

EVALUATION OF *SEXUAL LIVES AND RESPECTFUL RELATIONSHIPS PROGRAM* FOR LGBTIQ+ PEOPLE WITH INTELLECTUAL DISABILITY

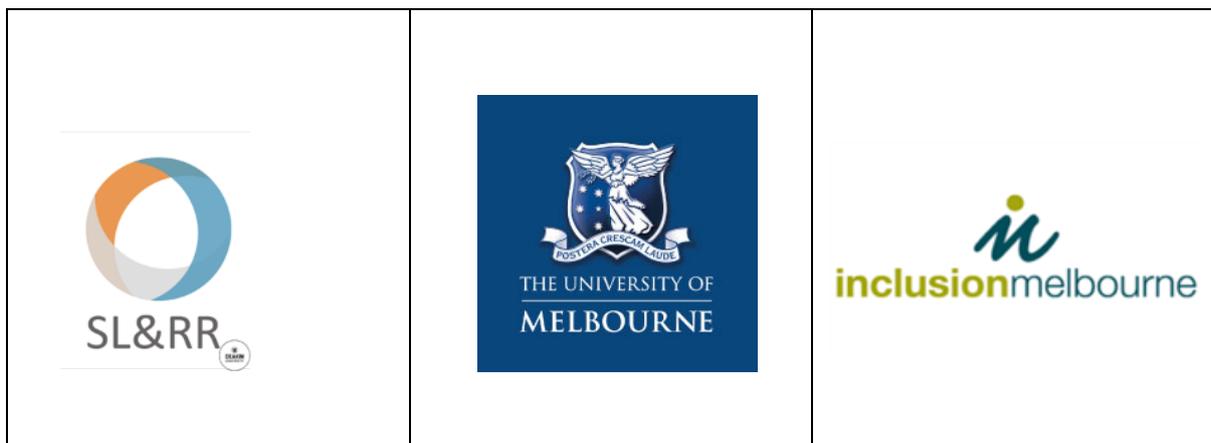
Final Report

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Evaluation: Sexual Lives and Respectful Relationships Program for LGBTIQIA+ people with intellectual disability

Background to the project

Inclusion Melbourne has had a long-standing commitment to the provision of community services that support and enable people with intellectual disability to live in an inclusive community, where everyone has the same opportunities to participate in community life and to take their place in society as respected citizens (refer Inclusion Melbourne's Vision Statement). In this context, Inclusion Melbourne identified the need of LGBTIQIA+ people with intellectual disability to have access to education and support with respect to the expression of their sexual identity and the pursuit of safe and fulfilling relationships; "When people with disability explore their sexuality they face challenges accessing information and support within the context of a narrow and regulated life, especially if they identify as LGBTIQ or gender diverse" (Inclusion Melbourne, 2017). To these ends, the Sexual Lives and Respectful Relationships program (SL&RR) (Frawley, Barrett & Dyson, 2012) was identified as a potential resource.

The SL&RR program is a long-established educational program that is designed to enable people with intellectual disability (ID) to acquire the knowledge and skills to pursue healthy, safe and respectful relationships through sexual lives of their choosing, and to have good reproductive and sexual health outcomes. It is an educational program grounded in research and has been presented on multiple occasions over the past fifteen years or more. Led by Associate Professor Patsie Frawley of Deakin University, in its current form it is regularly delivered across seven sites in Australia.

Key features of the model informing this program include the engagement of people with an intellectual disability as peer educators. It also utilises community professionals as co-facilitators of the program. These co-facilitators are also actively engaged in networks at a local level to raise awareness of sexuality and relationship rights for people with an intellectual disability, and to work towards the prevention of sexual violence and abuse perpetrated against people with an intellectual disability.

The program makes considerable use of narratives and stories told by people with intellectual disability, to "help people think and talk about sexuality and relationships and relate what the storytellers said about their own experiences and own relationships." (Frawley, O'Shea & SL&RR review team, 2017a). Peer Educators and Program Partners run the group, and "lead the sessions, introduce and present the stories, and help the group to talk about them. They help the group work together and help everyone to feel safe about being in the group." (Frawley *et al*, 2017a). The emphasis on rights, privacy and safety in relationships is conveyed through the narratives of people with intellectual disability, and is at the core of this program (Frawley and Anderson, 2014).

However, the program had not previously been run specifically to address the needs of people with intellectual disability who identified as part of the LGBTIQIA+ community. Consequently, this was the first time the program had been adapted and specifically presented for LGBTIQIA+ adults with intellectual disability. As part of this new initiative, three

additional narratives were curated for inclusion in the program, specifically focusing on the life experiences of LGBTQIA+ adults with intellectual disability.

The evaluation was conducted as a collaboration with Inclusion Melbourne as the host for the program and Deakin University as the facilitator of the modified version of SL&RR. The University of Melbourne carried out the independent evaluation of the program, which took the form of gathering and analysing interview and focus group data from trainers, program participants and those involved in establishing the program, together with field notes from observations of the program implementation in real time.

The project was funded by: GALFA, the Sidney Myer Foundation, and The University of Melbourne Humanities Foundation Board.

Project Objective

This evaluation investigated and evaluated the trial of the *Sexual Lives and Respectful Relationships* program for people with intellectual disability, in this case specifically adapted for and targeting LGBTQIA+ participants.

In particular, it focused on:

1. Experiences of participating in the program for program participants
2. Access to and engagement with the adapted program by the target audience
3. Identification of program enhancement opportunities and recommendations based on the qualitative evaluation

Specifically, the evaluation addressed the following questions:

- 1 How might an evidence-based sexuality and relationships program for people with intellectual disability be adapted to meet the needs of LGBTQIA+ people with intellectual disability?
- 2 What can be learned from the pilot LGBTQIA+ SL&RR program to support inclusion of LGBTQIA+ people with intellectual disability in sexuality and relationships programs?

Here it should be noted, it was not proposed that in the long-term, the pilot LGBTQIA+ program being trialled would become a stand-alone program, but rather that what was learned from the pilot would be incorporated into the regular program, to ensure greater inclusivity of all sexual and gender identifications.

Background Literature

There is a paucity of literature that addresses issues specific to people with intellectual disability who identify as LGBTQIA+ (or any other variations/combinations). While McCann, Lee & Brown (2016) argued that “there is a growing and evolving evidence base” (p.39) about the specific needs of LGBT people with intellectual disability, a systematic literature review found only fourteen papers published over a twenty year period, from 1995 to 2015. McCann *et al* (2016) identified five major themes in this literature: accessing health services; gender and sexual identity; attitudes of people with intellectual disability regarding their LGBT status; education; and support and therapeutic interventions. Yet education and training were only recognized in six of the studies, and it was argued that there was a necessity for further enquiry into the effectiveness of education programs for people with intellectual disability who identify as LGBTQIA, “with an opportunity to undertake pre- and post-evaluation studies of education and training, thereby measuring long term outcomes and their benefits” (McCann *et al*, 2016, p.49).

Meyer (2003) argue that LGBT people with ID are often subjected to what is acknowledged as ‘layered stigma’... resulting in ‘minority stress’. Further Hall (2010) observe how prejudice and discrimination may create further marginalisation, social exclusion, and limit the opportunity for developing meaningful relationships”. They highlight other issues for concern, including social stress, social exclusion, homophobic and transphobic hatred, bullying and violence, and further emphasise the possibility of institutionalized prejudice. McCann *et al* (2016) note that services must recognize that people with ID can also be LGBT, and that paternalism, heteronormativity, prejudice and negative attitudes may exist within organisations” (p.50). Such issues, they note, may be exacerbated because of communication challenges inherent in intellectual disability.

While McCann *et al* (2016) observe “that there is a requirement for a sustained and specific research focus on the needs of people with ID who identify as LGBT to further identify support mechanisms, interventions and service responses that meet their distinct needs” (p.49). Ramasamy *et al* (2016) comment on the McCann *et al* (2016) literature review with what might be seen as strong criticism, for regarding LGBT people with intellectual disability as “service users”, rather than taking what they assert to be a more person-centred approach. Ramasamy, Rillotta & Alexander (2010) observe: “An integral element of person-centered planning is taking into account the subjective knowledge by drawing upon individual perceptions and expressed needs to formulate a personalized meaning. Person centered planning also strengthens a person’s voice by identifying what’s important to that person based on individual merits” (p.x). It was their stated intention to consider the lived experiences of adults with ID who identify as lesbian, gay, bisexual, transgender, queer or questioning, intersex or asexual (LGBTQIA) to not only provide an authentic reflection about one’s life pertaining to sexuality but also attempt to “bring lost or silent voices to the fore.” (Ramasamy *et al*, 2016; p.x). Here Ramasamy *et al* seek to emphasise the importance of the personal narrative in advocacy and education.

Methodology

The protocol for this research was reviewed and approved by the University of Melbourne Human Research Ethics Committee; Approval Number: 1750795 (See Appendix 1)

Evaluation Design

This project evolved over a number of phases, but only the actual trial of the new materials is being reviewed in this report. However, for the benefit of context, the preliminary phases included Deakin University academics working with three people with intellectual disability who identify as LGBTQIA+, to gather narratives from their lives about their relationships, in order to augment the materials previously being used in the Sexual Lives and Respectful Relationships Program. Key messages on the stories were produced in conjunction with the SL&RR team at Deakin University (comprising research staff and Peer Educators). The key messages will be further refined based on the input of the pilot program attendees after each story was discussed. The development of these additional materials was funded by GALFA and the Sidney Myer Foundation, applied for by Inclusion Melbourne. The trial of these new materials was carried out over a four-day program, with two consecutive days each week, a fortnight apart. Each session ran for approximately six hours. It was run at Inclusion Melbourne's premises, which was seen as venue that afforded a degree of safety. Transport and lunch were provided for participants. This report is an evaluation of the trial process.

To achieve the project objectives, a qualitative design was employed. The initial intention was that The University of Melbourne evaluation team would:

1. Undertake qualitative focus groups with the training team before and after the program
2. Attend the program delivery to observe engagement of participants and program delivery approaches of the training team, and to take field notes
3. Access program materials
4. Access materials developed in the program documenting participants' pre-program expectations and post program evaluative feedback
5. Carry out individual interviews with program participants pre- and post-program (see interview schedule for an outline of questions used in these interviews.)

Some modifications to this framework were necessary in the field, and these are noted as a caveat to the report. Significantly though, the team presenting the program requested that there be no pre-program interviews with participants due to difficulties with transportation, access and timeframes for informed consent. This was agreed. Additionally, due to changes in the program as it ran, it was not possible to access participants' pre- and post-program expectations and feedback, except in an informal manner. These issues serve to highlight the challenges of conducting applied research involving people from 'hard to reach' communities.

Participants

Ten people with intellectual disability who identified as LGBTQIA+ were sought to participate in the program. A recruitment flyer was developed (See Appendix 2) and circulated through the auspices of *Inclusion Melbourne*. One of the Deakin University team

interviewed all potential participants to ascertain their suitability, and whether they were able to understand the purpose of the program. Inclusion Melbourne contacted most participants to ensure support and dietary needs. In general, most participants had contact with both Inclusion Melbourne and Deakin University. Inclusion Melbourne met with up to two thirds of the participants in person, and visited the Rainbow Rights and Advocacy group to talk about the program. An important ethical consideration was that all participants had to have sufficient cognitive ability to provide informed consent. Subsequently, of the 12 who expressed an interest in the program, nine were actually suitable to attend.

Referral points for the program included Inclusion Melbourne, Pride Vic, SECASA and the SL&RR program networks. As it was a pilot program with limited capacity, and as the LGBTQIA+ community was recovering from the Australian Government postal survey addressing same-sex marriage, which affected its capacity to engage with additional projects, the team did not circulate information on the program any further. Strongest interest in being part of the program was received through the Deakin University networks, and through the group Rainbow Rights and Advocacy, which is a self-advocacy group for people with intellectual disability who identify as LGBTQIA+. Despite these limitations it was still possible to reach the desired number of participants. Of the nine participants, two identified as female, one as sometimes female and sometimes transgender, and six as male. Ages varied from an eighteen year old, to a participant in their fifties. Living situations of participants varied from supported accommodation, halfway houses through living with families, to living more or less independently.

The team articulated that the screening reflected the fact that they had very limited capacity to directly support people after they completed the program. Careful consideration was made as to what attendance might mean for people where it might have created family discord or might have outed them to paid staff. In recognition of those consequences not everyone who expressed an interest came to attend the program. It was observed that this is more work than is usually required when running the program, but this has to do with homophobic and heterosexist ideas, particularly as they intersect with intellectual disability, and ensuring the team acted in ethical ways that protected participants. It was also about ensuring the space remained LGBTQIA+, and potential participants who were not gender diverse or (in whatever way) queer identified would have been able to be connected with other programs running in existing sites. As the team member from SECASA noted: “We didn’t ‘weed out’ or ‘cherry pick.’” Processes followed were important, but it is stressed that potential participants were not rejected because it was ‘too hard’ for people who might be considered ‘too vulnerable’.

The other participants were:

- a Peer Educator with intellectual disability who identified as GLBTQIA+, and was paid and trained to deliver the SL&RR program;
- a Program Partner from South East Centre Against Sexual Abuse (SECASA), with a range of experience in sexual assault and domestic violence; and
- the National SL&RR coordinator from Deakin University.

Methods of Data Collection

Data were collected by:

- a desk audit of previous iterations of the program, and of publications of relevance
- written observations of all of the four training days
- review of the program materials
- a post program interview with one participant
- a focus group interview with the program leaders including the Peer Educator, the Program Partner from SECASA, and Deakin University
- an interview with a representative from *Inclusion Melbourne*, as the auspicing organization.

Observations

For ease of discussion, data are considered in relation to the three main focus areas.

Experiences of participating in the program for program participants

Trust and personal safety

Participation in the program was doubtless experienced differently by the various participants. From the outset, the team presenting the program worked to create an environment where the participants were able to feel as safe as possible being open about their sexuality, and the issues they face with regard to relationships and their lives in general. The atmosphere in the room was made welcoming with display of the rainbow flag, and other materials that the participants could relate to, and the team was always there to meet the participants, and to help them comfortably settle into their day. In some cases, this included meeting them at the railway station and walking with them, providing coffee, rearranging seating and so forth. The importance of planning for and providing such assistance should not be underestimated.

The Program Partner noted in the focus group discussion: *“I never tell people this is a safe place. We wanted them to feel safe. There’s been a lot of work put into getting people there so that they felt really welcomed and invited.”* This was an aspect that demanded considerable commitment and the management of logistics. Some participants, for example, had a fear of being in a taxi with male taxi drivers. Clearly there was work to be done on how to feel safe in taxis, and making it clear to the person. This involved considerable before and after work. Some people might have their own preferred taxi drivers, while others would only go with female taxi drivers. This emphasised to the team that needing a female taxi driver is a totally reasonable request, and in future, some advocacy may be needed to ensure an account is held with a company like *Shebar*, as they do not accept CabCharge. Only using one taxi company does not guarantee to keep participants emotionally safe, even if they are safe physically. The Program Partner noted: *“And the walk from the station too. We need to accept that people may need support with the walk. We had to be prepared to put in extra time and sort out the timetables.”*

The introductions were very empowering, with all who were in the room declaring their sexuality (including the evaluator), and the facilitator from Deakin University used people in the room as a resource for others in the room, thus building an environment of trust. The icebreaker activity enabled the people in the room to get comfortable interacting with each other very quickly, and a supportive environment developed very quickly amongst the participants. This interactive environment was made very clear when one participant raised an issue they were having with a government agency, and a supportive discussion followed, with other participants expressing empathy, requesting greater explanation, and seeking to support the participant who raised the issue. This set a clear direction of trust, safety and personal support that continued throughout the program.

Some time was spent during the first session talking about language, and what words participants felt were acceptable to describe their sexuality and/or gender. For example, for some people, the word ‘queer’ was a flashback to verbal or other abuse, a negative word, while for others it was more positive and ‘all encompassing’. The trainers were called on to

make a decision about how to include everyone in our language (and to consider both sexuality and gender when doing so) which they felt needs consideration for the overall program. On reflection, it is imperative that the trainers be aware of the rapidly changing nature of language in this field. This may ultimately be part of the educative role they play as they are more readily exposed to the shifting nature of the lexicon and semiotics of the territory.

Time was spent generating behavioural guidelines for the four days, as well as discussing the nature of privacy. There was an enthusiastic discussion about the nature of *safe space*, and how the group could work towards ensuring that the room was considered a safe space by all. This included a discussion about the sort of language people accepted. The guidelines were posted as *Our Agreement* (Figure 1), and in the main, they were seldom breached. However, the team made sure the guidelines were reiterated in non-threatening ways, and regularly drew on them as reminders to the group.

Our Agreement

We all belong.
We are all accepted.
Keep it in the room.
Respect each other and be caring.
Mobile phones away.
Respectful language.
No judging
Look after yourself.

Figure One

Perhaps the most obvious of the guidelines that emerged repeatedly was the need to: “*Look after yourself.*” This was reiterated frequently throughout the program, and a key theme.

[Looking after yourself: The Peer Educator \(PE\)](#)

In the focus group with the team, the Peer Educator (PE) noted that when the program started on the first day, the team had been very nervous. But very quickly, they observed, ‘the nerves passed’, because they felt at home and safe in the group. The Program Partner (PP) picked up on this, and made a significant observation:

People disclosed some very difficult histories, including directly to PE. [They were] hearing some very difficult things. [They] responded really well. And it was very healing for those people to tell a peer. PE created a really supportive environment. Everyone was very supportive in the room, and PE modelled that.

This was discussed further in relation to the story of ‘Hussein’, which addresses respectful relationships and sexual assault (Frawley, O’Shea, Ardley, Cini, Stokoe & Wellington, 2017b). The trainer from Deakin University (DU) observed:

Lots of people needed to go outside the room. PP went out of the room to support them. PE really stepped up [with DU] to keep things going. PE, your shoulders went back and you listened and engaged a little more.

This was especially significant as the Peer Educator is very much a role model for the other people with intellectual disability in the room, and if they are able to model looking after herself, then the participants are likely to follow suit. This was also observed by the Deakin University member of the team later in the program: “*And in the sex education, you led by asking questions. You were open about what you knew and didn't know. It set the tone for the whole room.*” By their attempts to look after themselves, the peer educator contributed very strongly to ensuring a safe space for other participants to feel free to look after themselves in this potentially challenging context without fear of judgement.

Respect each other and be caring

Throughout the program, the atmosphere was marked by a high degree of respect between participants. There were times when particular participants were triggered by one or other of the narratives that were being used, and at no time was anyone in the room judgmental about the responses of others. In fact, to the contrary, people were highly supportive and empathic. During the session on safe sex, one of the participants chose to leave the room because they felt uncomfortable handling the condoms and lubricant that were being shared around. Nobody in the room criticized their decision, and one of the participants approached the evaluator and asked to check that the one who had left the room was okay and did not need further support. This was dutifully done, and reported back to the participant who had expressed concern. (The team presenting the program had already checked on the well-being of the participant who had left the room.)

One participant noted that: “*I really enjoyed hearing other people's stories, and hearing about the struggles they have gone through, with people taking advantage of them sexually.*” They observed that it helped him feel safe and respected, and to feel comfortable in the room, because his experiences were not out of the ordinary, and nobody was judging them for what they had been through. They said: “*I was at no time uncomfortable. The way it was presented helped that.*”

It should be emphasized here that the team overall modelled respect and empathy. In particular, the PP was able to step in and role model being supportive, and showed ways of communicating with each other. They asked permission to share what had been said by people who had left the room. They observed the need to be watchful for referral points as well, as some people were very triggered by the narratives. They noted that their personal stories changed over the day because of referrals, discussions and so on, which allowed people to grow through the processes while they were in the program.

The safe and supportive environment enabled participants to feel comfortable about disclosure, with discussions about victims of sexual and physical abuse in relationships feeling guilty or dirty, and about who should really feel guilt in such situations. This led to discussions about safe and unsafe places to seek sex. One participant brought up that such situations were actually more about power than anything else, and people seeking to have control over others. They reminded other participants that going to the police is a strategy people can use so that their rights are respected.

The issue of community respect was raised, and the challenges of having an intellectual disability and how people treat an individual on the basis of this. One participant raised that they were sick of the community treating them as a child, and this was supported by much nodding and many supportive comments around the room. One participant observed: *“We should be free to tell everyone or not tell anyone who we are. That’s our god-given right, but people are very 1950s. They assume that because we have disabilities we don’t know what we are doing. I know what I’m doing!”*

The personal is political

During a coffee break, one of the participants asked the evaluator how long she had worked with people with intellectual disability. When she told him since the early 1970s, they asked what sort of sexual experiences people with intellectual disability were allowed then. She told him a story of people at a sheltered workshop/centre having to sneak off to have sex in the back of a newspaper recycling truck. After initial shock, they were thoughtful for a moment, and then commented: *“Where is the human dignity in that?”* This interaction demonstrated just how far our understanding of the rights of people with intellectual disability of any sexuality has come, and also the strength of political awareness among many people with intellectual disability. For the participants in the Sexual Lives & Respectful Relationships program being piloted, the personal is clearly political, and to be sexual is regarded as being a right.

The Deakin University member of the team reflected on the narratives being used in the program, and observed: *“People really connect with these stories and remember them really well.”* When the story of ‘Carol’ (Frawley *et al*, 2017b) was presented to the participants, the group showed a good level of understanding of the emerging issues of relationships and sexuality, which they were able to reflect on and discuss. This indicated that even though some of the stories were quite long, they were pitched at an appropriate level for the targeted group. The responses of the group were at a far more sophisticated level than the questions directly linked with ‘Carol’s’ story. For example, one participant noted that ‘we should not judge a book by its cover’. They spoke of their own experiences coming out, and their parents’ not accepting (judging). They related their own experiences well to the story. The trainers drew the discussion back to skills of strength, courage and resilience, and this was well received.

Similarly, there was further discussion about control, and one participant related the reflections back to the earlier discussion about the State Trustees. The team took advantage of the discussion to get people to talk about advocacy groups such as Rainbow Rights and Advocacy. This led to participants raising the issue of the recent same sex marriage campaign, and a number of people in the room stated that they felt it had been a waste of resources and time. Some noted though, that it had caused stress in the LGBTQIA+ community, arguing that all people should have the same rights. One participant observed that it made her angry, and another said he felt physically sick during the campaign. This evolved into a discussion about Tony Abbott (a former Prime Minister) trying to stop the same sex marriage act, and then when his sister got married to another woman, he just smiled and walked away. This was followed by a discussion about not trusting politicians.

During the focus group, the trainer from the Program Partner observed:

There was a calm feeling in the group compared with the others we have done. It was really about allowing the space for the people to find their own words and terms. And we checked how people felt about them. And it blew me away how well the people can articulate their sexual and gender identities. People with intellectual disability haven't usually had access to all the theory, and yet they articulated so much.

In fact, it appeared to be more about what people in the program *gained*, rather than what they *learned*. “*There was a strong sense of validation and connection. They were able to reflect on who they are, and express belonging and acceptance, and appreciate who they are.*” (PP) What is clear is that people with intellectual disability have a good capacity to make meaning, and do not need the patronizing approach that has often been a hallmark of training programs in the past. Intellectual disability, sexual rights and relationships are part of the story of adulthood for the participants in this program. The Program Partner noted: “*It's a journey where people come out in the program, and there is space to process that.*”

Access to and engagement with the adapted program by the target audience

Input into program content

Drawing effectively on principles of co-design, at the start of the second day, when participants were feeling comfortable in the room and with each other and the team, the team member from Deakin University asked the participants what additional areas they would like to see covered in the program. Responses from around the room included:

- information about relevant advocacy organisations, such as *Reinforce* and *Rainbow Rights and Advocacy*;
- more understanding about domestic violence and partner violence; and
- sex education, with a comment that that it would be useful if this extended beyond what they had done at school, which was often not relevant to anyone who was not heterosexual.

While the program did contain further material about domestic and partner violence, having this raised encouraged some disclosures from the group, including from one of the men who disclosed domestic violence in his previous relationship. Support was widely given within the group, and the participant's new partner was very empathic and consoling. This was however, an issue that needed some professional support, and the Program Partner, who was from an appropriate community service, invited the participant outside and provided counselling and support. This was provided in an ongoing way throughout the day, as various aspects of the violence surfaced. The other participants were extremely supportive and empathic. The provision of counselling and related supports on a one-to-one basis during the and following the program emerged as an important consideration.

Dealing with stereotypes

The issue of stereotyping was one that concerned a number of the participants, and across the four days there was discussion about how this can lead to stigmatization, not only in the wider community, but also within the disability community. This is an area that arose in the discussion about ‘Carol’s’ story, in response to using *Strength Cards* (Veeken, 2003). The apparent intention of the activity was to revisit what had been covered the previous day, but it

served to enable the participants to reflect on their own relationships in relation to the narrative about ‘Carol’. Issues raised including the challenges of living in a hostel and the stigma that arose telling people in the hostel about one’s sexuality. The group noted that if you wanted to be open and honest you needed to be cautious. The problems highlighted addressed the responses of both the staff in the hostel, as well as the other, presumably heterosexual, residents. It was noted that it is about “*acceptance*”, but that others were “*too ignorant*” about the existence of LGBTQIA+ sexualities. It was generally agreed that if you are going to be open in your living arrangements, you need to: “*Believe in yourself. Love yourself.*”

The value and importance of private time was raised here, along with the scarcity of privacy in any sort of shared accommodation. This further emerged during the discussion of ‘Johnno’s’ story about sexual identity (Frawley *et al*, 2017b), which was presented by the peer educator and a group participant. The group stressed the importance of the individual in the story being able to access private time, and having his privacy respected. It was mentioned in the discussion that staff in residences are there to support the people who live there, and that it should be possible to talk about issues of sex and sexuality in front of them. Several participants observed that this is not always possible, and the Program Partner talked of approaching the Disability Ombudsman or the Disability Support Commissioner if you do not feel safe at home (with regard to privacy and sexual assault), or if your sexuality and needs for privacy in relation to that were not being respected. The discussion tied these issues into personal concerns about being stereotyped because of non-heterosexuality. It was raised more than once that there is a need to educate people about LGBTQIA+ and intellectual disability so that stereotypes may be addressed.

Discussion about this concern was quite intense at times, and it is clearly an area of great concern for participants in the group. The most significant question that was raised by the team in relation to these concerns was: *What do you want them to know?* There was a lengthy discussion about the value of relationships, and the nature of human beings at this point, along with the importance of being loved and nurtured, and feeling loved. The participants felt it was paramount that other people with intellectual disability, and the staff they work with, that this be understood. They also wanted people to know that they “*didn’t choose to be gay*”. Some of the statements included:

- *It’s not good enough!*
- *It’s prejudice!*
- *It’s bullying!*
- *It’s against the law!*
- *People close themselves in, lock the door, to turn themselves around! And just hide away!*

(These responses were general across the group and so have been included as it is not possible to identify participants from them.) The group stressed the importance of looking after yourself in this context, and one participant said: “*Sometimes I feel like I want to leave but I’ve got nowhere else to go. I need to live and love.*” When focusing on how these issues might be addressed in a wider Sexual Lives & Respectful Relationships program, it was emphasized that people who were heterosexual should “*not be afraid*”, but understand “*We are just like them. We’re the same people in different packages or different pages.*” It must be made clear in any training that stereotypes are wrong, and that everybody is an individual and unique, with their own stories and personalities. Lots of personal stories and anecdotes

should be used to set up discussion, and it was suggested to perhaps show pictures of groups of people and ask the participants to consider who in the crowd might be LGBTQIA+ and why they think that, as a starter for discussion.

Making use of services such as self-advocacy

The significance of self-advocacy became clearer as the program progressed, with participants raising concerns about how hard it is to find social or sexual connections: *“It’s difficult when all your mates are straight!”* One of the participants ran an excellent session for the group on the *Rainbow Rights and Advocacy* and *Rainbow Labor* groups, and how helpful they are for LGBTQIA+ people with intellectual disability who want to make connections. (The team who ran the program organized this session with the participant in response to the group requesting to know more about relevant aspects of self-advocacy. The session generated considerable discussion about the needs for such groups and how people can engage with wider community events such as Midsumma (in Melbourne) and Mardi Gras (in Sydney). Other groups of relevance were also mentioned, such as *Reinforce*, *PrideVic*, *Out on the Peninsula* and *CASA*, and there was extended discussion about the purposes of each of these organisations, the services they offer, and how they can be accessed. The role of self-advocates was explained.

In relation to this and similar issues, the focus group discussion with the team observed that some of the material went quite differently when used with an LGBTQIA+ group, compared with a heterosexual group. The response to ‘Hussein’s’ story for example, was apparently very different, and the Program Partner commented: *“This group just got it.”* They observed that they were much more aware of *beats*, for example (noting that some people in the other groups had been very shocked by this aspect of this story). It was noted that much about safety for people with disability focused on Stranger Danger but overlooked areas such as beats. This is very worrying. It became clear from the discussions with the LGBTQIA+ group that they were interested in how to safely connect with similar people online. The Program Partner commented that some of the materials needed to be used differently for people who were LGBTQIA+. For example, in working with the cards on Close/Not Close, the card addressing “people you have never met” really needed to be handled differently with this group. The tools need to be tweaked differently for different groups. This group shared their own strategies about meeting someone who is safe, and someone said: *“Just don’t go on Grinder!”* The Deakin University team member asked: *“How do we honour all the places where we come from and the bits about being that person?”*

Inclusion of sex education

In response to the request for sex education that goes beyond what people were taught at school (for those of the group who were young enough to have had that experience), the team asked the representative form *Inclusion Melbourne* to contact the Victorian AIDS Council to come and do a presentation on safe sex. For most of the participants, this was an extremely popular part of the program. (The one exception has already been mentioned, and they chose to leave the room when the group was handling condoms and lubricants.) The trainer who came out and presented had no experience working with people with intellectual disability, but it was clear that different participants in the room benefited from different aspects of the program due to his flexibility and empathy. One very quiet participant wanted to learn how to use a condom, and both the trainer from Deakin University and the trainer from the AIDS Council spent a good deal of respectful time with them on this. Others had queries about

other aspects of safe sex, and most had never been exposed to dental dams. The participants were supplied with a vast array of samples, and also told how to obtain condoms, lubricant and dams at a very low price. The participant who agreed to be interviewed, noted that for him: *“The best thing in the program was hearing about the dams.”* They also commented that the trainers answered in a way that was readily understandable. Here it was evident that it was important to be able to adapt and individualise elements of the program as it unfolded. Flexibility among the facilitators was critical, and having kept the group size relatively small proved to be a positive and an important decision.

Identification of program enhancement opportunities and recommendations based on the qualitative evaluation

Political awareness

The significant level of political awareness in the room provided program enhancement opportunities. This has already been discussed in some depth but needs to be re-emphasised here. For the participants in this pilot program, it is the strong intersections between identifying as being LGBTQIA+ and having intellectual disability that raises issues that must be kept clearly in view when providing an inclusive version of the Sexual Lives & Respectful Relationships program across an array of sexualities. The issue of stereotypes, for example, is one that needs to be addressed carefully within the broader program. As noted earlier, one participant said *“don’t be afraid!”*. This related to *being* LGBTQIA+, *meeting* people who are LGBTQIA, or just being rejected because you are or are not LGBTQIA+.) The group strongly felt that heterosexual people with intellectual disability need to understand that stereotypes are wrong, and that everybody is individual and unique, irrespective of their sexuality or gender identity. But they also pointed out that people also needed to be aware of the stigma of disability: *“It’s a stigma, disability. People think we’re not really people. They try to take our rights away. People who don’t understand, or don’t really want to understand, about disability.”*

The participants also felt that it was important to have strong discussions on human rights, and how they applied. *“Everybody has a right to have a say in the world.”* This includes the right to have voices and opinions heard. The use of the *Rights Cards* from Anne Craft stimulated a great deal of discussion. One participant commented that their parent was a bit overpowering, and found it hard that they were LGBTQIA+, but *“it’s just a decision of mine that I am totally... And [they] can’t change that. And I’m proud to be me.”* A discussion of this was linked into debates about rights, and other participants provided counselling at coffee break about this, and the right to be who you really are. In the discussion about one of the stories, one participant actually referred to *“the seven stages of grief”*, and related it to anger and the loss of human rights in the story.

Independence and stronger sense of identity

It is important to remember that, as noted by the team member from Deakin University, for people to come to this group, they needed enough independence, and needed supportive accommodation. This group was not representative. And they were very broadly spread geographically. *“We talked about the coming out issue with parents and friends. It was a much bigger trip into the unknown than usual.”* This being the case, however, provided an opportunity to explore how such issues might be addressed, and what local support and

services might be available to meet the needs expressed by participants. For many people with intellectual disability, having a sex life, whether it is straight or gender diverse, may be confronting to parents, and so many of the same issues may actually be significant. When a trainer raised the topic of Angela's masturbation (from one of the stories), and said: "*Well she enjoys that.*", one of the participants responded: "*We all do!*" The situation is no different whatever the sexuality or gender identity. It may just be that this group of participants in the pilot program felt a stronger sense of who they were, and felt empowered to express it.

This independence and stronger sense of identity probably has implications for the choice of trainers. The trainer from Deakin commented on the process of selecting peer educators for this program:

We had discussions about who we should have as trainers. We approached all our peer educators and checked who if anyone was gender diverse. We realised we only had a team of 3, and we didn't have a fourth. We had to decide do we go ahead with 3 trainers, or involve a peer educator who is straight. We held it as much as possible as a queer space. A queer man would be awesome but we didn't have it. We need to encourage sites to think who would engage as peer educators, and that will filter through.

Some of this pilot group expressed an interest in becoming peer educators, and one co-presented with the Deakin University at a forum on LGBTQIA+ people with intellectual disability several weeks after the program. Others from the group offered to be readers on the video presentations of the discussion stories. These unanticipated eventualities can be interpreted as indicators of how empowering the program was for the participants.

The personal strength of the pilot group may be due to the rigorous selection processes that took place, and this may be something that would warrant consideration for other iterations of the program with all sexualities present. At the focus group interview, the program partner noted: "*How you put all that time into checking all that stuff so important. We don't want to accidentally out a whole lot of people. We can't cut the time short in that.*" This was affirmed by the Deakin University representative, who added: "*And how do we do it in ways that would be ethical, and demonstrate safe practice.*" This led to the question of people who would have been selected to come to the program, but did not actually identify with any of the labels. The program partner asked: "*How do we bring them into the relationship? How do we bring those across so that everybody who does the program has access to it?*"

The team also observed that it was different presenting to such a politically aware group of participants. The peer educator raised this when they said: "*We did things differently because of the group. That group is much better... calmer. Not as nerve wracking for me.*" They observed that because of the nature of the group they ensured that they were especially well prepared. "*It was important for people to be here early every day. I worked out bits I wanted to read. I circled which parts and was then able to practice. And I let [the other facilitators] sort out which parts they wanted to so. I was preparing myself because of the stories.*" The demanding nature of the group was also felt by other trainers. "*We had to be really flexible. Behind the scenes we were ducks with our legs flapping. We had to be flexible to respond to what people needed.*" (DU) While the program partner felt: "*It was all very well organised and planned. It was okay to skip in the plan*", the peer educator observed: "*We needed to be more organised with this group because they were more chilled.*"

Flexibility: Make the activities more stimulating

One criticism that emerged was from the participant who was interviewed, and suggested: *“Make the activities a bit more exciting. Get up and move around more.”* This suggestion was explored, and it seemed they felt there were too many activities just using the cards or stories, and that perhaps role plays or other activities where people moved around might have been more stimulating. Interestingly, this was from a participant who was not going outside for a smoke, leaving the room for regular toilet breaks, or absenting themselves as a response to different activities. Perhaps it is possible that some of the movement in and out of the room by other participants, especially relating to smoking or toileting, was because of a need to move around more.

On the other hand, the inclusion of the sex education segment was an excellent example of flexibility, and of the workshop being more stimulating. It was a very well received segment of the program, and may well be worth carrying into the other iterations of the Sexual Lives & Respectful Relationships. The peer educator commented: *“Yes I think we should definitely bring that sex education. People expect sex education. We thought the sex education went particularly well. Fun activity.”* The trainer from Deakin University noted that while sex education was responding to the needs of the group, it tied in very well with ‘Carol’s’ story, where sex education had been inadequate. They noted that:

We rejigged the schedule to see if it could fit in. Also the talk on Rainbow Rites. And they all had a strong desire to see each other again. We took the time when we normally do the hands, and we worked with informal evaluation instead, because Rainbow Rites was really important

It was also observed that the sex education raised a wide array of emotions, and that such diversity needs to be carefully considered. They commented: *“They didn’t avoid the really hard stuff. Sadness, but lots of laughter too. It wouldn’t be real if we didn’t have real stories. There wouldn’t have been the same authenticity (encouraged people to relate to it and speak out).”*

It was noted too, that the group really wanted to stay connected, and asked *“What’s next?”* There was a brief debate as to whether they would have support group, but the team pointed out the value of connecting with organisations such as *Rainbow Rights and Advocacy* and *Reinforce*. As the program partner observed: *“It’s about inclusivity, facilitating something ongoing, about linking with the wider community, rather than staying a separate group.”*

The value of life stories: Ours and theirs

The pilot group of participants saw considerable value in the use of personal stories and anecdotes to set up discussion, and individuals were eager to be part of the presentation of these stories in the future. One participant, when interviewed, commented: *“The life stories and the trouble they go to really helped.”* The training team was very open in sharing their own stories, and this modelled that openness for the participants in the group. The program partner contended: *“It was humbling to be part of itself and really witness it. Coming about straight lived experience or being on the other side. We really all can learn from each other”* and noted further *“I dropped a few hints about being single myself, as a way of modelling*

again.” This was very well received by the participants who clearly felt free to share their own stories.

Similarly, the use of the narratives being trialled in this program showed a great deal of value that would readily carry across to people with intellectual disability who did not identify as LGBTQIA, irrespective of the sexuality of the people in the stories. ‘Hussein’s’ story, for example, triggered discussion in relation to the law and the age of consent, as well as raising the issues of sexual assault and child sexual assault specifically. A number of the participants in the room, as well as the peer trainer, disclosed their own direct experience of sexual assault, and the discussion was very moving as well as empowering. One of the participants, as noted earlier in this evaluation, related sexual assault to issues of power relationships. This generated extensive discussion, including (at the tea break) in reference to sexual assault within the church.

When *Angela’s Story* about sexual harassment was discussed, one participant related the story to their own experience of being assaulted on a bus, and how they no longer feel they can safely catch the bus or train. Interestingly, the discussion went from there to a recent news item in which a grandfather had murdered his children and grandchildren because they were on the autism spectrum. The group expressed concern about this sort of attitude to disability, and it was clear that the story, in relation to the recent news item, had clearly triggered many issues in the room. The team very successfully drew on this link, and took the discussion back to *Angela’s Story*, and used the situation to explain the role of CASA in dealing with sexual assault. The group was also guided as to how to report the situation if it involved a worker in their accommodation for example, or abuse from someone else who works in an organization. This linking of the program stories with the stories of individuals is an effective strategy that warrants carrying across all versions of the program.

Discussion and Recommendations

As outlined earlier, this research project asked a variety of questions about how an evidence-based sexuality and relationships program, such as the *Sexual Lives and Respectful Relationships* program for people with intellectual disability might be specifically adapted for and target people who with intellectual disability who identify as LGBTQIA+. In order to do this, the program was run with predominantly new materials, and presented to a group of carefully screened participants with intellectual disability who also identified as LGBTQIA+. While it is recognized that it is not possible to derive widely applicable conclusions from a project of this size, it is acknowledged that the outcomes and observations provide a suitable case study of how effective a program of this type may be, both as a program in its own right (although this was not the purpose of the pilot study), and in adapting the existing program to the needs of the ID LGBTQIA+ community.

Through reflecting on the research focus themes it has been possible to consider tentative answers to the specific research questions. Section 5, above, described observations in relation to the three focus areas, specifically:

1. Experiences of participating in the program for program participants
2. Access to and engagement with the adapted program by the target audience
3. Identification of program enhancement opportunities and recommendations based on the qualitative evaluation

These three areas were considered closely, drawing on observations of the workshops, input from an interview with one of the participants, focus group discussion with the presenting team, and an interview with a representative from *Inclusion Melbourne*. These observations are now considered briefly in relation to the two key questions asked by this project.

RESEARCH QUESTION 1: How might an evidence-based sexuality and relationships program for people with intellectual disability be adapted to meet the needs of LGBTQIA+ people with intellectual disability?

It can be concluded that the inclusion of specifically developed, and appropriately sensitive case studies into the existing program has the potential to meet the needs of LGBTQIA+ people with intellectual disability. Participants in the pilot program reported that the stories that provided the basis for discussion in this pilot were relevant and valuable, and caused them to think about a variety of issues. This was strongly evident from the quality and directions of the discussions, which covered a remarkably broad spectrum of issues, not only about respectful relationships and sexual lives, but into the broader domain of human rights, the nature of grief, issues of stigmatisation and institutional abuse, to name just a few.

One issue of concern for the participants that would require careful consideration if these materials were included in the more general *Sexual Lives & Respectful Relationships* program, is that there is still a broadly applicable fear and misunderstanding about diverse sexualities among heterosexual people with intellectual disability, as well as among many workers in residential facilities. It was the expressed feeling of the group that this fear needs to be unpacked within the general program, if people who identify as LGBTQIA+ are to feel safe, both in the program, and in their homes and community. Whether it is wise that this is unpacked and addressed with LGBTQIA+ people in the room demands further consideration.

Would this undermine the concept of a safe space for the LGBTQIA+? While running ‘inclusive groups’ might have theoretical/ideological appeal, the extent to which LGBTQIA+ adults with intellectual disability might support this remains unknown, and warrants further investigation.

The inclusion of additional content areas that emerged during this pilot was also significant, with participants responding extremely well to the inclusion of the sex education component provided by the Victorian AIDS Council being a case in point. This component of the workshop would carry across well to a more general group, with the safe sex content being applicable across all sexualities.

On the other hand, the discussions about self-advocacy and moving out into the community were far more LGBTQIA+ specific, and may be of less concern to the heterosexual population. This emerged as an extremely important area of concern to the participants in this pilot. If future programs are to be considered to meet the needs of all sexualities, then the teams presenting the workshops will need to consider very carefully how this aspect of the program might be addressed. The well-publicized existence of some high-risk sexual behaviours in the LGBTQIA+ community (**Add citation**) must be taken into consideration, if people with intellectual disability within this community are to lead safe and respectful sexual lives.

RESEARCH QUESTION 2: What can be learned from the pilot LGBTQIA+ SL&RR program to support inclusion of LGBTQIA+ people with intellectual disability in sexuality and relationships programs?

What became clear from this evaluation, is that there are really two separate issues being considered here. The first of these is whether the materials trialled with this group are suitable for presenting to the broader *Sexual Lives & Respectful Relationships program*, in order to cater for the needs of all participants in the program, but specifically, to address areas of concern, fear and stigmatization within the intellectual disability community. Secondly however, there is also the question of whether such a program actually meets the needs of people with intellectual disability who are LGBTQIA+. The final recommendations in relation to this cannot be seen to be clear cut.

There is no doubt that an inclusive program is an ideal end-point, and should meet the needs of all people with intellectual disability, irrespective of their sexuality or gender identification. Indeed, including visual materials to display gender/sexual diversity in the training manuals would go some way towards education and respect for diversity. However, it is possible to propose that from the evidence of this pilot program, that it is too early for such a program. That the materials piloted should be included in the broader program is confirmed without doubt. The evidence is less convincing that there should not also be programs specifically addressed to the LGBTQIA+ community.

Participants expressed considerable concern about the fear among non-LGBTQIA+ people with intellectual disability, and how this means that some LGBTQIA+ people do not feel safe yet disclosing aspects of their identity and their concerns amongst their straight friends and colleagues. It was commented on throughout the program that it was great having a space where individuals could be themselves and did not have to pretend to be straight.

The choice of an LGBTQIA+ peer educator was noted and valued, and this was also commented on by the workshop team on reflection. The Peer Educator observed: *“After the last day, I felt that all through the four days I have totally connected with that group.”* The team member from Deakin University noted: *“We chose PE because they are] bisexual. We wondered if the group would have felt the same connection if the peer educator was straight.”* In response, the Peer Educator said: *“No, I really connected with them on a mental level. It was totally calming. I felt they understood me, as well as me understanding them.”*

A second issue that would be difficult to transfer across to a group of mixed heterosexual and LGBTQIA+ people with intellectual disability is that of how to find safe sexual and social space within the wider LGBTQIA+ community. While there is obviously some degree of overlap that would work across all sexualities, the needs of the LGBTQIA+ participants emerged as being very specific. Disability service organisations very seldom provide appropriate activities that would meet the adult sexual needs of this group, but many enlightened organisations do go some way to support heterosexual people with intellectual disability seeking sexual lives. How this could be addressed within a program that covered both heterosexual and LGBTQIA+ participants with intellectual disability would have to be very carefully considered, and from the data gathered, it is unlikely that people who are LGBTQIA+ would currently see this as a safe space. The Peer Educator asked of the team: *“Are we going to be able to do another one, because I would like to do it.”* The team member from Deakin University asked: *“Do you mean shall we do it again, or include it?”*, and the Peer Educator replied: *“Separate space. Doesn’t have to be either or....”* The team member from Deakin replied that it *“Needs to be properly funded. Money is a practical thought.”*

It was proposed that the Deakin University *Sexual Lives & Respectful Relationships* team would build on the findings of the evaluation to enable this component to be incorporated into program once the evaluation findings have been reported. It was not proposed that in the long-term, the pilot LGBTQIA+ program being trialed would become a stand-alone program, but rather that what was learned from the pilot would be incorporated into the regular program, to ensure greater inclusivity of all sexual and gender identifications.

However, the emerging evidence from the current evaluation would support the provision of a stand-alone program that runs alongside an inclusive program. Based on the findings from the current study, such a specialist program would be not only worthwhile, but necessary to meet the needs of this group. It is recognized that there is a dynamic focus on programs like this being scalable. But at this stage, it may be too early to reduce the needs of LGBTQIA+ people with intellectual disability to fitting into a program where the predominant group attending will be heterosexual. To combine the two groups, irrespective of whether the materials are suitable, may prove to be reductionist at this stage. It is therefore strongly recommended that further funding is sought to provide programs specifically addressing the needs of the LGBTQIA+ community members with intellectual disability. The reality is the volume of people that need this support who are still facing the issues of ‘coming out’ as LGBTQIA+ in a potential hostile, and at this stage, still naïve, intellectual disability community.

In discussion of observations and outcomes generated by this evaluation, a number of caveats must be kept in mind.

This is a very small scale, one-off study that did not have the capacity to generate quantitative data. The data that were generated were observational, and came out of interviews and focus

groups of a very limited number. With only nine participants, and a dearth of relevant literature in the field, this must be viewed as a case study of a much wider population, and any observations and conclusions must be viewed relative to this. The most that can legitimately be inferred from this evaluation is the effectiveness of these materials for *this* group, and the possibility that these materials will also prove to be useful in meeting the needs of other similar groups. It is not possible to infer, for example, that the new LGBTQIA+ training materials will suit people with intellectual disability who identify as heterosexual. It can only be observed that the group who participated in this pilot of the materials felt that the materials were suitable from their perspective.

Secondly, as previously observed, some modifications to the intended research framework were necessary in the field, and these emerged in discussions with representatives from Deakin University and Inclusion Melbourne. Apart from revision of some research questions, the team from Deakin University who were presenting the program requested that there be no pre-program interviews with participants due to difficulties with transportation, access and timeframes for informed consent. These pre-program focus groups were removed. (The ethics application was revised and resubmitted to The University of Melbourne Human Research Ethics Committee, accepted the amendments.) However, this meant an absence of baseline data as it was not possible to access participants' pre- and post-program expectations and feedback, except in an informal manner.

It was originally proposed that there would be two research focused sessions; one at the commencement where participants stated their expectations of the program, and one at the end of the program where they reflected on the experience. However, for various reasons, including difficulties with available time at the start of the program, and a relevant participant-led change in the program towards the end, the proposed reflective sessions did not occur. This limited the amount of actual participant data that were available. Further, of the nine participants, only one elected to be interviewed after the program. This meant not only a limited amount of interview data from the participants, but also that it was not possible to use quotations that were collected during the program, as ethics release had not been made available. While it was possible to draw on content of the discussions, and data from the participants' quotations which were insightful, the transcription of direct quotations would have amounted to a breach of ethics.

In conclusion, the current adaptation of the *Sexual Lives & Respectful Relationships* program for LGBTQIA+ adults with intellectual disabilities was well received by the participants and proved to be very successful. In addition to the positive comments during and following the program, there was evidence that participants wanted to continue the connections they had made during the program, and a number of participants indicated they would like to be involved in the delivery of the program in the future. Notably, it was evident that the LGBTQIA+ narratives used to promote discussion were received by the participants as relevant and thought provoking. While a future program inclusive of LGBTQIA+ and heterosexual participants might have some ideological appeal, the feasibility and acceptability of such a program to people with intellectual disability is yet to be determined.

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Appendices

Appendix 1:

The University of Melbourne Human Research Ethics Committee Approval letter
Plain Language Statement and Consent Form: Team member
Plain Language Statement and Consent Form: Participant

Appendix 2:

Letter of Invitation to Participate

Appendix 1: The University of Melbourne Human Research Ethics Committee Approval letter

-----Original Message-----

From: themisPROD-noreply@unimelb.edu.au [<mailto:themisPROD-noreply@unimelb.edu.au>]

Sent: Thursday, 12 April 2018 10:11 AM

To: Keith McVilly <keith.mcvilly@unimelb.edu.au>

Subject: Ethics Application 1750795.2

I am pleased to advise that the Humanities Law & Social Sciences Human Ethics Sub-Committee has approved the following Project:

Project Title: Investigating the Impact of the "Sexual lives and Respectful Relationships Programme" for LGBTIQI People with Intellectual Disability

Researchers: Dr G D Marks, Prof K R Mcvilly Ethics ID: 1750795.2

A signed letter confirming this approval will be forwarded to you shortly.

It is your responsibility to ensure that all people associated with the Project are made aware of what has actually been approved.

Research projects are normally approved to 31 December of the year of approval. Projects may be renewed yearly for up to a total of five years upon receipt of a satisfactory annual report. If a project is to continue beyond five years a new application will normally need to be submitted.

Please note that the following conditions apply to your approval. Failure to abide by these conditions may result in suspension or discontinuation of approval and/or disciplinary action.

(a) Limit of Approval: Approval is limited strictly to the research as submitted in your Project application.

(b) Variation to Project: Any subsequent variations or modifications you might wish to make to the Project must be notified formally to the Human Ethics Sub-Committee for further consideration and approval. If the Sub-Committee considers that the proposed changes are significant, you may be required to submit a new application for approval of the revised Project.

(c) Incidents or adverse effects: Researchers must report immediately to the Sub-Committee anything which might affect the ethical acceptance of the protocol including adverse effects on participants or unforeseen events that might affect continued ethical acceptability of the Project. Failure to do so may result in suspension or cancellation of approval.

(d) Monitoring: All projects are subject to monitoring at any time by the Human Research Ethics Committee.

(e) Annual Report: Please be aware that the Human Research Ethics Committee requires that researchers submit an annual report on each of their projects at the end of the year, or at the conclusion of a project if it continues for less than this time. Failure to submit an annual report will mean that ethics approval will lapse.

(f) Auditing: All projects may be subject to audit by members of the Sub-Committee.

If you have any queries on these matters, or require additional information, please contact me using the details below.

Please quote the ethics ID number and the title of the Project in any future correspondence.

On behalf of the Sub-Committee I wish you well in your research.

Ms Belinda Kelly

Secretary, Humanities Law & Social Sciences HESC

Phone: (03) 903 59095, Email: belinda.kelly@unimelb.edu.au



PLAIN LANGUAGE STATEMENT

*To be read to and discussed with the person with disability considering participation,
by a person they know and trust*

Date: March 2018

Full Project Title: Investigating the Impact of the *Sexual lives and Respectful Relationships Programme* for LGBTIQI People with Intellectual Disability

Principal Researchers: Professor Keith R. McVilly, Dr Genée Marks

HREC ID: 1750795

Why have you been invited to participate in this research project?

You have agreed to take part in the *Sexual Lives and Respectful Relationships* program for LGBTIQI people who have a disability.

We want to know what you think about the programme and if it helped you.

If you don't want to talk to us about the programme, that is OK. You can still do the programme. You don't have to talk to us.

If you say YES, you can talk to Professor Keith McVilly and Dr Genée Marks about the *Sexual Lives and Respectful Relationships* program.

Why is this research being conducted?

The *Sexual Lives and Respectful Relationships* program has been running for many years.

But it has not been run for people with disability who are LGBTIQI people.

Some people with intellectual disabilities are LGBTIQI.

We think there needs to be a *Sexual Lives and Respectful Relationships* program for LGBTIQI people with disability too.

Now the program is being changed so it is useful for LGBTIQI people.

Evaluation of 'Sexual Lives and Respectful Relationships Program' for LGBTIQIA+ People with Intellectual Disability: Final Report. October 2018.

We want to know if the changes made to the *Sexual Lives and Respectful Relationships* program will be helpful to people who are LGBTQI.

What will I be asked to do, and are there any risks or benefits?

If you say YES to being involved with the project,

Genée Marks will sit in to hear what you are learning. She will be there to learn about how the program is run. She will NOT be gathering information about you or your stories.

At the end of the program, you will have the chance to answer some questions that Genée will ask. You have a choice about whether you want to answer these questions or not.

We will also interview the training team.

We will do the interviews at the place where you do the program. What you say will be written down. It will not be recorded.

Your interviews will be done in private.

If you want to stop at any time, you can say "STOP". It is your choice. You do not have to keep being part of the research. You do not have to talk to us.

If you become upset or distressed, we will help you to find a person to talk to, who understands your communication support needs. Or you could talk to your GP, or someone you trust.

How long is my participation expected to take?

The optional interview afterwards will take about 30 to 45 minutes.

How will my confidentiality be protected?

What you tell us will be private and confidential. We will not tell other people what you said. When we write-up our report on what people told us, we will write it in a way so people should not know who said what to us. However, people who know you well might recognise some of the things in the report as something you said or did.

If we think you are in danger, we will need to tell someone who can protect you.

Do I have to take part?

It is your choice. You can say YES or NO.

If you say NO, you can still do the *Sexual Lives and Respectful Relationships* program.

If you say YES, you can decide to STOP at any time. If you decide to stop, you can still do the *Sexual Lives and Respectful Relationships* program.

What happens after the project is finished?

After the project is finished, we will send you a summary of what we found.

We will talk to people at conferences and meetings about what we found.

We will write about what we found, and send a report to the government.

But we will never tell people your name or where you live or work.

We will keep your information in locked filing cabinets or on a password protected computer file for use in future projects that are closely related to this project, or in the same general area of research as this project. When this information is stored, it will not include your name or other potentially identifying information.

What if you have Questions or Complaints?

If you have any questions or concerns about the project, please contact:

Professor Keith R. McVilly

School of Social & Political Sciences, The University of Melbourne

Tel. 03 8344 5366; or

E-mail keith.mcvilly@unimelb.edu.au

If you would like to volunteer, please return the attached Consent Form, signed and with your contact details electronically to: E-mail keith.mcvilly@unimelb.edu.au

If you have any complaints about any aspect of the project, the way it is being conducted, or any questions about your rights as a research participant, then you can contact:

The Manager, Office for Research Ethics & Integrity

Telephone: +61 3 8344 2073

Email: humanethics-complaints@unimelb.edu.au

Quoting the HREC Reference Number: 1750795



CONSENT FORM

To be read to and discussed with the person with disability considering participation, by a person they know and trust

Date: March 2018

Full Project Title: Investigating the Impact of the *Sexual lives and Respectful Relationships Programme* for LGBTIQI People with Intellectual Disability

Principal Researchers: Professor Keith R. McVilly, Dr Genée Marks

HREC ID:

Name of Participant: _____

1. I know that people will come to talk to me about what I expect from the *Sexual Lives and Respectful Relationships* program, and how useful I found it.
2. If I chose to be interviewed at the end, they will write down what I say.
3. What people say and what is written down will be private and confidential, unless people think I am in danger. If people think I am in danger, they will get me help.
4. I can ask questions at any time.
5. I know I can say STOP at any time. If I say STOP, I can still finish the *Sexual Lives and Respectful Relationships* program if I want.
6. I know that my information will be kept in locked filing cabinets or on a password protected computer file for use in future projects that are closely related to this project, or in the same general area of research as this project. When this information is stored, it will not include your name or other potentially identifying information.

Participant Signature:

Date:

Participant Phone No.:

Participant Organisation:

Address:

Support Person Name & Signature:

Date:

Support Person Phone No.:



PLAIN LANGUAGE STATEMENT

*To be read to and discussed with the person with disability considering participation,
by a person they know and trust*

Date: March 2018

Full Project Title: Investigating the Impact of the *Sexual Lives and Respectful Relationships Programme* for LGBTIQI People with Intellectual Disability

Principal Researchers: Professor Keith R. McVilly, Dr Genée Marks

HREC ID: 1750795

Why have you been invited to participate in this research project?

You have agreed to be a member of the Training Team in the *Sexual Lives and Respectful Relationships* program for people who are LGBTIQI who have a disability.

This project is finding out if the *Sexual Lives and Respectful Relationships* program is helpful for people with disability who identify as LGBTIQI.

The project is run by Professor Keith McVilly and Dr Genée Marks.

We have been paid some money by The University of Melbourne and some from Inclusion Melbourne to do this research.

What we are going to do has been checked out by the University of Melbourne Human Research Ethics Committee. They said it was okay to go ahead and do the project.

Why is this research being conducted?

The *Sexual Lives and Respectful Relationships* program has been running a long time for people with intellectual disabilities. It has not focussed on LGBTIQI people.

Some people with intellectual disabilities are LGBTIQI.

There needs to be a *Sexual Lives and Respectful Relationships* program for them too.

Now the program is being changed so it is useful for LGBTIQI people too.

Evaluation of 'Sexual Lives and Respectful Relationships Program' for LGBTIQI+ People with Intellectual Disability: Final Report. October 2018.

We want to know if the changes made to the *Sexual Lives and Respectful Relationships* program will be helpful to people who are LGBTQI.

What will I be asked to do, and are there any risks or benefits?

If you say YES to being involved with the project, we will interview you before the program about what you expect the new version of the project for people who are LGBTQI will be like.

We will also interview you after the program to find out how useful you think the changes are and what you learned as a member of the Training Team.

During the program, Genée Marks will sit in to hear how the changes to the program are working.

We will also interview the participants in the program at the end of the program if they want to participate.

We will do the interviews and the focus group at the place where you do the program. Your interviews will be done in private. What you say will be written down.

If you want to stop at any time, you can say “STOP”. It is your choice. You do not have to keep being part of the research. You do not have to talk to us.

If you become upset or distressed, we will support you to find a person to speak with who understands your communication needs. You could also ask to speak with your General Practitioner (GP), or a person you trust.

How long is my participation expected to take?

The interview before the program will go for about 15 minutes.

The interview after the program will go for about 30 to 45 minutes.

How will my confidentiality be protected?

What you tell us will be private and confidential. We will not tell other people what you said. When we write-up our report on what people told us, we will write it in a way so people should not know who said what to us. However, people who know you well might recognise some of the things in the report as something you said or did.

If we think you are in danger, we will need to tell someone who can protect you.

Do I have to take part?

It is your choice. You can say YES or NO.

If you say NO, you can still be a member of the Training Team in the *Sexual Lives and Respectful Relationships* program.

If you say YES, you can decide to STOP at any time. If you decide to stop, you can still be a member of the Training Team in the *Sexual Lives and Respectful Relationships* program.

What happens after the project is finished?

After the project is finished, we will send you a summary of what we found.

We will talk to people at conferences and meetings about what we found.

We will write about what we found, and send a report to the government.

But we will never tell people your name or where you live or work.

We will keep your information in locked filing cabinets or on a password protected computer file for use in future projects that are closely related to this project, or in the same general area of research as this project. When this information is stored, it will not include your name or other potentially identifying information.

What if you have Questions or Complaints?

If you have any questions or concerns about the project, please contact:

Professor Keith R. McVilly

School of Social & Political Sciences, The University of Melbourne

Tel. 03 8344 5366; or

E-mail keith.mcvilly@unimelb.edu.au

If you would like to volunteer, please return the attached Consent Form, signed and with your contact details electronically to: E-mail keith.mcvilly@unimelb.edu.au

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CONSENT FORM

To be read to and discussed with the person with disability considering participation, by a person they know and trust

Date: March 2018

Full Project Title: Investigating the Impact of the *Sexual lives and Respectful Relationships Programme* for LGBTIQI People with Intellectual Disability

Principal Researchers: Professor Keith R. McVilly, Dr Genée Marks

HREC ID: 1750795

Name of Participant: _____

1. I want to learn more about *Sexual Lives and Respectful Relationships* for people who are LGBTIQI.
2. I want to be in this research to find out if the program works well for people with intellectual disability who are LGBTIQI.
3. I know that people will come to talk to me about what I expect from the revised version of the *Sexual Lives and Respectful Relationships* program, and how useful I found it. They will write down what I say.
4. What people say and what is written down will be private and confidential, unless people think I am in danger. If people think I am in danger, they will get me help.
5. I can ask questions at any time.
6. I know I can say STOP at any time. If I say STOP, I can still be a Trainer in the *Sexual Lives and Respectful Relationships* program if I want.

7. I know that my information will be kept in locked filing cabinets or on a password protected computer file for use in future projects that are closely related to this project, or in the same general area of research as this project. When this information is stored, it will not include your name or other potentially identifying information.

Participant Signature:

Date:

Participant Phone No.:

Participant Organisation:

Address:

Appendix 2: Letter of Invitation to Participate



sexual lives
& respectful
relationships
LGBTIQA+ pilot

Do you have an intellectual disability, and are you lesbian, gay, bisexual, trans, gender diverse, intersex, queer - or just not straight?

Deakin University and Inclusion Melbourne are running a program just for you! It's called Sexual Lives & Respectful Relationships. The program uses stories told by LGBTIQA+ people with intellectual disability to talk about identity, sexuality, rights, and being safe in relationships. People with intellectual disability deliver the program alongside community professionals.

- Anyone over 18 can come
- You must attend all four program sessions
- There are transport assistance and other supports available if needed

Come together with other people with an intellectual disability to talk about your rights and share ways to have good relationships.

We talk about:

- ▶ Relationships and sexuality
- ▶ Your rights and being safe
- ▶ Respectful relationships
- ▶ Identities, gender and sexuality
- ▶ Where to get more information

Time: 10am-3pm
Dates: 30 April
1, 14, 15 May
Where: Inclusion Melbourne
67 Sutherland Rd,
Armadale, VIC

If you want to know more, speak to Amie on 03 5247 9273 or amie.oshea@deakin.edu.au or Nathan on 03 9509 4266 or nathan.despott@inclusion.melbourne

presenters and roles in the program

Peer Educators: people with intellectual disability who are paid and trained to deliver the SL&RR program. SL&RR Peer Educators for this pilot program will also draw on their experiences as LGBTIQ+ people with intellectual disability.

Program Partners: professionals from a range of local services such as community health, sexual assault or domestic violence services, or women's health. Program Partners provide specific information and skills as they are required during the program sessions. The cross-sectoral partnering that this involves strengthens the capacity of services to work in this area.

The SL&RR LGBTIQ+ pilot program will be delivered by SL&RR Peer Educators who are LGBTIQ+ people with an intellectual disability; with **Ginger Ekselman**, counsellor/advocate at South East Centre Against Sexual Abuse (SECASA), and **Amie O'Shea**, the National SL&RR coordinator from Deakin University.

Learning Partner: a person who is trusted by the program participant and can have conversations between sessions, helping integrate the knowledge. In this pilot program the learning partners are Inclusion Melbourne, Deakin University, SECASA and SL&RR Peer Educators.

Partner Organisations: partner organisations can support the project through identifying and facilitating the involvement of key participants including people with intellectual disability and by identifying and facilitating the involvement of sexual health and abuse prevention specialists, counsellors or domestic violence workers.

SL&RR

The *Sexual Lives & Respectful Relationships* program is delivered across four sessions. It is based around the real-life stories of people with intellectual disability collected in research. Themes covered in the stories include relationships, violence and abuse, sexuality, sexual health and sexual assault. Additional resources used in the program cover topics including rights, online safety, relationships and how to find help.

- ▶ Works with groups of people with intellectual or cognitive disabilities.
- ▶ These groups talk and learn about relationships, sexuality, being safe and being in respectful relationships.
- ▶ This program uses other people's stories and talking about their 'key messages' as a way of thinking about respectful relationships.

benefits to participants

- ▶ Access to information about mainstream services and supports.
- ▶ An opportunity to meet other LGBTIQ+ or gender diverse people with intellectual disability in a confidential, supported space.
- ▶ Peer support and discussion about important issues of rights, sexuality and relationships.
- ▶ Coming together to share experiences in a safe, supported environment.
- ▶ Being respected and treated as responsible adults.



67 Sutherland Road Armadale VIC 3143 | PO Box 8093 Armadale VIC 3143
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 Inclusion Melbourne Inc.  InclusionMelb