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**The experiences of professionals who care for people with intellectual disabilities who have
substance related problems**

Mc Laughlin, D., Taggart, L., Quinn, B. & Milligan, V.

School of Nursing, University of Ulster, Northern Ireland

Correspondence:

Dr Derek McLaughlin, Room 12J13, School of Nursing, University of Ulster, Shore Road,
Newtownabbey, Co. Antrim, BT37 OQB, Northern Ireland.

Tel: 028 90368113, Fax: 028 90368202, E-mail: DF.McLaughlin@ulster.ac.uk

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Abstract

More people with intellectual disability are living independent lives. They can and do experiment with substances that the wider community try, such as alcohol and drugs (both legal and illicit). Unfortunately for some, they develop problems related to their use of these substances. Face-to-face, semi structured interviews were conducted with thirteen professionals who work in Intellectual Disability Services and Alcohol & Drug Services to discover their experiences of caring for people with intellectual disabilities who hazardously use substances.

Although small numbers of people presented to these services, many more people with intellectual disabilities used Intellectual Disability Services for support rather than their local Alcohol & Drug Services. While the numbers may be relatively small, the challenges this client group pose are very perturbing in relation to their physical, emotional and social health. These professionals reported a lack of education in working with this doubly disadvantaged population, therefore neither group of professionals were adequately equipped to provide effective care for these individuals. Moreover, policies and procedures are absent to guide staff to work collaboratively with this often ignored population.

These findings are discussed in light of the innovative practices that are occurring in other parts of the UK regarding the recognition, assessment treatment and long-term management of this population. Intellectual Disability Services and Alcohol & Drug Services need to work more closely together if the needs of this population are to be effectively met.

Keywords: intellectual disability, alcohol and drugs, substance problems, services, integrated models

Introduction

People with intellectual disabilities can and do use a range of substances which include alcohol, illicit drugs and take prescribed medications contrary to advice, although at a lower rate compared to the non-disabled population (Sturme y et al., 2003, Emerson & Turnbull, 2005). There is a range of reasons for this hazardous use of substances and they appear to be comparable to those cited for their non-disabled peers (Degenhardt, 2000, Banerjee et al., 2002). In a recent study of 67 people with intellectual disabilities who were reported to be hazardously using substances, the majority had a borderline / mild cognitive impairment and were more likely to live either alone or in less supervised accommodation (Taggart et al., submitted, a).

The impact of such alcohol and drug consumption can also be similar to that described for their non-disabled peers: poorer physical and mental health, exploitation, offending behaviour and greater likelihood of being admitted to hospital (Mc Gillivray & Moore, 2001; Banerjee et al., 2002; Sturme y et al., 2003; Taggart et al., submitted, a, b). Although the causes and impact may be similar between these two populations, when it comes to receiving help/support the similarities end here. In reviewing the literature on such services for people with intellectual disabilities who experience substance problems, the needs of this population have rarely been addressed (Tyas & Rush, 1993, Christian & Poling, 1997, Lance & Longo, 1997, Sturme y et al., 2003, Huxley et al., 2005).

Some Alcohol and Drug Services (A&DS) have totally excluded people with intellectual disabilities believing that the type of services they provided would be ineffective in meeting the needs of this population. The main reason given is a lack of staff knowledge in this area (Lottman, 1993, Manthrope, 1997, Degenhardt, 2000, ARAC, 2002, Sturme y et al., 2003). On the other hand, some staff working within Intellectual Disability Service (IDS), struggle to manage this population claiming a lack of insight regarding the assessment, treatment and management of substance

problems. More recently the Merton Drug Action Team (ARAC, 2002) and the Wandsworth Drug Action Team (2003), in the South of England, both reported that IDS had no identified strategies regarding inter-agency working and joint care planning for this population with their colleagues in the A&DS. As a consequence of such fragmented and uncoordinated services, many people with intellectual disabilities who have substance related problems, continue to ‘fall through the cracks’ in both services.

The aims of this study were twofold: firstly to obtain the experiences and perceptions of staff working in both IDS and A&DS who care for this doubly disadvantaged population, and secondly, to examine staff views on how the needs of this group of people could be better met. This information would allow service providers, across both IDS and A&DS, to develop and implement appropriate services in order to effectively address the complex needs of this population: a population whose needs have mainly gone undetected. The findings of this study will enable managers to provide the necessary education / training for staff working in both service settings, and will also identify how effective joint working of both IDS and A&DS can be successfully achieved.

Method

Northern Ireland has eleven Community Health and Social Service Trusts. Each of these Trusts has six programmes of care: one is for people with intellectual disabilities while people with substance problems are cared for under the mental health programme.

This study employed a series of semi-structured interviews with a total of thirteen front-line professionals who voluntarily agreed to take part in this study. These professionals were working in both IDS and A&DS across Northern Ireland. The professionals were identified from an earlier paper that explored substance problems in people with intellectual disabilities (Taggart et al., submitted, a). Within this earlier study, 54 community informants such as social workers, community nurses or 'dual diagnosis' workers, across IDS and A&DS completed a questionnaire on a person(s) on their caseload who were deemed to be experiencing problems relating to their use of substances based upon DSM-4 criterion.

Professionals

In total thirteen health professionals took part in this study. There were eight staff from the IDS and five staff from A&DS. These staff included community intellectual disability nurses, intellectual disability social workers, community mental health nurses (from A&DS) and 'dual diagnosis' workers, that is mental health disorders and co-existing substance related problems. All these professionals were currently supporting at least one person on their caseload with an intellectual disability and substance related problems. All were agreeable to take part in this study.

Procedure

As identified earlier (Taggart et al., submitted, a) all the professionals had completed a questionnaire(s) on a person with an intellectual disability and substance related problems. From these records, letters were forwarded to each of these community informants explaining the purpose

and nature of this project. In total thirteen community informants responded out of a total number of 54 potential participants. While the number agreeing to be interviewed was low, a number of explanations may account for this response. Some staff may not perceive this population to be a priority while other staff may not have responded due to significant workload pressures and/or did not want to be interviewed.

The interviews followed structures that were developed from themes identified in two earlier studies that had been recently undertaken in Northern Ireland (Taggart et al., submitted a, b) and the available literature (ARAC, 2002, Wandsworth Drug Action Team, 2003, Sturmev et al., 2003).

There were six broad areas that were identified to generate discussion, these were:

- The size, nature and cause of the problem
- The assessment and treatment of this population
- Skills and knowledge
- Interagency working and availability of policies
- Prevention strategies
- The way forward

The research team contacted each of the professionals and arranged a date, time and location for the interview, which was suitable for the professional. After initial greetings the lead researcher read out an introductory statement regarding the purpose and nature of the study further, explaining how the interviews were to be audio-taped, and reassuring confidentiality and that this data would be destroyed after a report had been written. All the professionals provided written consent. The interviews lasted on average between 30-40 minutes.

Ethical Issues

Ethical approval was obtained from the Health and Personal Social Services Research Ethics Committee for Northern Ireland (2004). Informed written consent was obtained from each professional prior to interview. Each professional was assured of confidentiality, no identifiable information about the professionals was used and the respondents were informed that the tape recordings would be destroyed at the completion of the study.

Data Analysis

After completion of the semi-structured interviews, the audio-tapes were listened to on a number of occasions, they were transcribed verbatim and read and re-read to gain meaning and understanding from the data. The above themes were used as a template for content analysis, which is a recognised and accepted practice in qualitative research (Krueger, 1998). The first and second researchers carried out this task separately then met to discuss and compare their findings, they agreed the following results. Saturation was met during this study, when the researchers realised they could not identify any new themes or information to have emerged from the most recent interviews.

Findings

The size, nature and cause of the problem

All the informants reported that alcohol was the main substance that was used; and for a small number of people with intellectual disabilities they also used illicit substances such as cannabis and ecstasy and some also over-used prescribed medications such as diazepam contra to advice.

Although the numbers of individuals the professionals reported were in their single figures, variation was also found to occur between service settings with more people using IDS compared to the lower number that used A&DS. Similar results were reported by Taggart et al. (submitted, a) where 63 people with intellectual disabilities were in contact with IDS whereas 4 people were in receipt of services from the A&DS.

Moreover, one professional who worked within IDS highlighted that prevalence rates might even be higher, particularly given the numbers of users with borderline / mild intellectual disabilities who are not known to services. Furthermore, some professionals in A&DS also queried whether the service users they were in contact with had an intellectual disability:

“Well in my experience to date I have only met one...but I know other colleagues who have had several people and some clients we were not sure about whether they had a intellectual disability or not” (Professional 9, A&DS)

“..... the real size of the problem might not really be known as there are many people (persons with intellectual disabilities) in the community who we do not know.” (Professional 10, IDS)

Despite the numbers in contact with both IDS and A&DS reported to be low, the impact of this populations behaviours upon the persons' well-being is reported to be a serious worry for staff. This theme of *'vulnerability'* was a recurrent topic reported by many of the professionals, *'aggression'*, *'psychological trauma'*, *'sexual and financial exploitation'* by non-disabled peers, *'self-harming / over-dosing'*, *'getting involved with the police'* and *'loss of structure in the person's day'* were sub-themes cited by many of the professionals working within both IDS and A&DS.

The professionals reported a range of reasons as to why this population has used substances: these ranged from *'loneliness'*, *'their wish to fit in'*, *'learnt behaviour'* and *'the social context of their lives'*. The following quotes highlight some of these issues:

“Loneliness; the majority of people you are talking about have mild intellectual disabilities who are living alone and are terribly lonely.” (Professional 11, IDS)

“Again a lot of physical problems, maybe presenting to causality, overdosing, self harming, just self neglect again, one or two of them are very vulnerable and I feel that a lot of them have maybe exploited, financially and query sexually.” (Professional 3, A&DS)

“Well in the first instance, the first fella he lost his job, got involved with the police appeared in court and as I say he was involved in anti-social behaviour so there was paramilitary involvement as well. The second fella again lost his place in the day centre, admission to hospital, he became very aggressive regularly and went practically looking for beatings, it got so severe that his mum put his photograph, name and address in the (names hospital) causality because he was there so many times, so that they contacted her straight away.” (Professional 13, IDS)

The assessment and treatment of this population

When the A&DS professionals were asked how they had assessed the person with intellectual disabilities, they all reported that they used their standardised assessment schedule. This is the same assessment framework that they would employ with a person without a disability. Many of the professionals working within A&DS reported that the only real change in this assessment schedule was their language, using simpler words.

However, for the professionals working within IDS, the respondents reported using no specific alcohol / drug assessment schedule or framework. For many of these professionals it appears that there has been no formal assessment of the persons’ substance patterns including the persons’ motivation for such usage. Nevertheless, some of the professionals indicated the importance of developing a therapeutic rapport with their client rather than relying upon a formal assessment structure that examined their alcohol / drug patterns in an attempt to assess the persons’ situation.

For the professional working within the IDS, the majority of the respondents reported that because of limited knowledge and a lack of training, they could offer little in way of any evidence-based interventions. The core functions of IDS staff appeared to be supporting the person within their own environment, wherever possible, and referral to A&DS. One professional from IDS had begun to use a harm minimisation approach in an attempt to reduce the potential damage that a client may be placing himself in when hazardously using alcohol. This quote illustrates this:

“I made him up a wallet because when he had a lot of drink in him he couldn’t get his way home, his communication skills weren’t great. So I made him up a wallet to say who he was, where he lived that he had an intellectual disability and that his mum would pay the fare when he got him home.” (Professional 13, IDS)

When it came to the issue of the types of therapeutic interventions employed with this population, the A&DS professionals reported that their approach was no different than the interventions used with the non-disabled population, using a range of recognised interventions. The majority of these professionals reported that it can take longer to complete the intervention period and staff have to be resourceful in how such interventions were employed. More striking, these professionals also reported that for many people with intellectual disabilities who were referred to them, they were unable to successfully engage with these individuals as a result of their *‘lack of willingness’* to participate in educational / group sessions. Overall, a strong theme that emerged from the A&DS professionals was that they all agreed that their services did not effectively address the needs of this population. For example:

“...the type of service we provide isn’t particularly well geared up for people with intellectual disabilities...” (Professional 12, A&DS)

Unfortunately, the approach adopted by some A&DS professionals had the side-effect of treating the adult with an intellectual disability as a child as the next quote sadly illustrates:

“Try the softly, softly approach and again maybe I am undermining their abilities as well but I try to talk to them the same way I would maybe talk to a child.” (Professional 3, A&DS)

Skills and knowledge

All of the professionals from the A&DS reported that they had received no education in working with people with intellectual disabilities who were experiencing substance problems. However, the majority of these staff had some contact with people with intellectual disabilities via their initial nurse / social work training in previous years. This experience was not related to the co-morbidity between their disability and substance problem. Likewise, all the professionals working within the IDS although holding professional qualifications in this area had received no training in the prevention, assessment, treatment and management of substance problems in this population.

Both groups of professionals recognised the necessity for specific training in the early recognition and assessment of substance problems and, specific interventions for this doubly disadvantaged population. Many of the professionals indicated the possibility of joint working and sharing each group’s knowledge, standardised assessment schedules, education packages and information on treatment modalities. The following quote clearly shows the desire for training:

“Well I think if perhaps you had some specific training in relation to how to communicate and interact with people with intellectual disabilities...” (Professional 12, A&DS)

Similarly, many of the respondents from the IDS cited how futile they found their role in trying to change their clients’ substance use particularly given the underlying life events that many of this

population experience. This can be observed in the disturbing accounts reported by Taggart et al. (submitted, b), such as psychological trauma, physical and sexual abuse and exploitation. A professional from IDS reported that staff had many difficulties in giving care to this group of clients, stating the following:

“... I think we do struggle to provide therapeutic input in terms of motivational interviewing; we don't easily have access to medications or the ability to monitor in some cases, which is most important.” (Professional 10, IDS)

Interagency working

Professionals from both IDS and A&DS reported that there were no clear pathways or protocols in place regarding inter-agency working across these services. For some professionals this was at best ad-hoc, if present at all, with one or two professionals from IDS making contact with their peers within A&DS mainly to obtain advice and support. With regards to written policies regarding interagency collaboration, both groups of professionals reported that no policies existed.

Prevention strategies

The professionals from the A&DS highlighted that they were not involved in any particular preventive strategies to avert or minimise substance problems for this population. In fact many professionals felt that the remit for this would better be placed with the Health Promotion Agency rather than the A&DS. Similarly, the professionals working within IDS also indicated that no strategies were in place to prevent or minimise substance problems for people with intellectual disabilities.

The way forward

Finally, both sets of professionals were asked about their perceptions with regards to development of future services for people with intellectual disabilities who experienced substance problems. Two strong themes that emerged from the interviews were that of *'education / training'* and *'a cross-fertilization / collaboration of addiction and intellectual disabilities teams'*. Professionals within the A&DS could educate the professionals within the IDS with regards to general information about addictions, screening / assessing procedures, addiction treatment models, appropriate use of medication and the provision of supervision. The following quote highlights this well:

"...Intellectual disability nurses have the skills for communicating and working with people. Other people have the skills of dealing mainly with drugs and alcohol; you know a combination of both skills would be advantageous, like a link person between drug and alcohol and intellectual disability services." (Professional 13, IDS)

Conversely, professionals within the IDS could offer education / training to A&DS staff in relation to raising the profile of people with intellectual disabilities among staff, and how to effectively communicate with this population. Some professionals reported that staff working within IDS could also undertake a role of education, focussing upon initial awareness raising among informal and formal carers, and across schools, day-centres, colleges of further education and recreational clubs: thereby promoting prevention, early recognition and the need for prompt referral.

The majority of the professionals from both IDS and A&DS suggested the development of a *'link person / joint person between both services'*. The following quote from one A&DS professional demonstrates the benefit of such a joint person:

“Having skills in alcohol and drugs, and also somebody knowing how to work effectively with people with intellectual disabilities, or a link person, could draw up some sort of a joint strategy between both services that would help the client to get the right services.” (Professional 13, A&DS)

Discussion

The findings of this study illustrate that the numbers of people with intellectual disabilities that hazardously use substances is low. However as one professional highlighted, these numbers may be rudimentary estimates as these figures are based upon those users only known to services. Taggart et al. (submitted, a) highlighted that as the majority of this population have a borderline/mild intellectual disability, and live independently, many will not be known to services until their behaviours become a significant issue for their well-being. This negative impact upon the persons' well-being, causes grave concern for service providers particularly given the complex problems that this population present.

In terms of assessment and treatment, all of the professionals within the IDS reported a dearth of training and knowledge in this field. None of these staff had undertaken any formal assessment of the persons' pattern of substance use and the factors that have predisposed, precipitated and maintained this problem. Possible tools that have been developed to assess for such factors in the non-disabled population could be possibly used/adapted for this population such as AUDIT (Alcohol Use Disorder Identification Test) (Saunders et al 1993). Staff may also need to assess the person's mental health status given the larger numbers of people with intellectual disabilities who hazardously use substances who are also found to have a co-existing psychiatric disorder (Taggart et al., submitted, a). There are currently a number of instruments commercially available to screen for mental health problems in the non-disabled population such as Beck's Depression Inventory (Beck et al., 1979). Equally, there are also tools available to screen for mental health problems in people with intellectual disabilities such as the PAS-ADD schedules (Moss, 2002).

Alternatively, one innovative practitioner working in this field has developed his own assessment pack that includes a '*comprehensive client needs assessment*' that examines substance use as well as a number of other factors (Shaw, 2001). Furthermore, in today's climate it is important for service

providers to measure the effectiveness of their service: the outcome measures taken from the Quality in Alcohol and Drug Services (1999) could also be used for this population.

It can be argued from these findings that these professionals have frequently worked in a 'crisis management role' this is in comparison to a pro-active harm minimisation approach that includes a comprehensive therapeutic intervention package of care. Part of this 'crisis management scenario' that many staff within IDS face today, can be observed to stem from an accumulation of the negative circumstances that this population have experienced over the course of their life-span. Taggart et al. (submitted, b) found that this population as previously highlighted used substances to 'self-medicate against life's negative experiences': these included bereavements, mental health problems, self-harm, domestic violence, sexual and financial exploitation, isolation, loneliness and a lack of daily structure. From these findings, health and social care service providers need to ensure that they are addressing these underlying causes rather than dealing with the manifestations of such life-events: continual ignorance of these needs of this population will further lead to substance abuse and poorer physical and mental well-being. However, the availability of appropriate talk-therapies to address such issues of bereavement, domestic violence, sexual abuse and also addictions for people with intellectual disabilities across the UK remains low (Mencap, 1999, Abbott, 2003). This is despite the promising evidence of the successful application of these talk-therapies with people with intellectual disabilities (Beail, 1995, Collins, 1999, Hollins & Sinason, 2000).

As part of the persons' treatment package, some of the professionals working within the IDS referred their clients onto A&DS, however this was found to be limited. More striking, many of the staff working within the A&DS also reiterated how ineffective they found attempting to work with people with intellectual disabilities. One common difficulty offered for this failure was their lack of training / education in working with this population. This lead to problems in clearly

communicating within this population, assessing their level of comprehension and knowledge obtained from the educational materials used, and also engaging the person in the group sessions. What is required is for A&DS to be adapted for this population, and also new and innovative packages of care to be developed, and thoroughly evaluated, thereby providing an evidence-base for future practice: an evidence-base that is currently absent. This will involve a multi-disciplinary approach as no one-service provider can fully meet the needs of this population. Furthermore, as group sessions involving personal sharing have been shown to be unpopular for this client group, therefore a greater emphasis needs to be placed upon the provision of one-to-one counselling (Taggart et al., submitted, b). Similarly, educational material must be developed at a level that this population can understand using simplified formats.

Staff in the addiction services also reported many difficulties in fully '*engaging*' with this population from the initial meeting (Rivinius, 1988, Taggart et al., submitted, b). Recently, mainstream mental health services and A&DS have successfully been employing 'motivational interviewing' techniques to encourage clients to shift from a pre-contemplation to a contemplation mind frame (Miller, 1988). If 'motivational interviewing techniques' could be employed with people with intellectual disabilities, this may then encourage the person to-rethink about their substance related behaviours in a new light thereby wanting to seek help / support earlier, and fully engaging with any treatment programmes offered (Mendel & Hopkins, 2002). However, there is a lack of robust data of the effectiveness of 'motivational interviewing' with this population and more work needs to be conducted into how to utilise motivational interviewing with this population.

This study found that both groups of staff reported a lack of education / training in working with people with intellectual disabilities and substance related issues, consequently there is a need for better training for all front-line care staff. Training for both sets of professionals should be given based upon a two-tier approach. Firstly, an awareness day for all staff focussing upon prevention,

early recognition and referral. And secondly, the development of a specialist module(s) or a course to address the holistic needs of this population focussing upon prevention, assessment, treatment and inter-agency management of this client group.

More worryingly, all the professionals interviewed within this study have highlighted that no integrated service exists for this population across Northern Ireland with little if any collaboration being undertaken. It can be purported that service provision for people with intellectual disabilities who hazardously use substances within Northern Ireland is based upon a reactionary model rather than a proactive model. In line with the few service providers that are currently implementing a collaborative framework to address the needs of this population across the UK (Shaw, 2001, ARAC, 2002, Borough of Wandsworth, 2003), all the professionals in this study also reported that the way forward was through the development of a *'joint approach between intellectual disability and addiction services'*. These views also reflect those echoed in the documentation *'Valuing People'* (Dept. of Health, 2001) in England & Wales, and in *'Equal Lives'* (DHSS&PS, 2005) in Northern Ireland: *"that wherever possible people with learning disabilities should be supported to use mainstream services"*.

The majority of the professionals also indicated that given the small numbers that both service may engage with, that a *'link person'* between both IDS and A&DS should be created. This would be a practical and cost effective way of establishing clear channels of communications between both services offering expertise and advice on a range of evidence-based practices and management strategies.

Although the findings of this study are based upon the experiences and perceptions of a small group of professionals working across both IDS and A&DS with this specific client group, these findings echo similar research conducted across other parts of the UK and the Atlantic (ARAC, 2002,

Borough of Wandsworth Study, 2003, Sturmev et al., 2003). Although the views of the service user were not sought directly within this study, however these views have be gathered in an earlier study conducted by Taggart et al. (submitted, b) and have subsequently also be incorporated within this paper. Also absent are the relatives' voices, residential and day-care staff and our colleagues working across both moderate and severe intellectual disability schools: for a robust holistic alcohol and drugs strategy to be developed all views must be heard prior to the development of any service. Nevertheless, this study does offer a series of insights, and similar vision as seen in the rest of the UK into how services should be developed to meet the needs of this population.

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