



Substance use and misuse in persons with intellectual disabilities (ID): Results of a survey in ID and addiction services in Flanders



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ABSTRACT

Little is known about the characteristics of substance users with intellectual disabilities (ID). Nevertheless, this group is assumed to be at greater risk of developing substance misuse problems. This study focuses on substance users and misusers with ID, and investigates whether the two groups differ significantly in terms of the nature and consequences of their substance (mis)use. Information regarding the characteristics of the substance (mis)users, the substances used, the negative consequences of substance (mis)use, and the service use was collected through a questionnaire forwarded to ID and addiction services in Flanders. Caregivers identified 104 substance users and misusers with ID. Overall, few differences were observed between users and misusers. This finding underscores that substance use in persons with ID can have important consequences. Substance misusers, however, were found to have more mood changes, more suicidal ideation/thoughts, and more negative long-term consequences on their health, daily activity, and relationships due to substance misuse. Substance use and misuse were associated with mental health problems and were suggested to be a risk factor for offending behavior. To provide appropriate support for this specific population, an individualized approach is suggested that supports better intersectoral collaboration between services.

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1. Introduction

In the last two decades, researchers and practitioners have shown an increasing interest in the prevalence, nature, and treatment of persons with an intellectual disability (ID) who misuse substances (Burgard, Donohue, Azrin, & Teichner, 2000; Chapman & Wu, 2012; Christian & Poling, 1997; Cocco & Harper, 2002; Degenhardt, 2000; Lance & Longo, 1997; Lottman, 1993; McGillicuddy, 2006; Mutsaert, Blekeman, & Schipper, 2007). This interest has become more prominent since the deinstitutionalization era, which has resulted in increased autonomy for people with ID in community living. Although it is undeniable that community living has many advantages for persons with ID (Van Gennep, 1997; Van Hove & van Loon, 2010; Young, 2006), community living may also cause negative consequences, such as increased stressful events and a greater

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exposure to alcohol and illicit drugs (Christian & Poling, 1997; Lottman, 1993). Eventually, this exposure can lead to substance misuse and other related problems (Burgard et al., 2000; Christian & Poling, 1997; Clarke & Wilson, 1999; Edgerton, 1986; Krishnef & DiNitto, 1981; Westermeyer, Phaobtang, & Neider, 1988).

Previous studies have indicated that persons with ID who use alcohol and/or illicit drugs seem to be at greater risk for developing substance misuse problems (Burgard et al., 2000; Degenhardt, 2000; Didden, Embregts, van der Toorn, & Laarhoven, 2009; Krishnef & DiNitto, 1981; McGillicuddy, 2006; Moore & Polsgrove, 1991; Slayter & Steenrod, 2009; Westermeyer, Kemp, & Nugent, 1996) and other negative consequences in several domains of functioning that are (in)directly related to substance (mis)use (Didden et al., 2009; Krishnef & DiNitto, 1981; McGillivray & Moore, 2001; Taggart, McLaughlin, Quinn, & Milligan, 2006; Westermeyer et al., 1988). For example, Westermeyer et al. (1996) indicated that persons with ID appear to have a remarkably low tolerance for alcohol, which becomes apparent in marked changes in behavior or personality after only two or three alcoholic drinks. These findings suggest a blurred line between substance use and misuse in persons with ID. A better understanding of the nature of substance use and misuse in persons with ID and, more importantly, of its negative impact on this specific population is a necessary step toward supporting these vulnerable persons. Such an understanding is especially important because this group is often deprived from treatment and falls through the cracks between services. Mainstream addiction and ID services often lack the appropriate resources to identify and treat this specific population (Degenhardt, 2000; Lance & Longo, 1997; Lottman, 1993; McGillicuddy, 2006; Ruf, 1999; Slayter & Steenrod, 2009; Sturmey, Reyer, Lee, & Robek, 2003; Taggart, Huxley, & Baker, 2008; Tyas & Rush, 1991; VanderNagel, Kiewik, Buitelaar, & Dejong, 2011). Compared with substance misusers without ID, persons with ID are less likely to receive treatment or to remain in treatment once started (Chapman & Wu, 2012).

In this context, Taggart et al. (2006) conducted a survey on substance misuse in persons with ID in both ID and addiction services in Northern Ireland. Questionnaires were forwarded through the managers of ID and addiction services to their team. Team members who had a person on their caseload with ID that was misusing substances were questioned about this person's characteristics, substance misuse, and how it affected his/her well-being to identify the types of services and supports required to meet the heterogeneous needs of this population. The study identified 67 adults with ID who were misusing substances. Alcohol was the main substance of misuse. Three-quarters of the sample misused alcohol for more than 5 years. Being male and young, having a borderline/mild ID, living independently, and having mental health problems were reported to be risk factors. Substance misuse was frequently associated with a range of distressing negative behaviors, which resulted in substantial problems.

However, the study by Taggart and his colleagues only examined a sample of substance misusers, leaving the larger group of substance users unexplored. Consequently, a question that remains unanswered is whether substance misuse places people with ID at risk for adverse effects on wellbeing and negative (mental) health outcomes or whether substance use in general entails similar problems.

Therefore, the current study aims to characterize the nature and consequences of substance use in a sample of substance users and misusers with ID known to ID or addiction services. In addition, the study aims to provide information regarding the service utilization of these specific groups of people with ID.

2. Method

2.1. Setting and participants

This research was conducted in Flanders, the northern part of Belgium. The new support policy for persons with ID set out by the Flemish Ministry of Public Welfare and Public Health, named Perspective 2020, focuses on the citizenship model and person-centered support for persons with multiple problems, advocating intersectoral collaboration between various services in different fields, including special education, mental health, addiction and ID. Therefore, the Flemish situation lends itself well to an analysis of needs, service use, and intersectoral collaborations for the group of substance users and misusers with ID.

Based on the methodology used by Taggart et al. (2006), the present study investigated the perspectives of caregivers in ID and addiction services about their adult client with ID who uses or misuses substances. To identify all addiction services in Flanders, a collaboration with the Regional Board on Mental Health Care of East-Flanders (PopovGGZ) was set up to contact all Regional Boards on Mental Health Care in Flanders to provide the contact information of each addiction service within their region. Intellectual disability services were approached by consulting the website of the Flemish agency for persons with a disability (<http://www.vaph.be>), where the contact information of all disability services in Flanders is published.

All of the identified ID and addiction services in Flanders were sent an e-mail that explained the aim and nature of the study and included a link to an online questionnaire. The contact person in each of the identified ID and addiction services was further asked to spread the e-mail including the link to the online questionnaire to the caregivers in their service, if they agreed to participate in the study. The anonymous caregivers, who received this e-mail through the contact person of the service, were asked to complete the online questionnaire anonymously if they had an adult with ID in their caseload that was using substances on a regular basis. They were asked to report anonymous information about their client by means of the questionnaire. Criteria to participate in the study were as follows: (1) client is aged 18 years or older, (2) client has an intellectual disability as defined by the definition of the American Association of Intellectual and Developmental Disabilities (2013), namely “intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in

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