

RESEARCH REPORT

People with intellectual disability and their lived experiences of gambling

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Executive Summary

Overview

People with lifelong disability exhibit similar characteristics to that of other groups who are known to be at risk of experiencing gambling harm. Characteristics such as low income, reduced employment opportunities, receiving welfare payments, restricted access to health services, social isolation, reduced understanding of risk and limited access to health services are just some of the potential risk factors that may contribute to gambling behaviours and harm [Armstrong and Carroll, 2017; Department of Health and Human Services, 2018; Johansson et al., 2009]. While researchers have explored gambling attitudes and experiences in other at risk population groups [Deans et al., 2016; Dickins and Thomas, 2016; Gattis and Cunningham-Williams, 2011; Hing et al., 2014; Pitt et al., 2017b; Thomas et al., 2020], there has been very limited research that has explored gambling attitudes and behaviours in people with disability.

Approximately 18 per cent of Victorians have a disability, and approximately three per cent have an intellectual disability [Department of Health and Human Services, 2018; Monash Health, 2016]. The current gambling literature in relation to disability has mostly focused on young people with Attention Deficit Hyperactivity Disorder (ADHD) [Groen et al., 2013; Theule et al., 2016]. This focus is not surprising, given that people with ADHD often exhibit impulsive behaviours, a characteristic found in people who are at risk of gambling related harm [Dowling et al., 2017]. The following study aims to broaden our understanding of the risks gambling may have on someone with a disability, beyond ADHD, specifically focusing on intellectual disability (ID). Due to cognitive impairment, a person with ID may have difficulty interpreting and calculating risk, placing them at clear risk of gambling related harm.

Aim and research questions

Phase One aim and research questions

The aim of Phase One was to explore people with ID's lived experience of gambling, including their knowledge, attitudes, and behaviours. There were three research questions that guided Phase One:

RQ1. What are people with ID's lived experiences of gambling and the range of gambling products and environments that people with ID engage with?

RQ2. How do people with ID conceptualise the risks and benefits of engaging with gambling? Are there any unique experiences relating to gambling (and gambling related harm) that may be specific to people with ID?

RQ3. How do people with ID interpret and apply gambling harm minimisation messaging? What are the most appropriate and effective mechanisms for delivering these messages?

Phase Two aim and research questions

The aim of Phase Two was to explore supporters of people with ID and their attitudes and experiences relating to gambling and people with ID. There were three research questions that guided Phase Two:

RQ1. What are the experiences of supporters with people with ID and gambling?

RQ2. What do supporters perceive as being reasons why people with ID may want to gamble?

RQ3. How could the disability sector ensure that people with ID are protected from the harms associated with gambling?

Study phases

The study was comprised of two phases:

Phase One: Interviews with people with ID.

Phase One involved semi structured interviews with people with ID. This phase was designed to gain an understanding of the gambling experiences of attitudes of people with ID from their own perspective. Questions were focused on participants gambling behaviours and knowledge of different gambling products, their understanding of the risks and benefits of gambling products, interpretation of responsible gambling and gambling harm, and strategies to reduce gambling harm in communities, especially among people with ID. Thematic analysis was conducted using the six steps of analysis by Braun and Clarke [2006]. This enabled the voices of participants to be explored and documented in the research, with quotes used to illustrate the different concepts that were interpreted from the data.

Phase Two: Focus groups with supporters of people with ID.

Phase Two included online focus groups with supporters of people with ID in Victoria. This phase was designed to explore supporters' perspectives about gambling and people with ID. There was no requirement for participants to have experience supporting people with ID with gambling harm or gambling behaviours, the purpose was to gain understanding from experts in the field. This phase included a small summary of the key findings from Phase One to provide context for the discussion.

Key topic areas for the focus group included experiences of people with ID and gambling behaviours, perceptions of harm from gambling and potential risk factors for people with ID, and potential areas that could be improved to reduce the risk of gambling harm amongst this population group.

Key findings

Phase One: One-on-one interviews with people with ID.

Nearly two thirds of the sample were male (n=12, 63.2 per cent), with an average age of 41.6 (this does not include two participants who did not provide a specific age). All participants had indicated engaging in gambling.

Engagement in gambling products

Participants had gambled on a range of products. The most common form of gambling was electronic gambling machines (EGMs), with all participants describing a time that they had participated in this form of gambling. Some participants talked about gambling regularly, while others said they only gambled on specific occasions such as birthdays or special events. Most participants recalled gambling with their family or partners, with a few participants talking about going to gambling venues to gamble with friends.

Conceptualisation of the risks and benefits associated with gambling and gambling environments

Participants often described that gambling was an activity associated with money. There were a mix of both positive and negative attitudes when describing the meaning of gambling. For example, participants described that it was a fun or social activity, but also something whereby people could lose money or develop an addiction. Participants were aware of some of the negative consequences of gambling, including the financial and social harms associated with gambling. Some participants thought that some products were 'riskier' than others. For example, bingo and raffles were considered to be 'safer' forms of gambling because of the small amount of money needed to participate. EGMs were considered by some as having greater risk because of the speed that someone could lose money.

Understanding and comprehension of harm minimisation and help seeking information about gambling

Most participants could recall the phrase 'gamble responsibly', although found it difficult to elaborate on the meaning of this message. However, when describing their own gambling behaviours a few participants used terms or strategies that were consistent with the responsible gambling rhetoric. This included setting money limits, being in control while gambling, and acknowledging the risk of addiction – including the ability of individuals to become addicted to gambling.

Participants were prompted to think about how to reduce harm from gambling, especially for people with ID. Suggestions included more accessible and targeted education. Some described needing more specific information related to product risk, while others thought people with ID also needed to understand how to gamble. Information presented in more visual formats was perceived to be important for people with ID. Finally, participants stated that there should be a reduction in the number of EGMs in the community, to reduce the availability and accessibility of machines.

Phase Two: Focus groups with supporters of people with ID

Three focus groups were conducted in Phase Two with seven supporters. Supporters had a diverse range of experiences working with people with ID, including one-on-one support, community engagement, employment support, and advocacy. The key findings grouped around the research questions are summarised below.

The experiences of supporters with people with ID and gambling

While most participants could remember a person who had an ID who had gambled, few had thought about gambling in the context of disability until this research. While some supporters knew people who gambled regularly, they did not believe that any harm was being experienced. Participants only perceived that harm was occurring when they were clearly able to identify that an individual had developed a gambling addiction. There were also complex discussions relating to the role of a supporter and disability organisations in facilitating or supporting a person to gamble. Often it was considered the duty of the supporter to ensure that personal autonomy was respected. However, there was also a recognition that risk assessments needed to be made.

Supporters attitudes towards factors that make gambling appealing to people with ID

Participants thought that gambling could be appealing for people with ID, included wanting to find social connection and a sense of belonging, and to reduce feelings of loneliness. Participants also thought that gambling could be seen as a way of increasing income and financial gain especially due to the low income many people with ID are on. Participants also perceived that gambling could be a way for people with ID to assert their independence and to feel like they were engaging in a 'normal' and 'adult' activity. Finally, participants perceived that there were specific

features related to gambling products and environments that would appeal to people with ID, including the lights and the sounds of EGMs, the staff interactions at venues, and the glamour and sophistication of being in a casino.

Protecting people with ID from the harms associated with gambling

There were few established processes within services for clients who may present with gambling related harm. Participants stated that there was limited emphasis on gambling within services, including mechanisms for help seeking. Participants also stated that there were no specific gambling services for people with ID. This was something that could be addressed within services, and by Gambler's Help.

In terms of prevention, participants perceived that accessible and easy to understand resources and information were essential – and could be influential both for people with ID but also the wider community. There was considered a need for education at disability organisations to ensure that gambling was seen as an important health and social issue for people with ID. Finally, participants noted that research was needed to both develop appropriate resources and prevention initiatives, but also to ensure that the lived experiences of people with ID would be instrumental in guiding policy and practice aimed at reducing gambling related harm.

Discussion

This report discusses three key areas drawn from the study findings:

1. People with ID are gambling and have a range of experiences and attitudes towards different gambling products – with particular experience of EGMs. Given the harms that are caused by EGMs within communities, and the very limited knowledge about people with ID's gambling experiences there is a clear need for further research in this area as well as understanding the role that supporters can play in ensuring that people with ID do not experience harm from their gambling.
2. People with ID can conceptualise the risk and benefits of gambling. However, they may not perceive that they are personally at risk of gambling harm. This is a concern as there may be a false sense of security with their gambling behaviours. This is a key risk factor for gambling related harm. While autonomy over choices is important, there is also a need to ensure that the concept of harm and the risk factors associated with regular product use are provided to people with ID in accessible formats.
3. People with ID and supporters identified that there needs to be greater emphasis on the prevention of gambling related harm for people with ID. This included training within disability services, and more accessible public education resources.

Key recommendations

The findings from this study have highlighted some key areas for intervention. These recommendations have been separated into three key areas research, policy, and practice [McCarthy et al., 2019].

Research

- Documenting how people with ID engage with gambling products and environments. This is important given that data about the gambling practices of people with ID are not specifically captured within population-based prevalence surveys, with these types of surveys not readily accessible for this population sub-group
- Developing evidenced based harm prevention messages suitable for people with ID.

- Exploring how individuals with a broader range of disabilities, including acquired brain injury, physical disabilities and other cognitive disabilities may be vulnerable to gambling related harm
- Understanding how formal and informal supporters may influence pathways to gambling for people with ID, and how supporters may be more effectively used to prevent and reduce gambling related harm.

Policy

- Designing evidence based, easy to understand information that explains the risks associated with gambling products, and ensuring that these are accessible to all people, including people with ID
- Exploring options from a government perspective to address the significant links between social isolation and loneliness and gambling behaviours in vulnerable or socially excluded sub- populations
- Identifying, providing, and promoting alternative inclusive spaces to pubs, clubs, and casinos.

Practice

- Increasing supporters' understanding of gambling as a public health issue for people with ID and providing education about help services and signs of harm before people present with problems
- Designing evidence-based gambling workshops for people with ID and supporters through organisations
- Exploring how to support people with ID to find alternative venues for social connection.

Background

People with lifelong disability in Victoria: A potential at-risk group for gambling harm

In Victoria, 18 per cent of the population live with disability [Department of Health and Human Services, 2018]. While there is limited statistical information about people who live with a lifelong disability (for example an intellectual disability (ID), autism spectrum disorder, Attention Deficit Hyperactive Disorder (ADHD), or cerebral palsy) in Victoria, approximately three per cent (or 150,000) of Victorians have ID [Monash Health, 2016]. While government organisations have indicated that there is still limited research about the lives of people with lifelong disability [VicHealth, 2012], research does indicate that people with lifelong disability are a significantly marginalised group in the community. They have poorer access to health services, lower completed levels of formal education, reduced employment opportunities, receiving welfare payments and living in government residential housing, reduced access to public transport, as well as a range of negative health outcomes such as mental illness, obesity, and diabetes [Department of Health and Human Services, 2015]. Many of these factors are also risk factors for developing gambling harm [Johansson et al., 2009]. For example, evidence from the Household Income, Labour and Dynamic Survey (HILDA) demonstrated that people who were most likely to be classified as problem gamblers (at risk of the most harm) were people who had low levels of employment and were receiving welfare payments [Armstrong and Carroll, 2017]. People with lifelong disability may also be a ‘hidden population’ regarding gambling harm. Prevalence and longitudinal studies in Victoria (or elsewhere) do not collect or publish information about gambling related to an individual’s disability status.

Gambling context in Australia

Gambling expenditure (per capita) in Australia continues to be one of the highest in the world [The Economist, 2017]. In 2017/18 total gambling expenditure in Australia was over \$24 billion, with large increases in newer forms of gambling such as sports betting [Queensland Government Statistician’s Office and Treasury, 2019]. In Australia, gambling is highly commercialised, with a vast array of different opportunities to gamble. These include electronic gambling machines (EGMs) – the largest contributor to gambling expenditure, casinos in most capital cities, TAB’s, lotteries, as well as the influx of online gambling options. This expansion has had significant impacts on communities. A study by Browne and colleagues [2017] estimated that for Victoria, gambling had a social cost of \$7 billion due to costs on health services, individual financial loss, impact on the economy, and the criminal justice system. Gambling has a variety of different social and health consequences that impact not only the individual, but also families, friends and communities [Adams et al., 2009; Korn et al., 2003; Marshall, 2009]. This can include mental health problems, relationship breakdown, and financial stress [Browne et al., 2016; Holdsworth et al., 2012; Suomi et al., 2013]. Gambling harm has been defined by researchers as:

“Any initial or exacerbated adverse consequence due to an engagement with gambling that leads to a decrement to the health or wellbeing of an individual, family unit, community or population.” [Langham et al., 2016, p.4]

Current figures from the Household, Income and Labour Dynamics in Australia survey indicate that about 200,000 people were classified as being at risk of having a problem with gambling and a further 1.4 million at a low–moderate risk levels of gambling related harm [Wilkins, 2017]. This demonstrates the significant impact that

gambling has on Australian communities. Given that there could be over a million people who are experiencing some sort of harm from gambling, it can only be assumed that this would also include people with lifelong disability.

People with lifelong disability and gambling: The current evidence

Limited research has focused on people with lifelong disability and gambling [Scheidemantel et al., 2019]. Most studies are from clinical psychology, and have focused on specific personality characteristics of people with lifelong disability and their link to factors that may increase vulnerability to gambling harm, such as risk taking, impulsivity, or impaired decision making [Groen et al., 2013]. Research has also predominately included children or adolescents, with limited research specifically focusing on adult populations. This is predominately due to a major focus in the research literature on ADHD and problem gambling which is traditionally diagnosed during adolescence [Derevensky et al., 2007; Faregh and Derevensky, 2011; Theule et al., 2016]. Studies often use gambling tasks to predict gambling behaviours. For example, studies have used the Iowa Gambling Task with people with lifelong disability [Groen et al., 2013; Matthies et al., 2012], rather than seeking to understand the range of social practices that may be associated with gambling outside of 'lab based' environments.

While there are many gaps in the evidence base studies do show a clear association between people with lifelong disability and risky gambling behaviour. Breyer and colleagues [2009] explored gambling behaviours within adolescents and found that those participants with ADHD were more likely to score highly on problem gambling scales as compared to general populations. Similarly, Derevensky and colleagues [2007] found that adolescents who indicated risky gambling behaviours were also more likely to have ADHD symptoms. A systematic review by Groen and colleagues [2013] explored the relationship between individuals with ADHD and performance in gambling tasks, and identified that people with ADHD had higher risk gambling scores indicating that they may have different perceptions of decision making. Similarly, a meta-analysis exploring the relationship between ADHD symptoms and problem gambling, found that people who had ADHD symptoms were almost three times (2.85) more likely to have problems with gambling [Theule et al., 2016]. However, many of these studies did not specifically explore if this translated into actual gambling behaviours or gambling related harm.

Research findings are also similar amongst studies that include people with learning or intellectual disability. Parker and colleagues [2013] explored gambling behaviours within adolescents with a learning disability, and found that males in this cohort, were significantly more likely to be at risk of pathological or problem gambling than participants without learning disability. Another study found students who were classified as probable pathological gambling also had a learning disability [Hardoon et al., 2002]. This study also found that over 35 per cent of female students who were classified as a probable pathological gambler had been diagnosed with a learning disability. This study concluded that they thought being diagnosed with a learning disability was a risk factor for sustaining gambling behaviours and potentially experiencing harm from gambling. Wachter [2008] reported a study conducted by Dr Lakinowski, which found just under nine per cent of a sample of 79 individuals with ID were classified as either pathological or problem gamblers, using a modified problem gambling screening tool. This study also found that gambling was common among participants, with over 70 per cent having gambled in the past year. This was the second study that found that females were more likely to be classified as problem gambling than men [Hardoon et al., 2002]. The study concluded that the gambling behaviours of these participants were often determined by others around them who could facilitate gambling. A more recent article by Scheidemantel and colleagues [2019] also highlighted the lack of literature in the field, and provided a case study with people with intellectual disability and a psychiatric disorder, who were presenting to the clinic with gambling harms. They concluded that there needed to be more research to understand how to provide effective education and treatment options for this group to ensure that they can make well informed decisions about engaging in this behaviour and to prevent experiencing harm in the future.

A study by Bramley and colleagues [2017] also described the potential vulnerabilities that people with intellectual and learning disability may have around gambling. However, they also recognised the very limited research that had explored this in detail. They described a study which interviewed carers of people with ID and acquired brain injury and found that some carers or supporters believed gambling was a concern due to a misunderstanding of the risks associated with gambling, difficulties budgeting, and compulsive spending habits. This study also highlighted the need for improved education for families, supporters and venue staff and the need for more inclusive recreational activities that individuals could access. However, there was no discussion around the potential to improve the education and agency of the individuals with an ID or acquired brain injury, which may be an area that needs to be explored. This report also expressed concerns of the under reporting of the gambling behaviours and potential harm experienced from gambling for people with learning difficulties or disability. Further demonstrating the need for detailed studies exploring these experiences in this population group.

To date, there have been no studies that have specifically aimed to explore the lived experiences of people with lifelong disability and gambling from a public health perspective, or that have had a focus on qualitatively understanding the attitudes and behaviours of people with lifelong disability with gambling.

A public health approach to gambling: People with lifelong disability

The Victorian Responsible Gambling Foundation [2015], states the aim of a public health approach to the reduction and prevention of gambling harm is to:

“...address health inequalities by tackling the range of factors that impact on health beyond the individual level of lifestyle choice. These include social, economic and environmental factors.” [Victorian Responsible Gambling Foundation, 2015, p.6]

Although over the years many different researchers and even the Australian Productivity Commission have discussed the value of taking a public health approach to gambling [Australian Productivity Commission, 1999; Australian Productivity Commission, 2010; Korn and Shaffer, 1999], until recently research has predominately explored the individual drivers of gambling harm. However, as public health research has developed in gambling, research has explored not only the individual drivers of gambling harm, but also has recognised the role and interplay of environmental, social, commercial and political factors in the development of harm [Bestman et al., 2018; Hancock and Smith, 2017; Pitt et al., 2017b; Thomas et al., 2017; Victorian Responsible Gambling Foundation, 2015]. A public health approach to gambling from the perspective of people with lifelong disability includes acknowledging the range of determinants that may be influencing and impacting people's gambling attitudes and behaviours, and the strategies to then protect them. However, with the current evidence so limited to only individual personality traits of people with ADHD or learning/intellectual disability then there is a lack of understanding of how socio cultural, environmental and industry factors may be contributing to the people with lifelong disability's experiences of gambling and gambling harm.

More recently, public health researchers have called for an increased focus on factors that may contribute to the 'normalisation' of gambling. Thomas et al. [2018] define the normalisation of gambling as:

“The interplay of socio-cultural, environmental, commercial and political processes which influence how different gambling activities and products are made available and accessible, encourage recent and regular use, and become an accepted part of life for individuals, their families and communities.” [Thomas et al., 2018, p.54]

While there has been an increasing focus on the factors that may contribute to the normalisation of gambling for some population sub-groups, such as young people [Pitt et al., 2017a; Pitt et al., 2017b], there is limited consideration about the range of factors that may normalise pathways to gambling for other vulnerable populations such as people with lifelong disability [Groen et al., 2013; Theule et al., 2016]. This includes whether vulnerability factors may be similar to or different from those of other groups [Bramley et al., 2017; Fong, 2005]. Social networks have been found in other groups such as young men, to be highly influential in contributing to feelings that they need to gamble to be a part of a group [Deans et al., 2016]. Research have also shown the role families play in children's development of gambling attitudes and behaviours, as children and adolescents who have parents who have positive attitudes towards gambling, will more like also have positive attitudes and are more likely to want to try gambling when they are older [McComb and Sabiston, 2010]. Given that people with lifelong disability often have very small social networks [van Asselt-Goverts et al., 2015], this may increase the amount of influence that they may have on their engagement in risk taking behaviours.

There has been little research to our knowledge that has explored the influence of support people on the gambling behaviours of people with lifelong disability, understanding this will be important in providing more informed and effective gambling harm prevention strategies for this group.

It is also important to acknowledge that the factors contributing to the normalisation of gambling do not necessarily work in isolation, and often different scenarios demonstrate the way that this link together. For example, community gambling venues such as clubs and pubs/hotels, can play a key role in the development of gambling attitudes and behaviours for a range of subgroups such as older adults and young people [Bestman et al., 2019; Thomas et al., 2020]. This is due to the accessibility and availability of venues within communities, the influence of industry strategies on the promotion of gambling activities, and the social interactions and rituals that occur when attending venues. Within these environments there are a range of gambling and non-gambling activities that are available.

Bestman and colleagues [2016] have documented how these venues use marketing to promote themselves as 'family friendly' due to the range of facilities and activities that they provide. The authors concluded that there may be a normalisation pathway occurring whereby the venue itself is embedded within social and cultural rituals which result in the venue becoming normalised. It is then predicted that the potentially harmful products within these venues will also become normalised.

Community gambling venues may be particularly appealing for people with lifelong disability because of the accessible nature of the venue, the range of activities they can participate in while there, the ability to socialise where they feel safe and included, and for fun and excitement [Gordon, 2004].

Some peak bodies for gambling venues have highlighted the inclusiveness of the venue for the wider community, including people with lifelong disability. These venues describe themselves as "community hubs" and provide recreational facilities along with employment opportunities for people with lifelong disability [Clubs NSW, 2016, p. 6]. The establishment of welcoming, inclusive and accessible communities is clearly mandated in international legislation such as the United Nations Convention on the Rights of Persons with Disabilities [UN General Assembly, 2006], to which Australia is a signatory, as well as Australia's National Disability Strategy. These legislative drivers promote inclusion beyond physical access to incorporate the universal accessibility of strategies and approaches designed to reduce harm. While there is no argument that inclusion is important for Australians with lifelong disability, their supporters and loved ones, it is unclear how gambling venues that promote inclusive environments but also contain potentially harmful products will affect the wellbeing of people with lifelong disability.

An exploratory study by Pitt et al. [2020] conducted interviews with people with lifelong disability, in order to understand the role that pubs and clubs played in recreational activities. People with lifelong disability engaged in a range of different activities within the venues. They used venues for cheap meals with friends and family, watching live sport or entertainment, socialising, and engaged with gambling products (including EGMs, horse racing, bingo, Keno, and raffles) while they were there.

Some participants also indicated that they had experienced harm from gambling. This study demonstrated a need to further investigate gambling attitudes, experiences, product choices, perceptions of risk, and conceptualisation of harm.

Conclusion

This review of the literature identified that people with lifelong disability are at risk of experiencing gambling harm however there are significant gaps in their lived experience of gambling, their gambling attitudes and behaviours, and how they may interpret the risks associated with gambling. The current literature has mostly focused on young people, specifically with ADHD and learning disability [Groen et al., 2013; Theule et al., 2016], and found an association between lifelong disability and risk of gambling harm. However, this was predominately due to general personality characteristics such as decision making and risk taking which may lead people with ADHD to engage in risky gambling behaviours. There is a significant gap in evidence surrounding the engagement of people with lifelong disability in qualitative research to understand the range of factors that may influence their gambling attitudes and behaviours, in particular qualitative research that explores gambling attitudes, behaviours or their experiences with gambling harm. There has been even less research, if any, that we are aware of that has aimed to understand how people with lifelong disability interpret or are able to access gambling support services or harm minimisation strategies. Given the literature and the risk profile of people with intellectual disability, they were considered the most appropriate group for this study and will be the focus of the report moving forward.

Study Design

Study approach

This study aimed to acknowledge the value and importance of involving people with a disability not only as participants but as active members of developing the research [Gilbert, 2004; McDonald et al., 2013; Prosser and Bromley, 1998]. An advisory group were included in the design and development of Phase One. The two phases that comprised this study were:

Phase One: Interviews with people with ID.

Phase One was one-to-one interviews with people with ID. This phase was designed to gain an understanding of the gambling experiences of attitudes of people with ID from their own perspective.

Phase Two: Focus groups with supporters of people with ID.

Phase Two was focus groups with supporters of people with ID about gambling and disability. This phase was designed to explore supporters' perspectives about the gambling behaviours of people with ID, if there was any harm occurring and if there were any areas that could be improved to reduce the potential for gambling harm amongst this population group.

Phase One

The aim of this phase was to explore people with ID's lived experience of gambling, including their knowledge, attitudes, and behaviours. There were three research questions that guided Phase One:

RQ1. What are people with ID's lived experiences of gambling and the range of gambling products and environments that people with ID engage with?

RQ2. How do people with ID conceptualise the risks and benefits of engaging with gambling? Are there any unique experiences relating to gambling (and gambling related harm) that may be specific to people with ID?

RQ3. How do people with ID interpret and apply gambling harm minimisation messaging? What are the most appropriate and effective mechanisms for delivering these messages?

Phase Two

The aim of this phase was to explore supporters of people with ID and their attitudes and experiences relating to gambling and people with ID. There were three research questions that guided the phase:

RQ1. What are the experiences of supporters with people with ID and gambling?

RQ2. What do supporters perceive as being reasons why people with ID may want to gamble?

RQ3. How could the disability sector ensure that people with ID are protected from the harms associated with gambling?

Phase One: One–on–one interviews with people with ID

Methods

Approach

This phase took a qualitative approach, conducting one–on–one interviews with people with ID. The research team wanted to ensure the thoughts and perspectives of people with ID were involved in the study. This was achieved through initially building a relationship with a disability organisation to discuss the study and then an advisory group of people with ID was created where we were able to talk about the project and receive feedback. People with ID were the focus of this report as they may have difficulty interpreting and calculating risk, placing them at clear vulnerability of experiencing gambling related harm. While people with other disabilities may also be a risk it was out of the scope of this study.

Sampling and recruitment

The research team engaged an advocacy disability organisation to play a key role in the research development, recruitment, and translation of research findings. An initial meeting was established to discuss the project and to explain the study requirements to understand if this was a project they would like to be involved in. When this was confirmed, an advisory group was established to talk through the study, identify if it was worthwhile for people with ID, and to go through the interview schedule. This advisory group included three people with ID who the organisation had invited. Once the interview schedule had been confirmed the organisation proceeded to talk to potential participants about the study and asked if people would like to participate. The recruitment process was then left up to the organisation.

The inclusion criteria for this study was people with ID, living in Victoria, over 18 years, who could consent to their own participation, and who had gambled recently. Due to the difficulties that some people with ID have with determining time, there were no specifications given to the term 'recently'. Given that the recruitment was channelled through an advocacy organisation focused on providing support for people with ID, it was believed that all participants had ID however at no time was this confirmed or measured nor was it thought appropriate to do so.

Data collection

One–to–one interviews were conducted with 19 participants over three data collection time points across three months in 2019 (June–August). This included 15 interviews face to face and four interviews over the phone. All in-person interviews were conducted at the disability organisation. Telephone interviews were included to ensure that people who wanted to participate but were unable to travel were able to share their thoughts and attitudes towards this topic. Interviews were audio recorded with the permission of the participant. Participants received a \$50 grocery voucher as appreciation for their time. This phase received ethical approval from the Deakin University Human Research Ethics Committee (2019-012).

The interview schedule was divided into four key areas of interest:

- *Gambling attitudes and behaviours.* Questions included which products they gambled on and why, how often they gambled and where they gambled.
- *Knowledge and understanding of gambling.* Questions included knowledge about specific products such as favourite EGMs, dislikes about gambling, and experiences of winning and losing.
- *Gambling risks and harm.* Questions included what the good or bad things about gambling are, are any gambling products that might cause more harm than others.
- *Harm minimisation strategies.* Questions included what does gamble responsible means, what someone could do if they have a problem with gambling, what are some of the strategies that could be done to help people who might have a problem with gambling.

The interview was also assisted with a picture board of gambling products. This included a picture of eight gambling products: bingo, casino games, EGMs, horse betting, Keno, lotteries, raffles, and sports betting. Participants were provided with the picture board to stimulate discussion around products and to act as a prompt to discuss different gambling products that might not come to mind initially. Individual pictures of each of the products were also given to participants if they were overwhelmed by the picture board with multiple products. This was able to centre discussions on each product and remove distractions of pictures of other products if there was too much stimulus.

The advisory group were asked to provide feedback on the wording and interpretation of the questions that were asked. However, each participant had different levels of comprehension. During the interview, the researcher relied heavily on asking questions in different ways to ensure that the interview could capture if the participant had any knowledge about a specific topic. However, there were some concepts that some participants found more difficult or had not heard of, such as responsible gambling. However, given the broad range of experiences and comprehension it was important to ask questions of all participants.

Data analysis

Interviews were transcribed by a professional transcription company. Transcripts were uploaded to the data management software QSR NVivo 12. Interviews were read and re-read to ensure that the researchers had a deep understanding of the content and context of the data, notes were taken throughout the reading process. Once transcripts had been read, thematic analysis was conducted whereby open coding techniques were used to create initial codes [Braun and Clarke, 2006]. Thematic analysis was considered an appropriate analysis method given that it can be used to describe and showcase what the participants have said. These initial codes were then used to identify similarities and differences between responses and to identify the basic themes that were occurring within the data [Charmaz, 2006]. These concepts were then coded into subthemes and then broader top-level themes that encompass the whole data set. Analysis occurred simultaneously to data collection so that the interview schedule could be modified or adapted as the interviews progressed. The research team meet regularly to discuss the interpretation of the data, paying close attention to the language that was used by the participants and the contexts they answered questions to ensure the true meaning of the data was captured. Quotes were used to illustrate the themes that were identified.

Results

Sample characteristics

There were 19 participants in this sample, 12 men (63.2 per cent) and seven women, with an average age of 41.6 years (this did not include two participants who did not provide a specific age), ranging from 19–62 years. All participants had indicated engaging in gambling. The results are presented around the three key research questions.

Engagement in gambling products

The first theme represents participant's engagement with gambling. All participants indicated having some level of engagement with a range of different gambling products. While all participants had remembered gambling on EGMs, they reported varying levels of engagement. For most participants, it was difficult to determine how regularly participants were gambling on EGMs. Responses ranged between weekly and a few times a year. It was difficult to determine what was accurate as some participants said that they would go occasionally but indicated that they went what would be considered as regularly. Special occasions were also a time when some people gambled, this was because they would go to pubs and clubs for birthdays or family events.

Most participants described gambling with their family or friends, some differed depending on the occasion or the gambling product. Participants said that their family often drove them to pubs and clubs and while there they would gamble. Others talked about engaging in family horse sweeps and had memories of gambling either formally or informally with their family. One participant stated that he would not gamble if by himself but viewed it as a social activity with friends. Another participant talked about going to the TAB with his friend:

Like, we'll sit there. We'll go up to the TAB, put our bets on come back, put it on Channel 78 and then sit there and watch them [the races]. – Male

Three participants had attended pubs and clubs by themselves. One said, “*Yes I always go by myself*”. Another, who went to pubs or clubs with her husband said that they also gambled by themselves – “*I play by myself. He drinks I play the pokies*”. Two participants remembered times when they had gone to gambling venues with their supporters, with one clarifying “*of course they'll never gamble*” and the other saying “*I didn't win nothing*”.

The following outlines the different levels of knowledge, attitudes, and behaviours participants had related to specific products including EGMs, casinos, wagering, lotteries, and other (bingo and Keno).

EGMs

All participants had gambled on EGMs. However, some indicated that it was not the main reason why they attended these venues, but that gambling, particularly on EGMs was something that they did when they were there. They commented that venues were friendly, sometimes close to where they lived, and provided good food. One participant said: “*I only go the RSL 'cause I feel comfortable at the RSL*”.

When discussing gambling on EGMs, participants said they gambled on them because they were fun, enjoyable, or easy to engage with. Some participants viewed playing EGMs as a social activity and liked being around other people using EGMs. Others noted that playing EGMs relieved boredom or was relaxing. A few people said that they had gambled on EGMs at the casino, however this was not a regular venue for them.

The design of the machines was also part of the experience for some participants, who noted that they liked the variety of machines. Participants could recall the particular design of EGMs that they used or preferred. This included one cent machines, older style machines, or ones with animations such as dragons, or lucky coins. Participants also discussed some of the technical characteristics of EGMs such as “*features*”, free spins, lines, and jackpots.

Casino games

A few people said that they had gambled on EGMs at the casino, however casinos were not a regular venue, but rather for special occasions such as birthdays or when on holidays. Participants reported they had played blackjack and roulette. A few considered they were more in control of the outcomes of casino games because they could “*watch your deal, the dealers, how they react*”. This contrasted with another participant who preferred to play video table games, “*because it’s easier*”. One participant talked about how he preferred gambling on casino games compared to other gambling products but particularly liked blackjack:

I like blackjack better because it’s a perfectly balanced game. I never finish empty handed. – Male

However, some participants found casino games too difficult to understand how to gamble on.

Wagering

Discussion on wagering often included experiences relating to traditional forms of horse racing, informal bets, and engagement with wagering on the Melbourne Cup. Participants mentioned the TAB or that they used terminals within pubs or clubs. Betting language such as “*favourites*” or “*quadies*” were used by some participants. A few talked about their tendencies to select the “*favourite*” horse and relied on form guides to determine who to bet on. Another participant said that he picked horses easily based on the “*research*” he does from the Internet. Others selected horses at random, on the day, for example because of the name.

Two participants recalled gambling on sport, one said, “*sometimes I have sports bet sometimes I don’t*”, while the other participant went into detail about the different markets that he and his friends bet on such as the National Rugby League (NRL). He also spoke about special event betting such as the NRL State of Origin. Even if participants had not bet on sport, they were very aware of it. One participant said, “*sports betting is everywhere*”, and was able to list the variety of different sports and markets, including television reality shows, that were available for different events.

Lotteries

Some participants recalled specific brands of lottery games such as Powerball and TattsLotto. One participant said she had the lotto app on her phone but was not sure how it worked. Others had bought lottery tickets usually when there was a large jackpot advertised.

Other products: Keno, raffles, and bingo

Other gambling products discussed by participants included Keno, raffles, and bingo. Most of these discussions were instigated once participants had been shown pictures of different gambling products. Most participants who knew Keno had seen it at pubs, with a few remembering seeing it on the screens. When asked how to play Keno a few participants described going up to the machine and receiving a “*keno ticket*”, which could be put into a machine to “*see if you win or not*”. They recalled that Keno was “*Like a lottery, you know, draw numbers*”.

Raffles were often discussed due to the small amount of money needed for raffle tickets and the prizes that they had won such as seafood, meat, and gift cards to use at the venue. Bingo was recognised by some participants, with a few participants stating that they had played bingo. However, for some, bingo was too difficult to keep up with. For example:

Because I've got a hearing loss and them calling the numbers is like you've got... if you miss one number you are all out of shot. – Female

Conceptualisation of the risks and benefits associated with gambling and gambling environments

The next theme outlines how people with ID conceptualised the risks and benefits associated with gambling. This was explored by understanding participant's definition of gambling, perceptions of why people may or may not want to gamble, and explaining the negative outcomes associated with gambling.

Participants were asked to define gambling; this produced a range of different responses from participants with some finding it difficult to articulate. Some participants identified specific gambling products to demonstrate their understanding of gambling. While the majority associated gambling with money. When asked if gambling always had to involve money, one participant replied, *"Yeah, how else are you going to gamble without money"*. Although a few participants identified that gambling offered the potential to earn or make money, they also associated it with losing money and that gambling providers *"take your money"*. Participants noted positive outcomes such as winning or having fun. One participant explained gambling thus:

Gambling is basically, um, you can – gambling is something that you spend money and basically, um, you can win um, and sometimes you can get addicted to it um, but it's a form of – for some people it's a form of enjoyment but for other people it can be an addiction. – Male

There were three key sub themes that explored participant's views as to why people may gamble. The first was for fun or enjoyment. Gambling was thought of as being a form of entertainment and having a good time. The second was to win and to win money. Some participants thought that others would want to win money so they had some extra money to buy things, and another thought people would want to *"win big"*. One participant thought that you could win money and give it to charity. When asked how they felt when they had won from gambling participants said that they felt shocked, excited, lucky, and happy. One participant however said that he felt angry when he won because he did not *"deserve it"*. Third was for social reasons. Some participants commented on gambling being a social activity, and something you could do with family or friends. Some participants noted that when gambling changed from a social event to something they did by themselves the behaviour was concerning.

Participants were able to conceptualise what they perceived to be the negative consequences associated with gambling. Participants viewed spending too much money or losing money as the main negative consequences of gambling. Participants identified time spent gambling as another negative. These participants recognised that financial loss was not the only problem. A participant noted it was problematic when a person did not move from a machine or when they used the reserve sign (a sign that can be placed on EGMs so that no one else can use that machine). Such behaviour held the potential for isolation and was unhealthy. Participants were concerned that they or others could become addicted, however they also distanced their own gambling behaviours from anything that could be considered an addiction. They perceived that being concerned about addiction could be a reason why some people would not want to try gambling and likened it to using other harmful products such as alcohol and tobacco. For example, one participant said:

I think it's a bit of a risk of gambling because some can get pretty addicted to it, sometimes. And it's hard to give it up, like the smoking. – Male

Participants stated that gambling could not only result in financial hardship but also could affect families or relationships if gamblers lied about money. A few participants were also concerned that because of gambling people could lose their homes and become homeless. Others thought that gambling could lead to alcohol or drug use. A participant reflected on her own gambling and was glad that she did not end up like this:

People lose all their money; people lose so much that their marriages or relationships go down the drain. People stop eating because they love gambling so much...Thank God I never got there. – Female

Another theme that emerged was participants' conceptualisation of risk associated with different gambling products. Some participants considered EGMs the riskiest gambling products. Risk was associated with the amount of money someone could win and lose while gambling. Participants thought that there was very little chance of people winning when gambling on EGMs because you can "*lose money quickly*". Wagering was also considered to be a risky gambling activity. One participant said that EGMs and horse racing were the "*most likely to ruin someone*". Casino games were thought to be risky by some participants, but others thought that these products were some of the safest because "*you don't lose a lot on the casinos*". The products that were considered potentially not as harmful were bingo or Keno because of the small amount of money that could be spent to enter.

Understanding and comprehension of harm minimisation and help seeking information about gambling.

The third theme was the way participants were aware of and comprehended harm minimisation strategies and help seeking information for people who were experiencing harm from gambling.

Comprehension of responsible gambling messages

To gain an understanding of how participants were comprehending harm minimisation strategies there was a focus on exploring the interpretation of the responsible gambling messages. Over 60 per cent of participants said that they had heard of the term 'gamble responsibly'. A further two participants indicated they may have heard of it, and five participants said that they had not heard of the term. The main interpretation of the 'gamble responsibly' phrase related to money or time. Participants said that people should not spend all their money and put arbitrary safeguards in place using phrases such as "*shouldn't gamble too much*", or "*watch how much you gamble*". However, when asked how much money was appropriate or how would someone know if they were gambling too much, participants were not sure how to respond. A few participants found it difficult to describe what they believed 'gamble responsibly' meant and just restated the words. For example, "*you've got to gamble responsibly*", or "*I think it means to just be responsible*".

While participants had difficulty explaining 'gamble responsibly', when describing their own gambling behaviours terms that were associated with responsible gambling messages or personal responsibility rhetoric's were often used. This was predominately associated with setting limits, awareness of addiction, and using terms similar to the gambling industry such as a form of entertainment or having a "*flutter*". Setting limits was discussed in terms of limiting the amount of money that was spent on gambling or limiting time spent gambling. People often stated that when they gambled on EGMs, they set a limit and that other people should do this to make sure that they were being responsible.

Participants also described feeling in control, that they were not gambling excessively or becoming addicted. People explained that others who gamble should "*walk away*" whether they were winning or losing.

Understanding of gambling help services

Traditional gambling help services were recalled by many participants. This focused mostly around accessing gambling counselling services, specifically the “*Gambler’s Helpline*” or “*they could ring the 1800 number*”. Other places that were considered options for getting help included gamblers anonymous, a GP, the local community centre, friends or family, or the police. Participants mentioned that they had seen this information on signs on the machine, on coasters at pubs or clubs, in the toilets and at the end of television advertisements.

A few participants mentioned that they could engage staff at gambling venues to help someone who might be experiencing harm from gambling or ask support workers to help people with ID to contact help services. One participant thought that a support worker could be someone to help a person with ID stop gambling, and that supporters “*shouldn’t even be playing the pokies*”.

Potential harm prevention and minimisation strategies

The last part of the interview provided the participants with the opportunity to discuss potential strategies to help people who were experiencing harm from gambling. There were three clear subthemes that the strategies could be grouped. Education was considered to be a major strategy that was needed. This was in relation to reducing gambling harm among the wider community and through specific education that was targeted at people with ID and their networks. However, while some people had suggested education about the risks and harms associated with gambling, others thought it was important to educate people on the rules associated with different gambling activities and to explain to people how they could gamble

Second was the need for accessible information. This included having information that was easy to interpret and access before people initiated gambling and while they were gambling. Some participants identified how difficult it must be for some people with a disability to understand information about gambling. Suggestions included having educational videos about gambling, using pictures, and having signs up within venues or on EGMs. One participant thought that videos could be considered a useful tool because it was the best way for them to remember information. They also went on to talk about pictures and said:

Pictures are good. Maybe like a easy English, kind of something you could take –with you or people could take with them. – Male

Lastly, was in relation to the structural or product features that could be changed to make gambling on EGMs ‘safer’. This was often associated with designing a system where people could set predetermined limits of how much money or time could be spent when gambling. Another suggestion was to prompt people to reconsider if they wanted to continue gambling while on the machine. There were also some comments about reducing the number of EGMs or removing EGMs and making them less accessible in the community. One participant identified that there were some RSLs that did not have EGMs. This participant also remembered a time when EGMs were not present in pubs and clubs and consequently more socialising occurred.

Phase Two: Focus groups with supporters of people with ID

Methods

Study approach

Phase Two of this study was an exploratory focus group study with supporters of people with ID to discuss their perspective on gambling within this population group. Supporters were self-identified individuals within disability organisations who had an understanding of people with ID. The reason for this phase was to understand how people working within the disability sector could provide further insights into people with ID and their experiences of gambling, and to also understand if gambling was on the agenda for disability organisations. It was thought that this phase was important in order

Sample and recruitment

To be included in this study people needed to identify as being a supporter of people with ID. While originally the research team were looking for either paid or unpaid supporters, as the project progressed it was decided to include professionals from disability organisations because of the difficulties in recruitment and the potentially different perspectives each group would provide. There was no need for people to have any experience with supporting people with gambling specifically, as the main focus of the study was to explore how gambling may be seen (or not) as an issue within the disability sector in Victoria.

The research team used their networks with Victorian disability organisations to recruit participants. Emails were sent to key managers within organisations to share with people who might be interested. Many different efforts were made to try to engage people to participate in the study (for example one-on-one interviews, focus groups, workshops). However, due to a range of different circumstances such as increased research demands within the disability sector, increased workloads, difficult timing around Christmas holidays, and COVID-19, recruitment proved to be difficult. The study was advertised as a focus group with a discussion around the key findings from Phase One. People who were interested in the study emailed the research team and focus groups were organised. These groups were organised around people from the same organisation. Recruitment was again limited by COVID-19 restrictions and the focus groups were conducted over Zoom.

Data collection

Data collection occurred during March and April 2020. Participants were asked to read the plain language statement and if possible, send back the consent form prior to the focus group. However, if this was not possible then verbal consent was recorded. Participants were able to ask any questions before the focus group commenced. All three focus groups were completed with two or three people over Zoom. Researchers have demonstrated that in general the benefits of using online technology for interviews far outweigh the negatives or technical difficulties [Archibald et al., 2019]. When all participants had joined the focus group, Dr Pitt gave an overview of Phase One and the key findings to provide context for participants. Focus groups lasted approximately 60 minutes. Each focus group was semi structured and flexible to ensure that participants were able to drive the discussion. Key issues for discussion included any experiences that the supporters had with people with ID and

gambling, attitudes or opinions regarding gambling as an issue for people with ID, services for people with ID who may experience harm from gambling or how preventative measures could be implemented to reduce harm.

All focus groups were audio recorded with the permission from participants. Recordings were then transcribed by a professional transcription company. Ethics approval was received from the Deakin University Human Research Ethics committee.

Data interpretation

Interviews were professionally transcribed. Transcripts were then uploaded to QSR NVivo to manage the data. Thematic analysis was conducted utilising the steps proposed by Braun and Clarke [2006]. This included reading and re reading the transcripts to gain an understanding of the data. During this stage initial thoughts and observations were made on the transcripts to start the initial coding process, to further understand the context and content of the data. These thoughts and concepts were then developed into codes and were grouped into themes. Given the exploratory nature of this study and the small number of participants, the aim of this analysis was to identify semantic themes within the data rather than latent [Maguire and Delahunt, 2017]. This was because we were focussed on providing a voice to participants and documenting what they had to say about gambling and people with ID. Themes were then reviewed by the team and the results were written up [Braun and Clarke, 2006]. Quotes were used to illustrate the experiences and perspectives of supporters and the associated themes.

Results

Sample characteristics

There were three focus groups and seven participants, this included five females and two males (Table One). Each focus group consisted of people who knew each other, with two of the focus groups being recruited from two disability organisations and the third were people studying disability at a university together. The three participants in focus group three had also experience working within the disability sector. All participants had different roles and all had different levels of experience in the disability sector. One participant had additionally been involved with a Gambler’s Help organisation in an unrelated role.

Table One: Focus group participants

	Number of participants and gender	Roles in the disability sector
Focus group one	Two females	Advocacy
Focus group two	Male and female	Community development and engagement
Focus group three	Two females and one male	Children support, one-on-one support, and supported employment

The experiences of supporters with people with ID and gambling

The first overarching theme outlines the different experiences supporters discussed in relation to gambling and the disability sector and people with ID.

Gambling as a priority within the disability sector

Most participants had not thought about gambling during their time working in the disability field. Participants who had more direct daily contact with clients including in recreational or leisure activities had a greater understanding of the issue. However, participants considered that people with ID and gambling might be more common than is currently understood:

I think, well I think it is an issue. I think that just because we maybe aren't aware of the impact, that's only I suppose because you know we deal with lots of other different issues, we are not specific to obviously gambling.

There was also an acknowledgement that gambling was not a topic that was well understood and talked about within the broader community. One participant noted that if it was an issue for the wider community then the disability sector must be included.

Experiences with people with ID and gambling

There was a range of different experiences when it came to supporting people with disability and gambling. Some participants had supported individuals to gamble, while others had only heard anecdotally about people with disability who had gambled. EGMs was the most common gambling product recalled by participants however most had not had any real concerns about this.

I've got a couple of clients I suppose that, I've got one that I believe goes to the pokies twice a week. I don't believe he feels it's a problem, he's never discussed that it's an issue and he never appears to run out of money.

Three participants could remember specific clients that they knew who had experienced harm with gambling. For example, "So currently I'm an advocate for someone who seems to have a pretty extreme gambling problem". This participant noted that lives of people with ID are often complex and while gambling may initially provide enjoyment, inclusion and motivation, if supports are lost a reliance on using EGMs can be a substitute and cause significant emotional and financial harm.

Other participants also brought up the wide spectrum of gambling products available in the community and asked throughout the interview if gaming (mobile phone and computer games) was also included. A few participants had seen some potentially problematic behaviours with games on people's phones and individuals spending significant time and money playing these games. These participants thought that supporters needed to be more aware of some of the ways that people with ID may be engaging with different technologies and the potential financial harms that could be experienced while gaming.

The role of supporters and disability organisations in gambling and people with ID

There was a large amount of complex discussion regarding the role of supporters in facilitating and supporting the engagement of people with ID to gamble. Each supporter had their own perception about the different ways they should support people with disability in any decisions or choices to be made. This included whether it was the responsibility of the supporter to enable a client to gamble, given that it is a legal product. There were also discussions that different supporters had different amounts of influence depending on their job. For example, people who were in advocacy roles said they had limited personal interactions with people with disability, whereas those who worked as one-on-one supporters or people who worked in day or residential disability support services had a greater influence on enabling behaviours.

The participant's expressed mixed feelings regarding how their own attitudes and beliefs about gambling would influence those they support. While some people indicated this would have no influence, others were more sceptical. One woman said that supporting a person with ID with gambling could be considered similar to voting, and that there was a need to make sure that their own political beliefs did not influence their client's behaviours. She also noted that gambling can be a divisive topic in itself and someone with very "hard line views" about gambling could also impact and influence the person's choice to go to a gambling venue. However, one supporter said it was a very difficult situation as clients are able to choose their support worker, and so if they are not able to do something with one person they may find someone who will allow them.

There were also complex discussions relating to the difficulties faced by supporters in balancing a person's right to make their own decisions with a supporters' duty of care to minimise harm.

Participants recalled that they would have to look at and abide by their employment organisations policies in determining what was and was not allowed. These policies were often in place for other risk behaviours such as sexual experiences or alcohol consumption. However, gambling was not something that they believed was within the organisations' policies and were not sure if it was something that had been considered by organisations.

Supporters' attitudes towards factors that make gambling appealing to people with ID

The next theme was the perceived factor that may make gambling appealing for people with ID. There were four key factors supporters associated with this.

Social connection and reducing loneliness

First, participants agreed that people with ID often want social connections and to reduce feelings of social isolation and loneliness. Participants discussed that gambling venues such as pubs and clubs were places that fulfil some of those needs for people with ID. They recalled that the staff may know their clients by name and those interactions were important for people with ID. Although some supporters considered EGMs to be a "solitary activity" they thought that it was still an activity that could be done with friends and family. The following participant summarised the potential gambling venue experience for people with ID:

It's that feeling of belonging and that feeling of value I think because as you mentioned so many people are incredibly socially isolated, particularly people that might have more – I hate the term but it's the easiest way to describe it, mild intellectual disability, who are actually a lot of times more at risk if they're living alone of being more socially isolated, particularly if they don't have steady jobs and that kind of stuff and being able

to go to your local pub, club, whatever and people know your name and you can sit there and potentially win stuff, it is one of those things where a lot of people would consider that friendship.

Financial opportunities

Second, supporters identified that the financial aspects could be particularly appealing for people with ID. Many supporters spoke about the limited financial income that most people with disabilities have because they received a disability pension and/or because of limited employment opportunities. One participant, in jest, contemplated the possibility of a person with ID earning money from EGMs. While he was joking, he highlighted the significant financial disparity that people with disabilities face and that gambling may be something that could be seen as a potential way to make money. Furthermore, the ability to gamble and spend their money without influence from their family might also be a contributing factor why they enjoyed gambling. One supporter expressed concerns that some people with ID have a very limited understanding of the value of money and how money works. Consequently, the idea of making a “quick win” or receiving a “big payout” could be appealing.

Independence and inclusion

Supporters identified that gambling enabled people with ID to feel that they were doing something that everyone was doing and to have their own independence. The ease of EGMs allowed people to gamble without really understanding how the machine worked. Participants spoke about their clients wanting to be involved in an adult activity, and one suggested that if a person grew up in a family who gambled on EGMs then gambling could be seen as a “rite of passage”. For example, one participant said:

I can't speak on behalf of a lot of people but he knew pokies to be something that was a bit like over the age of 18 and an adult centred activity. So when he turned 18 that's what he really wanted to do.

Structural features of gambling products and environments

The last factor was in relation to the structural features of gambling products in environments that people with ID may find appealing. Some participants recognised that the lights and the sounds of EGMs were elements that could be particularly engaging and enjoyable for a person with ID. However, it was also recognised that this could be something that was overstimulating. One participant thought that the advertising for gambling reinforced the idea that gambling was considered a ‘normal’ activity that everyone participates in. Another supporter recalled a man who enjoyed going to the casino because he enjoyed the glamour and sophistication while he was there.

...he loved sitting at a table holding the chips in his hands and flicking the chips around in his hands and he'd sort of get a bit dressed up and in this big glitter casino it gave him a sense of – I don't know if pride's the word, but being cool.It's an escape from living in government housing, that he gets to go there and dress up and I guess that provides another need for him as well because he'd go with his friends. So many elements.

Protecting people with ID from the harms associated with gambling

The following theme explores supporters' awareness and understanding of gambling harm related services and the potential strategies that could be implemented or developed to reduce or prevent gambling harm for people with ID.

Current knowledge about gambling services

Firstly, participants perceived that there was limited education to support people with ID to gamble 'safely' and limited processes if a client presented to them thinking that they were experiencing harm from gambling.

Some participants stated that they would need to look up services to try to direct their clients to help, however there had been no formal advice as to who or what would be the best services. There was also recognition that there was limited understanding around gambling help information for even the general public. So, if a client had a gambling problem, supporters would have to find help services for gambling through traditional methods. For example, one participant said they would have to conduct a search to find help.

Supporters may only provide help for gambling harm if there had been concerns raised by the client or their family. Participants suggested that most help seeking services may be very difficult for people with a disability because of mobility issues, as face to face meetings may be physically difficult to access. One participant described the difficulties people with minimal supports can have in accessing services given that most of this requires literacy skills and the ability to use technology, which for some can be limited. Nevertheless, someone suggested information in Plain English might be helpful.

Strategies to reduce and prevent harms from gambling

The supporters proposed a range of practical strategies to prevent and reduce harms associated with gambling for people with ID. The first strategy was the need for accessible information and resources but the most important information for individuals should be easy to access. Strategies to create accessible information included animations or videos, easy English, and Plain English information sheets. They also proposed the need for gambling venues to do more for people with ID, whether that be a disability support person within venues, or providing more information and signs to remind people how gambling products are designed.

The second strategy was the need for education. This was in terms of increasing education for people with ID about money and about the risks and benefits of gambling. One potential strategy suggested was to work with pictures showing money spent on gambling, and what else that money could also purchase such as other healthier or useful products. The idea being to demonstrate how the money spent gambling could be spent on other things. Another strategy was using peer educators, such as having people who had experienced harm sharing experiences with people with ID. This was discussed as being a strategy that they had seen be effective for other topics such as sex education. A participant thought that it was important to be proactive now rather than wait to develop resources for people who already had developed a problem with gambling.

However, to effectively educate people with ID, participants recognised the need for disability organisations and supporters to be trained. Thus, it was important for the education to target the right people and the right organisations. Some participants suggested these were the people in direct one-on-one supports, and others suggested a top down approach so that whole organisations could understand the impacts gambling could be having on people's lives.

Lastly, a few participants also mentioned the need for research and how that could shape the disability sector's understanding of people with ID and gambling. This information and research on people with ID could be used to influence an organisations policy and practice. One participant said that research could be used to understand:

I think like anything about disability there is need for more research into gambling when it comes to people with disabilities. So I think probably it is something that needs to be advocated for, for people to really understand that, so far, people might look at it as if it's something that only affects the general public and not people with disabilities. So, it's about researching more into people with disabilities about gambling and trying to find out what is known or what is there at the moment, or what is lacking according to them. So, I think it's an area where more research is really needed.

Discussion and recommendations

The aim of this study was to explore people with ID's lived experience of gambling. The two phases aimed to understand people with ID's perspectives as well as supporters in the disability field. The findings from this study raise three points for discussion.

1. Like the rest of the population, people with ID gamble, and have a range of knowledge and understanding about gambling products.

This study has found that people with ID have a range of different gambling experiences. There is a clear gap in research evidence focused on how people with ID, and people with other types of disability, engage in gambling. To better support people with disability there needs to be more knowledge around the types of products they use, why they engage with these products and how much time and money is spent. This research will form the starting points for the development of effective tailored messaging campaigns. There is also a need for greater emphasis on including people with ID in research. Currently the literature has focused on young people and ADHD and comparing their risk taking and decision making to people without ADHD [Breyer et al., 2009]. From our knowledge there is not any information published from gambling prevalence surveys that report disability status. However, as approximately 18 per cent of Victorians have a disability [Department of Health and Human Services, 2018] it can be assumed that people are either being excluded because of study criteria or there are people within these samples who have a disability.

Participants described gambling on a range of products, often for fun and enjoyment or the chance to win. Participants indicated that they understood how to gamble on particular products, the most commonly reported being EGMs, typically because of their accessibility and perceived ease of use. This was consistent with findings from a pilot study by Pitt and colleagues [2020], who also found adults with ID in Australia commonly engaged in gambling, particularly EGMs. EGMs are considered to be one of the most harmful gambling products given their addictive design and the high amount of money Australians lose gambling on them each year [Dow-Schüll, 2012; Queensland Government Statistician's Office and Treasury, 2019]. Given the potential for harm that gambling can cause people with ID, it is important that there is information that explains the tactics of the gambling industry and how EGMs are designed in order to ensure that people with ID are able to make more informed choices around their gambling behaviours.

Participants were found to be gambling on their own or with friends, family or sometimes supporters. There is a complex dynamic between a supporter's role in supporting people's choice to gamble and fulfilling their duty of care to minimise harm. Public health focused education that also targets disability organisations and supporters may be important in providing supporters better information when they talk to their clients about gambling.

2. People with ID can conceptualise the risk and benefits of gambling, however there was a clear separation between their own gambling behaviours and harm.

Most participants in Phase One had a clear understanding of the positives and negatives associated with gambling. While the negatives were a very common theme throughout interviews, there was a clear separation around their own gambling behaviours and any potential for harm. This may have been due to the range of responsible gambling measures that they believed they were taking. Some participants were not familiar directly with 'gamble responsibly' terminology, but still referred to their gambling as being in control, setting limits, and only spending what they could afford. However, these attitudes may be creating a reduced perception of risk and a false sense of

security when it comes to their gambling behaviours. This is concerning given research that shows that responsible gambling messages can create more stigma around gambling harm and may be ineffective [Miller and Thomas, 2017].

Gambling in Australia has been considered to be highly acceptable and normalised within society [Thomas et al., 2018]. This has been in some ways due to the range of ways that the gambling industry promotes its products. In Phase One, participants indicated having favourite EGMs that they liked to gamble on. Having a favourite machine is often associated with people who are at an increased risk of experiencing harm from gambling as it can create a level of brand loyalty and can make gamblers feel as though they are more likely to win on certain machines [Millhouse and Delfabbro, 2008]. There were also perceptions that some gambling products can be more harmful or risky than others, including EGMs and horse racing, because of the amount of money that can be lost. EGMs have a range of design features that can be addictive such as the lights, sounds, and programming [Livingstone, 2017]. While it is important that people with ID have the freedom to make their own choices about how they spend their own money and time, a need to acknowledge the risks and harms that EGMs and other gambling products pose for not only people with ID but the wider community is important. Therefore, messages that explain the risks associated with gambling products, need to be developed in a way that are easy to understand and accessible to people with ID.

3. All participants identified a need not only for greater awareness about gambling for people with ID, but also a need for more accessible resources and education for individuals and the wider community.

Most participants, either people with ID or supporters, were aware that help existed for people experiencing harm from gambling. However, there was a clear recognition that these services would not be specifically tailored to people with ID in terms of their accessibility. People with ID may have limited literacy and numeracy skills, and technology can also be a barrier to accessing help services, making them more reliant on others to seek help. To ensure that people with disability are able to find the help that they may need if they are experiencing harm from gambling, there is a need for targeted evidence based campaigns that provide information about help seeking services. This could include materials that are in easy English or videos and animations. Gambler's Help services may also need to consider how they could tailor their services to be more accessible to people with disability.

An exploration of the literature relating to public health challenges beyond gambling, suggest there is much work to do in increasing the accessibility of such programs for people with ID. For example, there is little access to substance abuse treatment tailored specifically to people with ID [Robertson et al., 2020; Slayter, 2010]. Within the area of sexual health and ID there has been some research exploring how best to deliver information in an accessible way. In a systematic review of sex and relationship education programs for people with ID, the authors found that there were many areas of consideration that were needed in developing effective campaigns [McCann et al., 2019]. There was also the recognition of people with ID needing to have the ability to express their sexuality and the importance of providing accessible education for this group. Frawley and O'Shea [2020] report findings from a sex education program that was developed with and delivered in conjunction with people with ID. The program highlighted the importance of including people with ID as a source of knowledge and how to utilise those experiences to teach others. Integrating people with ID and their own experiences of gambling or gambling harm could be a potentially effective method to provide information to people with ID.

People with ID and supporters came up with similar strategies in how to reduce harm among the disability population. They highlighted a clear need for accessible information and education. People with ID thought that there needed to be education and support not only for people with a disability but also for the broader community. Interestingly, the suggestions that were provided by participants about the structural features of machines were systems that have previously been suggested by governments and researchers [Australian Productivity Commission, 2010; Thomas et al., 2016; Williams, 2010]. Participants thought having pre-determined limits before

gambling could be a way to minimise the amount spent on machines, to ensure they could only spend what they could afford. Pre commitment is a measure aimed at limiting the amount of money a person can lose. While there are a range of different ways this could be implemented a mandatory system has been found to be the most effective, especially when people who are experiencing harm find it difficult to control spending [Thomas et al., 2016]. The responses from people with ID in this study highlight the need for research to include potentially at-risk communities to have a say in the development and implementation of harm prevention strategies that are targeted towards their own communities.

Key recommendations

Taking a public health approach to reducing and preventing gambling harm acknowledges the multi-factorial approach that is needed to make change [Thomas et al., 2018]. The findings from this study have highlighted some key areas for intervention. These recommendations have been separated into three key areas: research, policy, and practice [McCarthy et al., 2019]. While the following is specific to people with ID and the disability sector, the strategies could also be considered as an approach for reducing harm amongst the wider Victorian community.

Research

There are some key areas of research that could be considered to further extend the knowledge that has been found from this study, but also some new areas that could be explored.

- Documenting how people with ID engage with gambling products and environments. This is important given that data about the gambling practices of people with ID are not specifically captured within population-based prevalence surveys, with these types of surveys not readily accessible for this population sub-group.
- Developing evidenced based harm prevention messages suitable for people with ID.
- Exploring how individuals with a broader range of disabilities, including acquired brain injury, physical disabilities and other cognitive disabilities may be vulnerable to gambling related harm.
- Understanding how formal and informal supporters may influence pathways to gambling for people with ID, and how supporters may be more effectively used to prevent and reduce gambling related harm.

Policy

There are a range of policy recommendations that are consistent with a public health approach to addressing gambling harm that have emerged from the findings. Some of these recommendations are not necessarily specific to people with ID and could be helpful for the wider community.

- Designing evidence based, easy to understand information that explains the risks associated with gambling products, and ensuring these are accessible to all people, including people with ID.
- Exploring options from a government perspective to address the significant links between social isolation and loneliness and gambling behaviours in vulnerable or socially excluded sub-populations.
- Identifying, providing, and promoting alternative inclusive spaces to pubs, clubs, and casinos.

Practice

The findings from this study have identified some potential areas that could be considered by disability organisations when it comes to gambling as an issue for people with ID. The following are a few key areas that could be addressed.

- Increasing supporters' understanding of gambling as a public health issue for people with ID and providing education about help services and signs of harm before people present with problems.
- Designing evidence-based gambling harm prevention workshops for people with ID and supporters through organisations.
- Exploring how to support people with ID to find alternative venues for social connection.

Limitations

It is important to recognise the limitations of this study. First, there was a small proportion of people with ID that participated in an interview over the telephone. Telephone interviews may not have given the same depth of detail or built a strong rapport with participants compared to face to face interviews. However, it was important to provide an opportunity for people who wanted to participate but were unable to travel. Second, the study cannot be generalisable to the broader disability community. While the research team assumed that all participants had ID, it was not considered necessary to confirm this. This study was exploratory in nature so aimed to provide insights into the group of participants that were included in this study and not to specifically explain how all people with ID may engage with gambling. Third, there was very limited participation from supporters. There were a range of different methodologies that were proposed with this group (face to face interviews, large seminars, workplace focus groups) however we were unable to engage more participants. This was also exacerbated as data collection began during COVID-19. Research with unpaid supporters such as family members is also an important perspective to consider, to gain more insights into the role of supporters in facilitating gambling. However, while this was proposed, the difficult nature of recruitment meant this was not possible.

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