



# LGBTIQ PEOPLE WITH INTELLECTUAL DISABILITY

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Sexual Lives & Respectful Relationships (SL&RR) is a rights based peer education program for people with intellectual disability about their rights in sexuality and relationships. The SL&RR model contains four key components; peer education by people with an intellectual disability delivering a respectful relationships program; supporting change in support relationships through learning partnerships; sector development through partnerships with community health, sexuality and violence and abuse support and disability services and systemic change through research and translation of outcomes (Frawley et al., 2017). SL&RR is part of a research program at Deakin University led by a team of researchers and project workers including people with an intellectual disability. The respectful relationships program is run by people with an intellectual disability trained as peer educators and professionals who work in the partner services who are trained as program partners. In May 2018 SL&RR partnered with Inclusion Melbourne through a grant from the Gay and Lesbian Foundation of Australia to pilot a version of the SL&RR program featuring and targeted to LGBTIQ (lesbian, gay, bisexual, trans\*, intersex, queer) people with intellectual disability. The program was delivered by a SL&RR Peer Educator with Ginger Ekselman from SECASA (South Eastern Centre Against Sexual Assault) and Amie O'Shea (Deakin University) and has been independently evaluated by a research team at the University of Melbourne. SL&RR uses the real life stories of people with intellectual disability as the core learning resource.

These stories are gathered with people with an intellectual disability who are interested in sharing their experiences about sexuality and relationships. There is a core set of stories that were collected through research (Johnson, Hillier, Harrison, & Frawley, 2000). Following evaluation of the program these stories were augmented by a research project in which new stories were gathered from LGBTIQ people with intellectual disability. In this article we will introduce some of the key themes to emerge from that research, and reflect on the processes of organizing and facilitating this program and what this can mean for LGBTIQ inclusion in other intellectual disability spaces.

Developing new stories – LGBTIQ people with intellectual disability

With human research ethics approval from Deakin University, researcher Amie O'Shea worked with participants to gather their stories. This involved meeting together several times to talk about the person's life and what they wanted to share about their experiences and sexuality. Such accounts are scarce in the current academic literature, particularly from women and non binary people with intellectual disability. Early themes to come from the new stories collected showed some areas of similarity with existing SL&RR stories. Themes are worked into key messages about sexuality and relationships which are discussed with program participants. Common themes included the desire for a relationship, experiences of violence or abuse, and the importance of others in people achieving their desired outcome. In addition there was a strong message that people managed their identities in complex ways: Carol , talked about

not telling people at her Church about her sexuality, for example. Another storyteller Johnno said most of the staff in his residential home were OK with him being gay, but that “you don’t talk about being gay in front of Leigh”, referring to a particular staff member he described as homophobic. Both Carol and Johnno talked about how they navigated public spaces with an eye to being safe from verbal or physical homophobic abuse: making decisions about if and when to hold another person’s hand, for example.

Another key theme from the stories was the poor experiences with sex education to date, including at school. Storytellers felt excluded from sex education which assumed they were heterosexual – something which is also reported in a review of sex education programs for people with intellectual disability (Gill, 2015). The pilot program delivery trialled a ‘blank spot’ of unallocated time on the third day where participants could decide in advance what they would like to discuss. Reflecting on their poor experiences of sex education, the group sought information of safer sex resources and so the Victorian AIDS council were invited to present to the group on this topic.

### **Piloting the new stories in SL&RR**

We learned a number of things while working together on this project. Across the research recruitment and pilot program delivery we saw an over representation of men with intellectual disability. This is in line with international reports on the same phenomenon, leading to an ‘almost total invisibility’ of women with intellectual disability, and an entire absence of non binary people with intellectual disability, in the literature (Abbott, 2015). We will continue to focus on this area to ensure that everyone’s voices can be heard.

Organizing the SL&RR program meant that we spoke to potential participants beforehand. This was for several reasons: to confirm people identified themselves with the target group of LGBTIQ people with intellectual disability, to discuss the program content, and to work out the logistics for individuals to attend. This meant that people who attended the program already had support for their LGBTIQ status at home (with their families or in residential services). We had to consider what it would mean for people to attend a program which might inadvertently out them, talking through questions of who would know where they were going, how that might be received, and who could be a support person if they wanted to talk about any issues raised in the program or through their attendance. While this process meant that pilot program attendees were adequately supported at home and at the program, we know that this is not the case for all people with intellectual disability, and we see the need for support providers and advocacy organisations to encourage acceptance and visibility by including all sexualities and genders when working with people with intellectual disability,

### **SUMMARY**

- Researchers worked with LGBTIQ people with intellectual disability to gather their stories for use in the SL&RR program
- The stories formed part of an SL&RR program for LGBTIQ people with intellectual disability run by Deakin University and SECASA with Inclusion Melbourne
- There were additional considerations when running the LGBTIQ SL&RR program to ensure it was accessible and comfortable for everyone
- LGBTIQ people with intellectual disability who participated in the SL&RR program agreed with the key messages to emerge from the stories, which we will continue to work with to inform an understanding of their needs and experiences

and being proactive by engaging with staff to reflect this approach. This is an area we hope to elaborate on in a future publication.

Moving forward, the SL&RR team will continue to work with the new stories to articulate their key messages for use in the SL&RR program, using the same approach followed for the existing SL&RR stories. A group of LGBTIQ SL&RR Peer Educators and Program Partners will be working with the SL&RR research team to incorporate the stories and other things we learned from the pilot and its evaluation into the overall SL&RR program. This research will continue to inform the way we consider sexuality and relationships rights for LGBTIQ people, and inform our advocacy and responses to policy and practice and approaches to sexuality rights for LGBTIQ people with an intellectual disability.



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### References

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