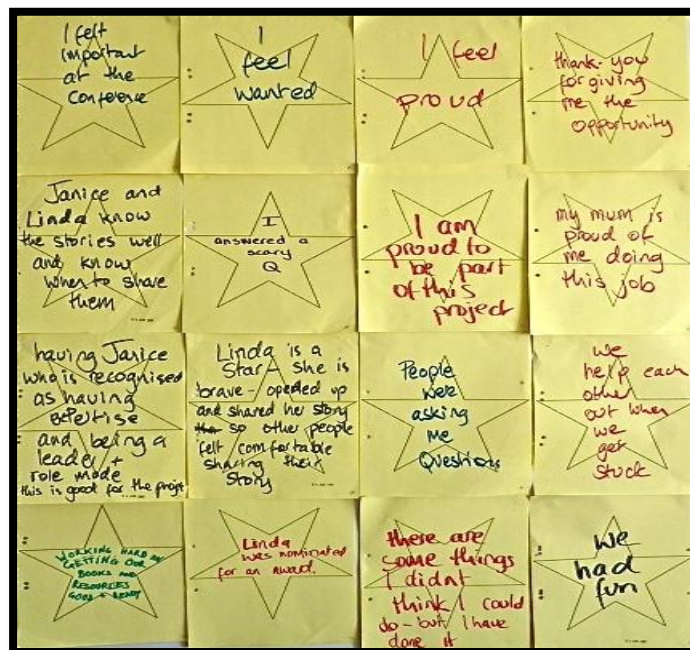


Real people, core business

Living Safer Sexual Lives: Respectful Relationships

Report on the development and implementation of a peer led violence and abuse prevention program for people with an intellectual disability



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Executive summary

Violence against women is a major social issue in Australia. The majority of victims of sexual assault are women, and most sexual assault (65%) occurs in residential locations (Australian Institute of Criminology, 2003). It is estimated that only 20% of sexual assaults are reported (Australian Bureau of Statistics, 2002). It has been estimated that 18% of women have experienced sexual violence and 33% physical violence since the age of 15 (Australian Bureau of Statistics, 1996). Younger women aged 10 to 19 years are three times more likely than the general female population, and fifteen times more likely than the general male population to be the victims of sexual assault (Australian Bureau of Statistics, 2003). The situation for people with an intellectual disability is even more alarming, as they are even more likely to experience sexual assault or abuse than the rest of the population (McCarthy, 1999; 2000). Furthermore, because decisions about their lives are often made by their families or service providers, they often lack the information or skills required to enter into respectful, and avoid exploitative relationships.

In 2009 the Australian Research Centre in Sex, Health and Society (ARCSHS) was funded by the Federal Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) to develop and implement a peer led primary prevention of violence program for people with an intellectual disability. Prior to this, between 1999 and 2001, ARCSHS had developed a sexuality education program called *Living Safer Sexual Lives* (Frawley, Johnson, Hillier & Harrison, 2003), based on research carried out with people with an intellectual disability. The program described in this report is known as *Living Safer Sexual Lives: Respectful Relationships* (LSSL: RR) and combines the findings of *Living Safer Sexual Lives* (Johnson, Frawley, Hillier & Harrison, 2002) with the principles of primary prevention of violence.

The goals of the program were to:

1. Develop, implement and evaluate a peer-led primary prevention of violence against women strategy that will enable people with an intellectual disability to engage in respectful relationships.
2. Develop a training resource that is transferrable to other sites.
3. Develop an evidence base concerning respectful relationships education with people with an intellectual disability using the Program Model.

Program development and implementation

The program used a community development approach to facilitate the introduction of the Program in five sites - two in Tasmania and three in Victoria. Rather than simply developing and running a program for people with an intellectual disability (PWID), an inclusive approach was adopted. In each site local planning groups were recruited to plan and implement the Program. This was to ensure that the education component was not a one-off event run by outside providers, but one where local 'ownership' of the program ensured its sustainability in that community. Members of the local planning committees included people with an intellectual disability and service providers from a range of organisations and groups.

Central to the approach was the incorporation of a peer education model. People with an intellectual disability worked alongside co-facilitators who were trained to work together to plan and run groups. Twenty peer educators and co-facilitators participated in a three day peer education training program. Education programs were subsequently delivered to 41 participants with an intellectual disability.

Program Evaluation

The evaluation aimed to:

- Investigate program processes and outcomes from the perspectives of key stakeholders in the service sector.
- Develop a feedback loop with the program team to enable identification and setting of benchmarks for good practice and continuous program improvement.
- Understand the processes employed in the establishment and program delivery phases of the Program, and the ways in which these contribute to the sustainability of the program.
- Identify and describe the adaptation of an international framework known as the 'Ecological model' in the program.

Five workshops were carried out with members of the program team to review progress and promote critical reflection. The workshops utilised creative arts approaches to engage emotional aspects of experiences (Eisner, 2008), promote deeper reflection, and provide an engaging process that was accessible to all team members. Workshop participants were asked to review the achievements of the program. Further reflection on the program was aided by data from confidential interviews with 24 members of local planning groups.

Findings

Data from evaluation workshops and stakeholder interviews was sorted into themes relating to the principles of the ecological model of the Program. In particular, the evaluation findings relate to the primary prevention of violence by people with an intellectual disability and the engagement of the sector and sector development.

There was a significant level of scepticism in local planning groups in the establishment phase of the Program about the capacity of people with an intellectual disability to be involved. Because of this, some delays were experienced in recruiting local peer educators, a phenomenon referred to here as 'gate-keeping'. The main concern was that people with an intellectual disability would not have the requisite skills or experience to undertake this role and that locally based services would not have the capacity to support them. Despite these concerns, twenty people with an intellectual disability were trained to be peer educators across four of the five sites. It is argued in this report that the gate-keeping by locally based services in all five sites impacted on the time it took to establish the program and in particular the number of PWID who became involved as peer educators.

Engagement with the disability sector and the community sectors occurred throughout the project. In each site locally based planning groups were formed with representation from government and non-government disability service providers, disability advocacy and self advocacy organisations, sexual assault services, sexual health services and the family and domestic violence sectors. These cross-sector groups met to plan the establishment and implementation of the programs locally. These groups shared information about community events associated with violence and abuse prevention and ways that PWID could be supported to be involved. They also developed approaches to the recruitment of peer educators and co-facilitators via their networks and disseminated information about the program. This locally based approach was developed to address gaps in cross-sector responses to violence, abuse and disability and to establish the relationships and processes necessary to sustain the Program when the funded period ended.

These groups have continued to meet in three sites beyond the funded program period to 'practise' program delivery, run programs and develop funding applications to support the program.

More than twenty people from disability and community organisations were trained as co-facilitators for the LSSL:RR program. This strategy was aimed at developing the sector and ensuring

the skills, knowledge and expertise needed to run the program were maintained in the local areas. As a way of gaining insights into the success of this approach, a sample of this group and the planning group members were interviewed. The evaluation report highlights some of the attitudinal and practical barriers to sector development and makes some recommendations for refining this approach to improve cross-sector engagement with primary prevention programs for people with an intellectual disability.

Summary

At the end of the two year program, four sites had completed the training and three of these were actively working together in their local networks of peer educators and co-facilitators planning and running groups for people with an intellectual disability. Most were applying for ongoing funding to continue this work and some had negotiated to have their work in the program acknowledged in their work plans. The program had forged partnerships with people from the disability government and non-government sectors, sexual assault services, domestic and family violence services, TAFE sector and self advocacy groups. This broad engagement assisted in reaching people with an intellectual disability to be peer educators, to run programs, and to develop skills in the disability and community sectors to work with people with an intellectual disability in violence and abuse prevention.

The peer education component was the non-negotiable aspect of this program. Self advocacy by people with an intellectual disability has done much over the past three decades to raise awareness about their rights to recognition, participation, and self-determination. However, this program has indicated that there is still much to do to ensure these messages are heard and respected. The twenty people who became trained as peer educators are a testament to the strength of this movement and to their own will to participate. The twenty trained co-facilitators and the smaller number who are now directly supporting people to work in this program are representative of the principles and attitudes that need to be embedded in both disability and community services to ensure there is a sustained effort to prevent violence and abuse of people with an intellectual disability.

Living Safer Sexual Lives: Respectful Relationships

*A violence and abuse prevention program
for people with an intellectual disability*

Part One: Program design & implementation

Dr Patsie Frawley



Acknowledgments

I would like to acknowledge the *Living Safer Sexual Lives: Respectful Relationships* program team, who worked together for eighteen months to develop, implement and review this program: Janice Slattery, Linda Stokoe, Amie O'Shea, Danielle Houghton and Rachel Boadle. We travelled many miles and sat together for many hours working hard to get this program happening.

I would also like to acknowledge the many people in Victoria and Tasmania who supported the Program and participated in it, and in particular the twenty women and men with an intellectual disability who became peer educators.

Thanks also to the staff at the Australian Research Centre in Sex, Health and Society, (La Trobe University) and the evaluators Dr Catherine Barrett and Dr Sue Dyson.

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Part One: Program design and implementation

Introduction

This report describes a program to promote respectful relationships with people with intellectual disability, *Living Safer Sexual Lives: Respectful Relationships (LSSL:RR)*. The two-year program was funded by the Australian Government from 2009 to 2011 and implemented in three sites in Victoria and two in Tasmania. It sought to build on an earlier research and education project developed by the Australian Research Centre in Sex, Health and Society at La Trobe University that found that safety in relationships and support for developing and maintaining safe relationships was a significant issue for people with an intellectual disability (Johnson et al., 2001; 2002; Frawley et al., 2003). Utilising the materials and approaches developed in the earlier project, in particular the stories of people with an intellectual disability that focused on sexuality and relationships the LSSL:RR program introduced a peer-led approach with a focus on primary prevention of violence and abuse.

Central to the development and implementation of the Program was the inclusion of people with an intellectual disability as peer educators, collaborators in program design and development and trainers. The program team was led by Dr Patsie Frawley with research assistants and project workers, Amie O'Shea, Janice Slattery, Linda Stokoe and Danielle Houghton. Janice and Linda are women with intellectual disability; each brought her personal experiences and skills to the team. A third woman with an intellectual disability, Rachel Boadle, joined the team later and worked primarily as a peer educator and trainer.

The program evaluation was conducted by Dr Catherine Barrett and Dr Sue Dysob at the Australian Research Centre in Sex, Health and Society. In order that the process was inclusive and accessible for all team members a creative arts-based approach was used for the evaluation. Research was also undertaken by Dr Frawley and Amie O'Shea on the experiences of the twenty people with an intellectual disability who were trained as peer educators in the program. The evaluation results form part two of this report.

Program goals

The goals of the LSSL:RR program were to:

- Develop, implement and evaluate a peer-led primary prevention of violence strategy that would enable people with an intellectual disability to engage in respectful relationships.
- Develop a training resource that would be transferrable to other sites.
- Develop an evidence base concerning respectful relationships education with people with an intellectual disability using the program model.

The program was conducted in consultation with a broad range of disability and community sector stakeholders including local and state disability services, and domestic violence, family violence, and sexual assault advocacy organisations across the five sites.

Program development and implementation

The *Living Safer Sexual Lives: Respectful Relationships* program model acknowledges the multi-layered and interactional factors at play that increase the risks of violence and abuse generally (VicHealth, 2007), and in the lives of people with an intellectual disability (Sobsey, 1994; Hollomotz,

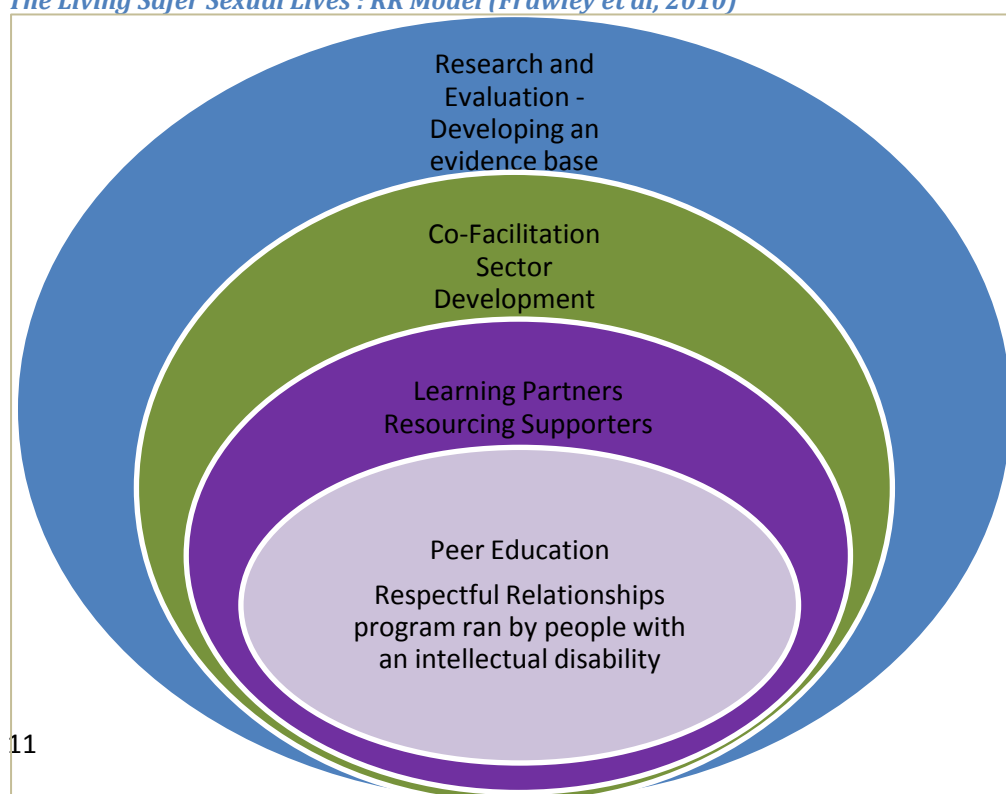
2011). It adopts the definition of primary prevention in the VicHealth Primary Prevention framework:

Primary prevention strategies seek to prevent violence before it occurs. Interventions can be delivered to the whole population (universal) or to particular groups that are at higher risk of using or experiencing violence in the future (targeted or selective). Some primary prevention strategies focus on changing behaviour and/or building the knowledge and skills of individuals. However, the structural, cultural and societal contexts in which violence occurs are also very important targets for primary prevention (VicHealth, 2007 p. 9).

Research indicates that people with an intellectual disability are at higher risk of abuse, in particular sexual abuse, than the general population and are at higher risk than other disability groups (Horner-Johnson & Drum, 2006). This vulnerability to abuse is a result of a complex interaction between the effects of impairment and the disempowering actions of those in their lives and the broader society. Researchers including Sobsey (1994) and later Fitzsimons (2009) and Hollomotz (2011) agree that the lack of power that people with an intellectual disability have in the environments in which they operate – families, care services and the community is central to this increased incidence of abuse. These researchers have developed and applied ecological models of abuse to people with an intellectual disability that reflect the interactional model put by VicHealth (2007) and the World Health Organisation (WHO, 2002). They seek to understand violence and abuse from a similar ecological perspective and advocate prevention approaches that address individual, community and broader social factors.

The *Living Safer Sexual Lives: Respectful Relationships* model reflects the principles put forward in these models, in particular the interactional aspects, and addresses violence and abuse prevention by acting on a number of levels (Figure 1). The individual/relationship level is addressed through the primary prevention program led by people with an intellectual disability and through resourcing supporters using a learner-partner approach. The community/organisational level is addressed through the recruitment and training of co-facilitators from the disability and community sectors and embedding research and evaluation into the model addresses aims related to societal change through increased knowledge, awareness and attitudinal change. These components of the model are discussed below.

The Living Safer Sexual Lives : RR Model (Frawley et al, 2010)



Abuse prevention with people with an intellectual disability

People with an intellectual disability often miss out on opportunities to learn about relationships, as well as lack the support they need to develop healthy relationships and deal with unhealthy or unsafe relationships. This can be because of isolated lifestyles as they move through adolescence and into young adulthood (eg. segregated schooling, limited independence), limited social and friendship networks, and difficulties accessing mainstream health, counselling and support services. Families or other carers can shelter people with an intellectual disability from opportunities to access learning and support services based on an assumption that they are not, or will not be involved in intimate or other relationships that involve abuse and violence. This isolation and gate-keeping can increase people's vulnerability to potentially abusive environments. Hence their opportunities to develop networks of support and personal growth and self determining skills can also be hindered.

Research indicates that there is a lack of education, training and support programs for people with disabilities. One Victorian report concluded that women with disabilities are often more disconnected from services and supports, resulting in them having fewer opportunities to develop the knowledge and skills necessary for safer relationships or for seeking help if needed (Healy et al., 2008). People with an intellectual disability experience similar issues. However, their access to education and support may be even more limited. Barger et al., (2009) in their review of sexual assault prevention programs for people with an intellectual disability found few prevention programs that target people with an intellectual disability and those that do are often too narrowly focused, not research-based. They recommend that programs need to be more comprehensive in their approach to address the multiple factors impacting on vulnerability to abuse. In particular they note the need for programs to be developed in consultation with people with an intellectual disability and to incorporate best practice from general prevention programs. These recommendations informed the development and implementation of the *Living Safer Sexual Lives: Respectful Relationships* program.

Peer Education

Peer education has been used in mainstream sexual assault prevention programs (CASA, 2010) but there are few examples where it has been used with people with an intellectual disability (Fitzsimons, 2009). The aim of the peer education approach in the LSSL:RR model was to engage more directly with people with an intellectual disability as 'the experts' in exploring what respectful relationships are, understanding the range of personal and social factors that impact on their risk of violence and abuse and positioning people with an intellectual disability as knowledgeable and skilled rather than as 'vulnerable victims'. This correlates with Sobsey's (1994) ideas about the need for personal empowerment to combat violence and abuse, as well as Hollomotz's (2011) view that there is a need to provide education for people on their rights, decision making, knowledge and awareness about sexuality and relationships to address the risk of sexual violence.

Twenty people with an intellectual disability were trained as peer educators across five sites in the pilot phase of this program. Together with the twenty co-facilitators, professionals from disability and the community sectors, peer educators completed a three or four day 'train the trainer' program conducted by the project team. This training focussed primarily on developing an understanding of the stories, how to use them in the program and development of facilitation skills. The aim of this training was to help equip the peer educators and co-facilitators to develop as teams and to become skilled in running the Program together in their local areas.

Research was undertaken on the peer educator model and the experiences of peer educators in the pilot phase of the program. This is discussed in more detail later in this report.

The LSSL:RR program

LSSL:RR was developed using the stories and broad approach to training first developed in the *Living Safer Sexual Lives* training manual which included the use of life stories of people with an intellectual disability (Frawley et al., 2003). These life stories were gathered as part of a research project that aimed to develop an understanding of the role of relationships and sexuality in the lives of people with an intellectual disability (Johnson, Frawley, Hillier & Harrison, 2002). In their review of sexual assault prevention programs for people with an intellectual disability, Barger et al (2009) concluded that the strength of LSSL was these stories: they 'offered real life examples of sexual experiences of people with intellectual disabilities and ...the narratives [were used] to inform the intervention' (p. 257). LSSL:RR uses four of these stories focusing on the messages they have about the rights and barriers to respectful relationships experienced by people with an intellectual disability.

The program was developed by the project team who worked through each of the stories to determine 'key messages' about respect, self determination, rights, decision making and safety, as well as broader messages about sexuality, sexual health, women's health and relationships. In each session one story is used as the focus story reflecting the theme of the session. There are four sessions in the program (Frawley et al, 2011) each addressing different themes: Talking about sexuality and relationships; Having rights and being safe; Respectful Relationships; Men and respectful relationships. Each session uses one of the LSSL stories, has time for facilitated discussion and reflection and uses an additional activity to further explore the theme. Adult learning principles underpin the program acknowledging the life experiences of participants and their capacity to learn through exploration of and reflection on these individual and collective experiences. This process is aided by activities focussed on rights in relationships, intimacy and personal strengths. Information is also provided on understanding sexual assault and supports and services for reporting and responding to sexual assault.

Resourcing supporters: the learning partner component

Ecological prevention models including the *Living Safer Sexual Lives: Respectful Relationships* model acknowledge that people do not, and sometimes cannot, function independently of a range of supports and networks. For people with an intellectual disability this often includes those people who have some input into planning and support in their lives. These people can include family members, paid and unpaid carers and support workers, advocates, and friends who influence the way people with an intellectual disability engage in the range of opportunities to be self-determining, to learn and to participate. The LSSL:RR model offers an opportunity for these people to support the learning and development of participants in the program and subsequently to gain a better understanding about how they can support people to have respectful relationships. Workshop participants are encouraged to identify 'someone in their life ... who can help them make sense of what they are learning and the ideas they are developing from their participation in the program' (Frawley et al, 2010b, p. 3). This component of the program was underutilised in the pilot program; reasons for this are discussed later in this report, however it has become a stronger focus in subsequent programs.

Sector development: training and engaging co-facilitators

Engagement with 'community' to influence the way people with an intellectual disability are perceived, supported, understood and included is another important component of ecological prevention models like those developed by Sobsey (1994), Fitzsimons (2009) and Hollomotz (2011). They aim to influence the way people with an intellectual disability are perceived and understood by various communities that have some potential to impact on outcomes for the safety and respect of people with an intellectual disability. In the LSSL:RR program this component of the model sought to influence the community of professionals, paid carers or support workers from the disability sector and from other community sectors who could be directly involved in supporting people to access a

violence and abuse prevention program. Historically, a 'silo' approach has seen each sector working in isolation, often resulting in the disability sector functioning separately from other community supports and services. The model therefore sought to engage across these sectors through recruiting co-facilitators to be trained to implement the program with the peer educators.

Twenty people were recruited and trained as co-facilitators for the program. They were drawn from government and non-government disability services, disability advocacy services, sexual assault services, sexual and community health services, local government and domestic and family violence services. The expertise and resources of these professionals supported the work of the program and linked community supports and services directly to people with an intellectual disability. Co-facilitation was also seen as a way to build the capacity of the community sector to work with and include people with an intellectual disability and for professionals from the disability sector to work with people with an intellectual disability in a different context; one that acknowledges the issues of violence and abuse in their lives and seeks to prevent and address it.

Program research and evaluation

Barger et al. (2009) found that too few violence and abuse prevention, or sexuality and relationship programs for people with an intellectual disability were evaluated. They reported a 'do and hope' approach due mainly to the scarcity and short-term nature of funding for such programs. Furthermore, there remains a dearth of research on the topic of sexual violence and particularly on approaches that actively include people with an intellectual disability in preventing violence and abuse in their lives. The LSSL:RR model included a research and evaluation component. Evaluation was built into the prevention workshops and the overall program was evaluated to ensure continuous improvement throughout the implementation phase. The program evaluation is reported in Part two of this report.

Program activities and output

A range of Program activities were implemented in each site. The following section summarises the output, or activities of the Program in relation to its three goals.

Program Goal 1: Primary prevention

The first goal was to develop, implement and evaluate an education model for the primary prevention of violence against people with an intellectual disability and one that would enable people to have respectful relationships. The development of the model formed the first phase of the program, lasting six months. Further refinement and improvement continued throughout the life of the project. Program implementation served to test the model, with the evaluation reflecting on key components and the overall impact of the model.

The peer education model incorporated the recommendation of Barger et al (2009) that such programs 'reflect not only existing research on sexual violence prevention for the general population but the specific concerns of women with intellectual disabilities' (p. 259). The authors also identified a need for a comprehensive approach that engaged the systems involving people with an intellectual disability and did not focus on one aspect of prevention. LSSL:RR drew, in particular, on the VicHealth (2007) framework, which is:

...based on an ecological model for understanding violence. This model, proposed by the World Health Organization (WHO) in its *World report on violence and health* (WHO 2002), recognises that factors influencing violent behaviour or vulnerability to violence lie at multiple and interacting levels of influence – individual/relationship, community and organisational, and societal (VicHealth, 2007 p. 12).

The ultimate aim of prevention programs is to decrease the likelihood of the target population experiencing violence and abuse. However, in a short-term pilot program such as *Living Safer Sexual Lives: Respectful Relationships*, it is not possible to specify these outcomes. Program participants reported that they had:

- Increased their knowledge about their rights in relationships
- Increased their awareness about local services
- Increased awareness about resources they could use to support them to have and maintain respectful relationships, and
- Increased their confidence in talking about relationships with each other and support people.

Barger et al (2009) also observed that many existing programs for people with an intellectual disability focus on teaching protective behaviours, rather than engaging more broadly with questions about rights, responsibilities and respect in relationships. LSSL:RR was an important departure from these narrow approaches that focussed only on behaviour change for potential victims of abuse. The approach taken did not seek to alter specific behavioural patterns, so therefore did not seek to identify whether behaviour change was an outcome of the program. Instead a multi-layered approach with multiple aims was used, reflecting best practice frameworks in primary prevention.

Systems and attitudinal change, changes to practice, increased capacity for engagement, or increased access to, and use of information and supports, takes time and are difficult to measure in the short term. What *can* be measured is direct participation in programs. The delivery of the pilot Program resulted in:

- Twenty people with an intellectual disability and co-facilitators participated in a 3 or 4 day peer educator training program across 4 sites.
- Three education programs (up to 4 sessions per program) delivered by the trained peer educators and co-facilitators in three sites.
- A total of 41 people with an intellectual disability completed the *Living Safer Sexual Lives: Respectful Relationships* education program.

Program Goal 2: Resource development

The second goal was to develop a training resource for peer education that would be transferrable to other sites. As discussed earlier the LSSL:RR program used the existing resource LSSL (Frawley, et al., 2003) and expanded on this to have a focus on prevention of violence. Like LSSL which was developed collaboratively with a reference group comprising people with an intellectual disability, advocates and researchers, LSSL:RR was also developed using the expertise of people with an intellectual disability in the project team. As Barger et al., (2009) note in their review of LSSL, it is significant that this resource was developed from research with people with an intellectual disability, directly reporting and using their stories as the basis for learning within the program.

Few sexuality or relationship programs for people with an intellectual disability use this approach, nor do they use adult learning principles. Many of these traditional programs assume that people with an intellectual disability learn through instruction. The approach used in LSSL: RR acknowledges the capacity of people with an intellectual disability to use and reflect on their own and others' life experiences, using these reflections to develop more knowledge and skills, and to advocate for changes in their lives. The stories are central learning resources; in addition there are activities about rights, strengths, development of intimacy in relationships, issues relating to violence and abuse in relationships and ways of developing respect in relationships. All of the learning resources and approaches to using them were developed by the research team (see Frawley, et al 2011a).

Three new resources were developed, piloted, reviewed and final copies distributed to the 20 trained peer educators and the 20 trained co-facilitators. These are:

- Living Safer Sexual Lives: Respectful Relationships - Peer Educator and Co-Facilitator Manual.
- Living Safer Sexual Lives: Respectful Relationships - Participant Handbook.
- Living Safer Sexual Lives: Respectful Relationships - Learning Partner Booklet.

Other resource materials were also developed and sourced to include in the program, these include a set of rights cards based on the work of Ann Craft (1994) an activity on intimacy in relationships, a booklet on sexual assault for people with an intellectual disability (SECASA) and a DVD about responding to violence and abuse in a relationship (WHIN). The manual, books and resources have been distributed to all trained peer educators and co-facilitators and are only available to people who complete the 3 or 4 day training by the project team.

Program goal 3: Developing an evidence base

The third goal was to develop an evidence base concerning education on respectful relationships with people with an intellectual disability using the project model. The project team were very aware that without research and evaluation, important findings from the program development and implementation would be difficult to transfer. From the beginning these two activities were prioritised, with funding made available for the evaluation to the independent evaluation team at ARCSHS and some program funds used to employ a research assistant to undertake the data collection on peer education.

Peer Education Research

The aim of the research was to develop an understanding about how peer education could be used in a relationship program for people with an intellectual disability. Peer education fitted with the aim to include the voices and experiences of people with an intellectual disability, addressing this gap in existing programs and in the research literature on sexuality and relationship education for this population.

A research proposal was developed and ethics approval gained from the Faculty of Health Sciences Ethics Committee at La Trobe University to undertake research about the peer education component of the model. The research questions were:

1. How can peer education be used in violence and abuse prevention education for PWID?
2. What do PWID bring to the role of peer educator and get from this role?
3. What can be learned and gained from involving PWID as peer educators?

Recruitment of peer educators

Early interviews from the evaluation indicated that the idea of peer education was challenging to the disability and community sectors which were being sought to disseminate information to people with an intellectual disability and to aid recruitment to the program. This scepticism was a key theme over the course of the Program and led to 'gate-keeping' by some people who had initially been sought to be champions of the Program. For some of these people, primarily from the disability sector, direct participation in the Program through training as a co-facilitator shifted this thinking and resulted in some of these gatekeepers becoming champions. In other sites and for other people the scepticism remained and directly impacted on the uptake of the Program in their locations. In particular this impacted on recruitment of peer educators. In one site potential peer educators contacted the program manager directly and organised a meeting without their advocacy support worker so they could find out more about the program without it being filtered. This resulted in a much larger group of people with an intellectual disability being trained as peer educators as the

advocate support worker had initially ‘hand picked’ only those people they felt were right for the role.

Method

In depth semi-structured interviews were undertaken with 16 of the 20 people with an intellectual disability who participated as trained peer educators, both upon completion of their training and upon delivering education sessions. Observational data was also collected on the peer educator and co-facilitator training (five sites) and from program sessions (three sites). All data including the interview transcripts and the reflective group work were transcribed and thematically coded using NVivo.

Findings

The key finding from this research is that people with an intellectual disability can be peer educators in a relationship program. With adequate training, and the support of a co-facilitator people reported that they considered themselves competent in the role. In particular, they indicated that they had more insights into the issues and were able to share these with their peers because of their own experiences. Overwhelmingly these peer educators noted that they wanted to help others so they could have respectful relationships and avoid the more negative experiences of relationships. Being a person with an intellectual disability meant for some, they could relate to the participants commenting, ‘I am in their shoes’. Peer educators also saw this role as an opportunity to learn and develop their own knowledge, skills and resources to have more respectful relationships. Importantly they also saw it as an opportunity to be a role model, not only for other people with an intellectual disability but more broadly in their community. The findings are summarised in Figure 2 below.

Figure 2: Summary: Peer education research findings

Why people got involved	Personal experience of relationships – a good basis for being a peer educator	Already have skills – program provided a good opportunity to develop these further	Self advocacy – link for peer educators to program, place and where they have learned to ‘speak up’ and share experiences
How they saw their role	Helping peers so they can have better experiences in relationships	To share their own experiences, help others talk about relationships through stories and their own experiences	Can be an educator because ‘I am in their shoes’. Being a role model
What they got out of it	Helping others and self	More confidence and being respected	New knowledge and skills – about relationships, support services and being a facilitator

Discussion

The peer education approach was central to the program model. This approach was grounded in the belief that people with an intellectual disability should be given the opportunity to become peer educators and should be supported in this role by those people and services that support them in their life pursuits. It is clear that many people with an intellectual disability did not get the opportunity to take on this role in the five program sites due to the effects of gate-keeping. There seemed to be strongly held views that people with an intellectual disability could not or should not be peer educators in a program about relationships, sexuality and violence and abuse prevention. Interviews undertaken as part of the evaluation with a sample of people from the disability and violence/abuse sectors who had been engaged in shaping local implementation found strong

resistance to the idea of peer education. In particular, people were concerned that the approach to recruitment of peer educators was too 'open' (because, after attending an information session, people could choose for themselves to go on and participate in the peer education training). However, the research with the peer educators offers a counter view; one that suggests this is an important role for people with an intellectual disability to have and one that can shift the view that people with an intellectual disability can only be 'vulnerable victims' who need protection and protective education.

Further research about the peer education component of this program is needed, particularly following these peer educators through as they continue to implement the program. A longer-term study would enable a more in depth analysis of the outcomes. Further research with people with an intellectual disability who complete the program delivered by peer educators is also needed to determine the learning outcomes from using this approach. At the time of writing additional funding to continue this research component was not available, however the pilot sites were still continuing their work locally.

Conclusion

The LSSL:RR program is the first of its kind in Australia and the first to involve people with an intellectual disability as the focus of peer education programs in violence and abuse prevention internationally; others have involved a broader range of people with a disability (Fitzsimons, 2009) . Importantly, this program also involved people with an intellectual disability in the program development, as trainers and in the collaborative evaluation of the program as discussed in the following section. The centrality of people with an intellectual disability in this program and the focus on personal development of ideas about respect in relationships is what sets it apart from other work with this population. This program has enabled people with an intellectual disability to have 'powerful roles' in the program and subsequently in the local areas where they are running these programs, challenging the dominant view that people with an intellectual disability can only be 'vulnerable victims' in need of protection and 'training' to protect themselves.

LSSL:RR aimed to shift the power for change to people with an intellectual disability and develop strong and supportive networks that could continue this work beyond the funded project. Whilst this outcome is unlikely to be seen in the short term, at the time of writing the model was continuing to be used across Victoria and Tasmania and there has been international interest in the program. Follow up research is planned to consider the impact of this work over a longer period and to consider the role people with an intellectual disability can have in broader prevention initiatives.

The following section outlines the evaluation of the program model and describes in detail the collaborative approach used to involve the whole program team in this iterative evaluation. This is another example of how the centrality of people with an intellectual disability was valued and supported in this program.

Real People, Core Business

Part Two: Program evaluation



Dr. Catherine Barrett
& Dr. Sue Dyson

Acknowledgements

The evaluators would like to thank all the Program team working on the *Living Safer Sexual Lives: Respectful Relationships* peer education program for their generosity and openness. The Program team included Patsie Frawley, Amie O’ Shea, Danielle Houghton, Janice Slattery, Linda Stokoe and Rachel Boadle.

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Part two: Program evaluation

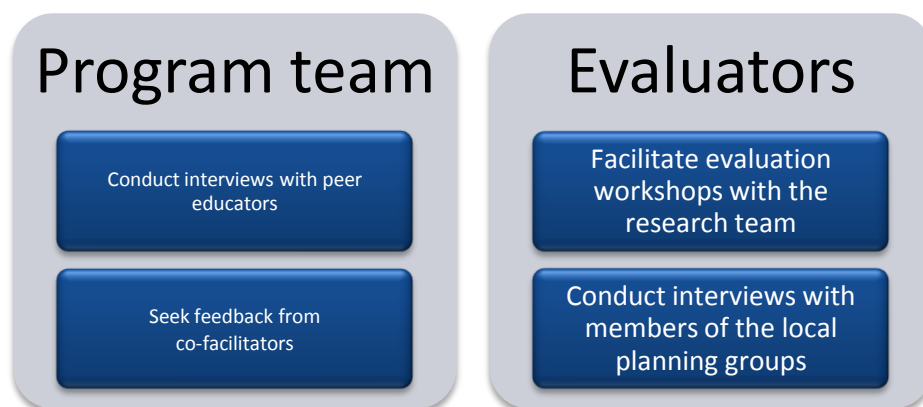
The evaluation of the program was prioritised for a number of reasons. Firstly, few violence and abuse prevention programs for people with intellectual disability have previously been evaluated because of insufficient funding (Barger et al., 2009). Secondly, there is a lack of research evaluating the participation of people with intellectual disability in programs, particularly as peer educators. Consequently, the evaluation sought to understand the effectiveness of the program, make improvements to it and determine the outcomes. It was anticipated that this information would provide insights about how the program could be sustained in the local sites and further disseminated. Therefore, the aims of the evaluation were to:

1. Investigate program processes and outcomes from the perspectives of key stakeholders in the service sector.
2. Develop a feedback loop with the Program team to enable identification and setting of benchmarks for good practice and continuous program improvement.
3. Understand the processes employed in the establishment and program delivery phases of the Program, and the ways in which these contribute to the sustainability of the Program.
4. Identify and describe the adaptation of the ecological model to the Program.

An empowerment evaluation approach

Evaluation strategies were conducted by both external evaluation and members of the program team (Figure 3). This evaluation section of the report primarily focuses on the findings from the evaluation workshops and interviews with members of the local planning groups. However, comparison will be made with the perspectives of peer educators.

Figure 3: Evaluation activities



The evaluators met with the program team to discuss the evaluation aims and to identify the most appropriate evaluation approach. An evaluation proposal was developed and ethics approval was provided by the La Trobe University Human Research Ethics Committee. An interactive evaluation form was selected to support the program team's action research methodology to provide dynamic opportunities to identify program improvements (Owen and Rogers 1999). This approach involves discovery and synthesis to identify new understandings, with feedback a necessary feature to enable these understanding to be incorporated into practice improvements (Guba and Lincoln 2001). The particular interactive approach selected is known as empowerment evaluation.

Empowerment evaluation is a tool particularly suitable for interactive projects and those that aim to lead to improvements. Empowerment evaluation has been described as a self-evaluation, generally facilitated through evaluation workshops, empowering team members to self-assess to determine

the progress of a program and to make improvements (Fetterman 2001). The approach involves four pragmatic steps:

1. Develop a shared vision and identify key activities critical to the function of a program.
2. Rate performance in relation to the key activities.
3. Collect documentation to substantiate ratings.
4. Plan for the future.

Evaluation steps

These steps were adapted to suit the program and implemented through five evaluation workshops with the project team, as described in the following section.

Evaluation step 1: setting ground rules and clarifying evaluation aims

The first step in the evaluation involved developing a shared vision and clarifying the values of the Program team to provide the foundation for the evaluation workshops. At the first workshop the team were provided with information sheets in plain English that outlined the aims and processes for further evaluation meetings. The information sheets were discussed and the program team were invited to sign consent forms. The team were then invited to explore how the group would work together in the evaluation workshops and identified that each team member needed to:

- *Be responsible for what comes out of my mouth.*
- *Listen to others.*
- *Respect the confidentiality of people we are working with.*
- *Ask permission (including if taking a photo).*
- *You don't have to share: you can speak up or be quiet.*
- *Privacy: what is said in the room stays in the room (personal things).*
- *Challenge each other in a supported and respectful way.*

Notes from the evaluation workshops were made by the workshop facilitator and placed on a shared computer drive accessible by the Program team. In discussion about the close working relationship between the Program team and the evaluators (both teams were based at ARCSHS) it was agreed that their existing working relationship could enhance communication and opportunities to improve the Program. However, it was also agreed that it was important to differentiate the responsibilities of each group and agree on processes to protect the identity of stakeholders participating in confidential, evaluation interviews. The evaluators agreed that a shared computer drive would include most of the evaluation documents to enable the Program team to review the status of the evaluation as it progressed. An exception was data from interviews with stakeholders, which were kept on a separate computer drive until they had been verified and de-identified by interviewees.

Evaluation step 2: Identifying key activities and checking progress

The second empowerment evaluation step involved identifying key activities that were critical to the function of the program. Fetterman (2001) suggests that these activities then form the focus of the evaluation, enabling the team to check their progress in relation to these activities. The program team identified the key activities as: participation by people with intellectual disability as researchers and peer educators; community engagement and cross-sectoral collaboration; and the Program model. Subsequent workshops then focused on team reflections on progress within each key activity.

Key informant interviews

To assist the LSSL:RR team to reflect on their progress, in-depth interviews were conducted with 24 participants drawn from local planning group in each of the five program sites to explore their perceptions of the program.

Recruitment was sought through a flyer circulated to each planning group. People who expressed interest were given a plain language statement and consent form. The interviews explored impressions of the program, how it could be improved and what aspects were working well. Participants were also asked specific questions about the involvement of people with an intellectual disability, what they would like to see the program achieve and how it could be achieved. The interviews did not cover the evaluation of the peer education training or the local workshops, as this was not the focus of this evaluation.

Twenty-four semi-structured phone interviews were conducted between June and November 2010. Most interviewees (23) were service providers and all had participated in the program through the local planning group, with at least four interviewees from each site. Most interviewees (23) were female, from a range of backgrounds including community health service provider (10), state government disability service provider (4), disability service provider (3), education provider (2), disability advocacy (2), sexual assault service provider (1), and intellectual disability self-advocate (1). Interviews were taped and transcribed and returned to participants for verification and to enable interviewees to remove any information that may identify them.

The verification of interview transcripts was considered important to ensure that the evaluation report was credible. In particular the evaluators wanted to ensure trustworthiness and authenticity and that the evaluation report did not contain a biased distortion of the data (Patton 2002). The verification processes also aimed to demonstrate authenticity of stakeholder voices by giving genuine voice to the interviewees (Winter, 2002). Such processes are commonly used in qualitative research and in the evaluators' experiences, interviewees engage in verification processes to a limited extent. Consequently, it is interesting to note that over half the interviewees requested significant changes be made to their interview notes. For example, three interviewees returned their transcripts to the interviewer on three occasions for further changes and one interviewee removed 1700 words from their 3900-word transcript. A number of changes made were deletions related to statements about the capacity of people with an intellectual disability to participate in the Program and the challenges of cross-sectoral collaboration. Further reflections on the changes to transcripts are provided throughout the report.

Evaluation step 3: Planning for improvement

The final step in an empowerment evaluation process is to plan for the future. For the peer education program this was primarily achieved at each evaluation workshop through team reflections and feedback from stakeholder interviews. To aid further planning for improvements, the notes from each evaluation workshop were placed on a shared drive accessible to the Program team. The final evaluation report was also placed on the shared computer drive so that the Program team could review the evaluator's findings as the report progressed.

Using creative arts in the evaluation workshops

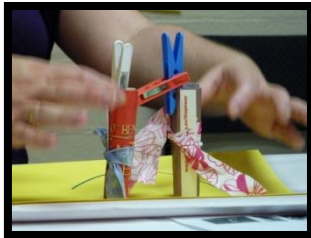
A creative arts approach was used in the five evaluation workshops to engage with the emotional aspects of the project team's experiences and enable deeper reflection (Eisner, 2008). The use of creative arts methods provided a fun and engaging way of eliciting reflections on the program and these less formal, more creative approaches enabled greater access to all participants. A different creative arts theme was developed for each of the five evaluation workshops including:

- Mapping workshop: to identify program processes and achievements

- Bubble workshop: to explore myths about people with intellectual disability
- Awards workshop: to celebrate and consolidate achievements
- Hats workshop: to explore a range of perspectives (feedback from stakeholder interviews)
- Building bricks workshop: to clarify components of a successful program

In the following section each of these workshops is outlined and key achievements described.

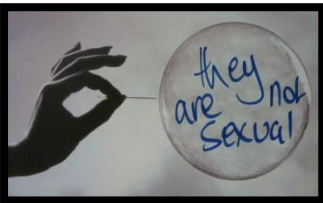
Mapping workshop



The first workshop involved a 'mapping' theme to explore program processes and achievements. Participants were invited to use arts materials provided to represent the progress of the program along a ten-metre strip of paper. Participants drew images and used materials to represent their experiences and then talked about their representations. As shown in the adjacent photo, one participant used clothes pegs and cloth to make silos representing the challenge of encouraging disability and community sector organisations to work

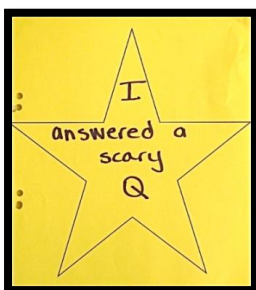
together.

Bubble workshop



A 'bubble' themed workshop was facilitated after feedback from the program team about the myths relating to people with intellectual disability that they encountered in their work. The myths were seen as 'bubbles', or things that had no substance and needed to be dispelled. An image of a bubble being burst was printed onto A4 paper and each time a myth was identified it was written into a myth bubble. The myth bubbles were then posted onto the walls at each evaluation

workshop to provide a visual record of the myths and to stimulate further discussion. At the bubble-themed workshop, devices for blowing bubbles were provided and participants were invited at strategic points to use the devices while they reflected on the myths that they encountered. The bubble-myth approach was utilised for six months and the program team were given pocket-sized 'bubble books' to record myths that they encountered in the field. Over the course of the program the team identified 49 myths. When asked to provide feedback on the bubble book concept one participant wrote, *Dear Catherine, the book is really useful for me. It is an easy way to record thoughts, feelings and reflections about the work I am doing. The 'bubble' concept works for me. ... Thanks for encouraging new ways!!*



Awards workshop

An 'awards' theme workshop was facilitated in response to feedback that the bubble books focused on what was not working, rather than what was working. A member of the team wrote: *[the bubble books] are fun and pretty. I'd like to use the back of the book to write some positives, because sometimes the bubble-thinking feels negative. I think I have been slow to 'get' the books, not the idea but actually writing in them. I have talked more than I have written.* This feedback led to the development of a template to celebrate and consolidate the achievements of the team. A star icon was

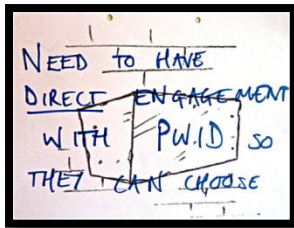
printed onto A4 paper and participants were encouraged to nominate themselves, their colleagues or other stakeholders for an achievement 'award'. In total 46 stars were identified, with the aim that this 'appreciative inquiry' approach (Ludema et al, 2001) would encourage participants to reflect on and consolidate what they were doing well.



Hats workshop

A 'hats' themed workshop was designed to give the program team feedback from stakeholder interviews. The team were invited to bring a hat to the workshop that represented an aspect of their life (see the adjacent photo). During the workshop participants were invited to swap hats and discuss the Program from the perspective of another team member. At strategic points the facilitator provided input from stakeholder interviews to highlight further perspectives. The approach is modelled on de Bono's 'Six thinking hats' which are

utilised to encourage people to imagine switching thinking and understanding situations from a range of perspectives.



Building bricks workshop

The final evaluation workshop, held in November 2010, encouraged the program team to reflect on what was required for the LSSL:RR program to be successful. The team was invited to imagine that they were explaining it to an outsider who wanted to replicate it. A template was developed representing a 'building brick' and was used to identify the key 'bricks' required to establish a successful program. A total of 16 bricks were made in this session to capture some of what had worked.

The building bricks and the stars and myths identified in the workshops are presented throughout this report.

Evaluation data sources and analysis

Key sources of evaluation data were reflections by the program team in evaluation workshops and transcripts from stakeholder interviews. In addition to the notes from evaluation meetings, several registers recorded myths, stars and building bricks (as above) gate-keeping strategies identified from the second workshop.



Gate-keeping register

The phenomenon of gate-keeping was identified as something that occurred when stakeholders espoused support for the program but engaged in behaviours that seemed directed at hindering its success. For example, one organisation described their support for the program but then delegated representation on the local planning group to a staff member that had no power to support it. Twenty-two gate-keeping strategies were ultimately identified. Six key sources of evaluation data were also identified and analysed to determine the progress of the Program in relation to the key activities (Fig.4).

Figure 4: Sources of evaluation data



Data from each of these sources were collectively analysed using the five stages of framework analysis: familiarisation; application of a framework; indexing; mapping; and interpretation (Ritchie and Spencer 1994). The data were initially mapped onto the five key activities identified as critical to success. Meetings were then held with the program manager to reflect on emerging sub-themes and to check the evaluators' understanding of progress.

Thematic analysis of data



At meetings with the program manager the themes were mapped using sticky notes to enable them to be shifted and reconsidered. These meetings provided the opportunity to give detailed feedback on the interviews to the manager. The data were further analysed into four core themes relating to the program principles.

These steps were adapted and implemented through five evaluation workshops with the program team carried out between 2009 and 2011.

Evaluation Findings

The general attitude to women with intellectual disabilities is that they have no sexuality; they're not 'real' women ... Some of the service providers said, it's actually not our job, we've got our own work to do. They didn't see this project as part of their core business if you like. It was kind of like, we're not funded to do that (Toni, disability advocacy).

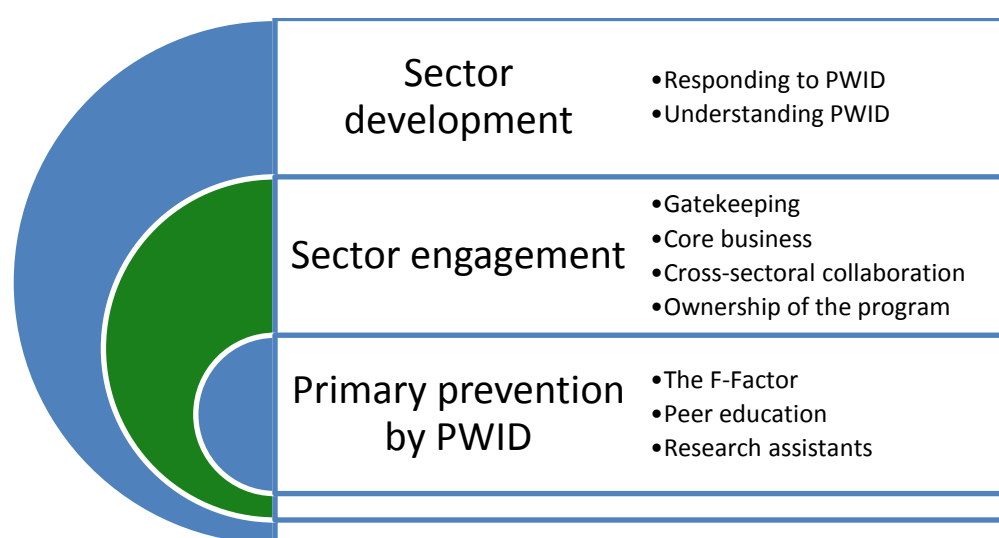
The findings of the evaluation are presented in four sections. The first three sections describe the findings in relation to the principles of the ecological model of violence prevention (Fig 5):

- The first section explores the role of people with an intellectual disability in the primary prevention of violence, including their roles as project workers and peer educators.
- The second section describes the principle of sector engagement, including perceptions of core business, the importance of cross-sectoral collaboration and the anxiety about the openness of the program. This section also outlines the phenomenon of the gap between espoused support and actual support, by local planning groups, which the project team termed 'gate-keeping'.
- The third section addresses the principle of sector development by describing responses to ideas about violence, abuse, and the people with an intellectual disability raised in the planning of the program. These three sections draw substantially on interviews with stakeholders from the local planning groups and reflect the context in which the program was working, rather than an evaluation of program processes and outcomes. However,

this contextual information is pivotal to primary prevention programs and related to the evaluation aim regarding sustainability.

- A fourth section is presented to summarise the program outcomes. Given that most of the stakeholder interviews were conducted before the workshops for people with intellectual disability, interviewees were unable to describe the outcomes. Consequently, a fourth section presents a summary of what stakeholders thought would be indicators of program success and lists the outcomes described by the program team. In each section of the findings data are presented from the evaluation workshops and stakeholder interviews before providing recommendations to promote program sustainability.

Figure 5: Evaluation findings relating to the ecological model



Primary prevention by people with an intellectual disability

The participation by people with an intellectual disability as project workers and peer educators was central. Historically they have been perceived as vulnerable and victims and rarely given meaningful opportunities to participate in planning, education and research. By contrast, the LSSL:RR team explored the various potential roles of people with an intellectual disability and agreed that their meaningful participation was important because they:

- Have rights, thoughts, aspirations and insight
- Are adult learners, equal learners and have the capacity to learn and develop
- Can support each other
- Are experts
- Deserve this opportunity

The team also agreed that, while the involvement of people with an intellectual disability added complexity, it provided considerable benefits. The following section discusses the value of peer engagement as well as the leadership provided on this issue from the program team.

Project workers

The program team provided reflections on the importance of involving people with intellectual disabilities as project workers. They:

- Are real researchers
- Are equally valued as other research staff

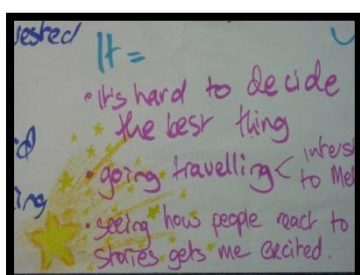
- Have got guts, keenness and life experience
- Deserve the opportunity.

The team identified that people with intellectual disabilities would be involved in all stages of the program, including the planning, delivering education, conducting research, access to learning and input into the evaluation. The project workers were employed as contract staff of La Trobe University with the same rights and benefits as other staff.

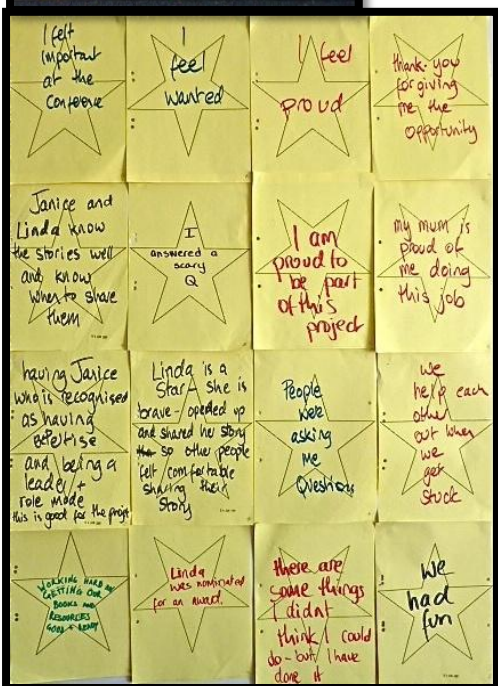
Their involvement as project workers required additional resources and effort to assist with government social security requirements, travel reimbursements, transport and accommodation, and provision of general support. However, the program team reported that it was important that they embodied their espoused principle of valuing the rights of people with intellectual disability to be given information to make choices. The team viewed the project workers as 'real researchers'. They also identified that working together required that they share information, clarify boundaries, work with flexibility in unknown territory, explore and understand how to work together as a team, and admit frequent uncertainty.

However, despite these challenges there were a number of benefits. For example, the project workers were able to identify aspects of the program that might be difficult to understand for their peers. At information sessions the project workers were able to talk about their own experiences and share their stories with their peers. This resonated powerfully with other people with intellectual disabilities, provided education for service providers and modelled a valuing of such experiences. The role of the project workers was particularly important in the information sessions provided in each site for people interested in participating in the workshops as peer educators or participants. The program manager reflected on an information session where one of the project workers shared her story. She noted that the project worker was *very brave and that gave permission to others to share their story. It was moving and productive; this is a great example of working inclusively* (evaluation workshop 2).

Project workers and storytelling



The role of the project workers in storytelling was also highlighted in one evaluation workshop where the program team were invited to explore the best things about the LSSL:RR program. One project worker said *seeing how people react to stories gets me excited*. While sharing stories for some project workers was emotionally difficult at times, the team acknowledged that people with intellectual disabilities had the right to retell stories, experience any upset and be supported and adequately debriefed.



Feedback from project workers

Across all the evaluation workshops the project workers made a number of comments about their roles in the program. The project workers identified a number of 'achievement stars' symbolising their role in the program. As shown in the collage below, these achievements provided valuable insights into how the project workers saw their role.

Collage of stars from project workers

The project workers were proud of their roles and felt wanted and important. Other achievements that were valued included the sharing of stories with peers and

feeling a 'click', or a knowing when the time was right to share a story. Project workers also noted that they were able to answer 'scary' questions from others and accomplish tasks that they did not feel that they would be able to.

The project workers were viewed by the program team as having expertise that added value to the program and providing role models for other people with intellectual disability. An achievement award was also given to a project worker who was nominated for a community award for her contribution to the program.

Peer educators

The primary role of the project workers with an intellectual disability was as peer educators and peer trainers. The project workers presented information sessions for people with intellectual disability, provided training for peer educators, and provided peer education in workshops. These activities were key to the development of a peer-led, primary prevention strategy. Peers are generally considered as credible role models, whose use of similar vocabulary enables better relation to other peers (Ehly & Topping, 2009). Peers play an important role in cognitive, social and emotional development (Schunk, 1998) and peer education is a powerful tool for change (McCarthy, 1999). Peer education has only been used in a small number of sexual health programs for people with intellectual disability, including two programs conducted by Women's Health West in Victoria, *Paps I should* (Farnan, 1994) and *Breast for Me* (O'Shea, 1997).

As the cornerstone of LSSL:RR, the peer education approach aimed to :

- Engage directly with people with intellectual disability to explore what respectful relationships are and to consider factors that impact on risk of violence and abuse.
- Provide education for people with intellectual disability on their rights, decision making and knowledge and awareness about sexuality and relationships to address risk of sexual violence.
- Acknowledge the social factors that impact on the risk of sexual violence.
- Acknowledge the opportunities, rights and social and personal barriers to respectful relationships experienced by people with an intellectual disability.

To recruit peer educators, information flyers were distributed through members of the local planning groups and information sessions were facilitated in each site. Peer education requires adequate levels of training and support (McCarthy and Brown, 1999) and resourcing to ensure meaningful inclusion (Walmsley, 2004). Training for peer educators was undertaken in all sites over a three-day period, with follow up in some sites. In total, 20 women and men with an intellectual disability completed the peer educator training. Peer educators from three of the sites facilitated workshops for a total of 41 participant and in a fourth site, had facilitated information and practice sessions for people with intellectual disability.

In peer education workshops, stories from *Living Safer Sexual Lives* (Frawley et al., 2003) were utilised as a stimulant for discussion about sexuality and relationship rights, relationship experiences, sexuality and sexual experiences, decision making, power and control, and respect in relationships. The stories were supplemented by activities about rights, strengths, development of intimacy in relationships and forms of violence and abuse in relationships (Frawley et al., 2011a). The involvement of people with intellectual disability as peer educators relied on members of local planning groups and disability and community sector groups disseminating information about the program to this group. The program team modelled the principles and practice of inclusion by requesting that people with intellectual disability be able to choose whether or not to participate. However, as described next, while some valued peer education and saw it as empowerment, many others identified a number of reasons why it wouldn't work and chose not to provide information to people with intellectual disability.

Peer educators as real and relevant

Planning group members with prior experience of peer education supported this approach. The support included a belief that peer education *means a lot more to someone with a disability* and that participants would *understand more* (Kim, disability service provider) and *listen most* when education was provided by a peer (Marnie, education provider). One participant noted that people with intellectual disability were reluctant to listen to people who knew nothing of their lives but, *by bringing in peers who have similar life experiences, then they feel that you are listening to them, you're actually seeing them, seeing their life, and who they are as a person* (Deborah, State Government disability services).

Peer education was also seen as important because it involved people being able to tell their own stories which was seen as a powerful education tool.

I think the power of the story is amazing and also the power of having their peers as facilitators. Reading the story, telling the story, I think it's really positive as well. The power is that it's a story from the person who has an intellectual disability; I think that is a strong connection. ...I think personal stories, they often... touch a cord, that's what these stories achieve. With the peer educators it's about when they can talk about stuff from a personal point of view. Again it's that true story ... helping make connections for people ... it makes it real in a way (Karen, community health).

Others noted that no one understands what life is like for people with intellectual disability like people with intellectual disability themselves. Some interviewees noted that people with intellectual disability were more likely to disclose to their peers and *feel safe to talk about complex issuesit enables people to also be able to ask the questions that they may not ask in a different context* (Haille, community health). One peer educator commented:

I'm hoping that we keep the project going really well. It's been going so well so far because of the people that are helping us out like [the program manager] and some of the others around the staff. The core people that work on it come and say, 'Are we doing it right?' If it wasn't for them I really don't think you'd have it up and running. And it's exciting because you don't get to do this very often. Once you get asked you think, 'Oh wow, I can actually do this, I can go and talk to these people about this' (Janet, disability self advocate).

While a number reported that the concept of peer education was important, several interviewees particularly related the concept of peer education to empowerment.

Peer education as empowerment

The peer educator model was noted by some interviewees to be empowering. One informant alluding to 'partnership' and 'equality': *When you're educating, you're educating with, you don't do it for* (Bette, education provider). Others noted that peer education was *empowering* and *really positive stuff* (Angela, community health). The approach was reported to send a message to the general community that people with intellectual disability *just really do have a voice and they actually are out there promoting and having more control of their lives* (Kim, disability service provider). This was particularly highlighted in the response of one participant who, when asked what she would like to see the project achieve, reflected:

I've got a heart and a head response so I'll give you both of them. ... My head response is that what we're needing to do out there is to provide people, empower people with disabilities to actually tell others to f__k off to be perfectly honest, in some ways. ... Well yeah, just like what I mean is like, let me make my decisions. ... So I think probably what we need to do [is

to] get this out there so that people get a sense that a person with a disability is the same as anyone else. They've got sexual needs, they've got needs for friendships, they've got needs to feel safe, just like everyone else, and they've got a need to learn to risk failure and to risk success, just like everyone else (Bette, education provider).

Others, like Angela, believed that these insights would be valuable for service providers, who may underestimate the capacity of people with disabilities, to see them in a different light rather than just as their clients (Angela, community health). Peer education was noted to assist people with intellectual disability to grow personally, become more confident and develop increased knowledge about themselves. The contributions of the project workers in information sessions impressed some service providers who reported the contribution was *quite something* (Tess, State Government service) and that the project worker was *a really fabulous role model* (Bette, education provider).

While some saw peer education as providing people with intellectual disability with a wonderful opportunity to participate in the primary prevention of violence, many more interviewees reported concerns that peer education would not work.

'It won't work because': Service providers' perspectives on peer education

A number of service providers reported concerns about the potential success of peer education. Peer education was considered an unrealistic expectation because they believed people with intellectual disability were not in respectful relationships, did not have the cognitive capacity to act as educators, and because organisations did not have the capacity to support people as peer educators.

One service provider reported that respectful relationships were *a rarity* for people with intellectual disability (Deborah, state government disability services). Some participants suggested that successful peer educators would need to be in respectful relationships because:

... they need to be people that are role modelling healthy relationships. Because it's difficult to be a peer educator about something that you are really not doing so well [yourself]. If you are not in respectful relationships and if you don't have experience of respectful relationships, is that something that you can do? ... The people that work in the disability sector know if you are in a respectful relationship or not. I think if we have got people that are facilitating a program and it's about respectful relationships you do need to be role modelling that to some extent ... I think that is a reasonable expectation (Marian, community health).

Other service providers reported that it was okay for peer educators to have had relationships that were abusive as long as they were able to reflect on that:

So many of them have a history of abuse or other previous bad experiences, and most of them won't have had counselling. So generally speaking... I'm generalising here ... a lot of them will just put things to one side and get along with their lives. But that doesn't mean that the issue isn't still there. So what it seems to us for someone to be able to do this project and participate properly and do the training to become a peer mentor, they need to have had sexual experiences, but they also need to have some good ones. ... If they have had abuse or other bad experiences, they need to be able to get past that so that they can move on and be able to explain and mentor other people (Pia, Disability advocacy).

Not everyone held a belief that people with intellectual disability need to be in a respectful relationship. One participant noted that one peer educator had significant life experiences and that this was *very conducive to her being non-judgemental* (Bette, education provider). Similarly, Marnie

noted that *probably the key to her being a very effective peer educator is that she's had life experience of not being treated with respect* (Marnie, education provider).

However, the concerns that many people with intellectual disability were not in respectful relationships meant that some service providers were reluctant to pass on information about the program potential participants:

I think some ... staff from disability agencies early on were perhaps a bit reluctant to pass on the messages to people. I still hear people say ... they have really poor relationships. I am thinking, yes, they might, but ... peer education is really about their ability to develop leadership skills and communication skills and they will learn in the program ... how to manage their own personal stories. ... I think that staff are worried that peer educators are not going to be able to get up and help other people (Poppy, State Government disability services).

Poppy believed that people with intellectual disability could learn from the program but was not entirely sure what it was that they would learn. A number of participants outlined their concerns that people with intellectual disability did not have the cognitive capacity to participate as peer educators and that the program was primarily *targeting the higher functioning person* (Jenny, community health). Others noted that some of their clients *are really keen to be peer support educators ... but at this point in time don't really have the necessary skills* (Kim, disability service provider) and therefore the projects' *expectations were too high for them* (Chris, disability service provider).

In particular, service providers argued that people with intellectual disability were impulsive, had difficulty reflecting on situations and lacked sufficient communication or listening skills to participate. Some service providers reported that this group would not be able to absorb the information that they are required to learn. A number of participants reported that they thought that people might agree to be peer educators without really understanding what they were being asked to do. For example, Raylene commented:

Sometimes I wonder if, like there's been some particular participants that seem to understand ... what's being asked of them, in one session but then the next session they've forgotten and things like that. So I guess I wonder how that's going to play out. But obviously that's part of the conditions ... when we're talking about intellectual disabilities, people with memories and things like that. I can see that the process might be a little bit, I don't know what the word is, a little bit hampered by that (Raylene, sexual assault service).

As a result of the concerns about cognitive capacity it was apparent that many of the services were actively trying to select certain individuals to participate. For example, Toni noted that service providers were *handpicking* women that *will guarantee a level of success for the project* (disability advocacy) rather than throwing the invitation open to all. This approach was at odds with the ecological model of the program that sought to empower people through the provision of information.

Addressing these gate keeping strategies was difficult because much of the concerns about the ability of people with intellectual disability to be peer educators was not openly discussed, or could not be discussed. This was apparent in requests by interviewees to have comments removed that describing the capacity of PWID to be effective peer educators. One interviewee agreed that the information could be retained in the evaluation report as field notes as follows:

A lot of our clients are not necessarily verbal... and I think they need to be able to stop and listen. Unfortunately sometimes the clients that I work with in particular are quite impulsive and don't have that ability to reflect on someone else.... Even if they did sit back and listen they then might say something quite inappropriate (FN, 05/10/10).

Perhaps because of these beliefs, many service providers expressed concern that they were unable to identify anyone suitable for the role. As Jenny observed:

I think [the peer education model] is fantastic. I do think unfortunately it's quite limited. I could think of 100 clients that I'd like to say had this opportunity to be a peer educator but I know it wouldn't be good for the program ... even though I'd like them to have that opportunity. They don't quite have the skills and the ability ... I feel quite bad about that. I sort of feel like, oh I'm not supporting the program because I can't. I'm after someone who can fulfil the role (Jenny, community health).

Such concerns about the quality of relationships and cognitive function led some organisations to make decisions about whether or not to participate on behalf of people with intellectual disability. While there were no particular selection criteria, some interviewees described their process:

One of the disability organisations who have been involved in the project was really clear about how to go about doing a good screening process for peer educators. They really targeted ... they thought about the kind of women who would get something out of it but who also had experience with relationships. It's a huge issue around how do you support a woman who has never been involved in doing training or has never been an educator, to become a peer educator. I believe we need to do more work and long-term support and capacity building with the women (Jeanette, community health).

Jeanette's belief that her organisation needed to do more work and provide more support to build clients' capacity highlights a key component of the program: building partnerships between people with intellectual disability and professionals in local areas and finding ways to continue these relationships. Tracing who decides and how it is decided could be useful information to clarify for future programs. The issue of support and the related workload are also important and discussed in the following section.

We can't provide the support

Some service providers expressed concerns that the peer education program wouldn't work because of the *slow pace that people with intellectual disability would work at and the cost of planning and paying for peer educators* (Jeanette, community health). Others questioned whether supporting peer educators was their role:

I suppose for me the peer educator stuff ... to expect women with intellectual disabilities to be able to ... they need a lot of support and a lot of reassurance. ... If we're going to expect them to be peer educators of that program, it's a long-term project and who's going to take it on long term? And this sounds like a cop out, but I'm a service provider, I don't necessarily think I'm the ideal person. I'm not saying that as a cop out, but I just think... Is this my role? Should I be doing that (Chris, disability service provider).

Several service providers reported that, for successful implementation, there was a need for organisational supports, in particular, support for people with intellectual disability who recognised or recalled sexual abuse. A number of service providers described the difficulty in implementing a program in an organisation that was already overstretched and underfunded.

I think the theory is great, I just don't think you can do it. ... I think the peer education is something that takes a lot of support and a lot of resources, and I suppose it's a bit easier in other areas where [the program manager] is there and can support the group. But it really adds to the workload here (Chris, disability service provider).

Providers from rural services identified that there was a significant amount of resources involved in getting people with intellectual disability to and from the sessions and that this was a cost that needed to be considered. Others described how it would take months of support to get a peer educator skilled and confident. Others were concerned about it being sustained if there were not resources available *for ongoing, continual support* (Katie, community health). One participant noted that some organisations didn't seem keen and perhaps this meant that they *haven't quite got the picture of it and what it could mean for them and their organisation* (Poppy, state government disability services).

Those who were already working with peer educators seemed to hold more positive views, including an awareness of the benefits for people with intellectual disability. For example, one participant noted that people who had been involved in peer education were *quite comfortable talking about their feelings and they've done it in a lot of different forums before ... have been receptive to this program* (Nat, disability advocacy).

Putting people with intellectual disability at the centre of the ecological model

The intent of peer education in the program was to place people with an intellectual disability at the centre. This approach differed from the earlier *Living Safer Sex Lives* program where the emphasis was on staff development. Indeed the previous program was highly regarded by participants and some were challenged by the shift to peer education. For example, Chris noted the difference between the two projects:

For me... in my head, we're going to train a group of women who are going to become peer educators, right? But then who do they peer educate? How does that happen? You need some long-term commitments. ... Who's going to support that project when this money runs out? Having set up that ... we spent a large amount of money training these women to do what? What are they going to be doing when there's no more money to continue it? Would we have better to spend that money running the [original] *Living Safer Sexual Lives Program* (Chris, disability service provider).

This perspective highlights the need to educate service providers to be supportive of peer education. Across many of the interviews there was an apparent need for the disability services sector to have policies and policy training about relationships, sexuality while also addressing issues of violence, abuse and neglect. Without this education, the potential of LSSL:RR for people with intellectual disability was not fully recognised. For example, Poppy noted:

The thing that disappointed me about the peer educator ... engagement was that I don't think many people saw it as the opportunity that it was. That for some people it was an opportunity to have some free training to perhaps do something different if they are engaging in the day program that is pretty much the same all the time. That they would essentially be employed or paid to do this work and have the experience of going around and talking to other people. ... I just sort of thought that I can't believe that people aren't seeing this as the opportunity that it is. ... Staff members aren't encouraging people ... to go and take on this sort of role (Poppy, State Government disability services).

Other interviewees identified that there was a need to educate service providers on how to work with people with intellectual disability, so that they could *actually get their head around the*

importance of respectful relationships (Clarke, disability service provider). Others noted the role peer educators could play in educating service providers but thought that the program *hasn't been about practice changes* and needed to be *packaged with some practice change ... and structures that can sustain it* (Jacki, community health). The education of service providers was also viewed as important, *otherwise you might be giving the women the skills and the courage and the information [to talk about abuse but] if they tell [a staff member] who doesn't do anything about it then that's a double whammy* (Tess, state government other). Tess also noted that it was important that services had processes to address this. Jeanette said:

I would have liked to have seen better cohesion of the services to actually support a group of women to become peer educators, that's what I'd ultimately like to see. ... If we can get agreements that this is something in the future to be done that would be a positive move forward for us. I think the thing is the services are saying that they're so stretched with their time and this has impacted on their capacity to participate in an extra program (Jeanette, community health).

It is interesting to consider the scepticism of the service providers interviewed in relation to the timing of interviews. Many of the interviews were conducted when peer educators were being recruited and trained. Indeed, as noted by Tess, it appeared that those who saw peer education in action were supportive:

Well, I'll tell you what. When [the program manager] came with a woman that she works with ... just hearing [the project worker] talk about her work is, was sufficient for me to say what a benefit it would have been for [the project worker]. ... She spoke about her work and how important her work is for other people ... to get other women empowered to stand up for themselves and [this is] what is achieved, not all the time, but most of the time. But her relaying of that ... was so good for her was that shone for me. You know, she told us that she now has the ability and the skills ... to do this. So I thought that was excellent ... unbelievable (Tess, state government service).

These comments highlight the impact on service providers who witnessed the principles of the ecological model being demonstrated in action. The leadership demonstrated by the program team was raised in interviews and evaluation workshops.

Leadership and equal partnership

In the first evaluation workshop, members of the program team explored the central role of people with intellectual disability and identified a phenomenon they named the 'F-Factor'. The F-Factor referred to leadership offered by the program manager, Patsie Frawley who embodied the belief that people with intellectual disability are equal.

The importance of such leadership in challenging historical approaches to people with intellectual disability was also noted by a small number of interviewees. For example, Jenny noted that:

I think [the program manager's] main strength is that she treats them [PWID] as normal people and values what they have to say. ... She also has the unique ability, which I think a lot of us struggle with. A lot of people stand back and think, oh I don't want to offend them. They don't want to say ... you know, they've got cerebral palsy to their face. Whereas she can sort of see that as, okay, you've got cerebral palsy, big deal, let's move on from that and let's talk about (it only?) if we need to. Whereas a lot of other people tend to shy away from that... and they pretend that they haven't got cerebral palsy or they haven't got an intellectual disability of some sort. ... Whereas [the program manager] has that unique thing of ... there it is, big deal and move on and I think it's a really, it's an amazing skill. Even when she speaks to

peers, the way she speaks ... there's also that underlying, true belief in what she's doing which I think shines through (Jenny, community health).

In her interview, Jenny noted that some service providers were uncomfortable acknowledging disability and the way that the ecological model demonstrated a partnership with people with intellectual disability that is valuing and respectful. The leadership provided in this regard was recognised by some like Haille (community health) who noted that the program manager was *really charismatic and really an expert and she instils a lot of confidence, you know. ... I think that's vital. ... absolutely vital* (community health).

Sector engagement

A local planning group was established in each of the five program sites. Most groups met monthly and included women and men with an intellectual disability, disability support organisations, disability advocacy, state government disability services departments, family violence organisations, sexual assault services, domestic violence services, women's health services, sexual health services and community health organisations. The engagement of the disability and community sector was considered pivotal to successful implementation and sustainability of the program. It was also expected to provide an opportunity for sector development, and in particular, to influence the way people with intellectual disability were perceived, supported and understood. The opportunity to have representatives from the disability and community sectors work together on the local planning groups was significant given that historically each sector has worked in isolation, resulting in fragmented services. The program provided the opportunity for dialogue across sectors.

The program manager met with each local planning group to outline LSSL:RR and discuss the aims of the group. The key function of each group was to oversee coordination of the Program in their area, including disseminating information and facilitating an information session for recruitment of people with intellectual disability. It was also hoped that ownership by the local planning groups would result in the peer education continuing sustainably beyond the involvement of the program team. In an evaluation workshop, the team described what they meant by community engagement.

- Involve all sectors that work with people with intellectual disability including disability groups, women's groups and sexual assault groups.
- Involvement includes planning and delivering the program and in becoming more receptive to talking to people with intellectual disability about sexual relationships.
- Community engagement is required to get the program going and keep it going and to build skills in community groups so that they have the capacity to sustain the program.
- Modelling how involving people with intellectual disability works because people need us to describe for them how it is done but particularly to show them and to support that with the development of protocols (resources) to support people with intellectual disability.
- Working with early adopters as a way of getting the program started.

The LSSL:RR team sought expressions of interest from sites where there was enthusiasm for the program, and where they had built relationships with people who might be open to this approach. This early adopter approach is described by Rogers (1995) as engaging champions in the first instance to demonstrate how others can then take up an innovation. In the establishment phase, some of the early adopters were referred to as 'fragile early adopters', referring to those who espoused support but in practice demonstrated reluctance and lack of support for the program.

The following section explores the issues that arose in relation to sector engagement, and concludes by examining the phenomenon of gate-keeping as a manifestation of service reluctance.

Local ownership and adaptation of the program

It was identified that for local planning groups to make the Program sustainable they needed to be able to adopt it to their own work practices and organisational needs. The program team identified the importance of being flexible and making compromises by allowing service provider adaptations to the program.

However, it was noted that this flexible approach raised concerns amongst some service providers. A number of organisations wanted explicit instructions on how the program would work and wanted clarity as to what their organisation was agreeing to do. The program team believed that the program flexibility was often misconstrued as a lack of direction by organisations that wanted more specific information on the steps involved. The program team recognised that they *lost some people along the way* who could not commit to the process without being given a description of all the steps involved. One such example was Clarke, who felt that the Program was based on:

... great ideas, really good sort of concept behind it, but I think it took quite some time to get their heads around what's this actually, what's the delivery of it going to look like? ... I suppose I ... started to question my commitment to it and involvement because it didn't feel like it was getting places. ... I sort of just pulled out. When I say pulled out, I mean you know, even just [from] those meetings, I believe, yeah, just things hadn't really furthered and [we] weren't sure where the project was going and we've had a couple of sessions now (Clarke, disability service provider).

While Clarke was unwilling to continue to be involved until he was clearer about implementation, others continued but were concerned that the flexibility threatened the quality of the program. For example, Angela noted:

One more thing that concerns me a little bit [is] what seems to be a real want to make it really fluid and to allow agencies to really adapt the program. It seems like it can be ... so flexible. ... I am not sure how you keep the quality of the program and ensure that the same quality of program that is going to do the same things is delivered everywhere. So ... then [you] say to them that they can be flexible and adapt it ... and that concerns me in terms of the quality and if the original intentions of the project are actually still going to be what is delivered in two or three years when there is not project support and people are possibly going to do what they want with it (Angela, community health).

Others were concerned that some organisations didn't understand how the program worked and would not understand how to *screen with their client groups for suitable women to come to a workshop or whatever was going to happen* (Jeanette, community health). Others noted that even though information was provided, some organisations needed more information and more time to establish processes to support the program.

The lessons for others to set up a successful planning group, they need to set up clear processes in the beginning about how decisions are made and the roles of people in the group, that kind of stuff that might be helpful. [In our group] ... things are said and you think things are agreed upon but [names a member of the local planning group] seems to have a different agenda ... I don't know how you protect against people like that ... [its] just one of those things that you have to work around. There are a few people involved [in the planning group] that are really committed to the Program so they will make sure that it still happens. It would be easy to think it is too hard and too frustrating so just forget it, which is maybe what some people have done (Marian, community health).

Cross-sectoral collaboration

Collaboration between the disability and community sectors in each of the sites was identified as a key activity essential to program success. Such collaboration was deemed important to ensure that services understood and valued what each other did to provide coordinated services for people with intellectual disability. However, the program team expressed concern that some services had significant difficulty working together. Members indicated that some disability services believed that primary prevention was not their responsibility and some violence prevention services did not believe they needed to provide services to people with intellectual disability. The challenges of cross sectoral collaboration were also noted by interviewees like Toni:

[the program] assumes that these sectors will work well together and have an ethos of partnership and collaboration. But that's not necessarily the case. ... Some of the service providers said, it's actually not our job, we've got our own work to do. They didn't see this project as part of their core business if you like; it was kind of like, we're not funded to do that (Toni, disability advocacy).

A number of service providers described cross-sectoral collaboration as a positive outcome from the Program. Some, like Chris, reported making *connections [with other organisations and] now I know who I can talk to when I need them* (Chris, disability service provider). Others noted that the program gave the organisations *a real tangible reason why we're networking* (Haille, community health). For example, Raylene reflected that her local planning group had:

...involved a number of different organisations getting together which has brought up stuff. It certainly has, because like I said I haven't really been involved much in the disability field and so I'm actually using it as a networking tool as well so I've made a few contacts ... that I will be able to focused past this project. After [the Program manager] finishes her research, hopefully those networks will remain and things can continue (Raylene, sexual assault service).

Some service providers reflected that the cross sectoral collaboration on the local planning groups could *actually be used to strengthen the program* (Sandra, community health sector) and *have those services exchanging possibly their views and ideas together* (Tess, state government service). Some of the benefits of cross sectoral collaboration for people with intellectual disability were articulated by Poppy who worked in a state government disability service partnered with a local Centre Against Sexual Assault: *debriefing support ... and referral pathways ... for anyone that might have gone through the Program that might have needed further counselling and support*.

While the program provided the opportunity for cross-sectoral collaboration there were a number of indicators that this collaboration was at times tenuous. For example, one interviewee requested the removal of a paragraph describing their collaboration with another service. The interviewee was concerned that it might be read as critical of the other service and might jeopardise their partnership. In a phone conversation to clarify the verification process, the interviewee agreed that the paragraph could be included in field notes as follows:

One interviewee reported on negotiations with a local youth health agency and described the disappointment that a manager in the agency did not recognise people with a disability as their priority target group. Eventually the agency became very involved. However, the interviewee expressed concern that the manager could have prevented the agency from being involved in the Program. Comments about the manager were deleted from the interview at the interviewee's request. The interviewee was concerned that the youth health agency might identify the comments and that this might challenge the collaboration (interviewer field notes 11/9/10).

The request for changes to this interview appears to reflect what was described by Toni as *a lot of politics between sectors* (Toni, disability advocacy). She suggested each site needed a local coordinator to ensure the program was taken up as core business.

Core business

The policy context in Victoria at the time of the pilot program identified the importance of supporting people to live a whole life and clarified that the prevention of violence against women is the responsibility of all health and human service sectors (Office of Women's Policy, 2009). In contrast, feedback from the program team and service providers indicates that many services do not understand the primary prevention of violence against people with intellectual disability as 'core business' for their organisation. For example, Maria (community health) noted that *doing things like this is certainly a part of core business [therefore] I am willing to prioritise this project ... because I think it is really important*. Others like Jolene agreed that the program had strong links to existing approaches in her disability service:

The peer stuff I think is quite powerful ... I guess it's combined with a lot of other projects or procedures that we've been involved in so it's kind of complementing that. Quite a few people from this group are also involved in self-advocacy and I think all these things go hand in hand really. ... The whole lot kind of entwines (state government disability service).

While Jolene was able to see the program as complementing other activities in her organisation, a number of interviewees did not make that connection. Toni (disability advocate) commented that some service providers said, *'It's actually not our job; we've got our own work to do.'* *They didn't see this project as part of their core business if you like. It was kind of like, 'We're not funded to do that'* (disability advocacy). This was also reported by Pia (disability advocacy) who was reluctant to take the Program on as core business because *it's not our area of expertise and we're funded to do individual advocacy. ... I don't know what to do with it*. Toni added that not only did these organisations not consider violence against people with intellectual disability as a priority, *it's not even on their radar* (disability advocacy). Others expressed concern that supporting peer education was not part of their service. For example, Chris said, *I'm a service provider, I don't necessarily think I'm the ideal person*, and added:

I don't think that the project is our core business. That's sounds like I put people into neat little boxes, but I don't actually think that this is our core business in terms of the approach. ... I'll support people to become peer educators but I'm not necessarily the person to run that [program]. ... I don't think that's my core business. My core business is to skill people up to do what they want to do, but it's not then to find them a job. I don't think as a disability service provider that the amount of time used would be justified (Chris, disability service provider).

The failure to view the program as 'core business' was evident across the disability and community sector, with several interviewees noting that neither sector understood their role in the primary prevention of violence against people with intellectual disability. For example, one representative from the community sector commented:

The people from disability services don't necessarily have a good understanding around violence against women ... while their core business is disability, it's not violence against women or respectful relationships. So I think you need a bit more balance around that stakeholder whose core business is that stuff, and stakeholders whose core business is disability (Angela, community health).

While it appeared that those from disability sector did not understand their role in the primary prevention of violence it also seemed that those from the violence prevention sector did not

understand the importance of providing services to people with an intellectual disability. Toni (disability advocacy) noted that, in response to efforts to engage some violence prevention and crisis services in assisting women with intellectual disabilities, she was often told, *We're not resourced to do that; we don't have the capacity to do that; we don't 'do' women with intellectual disabilities; they don't meet our criteria etcetera.*

The opportunity for sectors to work together and explore each other's roles was considered important to the provision of seamless violence prevention and support services to people with intellectual disability. However, it appears that a number of services thought it was the responsibility of others, rather than their own organisation. While there was disagreement about responsibility, there was agreement that without ownership the program would not succeed. As Pia (disability advocacy) noted, *Somebody will have to do the coordinating. None of it's complicated, but it's just time consuming. ... Unless that is somebody's core business to do, it just becomes an added task that somebody has to do on top of the work they need to be doing.* In one site, people noted that there wasn't an organisation available or willing to take a lead role and this contributed to the program not gaining traction. Tess (state government other) observed that in her site there was a need to ask, *Who is going to commit to what and what sort of time, and who is, you know, who is going to take the lead of this here.* It appears that both the disability and community sector could benefit from information to highlight their roles and responsibility in the primary prevention of violence against people with intellectual disability.

Gate-keeping: the gap between espoused and actual beliefs

The program team raised the theme of gate-keeping in the second evaluation workshop. They noted that some service providers espoused support for the program but provided little in practice. For example, some service providers described the importance of the program but would not return calls or emails made by the program team. While this was initially attributed to the busy lives of service providers, as the program progressed the pattern became more pronounced. It was identified by the LSSL:RR team as a gate-keeping strategy.

The evaluation workshops were utilised as an opportunity to list other gate-keeping techniques and to explore the characteristics of gate-keepers. The program team suggested that gate-keeping was a subconscious activity with many gate-keepers being unaware that their actions were subverting the program. They speculated that gate-keepers were motivated by reluctance to relinquish control over the lives of people with intellectual disability and a desire to cling to a fixed model of self advocacy or a belief that they were already doing groundbreaking work. The fear of losing control was noted by Jenny who reported that:

Some of the things other people do that is around not treating people with intellectual disabilities as normal, I think it's lip service. ... It's really about lip service of, 'Yes you have a choice but okay, I'm going to narrow down your choices and they're really what I want' (Jenny, community health).

The program team noted that gate-keeping appeared to be a defensive response by some service providers to a perception that the program would threaten or criticise their work. This view was supported by Toni who noticed that the program team had to:

... deal with a level of defensiveness from service providers. I have witnessed it a bit during this project, when the issue of violence against women with disabilities starts to be teased out, there's an immediate level of defensive behaviour from service providers. It's like they think you are criticising their service. It's almost like it's better to sweep the issue under the carpet and pretend it doesn't exist. To admit that violence against women with disabilities exists, potentially reflects on the disability service sector, so then it becomes a case of service

providers finding excuses, like, we don't have the resources, we don't have enough staff, we're not funded adequately, etc etc etc (Toni, disability advocacy).

Understanding the phenomenon of gate-keeping is particularly important given the program principle that interaction with people with intellectual disability can become abusive when one person has more power than the other. In other words, vulnerability to abuse is a result of the effects of intellectual disability and the disempowering actions of families, care services and the community. Holding this lens to gate-keeping strategies suggests that the empowering nature of peer education may have threatened the power held by some service providers. Understanding this phenomenon may provide the opportunity to stimulate reflection and discussion amongst service providers about abuse and power.

The potential loss of control

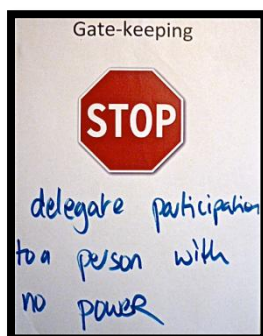
According to Argyris (1990), the gap between espoused and actual beliefs is highlighted when humans are faced with situations of change that may cause embarrassment, threat or fear of the potential loss of control. Argyris suggests that while we may espouse support for change, we may also unconsciously act to defend our control and avoid embarrassment. Consequently, this defensive response is at odds with our espoused values and sends a mixed message. The theory of defensive responses is enacted in a number of gate keeping strategies.

Defensive responses: gate-keeping strategies

Simmons (1998) suggests that in response to a perceived threat to something we value (our territory) we have a defensive or territorial response. Simmons refers to these responses as territorial games and explains that most people are unaware that they are engaging in territorial games. People make rational excuses for their behaviour and rarely stop to think and consciously choose their behaviours. Territorial games include: information manipulation, the invisible wall, strategic noncompliance and shunning. These were described by the program team as gate-keeping strategies and are outlined below.

Information manipulation

According to Simmons (1998) the information manipulation game is an approach that is based on the premise that knowledge is power and that those with the responsibility for assembling, interpreting, and formatting information are as powerful as the information itself. In this game omitting or withholding information is almost always a covert process with quite elaborate justifications and rationalisations. The most important information to withhold is information that might make a subject look bad or in need of assistance. The program team noted that information manipulation occurred when information about the program was withheld from people with intellectual disability by service providers.



One of the strategies for withholding information from the local planning group was through a strategy the program team referred to as 'plonking' (see illustration on left). This involved some organisations delegating participation in the local planning group to a person who did not have sufficient information or power to constructively participate. The technique of 'plonking' was also apparent in one site where the local planning group recruited people with intellectual disability to a program information session without providing adequate information about the session. Some people with intellectual disability had not been told that the program was addressing the potentially sensitive issues of respectful relationships and the primary prevention of sexual assault.

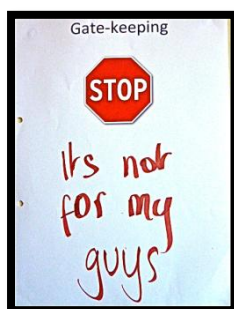
Another manifestation of information manipulation was the reluctance of some service providers to disseminate information about the program to people with intellectual disability. This was noted by Poppy (state government disability services) who reported that one member of the local planning group was enthusiastic about participating in the group but *I don't think she was taking anything back to the organisation*. The controlling of information was also witnessed in the provision of program information to people with intellectual disability. As Poppy reflected:

I think some ... staff from disability agencies early on were perhaps a bit reluctant to pass on the messages to people [with intellectual disabilities]. ... There is gate-keeping that goes on. ... I haven't got really solid evidence that people are going back and chucking the brochures out thinking, I'm not going to tell anyone about that. But I think that probably there's not a lot of passing on of the brochures to the people that might be appropriate. ... There's not a lot of time perhaps put into it, it might be passed on but I don't think people are really encourage or supported (state government disability services).

This strategy highlights Simmons' (1998) assertion that knowledge is power and those responsible for disseminating or withholding information are as powerful as the information itself. This strategy is particularly relevant, given the program principle that people with intellectual disability are made more vulnerable when one person (eg. service provider) has more power than them.

The invisible wall

The invisible wall involves maintaining the appearance of sincere effort whilst at the same time impeding, blocking, delaying or putting enough obstacles in place to make the task difficult to complete (Simmons, 1998).

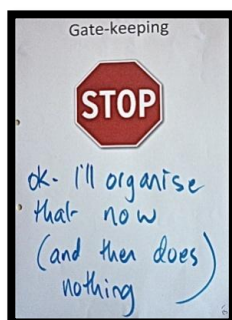


The image on left illustrates a common manifestation of this strategy: service providers fed back that they supported the program but didn't have clients that were suitable to participate due to their relationship status or cognitive abilities. Others noted that people with intellectual disability on the program team had a high level of cognitive function and that there was not a local equivalent of them..

Strategic noncompliance

The third defensive response witnessed was strategic non-compliance.

According to Simmons (1998), this involves an agreement up-front to cooperate, creating a false sense of security but defaulting on the agreement at the last minute. The program team noted this strategy on a number of occasions where a service provider promised support for the program that was then not provided. Some service providers agreed to attend meetings, organise meetings, and/or contact people with intellectual disability but did not follow through. This was particularly evident in the establishment phase of the program where service providers did not return the calls and emails.



The team also reported that some service providers attended local planning group meetings but did not contribute. In other instances a key person was withdrawn from the program at a critical moment and a local convenor of an information session chopped and fried onions while contributing to discussion in an information session. Strategic non-compliance strategies were noted in an interview with Poppy who questioned the commitment of a local service provider:

Another disability agency didn't feel that they had a lot of clients to refer into the program but felt really strongly about the need for the program. ... They engaged really well but then the key person got sick and went off and then emailed me yesterday to say that he has got too much to do ... and so hopes it all goes well sort of thing. It's not often passed on ... it doesn't seem to be that if an agency disengages that they say, 'Oh, here's a better person in my organisation that could be dealing with this'. ... Maybe they haven't quite got the picture of it and what it could mean for them and their organisation, or it could be that they just didn't think about it (Poppy, state government disability services).

These observations demonstrate how some organisations espoused their support for the program but didn't get the 'full picture' of its importance and so did not provide adequate support.

Shunning outsiders

The final gate-keeping strategy related to 'shunning' or branding someone as an outsider to deliver a message that they were not wanted. The stakes are raised just enough to justify discontinuing a project that seems to be invading protected territory. This strategy manifests as silence or deliberately ignoring the message being sent in order to communicate to trespassers to get out (Simmons, 1998). This strategy was not noted in the evaluation workshops but was reported in an interview with Pia who worked in disability advocacy. She considered the difficulties encountered by the local planning group establishing the program, given that the program was:

... coming from outside. So there is a difference and what it seems like is, that even though there is goodwill and acceptance amongst the services here that ... this group of people need something, somehow there's something different about a project that comes in from somewhere else. There's a difference between that and a project that's kind of organically grown locally where a couple of services gradually realise that there's a need and they get together and they try and work out how they as organisations can deal with that need (Pia, disability advocacy).

From this perspective, 'coming from outside' meant not as relevant or cognisant of local needs. Indeed, Pia noted that the program:

... doesn't feel helpful to me. It feels like a real muddle. I have to say that [the program manager] has probably driven around [our local areas] a bit and she sends out emails and we all ignore them. It's not that, we're not meaning to be rude; it's just that we haven't really known how to deal with it. So we've felt at various stages that we were letting [the program manager] down 'cos she's come forward with what felt like a fantastic proposal. It's not often that people come and say, "We've got some funding, we can offer this thing". That's a rare thing, so I think we probably felt like that [the Program manager] might feel like we're being ungrateful. It's just that every time we think about it, all we seem to see is the barriers and we haven't been very good at getting past them (Pia, disability advocacy).

This highlights the mixed messages sent by some service providers about their commitment and the need for sector development to complement the central role of peer leadership in such an initiative. Perhaps discussion of some of these gate-keeping strategies might be useful in future to stimulate reflective practice and debate on the extent of support for new initiatives.

Sector development: understanding and responding to people with intellectual disability

The program contributed to the development of the disability and the community sectors through the training of co-facilitators and through working with the local planning groups to influence the

way people with intellectual disability are perceived, supported and understood. Twenty-one co-facilitators were recruited from disability services, sexual assault services, youth sexual health, local government, state government disability services, non-government disability services and women's health services. Similar representation was achieved on the local planning groups. For most recruits, the opportunity to be a co-facilitator was seen by the person or their managers as a form of professional development and in some cases, a way to engage with people with intellectual disability, a target group that had previously been hard-to-reach. Co-facilitators needed to be provided with time release by their organisation to attend the three-day training and all 21 co-facilitators completed the entire training.

Influencing the way service providers in these sectors understand and respond to people with intellectual disability was an important component of the program. The ecological model acknowledges that there is a connection between the way that society understands and responds to people with intellectual disability and their risk of abuse. Therefore, influencing the way that people with intellectual disability are understood in the sectors was achieved to reduce the risk of abuse. Concerns about the way service providers understood and responded to people with intellectual disability were raised by the program team in evaluation workshops. The team identified a number of myths about people with intellectual disability and their sexuality, relationships, autonomy and self-determination held by the community sector (Fig. 4). These myths presented an obstacle to the successful implementation of the program.

Figure 6: Myths about people with an intellectual disability: Attitudinal factors that impact on participation



In the next section of the report the understandings of people with intellectual disability in the disability and community sectors are explored. The section begins by outlining understandings of PWID as asexual and how this is reflected in sex education, service provider discomfort and concerns about upsetting parents. Next, the impact of these perceptions on service provider's responses to sexual assault and the primary prevention of abuse is examined.

Understanding people with intellectual disability as sexual beings

A problematic characteristic in service providers' understanding of people with intellectual disability was their perceptions of sexuality. While some interviewees described their own views, most described concerns about the perspectives of their colleagues.

The myth that people with intellectual disability are asexual was reported to be prevalent in the community and reflected in the views of service providers. One interviewee noted that this myth was also apparent in government and funded services, as suggested in the following comment:

Services and programs in this country that are funded by government and supported by the community where women with intellectual disabilities continue to be infantilised and treated as asexual and inert, and still others where women with intellectual disabilities are stereotyped as hypersexual and uncontrollable. Women with intellectual disabilities are denied the right to experience their sexuality; they are not seen as women. So, governments and the community are happy to fund and support 'nice' programs—basket weaving, macramé, pottery, craft, and deliver the women to these programs on the bus with the name of the service proudly emblazoned on the side. All this is much easier and much nicer than looking at, and funding issues to do with violence, sexuality, rights to bodily integrity, and so on (Toni, disability advocacy).

This denial of the sexuality was certainly a concern shared by other service providers interviewed.

Service provider discomfort with, and denial of, sexuality

The discomfort of service providers, particularly in the disability sector, with the sexuality of people with intellectual disability was discussed in most interviews. Sexuality was considered to be a *big scary thing* (Nat, disability advocacy) or a *threatening topic* (Pia, disability advocacy). While one interviewee reported that all the staff in her organisation were open to talking about sexuality, most service providers in disability services reported that sexuality was a challenging topic. For example, Jolene (state government disability service) noted that *there is still a lot of ... opposition within the staff areas around human relations and sexuality*. Others reflected that recognition of people with intellectual disability as sexual beings was also challenged by a perception that people with intellectual disability were lesser humans:

Many in the disability sector work on a medical model and there's attitudes and beliefs about people with disabilities, that they're kind of sub-human. ... You know, that because they have a disability, that sexuality is not part of their being. ... So they're seen as, well we need to give them the care and support they need and that means community inclusion, which means they go to a day centre or they go bowling a couple of times a week or they go to the cinema. ... You know, the real essence of what makes us human, sexuality is part of, and relationships are part of that. But there's this huge denial that people with disabilities that it's part of their humanity (Katie, community health).

Others agreed and said that when sexual expression occurred it was often labelled as deviant by disability staff. For example, Poppy noted that service provider's responses were often grounded in the belief that the person *has a problem and they need to have some specialist attention to address it and that might be some behaviour interventions or medications*. Katie lamented that the

opportunity to conduct a holistic assessment of the needs of people with intellectual disability was often missed:

I've just found the disability sector might be more inclined to refer that person to a behavioural program to nullify their behaviour ... there hasn't been in my experience a lot of, 'Well I wonder why that person's displaying inappropriate sexual behaviour? ... Maybe somebody has sexually assaulted them. Has there been any assessment to identify whether that is happening?' ... There is a focus on changing their behaviour rather than [asking] what the cause of it is (Katie, community health).

Reflections from Katie and others indicated that sexuality was often conceptualised only as sex or sexual behaviour and hence, service providers believed that many in the disability sector were not having sex. Consequently, some disability service providers reported that people with intellectual disability were not interested in talking about sexuality. In one site, reference to the word 'sexual' was removed from the program title because some service providers were concerned that people with intellectual disability would be upset.

The actions of some service providers to 'protect' or withhold information about sexuality to avoid upsetting people with intellectual disability was seen by some interviewees to be a projection of service provider discomfort. For example, Haille acknowledged that:

... as educators we are sometimes wanting to protect ourselves from what young people are exposed to ... because we don't know what to do when we're exposed to it. ... So for instance, you know, if ... some young person shows a sexually explicit, sadomasochistic-influenced Facebook photo or something, there's an aspect of me that is immediately horrified and shocked and I don't know what the response is for myself (Haille, community health).

Haille's capacity for self-reflection was not shared by others working in disability services. A number of interviewees described how service provider discomfort resulted in sexual expression being suppressed. One example given was the practice of menstrual suppression (medical intervention to stop women having menstrual periods). Toni suggested that menstrual suppression appeared to be:

... rampant practice in group homes across Australia and what does that say about attitudes towards women with intellectual disabilities? ... Menstrual suppression is a form of sexual violence against women with intellectual disabilities. But I've had disability service providers say to me, don't be ridiculous; if they have their periods they have challenging behaviour. ... They go on to argue that menstrual suppression is in the best interest of the women because it puts a stop to the 'burden and suffering' of period pain and the supposed 'challenging behaviours' that present as a consequence of women with intellectual disabilities having periods (Toni, disability advocacy).

Comments by Toni and other interviewees suggest that, in the disability sector, decisions being made about 'what is best' for people with intellectual disability included a perception that it is best not to discuss sexuality. This may have contributed to reluctance on the part of some service providers to support the program. The discomfort of service providers with the sexuality of people with intellectual disability may have also contributed to their sensitivity to potential parental concerns.

Service provider concerns about parental upset

A number of service providers expressed concern that the program would upset participants' parents by talking about sexuality. Interviewees described how some parents clung to a notion of the *eternal child* (Bette, education provider) and would *just freak out with the thought of their child*

masturbating, let alone taking part in a relationship, and talking about having sex and discussing it with other people (Jenny, community health). Another interviewee described how a parent reported that her daughter had been sexually assaulted but on investigation ... *what we found was that mum was just struggling with the fact that her daughter was sexual and there was actually no sexual assault disclosed or identified* (Raylene, sexual assault service).

Parental fear of their child's sexuality was thought to result in some parents acting to protect their children from information about sexuality. However, some interviewees noted that such protective behaviours *actually makes them more vulnerable because at some stage they might be in a situation and have no idea how to deal with it because they haven't been provided with education and everybody else has been* (Katie, community health). Others agreed there was a need for parents to support the provision of information on sexuality:

A lot of parents, because it can be a bit daunting that their son or daughter might have a sexual relationship and things might go wrong ... they might get pregnant and not be able to manage But I think education would make a big difference. You know it's easy to make the mistake if you don't know the mistake is being made (Jolene, state government disability service).

Working with families was considered important to *[allow family members] to let go ... it's really about small steps; that's the key. Change is really difficult for families sometimes, but it's about whole families including the younger person to take small steps and develop confidence* (Marnie, education provider). Others who had gauged the positive responses to existing human relationships courses thought that the Program would be welcomed and felt that *families would be grateful and very pleased that this is something that is going to be addressed* (Marnie, education provider). The concerns about adverse responses to the program from parents were also articulated by Denise, a parent of a child with an intellectual disability and a worker in disability services:

In the past people with intellectual disabilities have not been considered sexual beings. That's very strong within our program [service], within the department, just generally within the community. I think it's hugely important that people with intellectual disabilities [are] speaking up for themselves It would it be scary for parents to have a project like this happening. Absolutely. I think it would be quite confronting in some areas because it is something that ... you know, people deal with sexuality in a lot of different ways. It can become quite emotive when ... [for a parent with a son, if] he's starting to have erections. ... Others just don't want to know about it. So people would find this program challenging. I would think so. So it's about getting that information out and breaking down barriers.

Denise identified that the program might raise difficulties for parents who did not want to acknowledge their child's sexuality. She suggested there was a need to provide parents with information to break down this barrier to program success. In contrast, a number of service providers appeared reluctant to participate in the Program because it would upset parents. The program team suggested that service providers' own discomfort resulted in suppression of people with intellectual disability's sexuality and heightened their awareness of potential parent discomfort. The reluctance to address the sexuality of people with intellectual disability was seen to be reflected in existing sex education programs for this group.

Education about sex

Several service providers reported that there were limited programs providing people with intellectual disability information on their sexual rights; those that existed focused on biology, rather than respectful relationships. For example, Bette, an education provider, lamented that *there's an*

enormous gap out there and the notion of sex education is so really last century. She was asked to identify what the gap was about:

The aspect of sex education that is last century I think is that you give people information about their bodies, you teach them about contraception but you don't necessarily deal at the most important element of sexuality, which is relationships, and how safe you feel in them. [That doesn't deal with] ... the joys and the dangers and the development, I suppose, of one's intuitive intelligence around those things.

Bette highlighted the importance of addressing respectful relationships and reported that such an approach was well received by people with intellectual disability, as witnessed by the small number of existing human relationships courses being fully booked well in advance. Not everyone shared Bette's insights about the need for information on respectful relationships. Poppy reported having a conversation with a school welfare officer:

She was telling me about all these terrible things ... that young women were getting into trouble around relationships. ... She is going to do a program at the school later in the year ... but it's more around ... the contraception side of things but not around the management of relationships. Yet everything she was telling me was about the issues around management of relationships (Poppy, state government disability services).

Poppy was surprised that the welfare officer did not see the need for education on relationships. She thought that existing approaches to sexuality education for people with intellectual disability were designed *like what you get in primary school* and needed to be updated.

The understandings of people with intellectual disability described in this section illustrate some of the myths regarding sexuality which can undermine a program.

Responding to people with intellectual disability: sexual assault and primary prevention

Evidence demonstrates that people with intellectual disability are more likely to experience sexual assault or abuse than the rest of the population (McCarthy, 1999; 2000). In response, there is a common perception that people with intellectual disability need to be protected. This may involve families and service providers making decisions on their behalf. Indeed, women with disabilities who experience violence find they have less information about what constitutes violence; experience high levels of social isolation and sometimes increased dependence on perpetrators; are often not believed and have greater difficulty accessing support services (Healy et al, 2008). Furthermore, because decisions are often made by their families or service providers, people with intellectual disability may lack the information or skills required to enter into respectful relationships.

This vulnerability to abuse is compounded by the reluctance of the community and service provider to address sexual assault. Some interviewees noted that the dependence of some people with intellectual disability increased their vulnerability:

They need the care and they're not in a situation to actually be independent, live independently or to make independent decisions. They ... are frightened ... if they leave... then they're not clear about what care that they'll be able to access. ... It's like ... will I choose the violent person that's there all the time ... and still looks after me and feeds me, or do I go out on my own? ... Then if you've got kids, then that partner will say she's incapable of looking after them. ... They might ... lose their children because of that as well. So ... they're vulnerable. They're vulnerable to ... the sort of gender violence that affects all women, but they're even more vulnerable because of ... the care issues (Jacki, community health).

This quote highlights the principles of the ecological model: the vulnerability of people with intellectual disability to abuse is not just a consequence of their intellectual disability but also a result of the disempowering actions of families, service providers and the community.

In Victoria, a framework to promote appropriate responses from disability services includes policy and guidelines on personal relationships, sexuality and sexual health that includes the right to enjoy relationships and sexuality without being abused or exploited (Victorian Government, Disability Services, 2006). It includes people's right to receive information and education about appropriate touch, boundaries and relationships, assertiveness skills, and how to avoid or end abusive and coercive situations or relationships. Consequently, the program utilised a primary prevention approach to understanding and addressing sexual assault within the broader context of violence and abuse. This involves understanding community contexts and the underlying causes of sexual assault to enable attitudinal and behavioural changes necessary to prevent violence. In other words, it seeks to prevent violence before it occurs and focuses on building the knowledge and skills of individuals. It also seeks to address gender inequality.

This evaluation indicates that the concept of primary prevention was challenging for some in the disability sector. One interviewee relayed a conversation with a community development worker involved in social development programs who *couldn't see how prevention of violence against women would fit into their work or was related to their work* (Angela, community health). Others thought that violence against people with intellectual disability *was hardly going to be a priority for service providers ... it's not even on their radar* (Toni, disability advocacy). In addition, Katie (community health) recalled a conversation with a senior manager who had been working in the disability sector for over 30 years who reported that *our clients don't have intimate relationships and I've never seen any sign of family violence in all the years that I've been working*.

The lack of awareness meant that it was difficult for the program to engage parts of the sector, particularly disability services, in this work. As Jacki (community health) said, *We have a lot of trouble engaging disability services; even when the departments try to engage their own service workers it still doesn't seem to work*. Another interviewee suggested that the abuse of people with intellectual disability was *in many ways ... accepted as the issues are too big to tackle* (Deborah, state government disability services). Toni (disability advocacy) noted that the program assumed and relied on *good faith and good will and service provider commitment to a human rights approach to preventing violence against women with disabilities*. However, as she pointed out:

The service providers are in many cases, actually the perpetrators ... of violence, abuse, neglect, maltreatment, all of those words ... towards women with intellectual disabilities, particularly those who live in group homes and supported accommodation. And so the other problem is when you're relying on service providers to actually get to the women, that's actually problematic because some of those providers may in fact be the perpetrators.

Toni suggested that the response from some service providers to the program was resistant or defensive: *to sweep the issue under the carpet and pretend it doesn't exist*. Others noted that this defensiveness generated numerous reasons as to why the program should not exist. For example, Chris suggested that it was not the role of disability services to address sexual assault because:

... if for instance I had been abused I would go to someone in the office and they'll take me to the place that I need to go. ... I don't necessarily think that as service providers we should be running those programs. ... We need to be accessing mainstream agencies. This makes me think that the Program needs to be sexual assault or the domestic violence unit that runs this program (Chris, disability service provider).

This quote typifies the discomfort experienced by service providers encountering sexual assault.

Service providers' discomfort responding to sexual assault

In meetings with the local planning groups and in information sessions for people with intellectual disability, the program team acknowledged that raising issues of sexual assault that may be difficult for people with intellectual disability and service providers. In anticipation of this, they provided participants with a list of counselling and support services including sexual health counsellors. Despite this, a number of service providers questioned the value of talking about sexual assault:

The stuff that it raises and what do you do with it? I think in some ways people don't feel comfortable with it. And for me, as a service provider and a manager of staff, I don't really think they have the skill to go there with clients. Part of my concern is confidentiality and I know that goes for anything, and some would love it. ... I know that I sound very negative ... but I just think sometimes it's out of people's comfort zones (Chris, disability service provider).

While Chris acknowledged her own discomfort, a number of service providers expressed concern that the Program would upset people with intellectual disability by talking about sexual assault. For example, Karen was worried about the emotional safety of workshop participants hearing peer educators stories about sexual assault. Karen felt that some of the stories were *quite graphic in the abuse that occurred* and was concerned that this might *be quite traumatic for people, bringing past or present abuse issues to the surface. We don't know the backgrounds of the participants ... so I believe we need to take care that we don't traumatise people further* (community health). Similarly, Angela reported concerns on behalf of a person with an intellectual disability from her local planning group who attended a forum:

Some quite confronting material [was] presented and I was asked to accompany the woman home ... she was actually quite distressed from the content of the forum and it was bringing back a lot of memories for her which she was talking to me about and I was quite worried about her (Angela, community health).

Angela was concerned that the program did not provide support for women to deal with issues that were raised and wondered whether there were sufficient systems in place to support them. Others like Sandra were concerned that the program was imposing the need on people with intellectual disability to talk and disclose about sexual assault:

If we're talking about trying to challenge dominant assumptions about them being inherently vulnerable, we've got to ensure that they're the person who's coming forward saying, I need help with this. ... Otherwise I wonder if we can be making it worse, as we can do for women without an intellectual disability, by insisting that they need to be counselled (Sandra, community health sector).

It is important to note that there were no program requirements that participants to talk about sexual assault or be counselled, although there was recognition amongst a small number of interviewees that people with intellectual disability had the right to recount sexual assault. For example, Raylene described how group discussion of experiences in sexual assault services would be considered:

... the voice of many. ... The group dynamics together, it's more reinforcing, especially when its group peers. ... Running sexual health support groups, people that share that common experience really can connect. I guess it just ... validates their experience, which is therapeutic in itself (Raylene, sexual assault service).

Coming from the perspective of a sexual assault service Raylene was able to identify the empowering nature of facilitated discussion about sexual assault. The value of this opportunity was also highlighted by Janet, a self advocacy representative with an intellectual disability. She observed that after a information session, some of the attendees:

... had a lot of issues to deal with ... and they went away and discussed that. I don't know very much but I think there were a lot of undealt with issues in their lives that were sort of brought back. I think that was a good thing because I think it brought out in the open for everyone to say, 'Hey, well look, I've been in this situation and I know what it's like (Janet).

Janet believed that, whilst discussing sexual assault was upsetting for some, it was a positive opportunity because the program provided a safe environment to do so. Nat (disability advocacy) thought that a supportive space was one where service providers made sure that participants were *not going home to an empty house ... that there's somebody around or checking in*. Nat described how participation:

... did bring up stuff for one client. ... She's been supported through her house and through here as well ... I think it's quite important to have focused because there might be some people that are living on their own and don't have agencies closely involved in their lives. ... She'll be in tears on and off and may not have identified ... that she's struggling or flailing at the time, she'll just break down. So issues around respectful relationships are coming up for her but she's not necessarily articulating it overtly, there's more like tears and stuff (Nat).

Some service providers' discomfort may have led to concerns that there were not sufficient supports in place to assist participants in the process of disclosing sexual assault. Karen (community health) noticed that *the more I've got involved in the program the more I've realised that they've put measures in place to make sure that people are well supported*. Others were concerned that the program was putting them, their jobs and people with intellectual disability at risk. The program team suggested that there is a risk-averse culture in the disability sector that may have contributed to a level of discomfort at the perceived risks taken when enabling people with intellectual disability to talk about sexual assault.

Acknowledging gender and power

Concerns about recognising the role of gender in the program were raised in most interviews. Some believed that service providers in the disability sector often viewed women with intellectual disabilities as genderless. For example, Angela (community health) noted how *...another disability worker ... said that she'd always focused on disability and hadn't thought about gender, that someone with disability is actually more disadvantaged because of gender*. A number of service providers were also concerned that a gender lens was missing in the program. In particular, concerns were raised about the participation of men with intellectual disabilities. About half the interviewees raised concerns that, at some sites, men and women with intellectual disabilities shared training, information sessions and participation on the local planning groups. Toni thought that this indicated a lack of gender analysis:

The project has tended to view people with disabilities as genderless, and as a homogenous group. We have had concerns that the project has viewed men and women with intellectual disabilities as having a common set of issues and that they experience disability in the same way. Given the extensive and pervasive incidence and prevalence of violence against women with disabilities, coupled with the fact that women with disabilities have fewer opportunities, lower status and less power and influence than men with disabilities, we

remain concerned at the apparent un-gendered approach of the project (Toni, disability advocacy).

Others expressed concern that male participants might take advantage of the vulnerability of women who disclosed abuse in program workshops. For example, Angela suggested that the disclosure of abuse by women in mixed groups:

... could impact on the relationships between the participants ... and if you did have a male that wanted to abuse that after the course had finished, he could actually abuse that relationship in what he had heard from a female participant. ... I am actually talking about ... that they could actually then try and start a relationship; they have sort of heard all those stories and abuse or vulnerability and play off that (Angela, community health).

She raised concerns about disclosure in the mixed groups, suggesting that the safety of women in mixed groups did not appear to be adequately considered. Angela was also concerned that women in mixed groups would not express themselves as freely and might find it difficult to hear from men disclosing abuse of female partners. In contrast, other service providers like Jenny (community health) argued that *young men with an intellectual disability, whether ... in gay or straight relationship, they have a huge need to be acknowledged too*. Another interviewee suggested that gender-segregated groups would probably work best for men because *they'd probably might just feel more comfortable with their peers in a male only group and ... actually talking about what's been happening* (Clarke, disability service provider).

Support for mixed groups was increased where mixed groups were already established. Deborah (state government disability services) suggested that mixed groups would provide *a balanced view/representation and assist women to acknowledge their role in abuse, believing the level of abuse for men was as high as it was for women*. She reported that each site needed to be given the option to decide whether or not to facilitate mixed groups and added that it was useful to involve men to hold women accountable:

I think it is positive to involve men because we have found that the women sometimes feel that it is alright to do the same things that some men do e.g. like the throwing of the ashtray, but because they are a female it is not abuse. If it is called abuse for one then it is called abuse for all (Deborah).

One interviewee with an intellectual disability attended a mixed information session with her husband. She reported that the mixed nature of the group was *really good because we're all sort of open and honest*, but was also concerned that *women are not going to be as open as much* when men were present (Janet, PWID self advocate). In addition, Raylene (sexual assault service) noted that women in their catchment wanted men involved and as a result *it's probably really positive in sending the message that ... violence against women is not okay*.

The varied and emotive perspectives on the involvement of men in the program highlight an opportunity for the Program team to clarify the role of men and the importance of clarifying what is required to address gender issues if men are involved.

The importance of information

The provision of information to enable people with intellectual disability to make informed choices was seen as a key component of achieving respectful relationships. Some service providers reported that people with intellectual disability were often not in respectful relationships because they often did not understanding the choices that they could make about relationships. Information was seen to provide support for people with intellectual disability for *managing and navigating the whole*

world of relationships (Poppy, state government disability services), to identify *what's okay, what's not okay*, [and] *how to call for help* (Katie, community health). The lack of information for PWID was viewed as potentially *debilitating* (Jolene, state government disability service). To illustrate the empowering effects of information, one interviewee recounted how a participant moved out of home after completing the program because:

... it was like that clicked for him and that he did have some choices and that it wasn't working with him living at home and that he was able to access other accommodation. ... So he seemed to make that connection between the story [told by the peer educator] and how it impacted on his life (Karen, community health).

This example highlights the empowering nature of information in achieving respectful relationships. Some interviewees noted that respectful relationships were about *giving information and allowing them to discuss things in a neutral sort of way ... and make their own choices* (Jenny, community health).

In contrast, many interviewees like Katie described how information about sexuality was often withheld from people with intellectual disability by carers who:

... take on this protective role ... and try and protect them from information around those issues, and seem to think that that's sort of part of their role is as their protector. But it actually makes them more vulnerable because at some stage they might be in a situation and have no idea how to deal with it because they haven't been provided with education and everybody else has been (Katie, community health).

Katie and others argued that information was withheld in a belief that this would protect people with intellectual disability. However, other service providers like Haille disagreed:

Once we start to talk about prevention of violence in relationships, often what we found is there will be disclosures of violence where as people ... realise in a context of being educated about better relationships, that maybe their own relationship is dangerous (Haille, community health).

Tess (state government service) also discussed how information could raise awareness for women with intellectual disabilities: *That this is not what should be expected in your life. This is not what you have to put up with, that what you do is you go and tell someone*. Other interviewees suggested that while many service providers espoused the importance of providing information to people with intellectual disability, in practice this did not occur. Jenny suggested the commitment to empowerment was 'lip service':

It's really about lip service, 'Yes you have a choice but, okay, I'm going to narrow down your choices and they're really what I want'. ... There's a lot of subtle pushing and directing as people. ... [It's health care workers or disability workers], parents and friends of [people with intellectual disabilities that do that] and I guess it's that thing of being the bystander and not wanting to see a disaster happen and, thinking you're doing the best and it's that perpetual child that people with an intellectual disability. ... They sort of live in that fishbowl world where they've got so many professionals involved with them and I guess so many people making choices for them instead of being able to have the opportunity themselves. I think it's a good thing I see it through Patsie ... seeing that it's okay for anyone to make a mistake regardless of their intellectual ability but then putting things in place to move on from that and learn from that. ... Yeah, just like, you know, everyone makes a mistake and things go wrong but it's not the end of the world (Jenny, community health).

A number of participants identified that there was a need for service provider education so that the staff understood the difference between their espoused support for the program and their actual beliefs that the program was not valid because people with intellectual disability were not 'real' people. Tess (state government service) suggested this was important so that participants who wanted to disclose sexual abuse were not made more vulnerable *if they tell someone who doesn't ... want to know*. Tess added that some service providers in disability services may not respond and recalled: *I've been guilty of this, and I'll never forgive myself. When I worked in the area of disability a very long time ago, for the first time in my life, one of the women in the house was raped. ... I didn't do much. ... I'll never forget that*. Tess reported concerns that for women with intellectual disability, it was a *double whammy* to give women the courage, skills and information to report assault and then find that service providers don't do anything about it.

This section of the evaluation findings further explored the sectors' understanding of people with intellectual disability and their subsequent responses to the program. It highlighted how people with intellectual disability are often not considered sexual and that many service providers are not comfortable addressing sexuality. The perception of vulnerability means that some service providers take action to protect clients from information about sexuality. These understandings have shaped the responses of service providers to abuse and limited the opportunities to address respectful relationships. Denise (state government service) described the essence of a respectful relationship as *treating people with intellectual disabilities as equal and ... valuing their contributions*. Many other service providers agreed that a key to respectful relationships was the provision of information that enabled people with intellectual disability to make informed choices. This is a particularly interesting finding given the previous sections that described the efforts of some service providers to subvert the Program, including withholding information about the program from the intended recipients.

Program outcomes

One of the aims of the evaluation was to investigate the outcomes of the program from the perspectives of stakeholders. In the following section we review the four program aims as a framework for reflecting on the Program outcomes.

Evaluation aim 1: investigate outcomes from the perspectives of stakeholders

The first aim was to identify the program outcomes from the perspective of key stakeholders. The perspectives of stakeholders were sought through interviews with service providers. To further enrich the understanding of program outcomes, the program team were invited to provide summaries of relevant data from their interviews with people with intellectual disability.

As described in part one of the report, the program resulted in 20 people completing the three-day peer educator training across four sites. These peer educators were supported by 20 co-facilitators to deliver the education program to 41 people with intellectual disability. A fifth site encountered a number of delays establishing the program and at the time of report writing, the site had a plan to bring in peer educators and co-facilitators from a neighbouring site to facilitate workshops. In each of the four sites that implemented the program, members of the local planning group had identified strategies to continue the program beyond the involvement of the team. These strategies include applications for government funding in two sites, the development of a TAFE module from the program in another, and working to implement the program in a neighbouring site in another. The program also resulted in the development of resources to enable its further dissemination.

In the following section the perspectives of service providers on program outcomes and indicators of program success are outlined.

The perspectives of service providers

It was expected that interviews with service providers might provide the opportunity to explore their perspectives on what the program had achieved. However, given the length of time required to establish the program in each site, most service provider interviews took place before the workshops had been facilitated. To check whether service provider's perspectives had changed after implementation, invitations for follow up interviews were made to each site. Two service providers agreed to review their initial interview transcript and reflect on changes to their experience and perspectives. However, given most interviews occurred prior to program completion, service providers were invited to describe what they thought would be indicators of program success. Several interviewees reported that having a maximum number of people with intellectual disability participating would be a measure of success. The exact measure of this was articulated by Tess:

I reckon that if we get a handful or maybe three or four women with intellectual disabilities who want to be, or are then at the point of being educated, and if that is the end of the project, I reckon that's a real achievement. ... I think that will be a fantastic outcome (Tess, state government service).

This indicator of program success identified by Tess was far exceeded, with a total of 41 people with an intellectual disability participating. Others suggested that they would measure success as people with an intellectual disability choosing to be educated and it make a difference to their lives and made their relationships. This outcome was not directly measurable as part of this evaluation.

Other perspectives on program success identified by service providers included the effect of the Program on opening up conversations about respectful relationships for people with an intellectual disability. As noted by Karen in a follow-up interview:

I think one of the outcomes of the program has [been that it has] opened the discussion about respectful relationships. That has not necessarily been achieved with this group of people before. Discussion about this has not been allowed. Allowing this conversation to happen is important for workers and for people with disability (Karen, community health).

A further outcome identified by stakeholders related to cross-sectoral collaboration. A number of service providers described the cross-sectoral collaboration required in their local planning group as a positive outcome because it provided opportunities to understand the roles of other organisations, work together, exchange views and network. Some service providers believed the cross-sectoral collaboration would make a difference to people with intellectual disability through services' capacity to work together and make referrals. However, Karen (community health) noted that, while *the consolidating of support networks, the coming together of organisations, happened towards the end of the Program. ... There is the makings of a support network to be able to roll it out, it's just a matter of whether it will happen*. Karen was also concerned about the momentum and felt that it would have been better if this support network had been achieved earlier in the program.

A dominant theme from the perspective of stakeholders related to peer education. As previously discussed, most interviewees were concerned that peer education would not be successful because people would not have the capacity to take on this role. Service providers may have been more supportive of peer education if interviews had taken place after they had seen peer education in practice. This can be extrapolated from the positive response to peer education from service providers who had already witnessed people with intellectual disability as peer educators in other contexts. Nat, reflecting on the success of the program in her site, observed that:

Peer education is a fantastic and holistic way of sharing information and I think it is really important to have the information coming from people in the same target group. Peer

education, the videos and sharing stories, are a great way of sharing or putting information across. Our group enjoyed talking about relationships and their rights. Here, there weren't so much negative experiences; it was a nice open discussion. The negative experiences - well it wasn't really negative - was one client who was a peer educator, initially her participation triggered some past traumas. Her upset was not necessarily about the course, the course was a safe environment and she could talk about her experiences and we could make sure she had adequate support. She did then decide not to continue with peer mentoring, that was where she was at the time. It was all a bit raw (Nat, disability advocacy service).

The quote highlights Nat's perspective on the outcome of the Program as providing people with intellectual disability with the opportunity to talk about their rights. It is also interesting to note that Nat's response to the emotional reaction of a participant emphasised the need to provide support. This response sits in stark contrast with feedback from other service providers who responded to such incidents by questioning the value of the Program. Perhaps because Nat had witnessed the benefits of the Program she understood the reaction in context. Indeed Nat noted that, in response to the program, her service:

... had really good responses from the clients that did the peer education. They got a lot out of it. They enjoyed talking about their rights. They particularly enjoyed the feeling that they were respected and that they were the same as everyone else and that the training was all about their day-to-day lives. The feeling that they were respected came out of the program. They were proud that people were asking about their lives (Nat, disability advocacy).

It is also interesting to note that, while the process was positive, Karen raised the issue of the program's effects on respectful relationships for people with an intellectual disability and recalled:

We had a young couple that moved in together after attending the Program but it didn't actually work out well for them. It was not a respectful relationship. One course will not change the way people respond in relationships. They have a lifetime of history that influences the people they are and how they treat another person in a relationship. Some people need long-term support and counselling to make those changes (Karen, community health).

Karen also raised the issue of whether or not people with an intellectual disability that participated in the program would be able to retain the information that they had learned. She recalled a session facilitated six months after the initial workshops that included three people who had participated in the program:

It was like doing a new program with them. Probably a few messages had been taken on board but their recollection of what went on was minimal. They were people with a greater level of intellectual disability. There are different levels of disability and how much people take on needs to be considered. This group had higher needs. There was one person that hadn't done the program before; she had difficulty understanding it. It needed to be more one-on-one for her. I think that a fundamental part of the program is how it is taken up by people with intellectual disabilities.

The issues raised by Karen and Nat highlight the opportunity to clarify what constitutes successful program outcomes. The program team responded to the point made by Karen about the complexity of change for people with an intellectual disability by noting its importance and recognising that the it had sowed the seeds for change by presenting a model and resources for change processes.

The perspectives of people with intellectual disability

The perspectives of participants were sought through interviews with 16 peer educators before and after the delivery of the education workshops. The program team invited the peer educators to describe their reasons for wanting to become a peer educator, how they saw their role, and their perspectives on the outcomes for program participants. The team were invited to provide a summary of the interview findings and some quotations to highlight commonalities and differences in perspectives on program outcomes between people with intellectual disability and service providers.

Amongst the reasons for choosing to participate as peer educators, people with intellectual disability identified that their personal experiences of relationships, including abusive relationships, gave them knowledge and skills that would be valuable to share with their peers. This finding contrasts with the perspectives of service providers who reported that people with intellectual disability could not be peer educators because they did not have skills and were not in respectful relationships. Peer educators believed that they had the capacity to perform these roles and felt that in doing so, they could assist others to gain confidence, respect, new knowledge and skills. Indeed, their perspectives on the program were overwhelmingly positive. One peer educator reflected:

I took [the other peer educator] home a couple of times and I said, wow, wasn't that awesome? You know? And it was. I reckon we sat in the car for half an hour just talking about it, you know? ... She had to turn the engine off. It was so funny. It was so funny. We were like sitting there nattering away and I said I was going and twenty minutes later we're still sitting there. ... It was awesome (PJH).

A number of other differences between the perspectives of peer educators and service providers demonstrated support for an ecological model, and an understanding of the links between vulnerability and abuse of people with intellectual disability with the disempowering actions of families, service providers and the community.

Power imbalances

The ecological model recognises that human interaction can become abusive when one person has more power than the other. This power imbalance was identified by people with intellectual disability who reflected on a story about Hannah, a woman with intellectual disability who put a sign on her door asking service providers for privacy to be with her partner Kevin. Service providers removed the sign. A peer educator noted that:

They ripped it down on them. Like these [PWID] are grown adults, consenting adults. They don't need to be treated like they're children. And yeah, that really got on my nerves. I had to go home and cool down after hearing that. Yeah, I was quite grrr (PJS).

This peer educator's response to the power imbalance is particularly interesting given feedback from service providers that people with intellectual disability do not have the cognitive ability to be peer educators. Indeed the quote indicates that this peer educator has the capacity to reflect on power imbalances between service providers and people with intellectual disability and how this resulted in a violation of rights. The interviewee implied the responses of service providers to sexuality places people with intellectual disability at risk of abuse.

People need to just grow up and leave, you know, leave these people [with intellectual disabilities] alone in some way. Like leave – I mean like leave, leave Hannah alone. Leave her life like a grown adult like she is. And like her and Kevin have a beautiful, loving relationship. They're a beautiful, loving couple and they really deserve a life together. Um, and I really do feel sympathy because they're not...they haven't got their freedom. They, they can't express

themselves the way they want. As it is they have to sneak out and um have sex elsewhere, and that's wrong. If they get caught having sex in public then ahhh how's that gonna look? Not to mention the place probably isn't clean where they're going. There, there's a lot of different factors (PJS, peer educator).

Some service providers felt that people with intellectual disability would not be effective peer educators because they would not be able to reflect on their lives and therefore suggested that the Program would not be successful. In contrast, interviews with peer educators provide evidence of people with intellectual disability reflecting on their own lives and the responses of services providers. Perhaps then a successful outcome from the Program could be having demonstrated the capacity of people with intellectual disability to be peer educators.

The right to talk about sexual assault

Another difference between the perspectives of service providers and people with intellectual disability on positive program outcomes related to providing participants with the opportunity to talk about sexual assault. As previously described, some service providers recalled people with intellectual disability become emotionally upset when recalling experiences of sexual assault. In contrast, interviews with peer educators acknowledged the emotional difficulties experienced by people with intellectual disability. They felt that, rather than shy away from this, it was important to support their peers to recount experiences of sexual assault. Their own experiences of sexual assault meant they were well placed to provide such support. As one peer educator said, *Yes it brings bad back, bad, brings back bad memories but, um, if you sort of, if you've gone through it and you know what it's like, you can help them* (PJS). When asked if they were going to be a good peer educator, one interviewee reported that they would be and suggested that this would be because *certain bits in my story could help them. They might, they might think it - they're like what I've been through* (P). The program supported the right of people with intellectual disability to talk about sexual assault and enabled the reflections by peer educators on their own relationships to assist other people with intellectual disability.

Primary prevention led by PWID

Feedback from peer educators indicates that the peer education concept was valued by other people with an intellectual disability. The importance of being able to relate to others was highlighted by one interviewee who noted that in one service, *I have trouble dealing with [names a staff member] because she doesn't have a disability and I feel uncomfortable. I'd prefer to talk to [the self advocate] because I know she's got a disability and I know she knows where I'm coming from*. In relation to the program, this peer educator reflected:

You, you get so much out of it. It's so worth it. Especially people with disabilities. There's no better way to get a message across from someone that you can relate to. And that's just putting it blunt. If you can relate to someone, you're gonna listen to them (PJS, peer educator).

Another participant noted that the value of peer educators was that their approach. It was very different to the common directive style used by non-disabled people when telling people with intellectual disability how to live. This participant requested that the program continue:

Seriously. Keep it going. And keep, keep it going with people with disabilities. Don't make it like lecturers going, this is how it goes, yep. I think personally its better with people with disabilities. As I said, you can reflect. So you're going to listen, you're going to be interested because, hey! They're just like me. And I think that's a big draw card is: 'Hey look; if they can do it, I can do it too' (PJS, peer educator).

This departure from a lecturing approach to the program approach of peer-led information and support was information, and supported, by peers was a further important outcome for the program.

Evaluation aim 2: develop a feedback loop

Consistent with the program's action research framework, the second aim was to develop a feedback loop between the evaluation findings and the program team to identify ongoing opportunities for improvement. This was achieved through evaluation workshops with the team, reviewing de-identified interview data with the program manager, and by placing de-identified evaluation documents onto a shared computer drive. The evaluation process, as whole, highlighted opportunities to strengthen the program.

Evaluation aim 3: understand processes for sustainability

The third aim involved understanding the processes employed in the establishment and delivery phases of the program, and the ways in which these contribute to its sustainability. In the following section, reflections on sustaining the program through ongoing funding, providing ongoing support, mentoring and sector development are outlined.

Identifying sources of ongoing funding

A number of sites identified that there was a need for funding for the program to continue. This proved a challenge because others did not think that the program was core business and so required additional funding. Indeed, in two sites funding was sought to employ project coordinators to keep the program going. Toni (disability advocacy) noted *there has been virtually no projects or programs funded in Australia that look at the issue of violence against women with disabilities. So the fact that this project has been funded and is happening at all is a really good thing. We just need a lot more of them.* Others noted that there was a need for funding for the program to continue and that while they were *trying hard to get the program to continue...it's been quite difficult to find funding for it* (Nat, disability advocacy). Funding was being sought for project staff, including people with intellectual disability, to help coordinate the program locally as well as for service development.

Service development: ongoing support and mentoring

One of the factors that seemed to be important to sustainability was a more nuanced development of the sectors, particularly the disability sector. Without this there were some concerns about program success, as Toni noted:

The lack of a human rights approach within the disability service sector is particularly problematic for a project like this. That, coupled with the lack of knowledge and understanding about the issue of violence against women with disabilities, makes a project like this really difficult to not only implement, but also to sustain once the project funding ceases. We're talking here about a project that is concerned with preventing violence against women with intellectual disabilities, and yet, we still have a sector, and indeed a society, that sees nothing wrong with issues such as sterilisation and menstrual suppression of women and girls with intellectual disabilities (Toni, disability advocacy).

Toni suggested that the program would have been so much stronger in a way if it had factored in the level of ignorance of the issue itself, along with the apathetic attitudes held by some people. She went on to suggest that it would be useful to have a person employed in each site for service development, to challenge some of these entrenched attitudes, and to work on ways to sustain the project once the funding ceased.

Others noted that in order for the program to be sustained, there was also a need to build the skills and confidence of those who were supporters. This point was articulated by Jenny who recognised the value of having the program manager provide mentoring for others to build confidence:

The [program manager] has obviously got to move on with her life after the project too but whether it could be ... that she mentors the mentor. ... She can't be there for every young facilitator but I wonder if there's that opportunity for ... everyone involved if they could go back and touch base with her and clarify things with her. ... I think even just having, even if you don't necessarily ring her up ..., just knowing that she's there can sometimes empower. [She could be] the mentor to empower everyone else down the chain if that makes sense (Jenny, community health).

The feedback reflects a point made earlier about the capacity of the program manager to inspire others by modelling approaches to partnerships of equality with people with intellectual disability. This was a source of concern for Karen (community health): she described how she co-facilitated a group discussion with peer educators and was unsure how to respond when participants directed questions to her, rather than the peer educators. Karen reflected: *perhaps it is something about my level of confidence, but trying to redirect to peer educators can be challenging. [the program manager] does that well but I found it difficult* (community health). Karen felt disappointed that:

... there has been limited time with the [program] team. It would have been good to have the opportunity to present the program again to consolidate skills and confidence in delivering the Program. We have plans to deliver the program again but it would have been good to do it one or two more times with the team, when they were around (Karen, community health).

Comments about the program's sustainability highlight the opportunity to provide support to consolidate the skills and confidence of co-facilitators. They also highlight the opportunity to provide education to challenge entrenched attitudes and values in the disability and community sectors that are unhelpful to people with intellectual disability.

Evaluation aim 4: understanding the adaptation of the ecological model

The final aim of the evaluation was to assess the adaptation of an ecological model to the new context. The ecological model underpinning this program recognises that the vulnerability of people with intellectual disability to abuse is a result of the effects of intellectual disability and the disempowering actions of families, care services and the community. The program addressed the primary prevention of violence in a way that recognised a connection between the way that society understands and responds to people with intellectual disability and their risk of sexual violence. People with intellectual disability led the program in recognition of the fact that human interaction can become abusive for them in situations where others have more power. Consequently, people with intellectual disability were employed as project workers and peer educators to provide participants with information about their sexuality and relationships in order to address vulnerability to abuse. The implementation of these innovative program principles represents both the program's achievements and successes and its greatest challenges.

The success of primary prevention led by people with intellectual disability

By placing people with intellectual disability at the centre of program activities, the program sought to enable and empower people with intellectual disability to protect themselves from abuse. As such the program team have been successful in demonstrating that people with intellectual disability are capable of learning, teaching and supporting each other. This strategy was a further development on *Living Safer Sexual Lives* project, which focussed on training service providers to be educators.

It may be difficult to measure the outcomes of peer education in the lives of individual people with intellectual disability who participated. However, an indicator of success may be the process itself. In particular, the achievements of the program team in challenging negative perceptions of people with intellectual disability and presenting them in leadership positions is significant. The documentation of resistance to this process provided a valuable opportunity for further education.

This report has sought to address the phenomenon of gate-keeping, or practices that restrict the opportunities for people with intellectual disability to participate and control their own lives. The program team acknowledged that self-advocacy groups have done much over the past three decades to raise awareness about the rights of people with intellectual disability to have their rights recognised and to determine the directions of their lives. However, the LSSL:RR program has demonstrated that there is still much to do to ensure these messages are heard and responded to. The 20 people with intellectual disability who became peer educators and took a lead role in this primary prevention program are a testament to the potential and strength of this movement and to the will and capacity of people with intellectual disability to participate. The principle of participation by people with intellectual disability needs to be embedded in disability and community services. It is hoped that the peer leadership demonstrated in this project might assist other services to recognise that primary prevention education is core business, and that people with intellectual disability have the right and capacity to take a lead role in such initiatives.

Gate-keeping: implications for service development

The documentation of gate-keeping behaviours is an important evaluation outcome. The program challenged the status quo in some parts of the sector where power is held/withheld by service providers. The problematic nature of gate-keeping is highlighted in an ecological model: it was apparent that gate-keepers use their power to make decisions about whether or not to provide their clients with opportunities to participate in the program.

The program team believed that the model challenged attitudes and values about intellectual disability, sexuality, relationships and rights, and raised questions about power and control over information. They understood the central role of people with intellectual disability to be a challenge to the existing power of service providers. Many service providers were aware of this challenge. For some, it led to anxiety and attempts to subvert the program, or attitudes that were sceptical of people with intellectual disabilities' capacity to be peer educators. In some instances, this might have been a reflection on the timing of service provider interviews, with most taking place during the establishment phase. Some service providers may have been more supportive after peer education processes had been implemented.

The identification of gate-keeping strategies highlights a challenge in sustaining and further disseminating similar programs. It may be helpful if such programs provide further opportunities for service provider development alongside peer education so that service providers can reflect on their own values and beliefs, and become more supportive of participation by people with intellectual disability in empowerment strategies.

The evaluation findings indicate that the disability sector in particular must develop and embed new ideas about the role that people with intellectual disability can have in addressing violence and abuse prevention. In particular, there needs to be a shift in ideology to enable them to support each other to learn about, and be supported to have, respectful relationships. The shift in ideology also needs to occur so that people with intellectual disability have the same rights as others to information to raise their awareness of, and skills and knowledge in negotiating, and having, respectful relationships. While the LSSL:RR program has begun this process, future programs may benefit from complementing peer-led primary prevention education programs with education for service providers. Such education could provide feedback on the effects of gate-keeping and invite

service providers to reflect on issues of power and control in the lives of people with intellectual disability as well as address the primary prevention of abuse of people with intellectual disability as core business.

Part Three: Discussion and conclusions

One of the emerging and significant findings described in this report was the strong, and in some cases enduring view, held primarily by some in the disability sector, that people with an intellectual disability could not be peer educators. There was also the view that the program model did not adequately resource local groups to further develop and run the program in their areas. In questioning the capacity of people with an intellectual disability to be peer educators, service providers believed that these people would be traumatised by remembering past experiences, not be able to respond to difficult questions, and further, that people with an intellectual disability do not want to talk about sex. In addition, service providers questioned the capacity of the sector to accommodate the program because it added to their workload, was not core business, was not something they were funded to do, and because they could not justify the time required to participate.

The evaluation findings indicate that the disability sector should develop and embed new ideas about the roles that people with an intellectual disability can play in addressing violence and abuse prevention. As noted above this requires a shift in ideology about the place of people with an intellectual disability in abuse prevention approaches and use of collaborative approaches to advocating for the rights of people with an intellectual disability to have lives free of violence and abuse. This program sought to address this by working with local groups, across sectors, and by having people with an intellectual disability at the centre of this work. This approach assumed a number of shared principles with those who supported the program by participating. However, the evaluation findings have indicated that some of these key principles were not always shared, and at times were strongly questioned. That people with an intellectual disability can occupy roles other than vulnerable victim, that they can have the capacity to work alongside each other to create personal and social change, and that supporting this was a role of funded disability and community services, were all points of contention.

At the completion of the two year program, however, three out of the five sites had completed the first round of training and are now working together in their local networks of peer educators and co-facilitators planning and running groups for people with an intellectual disability. Most are applying for ongoing funding to do this and some have negotiated to have their work in the LSSL:RR program acknowledged in their work plans. In these sites it has brought staff from the government and non-government disability sectors, sexual assault services, domestic and family violence services and the TAFE sector together with people with an intellectual disability. They have formed these partnerships to learn about, and in turn facilitate, a program that can potentially reach many people with an intellectual disability in the community and raise their awareness of, and skills and knowledge in, negotiating and having respectful relationships. The evaluation report will be an important addition to the body of knowledge and evidence base about primary prevention of violence and abuse in the lives of people with an intellectual disability.

Discussion

The LSSL:RR program is an innovative model. It is based on research that recommends a comprehensive, multi-layered approach using an ecological model to understand and respond to violence and abuse in the lives of people with an intellectual disability. It also reflects a rights-based

approach to disability and an understanding of the experience of disability as an interactional, rather than a medical or purely social, phenomenon. Together, these understandings have informed the program model, in particular the direct engagement of people with an intellectual disability as peer educators and the overall approach of collaboration. The program challenges ideas about intellectual disability, sexuality and relationships education, and violence and abuse prevention science as it applies to people with an intellectual disability. It also raises and seeks to address issues about inclusion of people with an intellectual disability in broader society, and social issues like violence and abuse, and the community's responses and capacity to address these issues.

The core, non-negotiable component of this program was the peer education role for people with intellectual disability. Much has been said in this report about the limiting views and attitudes that led to gate-keeping and restricting of opportunities for people with intellectual disability to participate. Self advocacy has done much over the past three decades to raise awareness about the rights of people with intellectual disability to participate, to have their rights recognised and to determine for themselves their lives. However, this program has indicated that there is still much to do to ensure these messages are heard and responded to. Those twenty people who managed to participate and become trained as peer educators are a testament to the strength of this movement and to their own will to participate. The twenty co-facilitators who were trained, and the smaller number who are now directly supporting people to work in this program, reflect the principles and attitudes that need to be embedded in both disability and community services. Addressing the violence and abuse of people with an intellectual disability has become their core business.

Limitations

As noted, this program was innovative, but it was also challenging on a range of levels. There is a history in the disability sector of not addressing violence and abuse, and a history in the community sector of not engaging with this population. There is also a history of these two sectors not working together. It also challenged attitudes and values about intellectual disability, sexuality, relationships and rights, and raised questions about power and control over information, resources and opportunities and how they are used when working on issues relating to the lives of people with an intellectual disability. Over the course of the program the team have talked about challenging the existing power relationship between service providers and people with intellectual disability by: shifting concepts such as who can be an educator; who can make decisions about who and how people participate, and who has the power, knowledge, skills and ability to create change in the lives of people with intellectual disability.

Systemic, cultural and attitudinal change takes time. One major limitation in this program was time and the resources to develop, implement, review and support the sustainability of the LSSL:RR program and the change that has stemmed from it. Other limitations were the capacity of the sectors to engage with the program productively and capacity of the program team to meet the community development needs of the range of stakeholders in five sites across two states. The strongly held ideas that were challenged by the program led, in some instances, to the significant difficulties in engaging service providers. Underpinning this was a strong sense that by participating in the program, organisations and individuals were putting themselves, their jobs, their 'clients' at risk. This risk-averse culture is strong, in particular in the disability sector. Often, if there is not a

policy or a guideline to prompt the sector to action or change, little will change. The LSSL:RR program was attempting to operate within this risk-averse culture.

Part Four: Appendix – program outputs

Site	Planning	Implementation	Output
Geelong, Victoria	<ul style="list-style-type: none"> Local planning group established 2009 (DHS Disability Services, non government disability day services, Centre Against Sexual Assault, family violence). Planning group coordinated by DHS health promotion worker and meetings held over a 12-month period. 	<ul style="list-style-type: none"> Information sessions held at two disability organisations. Peer educator (2) and co-facilitators (4) trained in 2010. Pilot program ran with 15 participants at a non-government disability service. Further planning led to second round of training: peer educators (2), co-facilitators (5). 	<ul style="list-style-type: none"> A group of 3 peer educators and 6 co-facilitators meeting regularly to plan program to be held in term four 2011 at an adult disability service women's group. Co-facilitators from government disability service, non-government disability day services, youth sexual health and the Centre Against Sexual Assault also seeking additional funding to employ peer educators and resource program implementation.
Gippsland, Victoria	<ul style="list-style-type: none"> Local planning group established 2009 (DHS Disability Services, Centre Against Sexual Assault, local government, self advocacy). Planning held mainly with self advocates who then engaged other supporters. 	<ul style="list-style-type: none"> Information session ran in two localities for people with an intellectual disability. Peer educators (7) and co-facilitators (5) trained in 2010. Pairs of peer educators and co-facilitators presented information to three groups of disability staff and a TAFE. No program conducted at time of writing. 	<ul style="list-style-type: none"> Peer educators and co-facilitators meeting in two localities. One group have recruited 6 people with an intellectual disability to participate in a program in September 2011. The CASA has committed ongoing resources to enable a counsellor/co-facilitator to work with the local group. DHS Disability Services have supported a worker to undertake program co-ordination as part of her role. The self advocacy group has the Program on their yearly calendar of activities to undertake in the region.

Northern metropolitan Melbourne, Victoria	<ul style="list-style-type: none"> Local planning group established 2009 (TAFE, women's health service, family welfare, CASA). Planning meetings held over a 6-month period. Focus shifted from broad group to a more focused planning group with the TAFE coordinating and leading the Program planning. 	<ul style="list-style-type: none"> One peer educator recruited through TAFE (past student). Peer educators (1) and co-facilitators (3) training held at TAFE. Program delivered with students from the Transition Education program (15). 	<ul style="list-style-type: none"> TAFE have commitment to running the Program through their Work Education Unit in 2012 and to advocate for this approach to be used in the national curriculum.
Burnie, Tasmania	<ul style="list-style-type: none"> Local planning group established 2009 (Department of Health and Human Services, self advocacy, family violence, non-government disability services). Planning meetings and information sessions held over a 6-month period. 	<ul style="list-style-type: none"> Peer educators recruited through a support group for mothers with an intellectual disability. Information session held for this group. Peer educators (9) and co-facilitators (7) trained. Program ran at TAFE May 2011 with 11 participants with an intellectual disability. 	<ul style="list-style-type: none"> Local group of peer educators and co-facilitators supported by the self advocacy manager meeting regularly to practice the Program. Peer educators presented at a community development conference in 2011 with the LIVING SAFER SEXUAL LIVES: RESPECTFUL RELATIONSHIPS program team. Plan to run the Program again in 2011 and offer it in 2012 in the community. Plans for this group to run an information session in Hobart and support the development of the Program there.
Hobart, Tasmania	<ul style="list-style-type: none"> Local planning group established 2009 (Department of Health and Human Services, non-government disability services, women's health, family violence, family planning, self advocacy). Meetings held over 6 months. Ongoing email and telephone contact with core group members in 2010 and 2011. 	<ul style="list-style-type: none"> In March 2010 the first pilot session for the Program was held in Hobart. 5 women with an intellectual disability attended a 2-day camp with members of the planning group. These 2 days were used to pilot ideas for the Program and for developing the train-the-trainer program. 	<ul style="list-style-type: none"> the Program did not get established in Hobart. Regular contact with the planning group failed to lead to any commitment to implementing the Program. A key issue raised was lack of resources and difficulty with the Program model. The Hobart-based self advocacy program is liaising with the Burnie-based program to hold an information session in Hobart in 2011.

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