

# **ALCOHOL AND OTHER DRUG USE IN THE AUSTRALIAN DEAF COMMUNITY: A NEEDS ASSESSMENT**

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**for the Victorian Deaf Society**

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The responsibility for all statements made in this document lies with the authors. The views of the authors do not necessarily reflect the views and position of the Alcohol Education and Rehabilitation Foundation.

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## Acronyms

AER	Alcohol Education and Rehabilitation Foundation
AOD	Alcohol and other drugs
DDA	Disability Discrimination Act
MCDPDHHI	Minnesota Chemical Dependency Program for Deaf and Hard of Hearing Individuals
NABS	National Auslan Interpreter Booking and Payment Service
VDS	Victorian Deaf Society

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## Key points

The Victorian Deaf Society asked Turning Point Alcohol and Drug Centre to find out about alcohol and drug use among people in the Deaf community. The Victorian Deaf Society wanted to know how many Deaf people drink alcohol and take drugs and what information people receive and need about alcohol and drugs.

This report uses capital D for Deaf, as the Deaf community is a culturally and linguistically distinct community.

- The study used three types of data:
  - Information from journal articles, reports and internet sites.
  - Comments and stories from Auslan Interpreters and VDS Case Managers and VDS Independent Living Skills workers.
  - Responses from a national online survey posted on Deaf organisations websites. Sixty eight people filled out the survey.
- The extent of alcohol and drug use in the Deaf community remains unclear, but there is no evidence to suggest that it differs from the hearing population.
- Alcohol and drug education is rarely delivered in a Deaf friendly format and there was a strong call for Deaf friendly information.
- The Deaf friendly information should cover all the topics that are available to the hearing community.
- A Deaf person or someone trained in Auslan and Deaf awareness should deliver alcohol and drug information to the Deaf community.
- The Deaf community has a right to culturally and linguistically appropriate AOD services.
- The lack of services is a source of much frustration and concern.
- There is a need for training for both Deaf and hearing staff on the role of interpreters, how to address confidentiality and privacy issues, and ways to bridge the language barriers.
- The research said that Deaf people may prefer to use a mainstream service, if they can communicate effectively with staff through interpreters. Choice is important.
- Future action and research may include:
  - Deaf Awareness sessions for mainstream workers
  - AOD information sessions for Deaf community members, case managers and support workers
  - Production of Deaf friendly alcohol and drug material such as DVDs, based on reliable and accurate information.
  - Supporting staff in mainstream AOD services to learn Auslan

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- Educating mainstream services about the Commonwealth funded National Auslan Interpreter Booking and Payment Service, and other interpreting services.
  - Advocating for services to collect information on their contact with Deaf and Hard of Hearing clients and use it in their planning.

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## EXECUTIVE SUMMARY

### Background

This document reports on an evaluation of the need of the Australian Deaf community for better access to education on alcohol and other drug (AOD) issues. Commissioned by the Victorian Deaf Society (VDS) with funding from the Alcohol Education and Rehabilitation Foundation (AER), Turning Point Alcohol and Drug Centre conducted the evaluation between May 2006 and February 2007.

The twin objectives were to estimate the extent of AOD problems in the Deaf community and to gather information on the AOD educational resources that were available or needed. Little was known on these subjects and funding for specialist Deaf AOD work in Victoria had been valuable but short term.

### Method

The evaluation included a literature review and focus groups leading into the conduct of an anonymous national online survey publicised through Deaf networks and attracting 68 participants. Data from the three methods were triangulated.

### Findings

Limited findings emerged on the extent and type of AOD use in the community. Consistent messages emerged about the AOD education that was required and, most importantly, the preferred means of communication.

#### *1. Prevalence*

The extent and nature of AOD use in the Deaf community remains unclear. There is no evidence to suggest that it differs from that of the general population. The drugs most commonly used are alcohol, cannabis and methamphetamines.

#### *2. Communication is key.*

The Disability Discrimination Act 1992 aims to promote recognition and acceptance within the community of the principle that people with disabilities have the same fundamental rights as the rest of the community. Deaf people have a right to equity of communication. The need for better communication between Deaf and hearing should hardly need emphasis but we conclude that the barriers remain significant. Public information is not generally delivered by Deaf-friendly means and it is likely that the Deaf community has not picked up health promotion messages concerning AOD issues to the same extent as the hearing community.

#### *3. The Deaf community context*

When AOD problems are encountered the effects may be compounded by lack of access to public services and by a lack of understanding in the (generally supportive) Deaf community. Community education should aim to minimise harm by increasing understanding of safer AOD use, reducing stigmatising attitudes towards illicit drug users and dependent drinkers so that they are less isolated, and encouraging people to seek help when they are negatively affected by their own AOD use or that of the people around them.

#### *4. Education resources*

There was a strong call for Deaf friendly information to be available to the Deaf community.

The resounding message from the Deaf community is that they need the same information that is available to the hearing community, and that it is not available. Information clearly needs to cover the broad range of AOD messages including harm minimisation, early intervention, treatment options and effect of different drug types.

Providing information in a person's language of choice is a necessary part of the education process: information may be absorbed more readily and people may be more comfortable to ask questions and seek clarification. As Auslan is the language of the Deaf community, information should be presented in Auslan, either by a Deaf person or a hearing person fluent in Auslan. Alternatively, an interpreter should be used.

Information needs to be presented in a way that promotes general discussion and confronts the stigma attached to alcohol and drug use. It may capitalise on the word-of-mouth networks in the small Deaf community.

Auslan can be incorporated into online information and DVDs. Harnessing the available technology and increasing the use of visual information within text-based mediums will address the language barriers and can be tailored to different audiences such as young people, parents and friends.

#### *5. Continuum of services*

While the issue is beyond the stated objectives of the evaluation, this study suggests that there is a need for better access to a range of AOD treatment services such as counselling, rehabilitation and post treatment support. Central to the discussion is a sense of frustration around the lack of choices available to Deaf people and the shortage of professionals with both AOD skills and Deaf awareness.

Currently there are no Deaf specific AOD services in Australia and, based on the information available to us, there appear to be few AOD services equipped to meet the communication needs of Deaf clients. The current system appears to leave the Deaf community and the staff involved in a potentially precarious situation in terms of receiving and providing an equitable service.

For anyone, the decision to engage in treatment takes courage, as it demands personal reflection and change. For Deaf people accessing a service is only the first of many hurdles: treatment does not just involve reassessing their drug use and life style, but it requires managing the logistics of finding an interpreter – preferably one familiar with the field of AOD - and working within a hearing framework. Relying on interpreters during treatment presents additional challenges on several levels, especially in terms of an episode in a residential unit. Financial costs, booking requirements and group dynamics aside, effective communication via an interpreter requires that all parties involved are skilled in this form of communication and have some level of deaf awareness. Above all, services need to be conscious of the risk of exacerbating a person's distress by increasing their isolation.

What the ideal service looks like is unclear. We heard suggestions of Deaf only AOD treatment but the main message was that mainstream AOD services needed to be Deaf friendly. While both service models pose a different set of challenges and benefits, a common thread is the need to develop a multi-skilled workforce. In the

short term it is reasonable to see that promoting relationships between Deaf services, AOD clinicians and Auslan interpreters may create opportunities to learn from each other and open up more avenues for clients. This study only provides a glimpse of the situation, and further research is needed in order to build a more complete picture.

#### *6. Further research and action*

If understanding is to be increased it is important that research (including action research and evaluation) is designed, funded and conducted to culturally and linguistically appropriate standards (Berman et al 2000). The current project made optimum use of its resources but much was learned about potentially better approaches.

Action towards more equitable service can be pursued through collaborations between Deaf and mainstream services to raise awareness, set realistic priorities and trial incremental improvements in service delivery. These may include:

- Ensuring mainstream organisations are aware of how to book government funded interpreters (e.g. through state Deaf organisations and through the National Auslan Interpreter Booking and Payment Service, NABS) for private medical appointments<sup>1</sup>.
- Deaf Awareness sessions for mainstream workers
- AOD information sessions for Deaf community members, case managers and support workers, in Auslan and preferably by Deaf people in person.
- Production of Deaf-friendly DVDs based on Australian Drug Foundation AOD information
- Joint presentations at conferences and other professional development occasions
- Secondment of treatment and support staff between Deaf and mainstream organisations
- Mainstream organisations reviewing routine data collection so that more is known about their contact with deaf and hearing-impaired people (i.e. do they include Auslan in their list of preferred languages used? do they ask about sensory impairment?)
- Supporting staff to learn and use Auslan
- Seeking opportunities for the recruitment, training and support of Deaf staff in mainstream agencies.

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<sup>1</sup> NABS provide free interpreting services for private medical appointments in the following areas: GP and Specialist, Chiropractors, Dieticians, Psychiatrists, Physiotherapists, Endocrinology, Medical Imaging, Naturopath, Iridology, Podiatrists or Chiropodists, Audiologists, Psychologists, Occupational Therapists, Dentists, Family Planning/Sexual Health, Paediatrics, Remedial Massage, Aboriginal Health Workers, Osteopaths, Mental Health Workers, Speech Pathologists, Optometrists, Gynaecology/Obstetrics/IVF, Specialists, Acupuncture (National Auslan Interpreter Booking and Payment Service, Accessed 19 February 2007).

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# 1. INTRODUCTION

## 1.1 Background and aims

The Alcohol Education and Rehabilitation Foundation (AER) awarded a grant to the Victorian Deaf Society (VDS) to identify specialised deaf drug education resources and evaluate the level of substance misuse within the Australian Deaf community. The Victorian Deaf Society commissioned Turning Point to conduct the evaluation.

The two organisations had begun to develop a collaboration inspired by VDS staff, including the then alcohol and drug worker, who successfully completed a Graduate Certificate in Alcohol and Other Drug Studies with Turning Point and supported by an AER scholarship. It was apparent that there was potential for improving service access for Deaf people with alcohol and drug problems. Workers in both organisations discussed potential joint work specialist treatment and support for Deaf community members affected by alcohol and other drug problems; workforce development for workers who came into contact with the Deaf and hearing impaired; and tailoring AOD training to suit Deaf recipients.

It was clear, however, that a necessary first step was to clarify the needs of the community in regard to alcohol and other drug education. There was very little literature about the Deaf community and the nature and prevalence of substance misuse, and even less on specialised deaf drug education resources.

The Victorian Deaf Society aimed to use the research findings to support a search for more consistent sources of funding to provide regular and ongoing information and educational services to the Deaf community with regard to AOD. The study would also be a small step towards action on better access to AOD education, treatment and support for the Victorian deaf community and towards increasing the capacity of AOD services to work with the Victorian deaf community. Further research and significant resources were needed for this larger agenda.

It was intended that the research process would itself have an educational effect: the survey included information on safer drinking and on options for seeking support and treatment; focus groups were planned in the knowledge that they frequently raise awareness of the topic under discussion.

The report begins with an outline of, and some reflections on, the method. Findings from the three types of data source follow – first the messages from the literature and the focus groups, followed by results of the online survey. Recurring themes are drawn together in a conclusion and suggestions are made for future research and action.

## 2. METHOD

### 2.1 Design and rationale

The study, conceptualised as a needs assessment, included two stages of data collection:

1. focus groups and a targeted literature review, providing information for the design and content of:
2. an online survey of the Deaf community in Australia

Project coordination was achieved through a steering group comprising the VDS Rehabilitation and Information Manager, the researchers and a Deaf Auslan teacher with experience of participatory research. Meetings were interpreted and some communication occurred by email.

In the study's planning stage the VDS provided the two researchers with a half-day cultural and linguistic awareness session, delivered by David Peters (the Information Officer responsible for Deaf Awareness Training) with Auslan interpretation.

### 2.2 Data collection and analysis

#### 2.2.1 Literature review

Current literature was explored in a review aimed to scope out the survey questions, and to find existing educational AOD resources for the Deaf community.

The scarcity of literature relating to substance misuse and alcohol and drug education resources in the deaf community, especially in Australia was initially identified by the VDS and then confirmed by our literature search.

To effectively locate relevant information, the following key words were used: *Deaf community, deaf, hard of hearing, substance use and/or misuse and/or abuse, alcohol, drugs, education, information, treatment, services*. The key words were combined to modify the search.

An initial search of the World Wide Web identified peer reviewed publications and a range of 'grey literature' such as government publications, forums, presentations, organisations, services and reports from overseas and Australia. This informed a search of online databases including DrugInfo Resource Centre, Australian Drug Foundation, PubMed, ProQuest, EBSOChost and ScienceDirect.

To identify further material, the researchers reviewed the contents of specific journals such as American Annals of the Deaf and the reference lists of relevant articles. The researchers used 'citation linker' available through university library websites to access the article.

In addition, the researchers searched the web sites of key Australian deaf organisations and societies for information and services relating to alcohol and other drugs. A number of small scale mixed methods articles, evaluations, prevalence studies and discussion papers were reviewed.

The findings from the literature review were analysed thematically.

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## Focus groups

The purpose of the focus groups was to gain insight into the general issues pertinent to the Deaf community and to scope out the survey questions (Krueger & Casey, 2000).

Four groups were planned:

1. Two groups from the Deaf community – a mixture of generic Deaf community and any volunteers who may have used drugs / alcohol and who have accessed AOD services in the past.
2. One group of Case Managers and Independent Living Skills Workers from the VDS who support clients in the community to access AOD services.
3. One group of Auslan interpreters who support clients in their drug treatment, recruited through the Australian Sign Language Interpreters Association, Victoria (ASLIA Vic).

Participants were recruited through the VDS. Case managers, client support workers and interpreters were asked by email and personal contact. Community members received an invitation flyer distributed through VDS' usual paper and electronic newsletters and by case managers and support workers. The flyer was followed up in person by VDS staff.

As only one community member responded, these groups were regrettably cancelled.

Groups 2 and 3 attracted ten and four members respectively.

The Deaf facilitator moderated the groups, which were interpreted. The researchers assisted as whiteboard scribes and to provide additional AOD information when required. Sound recordings and notes taken during the session were later transcribed for analysis.

Questions were designed to elicit views and prompt discussion on current resources available to Deaf people who experience substance abuse difficulties, the need for improvements, and the perceived level of substance misuse in the Australian Deaf community.

The focus group discussion was analysed thematically.

## Survey

An online survey was created from the issues identified in the literature review and the focus groups and advertised to the Deaf community nationally. The survey included questions regarding substance use as well as knowledge and usefulness of resources currently available to the Deaf community. Questions were directed at the Deaf population in general as well as towards those with experience of problematic AOD use.

The researchers were aware at the outset, and the message was reinforced throughout, that written surveys were a far from ideal method of consulting Deaf people. English was a second language for the majority of Auslan users, and many terms commonly used in AOD studies would be meaningless or confusing (Alexander 2005; Guthmann & Sandberg, 1998). While aware of the need for more culturally and linguistically appropriate methods we chose, within our resources, to attempt a

simple survey design that used Deaf-friendly language. At the same time we wanted to be able to compare findings with research on the general population. This led us to introduce questions from the National Household Survey (AIHW, 2005) and from another recent study conducted in Glasgow (FMR Research, 2002).

The VDS 'Fix my English' team reviewed the survey's language and it was edited accordingly.

The survey was promoted through the State Deaf Societies as broadly as possible.

Online surveys anticipate that intended participants will have access to the internet and basic computer literacy. The survey promotion encouraged people to seek help if required.

On average the survey took approximately 14 minutes to complete. Only one person said they had asked someone else for help with completing it.

The final survey question asked for feedback. Some participants considered the language inappropriate for people with low English literacy skills and suggested that some of the questions be simplified.

Quantitative analysis was assisted by SPSS. Many participants provided extensive and useful written comments, which were analysed thematically.

## **2.3 Dissemination**

Planned reporting methods included the current document with Deaf friendly key points, presentations and workshops at AOD conferences conducted jointly by Turning Point and VDS, journal and newsletter articles.

## **2.4 Ethics**

The project was taken through Turning Point's internal ethical facilitation process and was also approved by the Victorian DHS Human Research Ethics Committee.

## **2.5 Limitations**

Findings on the prevalence of alcohol and drug problems in the Deaf community can only be taken as indicative, given that survey respondents were a self-selected convenience sample and few in number. Future studies may be strengthened by including AOD prevalence questions in larger surveys (i.e. covering more topics) of a random sample of the community.

Barriers to survey responses may have included:

- Deaf networks lacking capacity to promote the survey
- Community reluctance to engage with AOD as a topic
- Individuals' capacity to reply online
- Individual assumptions that the survey was intended for problematic users only
- Individuals not understanding that responses were anonymous

Focus groups with Deaf community members were missing from the first stage of the project and may have illuminated more information about community needs. Two

focus groups were less than the four or more considered advisable to elicit rich information on a given question. In future, the Deaf facilitator suggested to the researchers that recruitment may be better conducted in a snowball approach and the interviews confidentially and one-to-one. Themes raised by the other focus groups and by survey participants in their written comments were however quite consistent. We can be reasonably confident that the study has touched on the principal needs in terms of education content and communication methods.

### **3. MESSAGES FROM THE LITERATURE AND THE FOCUS GROUPS**

#### **3.1 Summary**

The literature said:

- The Deaf community is a unique group of people with their own culture and language. For many Deaf people, English is their second language.
- Most hearing people who conduct research projects have little understanding of sign language and Deaf culture. Also very few research projects provide information and questions in sign language, making it difficult for Deaf people to be involved. Using computers to sign information to Deaf people or using Deaf researcher may make research questions more visual and accessible for Deaf people.
- The size of the Australian Deaf community is unknown. Estimates range from 6,500 to 15,000.
- How much alcohol and drugs Deaf people use is unknown. There is no evidence to say that the Deaf community uses alcohol and drugs more or less than the hearing community.
- It seems Deaf and hearing people drink alcohol and take drugs for similar reasons. Wanting to be accepted, wanting to experiment and wanting enjoyment are a few of the main reasons why people take drugs. Some studies recognise that communication and cultural differences may influence a person's decision to drink alcohol and take drugs.
- Stigma is a very real concern within the Deaf community and stigma is often attached to taking drugs and drinking lots of alcohol. As a result Deaf people may not be willing to discuss alcohol and drug problems with hearing or other Deaf people.
- Alcohol and drug services are generally not Deaf friendly. Most staff speak English and alcohol and drug treatment services often use language and words that are hard to translate from English to Auslan. Interpreters help Deaf and hearing people to communicate, but having Deaf staff seems to be the preferred option.
- Most alcohol and drug information is written in English. Deaf people with low levels of English literacy find it hard to read and understand the information. It is possible that the Deaf community may not receive the same level of information that the hearing community does.

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## 3.2 The research literature

Every day people communicate with others. Communication is the porthole through which people gain knowledge, give and receive support, express emotions and interact. But what if you can't hear? What if you communicate via sign language? What if English is your second language? This is the reality for people in the Australian Deaf<sup>2</sup> community.

Access to education material on alcohol and other drug (AOD) use is generally only available in English or other written languages and Deaf specific AOD treatment services are extremely limited. At the time of this review the level of alcohol and other drug use in the Australian Deaf community was unknown. Also there was limited information about how the Australian Deaf community accessed AOD resources. This review draws on international and Australian literature to provide a framework for understanding alcohol and drug use and access to education and services within the Australian Deaf community.

### Deaf culture

The focus of this project is the Australian Deaf community. The literature distinguishes the Deaf cultural and linguistic community from populations who have hearing loss. For a minority of Deaf people, those born to hearing parents, access to this community may not occur until later in life.

Members of the Deaf community are proud of their deafness, and deafness is not considered synonymous with a disability or suffering from a physical loss. Rather, it is society's inability to recognise and meet their communication needs, which perpetuates the notion of deafness as disabling (COI Communications, 2004).

Language is one of the key distinguishing features of any culture. Auslan, Australian Sign Language is an entirely visual language, used widely in the Australian Deaf community. Auslan combines hand-shapes, facial expression, hand-body orientation, location and movement to create a fluid and concise language. Sign language has its own grammar and vocabulary and is not based on spoken languages, and there is no written form. Auslan is similar to British Sign Language (BSL), but is unrelated to American Sign Language (ASL) (Australian Communication Exchange, 2006). Since 10% of deaf people are born to hearing parents, children may learn a mix of English and sign, though few hearing parents learn sign language. The lack of a common language within families is thought to distort communication and leave members feeling isolated (Rendon, 1992). According to Lipton and Goldstein children born deaf to hearing parents tend to learn sign later in life as they gravitate towards the Deaf community (1997).

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<sup>2</sup> In the literature, and this report, capital 'D' typifies a cultural, linguistic community, whose membership is based on a sense of shared understanding and self-identification with Deaf cultural norms, language, behaviours and history. Capital D is used deliberately, as deaf (lower case 'd') generally refers to the physical condition of not hearing. Also, the Hard of the Hearing community and the Deaf community are culturally distinct (Australian Association of the Deaf, 2006).

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## Researching AOD in the Deaf community

The use of written languages, such as English, hinders the recruitment and involvement of the Deaf community in research projects, although advances in multimedia technology have the capacity to bridge the communication gap. Also, research led by hearing people with limited understanding of sign language and Deaf culture may impact on Deaf people's willingness to participate.

Studies show that survey instruments designed predominantly for hearing populations are unsuitable for Deaf people. While language is one of the main differences between hearing and Deaf people, its impact is far reaching. Reasons cited in the literature include: varying degrees of English literacy skills (COI Communications, 2004); sensitivity around reading ability and fear of scrutiny (Alexander et al, 2005); unfamiliar terminology used during assessment and treatment (Guthmann, 1999; Alexander et al, 2005); inexperience with survey research (Berman et al, 2000); distrust of hearing researchers (Guthmann, 1995) and fear of stigmatisation (Lipton & Goldstein, 1997). Written surveys are therefore culturally and linguistically inappropriate, but on a more pragmatic level, misunderstanding may risk compromising the validity of the survey tool and distorting the results.

Two recent studies highlight the pitfalls of using mainstream tools and the importance of producing Deaf friendly validated screening instruments. Alexander and colleagues (2005) asked Deaf individuals to comment on the language used in the two widely used screening instruments: the AUDIT (Alcohol Use Disorders Identification Test) and CAGE (cut down/annoyance/guilt/ eye-opener). Deaf participants reported difficulty with both instruments, with some words problematic for 88% of participants. The terms participants struggle with included 'containing', 'typical' 'occasion' 'remorse' 'injured' 'session', 'criticizing', 'steady your nerves' 'annoyed', 'hangover'. Deaf participants also reported difficulty with questions that included more than one time period. Of the 21 participants, five people could not read any of the items and asked that the test be signed (Alexander et al, 2005). Guthmann and Sandberg have also found certain words such as 'black out' 'withdrawal' and 'tolerance' confusing for Deaf people and have questioned the usefulness of general screening and assessment (1998).

In order to measure the level of alcohol use in Deaf psychiatric patients Davidson and colleagues (2005) adapted three instruments; the AUDIT; the Composite International Diagnostic Interview (CIDI) and the EuroQol (EQ-5D). Deaf mental health staff and BSL interpreters with experience in mental health identified terms and phrases in the instruments which Deaf people would find problematic and suggested alternatives. Independent British Sign Language (BSL) interpreters translated each new question back to the original to verify its intent. Clients were interviewed face to face and all staff administering the survey received training in both the tools and how best to sign the questions. In summary the results found the AUDIT to be an effective tool for assessing Deaf people, though addressing the client's communication needs was the key.

Recently, Berman et al (2000) described the process of developing an interactive multimedia data collection instrument as part of a tobacco study among American deaf youth and young adults. Berman and colleagues used the Interactive Video Questionnaire (IVQ), an interactive multimedia computer and video technology developed by Douglas Lipton and his colleagues at the National Development and

Research Institute (NDRI). The IVQ includes a signed digital video clip, and the viewer is offered the choice of three language options: American Sign Language (ASL), Signed English (SE), and Speech Reading (SR); written English is also an option. This technology standardises the survey instrument, provides privacy and anonymity and does not require English language proficiency. Berman's article focused primarily on the process of establishing a culturally and linguistically appropriate survey, and at the time of publication the questionnaire had not been administered in the field.

The language and cultural differences between hearing researchers and Deaf participants are thought to influence recruitment and data collection. Whitehouse et al note that Deaf people have often been neglected, patronised and treated as less intelligent by hearing people. Such negative experiences and feelings are attributed to the low response rate of Deaf people in research (1991). According to Alexander et al (2005), Deaf people are more likely to participate in research if they are approached in ASL as opposed to hearing researchers using interpreters. Adherence to Deaf culture such as asking each other where they grew up and their sign name is also thought to encourage involvement.

## **Population size - how many?**

The size of the Australian Deaf community is unknown. Estimates have ranged from 6,500 to 15,000 and there is disagreement among researchers on whether the population of Auslan users is increasing or decreasing.

One in six Australians is affected by hearing loss, with prevalence rates increasing with age. By 2050, hearing loss is projected to increase to one in every four Australians (Access Economics, 2006). As belonging to the Deaf community is more about cultural and linguistic identity than hearing ability, only a proportion of this group may consider themselves Deaf.

Both in Australia and overseas, government departments and researchers have struggled to precisely measure the size of the Deaf community. National censuses are considered inappropriate, mainly because they infer a certain level of literacy and secondly, they are culturally insensitive. For example, prior to 1996 the Australian Census of Population and Housing used the term 'deaf and dumb' in an attempt to capture the number of deaf people living in Australia (Australian Association of the Deaf, 2006). While this term is highly offensive and inaccurate, it fails to differentiate between deaf and Deaf. More recently, the Australian Census asked "Does the person speak a language other than English at home?" In response, 5,305 people reported that they used some form of sign language. This figure is thought to underestimate the size of the Deaf community because:

- some Deaf people may not be aware that Auslan is a 'language';
- Auslan is signed not 'spoken'; and
- some Deaf people who regularly use sign language to communicate do not use sign language at home (e.g. with hearing parents) (ORIMA, 2004).

In addition, Clyne and Kipp (2002) cite the inappropriate use of the word 'speak' as opposed to 'use' may deter people from answering the question correctly, and suggests that reporting could also be affected by hearing family members filling out the Census on behalf of Auslan users.

For over a decade, the Australian Deaf community was estimated to be 15,400. Hyde and Power (1991) based this estimate on a study using snowball sampling to identify signing deaf people. More recently Johnston (2004) estimated the size of the signing Deaf community in Australia to be approximately 6,500, and predicted the Deaf population will decline. Johnston (2004) derived the estimate of the Deaf community from audiological tests, school enrolments for the Deaf, neonatal screening programs and the National Acoustics Laboratory (NAL, now Australian Hearing). A number of commentaries were published opposing Johnston's view on the fate of the Deaf community, and more specifically the future of Auslan. Essentially, the commentaries claimed that Johnston underestimated the strong sense of cultural identity within the Deaf community (Burke, 2006; Carty, 2006; Mitchell, 2006). Similarly, the Australian Association of the Deaf (2006) questioned Johnston's findings since many members of the Deaf community learn Auslan as teenagers or young adults, therefore the number of people using Auslan is much larger than those identified as native signers.

### **Level of Substance use in the Deaf community**

The extent of substance use among the Deaf community in Australia is another unknown factor and the few available UK and US studies give no indication that it differs from that of the population as a whole.

US studies suggest that the rate of alcohol and other drug use in the deaf community is similar to the rate of use in the general hearing population (Buss & Cramer, 1989, Lipton & Goldstein, 1997; Whitehouse et al, 1991; Guthmann & Blozis, 2001, Alexander, 2005). According to a Wisconsin study the incidence of heavy drinking among deaf persons in Wisconsin was equal to that of the general population (Buss & Cramer, 1989). Few studies have recruited sufficient samples to fully explore the rate of alcohol and drug use in the Deaf community.

While most research on the Deaf community and alcohol and drug use is based on the United States, a number of studies have been conducted in the United Kingdom. One study investigated substance issues focusing on people with a sensory impairment (including Deaf, Hard of Hearing, Blind and Partial Sight) living in Greater Glasgow. Information was mainly sourced from self-completed questionnaires, focus groups with Deaf people and Hard of Hearing (held separately), interviews with Deaf people and telephone interviews with blind people. A total of 118 sensory impaired people participated in the study, with 59% identifying as Deaf (FMR Research, 2002). The FMR Research team found that nearly half the survey respondents drank alcohol once a month or less, and 28% drank alcohol twice a week or more, though there was little evidence to support heavy drinking. Generally people drank in a social club with friends and the majority of respondents reported that at least some of the people they socialised with drank alcohol. Deaf people tended to socialise with other Deaf people, suggesting a sense of community. This was not the case for blind and/or sensory impaired respondents. Few sensory impaired people (10 respondents, 11% of the total sample) had tried illegal drugs, with most having tried cannabis. Of the nine Deaf people who participated in a face-to face interview, four young people had smoked cannabis. Reasons for using cannabis included feeling pressured by friends, and simply because their friends smoked cannabis. While very few people had accessed an alcohol and drug service, focus group participants mentioned knowing someone with a problem with alcohol and/or drug use (2002). Results from this study are only indicative, as samples were not representative of the sensory impaired population living in Greater Glasgow.

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## Reasons for use and risk factors

Whether people are Deaf or hearing, the reasons for using drugs are thought to be similar, though it is possible that additional pressures associated with communication difficulties may play a part in the decision to use substances or not.

International research, especially from the US and more recently the UK, reports that deaf people may be vulnerable to developing problematic substance use. The main factors cited in the literature include isolation, marginalisation, frustration, loneliness, depression and desire to gain peer acceptance (COI Communication, 2004, Lipton and Goldstein, 1997; Whitehouse et al, 1991; Guthmann and Blozis, 2001). Hearing people use and misuse alcohol and other drugs for very similar reasons, though Deaf people tend to receive less information and have limited knowledge about chemical dependency (Guthmann, 1998). A report from the United Kingdom suggested that Deaf people may also use drugs and alcohol as a way to cope with the stress, frustration and anger from communication difficulties with the hearing world (COI Communicate, 2004). Overall, researchers find that Deaf people tend to use alcohol and other drugs for the same reasons as everyone else.

Hearing-impaired adolescents are thought to be more vulnerable to substance abuse than their hearing peers (Whitehouse et al, 1991 and Drug and Alcohol Education and Prevention Team, 2004) and may use drugs or alcohol to identify with and be accepted by their hearing acquaintances (COI Communicate, 2004). Guthmann concurs with this view, adding “deaf adolescents may experience a higher level of stress in their lives than adolescents who can hear” (1998:2). Also Skelton & Valentine (2003) found that some young deaf people experienced high levels of distress, isolation and bullying resulting in exclusion from the school culture.

In the general population the link between substance misuse and poor mental health is well documented. Due to linguistically inappropriate assessment tools and diagnostic procedures the rate of dual diagnosis within the Deaf community is uncertain (Vernon and Daigle-King 1999). The relationship between substance use and mental health is well documented though very few studies have included the Deaf community. In part, this is due to the language difficulty inherent in standard diagnostic tools such as the AUDIT. By addressing a number of the communication issues, Davidson and colleagues (2005) reported that within their sample of 144 Deaf people with a psychiatric illness AUDIT scores were highly predictive of CIDI categorisation. Also, the prevalence of alcohol use disorder among Deaf psychiatric patients was 29.9% (based on a cut off score of 8 on the AUDIT). According to Davidson et al (2005), this rate was higher than the prevalence of alcohol use found in the ‘general’ Deaf population by Dye and Kyle, 2001 (cited in Davidson, 2005).

Other recognised factors associated with high-risk behaviours and abusing substances include unemployment, learning disabilities, maltreatment in childhood (COI Communicate, 2004) and violent crimes (Miller et al 2005). In a recent assessment of the financial impacts of hearing loss in Australia, Access Economics reported that hearing loss impacts directly on a person’s life chances through reduced opportunity to equitably participate in education, employment and the broader community (Access Economics, 2006).

A less cited factor, but one worth further examination, is the attitude and behaviour of the hearing population towards the Deaf. Expectations of the hearing community that Deaf people should learn to read, write and speak compound communication differences. This insensitivity to a person’s culture and communication needs may

heighten a sense of isolation, alienation and frustration, which may increase the risk of alcohol and other drug abuse (Bureau of Mental Health and Substance Abuse Services, 2001 and COI Communicate, 2004).

### **Barriers to getting help – attitudes**

As a culture familiar with negative name-calling, and unrealistic social expectations, the fear of stigma places the Deaf community at odds with recognising problematic substance use and seeking assistance.

Archaic terms such as ‘deaf and dumb’, ‘deaf and silent’ and ‘deaf mute’ are no longer condoned in public discourse though they form a significant part of Deaf history. Studies discuss the impact of negative double stigma such as ‘deaf and drunk’ or ‘deaf and drugged’, especially in reference to deaf communities dealing with the general public (Lipton & Goldstein, 1997; Whitehouse et al 1991, Bureau of Mental Health and Substance Abuse Services, 2001).

Within the Deaf community the sense of being ‘different’ can be acute, and for some the misuse of AOD is perceived as an additional stigma. The fear of being labelled with the dual stigma may discourage Deaf persons from admitting a problem and seeking help (Guthmann & Blozis, 2001 and Alexander et al, 2005). It appears this reluctance to address alcohol and other drug abuse issues may lead to further social isolation and denial.

### **Barriers to getting help – language**

Linguistic and cultural differences are viewed as major obstacles in regards to accessing services. Also, the effective use of an interpreter in therapeutic situations raises important questions for hearing services and the Deaf community.

Researchers have found that access to mainstream services (both general health and AOD services) is problematic for Deaf people compared with the hearing population (Whitehouse et al 1991). This may be due to the inherent nature of mainstream services and the vast difference between the spoken word and sign language.

Throughout the world most treatment programs are designed by hearing people for hearing people (Lipton & Goldstein, 1997). Inaccessibility to telecommunication technology, lack of qualified sign interpreters with expertise in substance treatment, and general staff’s limited awareness about Deaf culture and customs are cited as key barriers to treatment for Deaf people (Whitehouse et al, 1991). When accessing general health services problems may include difficulty making appointments, insufficient time during consultation to meet communication needs, cost of interpreters and ineffective systems of letting Deaf patients know it is their turn to see the clinician (COI Communication, 2004).

Studies have found that Deaf people are often required to lip-read, rely on written notes, gesture or communicate through unqualified interpreters, either family or friends (Drug and Alcohol Education Prevention Team, 2004; and Queensland Deaf Society, 2004). According to Rendon “generally, not more than 26% of one-to-one conversation can be understood through lip reading” (1991:106). Similar, pen and paper may be unsuitable as 90% of pre-lingual Deaf adults in America read at or below a fifth grade level (Rendon, 1992). Using alternatives modes of

communication, instead of a Deaf person's preferred mode, raises issues of clients' rights and equitable access to service.

Employing qualified interpreters minimises the risk of information being distorted though factors such as language, setting arrangement and lighting need to be considered. Interpreting services are not only required to translate between Auslan and English, but there is also a need to consider other languages both spoken and sign. The Victorian Deaf Society is currently investigating the communication and language needs of deaf migrants and refugees. This study will provide valuable information for future service delivery (Victorian Deaf Society, 2007).

Confidentiality is a vital part of any therapeutic relationship, though some Deaf people fear their life story may become public knowledge when they disclose sensitive information in the presence of an interpreter (Guthmann & Blozis, 2001). Alexander et al confirms this view, stating that confidentiality is an enormous issue as the Deaf community is small and information can be passed quickly along the Deaf grape-vine, presenting real issues around confidentiality (2005). Confidentiality is also a very real issue for young deaf people, as they expressed concern about using interpreters when discussing sensitive information (Drug and Alcohol Education Prevention Team, 2004). FRM research found that most respondents would prefer a counsellor with BSL skills rather than rely on an interpreter. While they felt the interpreter would uphold confidentiality, they felt more comfortable discussing sensitive topics one-to-one (2002). Also the presence of a third person can alter the dynamics of the client-clinician relationship. According to Teuma (2005) a Deaf client will generally develop a trusting relationship with the interpreter first, then the health professional.

On the flip side, the absence of an interpreter can preclude Deaf and hard of hearing individuals from accessing equal support and can severely restrict their interaction with other clients in therapeutic settings (Guthmann, 1999). According to a study by Whitehouse et al general substance abuse services in Illinois reported that it was very costly to fund interpreters. Instead they chose family members, volunteers, hearing aids, and written notes as means of communicating with deaf people (1991). While Illinois staff tended to be unaware of their legal responsibilities to address Deaf clients' specific needs most identified a need for in-service training on various aspects of deaf culture, communication modes and accessing sign language interpreters.

Auslan is recognised as a community language by the Australian Government, though this status does not ensure that services are provided in Auslan (Wikipedia, 2007). To date no Deaf specific AOD treatment services exist in Australia, though research into mental health services mirrors evidence from overseas. In 2001, the Mental Health Unit (Queensland Health) investigated the mental health needs of signing Deaf and hearing-impaired people in Queensland. The report found that the major concerns included health professionals' lack of deaf awareness, the inappropriateness of services and the inequality of access to information for deaf people (Queensland Health, 2001). Again the report highlighted the need for deaf awareness training for general staff.

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## Limited deaf services

Hearing-centric services continue to dominate the AOD treatment sector, with few places skilled and equipped to meet the needs of the Deaf community. Lack of access to qualified staff, in terms of AOD and sign language skills is well recognised.

Few Deaf-specific treatment programs exist; further specialised assistance for Deaf people following treatment is rare (Guthmann and Blozis, 2001). One of the best known and widely documented Deaf treatment centres is the Minnesota Chemical Dependency Program for Deaf and Hard of Hearing Individuals (MCDPDHII). Established in 1989, the centre provides chemical dependency treatment based on the 12 Steps philosophy to deaf and hard of hearing individuals in line with their communication and cultural needs (Guthman and Sandberg, 1998). Throughout the United States and North America similar programs have been set up.

Deaf treatment services such as the Minnesota Program recognise the flaws in standard assessment tools. To minimise communication barriers during assessment MCDPDHII developed their own assessment protocols incorporating drawing tasks and role-playing. This approach aims to reduce the level of reading and writing required and increase the level of client involvement (Guthman & Sandberg, 1998). More recently, Alexander et al reported that no alcohol and other drug screening or diagnostic instruments have been validated for Deaf population (2005:63). The use and development of Deaf friendly standardised screening and assessment tools requires further study.

Recovery presents additional obstacles for deaf people. According to Sandberg the three factors that have a strong positive influence on staying sober include talking with family or friends about sobriety, employment, and involvement in self help groups (1996). More recently, Guthmann & Blozis (2001) reviewed follow-up reports for 100 people who completed inpatient treatment at the Minnesota program and identified two main obstacles people face when leaving the program. Firstly, local educational facilities, support groups, and counsellors may not be available and secondly, few people completed treatment and returned to a positive, supportive, healthy environment. Rendon (1992) concludes that many Deaf people recovering from substance abuse may find it difficult establishing new friends and support networks due to the size, cultural and level of knowledge around alcohol and drug use and treatment within the Deaf community.

When presented with the choice of a treatment service for everyone with special resources for sensory impaired clients or a treatment service for sensory impaired people only, the FRM survey participants selected a service for everyone, while focus group participants tended to favour a deaf/blind only service. Those opting for a mainstream service were concerned about further segregation and community gossip, whereas those wanting a service specifically targeting the needs of deaf/blind people thought they would have more confidence in the staff (FRM, 2002).

Whitehouse et al (2001) also supports the idea of specialised programs; however the report stressed the need for deaf services to access staff with addiction qualifications and the need for deaf and substance abuse service providers to work together.

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## Education

Access to mainstream education sources generally relies on English language skills. With limited resources available to the Deaf community, the flow of information can be fragmented.

Deaf people tend to be cut off from regular modes of communication; therefore they receive little or no information about drugs and alcohol and limited knowledge about resources available (Lipton & Goldstein, 1997). Limited information about alcoholism and substance abuse, according to Rendon may lay the groundwork for increased incidence of chemical substance abuse (1992). Furthermore, Deaf people may not know about the risks of using alcohol and other drugs and are not prepared with the necessary skills to deal with the dangers as they present (Guthmann & Sandberg 1998). For example, researchers in Glasgow found that sensory impaired people were unfamiliar with the term 'unit' in respect to alcohol content in a bottle of wine/pint of beer (FRM, 2002). However, it is unclear if it was the use of the word 'unit' or the actual concept that people were unsure of. Another UK study reported similar findings that Deaf people are often unaware of information such as the safe levels for alcohol consumption for example, or the dangers of sharing needles, because they do not receive much information from mainstream sources (COI, 2004: 16).

In term of young deaf people, Tamaskar et al (2000) found that deaf high school students are not as knowledgeable about health information as their hearing peers. In part parents and teachers may not have the appropriate vocabulary or level of knowledge to educate young deaf people when they seek advice and support (Drug and Alcohol Education and Prevention Team, 2004). In America, prevention curricula in schools generally do not accommodate the communication skills of deaf and hard of hearing children (Guthmann & Blozis, 2001).

Information provided through print, television, radio or telephones is inaccessible for many Deaf individuals. Unless captioned, television announcements are considered inappropriate. Young deaf people indicate they want drug education and information that is clear; not patronising; easy to assimilate; fairly direct; visual and has not much content (COI Communications, 2004). Similarly, deaf and hard of hearing people involved in the Queensland deafness and mental health project wanted access to the same information that was available to the hearing community but in an easier to understand format. While the focus of this research was mental health a number of participants requested information on alcohol and drugs (Queensland Deaf Society, 2004). According to the study in Greater Glasgow, Deaf people prefer to receive information from another person, preferably signed, and written information should be visual with simple dot points (FRM Research, 2002). Information should be available to professionals, community members, parents and young people. Tamaskar and colleagues (2000) advocates the use of peer educators to introduce accurate information to the deaf and hard of hearing. The Drug and Alcohol Education and Prevention Team also supports the use of peers, suggests integrating role-play to develop skills such as keeping safe and using visual material to support written documents. Peers are also an important link to understanding 'street' signs for different drugs (2004). Guthmann & Sandberg (1998) suggests prevention programs should incorporate the cultural aspects of deafness, a range of communication modalities, access to recovering Deaf role models, access to Deaf and/or impaired AA/NA meetings and materials available in sign language or modified written English.

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A wide range of Deaf friendly written and electronic resources is available in the United States. The MCDPDHDI centre has developed a range of signed and captioned videos and DVDs and produced written guidelines targeting practitioners and individuals dealing with and recovering from substance misuse. Fewer deaf specific resources are available in the United Kingdom and Australia. Alcoholics Anonymous Australia is currently developing a video in Auslan (AA Australia, 2006).

### 3.3. Focus group themes

The focus groups said:

- General services do not always use an interpreter when they have a Deaf client.
- Interpreters worry that their Auslan skills are not good enough to work with some clients.
- When people stop drinking alcohol and/or taking drugs after a long time, they may find it hard to make new friends in the Deaf community.
- Deaf friendly education material should explain the short and long term effects of alcohol and drug use. Also information about different alcohol and drug services should be available.
- Different information should be available for young people, older people and parents.
- Deaf people who use drugs and drink alcohol may not be connected to the Deaf community. These people may not receive information via the Deaf community. Deaf friendly education should be available in mainstream services.
- Some people like going to Deaf only services and other people prefer to go to a mainstream service. Deaf people want the choice.

The focus groups elicited discussion on communication issues, on aspects of Deaf community, on the educational resource needs of the Deaf community, and on directions for the service system. Themes echoed many of those raised in the literature and are summarised below, with examples of participants' words.

#### Communication

Interpreters are sometimes not sought:

*[In one homeless organisation] more and more young deaf people were actually there at nighttime to sleep. And there was no communication for them whatsoever, they just went there to sleep (FG1)*

On interpretation, finding an interpreter can be an issue:

*I've got a client who said I've wanted to get a couple of interpreters, and they book the interpreter and the interpreter asked who the client was and then panicked. And said 'oh no, I can't work with this person, you need a level 3, I couldn't possibly do the job' (FG2)*

Communication issues are complex in group and individual counselling:

*Group: Some people go into the situations and they feel completely out of place, they are out of their depths defining certain feelings, anger, shame, sadness, frustration, and perhaps a deaf person is not identifying with this*

*because they might not have had the education to identify with the kind of issues that would come up in a support group. They can actually feel more oppressed in that environment, rather than in the one on one situation. One on one is generally better and possibly very small group for Deaf people. Support groups are generally not Deaf friendly, so it is developing language about emotion as well.*

*Moderator: what about counselling services? Do you think one on one counselling service can be are they good, do they work well?*

*Group: If the counsellor has patience.*

*I'm laughing because I know some clients who go through counselling services and again it goes back to concepts, expressing emotions and that can be a really difficult thing for Deaf people to do. The same time I'm thinking, going through a third person, some clients are very very reticent, they don't trust the person, they don't believe the person will understand their issues, most counselling situations have an interpreter involved so there is another person involved in the scenario who is there getting involved in their life. So you wish it is simple to have a one on one but it is not. For some clients it is not a problem but for some clients it can be very difficult. (FG2)*

## Deaf community

There was thought to be a need for better understanding of how Deaf people can become isolated and how the Deaf community can help or hinder their coping with AOD problems:

*One thing I find when I am working with clients who have given up drugs or alcohol their emotional maturing is not age appropriate. If someone started drugs at 17 and continued on they give up in their 30s often they then go back to behaving like a 17 year old because emotionally they haven't developed through the rest of their life experiences...(...)And I find often they can't make new friends because the Deaf community has already stigmatised them (....) and if they don't get new friends they'll often get back into their own group. So we don't help them, we 'the Deaf community' don't help them. We have that responsibility but we are often unhelpful to people who have been entrapped. So it doesn't really resolve the issues that they are trying to get away from. That is something that I have observed. (FG2 p13)*

Focus groups in the current project did not venture any confident opinions on whether AOD problems were more or less prevalent in the Deaf community than in the general population.

## Education needs

Participants thought that education on alcohol and other drugs should include:

- Education about rights under the DDA
- Drug effects (FG1 12), including long term effects:

*I would like to know, drug education doesn't really cover long term effects, life long effects, effects on pregnancy and things like that. There needs to be drug education on a long term basis that really encompasses all of these factors.*

- Treatment types (FG2 – case managers - asked about these and received a summary)
- Need for reintegration after treatment (with an implication of reducing stigma)

*Just thinking what we said before, a very important aspect of treatment is the community reintegration skills – [they are] ignored. Getting people into these services might be one thing, but getting them back into the community I think is another very difficult step. (FG2)*

Education should be aimed at the whole Deaf community, with particular resources or styles designed for younger or older people, and for parents.

*Just thinking about the education and providing the kits, I believe we need to have two kits, one for adults and one for children. Because I think that the pictures would be quite different, for the two different target groups (FG2)*

Information also needed to reach people who have isolated from the Deaf community because of AOD problems, and to reach them through mainstream channels, including the health and justice sectors:

*...people are withdrawing from the Deaf community, if they stayed within their community people would help, but because they become embarrassed they don't want people to help, they don't want people to know about their addiction, they isolate themselves from the Deaf community, so you can't through the Deaf community help these people at all, so you need to get out there and inform all the agencies. (FG1)*

## Directions for the service system

The question arose as to whether services should be Deaf-specific or mainstream. It was agreed that choice was important but that there were distinct advantages to building capacity in mainstream services:

*Sometimes Deaf people like to go with hearing people, they feel it is more secure in terms of privacy issues, sometimes they like to go to Deaf people. I think if there were hearing organisations (..) with Deaf drug workers, I think they might be more effective rather than something here at the deaf society. It gives people more options as well, more choice. And it also means the [mainstream workers] can work with their colleagues and educate them about working with deaf people. (FG2, p17)*

*We don't need to set up services purely for the Deaf community but what we need to do is help those services become more accessible to deaf people and be more aware of the needs of deaf people. When a Deaf person accesses that service they need to know, automatically, I need to book an interpreter (FG1)*

*It is not just interpreters, but workers' attitudes. That is a big thing. The eye contact issue with deaf people, a lot of workers are not able to make eye contact and maintain eye contact (FG2)*

*Also how they give service, how they give information, often they will give it in a way that goes completely over somebody's head. They need to take time to explain maybe be using visual aids such as videos. It is how they provide the information. I think they just fail. Think of the amount of funding they have,*

*and how many clients they have, I don't think a lot of them are doing a good service (FG2).*

Deaf-specific services were mentioned as successful in a larger population and desirable in Victoria.

*I think we need to set up a specialist unit in a hospital for Deaf and hard of hearing people. Specialist drug and alcohol program is absolutely required. But they say St Vincent's hospital has a Koori service with 5 beds. In America in Minnesota they have a specific unit that is for deaf people, it is staffed by deaf people, counsellors are provided and it is a 10 month program where people can go in, it is very very successful and that I think is the best resource (FG2).*

In response, others considered the advantage of integrated Deaf-specific support around commonly co-occurring issues, such as mental health and AOD problems:

*Because the community is small, so you are always competing for the resources so trying to set up things in one base because you are not going to be able to replicate it across Victoria or even in different parts of Melbourne. But to try and have a specialist service somewhere that could offer that whole range of things, and then perhaps have the worker, the educator to go out to the different communities. That is the sort of model that I think we should be looking at. (FG2)*

There was a need for Deaf counsellors and support workers

Participants had frequent contact with mainstream agencies as part of their work and felt that much improvement was needed. They identified several characteristics of an effectively deaf-aware mainstream AOD treatment service:

- Staff are educated in deaf awareness (underlying issues related to deafness; how to start communicating, how to book an interpreter)
- Deaf staff are employed or there is an Auslan signer on staff and available
- The service is able and willing to secure prompt and adequate funding for interpreters ( a three-month wait was cited, and instances of no service at all)
- The client's right to choose the interpreter is respected
- Staff know how to work (counsel) with an interpreter in the room
- Staff understand confidentiality issues around interpreting
- The interpreter is briefed in advance about client background
- The service is aware of the risk of doing more harm

*rehab can't really help the person because there is no interpreter there so what is the point of sending them to rehab? So really they become more lonely and isolated when they are in the rehab situation with other hearing in-patients. (FG1)*

- There is a willingness to understand and deal with deep communication differences.

## 4. SURVEY FINDINGS

The survey response said:

- Limited Deaf friendly alcohol and drug information. People would be happy to get information from the internet, friends and doctors. People wanted to know where to go for help, the health problems associated with using drugs and alcohol, and the effects of alcohol.
- People thought that alcohol and drug information should be available in Auslan and Deaf people should present the information. Deaf friendly material needs to be available.
- Most people were aware of the term 'standard drink' and what it means. Also, most people accurately estimated the number of standard drinks men and women can drink before increasing the likelihood of experiencing alcohol related harm in the short and long term.
- Half the participants said they were worried about either of friend's or a family member's drinking.
- The majority of people who answered the survey said they have had a drink of alcohol at some stage in their life. Fifty five people had drunk alcohol in the past 12 months. The majority drank at levels considered low risk in the short and long term. People generally drank alcohol in their own home, at a pub or club, or a friend's house and they mostly drank with friends or a family member.
- A few people said they wanted or tried to drink less alcohol but could not stop.
- Less than half the survey participants said they had taken an illegal drug in their lifetime. Twenty nine people had used drugs in the last 12 months. The most common drugs ever used and used in the last months were marijuana/cannabis, methamphetamine, and ecstasy.
- The most common reasons why people use drugs were because they wanted to see what it felt like, their friends used drugs and/or gave them some to try and they wanted to do something exciting. People who didn't use drugs generally did so because they were not interested in taking drugs or they did not want to become addicted.
- People were concerned about young people's use of alcohol and drugs, and mental health. Participants also commented on the stigma attached to alcohol and drug problems, lack of privacy and identity issues in association to the Deaf community.
- The majority of people had noticed someone acting physically violent or using abusive words and/or sign while intoxicated. For most people they say this type of behaviour at a party, pub or in the street. In most cases the person using bad behaviour was a stranger or a friend.
- Very few participants had discussed alcohol and drugs with a health professional.
- If people needed to go to see a health professional about their alcohol or drug use, the majority of people did not want to go to a service for Deaf people only. Having a choice of different places to go where their needs would be met was considered very important.

This section includes summary data obtained from the online survey. A total of 68 people completed the survey. As the number of participants who answered each question varied, a comprehensive table of results is included in appendix 1.

Available results from both the 2004 National Drug Strategy Household Survey (AIHW, 2005) have been included throughout the results section to provide a picture of the national situation and prevalence rates. Due to sampling and other methodological differences between the national survey and this survey, these results are not strictly comparable.

Results from the FMR Research conducted in Greater Glasgow are also included and, for the same reasons, direct comparisons are indicative only.

## **4.1 Demographics of the survey participants**

Survey participants were asked a series of questions about their cultural and linguistic background, work status, living arrangements, communication modes, social networks, and general demographic information.

A total of 38 females (55.9%) and 30 males (44.1) completed the survey. The age distribution ranged from 22 years to 59 years, with an average of 35. The majority of participants lived in Victoria (73%) and a small number lived in New South Wales (21%). The remaining participants were from South Australia and Queensland.

Approximately 80% of the participants self identified as Deaf and 11.8% identified as Hard of Hearing. Three participants were hearing. One person self identified as both Deaf and Hard of Hearing and one person was Hearing Impaired and one person communicated orally.

Three out of four participants stated they were working (76.1%). Six (8.9%) participants were engaged in study, either full-time or part time (combined with other responsibilities such as parenting and working) and two participants were stay-at-home parents. Three participants indicated they were on a pension and one participant was unemployed.

The majority of participants lived with another person(s) (86.4%). When asked who they lived with, most people said either a spouse/partner (26.8%) or a spouse/partner and child(ren) (32.1%). Those living alone accounted for 10.6% of the participants.

Auslan was the main mode of communication used by the participants (52.9%), followed by speech (23.5%) and lip-reading (10.3%). Some participants stated that they mainly used a combination of Auslan, speech and lip-reading. All participants who stated that they mainly lip-read or spoke communicated in English.

Most of the participants were born in Australia (94.1%) and of those people 72.7% said their parents were also born in Australia. Of those with parents born outside Australia, most parents were born in Europe, followed by Asia, the Middle East and North America.

Three participants self identified as Aboriginal or Torres Strait Islander.

Close to half (43.9%) the sample reported spending most of their time with Deaf people and 33.3% of the participants mainly associated with hearing people. Ten people said they spent time with both hearing and deaf people and four people socialised with Deaf, Hard of Hearing and hearing people.

Participants were invited to comment on the way they communicate. The majority of people mentioned switching between Auslan and oral communication to match the communication skills of others.

*I transfer communication skills for certain people - sign for deaf, speak for hearing.*

*In my lifestyle, I communicate by lipreading and speech at work and at home, but socially, I prefer Auslan as it is the easiest and most comfortable method for me.*

## 4.2 Alcohol and other drug education

To gauge participants' awareness of and need for Deaf specific alcohol and drug education a number of questions were asked around content, source, format and usefulness of information.

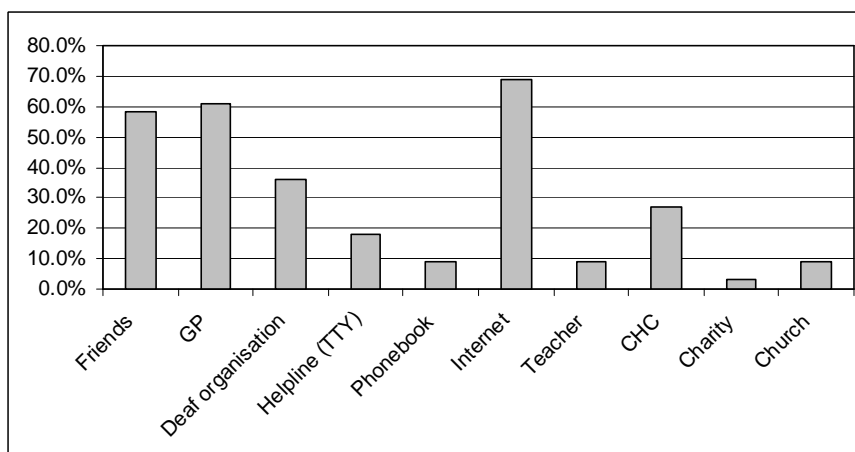
Most of the participants were unaware of any alcohol and/or drug information for the Deaf community (77.8%, n=63). Of those with knowledge of AOD information for the Deaf community (n=14), where to get help and the effects of drugs and alcohol were the three main messages gained from the information. In general people obtained AOD information from the Internet, friends and Deaf organisations. The information was provided via brochures, sign language, and internet sites.

Twelve of the 14 participants understood most of the information and only one person did not find the information useful. Generally participants considered the information to be good as it was easy to understand, the information was Deaf friendly and it looked good.

All participants were asked to nominate where they would go if they wanted information about drugs or alcohol, either for themselves or another person.

The most nominated source was the Internet (68.7%) followed by friends (58.2%), GPs (50.7%) and Deaf organisations (35.8%). Over half of the participants wanted information about the effects of drugs (65.9%) and ways to help a friend or family member who uses alcohol and/or drugs (65.9%). Participants also wanted information about where to go for help (56.9%), the health risks of using alcohol and drugs (55.2%) and the effects of alcohol (50.0%).

**Figure 1: Place where people would go for information (n=67)**



### 4.3 Alcohol and standard drinks

This section provides information about participants' knowledge of the 'standard drink' and their perceptions of alcohol related harm. As in the 2004 National Drug Strategy Household Survey (NDSHS), a definition of a 'standard drink' was provided together with a guide depicting the number of 'standard drinks' contained in common alcoholic beverages. The National Health and Medical Research Centre (2001), defines a standard drink as a drink containing 10 grams of alcohol (equivalent to 12.5 millilitres). A glass containing 100mls of wine or 285mls of full strength beer is regarded as a standard drink.

The NHMRC established guidelines on alcohol consumption based on a thorough literature review of alcohol-related morbidity and mortality. The guidelines considered consumption levels and the corresponding likelihood of experiencing alcohol-related harm. Alcohol-related harm is broken down into three risk categories. These are

...low risk consumption, where risks were minimal and included the potential for health benefits; risky consumption, where risk of harm was significantly elevated relative to any potential benefits; and high risk consumption, which represents substantial risk of harm that increases rapidly with increased intake (NHMRC, 2001: 18).

In order to account for a range of drinking patterns the levels of risk distinguish between acute harm (short term risk) and chronic risk (long term harm). Consumption levels and the associated risk of alcohol related harm differs for men and women due to metabolic and genetic differences (NHMRC, 2001).

**Table 1: Summary of the NHMRC risky drinking guidelines for the general population**

Short term	Low risk	Risky	High risk
<b>Men</b>	6 std drinks on any one day; no more than 3 days per week.	7–10 std drinks on any one day	11 or more std drinks on any one day
<b>Women</b>	4 std drinks on any one day; no more than 3 days per week.	5–6 std drinks on any one day	7 or more std drinks on any one day
Long term	Low risk	Risky	High risk
<b>Men</b>	An average of up to 4 std drinks per day.  28 std drinks per week	An average of 5–6 std drinks per day.  29–42 std drinks per week	An average of 7 or more std drinks per day.  43 or more std drinks per week
<b>Women</b>	An average of up to 2 std drinks per day.  14 std drinks per week	An average of 3–4 std drinks per day.  15–28 std drinks per week	An average of 5 or more std drinks per day.  29 or more std drinks per week

Source: NHMR, 2001.

Most of the participants surveyed were aware of the term ‘standard drink’ and its meaning (70.1%). Over half the participants were either unsure (29.9%) or did not know (26.9%) that the number of standard drinks was displayed on cans and bottles of alcoholic drinks.

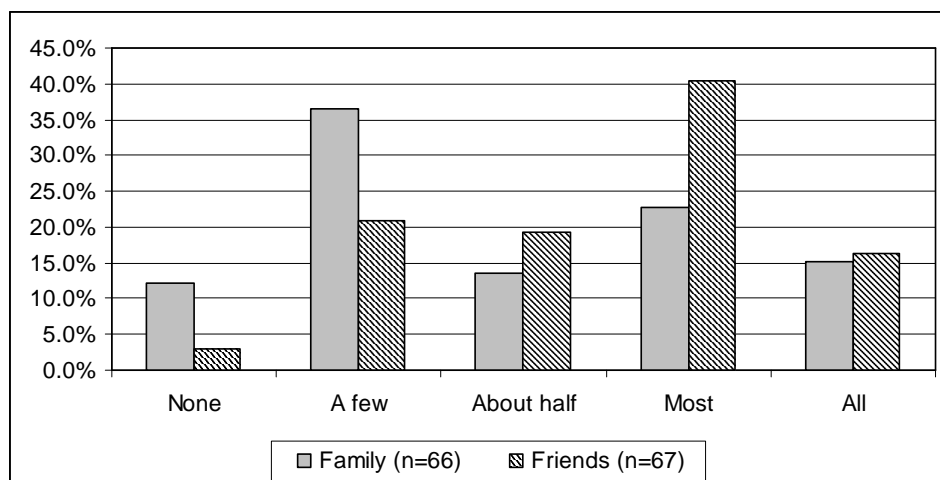
Participants were asked to estimate the number of standard drinks that males can consume over six hours and still be at low risk of experiencing acute alcohol-related harm. Approximately one out of three (32.2%, n=59) reported that males could drink 3–4 standard drinks and approximately another third suggested a male could have 5–6 standard drinks without increasing their risk of alcohol-related harm. A small number of participants (10.2%) thought that males could drink 7–10 standards drinks in six hours and remain healthy. Participants reported a lower number of standard drinks for females, with half (n=59) reporting 0–2 standard drinks in a six hour session and the remaining half spread between 3–4 standards drinks (37.2%) and 5–6 standard drinks (11.9%).

Respondents were also asked how many standard drinks a person could consume without increasing the likelihood of experiencing alcohol-related harm in the long term to risky or high risk levels. Forty per cent (n=60) of the participants though a male could consume two standards drinks every day, while 28.3% said three and 18.3% considered four standard drinks per day to be acceptable. A similar number of participants (45.8%, n=59) thought that women could drink two standard drinks every day. Very few participants (6.5%) thought that women could drink three or more standards drinks every day without increasing their risk of alcohol-related harm.

Based on this information the participants are aware of the standard drink and most make accurate estimates of what constitutes low risk drinking.

Participants were invited to estimate how many of their family and friends drank alcohol. Generally more of the participants reported that their friends consumed alcohol than their family.

**Figure 2: How many of your family and friends drink alcohol?**



Half the participants (n=65) reported that they were worried about either a friend’s or a family member’s drinking.

## 4.4 Alcohol use

Approximately 80% (n=67) of the participants had ever consumed alcohol. Based on the Glasgow study 75% (n=53) of the Deaf participants had ever drunk alcohol and the 2004 NDSHS reported that “83.6% of Australians aged 14 years and older had ever consumed a full serve of alcohol” (pg 25, 2005).

Of the 56 people who reported that they drank alcohol, one person had abstained and 55 participants had an alcoholic drink in the last 12 months.

Of these 55, the majority reported they drank alcohol either 1–2 days per week (29.1%) or 2–3 days per month (23.6%). Twenty per cent of these participants drank alcohol three or more days a week.

Participants were also asked to report how many standard drinks they would usually drink on a day when they drank alcohol. Of the 52 participants who provided a response, 48.1% reported to have 1-2 drinks and 25% indicated they drank 3–4 standard drinks.

On a yearly basis 52.8% (n=53) of the participants drank at levels considered at low risk of harm in the short term, and 45.3% drank at levels considered risky to high risk of harm in the short term. The level of risky to high risk harm in the short term decreased when drinking patterns were analysed on a monthly and weekly basis (22.6% and 9.4% respectively).

The majority of participants (85.7%, n=56) drank at levels considered low risk in the short and long term. In the Australian population the level of low risk drinking is 64.1% (AIHW, 2005).

The most common places that people drank were in their own home (70.9%, n=55), licensed premises such as pub, bar or club (67.3%), a friend's house (61.8%) and at a party at someone's house (60.0%). This is a similar picture to the national population, but it is important to note that the national figures are based on people aged 14 and over. The Glasgow study found that Deaf tended to drink at a pub or a social club more than at home (FMR Research, 2002).

Over 80% (n=55) of people drank with their friends and 45.5% drank with family members. A quarter of the participants drank alone. According to the Glasgow study, the majority of their Deaf sample drank with friends (89%) and family (31%), though only 3% drank alone.

Ten participants reported that in the last 12 months they wanted or tried to drink less alcohol, but could not stop (n=50) and 17 participants indicated they drank a lot more alcohol than they wanted to (n=53).

## 4.5 Illicit drug use

In this report the term ‘drug’ encompasses recreational drugs (excluding nicotine) and prescribed drugs used for non-medical purposes.

Less than half the participants (43.9%, n=66) reported having tried a drug. The national figure is 38.1% for Australians aged 14 years and older and over half the people aged between 20-39 had used an illicit drug (AIHW, 2002). Half the female participants (n=38) had ever tried drugs, while 35.7% (n=28) of the males had ever tried drugs. In the national survey men were more likely to have ever use illicit drugs compared to women (AIHW, 2005).

According to the 29 participants who had ever tried drugs, marijuana/cannabis (86.2%), methamphetamine (48.3%) and ecstasy (41.4%) were the three most common drugs ever used. Participants reported having tried an average of two illicit drugs (range 1 to 10 drugs). According to the national survey, marijuana/cannabis, meth/amphetamines, ecstasy, and hallucinogens were the most commonly used illicit drugs.

One in four (24.2%, n=66) had used drugs in the last 12 months, with more men (70.0%) than women (47.4%) reporting recent drug use. One in six Australians aged 14 years had recently used any illicit drug. Again, males were more likely than females to have used a drug in the last 12 months (AIHW, 2005).

Based on the 16 participants who had used drugs in the last 12 months, marijuana (75.0%), methamphetamine (37.5%) and ecstasy (31.3%) were again the main drugs reported. On average people had used only one drug in the last month (range 1 to 5, median 1). In the AIHW 2004 survey, the most commonly used illicit drugs were marijuana/cannabis, pain-killers/analgesics, ecstasy and meth/amphetamine, and the majority of recent users of illicit drugs had used only one kind of illicit drug in the last 12 months (AIHW, 2005, pg 33).

Of the 12 people who used marijuana in the last 12 months, four people had used every few months, three used once a week or more, and another three people used the drug once or twice in the last year.

Only two participants had ever injected, and one person had injected in the last 12 months.

Participants who had ever used recreational drugs were asked to nominate from a set list the reason(s) for first wanting to use a drug. Participants could select as many factors as they wanted. 'Curiosity, wanting to feel what it was like' (46.4%) was the most reported reason, followed by 'their friends used and/or offered them drugs' (39.3%), and 'wanting to do something exciting' (17.9%). The same reasons were the three most common factors reported in the national survey (AIHW).

Similarly people who had not used drugs were also asked to provide a sense of what may have contributed to their decision. Three quarters of the participants said they had no interest in taking drugs, and 50% reported they did not want to become addicted. Concerns about health problems (38.9%), and not thinking they would enjoy using drugs (36.1%) were also common reasons. The AIHW survey found that no interest, and reasons related to health and addiction were the most common influences (AIHW, 2005).

#### **4.6 Experience of violence or abuse ('Bad behaviour')**

The study also wanted to explore whether participants had observed people drug related incidents such as people acting violently or abusively while intoxicated. In the survey, violent or/and abusive behaviour was referred to as 'bad behaviour'.

The majority of participants (84.6%, n=66) reported seeing people 'acting physically violent' or 'using abusive words and/or sign' when using alcohol and other drugs. Based on responses from 54 participants, drug related abuse was generally observed at a party (77.8%), a pub or club (72.2%) or in the street (53.7%). According to the national survey, the street was the most common location where the abusive incidents occurred (AIHW, 2005).

Participants were also asked who they saw acting abusively and/or violently. From a set list of responses (e.g. my child, friend), 75.5% of the participants 53 said a stranger, and 54.7% said a friend. Less than 10% of the participants indicated that they observed their parent, child, relative, flat-mate or ex-partner using bad behaviour. The AIHW survey also found that strangers were in general the main perpetrators of alcohol and/or illicit drug related abuse (AIHW, 2005).

## **4.7 Health Services**

Ten participants had discussed alcohol and drugs with a health professional (n=65). Five participants talked to a health professional about the effect of drugs on health and four of the same five people discussed the effects of alcohol on health. Across the ten participants a range of other areas was discussed:

- what drugs they used (three people),
- ways to cut down or use less alcohol and other drugs (three people).
- safer ways to use drugs (three people),
- alcohol and drug use in their family (2 people),
- problems related to alcohol and drug use (2 people),
- places to go for help (2 people)

After talking with the health professional, four of the ten participants said that something changed: they knew more about drugs, two said they had reduced their drug and/or alcohol intake and two had thought about making changes.

Participants were also asked what kind of service was best suited for a Deaf person experiencing difficulties with alcohol and or other drugs. Participants were given the choice of four options and were required to select one. The majority of participants preferred services for everyone, either with Deaf staff available (40.3% n=67) or an Auslan interpreter (34.3% n=67). Approximately 10% suggested a service for Deaf people only. Three participants were undecided.

In the Glasgow study, a higher number of Deaf participants opted for deaf/blind only services (40%), than a mainstream services with special resources (33%) (FMR Research, 2002).

## **4.8. Survey participants' comments**

Participants were invited to comment on alcohol and drug education, AOD use in the Deaf community and the services needed either by the community or the individual to help prevent and solve AOD problems. Responses were coded according to the themes of education, community issues and ways forward.

### **Education**

Comments related to education covered the content of the education, how to deliver the information, possible formats, target groups and places where the education could be available.

In regards to the content, a broad range of topics was identified including:

- General AOD and ‘awareness of the impact on self, family, personal relationships, work, health etc’
- Young people and peer pressure
- Risk-taking behaviour associated with AOD use
- Short and long term health issues,
- How to recognise when you have drug problem
- How to stop using or drinking
- Treatment options such as support groups
- Mental health and AOD - ‘address the depression problem’
- How to remain sober
- Early intervention service
- Providing support to others
- Personal experiences
- Relationships
- Alternatives to taking drugs
- Services and where to go if need help

Across the board participants thought a Deaf person or someone with appropriate linguistic and Deaf cultural awareness skills should provide the information and/or services. In some cases participants suggested inviting people to share their personal experiences of using alcohol and drug as a way to educate others.

*Services with staff appropriately trained in Deaf language and cultural issues. Ideally Deaf and hard of hearing staff would be employed...*

*Workshops, clinics or discussions where deaf people can learn about people who've done drugs before and can relate to that person.*

*Information needs to be in Auslan and presented by a Deaf person for cultural and language purposes*

Appropriate language and communication media were considered essential. Possible formats included written material, comic strips and other visual information. Face to face formats might be workshops, discussion groups, presentations, community events and clinics. Also, captioned health promotion messages screened on television could be an effective medium, as well as use of multi-media technology such as videophone and websites.

*Provide workshops (in both languages) for secondary aged deaf students in their schools or at deaf facilities, youth groups. Kids will not go to a particular venue to learn about drugs and alcohol. You need to go where the kids are.*

*You can provide information about your services for older deaf people via workshops or by DVDs.*

*There should be education seminars for deaf people and written material available. I am not aware of any."*

*It has been a long time since I received drug/alcohol education - most 'awareness' nowadays come from Government sponsored ads which are captioned (which is good). But I remember getting a terrific comic series in my teenage years about many issues affecting teenagers, and this comic was written/drawn by Deaf people for Deaf people which was great and helped get the message across to Deaf teenagers.*

*Provide DVD format for people who have poor English skills so that they are able to understand the information about drugs and alcohol.*

In line with the need to provide young people with information, participants suggested incorporating AOD information into secondary schools and tertiary institutions.

*I would like to see this project expanded to incorporate an early intervention service for Deaf and hard of hearing adolescents, whereby an education program could be implemented in schools, TAFE campuses and universities etc. which service Deaf and hard of hearing clients to hopefully prevent future addiction to drugs and alcohol*

One person mentioned the usefulness of incorporating brief reminders into newsletters

*Think the deaf community would benefit if reminders were sent out in newsletters like the deaf society's hand on news that is emailed out regularly. reminders are important. deaf people might not have time to go to workshops nor think they need to, but reading briefly in a brochure/email in a captivating way is a good reminder/educational input.*

## **Community issues**

### *a. Prevalence*

The level of use in the community, either participants' own use or other people's use, was a common theme:

*...my good mate have drinking problem I have try to help him, but when I am go bed, he go drink bottle of wine most every night , sometime I wake up 3 or 4 am saw my good mate fall sleep in lounge or outside.*

*I have heard of drugs being used but have never seen anyone 'using' however have seen some being on a 'high' and most are responsible with their use. None are into hard drugs though. Plenty of them over indulge with alcohol however.*

*I believe that there is a problem with alcohol abuse in the deaf community.*

### *b. Specific groups*

A number of participants expressed concerned about young people's use of AOD, and different issues were mentioned for older people. Mental health problems were also mentioned in relation to AOD use.

*It's pretty bad. The younger ones are hitting it hard. My age group I can see brain damage because of continual use of drugs. Mental health issues are included.*

### *c. Attitudes to AOD problems*

Participants commented on the stigma attached to AOD problems, lack of privacy and identity issues in association to the Deaf community culture.

*Reputations are more prone to damage within the Deaf Community cos everyone knows each other.*

*Peer pressure is strong in the deaf community and young adults struggling with identity issues may succumb to drugs in order to be accepted. I have seen this happen.*

These factors may inhibit people from discussing AOD issues and, if they need help, from seeking it within the Deaf community.

*The Deaf are suspicious of anything that may stigmatise them.*

*The issue is Deaf community is small so by asking for help, may end up being helped by someone they know from the small community. It's a real difficult situation to resolve - maybe consider videophone using a national interpreter.*

## **Directions**

A number of participants noted the limited access to services and support, and some posed the question "where will they go for help?".

*I am okay with alcohol as it is legal however people with heavy drinking may need help as long they admitted that they have a drinking problem but where will they go for help ? I dunno!*

A few people indicated that the same choice of the services available to the general community (hearing community) should be available to the Deaf community.

*The same as a hearing person, with communication methods considered*

Apart from education, participants mentioned the need for the whole range of treatment and support services, including self help groups and help lines, and one person suggested a drop in centre for young people.

*The deaf community need to establish a youth group or a drop in centre with a cafe and a pool table where they all can hang around, free of charge, otherwise they would prefer to use their money on drinks or drugs.*

Some participants suggested employing peer workers.

*Deaf role models, deaf people (maybe past alcohol/drug users) working in places to help others break the habit.*

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In most cases, participants added that the service should meet the communication needs of the Deaf community and for many participants this meant providing an interpreter. The cost of interpreters and the need to provide free interpreters was also mentioned by a number of people.

*Need a counsellor who understands that the Deaf would be different from the hearing community and treated as such. Probably this would be the ideal situation for a Deaf Relay Interpreter.*

*I can't access sign language interpreters because they are cost prohibitive.*

The issue of confidentiality, both in terms of the need to provide a confidential service and the sense that people feel their privacy is not always assured within the Deaf community, was reported.

*Counselling and possible rehab. Needs to be very confidential because Deaf community is very small and word does spread around very quickly.*

Access barriers in rural regions were flagged, as was the increased sense of isolation experienced by Deaf people living in country areas.

#### *Action from this research*

For the most part, people were supportive of the project and acknowledged the need to encourage discussion about alcohol and other drugs within the Deaf community. A number of people indicated the need for action to flow from the study.

*A great opportunity to gather information on drug and alcohol use in Deaf community. A great idea to start! Hope it will help you all to make the next step!*

*Good initiative providing it results in action being taken rather than just an academic exercise. Results should be published and action to be taken stated.*

## 5. CONCLUSION

### Key points

- The extent of alcohol and drug use in the Deaf community remains unclear, but there is no evidence to suggest that it differs from the hearing population.
- Alcohol and drug education is rarely delivered in a Deaf friendly format and there was a strong call for Deaf friendly information.
- The Deaf friendly information should cover all the topics that are available to the hearing community.
- A Deaf person or someone trained in Auslan and Deaf awareness should deliver alcohol and drug information to the Deaf community.
- The Deaf community has a right to culturally and linguistically appropriate AOD services.
- The lack of services is a source of much frustration and concern.
- There is a need for training for both Deaf and hearing staff on the role of interpreters, how to address confidentiality and privacy issues, and ways to bridge the language barriers.
- The research said that Deaf people may prefer to use a mainstream service, if they can communicate effectively with staff through interpreters. Choice is important.
- Future action and research may include:
  - Deaf Awareness sessions for mainstream workers
  - AOD information sessions for Deaf community members, case managers and support workers
  - Production of Deaf friendly alcohol and drug material such as DVDs, based on reliable and accurate information
  - Supporting staff in mainstream AOD services to learn Auslan
  - Educating mainstream services about the Commonwealth funded National Auslan Interpreter Booking and Payment Service, and other interpreting services.
  - Advocating for services to collect information on their contact with Deaf and Hard of Hearing clients and use it in their planning.

## 5.1. Communication is key

The Disability Discrimination Act 1992 aims to promote recognition and acceptance within the community of the principle that people with disabilities have the same fundamental rights as the rest of the community. Deaf people have a right to equity of communication. Access to health professionals with expertise in their chosen field and proficiency in sign language is very limited and establishing effective means of communication is a challenge. Assessing the aetiology of a person's deafness and gaining an understanding of their education history and preferred mode of communication may provide valuable insight and improve the communication process. The need for better communication between Deaf and hearing should hardly need emphasis but we conclude that the barriers remain significant.

Although survey participants showed they were relatively well informed – at least in terms of low -risk drinking levels – they were people who could access a computer and the Internet and understand written English. All other data suggested that, in general, Deaf were not receiving the same quality of information as hearing people. Public information is not generally delivered by Deaf-friendly means and it is likely that the Deaf community has not picked up health promotion messages concerning AOD issues to the same extent as the hearing community.

In order to provide effective AOD resources to the Deaf community, communication methods need to acknowledge the fact that the Deaf community relies on sight, touch, movement, space and sensations to process information. Incorporating visual, tactile and performance-based information into all forms of communication may increase access to cultural sensitive resources.

## 5.2. Community considerations

Hearing loss affects one in six of the Australian population and is rising. People who identify as Deaf are less than 1% of the population, yet as a culturally and linguistically distinct group they face unique differences in access to public information. We have found no evidence that problematic AOD use is greater in this community than elsewhere, but when problems are encountered the effects may be compounded by lack of access to public services and by a lack of understanding in the (generally supportive) Deaf community. Community education should aim to minimise harm by increasing understanding of safer AOD use, reducing stigmatising attitudes towards illicit drug users and dependent drinkers so that they are less isolated, and encouraging people to seek help when they are negatively affected by their own AOD use or that of the people around them.

## 5.3. Education resources

There is little or no knowledge of any Deaf specific AOD education resources and a strong call for Deaf friendly information to be available to the Deaf community. Content, language, mode of delivery and the need to pitch information to specific groups were the main points discussed.

Equity of access is a major concern: the Deaf community cannot currently find accurate, comprehensive and current information in appropriate language. The need for the same information that is available to the hearing community is the resounding message from the Deaf community. Information clearly needs to cover the broad

range of AOD messages including harm minimisation, early intervention, treatment options and effect of different drug types.

Acknowledging the communication and language needs of the Deaf community is also part of the equation. Both the focus group and survey participants highlight the importance of having a Deaf person present the information in Auslan. Alternatively, an interpreter should be used. It seems fair to say that providing information in a person's language of choice is a necessary part of the education process. Also, information maybe absorbed more readily and people may be more comfortable to ask question and seek clarification in their own language.

Despite the lack of Deaf specific resources, the members of the Deaf community come into contact with alcohol and drugs and like the hearing community, alcohol, cannabis and methamphetamines are most common drugs that people use. Friends and the Internet are two of the main sources of information. Obviously, this is not unique to the Deaf community; however, the difference lies in the lack of alternatives available to the Deaf community. There seems to be resistance within the Deaf community to talking openly about alcohol and other drugs and the 'grapevine' system is thought to stymie the flow of information. In terms of delivering Deaf specific AOD education, the challenge lies in how to package information in a way that promotes general discussion and confront the stigma attached to alcohol and drug use. The role of the 'grape-vine' in raising awareness around alcohol and drugs requires further examination as it is regarded as a very effective communication system.

Capitalising on the advances in multimedia technology by incorporating Auslan into web pages or DVD is another strategy. Harnessing the available technology and increasing the use of visual information within text-based mediums will address the language barriers. Information can be tailored to different audiences.

#### **5.4. Continuum of Deaf friendly services**

This study suggests that there is a need for equity of access to a range of treatment services such as information, counselling, rehabilitation and post treatment support. Central to the discussion is a sense of frustration around the lack of choices available to Deaf people and the shortage of professionals with both AOD skills and Deaf awareness.

Currently there are no Deaf specific AOD services in Australia and, based on the information available to us, there appear to be few AOD services equipped to meet the communication needs of Deaf clients. Without specific data from all AOD agencies we cannot say how many services have staff with Deaf language skills, though anecdotal evidence suggests it is quite low. The current system appears to leave the Deaf community and the staff involved in a potentially precarious situation in terms receiving and providing an equitable service.

For anyone, the decision to engage in treatment takes courage, as it demands personal reflection and change. For Deaf people accessing a service is only the first of many hurdles: treatment does not just involve reassessing their drug use and life style, but it requires managing the logistics of finding an interpreter – preferably one familiar with the field of AOD - and working within a hearing framework. Relying on interpreters during treatment presents additional challenges especially in terms of an episode in a residential unit. Financial costs, booking requirements, and group dynamics aside, effective communication via an interpreter requires that all parties

involved are skilled in this form of communication and have some level of deaf awareness. Above all, services need to be conscious of the risk of exacerbating a person's distress by increasing their isolation as in the example of the Deaf person in residential rehabilitation without an interpreter or any other method of communicating with residents and staff.

What the ideal service looks like is unclear. We heard suggestions of Deaf only AOD treatment but the main message was that mainstream AOD services needed to be Deaf friendly. While both service models pose a different set of challenges and benefits, a common thread is the need to develop a multi-skilled workforce. In the short term it is reasonable to see that promoting relationships between Deaf services, AOD clinicians and Auslan interpreters may create opportunities to learn from each other and open up more avenues for clients. There is also scope to deepen understanding so that counselling practices more frequently encompasses visual and kinaesthetic modes of expression. This study only provides a glimpse of the situation, and further research is needed in order to build a more complete picture.

## 5.5. The future

If understanding is to be increased it is important that research (including action research and evaluation) is designed, funded and conducted to culturally and linguistically appropriate standards (Berman et al 2000). The current project made optimum use of its resources, but much was learned about potentially better approaches and VDS' role in providing training, facilitators, and interpretation was crucial to success. It is timely to repeat a participant's comment:

*Good initiative providing it results in action being taken rather than just an academic exercise. Results should be published and action to be taken stated.*

Action towards more equitable service can be pursued through collaborations between Deaf and mainstream services to raise awareness, set realistic priorities and trial incremental improvements in service delivery. These may include:

- Ensuring mainstream organisations are aware of how to book government funded interpreters (e.g. through state Deaf organisations and through the National Auslan Interpreter Booking and Payment Service, NABS) for private counselling.
- Deaf Awareness sessions for mainstream workers
- AOD information sessions for Deaf community members, case managers and support workers in Auslan and preferably by Deaf people in person.
- Production of Deaf-friendly DVDs based on Australian Drug Foundation AOD information.
- Joint presentations at conferences and other professional development occasions
- Secondment of treatment and support staff between Deaf and mainstream organisations
- Mainstream organisations reviewing routine data collection so that more is known about their contact with deaf and hearing-impaired people (i.e. do they

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include Auslan in their list of preferred languages used? do they ask about sensory impairment?

- Supporting staff to learn and use Auslan
- Seeking opportunities for the recruitment, training and support of Deaf staff in mainstream agencies

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