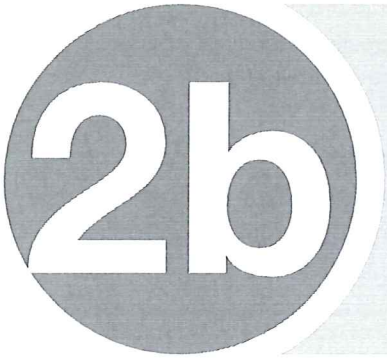

Adapting Substance use disorder Treatment for Individuals with (Mild) Intellectual Disabilities: a systematic review on obstacles and opinions

Unpublished paper

INTRODUCTION

While there is an optimism in the field that the pace of epidemiological research is quickening, there has been a bias toward research in interventional approaches (Moore & Polsgrove, 1991). Little is known about interventions for SUD in people with intellectual disabilities (ID) (McGillicuddy, 2006; Slayter, 2007; Slayter, 2010a; Westermeyer, Phaobtang & Neider, 1988). This group is typically denied access to the full range of available services, including prevention, (early) intervention and aftercare (Slayter, 2011). It is likely that individuals with ID are not receiving the services most appropriate for them (McGillycuddy, 2006; VanDerNagel, Kiewik, Postel, van Dijk, Didden, Buitelaar & de Jong, 2014). Specialized treatment programs are scarce and hardly any of these programs are evidence-based (Cocco & Harper, 2002; Huxley, Copello & Day, 2005; Kerr, Lawrence, Darbyshire, Middleton & Fitzsimmons, 2013; Westermeyer, Kemp & Nugent, 1996).

Moreover, the general absence of SUD treatment providers for those with intellectual disabilities could be a barrier to receive the appropriate service (Bachman, Drainoni & Tobias, 2003). When persons with ID are admitted to substance treatment programs they are often unable to benefit from general procedures, due to their limited vocabularies, poor development of memories necessary to retain information, and difficulties discriminating between relevant and irrelevant information (Burgard, Donohue, Azrin & Teichner, 2000; Christian & Poling, 1997; Degenhardt, 2000). In addition, persons with ID experience often problems with planning and attention (Barret & Paschos, 2006) and impaired abstract reasoning and decreased insight. Group-based programs are generally difficult to follow for people with ID because it is often too abstract, proceeds at too fast a pace or require adequate social skills (Campbell, Essex & Held, 1994). Therefore, a great need exists for more effective treatment strategies designed for people with ID.

The purpose of this study is to review the literature for obstacles for providing treatment for persons with ID, and the opinions of authors regarding the adaptations of existing treatment programs.

METHODS

Literature searches on the Internet, in Pubmed and Eric were performed in January and February 2015. Various combinations of key words and Boolean Operators were used: addiction OR alcoholism OR ((substance OR alcohol OR drugs) AND (abuse OR misuse OR problem)) AND (treatment OR intervention OR therapy) AND ((intel-

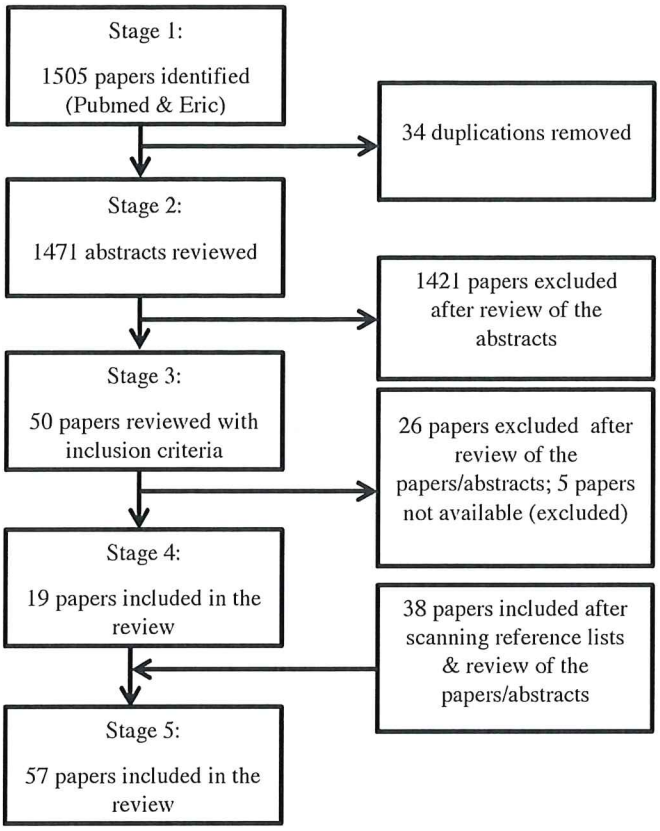

Figure 1. Search results and selection of papers

The first study described a group format and several methods, including in-vivo sessions in a local pub, the use of various video clips, role plays to refuse alcohol, and brainstorming on various topics and magazine advertising clips (McCusker, 1993). Five participants attended the group. Follow-up evaluations suggested positive changes in attitudes, alcohol-related knowledge and more appropriate drinking skills, although the sample size was small and biased. Another limitation is that they did not use a post-group assessment of alcohol consumption. As a result, it remains unclear if this approach leads to behavioral change in persons with ID. In another study, 84 participants were randomly assigned to receive a prevention program in either assertiveness building, modelling and social inference, or a delayed treatment wait-list control, and control condition. Results suggest that each program improved at least short-term substance knowledge and enhanced skills. However, substance use did not reduced (McGillicuddy & Blane, 1999). In the next study, five participants followed an alcohol awareness program (Forbat, 1999). This program consisted of eight sessions, focusing

on education of safe drinking and techniques for refusing alcoholic drinks. All participants had a higher level of alcohol-related knowledge immediately after the program and during the six months follow-up. However, the study did not measure behavioral change, so the effect on alcohol consumption remains unknown. Another study uses motivational techniques that can be applied to persons with ID (Mendel & Hipkins, 2002). The facilitators of the group used more interactive presentation techniques with small group exercises and visualizations to illustrate different themes. All seven participants attended the three group sessions. The results showed that the motivation of six participants and the self-efficacy of five participants increased. This study, however, did not measure actual alcohol use since the participants had restricted access to the community due to legal requirements. The next study (McMurran & Lismore, 1993) described a brief intervention which includes the use of a video-taped problem drinker to whom two clients were asked to give advice. Although clients were able to suggest more specific strategies for behaviour change after viewing the video, their own actual use wasn't measured. In the last study (Lindsay, McPherson & Kelman, 1998), 23 participants were included divided in smaller groups. The program made use of active teaching, specially-designed materials and comprised eight sessions for groups of approximately six persons. The program resulted in significantly increases of factual knowledge which had been maintained at three-months follow-up. No attempt was made to assess any changes in the participants behaviour.

Five studies focused solely on alcohol-abusing persons with ID (McCusker et al., 1993; Forbat, 1999; Mendel & Hipkins, 2002; McMurran & Lismore, 1993; Lindsay et al., 1998). Only McGillicuddy & Blane (1999) described an intervention for persons with ID for alcohol and other substance problems. The six studies included a total of 149 persons with ID. From the six studies, two were RCT's (Lindsay et al., 1998; McGillicuddy & Blane, 1999). The overall conclusion of these studies are that the substance related knowledge increased, but fails to impact substance-related attitudes, intention or substance use itself. The interventions are often short and fail to meet the needs of the complex nature of SUD.

Qualitative analysis

The results of our qualitative study showed five different barrier domains: barriers due to the characteristics of persons with ID, access barriers, service related barriers, treatment related barriers and barriers not otherwise specified.

The first barrier is that persons with ID may have great difficulty generalizing skills acquired in one setting to other, more unstructured environments and persons with ID are perceived as more difficult to treat due to expressive and language deficits

There are several opinions about the adaptation of treatment for persons with ID to improve the feasibility and efficacy. Four domains were identified: opinions regarding the adaptation of materials used in treatment facilities; procedural changes of the treatment itself; the need of involving significant others and other additional adaptations not directly focused on the content or procedure of the treatment.

Firstly, the content of treatment for substance misuse could be adapted in order to serve persons with ID. Easily understood educational materials, with visual components e.g. photos/illustrations (Watson, Franklin, Ingram & Eilenberg, 1998) or the use of video feedback (McMurran & Lismore, 1993), could help people with ID to make their own informed decision about drinking alcoholic beverages (Forbat, 1999; Clarke & Wilson, 1999; DiNitto & Krishef, 1983).

Secondly, according to Krishef & DiNitto (1981) it is recommended that several procedural changes of substance misuse treatment programs should be made to improve services for people with ID, including extension of the length or duration of treatment, use of more behavioral techniques and modification of motivational interviewing techniques (Frielink & Embregts, 2013) and more individual counselling in place of group counselling. Furthermore, Chaplin, Gilvarry and Tsakanikos (2011) suggested that careful assessment of substance use in specialist services for ID could lead to improved long-term clinical outcomes. VanDuijvenbode et al. (2015) recommended a stepped care implementation, to match the intensity of the intervention to the severity of SUD. In addition, treatment components should contain elements of relaxation training, attention to cognitive distortions (e.g. expectations about the consequences of using alcohol and/or drugs), increasing motivation to reduce or quit substance use (VanDuijvenbode et al., 2015; Didden, Embregts, Van der Toorn & Laarhoven, 2009) and improving social skills (McCusker, Clare, Cullen & Reep, 1993). Behaviors have to been trained with the client to successfully diverts himself when feeling tensed or angry, because intense negative emotions could increase the risk of relapse after a period of abstinence. It has been advocated (Degenhardt, 2000) to aim for abstinence rather than controlled drinking, since the first involves just one goal ("not drinking") instead of a set of rules about when or what to drink (e.g. which occasions) and how much to drink.

Thirdly, staff support of ID services appeared to be an important part of the process, in terms of facilitating the client's learning by explaining and exploring, appropriate support in completing the assignments during program sessions, acting as positive role models for their clients by reflecting on their own attitudes to alcohol and reinforcing the attendance of the program (Barrett & Paschos, 2006). Staff training on the other

be educated about the specific risks and pitfalls of this approach and target group. Teams must be coached to avoid demoralization. Collaboration with addiction treatment facility is essential in order to anticipate quickly on the various needs of clients. Unconditional support to the client, rather than the deferral from setting to setting, is crucial for the motivation for change. It has become clear that studies examining treatment of substance misuse in people with ID are only beginning to emerge. Further research to evaluate the efficacy of any interventions in this field would be of great help in the service for people with ID and substance misuse.

Frielink, N., & Embregts P. (2013). Modification of motivational interviewing for use with people with mild intellectual disability and challenging behaviour. *Journal of Intellectual and Developmental Disability, 38,* 279–291.

Huxley, A., Copello, A., & Day, E. (2005). Substance misuse and the need for integrated services. *Learning Disability Practice, 6*, 14-17.

Kerr, S., Lawrence, M., Darbyshire, C., Middleton, A. R., & Fitzsimmons, L. (2013). Tobacco and alcohol-related interventions for people with mild/moderate intellectual disabilities: A systematic review of the literature. *Journal of Intellectual Disability Research, 57*, 393–408.

Krishef, C. H. (1986). Do the mentally retarded drink? A study of their alcohol usage. *Journal of Alcohol and Drug Education, 31,* 64 – 70.

Krishef, C. H., & DiNitto, D. M. (1981). Alcohol abuse among mentally retarded individuals. *Mental Retardation, 19 (4)*, 151-155.

Kuckartz, U. (2007). MAXQDA 2007 Reference Manual MAX qualitative data analysis for Windows 2000 and XP.

Lindsay, W. R., McPherson, F. M., & Kelman, L. V. (1998). Health promotion and People with Learning Disabilities: The Design and Evaluation of Three Programmes. *Health Bulletin, 56,* 694-698.

Lottman, T. J. (1993). Access to generic Substance Abuse Services for Persons with Mental Retardation. *Journal of alcohol and drug education, 39 (1)*, 41-55.

McCusker, C. G., Clare, I. C. H., Cullen, C., & Reep, J. (1993). Alcohol-related knowledge and attitudes in people with a mild learning disability – the effects of a 'sensible drinking' group. *Journal of Community & Applied Social Psychology, 3 (1)*, 29-40.

McGillicuddy, N. B. (2006). A review of substance use research among those with mental retardation. *Mental Retardation & Developmental Disabilities Research Reviews, 12 (1)*, 41-47.

McGillicuddy, N. B., & Blane, H. T. (1999). Substance use in individuals with mental retardation. *Addictive Behaviors, 24 (6)*, 869-878.

McGillivray, J. A., & Moore, M. R. (2001). Substance use by offenders with mild intellectual disability. *Journal of Intellectual & Developmental Disability, 26 (4)*, 297-310.

McLaughlin, D. F., Taggart, L., Quinn, B., & Milligan, V. (2007). The experiences of professionals who care for people with intellectual disability who have substance-related problems. *Journal of Substance Use, 12,* 133–143.

McMurran, M., & Lismore, K. (1993). Using video-tapes in alcohol interventions for people with learning disabilities: An exploratory study. *Mental Handicap, 31*, 29-31.

Mendel, E., & Hipkins, J. (2002). Motivating learning disabled offenders with alcohol-related problems: a pilot study. *British Journal of Learning Disabilities, 30 (4)*, 153-158.

Moore, D., & Lorber, C. (2004). Clinical characteristics and staff training needs of two substance use disorder treatment programs specialized for persons with disabilities. *Journal of Teaching in the Addictions, 3 (1)*, 3-20.

Moore, D., & Polsgrove, L. (1991). Disabilities, developmental handicaps and substance misuse: a review. *The International Journal of the Addictions, 26 (1),* 65-90.

Paxon, J. E. (1995). Relapse prevention for individuals with developmental disabilities, borderline intellectual functioning, or illiteracy. *Journal of Psychoactive Drugs, 27 (2)*, 167-172.