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Substance abuse among individuals with intellectual disabilities

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ABSTRACT

Individuals with disabilities are a growing population that confronts multiple disadvantages from social and environmental determinants of health. In particular, the 7–8 million people in the U.S. with an intellectual disability (ID) suffer disproportionately from substance use problems, largely because of a lack of empirical evidence to inform prevention and treatment efforts for them. Although available research could inform future research efforts, studies are scattered across disciplines with the last review synthesizing findings written more than five years ago. To consider more recent findings with earlier works, PubMed, PsychINFO, and Google Scholar were searched and produced 37 peer-reviewed texts across multiple disciplines, 15 from 2006 or later. While the prevalence of alcohol and illicit drug use in this population are low, the risk of having a substance-related problem among ID substance users is comparatively high. Gaps in the research and population subgroups that warrant special attention are identified, such as individuals with borderline and mild ID, individuals with co-occurring mental illness, and individuals who are incarcerated. Compared with substance abusers without ID, ID substance abusers are less likely to receive substance abuse treatment or remain in treatment. Research is needed to better gauge the magnitude of substance use problems, identify prevention strategies, and specify treatment components that meet the unique needs of individuals with ID.

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1. Introduction

Individuals with disabilities constitute a growing population in the United States. They confront disadvantages from social and environmental determinants of health, including lower educational levels, lower incomes, and higher unemployment, than people without disabilities (Iezzoni, 2011). In particular, people with intellectual disabilities (ID) suffer disproportionately from substance use problems, due largely to a lack of empirical evidence on what substance-related disorder prevention and treatment efforts are effective for them (Cocco & Harper, 2002; Slayter, 2008). Available research is scattered across disciplines, with the last review synthesizing findings written more than five years ago (McGillicuddy, 2006). Researchers suggest that substance use and related problems among people with ID have been understudied. Findings could help inform future research efforts, so recent studies were reviewed to consider with earlier works. While there are still no good, population-based prevalence estimates for substance use or abuse among people with ID, research suggests that prevalence of alcohol and illicit drug use is low, while risk of abuse is relatively high among substance users in this population (McGillicuddy & Blane, 1999; Slayter & Steenrod, 2009). This review identified gaps in research, such as a need to assess the use of readily available substances (e.g., inhalants) in this population (Cocco & Harper, 2002), and subgroups with potentially high vulnerability to substance use problems, such as adolescents and those with a history of involvement with the criminal justice system (Chaplin, Gilvarry, & Tsakanikos, 2011; Cocco & Harper, 2002).

People with ID have significant limitations in cognitive functioning and adaptive behaviors that relate to everyday social and practical skills. Encompassed by but not the same as a developmental or learning disability (AAIDD, 2012), ID is diagnostically the same as mental retardation but is more respectful and the preferred term to identify the 7–8 million members of this population in the U.S. (HHS, 2012; Schalock et al., 2007). ID diagnoses occur along a spectrum ranging from borderline to severe with the diagnostic and statistical manual of mental disorders (DSM-IV) classifying individuals with an IQ below 20–25 as *profound*, from 20–25 to 35–40 as *severe*, from 35–40 to 50–55 as *moderate*, from 50–55 to approximately 70 as *mild,* and from 71 to 84 as *borderline* (APA, 2000). Around 87% of people with ID are only slightly slower than average (HHS, 2012: On-line). Many people with ID live in the community, an improvement over institutionalization, but such integration may increase their exposure opportunities to licit and illicit substances (Slayter, 2006a).

Like ID, substance use operates on a continuum ranging from low (e.g., experimental use) to high, with high-level use defined as abuse or dependence (Brucker, 2007). The DSM-IV defines current substance *dependence* as a maladaptive pattern of use leading to clinically significant impairment or distress as defined by 3 or more dependence criteria over one year (i.e., tolerance, withdrawal, substance often taken in large amounts or for long periods, persistent desire or unsuccessful attempt to cut down, a great deal of time spent in activities to get the substance, important activities given up, continued substance use despite knowledge of having recurrent physical or psychological problems) (APA, 2000). A substance *abuse* diagnosis is given when substance users do not meet the criteria for dependence disorder and manifest a maladaptive pattern of use leading to clinically significant impairment or distress as defined by one or more abuse criteria over one year (i.e., a serious problem at home, work, or school caused by using the substance; regular substance use that puts the user in physical danger; repeated use that leads to trouble with the law; problems with family or friends caused by continued use) (APA, 2000).

Because the literature on substance use among people with ID is scattered across disciplines, we reviewed it to identify common findings and gaps in the knowledge concerning substance use problems that will inform future research, intervention, and health policy efforts. This paper considers epidemiological findings from U.S. and non-U.S. studies, explores substance use disorders with co-occurring mental health disorders, incarceration, and other substance use consequences for this population with emphasis of findings from 2006 or later. The paper concludes with recommendations for future research and policy.

2. Material and methods

Searches of PubMed, Google Scholar, and PsychINFO using keywords, such as intellectual disability; mental retardation; and alcohol abuse; produced 37 journal articles and 2 dissertations on substance use and related problems among people with ID from the past 30 years. Of the 27 texts that reported original research; 14 were from studies outside the U.S. Most studies used community-based samples; included a small sample size ($n \leq 200$); considered the use of certain substances only (e.g., alcohol; cocaine); and relied on self-reported measures not validated for this population (Slayter, 2006a; Cocco & Harper, 2002). Of U.S. studies that used national data; all focused on treatment-related information from the 1990s (Larson, Lakin, & Huang, 2003; Slayter, 2008, 2010a); with the most recent studies relying on Medicaid claims; potentially limited by concerns of data completeness (Iezzoni, 2002; Slayter, 2010a). Research also lacked theoretical explanation and would benefit from use of a cohesive theoretical frame (Cocco & Harper, 2002).

3. Results and discussion

3.1. Epidemiology of substance use, U.S. studies

Provided for comparison, information in Table 1 is from the National Survey on Drug Use and Health (NSDUH), an ongoing annual national survey of approximately 67,500 individuals to assess incidence and prevalence of substance use, abuse, and dependence among non-institutionalized Americans aged 12 years or older. Table 2 reports information from the Monitoring

Table 1
Past month prevalence estimates of substance use in the U.S. population aged 12 or older.

Year	Cigarette smoking	Alcohol	Any illicit drugs[c]
1998[a]	27.7%	51.7%	6.2%
2010[b]	23.0%	51.8%	8.9%

[a] SAMHSA (1999).
[b] SAMHSA (2011). (Due to modifications of the study design over time, these rates cannot be construed as trend data; readers are encouraged to read the original study report for additional information.)
[c] Illicit drugs includes marijuana/hashish, cocaine/crack, inhalants, hallucinogens (including lysergic acid diethylamide [LSD], phencyclidine [PCP], peyote, mescaline, psilocybin, ecstasy/MDMA), heroin, and the nonmedical use of psychotherapeutics (i.e., stimulants, sedatives, tranquilizers, and analgesic opioids).

the Future Survey (MTF), an annual national survey of substance use and related attitudes among students in 8th, 10th, and 12th grades. Table 3 presents information on epidemiological studies of substance use prevalence among people with ID conducted in the 1980s and 1990s. Prevalence rates differed across studies, indicating variations in sample characteristics and designs. Overall, these results suggest that past-month prevalence of illicit drug use is lower among people with ID (1.5% for cocaine and 13% for marijuana). Alcohol use is also lower but is more similar to rates in the general population (35.5–47%). Cigarette smoking appears about the same as the general population (20.5% in the past 30 days).

While findings suggest a lower prevalence of alcohol and drug use among people with ID, results indicate a potentially elevated risk for experiencing a substance use disorder among those who use substances (Didden, Embregts, van der Toorn, & Laarhoven, 2009). McGillicuddy and Blane (1999) found an almost equal proportion of alcohol users to alcohol misusers (21–18% respectively, $n = 122$). Westermeyer, Kemp, and Nugent (1996) examined 642 individuals in treatment for substance use disorders and found that 6.2% ($n = 40$) had ID compared to 1-3% of the general population [Ruf, 1999]. Westermeyer et al. (1996) also compared survey responses of the 40 ID individuals with 308 of the non-ID individuals and found that those with ID began substance use at a later age, used fewer substances in their lifetime, and used them less often in the past year than those without. These findings indicate that ID users may require less exposure for substance use problems.

On the other hand, evidence suggests that some individuals in this population have greater exposure to substance use than others. Specifically, there is an association between the severity of ID and substance use spectrums, as problematic substance use increased with cognitive function (Burtner, Wakham, McNeal, & Garvey, 1995; Rimmer, Braddock, & Marks, 1995; Sturmey, Reyer, Lee, & Robek, 2004). Reasons for greater substance use in people with borderline and mild ID may relate to an increased level of physical or financial independence, opportunities for access to substances, and exposure to prejudice through increased community participation (Edgerton, 1986; Rimmer et al., 1995).

Studies of national data, however, cannot categorize individuals based on level of cognitive function. Using data from the 1994 to 1995 National Health Interview Survey (NHIS), Larson et al. (2003) estimated that one-year prevalence of treatment for alcohol or drug-use disorders in the non-institutionalized, adult (aged 18+) ID or developmentally disabled population was 2.2% ($n = 33$). Slayter (2006b) assessed 1999 Medicaid claims from 49 states and found that, of 366,606 people with a diagnostic code for ID, 2.6% ($n = 9484$) also had a code for a substance use related treatment (e.g., abuse, alcohol poisoning). It is likely that such prevalence underestimates problematic use or disorders for this population, as many in need may not have sought treatment services (Slayter, 2008). Using the same data, Slayter (2010a) found that being non-White, living in a nonurban area, having a co-occurring mental illness, and living in state with a more generous Medicaid policy for substance abuse treatment increased the odds of an ID person having a substance-related treatment code.

In another study of Medicaid data, Slayter (2010b) found that 2.7% ($n = 1669$) of ID youths aged 12–21 had a diagnostic code for substance use related treatment. Those with such a code were more likely than those without to be male and have a co-occurring serious mental illness (e.g., schizophrenia). Ages of treatment initiation were not different from those of people without ID, contradicting Westermeyer et al. (1996) who found later age of alcohol (ID = 17.5 ± 4.9, non-ID = 15.1 ± 4.7),

Table 2
Past month prevalence estimates of substance use among 8th, 10th, and 12th Graders in the U.S.[a]

Year	Grade	Cigarette smoking	Alcohol[b]	Any illicit drugs[c]
1998	8th	19.1%	23.0%	12.1.%
	10th	27.6%	38.8%	21.5%
	12th	35.1%	52.0%	25.6%
2010	8th	7.1%	13.8%	9.5%
	10th	13.6%	28.9%	18.5%
	12th	19.2%	41.2%	23.8%

[a] Johnston, O'Malley, Bachman, & Schulenberg (2011) (Due to modifications of the study design over time, these rates cannot be construed as trend data; readers are encouraged to read the original study report for additional information.)
[b] In 2004 question text changed slightly in half of the forms, and when an examination of data showed no significant effect, the remaining forms were changed in 2005.
[c] For 12th graders, illicit drugs includes marijuana, LSD, other hallucinogens, crack, other cocaine, or heroin, or any use of narcotics other than heroin, amphetamines, sedatives (barbiturates), or tranquilizers not under a doctor's orders. Narcotics other than heroin and sedatives (barbiturates) are excluded for 8th and 10th graders due to their tendency to over report use.

Table 3
Small U.S. based studies of substance use.

Author and Year	Sample	Setting/Residence	Substance	Prevalence
DiNitto and Krishef (1983–1984)	214 adults with mild intellectual disability (75% < 46 years)	Family, group home, or community	Alcohol use (i.e., 1 drink ever, a month, a week, or a year).	52% had consumed alcohol; 47% drank monthly; 33% drank weekly; 7% drank daily
Edgerton, 1986	48 independent living adults (mean age 20); 40 independent living adults (mean age 31); 45 black, inner-city resident adults (mean age 25); 48 independent adults released from hospital 30 years prior to research (mean age 34)	Assisted living environment (e.g., family or group home) or community	Alcohol or Illicit Drugs (Light use is ≤ 2 beers or glasses of wine or 1 marijuana cigarette, moderate use is use of beer, wine, or marijuana 1 to 2 times a week, heavy use is intoxication several times a week.	Current light use 4.6% to 19.1%; Current moderate use 0% to 16.7%; Current heavy use 0% to 13.6%
Burtner et al., 1995	56 adults with mild intellectual disability 66 adults with moderate intellectual disability 86 adults with severe intellectual disability 541 adults with profound intellectual disability (mean age 38)	State-run facility for people with ID	Tobacco use	7% past month for total sample ($N = 749$) 20.5% past month for mild-moderate ($N = 122$)
Gress and Boss (1996)	4114 total sample including students in grades 4 through 12 in and out of special education classes (371 in special education); results for grades 9 through 12, students with "developmental handicap." n not reported	Special education classes	Tobacco use Alcohol use Marijuana use Cocaine use Amphetamines use	26.9% past month 35.5% past month 13.8% past month 1.5% past month 2.5% past month
Pack, Wallander, & Browne, 1998	194 African Americans aged 13 to 16 with mild intellectual disability	Special education classes	Alcohol use Marijuana use	48% past year 39% past month 13% past year 10% past month
McGillicuddy and Blane (1999)	122 adults with mild to moderate intellectual disability (mean age 27)	Community	Alcohol use, Illicit drug use, Tobacco use (Misuse of any substance was identified with use of index developed by authors)	Alcohol – 39% Drugs – 4% Tobacco – 20.5% Misuse of any substance – 18%

tobacco (ID = 17 ± 12.2, non-ID = 15.2 ± 4.6), and drug (ID = 20.7 ± 9.3, non-ID = 16.5 ± 6.9) use initiation ($n = 40$). Slayter (2010b) unadjusted analysis showed that youths with diagnostic codes for ID and substance abuse had reduced odds of initiating or engaging in related treatment (OR = 0.9 and 0.8 respectively, $p < 0.05$) and had increased odds of dropping out of treatment between initiation and engagement (OR = 1.7, $p < 0.001$). These findings suggest that treatment may not meet ID persons' treatment needs or that ID related barriers (e.g., lacking transportation, poor intellectual functioning, lacking motivation for treatment) interferes with treatment retention (Slayter, 2010b).

Taken together, substance users with ID show an elevated likelihood of problematic substance use, and differential exposure to substances appears to create various levels of risk across ID population segments. The most common substances studied include alcohol, tobacco, and marijuana, with limited research on cocaine and amphetamines. Based on higher rates of legal substance use (i.e., cigarettes), additional research is needed to examine nonmedical use or misuse of readily available substances (e.g., inhalants) and prescription-type drugs (CDC, 2012; Cocco & Harper, 2002). Extant research data are generally dated, and new research using more recent data sources and large samples would better reflect recent trends and the magnitude of substance use among people with ID.

3.2. Epidemiology of substance use, international studies

Similar to studies in the U.S., several methodological reasons limit the generalizability of international study findings to a large ID population. Methodological reasons also complicate comparisons between studies and across countries. Reasons include differences in ID and substance use related definitions, time frame of substance use, small and highly selected samples (e.g., mainly treatment-seeking individuals), and differential study inclusion and exclusion criteria used to select study participants (Chaplin et al., 2011; Sturmey et al., 2004; Taggart, McLaughlin, Quinn, & Milligan, 2006). Prevalence estimates for ID substance users outside the U.S. also suggest lower rates of alcohol and drug use and similar rates of smoking when compared to corresponding rates for the general population (Emerson & Turnbull, 2005). In a United Kingdom (U.K.) study of ID and co-occurring mental health disorders, Cooper, Smiley, Morrison, Williamson, and Allan (2007) found that 1% of 1023 ID individuals aged 16–83 had a DSM-IV alcohol or drug-related disorder. In Australia, Tracy and Hoskin (1997) assessed 36 ID adults living in the community and found that 36% smoked compared to 25% of the general population. In the Netherlands, VanDerNagel, Kiewik, Buitelaar, and DeJong (2011) surveyed staff at 39 ID service facilities about substance use, user profiles, and related provider policies. Respondents provided information on 86 ID individuals aged 16–66. Results showed that 34.8% used both alcohol and cannabis, 32.6% used alcohol exclusively, 15.1% used stimulants, 8% used cannabis exclusively, 1.2% used opiates, and 7% used neither drugs nor alcohol. Rates of alcohol use were lower for those with ID compared to the general population, but drug use generally was more common.

Patterns of use outside the U.S. were also often similar to those in the U.S. In a sample of 67 ID substance users aged 18 and over in Northern Ireland, most were young (aged <30) or male, with borderline or mild ID (Taggart et al., 2006). However, study findings suggest that rates and substance use patterns differ by level of ID and age (VanDerNagel et al., 2011). Specifically, among those with borderline ID ($n = 42$), 38.1% used alcohol and cannabis, 23.8% used stimulants, 19% used alcohol exclusively, and 9.5% used cannabis exclusively. Among those with mild ID ($n = 44$), 45.5% used alcohol exclusively, 34.1% used alcohol and cannabis, 6.8% used cannabis exclusively, 6.8% used stimulants, and 2.3% used opiates. Older individuals were more likely to have mild ID and use alcohol exclusively (mean age 39.9 years), while younger individuals were more likely to use alcohol and cannabis together or to use stimulants (mean age 23 and 23.2, respectively).

We found that only two non-U.S. studies examined substance use among ID adolescents. Emerson and Turnbull (2005) compared smoking and alcohol use in a national U.K. sample of 95 adolescents with ID (aged 11–15) and 4069 without; they found a higher rate of smoking among ID adolescents than those without (14% vs. 8%). Rates of smoking more than seven cigarettes a day and ever smoking were about the same (6% vs. 4% and 15% vs. 14%, respectively). The prevalence of lifetime drinking was lower among ID adolescents (41% vs. 50%) as was drinking at least once per month (12% vs. 22%). In Greece, Kalyva (2007) found that, of 89 adolescents aged 12–16 living in the community with mild ID, 29% used tobacco compared to 20.2% of their non-ID peers.

Of note, researchers have emphasized methodological difficulties in estimating reliable rates of substance use in the ID population. U.K. researchers suggested that individuals with ID and their families might hide ID substance use out of fear that it would result in institutionalization (Taggart et al., 2006). Additionally, studies that combine people with various degrees of ID into one group may obscure the prevalence for subgroups (i.e., people with mild ID) with an elevated risk for substance use (Emerson & Turnbull, 2005). Fidler, Michell, Raab, and Charlton (1992) also found that ID smoking rates varied by U.K. community, suggesting that environmental factors influence smoking prevalence. Likewise, environmental factors influence use of other substances. Variables found to influence smoking in international studies included: Social pressure (particularly for those with mild ID, living with a smoker, or living in a less restrictive residential setting), being male (Kalyva, 2007), poverty, less punitive child management practices, and the level of psychosocial stress of an ID person's guardian (Emerson & Turnbull, 2005). Additional reasons suggested for increased substance use are inadequate coping skills for stress (Didden et al., 2009), a desire to fit in or increase social inclusion and overcome loneliness (Christian & Poling, 1997), stigmatization, and limited social skills (Degenhardt, 2000).

While the finding that some individuals with ID use substances to increase social inclusion indicates a potential intervention strategy, only two studies discussed ID targeted interventions. In the U.S., McGillicuddy and Blane (1999) randomly assigned 84 individuals to a once-a-week, 10-week, course that provided substance education and either taught

participants refusal skills, modeled appropriate behavior in new situations, or did neither. Participant knowledge improved across groups, but participants failed to change in attitude or behavior. In Australia, Tracy and Hoskin (1997) modified an existing smoking education intervention to meet the cognitive needs of people with ID. The intervention included seven 2 h sessions that incorporated videos, group discussions, information-giving segments, role-playing, and a board game. At intervention end, over half (54%) of participants ($N = 11$) had quit or cut down on cigarette use. Although not discussing a specific intervention, ID providers in the VanDerNagel et al. (2011) study rated psychosocial and restrictive measures as the most effective ways to address problematic substance use for people with ID but also stressed inadequate expertise in this area.

To summarize, research conducted outside the U.S. shows that age, level of ID, and environmental variations may influence rates and patterns of substance use and related disorders in the ID population. Studies concur with U.S. findings that legal substances, such as tobacco and, in the Netherlands, cannabis, may be particularly problematic for this population. As with studies in the U.S., they show that people with improved cognitive function (mild to borderline ID) are likely at greater risk of substance use and associated problems.

3.3. Synthesis of epidemiological findings

Based on epidemiological findings, it appears that an ID substance abuser often begins to use substances in early to late adolescence. If so, prevention efforts targeted to this point in the lifespan may provide the most benefit. However, little is known about substance use prevention information and strategies for this young and vulnerable ID population (Cocco & Harper, 2002). Even as late as the 1990s, basic education about drugs was lacking from health education programs designed for people with ID (Christian & Poling, 1997), and more recent literature has not addressed this topic. Clearly, prevention research is needed for this young group. Additionally, because a desire to fit-in and social or peer pressures are implicated in substance use initiation (Christian & Poling, 1997; Taggart, McLaughlin, Quinn, & McFarlane, 2007), interventions for this group can emphasize social skills over complex cognitive therapies or abstract analyses of reasons for substance use (Degenhardt, 2000). A limited number of intervention studies also suggest some positive effects of teaching refusal skills (McGillicuddy & Blane, 1999; Tracey & Hoskin, 1997). Another relevant direction is to examine whether victimization contributes to the onset or prolongation of substance use disorders and to incorporate self-protective skills into prevention and treatment programs.

As with many substance abusers, an ID substance abuser may have a history of trauma and physical or sexual abuse in childhood, adulthood, or both. Anecdotal evidence led Kinsler, Saxman, and Fishman (2004) to develop the heuristic '*horrible life disorder*' to discuss the lives of people in this population. Case studies by Ruf (1999) show histories of maltreatment can begin before the onset of substance related problems. History of familial physical and sexual abuse, neglect, and abandonment sometimes may implicate in the development of ID. Interviews with ten ID individuals with substance use problems found that the most often self-reported reasons for substance use were to escape past trauma and loneliness (Taggart et al., 2007). These findings suggest a need for greater social support and post-traumatic therapy for some ID individuals with substance use problems.

Further, ID service providers in the Netherlands reported that abstinence through restriction was more effective than abstinence through rewarding behavior (VanDerNagel et al., 2011). While abstinence through strict behavioral limits is common in general substance abuse treatment, it conflicts with paradigms used by ID service providers, who focus on self-determination regardless of cognitive limits and consequences (Slayter, 2008). Therefore, common ground between perspectives is needed. Researchers and service providers may benefit from social workers' experiences in assisting ID clients negotiate their complex aspects of life (Degenhardt, 2000; Slayter, 2008).

Lastly, synthesis of epidemiological findings published since the last literature review on this topic (i.e., McGillicuddy, 2006) shows that ID individuals are likely to begin substance use earlier than expected and that those with substance use disorders have a low likelihood of receiving or staying in substance abuse treatment (Slayter, 2010a,b,c). Patterns of substance use vary by age, presence of a mental health disorder (Slayter, 2010a), and level of ID (VanDerNagel et al., 2011). In addition, past trauma and physical or sexual abuse increase risk of substance use disorder for people with ID (Taggart et al., 2007), and abstinence is likely the best prevention and treatment strategy for them (VanDerNagel et al., 2011). These findings highlight a need for research to elucidate substance use patterns and consequences by subgroups (e.g., adolescents, those with a history of involving with the criminal justice system, individuals with mild or borderline ID, and those with a history of maltreatment) and to identify means to improve prevention and access to treatment.

3.4. Co-occurring substance use and mental health disorders

As with a need to fit-in and a history of trauma, mental health problems are also implicated in increased risk for problematic substance use in the ID population. People with ID have higher rates of mental health problems than the general population (Brunette, Mueser, & Drake, 2004), and an association between mental health problems and substance use disorders is well established (Wu, Ringwalt, & Williams, 2003). In a sample of 64 adults with mild ID and a comorbid disorder (i.e., personality syndrome, schizophrenia, atypical or not otherwise specified psychosis, depression, or organic mental disorder), 30% reported current smoking (Hymowitz, Jaffe, Gupta, & Feuerman, 1997). Medicaid claims for individuals aged 12–99 from 49 states in 1999 showed that 54% ($n = 5099$) of ID persons with a code for substance related treatment (e.g.,

abuse, alcohol poisoning) also had a code for: Schizophrenia, effective psychosis, paranoid states, nonorganic psychosis, or child onset psychosis (Slayter, 2010c). Among 185 ID individuals admitted to Dutch substance abuse treatment facilities, 42% had a co-occurring behavioral or emotional problem (Didden et al., citing Tenneij & Koot, 2007). Similarly, of 80 Dutch ID substance users, VanDerNagel et al. (2011) found that substance use was associated with having a psychiatric comorbidity and a lack of daytime activities. In a sample of 115 ID adults seeking mental health services in London, Chaplin et al. (2011) found that 8% were current substance users and 15% had a history of substance use (alcohol, 80%; cannabis, 28%; cocaine, 12%).

In summary, the available data reveal an association between substance use problems and other psychiatric disorders among individuals with ID. New findings published since the last review implicate schizophrenia spectrum disorders in particular as an important correlate for experiencing a substance use disorder (Chaplin et al., 2011; Slayter, 2010c). However, due to a limited number of studies on psychiatric comorbidity, more research is needed to better gauge the extent and temporal sequences of comorbid problems to inform prevention and treatment efforts. Nonetheless, findings suggest a need to incorporate comprehensive assessments of substance use and psychiatric disorders to treatment plans for individuals with ID in mental health or psychiatric settings.

3.5. Incarceration

Frequently overlooked, criminal activity is a repeatedly identified correlate of substance use for people with ID (Chaplin et al., 2011; Didden et al., 2009; Kinsler et al., 2004; Krishef, 1986; McGillivray & Moore, 2001). This suggests that there may be a disproportionate number of individuals with ID and a substance use disorder in the criminal justice system (Kinsler et al., 2004; Ruf, 1999). In Australia, McGillivray and Moore (2001) compared self-reported substance use between 30 incarcerated young adults with mild ID and 30 without and found that the ID group consumed substances more often than the non-ID group. Because no U.S. agencies formally track the number of incarcerated individuals with ID, it is difficult to evaluate their prevalence, but some data suggest that as many as 70% of incarcerated youth have a mental disability (Burrell & Warboys, 2000; Kinsler et al., 2004).

Often overlooked by previous literature reviews, substance users with ID may be at risk for being involved with the criminal justice system (Kinsler et al., 2004; McGillivray & Moore, 2001). Transfer of responsibility for ID services from the federal government to states, deinstitutionalization without proper community supports, and a recent increase in state's propensity to incarcerate people might have led to an influx of ID substance abusers in prison (Kinsler et al., 2004). Once an ID substance abuser is in the criminal justice system, he/she can have a difficult time navigating court procedures and requirements, which can exacerbate consequences for even minor offenses (Kinsler et al., 2004). Therefore, the prevalence of problematic substance use and associated treatment needs among ID substance abusers in prison deserves research.

3.6. Consequences of substance use or abuse and barriers to treatment

The diagnostic features of ID combined with medications commonly used by this population can result in ID persons experiencing greater adverse effects from substance use or abuse compared to individuals without ID. For instance, behavioral consequences associated with problematic substance use for this population include increased risk taking, moodiness, aggression, violence, vulnerability to exploitation, and problems in relationships (Didden et al., 2009 citing Tenneij & Koot, 2007; McGillivray & Moore, 2001; Taggart et al., 2006). Due to physical difficulties commonly associated with ID related conditions, physiological consequences can be serious for this group and include increased cognitive deficit, cardiovascular, respiratory, and gastrointestinal problems (Degenhardt, 2000), epileptic activity (Taggart et al., 2006), and greater motor deficit (Slayter & Steenrod, 2009). The combination of substances with medications commonly taken for these physical difficulties may result in mental confusion, sedation, dementia, coma, and death (Slayter, 2008).

Only two known publications offer service providers information on substance-related disorder assessment and treatment for people with ID, and neither was written with empirical data (Slayter, 2008). ID service providers indicate they have neither the knowledge nor skills required to assess, treat, or manage substance use and the related problems of their clients (Degenhardt, 2000; Lottman, 1993; Sturmey et al., 2004; VanDerNagel et al., 2011). Likewise, addiction treatment providers report difficulties serving people with ID, particularly when using the most common, group-based models of care (Lottman, 1993; Ruf, 1999). For those with ID, cognitive limitations impede comprehension of treatment concepts, which could lead other members of the treatment group to stigmatize, resent, and exclude them. Counsellors also may confuse ID-associated limitations with non-compliance (Ruf, 1999). Collectively, traditional substance abuse treatment programs may not be equipped with the capacity to meet the unique needs of this group (e.g., cognitive limitations), and tailored programs are needed (Bellows, 1995).

Further, poverty and insurance restrictions can further limit access to treatment for people with ID. Medicaid, the most common insurer for this population (Slayter, 2006b), often does not cover private substance abuse treatment. Medicaid coverage varies by state, with some states offering no services and others only offering services to select groups, such as pregnant women (Christian & Poling, 1997; Slayter, 2010a). Available public programs often have long waiting lists and questionable treatment success rates (Christian & Poling, 1997; Ruf, 1999). Ruf (1999) indicated that putting prevention and treatment for problematic substance use under the purview of ID service providers may generate improved outcomes and be cost effective.

Lack of research in this area clearly hinders the development of sound prevention or treatment plans for the ID population. Even though researchers stressed a need for studies in this area three decades ago, substance use and related treatment needs among people with ID remains largely overlooked and underserved. Many reasons for limited research in this area are suggested, including researchers' prejudice to difficulties working with this population (Harris & Edwardson, 2000; McGillicuddy, 2006; McGillicuddy & Blane, 1999). Therefore, barriers to research on substance use problems for the ID population need to be identified and addressed.

Traditional substance abuse treatment programs may be inadequate in meeting the unique needs of the ID population. Research published since the last review of this topic indicates that people with ID are less likely to initiate treatment than are non-ID substance abusers (Slayter, 2010b,c). The reported difficulties in receiving substance abuse treatment in traditional treatment programs plus inconstancies in the Medicaid system to support substance abuse care suggest a need to explore new treatment paradigms, such as treatment being in the purview of ID service providers (Ruf, 1999; Slayter, 2008).

4. Conclusions

People with disabilities are a growing health disparities population (Iezzoni, 2011). People with ID face more severe mental, physical, and social consequences from substance use related problems than members of other groups, but substance use problems and associated treatment needs among members of this population are understudied. Well-designed, theory-driven studies of large samples are needed to establish base rates of substance use and disorders (abuse or dependence) for this population and its subgroups, such as adolescents, those with mild or borderline ID or having a history of involvement with the criminal justice system (Chaplin et al., 2011; Cocco & Harper, 2002). Such research should include assessments of readily available substances (e.g., inhalants, diet pills, prescription-type drugs), delineate patterns of substances used, elucidate how substance use and escalation to problematic use interact with other co-existing problems, and clarify pathways to substance abuse care and treatment outcomes (Cocco & Harper, 2002). Longitudinal studies are required to better understand substance use patterns across the lifespan of people with ID and the range of outcomes for those with substance use disorders. Prevention studies, especially for adolescents with ID, are also recommended to determine the impact of prevention and intervention efforts on substance use behaviors and outcomes, particularly in terms of stopping nonuse from transitioning to use and use from transitioning to abuse (Cocco & Harper, 2002; McGillicuddy & Blane, 1999; Snow, Wallace, & Munro, 2001).

4.1. Policy suggestions

Deinstitutionalization and community integration have improved the lives of people with ID in many ways. However, deinstitutionalization might also have made people with ID more vulnerable to problems like substance use and abuse (Slayter, 2010c). There are many reasons for substance use related disorders in this population, which leaves multiple avenues for intervention. Effective intervention requires new research that will generate empirical data to inform prevention, treatment, and policy-making efforts. To keep individuals with ID and substance use problems independent and out of institutions of last resort (i.e., prisons), public health policy support is needed. Policy should incentivize research into the epidemiology, prevention, and treatment of substance use disorders among people with ID and identify means to remove or mitigate substance use problems in this population. In addition, policy makers should support programs to address the behavioral health needs and ongoing education about behavioral health issues of individuals with ID.

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Disclosures

None.

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