

**Title: Substance use among individuals with intellectual disabilities living independently in Flanders**

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## **Abstract**

*Background* Over the past decades, there has been increased scientific and clinical interest in substance use among individuals with intellectual disabilities (ID). Despite raised interest and awareness in the topic, lack of supportive data on prevalence and risk factors highlights the need for ongoing research. The aims of this cross-sectional multicenter study were to examine the nature and extent of substance use in individuals with ID living independently, to investigate group differences in substance use and related problems, and to explore the role of substance-related knowledge and attitudes in substance use behaviors.

*Method* Participants were 123 individuals with mild to moderate ID receiving support from independent living services. Data were gathered by means of a structured interview strategy (i.e. the Substance Use and Misuse in Intellectual Disability – Questionnaire; SumID-Q).

*Results* Findings revealed that rates of lifetime use of licit and illicit substances were higher than those found in earlier studies among individuals with ID and the general population. While cannabis use was the only illicit substance reported, current tobacco and alcohol use were shown to be highly prevalent (48% - 45.5%). Rates for the latter were similar to earlier studies among community samples of individuals with ID. In contrast to our hypotheses, few group differences in substance use behaviors were observed. Male gender was associated with age of onset of alcohol and tobacco use and tobacco use-related problems, while younger age was found to be associated with lifetime use of cannabis. No evidence was found regarding the role of knowledge; however, smokers and alcohol users rated tobacco and alcohol use more positively.

*Conclusion* This study demonstrated that individuals with ID living independently use a wide range of licit and illicit substances and present divergent levels and patterns of substance use. Notwithstanding the role of personal choice in substance use, more research is

needed to better understand the nature and extent of substance use and related problems, as well as the role of substance-related knowledge and attitudes in individuals with ID.

**Keywords:** Assessment, Independent living, Intellectual disability, Prevalence, Substance use

## **1. Introduction**

Living in the community has proven to be beneficial for individuals with intellectual disabilities (ID) in terms of self-determination, increased autonomy and independence, and opportunities for paid employment (Cocco & Harper, 2002). The transformation from institutionalized care towards community based living has, however, not been without its challenges (Sturme, Reyer, Lee, & Robek, 2003). Individuals with ID may be increasingly faced with stressors such as a lack of leisure and other social opportunities, as well as options for meaningful employment (Sturme et al., 2003). According to Scott and Haverkamp (2014), individuals with ID are likely to have fewer resources and adaptive skills to handle stressful events. For some individuals, increased exposure to community life has facilitated access to licit and illicit substances (Carroll Chapman & Wu, 2012; Pezzoni & Kouimtsidis, 2014; Taggart & Chaplin, 2014).

While substance use remains an under-researched topic in ID-literature (Van Duijvenbode et al., 2015), there is substantial evidence that individuals with ID use a wide variety of substances (VanDerNagel, Kiewik, Buitelaar, & De Jong, 2011a). Much of this research has portrayed substance use as a health-risk behavior and commonly emphasized individuals' vulnerabilities to and risks in engaging in these behaviors (Simpson, 2012). Although substance use behaviors in any population are often associated with significant adverse effects such as substance use-related, psychosocial and medical problems (VanDerNagel, Kemna, & Didden, 2013), studies often fail to acknowledge that substance use is not, by definition, problematic (Slayter, 2007). It is critical to recognize that the field of ID employs an approach to disability that encourages personal choice, inclusion, independence, equity and dignity (Luckasson & Schalock, 2015; Slayter & Steenrod, 2009), which highlights the importance of considering the basic fundamental right of all people to self-determination and respecting individuals' choices, including decisions about safe and appropriate substance use

(Slayter, 2007). Nevertheless, as with any other population, researchers and daily practitioners need to be able to detect the development of substance use-related problems and to provide adequate support and treatment attuned to the individuals' needs and choices (Slayter & Steenrod, 2009; To, Neiryneck, Vanderplasschen, Vanheule, & Vandeveldel, 2014).

While studies suggest that the prevalence of substance use in individuals with ID is lower as compared to the general population (Chaplin, Gilvarry, & Tsakanikos, 2011; McGillicuddy, 2006; Sturmey et al., 2003), individuals with ID are considered to be at increased risk of developing substance misuse and substance-related problems (McGillicuddy, 2006; McGillivray & Moore, 2001). Several studies state that individuals with ID may be more prone to these problems because of limited knowledge about the effects and possible risks associated with substance use and an increased likelihood of deficits in social skills and increased vulnerability regarding social influences (Miller & Whicher, 2013; Whitaker & Hughes, 2003). Other studies have underscored the influence of being male and an early age of onset of initial substance use for developing substance-related problems in this population (Cocco & Harper, 2002; Taggart, McLaughlin, Quinn, & Milligan, 2006). Male gender has also been identified as a risk factor for elevated levels of licit and illicit substance use (Chaplin et al., 2011; Robertson et al., 2000; Žunić-Pavlović, Pavlović, & Glumbić, 2013) and few studies have shown that poly-substance use and illicit substance use are more likely among younger individuals with ID (To et al., 2014; VanDerNagel et al., 2011a). Furthermore, previous studies on substance-related knowledge have indicated that while, overall, individuals with ID do have deficits regarding substance-related knowledge, there also appears to be a dissociation between substance-related knowledge and substance use, meaning that levels of knowledge were higher in individuals using substances compared to those who abstain from use (McGillivray & Moore, 2001; Taylor, Standen, Cutajar, Fox, & Wilson, 2004). In addition, Taylor et al. (2004) suggested that more health education is

needed for the group of substance users because, although their substance-related knowledge was higher, these individuals were less likely to express any concern about the risks. Furthermore, while only few studies have dealt with attitudes toward substance use, it is suggested that having a more negative attitude toward substance use can decrease actual use (Kiewik, VanDerNagel, Kemna, Engels, & De Jong, 2016).

There is, however, a pressing need for more extensive and detailed research to gain better insight into the extent and nature of substance use (problems) as well as to establish reliable (population-based) estimates (Carroll Chapman & Wu, 2012). Available studies are characterized by divergent methodological and practical challenges such as differences in operational definitions of substance use alongside with the scope of substance use (e.g. in- or exclusion of tobacco, (prescribed) medication and/or readily available substances such as inhalants), differences in the definition of ID (i.e. whether or not individuals with borderline intellectual functioning, IQ 70 – 85, are included), issues concerning the measurement of substance use (e.g. use of self- or informant-report), differences between and within countries, and variations across different subgroups (e.g. individuals supported by ID services or addiction treatment settings) (Taggart & Chaplin, 2014; Van Duijvenbode et al., 2015). These challenges have led to a wide range of estimates of licit and illicit substance use in this population. For instance, in a sample of 157 individuals with mild to profound ID living in a residential or family setting, McGuire, Daly, and Smyth (2007) identified 10.3% regular alcohol users, while VanDerNagel et al. (this issue) found 66.1% alcohol users in a sample of 112 individuals with mild to borderline ID who were clients of Dutch ID facilities. Studies of tobacco use in this population have found estimates ranging from 2.6% (McGuire et al., 2007) up to 36% (Steinberg, Heimlich, & Williams, 2009). Rates of illicit substance use vary between 1.5% and 13% (Carroll Chapman & Wu, 2012). In spite of a growing body of research, knowledge about the prevalence and risk factors of substance use among

individuals with ID remains limited (Van Duijvenbode et al., 2015) with many assumed factors as opposed to thoroughly reported evidence (Simpson, 2012).

The primary aim of this study was to investigate the extent and nature of substance use, substance-related knowledge and attitudes toward substance use in a sample of individuals with ID living independently in Flanders. Because previous studies have suggested gender and age differences in the prevalence and patterns of substance use among individuals with ID, this study also aims to examine the hypotheses that the prevalence of substance use is higher among men with ID and that a younger age is associated with higher levels of illicit substance use and poly-substance use. Furthermore, this study aims to explore the hypotheses that individuals who use substances have higher substance-related knowledge levels and that individuals who use substances have a more positive attitude toward substance use. In addition, we hypothesized that substance use-related problems are more prevalent among individuals with lower levels of substance-related knowledge, men with ID and individuals with a younger age of onset of substance use.

## **2. Method**

### *2.1. Participants and setting*

This study explored substance use among individuals with ID living independently in Flanders, the northern region of Belgium. Participants were eligible if they met the following criteria: (1) having an ID in accordance with the definition of the American Association on Intellectual and Developmental Disabilities (AAIDD; Schalock et al., 2010): (a) significant limitations in intellectual functioning (an intelligence quotient (IQ) of approximately 70 or below), (b) significant limitations in adaptive behavior as expressed in conceptual, social, and practical skills, and (c) onset before the age of eighteen; (2) being 18 years of age or older; and (3) living independently.



In Flanders, individuals with ID who live independently may apply to various professional systems of support, depending on required support intensity. In this study, Independent Living Services (ILS) were selected because they provide low-intensity community-based support to individuals with ID who live in their own home or rented house and who only need limited support in their daily life (Flemish Agency for Disabled Persons, 2007). A representative of the Flemish Agency for Disabled Persons stated that, in 2013, ILS in East-Flanders provided support to 754 individuals (J. Theunis, personal communication, October 25, 2015). In this study, 190 participants were initially included and 28 individuals who were asked to participate declined for divergent reasons (e.g. no interest, no time or not wanting to have anything to do with discussions about drinking or the use of other substances). Thirty-four completed interviews were omitted from analyses because they were conducted among individuals with borderline intellectual functioning (IQ above 70), which is not considered a diagnosis of ID in authoritative guidelines such as the Diagnostic and Statistical Manual of Mental Disorders V (DSM-V; American Psychiatric Association [APA], 2013). In addition, four interviews were excluded because the respondents had a normal to above average intellectual functioning and one interview was omitted because the respondent had a suspected ID. This resulted in 123 retained interviews (75.9%) among individuals with mild to moderate ID.

## *2.2. Procedure*

To recruit participants, the Federation of ILS, an umbrella organization unifying ILS across Flanders, was approached to set up a collaboration with all nine ILS located in East-Flanders, one of the five provinces in Flanders. Representatives of six ILS were presented with the aim and design of the study, while the remaining three organizations were contacted by e-mail. Eight ILS participated in the study. Seven ILS were located in a town with less than 50,000 inhabitants and one organization was located in a city with approximately

250,000 inhabitants. However, the eight ILS covered different districts in East-Flanders, ranging from less than 200,000, between 200,000 and 300,000 and over 500,000 inhabitants. Twenty-four professionals (i.e. direct support staff) from the participating organizations received training in the Substance Use and Misuse in Intellectual Disability-Questionnaire (SumID-Q; VanDerNagel, Kiewik, Van Dijk, De Jong, & Didden, 2011b) in order to gather the data. Individuals with ID were randomly assigned to the trained practitioners.

The participants were first approached by their caregivers, and received written and oral information about the purpose and procedure of the research. The authors provided an adapted, user-friendly informed consent. Written informed consent was obtained before interviews were initiated. Participants received a voucher worth €10 for a local supermarket as a financial compensation for their time invested.

This study was approved by the Ethics Committee of the Faculty of Psychology and Educational Sciences at Ghent University, in accordance with internationally accepted criteria for research (2014/35).

### *2.3. Instrument*

The professionals were trained by the third author of the SumID-Q (VanDerNagel et al., 2011b). The training consisted of one theoretical session on substance use among individuals with ID and the principles and administration procedures of the SumID-Q. Since the SumID-Q was developed in the Netherlands, a collaboration was arranged with the developers to make minor adjustments to the instrument in order to use it in the Flemish context (e.g. wording, type of employment and related daily activities, type of living arrangements). With regard to the validity of the instrument, preliminary results based on a Dutch study using biomarkers (i.e. analysis of hair, urine and plaster samples) revealed that the interview renders valid self-report data, but caregivers were less accurate in determining their clients' substance use (VanDerNagel et al., this issue).

The SumID-Q incorporates a self-report measure (i.e. an interview) and an informant-report measure (i.e. a questionnaire). In the questionnaire, informants (i.e. direct support staff) are asked to provide general demographic information of the participating individuals with ID they personally assist and to estimate these individuals' current substance use by answering "yes" or "no" to the question: "Does your client use tobacco/alcohol/cannabis/other illicit substances?". During the interview, self-reported substance use (i.e. tobacco, alcohol, cannabis and other illicit substances such as heroin, ecstasy and cocaine) is first assessed by asking participants about their lifetime use ("Have you ever used [substance]?"), which could be answered with "yes" or "no". Participants who reported ever having used the substances are asked to report the age at first use ("How old were you when you first used [substance]?"), past month use ("Did you use [substance] during the past month?") and substance use patterns ("Do you use [substance] most often alone or with others?"; "Do you use [substance] most often at home or elsewhere?"; "How much do you use [substance] each time?" (e.g. amount of cigarettes, standard units of alcohol). Alcohol consumption is measured as standard units of approximately 10 grams of alcohol (International Center for Alcohol Policies, 2016). Additionally, the SumID-Q measures the severity of alcohol use-related problems using the Alcohol Use Disorders Identification Test (AUDIT; Babor, Higgins-Biddle, Saunders, & Monteiro, 2001). Severity of tobacco use-related problems is assessed by asking the question "Have you ever experienced problems due to smoking?" and severity of cannabis and other illicit substances use-related problems by using the Drug Use Disorders Identification Test (DUDIT; Berman, Bergman, Palmstierna, & Schlyter, 2003). Following the guidelines of the SumID-Q, only participants who use or recently used (i.e. during the past month) alcohol, cannabis or other illicit substances are asked to complete the AUDIT and DUDIT. The level of knowledge about tobacco, alcohol and cannabis is assessed by 8 items for each substance (e.g. "Children

are allowed to buy tobacco.”) and participants’ attitude toward the use of these substances by 10 items for each substance (e.g. “Individuals who drink alcohol are cool.”). The items could be answered with “agree”, “neutral”, “disagree” or “do not know”.

#### 2.4. Analysis

To analyze the data, the Statistical Package for the Social Sciences 20 (SPSS 20) was used. Prior to data analysis, values were examined for inconsistencies, and the data set was checked for possible data entry errors and item non-response. Parameters for age groups were set ( $\leq 30$  years; 31-40; 41-50;  $\geq 51$ ) and several socio-demographic variables (e.g. employment or –related daily activities) were recoded into dummy variables. Responses were coded as yes (1) and no (0). Subscale scores were also calculated for the substance-related knowledge scales and substance-related attitude scales by aggregating the scores of the separate items according to the SumID-Q guidelines (VanDerNagel et al., 2011b). The AUDIT and DUDIT total scores were calculated. The results of the AUDIT were interpreted as follows: non-hazardous drinking (score  $< 8$ ), hazardous drinking (score 8-15), harmful drinking (score 16-19) or possible alcohol dependence (score  $\geq 20$ ; Babor et al., 2001). The internal consistency of the AUDIT was good ( $\alpha = .88$ ). The results of the DUDIT were interpreted using the guidelines by Berman et al. (2003): no indication of drug-related problems (score  $< 6$  for men; score  $< 2$  for women), drug-related problems (score 6-24 for men; score 2-24 for women) or possible drug dependence (score  $\geq 25$  for men and women). The internal consistency of the DUDIT could not be calculated because only two respondents completed this scale.

To determine if there were significant group differences, Mann-Whitney *U*-tests (for two groups) and Kruskal-Wallis tests (for  $\geq 3$  groups) were used for not normally distributed continuous data (i.e. age at first use, substance-related knowledge and attitudes scores), independent sample *t*-test for normally distributed continuous data (i.e. age) and  $\chi^2$ -tests or

Fisher's exact tests were used for categorical data (i.e. gender, level of ID, tobacco use-related problems, AUDIT categories, substance use patterns). A two-tailed test with  $p < .05$  was considered statistically significant. Where applicable, effect size (ES) statistics ( $r$ , *Cramer's V*, or *Phi*) were presented and interpreted as follows:  $< .30$  = small ES;  $\geq .30 - < .50$  = medium ES;  $\geq .50$  = large ES (Cohen, 1988). Agreement between self-report and proxy report for the measurement of current substance use (both self-reported and informant-reported substance use coded as 0 = no, 1 = yes) was assessed by percent agreement and Cohen's kappa ( $K$ ). Because percent agreement also includes agreement, which can be accounted for by chance Cohen's kappa was used as an estimate of agreement beyond chance. The kappa statistic estimates the amount of agreement that is independent of chance by comparing the observed agreement with the level of agreement expected by chance (Cohen, 1968). In this study, the kappa statistic was interpreted using the guidelines suggested by Landis and Koch (1977):  $< .21$  (poor agreement),  $.21 - .40$  (fair agreement),  $.41 - .60$  (moderate agreement),  $.61 - .80$  (good agreement) and  $> .80$  (very good agreement). The sample sizes presented in the results section may vary for some results depending on the applicability of the items and because of missing data. When the sample size on which the results were based differs from the total sample, absolute values were presented in the table or in the text. Furthermore, the general term 'current substance users' in the section client characteristics refers to the group of individuals who reported using at least one substance during the past month.

### **3. Results**

#### *3.1. Client characteristics*

An overview of the socio-demographic characteristics of the total sample ( $N = 123$ ) and of the group of current substance users ( $n = 83$ ) and the group of current non-users ( $n = 40$ )

is presented in Table 1. No significant differences were found between current substance users and non-users.

< Insert Table 1 >

### *3.2. Characteristics of substance use*

#### *3.2.1. Lifetime and current prevalence*

Table 2 displays the self-reported lifetime and current use of licit and illicit substances. Lifetime prevalence rates were highest for licit substance use (77.2% for tobacco; 92.7% for alcohol). Rates of lifetime illicit substance use (i.e. cannabis, cocaine, heroin, ecstasy, and speed) were the lowest for hallucinogens (0%) and ecstasy (0.8%), and the highest for cannabis (20.3%). About two-thirds of the total sample (67.5%) reported using licit and/or illicit substances during the past month. More specifically, past-month use of tobacco, alcohol and cannabis was reported by 48%, 45.5% and 1.6%, respectively. We hypothesized that male gender and a younger age would be associated with higher rates of substance use, but analyses revealed no significant gender or age differences in current use of any substance. With regard to lifetime use, there were also no gender differences, but a significant difference was found between age groups in lifetime use of cannabis. Analysis revealed that respondents who had ever used cannabis in their lives were more likely to be 30 years or younger ( $\chi^2(3, n = 72) = 11.63, p < .01, V = .40$ ).

< Insert Table 2 >

Almost two-thirds of the respondents had used tobacco (64.1%) and more than one-third had used alcohol (43.4%) or cannabis (48%) before the age of eighteen. With regard to age at first use of tobacco and alcohol (Table 3), male participants in this study were more likely to start using tobacco and alcohol at a younger age (mean rank tobacco = 38.69; mean rank alcohol = 43.98) than female participants (mean rank tobacco = 54.66; mean rank alcohol = 63.76). There was also a significant difference with small effect size between current alcohol

users and current non-users, suggesting that current alcohol users (mean rank = 47.58) as compared to current non-users (mean rank = 60.13) started using alcohol at a younger age. No significant differences were found between men and women, and between current users and non-users in terms of age at first use of cannabis and other illicit substances.

< Insert Table 3 >

### 3.2.2. *Informant-reported current prevalence*

Estimates from informants revealed similar current substance use rates. Direct support staff reported that tobacco, alcohol and cannabis were currently used by 50%, 47.9%, and .8% of the sample, respectively. The percentage of consistent responses (i.e. percent agreement) between self-reported and informant-reported substance use was 96.6% for tobacco use, 76.3% for alcohol use and 99.2% for cannabis use. The Kappa coefficient indicated very good agreement for tobacco use ( $K = .932$ ;  $SE = .033$ ;  $n = 118$ ), moderate agreement for alcohol use ( $K = .524$ ;  $SE = .078$ ;  $n = 118$ ) and good agreement for cannabis use ( $K = .663$ ;  $SE = .316$ ;  $n = 120$ ).

### 3.2.3. *Substance use patterns*

Overall, only using one substance was more frequent than poly-use: about one-third (32.5%) only used tobacco, just over one-fourth (28.9%) only used alcohol, just over one-third (36.2%) used tobacco and alcohol, and 2.4% used tobacco, alcohol and cannabis (Table 4). We expected to find that poly-use would be more prevalent in younger participants, but no significant age differences were found.

< Insert Table 4 >

Table 4 further shows the proportion and number of individuals in reference to frequency and circumstances of current substance use. The majority of smokers (94.9%) used tobacco on a daily basis or almost every day, and more than half of the current alcohol users (54.2%) consumed alcohol weekly. Daily alcohol consumption was reported by 14.6%. Cross-

comparison of the circumstances (i.e. location and with whom) in tobacco use and in alcohol use showed that just over one-fourth of the respondents (27.8%, 15/54) stated smoking alone at their own home most of the time, and that half of the respondents (50%, 28/56) reported drinking with others outside their own home most of the time. In addition, four respondents (7.1%) reported drinking alone in their own home most of the time. The two respondents, who reported cannabis use, both use it on a daily basis with others in their own home most of the time.

No information was available about quantity of tobacco use because of missing and inconsistent responses. With regard to alcohol use, the amount of standard units alcohol users generally consumed each time was:  $\leq 2$  (51.1%, 23/45), 3 or 4 (22.2%, 10/45), 5 or 6 (8.9%, 4/45), 7, 8 or 9 (4.4%, 2/45) or  $\geq 10$  (13.3%, 6/45). Analysis revealed no gender or age differences.

### 3.3. *Severity of substance use-related problems*

We hypothesized that substance use-related problems would be more likely among men with ID, individuals with ID with lower substance use-related knowledge levels and individuals who reported an early age of onset of substance use. Approximately one-third of the smokers reported ever having experienced tobacco use-related problems, and one-third of the current alcohol users had an AUDIT score that indicated alcohol use-related problems (Table 5). In this study, 17.8% (8/45) had a score that was consistent with hazardous drinking behavior (score 8 – 15), 4.4% (2/45) with harmful drinking behavior (score 16 – 19) and 11.1% (5/45) with alcohol dependence.

< Insert Table 5 >

Analysis showed that men with ID were more likely to report having experienced tobacco use-related problems at some point prior to the interview compared to women with ID ( $\chi^2$  (1,  $n = 59$ ) = 4.16,  $p < .05$ ,  $Phi = .27$ ), but no significant gender difference was found for the



AUDIT. There were also no significant differences for tobacco and alcohol use-related problems with regard to levels of substance use-related knowledge or age at first use.

The two respondents who currently used cannabis had a DUDIT total score of 21 and 25, indicating possible drug-related problems and possible drug dependency, respectively.

### *3.4. Substance-related knowledge*

The highest median substance-related knowledge score reported was with respect to tobacco, followed by alcohol and cannabis (Table 6). This study examined the hypothesis that individuals with ID who use substances have higher knowledge levels. No significant differences were found between current users and non-users. Further analyses of the individual items of the alcohol- and tobacco-related knowledge scales showed that both current users and non-users seem to be well aware of the legal implications and possible health risks associated with smoking and drinking alcohol. For example, the majority of the smokers (96.6%, 57/59) responded “yes” to the question “smoking is bad for your lungs” compared to all of the non-smokers ( $n = 62$ ), and the majority of the respondents in the group that uses alcohol (98.2%, 55/56) and all respondents of the group not using alcohol ( $n = 66$ ) reported that children are not allowed to buy alcohol. Concerning the possible consequences of alcohol use, three-fourths (75%, 42/56) of the group of current alcohol users and 87.9% (58/66) of the group of current non-users confirmed that if you drink a lot of alcohol, it might affect your memory. Respondents appear to be least knowledgeable about the effects and legal implications of cannabis use. For example, 87.1% (61/70) did not know that when eating ‘space cake’ it takes a while before it has an effect.

< Insert Table 6 >

### *3.5. Substance-related attitudes*

Rather low median scores were found for the three substance-related attitudes scales (Table 7). More specifically, participants reported the least positive attitudes toward cannabis

use, followed by tobacco and alcohol use. We expected to find that individuals with ID who use substances would rate substance use more positively. While analyses showed no statistical gender differences, there were significant differences between the mean ranks of current users and non-users of tobacco and alcohol, indicating that smokers (mean rank = 82.78) had a significantly more positive attitude toward tobacco use compared to non-smokers (mean rank = 40.27) and that current alcohol users (mean rank = 79.61) had a significantly more positive attitude toward alcohol use compared to current non-users (mean rank 46.14).

< Insert Table 7 >

#### **4. Discussion**

The primary objective of this study was to examine the nature and extent of substance use in individuals with ID living independently. Moreover, this study investigated group differences in substance use and related problems. It also explored the role of substance-related knowledge and attitude toward substance use in substance use behaviors.

The reported lifetime prevalence of licit and illicit substance use among 123 individuals with mild to moderate ID in this study was higher compared to previous studies among individuals with ID (e.g. Jobling & Cuskelly, 2006; Sturmey et al., 2003) and the general population in Flanders (Gisle, 2014a, 2014b, 2014c). Furthermore, current use of tobacco and alcohol was highly prevalent, yet similar to some previous studies involving community samples with ID (Carroll Chapman & Wu, 2012; Steinberg et al., 2009). Compared to the general population (Gisle, 2014c), rates of current tobacco use were considerably higher. Rates of current cannabis use, however, were lower compared to earlier studies among individuals with ID and the general population (e.g. Gisle, 2014b; McGillicuddy & Blane, 1999; VanDerNagel et al., 2011a). Interestingly, while studies have shown that alcohol is the most commonly used substance (Carroll Chapman & Wu, 2012), the proportion of smokers

in this study was slightly higher than the proportion of alcohol users. Although this study cannot provide conclusive explanations for this result, imitating the smoking behaviors of close others (Kalyva, 2007), level of tobacco dependence (Whitaker & Hughes, 2003), or having experienced a lack of advice and support in smoking cessation (Steinberg et al., 2009) could be possible explanations for the high rates of tobacco use. In addition, use of substances early in life has been shown to contribute to higher levels of use and misuse later in life (Griffin & Botvin, 2010). In line with the study by VanDerNagel et al. (this issue), tobacco was the first substance respondents in this study tended to use, followed by alcohol and illicit substances. This study, however, found no association between age at first use and current smoking behaviors. Additionally, a substantial proportion of participants used tobacco for the first time in early to late adolescence, which is comparable to earlier studies (e.g. Kiewik et al., 2016). Though not addressed in this study, parental and professionals' attitudes toward substance use and their substance use behaviors could play an important role in the onset of substance use (Jobling, 2001).

This study further examined the role of gender and age in substance use behaviors. In contrast with previous research (e.g. Chaplin et al., 2011; To et al., 2014), male gender and a younger age were not associated with higher levels of substance use. Although these variables did not correlate with higher use, it was noted that they did appear to have an influence on some substance use-related aspects. For example, while male gender was associated with a younger age of onset of tobacco and alcohol use, this study also found that lifetime use of cannabis was more likely in the youngest age group (< 30 years), which is similar to the findings of VanDerNagel et al. (2011a). With regard to substance use patterns, use of only one substance was more prevalent than poly-use, which was consistent with findings from the study conducted by Chaplin et al. (2011). In contrast with previous studies (e.g. To et al., 2014), this study found no evidence for the hypothesis that a younger age

would be associated with poly-use. In addition, the frequency of tobacco use and alcohol use reported in this study was comparable to earlier studies among individuals with ID (Hymowitz, Jaffe, Gupta, & Feuerman, 1997; McGillicuddy, 2006) and studies in the general population (Gisle, 2014a, 2014c). A noteworthy finding from the analysis was the identification of a small group of individuals who mostly consumed alcohol alone in their own home. Taggart, McLaughlin, Quinn, and McFarlane (2007) assumed that these individuals may drink as the result of problems in social relations and feelings of loneliness or isolation.

The role of substance-related knowledge and attitudes toward substance use in substance use behaviors was also examined as a part of this study. No evidence was found to confirm the assumption that the level of substance-related knowledge would be associated with substance use behaviors in this population. In line with previous research (e.g. Whitaker & Hughes, 2003), substance-related knowledge did not differ between current substance users and non-users, nor was there an association between substance-related knowledge and substance use-related problems. Although the lowest knowledge levels were reported in respect to cannabis use, in general, participants were well aware of the legal implications and health risks associated with tobacco and alcohol use, which is in line with the study by Caton et al. (2012). Jobling (2001) suggested that having an increased understanding of health might support individuals with ID in taking responsibility and control of their own health behaviors. However, while increasing the knowledge levels could be successful for some individuals, there still remains little evidence that the knowledge of health and other risks is a primary determinant of substance use behaviors (Simpson, 2012). In respect to substance-related attitudes, participants in this study did not appear to have positive attitudes toward substance use-related issues; however, significant differences were found between current

users and non-users of tobacco and alcohol, thus confirming the hypothesis that users rated substance use more positively.

This study also explored several group differences in respect to substance use-related problems. This study only found that male gender was associated with substance use-related problems (i.e. tobacco use-related), which is in line with previous research (e.g. Taggart et al., 2006). In respect to alcohol use, the majority did not report any signs of alcohol use-related problems. These results suggested that alcohol use in this population does not automatically imply problematic use. Drinking may perhaps be perceived by individuals with ID as key to social gatherings, and their cultural participation and social being in the community (Simpson, 2012). However, following the AUDIT guidelines (Babor et al., 2001), one-third of the current alcohol users (12.2% of the total sample) had an AUDIT score that indicated possible alcohol use-related problems. Consideration of substance use and related problems in ID services could provide important information for comprehensive physical and mental health assessment. In this respect, systematic screening for, and discussion of substance use with clients are important, as these are considered among the primary means to adequately support individuals with ID who are misusing substances (VanDerNagel et al., 2013). In addition, screening and discussion could also lead to increased awareness among clinicians (Chaplin et al., 2011), which is deemed important to address the challenge that substance use among this population often still remains undetected (Van Duijvenbode et al., 2015). In this study, the agreement between self-report and proxy-report was highest for tobacco, followed by alcohol and cannabis. Although tobacco use might often be more easily detected, professionals tend to underestimate clients' substance use (Van Duijvenbode et al., 2015).

This study has a number of strengths and limitations. Notwithstanding the cognitive and linguistic challenges in involving individuals with ID in research (VanDerNagel et al., 2013),

reliance on a self-report measure to assess substance use is a strength of this study. This measurement is highly valued within current literature because it helps to ensure that research truly reflects opinions and insights of the individuals themselves (Boland, Daly, & Staines, 2008; Taggart et al., 2007). In addition, this study is the first to focus on self-reported substance use among individuals with ID in Flanders.

Although several strengths have been identified within this study, a number of limitations should be taken into consideration. First, the results of this study must be interpreted with caution due to the relatively small sample. The limited sample size did not allow for a more detailed and thorough exploration of the relationships between substance use and different personal characteristics and environmental factors. A second limitation was that only participants with mild to moderate ID living independently in one province and known to ID services were included, which impedes the generalization of the findings. Future research could shed light on important differences in groups of individuals with ID by delineating the extent and nature of substance use among this population in different living arrangements. In addition, research could also focus on thorough and large scale comparisons with the general population. Third, the sections regarding cannabis and other illicit substances were only administered if the participant was familiar with the substance. Individuals could, for example, have refrained from openly discussing their substance use out of fear for negative consequences (Finlay & Lyons, 2002). The results may therefore be an underestimation of the true percentages of lifetime and current users of illicit substances. Fourth, while the AUDIT has been well-validated in different settings (Pezzoni & Kouimtsidis, 2014), there are no valid cut off scores for individuals with ID (Van Duijvenbode, Didden, Voogd, Korzilius, & Engels, 2012). In the literature, we also found no valid cut off scores for the DUDIT for individuals with ID. In addition, following the guidelines of the SumID-Q, the DUDIT was only completed by respondents who use or had recently used illicit drugs (i.e. during the past

month). The original DUDIT (Berman et al., 2003), however, uses a period of twelve months rather than one month. Fifth, while this study encompassed various licit and illicit substances, it did not include the non-medical use of prescribed medication or the use of readily available substances. Future research on substance use could widen the scope to the latter.

To conclude, substance use in individuals with ID living independently is a reality. This study has demonstrated that individuals with ID use a variety of licit and illicit substances and present divergent levels and patterns of substance use. In contrast to what was hypothesized, this study only demonstrated few differences between men and women and between younger and older individuals with regard to substance use and related issues. No association was found between substance-related knowledge and substance use behaviors either. However, individuals with ID who reported using tobacco or alcohol rated the use of these substances more positively. Notwithstanding the role of personal choice (Slayter, 2007), working on knowledge and countering positive attitudes toward substance use could be an interesting pathway to explore in preventing initiation of or decreasing actual substance use (Kiewik et al., 2016), and perhaps the development or exacerbation of substance use-related problems. In addition, it is critical that daily practitioners discuss substance use in an open and non-confrontational way and focus on outlining individuals' needs, vulnerabilities and choices (To et al., 2014; VanDerNagel et al., 2013). The results in this study further indicated the relevance of considering individualized strategies when clinicians aim to support them in making their own informed decisions; however, it remains difficult to provide population-based recommendations about fostering self-determination in individuals with ID regarding substance use (Slayter, 2007). Furthermore, the results on substance use-related problems call for awareness, since these problems may have serious consequences in various life domains such as work, relationships and physical well-being (Slayter & Steenrod, 2009). More research is warranted in order to better understand the nature and extent of substance use and

related problems, and the role of knowledge and attitudes in substance use in this population. In addition, future studies involving in-depth qualitative study designs could shed light on crucial elements pertaining to choice and decision-making in substance use, and reveal important experiences and reasons associated with initiating and continued use.

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**Table 1**

Socio-demographic characteristics for the total sample ( $N = 123$ ) and the groups of current substance users ( $n = 83$ ) and current non-users ( $n = 40$ ),  $N$  (%)

	Total	Users	Non-users	<i>p</i>
Mean age (SD), range <sup>a</sup>	45.3 (12), 22-77	45.2 (12.2), 22-74	45.5 (11.7), 23-77	.913
Gender				.333
Male	60 (48.8)	43 (51.8)	17 (42.5)	
Female	63	40	23	
Mean total IQ (SD), range <sup>b</sup>	59.7 (8.2), 35-71	59.8 (8.5), 35-70	59.5 (7.7), 43-71	.704
Level of intellectual disability				.056 <sup>c</sup>
Mild	111 (90.2)	78 (94)	33 (82.5)	
Moderate	12 (9.8)	5 (6)	7 (17.5)	
Household composition				.696 <sup>c</sup>
Alone	64 (52)	46 (55.4)	18 (45)	
With partner	24 (19.5)	16 (19.3)	8 (20)	
With partner and child(ren)	12 (9.8)	8 (9.6)	4 (10)	
One-parent family	8 (6.5)	5 (6)	3 (7.5)	
Other (e.g. siblings, friends)	15 (12.2)	8 (9.6)	7 (17.5)	
Employment (–related) daily activities				.611
Yes	76 (61.8)	50 (60.2)	26 (65)	

<sup>a</sup> Sample sizes for mean age: total ( $n = 121$ ), users ( $n = 81$ ) and non-users ( $n = 40$ )

<sup>b</sup> Sample sizes for mean total IQ: total ( $n = 77$ ), users ( $n = 48$ ) and non-users ( $n = 29$ )

<sup>c</sup> Fisher's exact test

**Table 2**Lifetime and current (past-month) prevalence of substance use for the total sample ( $N = 123$ ),  $N$  (%)

	Lifetime prevalence	Current use
Licit substances	117 (95.1)	83 (67.5)
Tobacco	95 (77.2)	59 (48)
Alcohol	114 (92.7)	56 (45.5)
Illicit substances	25 (20.3)	2 (1.6)
Cannabis	25 (20.3)*	2 (1.6)
Cocaine	9 (7.3)	0
Heroin	2 (1.6)	0
Hallucinogens	0	0
Ecstasy	1 (.8)	0
Speed	4 (3.3)	0

\* Significant difference across age groups;  $p < .01$

**Table 3**

Mann-Whitney analyses of age at first substance use across gender, and between groups of current users and current non-users

	Age at first use						
	<i>N</i>	Median (range)	Mean rank	<i>z</i>	<i>U</i>	<i>p</i>	<i>r</i> <sup>a</sup>
<b>Tobacco</b>							
Total	92	16 (7-44)					
Men – women	47 – 45	14 (7-30) – 17 (9-44)	38.69 – 54.66	-2.88	690.5	.004	-.30
Users – non-users	59 – 33	16 (7-44) – 17 (7-30)	43.26 – 52.29	-1.56	782.5	.119	
<b>Alcohol</b>							
Total	106	18 (6-52)					
Men – women	55 – 51	17 (6-40) – 19 (9-52)	43.98 – 63.76	-3.34	879	.001	-.32
Users – non-users	56 – 50	18 (6-30) – 18 (11-52)	47.58 – 60.13	-2.17	1068.5	.034	-.21
<b>Cannabis<sup>b</sup></b>							
Total	25	18 (11-48)					
Men – women	15 – 10	18 (11-48) – 18 (16-40)	12.57 – 13.65	-.36	68.5	.717	
Users – non-users	2 – 23	16 (13-19) – 18 (11-48)					
<b>Cocaine<sup>b</sup></b>							
Total	7	23 (17-45)					
Men – women	5 – 2	25 (17-45) – 17.5 (17-18)					
<b>Heroin<sup>b, c</sup></b>							
Men	2	17 (14-20)					
<b>Ecstasy<sup>b, c</sup></b>							
Men	1	18 (/)					
<b>Speed<sup>b, c</sup></b>							
Men	3	18 (14-23)					

<sup>a</sup> Effect size for the Mann-Whitney U-test calculated using the formula:  $r = z / \sqrt{N}$  and only presented when significant differences were found.

<sup>b</sup> No results are presented regarding between-group differences in mean rank when sample size in one or both subgroups was too small or equal to zero.

<sup>c</sup> *Total* not separately presented because no women reported on age at first use of these illicit substances.

**Table 4**  
Substance use patterns in current substance users, *N* (%)

	Tobacco <sup>a</sup>	Alcohol <sup>b</sup>	Cannabis <sup>c</sup>
Frequency			
Daily	48 (81.4)	7 (14.6)	2 (100)
Almost every day	8 (13.6)	1 (2.1)	0
Weekly	1 (1.7)	26 (54.2)	0
Monthly	2 (3.4)	11 (22.9)	0
Less than monthly	0	3 (6.3)	0
With whom			
Alone	24 (43.6)	7 (12.5)	0
With others	19 (34.5)	42 (75)	2 (100)
Both alone and with others	12 (21.8)	7 (12.5)	0
Location			
At home	32 (55.2)	15 (26.8)	2 (100)
Elsewhere	12 (20.7)	32 (57.1)	0
Both	14 (24.1)	9 (16.1)	0
Mono use <sup>d</sup> 51 (61.4)			
Only tobacco	27 (32.5)		
Only alcohol	24 (28.9)		
Poly use <sup>d</sup> 32 (38.6)			
Tobacco and alcohol	30 (36.2)		
Tobacco, alcohol and cannabis	2 (2.4)		

<sup>a</sup> Sample size: frequency ( $n = 59$ ), with whom ( $n = 55$ ) and location ( $n = 58$ )

<sup>b</sup> Sample size: frequency ( $n = 48$ ), with whom ( $n = 56$ ) and location ( $n = 56$ )

<sup>c</sup> Sample size: frequency ( $n = 48$ ), with whom ( $n = 56$ ) and location ( $n = 56$ )

<sup>d</sup> Based on current substance users ( $n = 83$ )

**Table 5**  
Tobacco and alcohol use-related problems, *N* (%)

	Total	Men	Women	<i>p</i>
Tobacco use-related problems <sup>a</sup>				.041
Yes	19 (32.2)	13 (44.8)	6 (20)	
AUDIT categories <sup>b</sup>				.776 <sup>c</sup>
Non-hazardous drinking	30 (66.7)	13 (59.1)	17 (73.9)	
Hazardous drinking	8 (17.8)	5 (22.7)	3 (13)	
Harmful drinking	2 (4.4)	1 (4.5)	1 (4.3)	
Alcohol dependence	5 (11.1)	3 (13.6)	2 (8.7)	

<sup>a</sup> Based on the group of current smokers (*n* = 59)

<sup>b</sup> Non-hazardous drinking (score < 8), hazardous drinking (score 8-15), harmful drinking (score 16-19) and possible alcohol dependence ( $\geq 20$ ); based on the group of current alcohol users that completed the AUDIT (*n* = 45)

<sup>c</sup> Fisher's exact test

**Table 6**

Mann-Whitney analyses of substance-related knowledge across gender, and between groups of current users and current non-users

	Knowledge score (/8)						
	<i>N</i>	Median (range)	Mean rank	<i>z</i>	<i>U</i>	<i>p</i>	<i>r</i> <sup>a</sup>
Tobacco							
Total	121	7 (4-8)					
Men – women	58 – 63	7 (4-8) – 7 (4-8)	61.39 – 60.37	-.222	1787	.824	
Users – non-users	59 – 62	7 (4-8) – 7 (4-8)	62 – 60.05	-.327	1770	.744	
Alcohol							
Total	122	5 (1-8)					
Men – women	59 – 63	5 (1-7) – 6 (2-8)	57.36 – 65.38	-1.298	1614	.194	
Users – non-users	56 – 66	5 (2-7) – 5.5 (1-8)	57.61 – 64.80	-1.161	1630	.246	
Cannabis							
Total	71	4 (1-7)					
Men – women	35 – 36	4 (2-7) – 4.5 (1-7)	35.91 – 36.08	-.036	627	.972	
Users – non-users <sup>b</sup>	69 – 2	6.5 (6-7) – 4 (1-7)					

<sup>a</sup> Effect size for the Mann-Whitney U-test calculated using the formula:  $r = z / \sqrt{N}$  and only presented when significant differences were found.

<sup>b</sup> Because the subgroup of cannabis users was too small ( $n = 2$ ) no comparison was made with the group of non-users.

**Table 7**

Mann-Whitney analyses of substance-related attitudes across gender, and between groups of current users and current non-users.

	Positive attitude score (/10)						
	<i>N</i>	Median (range)	Mean rank	<i>z</i>	<i>U</i>	<i>p</i>	<i>r</i> <sup>a</sup>
Tobacco							
Total	121	1 (0-9)					
Men – women	58 – 63	1 (0-9) – 1 (0-8)	63.60 – 58.60	-.804	1676	.421	
Users – non-users	59 – 62	3 (0-9) – 0 (0-4)	82.78 – 40.27	-6.838	544	.000	-.62
Alcohol							
Total	122	2 (0-9)					
Men – women	59 – 63	2 (0-9) – 2 (0-8)	63.64 – 59.49	-.659	1732	.51	
Users – non-users	56 – 66	3 (0-8) – 1 (0-9)	79.61 – 46.14	-5.295	834	.000	-.48
Cannabis							
Total	71	0 (0-6)					
Men – women	35 – 36	1 (0-6) – 0 (0-4)	39.46 – 32.64	-1.521	509	.128	
Users – non-users <sup>b</sup>	2 – 69	4.5 (4-5) – 0 (0-6)					

<sup>a</sup> Effect size for the Mann-Whitney U-test calculated using the formula:  $r = z / \sqrt{N}$  and only presented when significant differences were found.

<sup>b</sup> Because the subgroup of cannabis users was too small ( $n = 2$ ) no comparison was made with the group of non-users.

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