonal difficulties. Research findings from social skill interventions indicate that skill training is beneficial at all ages, but there are problems with generalization calling into question long-term effects.

Neighborhood

Low socioeconomic status (SES) neighborhoods have been described as having a high incidence of violence, drug abuse, and criminal behaviors. Findings from a recent investigation of inner-city youth and substance use found the neighborhood more strongly influences long-term outcome, including risk for early onset substance misuse, than the presence of maternal psychopathology. Importantly, the current literature suggests people with MR may be
exposed to low SES neighborhoods more frequently than peers without MR, thus increasing their risk for the early onset of substance abuse. Additionally, there is evidence that external cues or environmental factors significantly influence and contribute to the learning environment of people with MR. Therefore, when the available data related to learning styles and living situations that typically characterize people with MR are synthesized in the context of the literature related to risk for substance misuse, the gaps in the existing literature related to risk for substance misuse by people with MR become more pronounced and provide a compelling argument for research in this area.

Less research is available related to the impact of rural environments on early initiation of substance misuse in youth with and without MR. Available research indicates patterns of early substance misuse in rural youth parallel those of their urban peers; however, rural youth begin using alcohol at an earlier age than their inner-city peers. In addition, alcohol is the substance most frequently used by rural youth, and one study indicated that a significant portion (36%) of rural youth in the fifth grade had tried, or repeatedly used, alcohol. Moreover, approximately 33% of the fifth grade youth who used alcohol initiated drinking at nine years of age.

Importantly, the data suggest that risk factors related to the early initiation and escalation of substance use in rural and urban youth differ substantially. While the research examining substance-related risk in urban youth suggests the presence of conduct disorder and psychiatric illness are two of the more salient factors associated with early substance misuse, the data reveal that tobacco use, parental substance use, and male gender are the most significant predictors of early initiation of substance use for rural youth. Notably, the most significant predictor of early initiation of alcohol use was the concomitant tobacco use.

Significant differences in methodologies preclude a comparative analysis of the neighborhood influences that affect substance use in urban and rural youth. However, the demonstrated influence of neighborhood on risk for substance misuse in urban adolescents, and the differences in risk factors for early substance misuse between urban and rural youth, collectively suggest that environment is a significant factor to consider when assessing risk for early substance use in adolescents with MR. Specifically, the available literature on youth with MR indicate these youth are more likely to be exposed to neighborhoods characterized by lower SES that are often disorganized with more availability and accessibility to substances. It is not clear from the available data whether this type of neighborhood is differentially affected by an urban or rural location. Nonetheless, these data illustrate the need to explore neighborhood characteristics as contributors to risk in urban and rural settings. Equally important, these data support the need for early assessment of risk factors and implementation of appropriate intervention to facilitate positive adjustment patterns in youth with MR.

**Discussion and Directions for Future Research**

Overall, the literature suggests many of the individual and environmental characteristics of youth at high risk for substance abuse parallel many of the traits and behavioral response patterns demonstrated by youth with MR. Similar to high-risk youth, youth with MR have problems within the peer domain, demonstrate interpersonal difficulties, and exhibit high rates of psychiatric comorbidity. Moreover, some youth with MR might have greater risk for, and exposure to, substance use and misuse as a function of the linkage between maternal alcohol use and FAS, one of the most common preventable causes of MR. In addition, the literature indicates that people with MR frequently are exposed to low socio-economic environments, which are often characterized by substance use and other high-risk behaviors. Cumulatively, these findings suggest that people with MR might be at high risk for developing substance-related problems, especially in the context of full inclusion in the schools and initiates for community integration.

However, it is important to realize that “risk” does not equal “destiny.” Although “at risk” youth and youth with MR share many similar characteristics, youth with MR might have a completely different social experience with people in the community, consequently experiencing a developmental trajectory unrelated to the path of the “high risk” youth. As the more recent literature on “high risk” youth demonstrates, there is a synergistic, person-environment interaction that may or may not promote the emergence of deviant behaviors. The absence of base-rate information leaves many unanswered
questions regarding the extent of substance-related problems and the needed services to address these factors in people with MR.

Additionally, it is not clear from the existing data what parameters define “problem drinking” for people with MR. That is, how much is too much for individuals with cognitive and adaptive limitations? Importantly, existing research does not address, or assess, the interaction between alcohol and documented medical problems and related medications, that often affect people with MR, such as seizures and the use of anticonvulsant medication. The limited data available suggest that people with MR may experience substance-related problems from smaller amounts of alcohol when compared with individuals in the general population. Therefore, the amount of substance use that may be problematic for persons with MR may be well within the parameters of “social drinking” in the general population, thus precluding detection in health care settings. Further, significant others may make little attempt to intervene if the amount of alcohol use seems “normal.”

These data do not lend themselves to speculation about the individual or environmental characteristics that would maximize the potential for positive adjustment in people with MR. Additional investigation is needed to identify the situational determinants that promote healthy behavior and positive adjustment for people with MR, such as the number of community support groups, or focus of community support groups (recreational vs. skill building behavior, or both?).

Future research efforts are needed to facilitate a deeper understanding of the person-environment responses specific to people with MR that potentiate “at-risk” behaviors. It may be that people with MR are actually “protected” because of the presence of a developmental disability. That is, people may respond differently to behaviors typically perceived as inappropriate when demonstrated by youth with MR. Conversely, future research may reveal that youth with MR are at greater risk than previously thought, especially youth functioning within the mild to high moderate range. Youth in this range of functioning could be perceived as “antisocial” because of the absence of a label qualifying their behavior patterns. Clearly, this area of study has implications for long-term adjustment and warrants further exploration.

The results of the movement toward complete community integration are that young adults and adolescents with MR now face many of the same socialization issues that “high risk” youth encounter. Consequently, even if motivational differences exist, youth with MR may be at increased risk for substance misuse and the resulting poor outcomes. Emerging data indicate people with MR do experience problems with substance use, although the extent of the problem is unknown. The data suggest youth with MR may be at the highest risk when trying to socialize with peers who do not have MR. That is, the documented problems in processing emotional cues, inappropriate peer behaviors, poor decision making skills, and impulsivity that characterize youth with MR may be more pronounced and lead to rejection when exhibited in the context of well-adjusted peers without MR. The data on poorly adjusted children without MR suggest this process of social rejection may lead to affiliation with deviant peer groups and engagement in a number of high-risks behaviors, including substance misuse. Overall, these data provide compelling evidence for continued, community research exploring ways to facilitate positive adjustment for people with MR.

Although the absence of systematic research directly related to substance misuse in people with MR precludes definitive suggestions for prevention and intervention efforts, the available data provide some direction for interventions in this area. First, these data suggest health service providers working with people who have MR functioning in the mild to high moderate range should proactively assess psychosocial functioning at each developmental stage. As illustrated by the risk literature, children who are aggressive, or lacking in appropriate social skills, are at high risk to be ostracized by well adjusted peers. Under these circumstances, providers might offer parents suggestions that promote the development of a supportive, nurturing environment. Importantly, service providers might want to emphasize that a less-structured environment, outside of the school environment, may be more flexible and nurturing for a child with special needs than the regular classroom environment. Specifically, this type of environment may offer children who have difficulty regulating their behavior more positive reinforcement than the classroom and provide additional opportunities for practicing prosocial behaviors. The extant data suggest interventions that increase contact with well-adjusted peers in accepting environments might be beneficial.
Additional suggestions for interventions that require no additional training or support staff include: early assessment of risk factors for substance use; ongoing assessment of parental and youth substance use; increase in the accessibility of educational materials related to youth substance use, especially materials encouraging parents to discuss substance-related issues with children; and, encouraging adolescent involvement in support groups, especially groups focusing on social skills, including, assertiveness training, and drink-refusal skills. Providers also might encourage parents to explore community resources that support non-drinking, social activities. Since the data indicate risk for experimentation with substances peaks during adolescence through young adulthood, and that risk is an ongoing, interactive process beginning well before actual substance use is initiated, the earlier providers can assess whether risk factors are present and offer interventions that will interrupt the potential for negative outcomes, the more likely it is that youth and young adults with MR will benefit.

Importantly, future research examining the psychometric properties of existing substance-related, screening and assessment instruments in people with MR, or alternatively, developing screening and assessment measures specific to people with MR, would greatly enhance our understanding of substance-related problems in people with cognitive limitation. At present, reliability and validity data supporting the use of the existing instruments for people with MR do not exist. There is also a pressing need to determine if there are defined limits of what constitutes “healthy” alcohol use vs. “pathological” alcohol use in people with MR.

In conclusion, the existing literature indicates that people with MR have problems with substances, although to an unknown degree. There is a little understanding of the mechanisms that lead to substance use and the amounts that are actually problematic for people with special needs. It is clear from the existing literature that future research in this area would augment current efforts to enhance the quality of life for people with MR and provide appropriate services.

**References**


CORRESPONDENCE: Karen M. Cocco, Ph.D., Assistant Professor, Graduate Programs in Rehabilitation, The University of Iowa, N366 Lindquist Center, Iowa City, Iowa 52242-1529; tel. 319-335-6426; fax: 319-335-5291; e-mail: karen-cocco@uiowa.edu.