



**CENTRAL WEST  
GIPPSLAND**  
Primary Care Partnership



**Equal Access Extra Risk  
Research With Carers**

## Introduction

Although there has been a strong link made between problem gambling and people with intellectual disability (ID) or Acquired Brain Injuries (ABI), the reason for the link is currently unknown (DoJ, ND). Guercio (2007) found a rate of 25 percent of people with an ABI had gambling problems, compared to 1-2 percent of the general population. Kalinowski (2007) also found that problem gambling is over-represented in people with intellectual disabilities. While the reasons for the link is still being researched, possible explanations have been suggested which include difficulty processing the random nature of gambling or that it is used as a coping mechanism for social isolation (DoJ, ND).

An issue which is often overlooked is that a gambling problem for a person with a disability might not involve spending a lot of money, usually only around twenty dollars a week. However for an individual with a disability this may be a considerable percentage of their income and can quite easily cause them harm (DoJ, ND). It has been suggested that as people with an ID or ABI often experience limited access to recreational activities and social support which may lead people with an ID or ABI to develop gambling problems (DoJ, ND). D'Aegher and Robinson (2006) suggest that people with intellectual disabilities are at-risk of problem gambling in part due to isolation. The risk of problem gambling in people with an ID or ABI has been raised in the Gippsland Community as a serious concern, with lack of social activities being highlighted as an issue. To address this, a project has been initiated, funded by the Victorian Responsible Gambling Foundation and include Central West Gippsland PCP, LCHS, Rural Access Workers, the Department of Health, SCOPE and Monash University. Rather than focusing on the prevalence of problem gambling in people with an ID or ABI, the project took a health promotion approach, identifying areas in people's lives which play an inherent role in increasing their risk of problem gambling.

As there are so many life factors that can influence peoples gambling habits, the research was focused on social inclusion within the community and engagement for people with an ID or ABI. The aim of this research was to determine the views of carers of people with an ID or ABI on equal opportunities of those people that they care for in relation to social and community activities. The research will investigate the level of education/resources regarding social and community activities and the implications of such activities, including barriers and enablers to social inclusion and community engagement for people with and ID or ABI and their carers.

## Methodology

This research was one part of a multi strategy project which looked at improving resources, education, training and access to the community of people with and ID or ABI. The project focused on the carers, people with an ID or ABI and gambling venue workers. Ethics approval was received for this specific research from both Monash University and the Victorian Responsible Gambling Foundation.

Two focus groups of carers of people with an ID or ABI were undertaken in the Latrobe Valley and East Gippsland region in April 2013. The only requirements for participants were that they care for a person with an ID or ABI. The focus groups were led by an experienced facilitator, the CWGPCP project worker and LCHS community education officer. The attendees were recruited from carers support groups, local day services and through an advert in the local paper. They were audio recorded with permission. The explanatory statement and consent forms were given to participants for signed consent before the focus groups began, whilst the facilitator and project worker were also available to answer any questions.

The themes developed for the focus groups were;

- Social activities, barriers and enablers for people with an ID or ABI,
- Potential advantages and disadvantages of being involved in community social activities,
- People with an ID or ABI having the same opportunities and accessibility to resources or education and ability to discuss the advantages or disadvantages,
- Resources/education which would be accessible for people with an ID or ABI,
- Moving from managed budgets to individuals having control of their own money.

For ethical reasons the focus groups were facilitated around these topics and participants were not directly asked questions specifically around problem gambling. This research project did not target carers of people with a gambling problem. Pseudonyms have been used in this report to protect the identity of the participants.

## Results

Two focus groups were run for carers of people with an ID or ABI with a total of twelve people participating (8 at focus group 1, 2 at focus group 2 and 1 written response).

Of the participant carers, eleven were female and one was male. There were a total of eleven people the participants care for. The age range of those being cared for was between 15-70 with the average age being 36.9. Of those being cared for, five had an ABI, 3 had an ID and 1 had both an ID and ABI. Six of those being cared for still lived with their carers and five lived independently.

*From the focus groups the results have been themed into key areas. They are as followed:*

- *Enabler of community participation*
- *Barriers for community participation*
- *Risky behaviour*
- *Money and Budgeting*
- *What can be done?*

### **Enablers of Community Participation**

In both focus groups, social connectedness was seen as positive and an enabler of community participation. It was suggested that the people being cared for were most likely to participate in community events and be more social when they have lived in the same area for a long time. *“Mathew has lived here most of his life... he has a lot of blokes wrapped around his little finger”*. It was also found that *“there’s a real need or desire to have that sense of belonging and that sense of connectedness with other people and with the community”*.

Discussion also took place about people within the community supporting those being cared for and taking them along to community events. *“(They) have taken him under their wing so they will pick him up and take him to*

*different things....they remind me when he's due to play and where he needs to be and so on". This has helped to take the pressure off the carer and provide them with a break.*

Social connectedness is seen as a way to build self-esteem of those being cared for and *"helpful for the carer in terms of them having a break from the person"*. Social connectedness was also seen as creating a *"sense of belonging and something they have ownership in"*.

Although social connectedness, is seen as a vital part of life for people being cared for with an ID or ABI, it was reported to be lacking in the lives of almost all of those who were being cared for. *"Just being part of a community- you want to be normal and being normal is being a part of community. I think that's what everybody needs whatever their ability is."*

## **Barriers to Community Participation**

Social connectedness, being such an important and desired part of life, can also have a negative impact on the lives of those being cared for. *"The trouble is...he gets taken advantage of...they'll let him buy drink...There was this one guy who was getting him to go to the supermarket and pick up his case of beer and drop it at his place but he was not paying for it"*.

Peer pressure was another issue that carers felt those they looked after faced. *"Through peer pressure it wasn't long before they were into the pokies"*. It was also discussed that there is an obvious desire among those being cared for to be social which can lead to concerns. *"My son is very sociable, he wants to be (a part of things) but it gets him into trouble with alcohol"*.

The environment also plays a role as a perceived barrier in preventing community participation for those being cared for. For individuals with an ID or ABI, environmental triggers can prevent the individual being a part of the community. Those identified within the group include noise, smells, textures, flashing lights, the room being too hot and being patronised. *"Noise and a lot of it- my daughter tried going to the gym(but it was) too noisy. When she asked for the sound to be turned down the bloke turned it back up as soon as she started doing something else"*.

*"She can't stand noises- to take her to the shopping centre- forget it- it's a panic attack. She loves to go and feed the ducks where it's nice and quiet"*.

The perception of community members was also seen to be a barrier to participation. *"The person is in a wheelchair or someone who's obviously got a disability-they won't talk to that person, they will talk to the person they are with"*. It was also found that the people who were being cared for would act in a certain way that they consider to be normal, and that would allow them to fit in. *"He will let us buy his meal but he won't let us buy his drinks cause he wants to be seen at the bar with money"*.

Other barriers which were discussed include the behaviour of the person with an ABI or ID and a lack of understanding of social norms and lack of understanding of money. *"He doesn't understand the difference in spending \$10 v \$100 on an item. I can't take him to the shops unless I am prepared to buy him something he wants, pretty much, regardless of price"*.

Carers also noted that they experience high levels of stress regarding the safety of those who they care for. *"I worry about that, that part of their life (getting older) is going to happen and I'm not going to be there"*.



## Risky Behaviour

Risky behaviours were a key theme which was identified in both focus groups. The main behaviours discussed were high consumption of junk food, smoking, excessive drinking and gambling (including horse betting, raffles and electronic gaming machines).

*"We actually have a junk food problem, and so if my daughter was to focus on, say, more group situations where she has got a different sort of diversional thoughts in her head-(such as) I've got this group today or I've got that- she's got a purpose rather than thinking okay what takeaway am I going to have for lunch or tea today".*

Excessive drinking and smoking were also seen as risky social behaviour which was undertaken by some of those who were being cared for. *"He goes to the pub nearly every night... you'll go past and there he is parked in his spot... And nine times out of ten there's no one even in there to talk too".*

*"He smokes and drinks and he's on a pension of \$600 a fortnight, well when you smoke and drink there is no money".*

*"It seems to me that.... the big problem is the leisure hours ....just having support to find new ways to get away from the pokies and the horses .....most pubs have got a TAB or whatever ".*

Gambling is another theme which arose in the focus groups. Raffles came up as a common activity with participants spending excessive amounts of money on them. *"He pays for anything he wins 10 times over". "He says he's won and I'm not surprised, he's the only one who has brought any tickets".*

Betting on the horses was another form of gambling. *"They think it's normal to go to the pub, it's normal to bet on horses, yeah everybody bets on the Melbourne Cup so that's how they see their life should work but they just... haven't got the knowledge to stop".*

*"I find it easier for my daughter to do hands on-(things) like gambling- (she puts)\$10 through the machine and she doesn't win- thank god- in that sense to say to her you could put \$50 in; you could put \$100 in and you could come any with nothing. I said \$10 the limit on a 1 cent machine- that's it".*

*"They can't stop (gambling). They don't have the controls over their behaviour so they don't know when to stop. It's the same with drinking-it's the same with any destructive behaviour. They don't have the controls so it's difficult for them".*

## Money and Budgeting

Money and budgeting was another key theme from the focus groups. With the range of different intellectual disabilities and ABIs there is no one way of addressing an issue. One method may work with one individual but not another.

Carers expressed their concern around the people they care for not knowing the value of money. *"Our biggest problem is James's lack of understanding of the value of money".*

Compulsive buying was another issue raised. *"She will see something in a shop and instantly want to buy it".*

*"They need to have control (over their own money), but it needs to be properly done so that the control is actually what they need not their impulsive wants".*

## What can be done?

Public education was seen as a key driver to improve the community's perceptions of people with an ID or ABI. *"It's probably more education I think about in the community because people just don't understand, and it could happen to any of us"*.

Members in the focus groups talked about the stigma associated with people who had an ID or ABI which needs to be addressed. *"I think that the biggest problem I find is that people who are supposed to have normal children and normal things going on in their life (they) don't understand until it actually happens to them"*. *"How often do you see a wheelchair and you go 'oh oh' - off to the other side (of the path)"*.

Education around triggers for family members of people with an ID or ABI was also seen as a key way to improve community involvement. *"If carers, parents, families can learn what triggers people's behaviour and learn strategies from the professionals on how to deal with some of the things that they need to deal with it"*.

Having education for gaming venue staff was also suggested in the focus groups. Training was recommended for management around self-exclusion for people with an ID or ABI and what types of employee behaviour are classed as discrimination. *"Perhaps the management is the one who should be educating or being educated so he can pass down to his staff"*.

A volunteer system was also recommended in the focus groups where phone calls are made to those on a register daily. *"Someone calls up in the evening around or just prior or just after meal time or has a chat and says what are your plans for tonight or what are you doing on the weekend"*.

Events facilitated by clubs such as the RSL specifically for people with an ID or ABI were recommended by the group. *"I really don't like them being segregated and I think they have a right to be out in the community but it's got all these...risks, so I would actually like to see the RSL or someone like that in a venue to actually support the disability service to put on say a social once a month or something"*.

## Discussion

*Risky and compulsive behaviour is often a trait seen in people with an ID or ABI, combining this with a lack of awareness and innate desire to feel a part of the community and normal, can mean risky behaviours develop in those who have an ID or ABI.*

Results from the focus groups show that there are many factors that influence community participation in people with an ID or ABI. The overarching factor found was a desire to be a part of the community. This is often not easy for people with an ID or ABI taking into consideration numerous factors and barriers such as public perception, peer pressure, the environment, lack of understanding of social norms and lack of value of money.

Limitations of this research include a small number of participants involved with the study as well as only being able to consult with carers of people with an ID or ABI and not with those individuals who have the ABI or ID. Ideally the study would have included this section of the community but due to the time restraints of the project, getting high risk approval was not achievable.

From the focus groups the following recommendations were made in order to improve community participation for people with an intellectual disability;

- public education to reduce stigma,
- education around social norms for those with an ID or ABI,

- education on recognising and dealing with triggers for their families,
- education for gaming venue staff,
- a volunteer phone call system,
- Specific events facilitated by clubs such as the RSL.

## Conclusion

This research seems to support the theory that people with an ID or ABI often experience limited access to recreational activities and social support which could lead to the development of problem gambling behaviour. However, the issue of community connectedness for people with an ID or ABI is a complex one. There is no quick fix, but rather a process that involves multiple strategies and change over time.

This report is based on the perceptions and ideas of carers around the issues of community participation and advantages and disadvantages of social inclusion for people with an ID or ABI. To fully understand the issue it is recommended that research is conducted with people who have an ID or ABI to further understand the issue and how it can be improved.

## References:

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