

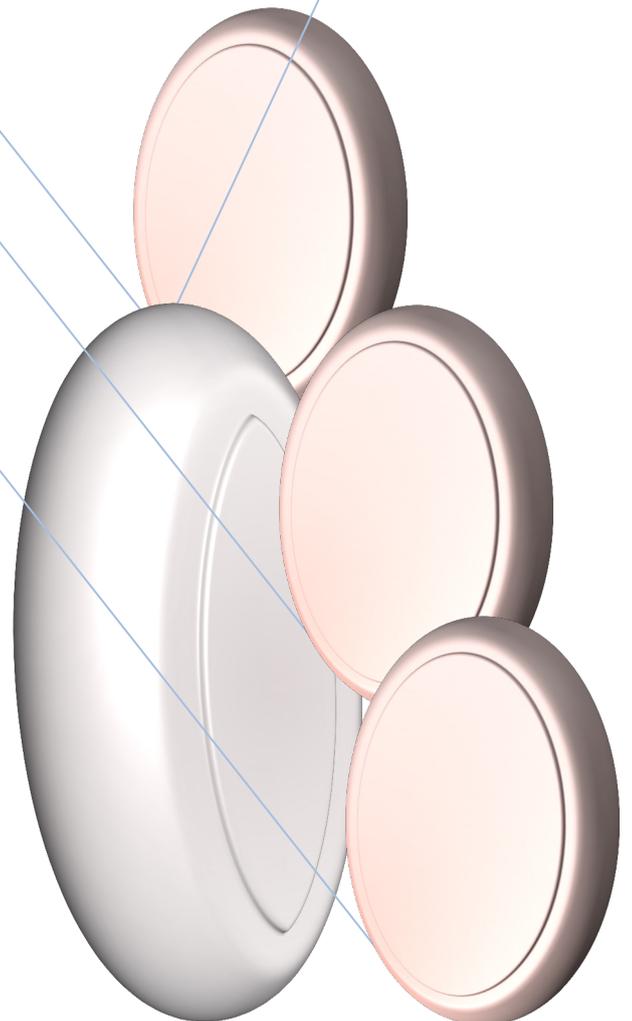


LA TROBE
UNIVERSITY

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**Adopting mainstream
approaches: Taking
account of and including
people with an intellectual
disability in violence and
abuse prevention
(VicHealth Innovation
Research Grant)**



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**Living Safer Sexual Lives: Respectful Relationships*

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Executive summary

The social exclusion of people with disabilities has a significant negative impact on their health and wellbeing. The health inequities they experience are defined by the World Health Organization as; "...differences in health status between population groups that are socially produced, systematic in their distribution across the population, avoidable and unfair" (WHO, 2014). These impacts are compounded by the high incidence of violence and abuse experienced by all people with disabilities, but in particular by women. It is also reported that people with a disability have a 50% higher chance of experiencing violence and abuse (Hughes, et al, 2012).

Research has found that the poor health outcomes experienced by people with disabilities are 'socially determined' rather than the effect of characteristics of particular impairments (Emerson et al., 2011). People with disabilities are often poorer, have less access to education, health and welfare services, poor quality and insecure housing and lower levels of employment than the general population. Like others in society who experience health inequities, the health and wellbeing of people with a disability, including issues relating to violence and abuse, is a public health and human rights issue (Mikton & Shakespeare, 2014a, p.1). The continuing exclusion of people with disabilities from public health policy and generic health promotion limits the impact of generic preventative health strategies, including violence and abuse prevention, and has led to an absence of preventative health and violence and abuse prevention policy and strategies within disability policy.

Aims and Method

This research aimed to develop an understanding about how people with an intellectual disability could be taken account of and included in mainstream violence and abuse prevention utilising a targeted cross sector abuse prevention model for people with an intellectual disability; Living Safer Sexual Lives: Respectful Relationships (Frawley, Slattery, Stokoe, Houghton, O'Shea, 2011).

Partnerships were developed between mainstream and disability service providers in three sites to look at the ways people with an intellectual disability could be included in violence and abuse prevention. Action research was undertaken to explore ways in which mainstream primary prevention programs include or exclude people with intellectual disabilities, the obstacles to access for these programs and the ways in which the voices and experiences of people with intellectual disabilities might be included in developing more effective, accessible prevention programs.

Interviews and surveys were undertaken with service providers and individual professionals from local government, disability service providers and mainstream violence and abuse support services as well as focus groups with people with intellectual disabilities to gain their perspective on services in their local areas.

Qualitative data was analysed using NVIVO to draw out key themes. Quantitative data gathered through use of the survey instrument was analysed using SPSS software.

Findings

The research identifies five key components necessary for the inclusion of people with intellectual disability in programs and services which focus on the primary prevention of violence and abuse. These were:

- (1) a recognition of the need to include people with an intellectual disability
- (2) the importance of cross-sector partnerships
- (3) linking targeted programs to the mainstream
- (4) a strong foundation, and
- (5) a recognition of what has worked well in the past and the importance of having individuals within services who will 'champion' such programs and drive and support their delivery.

The research also found that the Living Safer Sexual Lives respectful Relationships program had had significant positive impacts on tackling the issue of the exclusion of the experiences and voices of people with intellectual disabilities in violence and abuse prevention programs and services.

Conclusion

Support to access services, relevant information to gain access to education and employment, and to develop connections and relationships, are central to addressing the poor health status and social exclusion experienced by people with intellectual disabilities. By bringing people with an intellectual disability into the violence and abuse prevention space, this research has sought to identify what works to raise awareness of their specific needs and include them as expert voices in creating targeted and effective programs and services which have a positive impact on the status of the health and wellbeing. Emerging from the research are recommendations that further work is undertaken to develop cross sector partnerships in violence and abuse prevention and to further support the delivery of the Living Safer Sexual Lives Respectful Relationships program.

Background

Social exclusion and health and wellbeing inequity

Life experiences of people with disabilities and research illustrate that people with disabilities in Australia and internationally face social exclusion and experience health inequities as a result of this exclusion. The World Health Organization defines health inequities as, "...differences in health status between population groups that are socially produced, systematic in their distribution across the population, avoidable and unfair" (WHO, 2014). The health status of people with disabilities is reported as being poorer than the general population with higher incidence of diabetes, mental health and obesity (VicHealth, 2012, 2014; WHO & Bank, 2011). It is also reported that people with a disability have a 50% higher chance of experiencing violence and abuse (Hughes, et al, 2012). Women with a disability are at particular risk due to gender and disability based discrimination and their health and wellbeing and social participation is significantly impacted by this (Dowse, Soldatic, Didi, Frohmader, & van Toorn, 2013; Healy, Howe, Humphreys, Jennings, & Julian, 2008; Mikton & Shakespeare, 2014a; Sobsey, 1994; Sullivan & Knutson, 2000).

The health inequities of people with a disability have been found to be 'socially determined' rather than the effect of characteristics of particular impairments (Emerson et al., 2011) with people with disabilities being poorer, having less access to education, health and welfare services, poor quality and insecure housing and lower levels of employment than the general population; these inequities are particularly prevalent for women with disabilities (ABS, 2012; Productivity Commission, 2011; WHO & World Bank, 2011). Like others in society who experience health inequities, the health and wellbeing of people with a disability, including issues relating to violence and abuse, is a public health and human rights issue (Mikton & Shakespeare, 2014a, p.1). Victoria's health promotion organisation notes however that "...people with a disability have generally not been prioritised in the same way as other population groups experiencing [health] inequity" (VicHealth, 2014 p.5). Their exclusion from public health policy and generic health promotion limits the impact of generic preventative health strategies, including violence and abuse prevention and there is an absence of preventative health and violence and abuse prevention policy and strategies within disability policy.

The health status of people with disabilities is reported as being poorer than the general population with higher incidence of diabetes, mental health and obesity (VicHealth, 2012, 2014; WHO & Bank, 2011). It is also reported that people with a disability have a 50% higher chance of experiencing violence and abuse (Hughes, et al, 2012).

The social exclusion and socially determined health and wellbeing inequities of all people with a disability is a significant issue for mainstream and disability services in Australia and internationally. People with disabilities make up around 15% of the world's population (WHO & World Bank, 2011) and are currently experiencing significant marginalisation despite progressive, rights based and inclusive policy. It has been argued though that people with an intellectual disability are significantly more marginalised and experience more social isolation than people with other experiences of disability. This increased marginalisation is due primarily to values and attitudes about intellectual

disability formed and embedded in historical and current policy and practice that segregates them decreasing their 'presence at street level' from society and that 'misunderstands and misrepresents' them as incapable of active and engaged inclusion, leading to problems of fear and prejudice (Hall & Kearns, 2001 p. 241). In Australia, people with an intellectual disability make up at least 3% of the population and are reported as being the highest users of disability funded services (AIHW, 2008). Australian data on intellectual disability reports that 62% of people with an intellectual disability "always or sometimes need help with mobility, self-care or communication" (ABS, 2012) making their experience of disability one that is significantly impacted by the level and quality of support they have in all areas of life. In comparison to the general population they are reported to have higher risk of obesity, heart disease, depression and lower levels of screening for cervical and breast cancers (DHS, 2011; VicHealth, 2012). They also have a lower life expectancy than the general population (Bittles et al., 2002; DHS, 2011) and higher incidence of violence and abuse, in particular sexual abuse than the general population and people with other experiences of disability (Horner-Johnson & Drum, 2006). Using the WHO definition of health inequity it is clear that people with an intellectual disability do have poorer health status than other population groups in Australia and in comparison to people with other experiences of disability. Eric Emerson suggests that without "...explicitly addressing the health inequality of people with an intellectual disability they will fail to benefit from generic policies" (Emerson et al., 2011).

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Support to access services and information, to gain access to education and employment and to develop connections and relationships are central to addressing the health status and social exclusion experienced by people with an intellectual disability. Emerson et al, (2011) note though that the social barriers that impact on health and wellbeing outcomes for people with an intellectual disability also need to be the focus of policy, research and advocacy. It is argued that their social exclusion and the socially determined inequities they experience need to be addressed through universal and targeted approaches. A first step towards this is to make people with an intellectual disability and their experiences visible where they have previously been absent politically and socially (Hall & Kearns, 2001). This includes the area of public health, preventative health, health promotion and violence and abuse prevention where they are not currently included or taken account of.

Social inclusion: becoming visible

Social inclusion of people with an intellectual disability has been the focus of policy, practice and research in most Western societies since the devolution of the institutional model of care (Johnson, Traustadottir, Bigby, & Kristiansen, 2005). The principle or principles of normalisation (Baldwin, 1985) dominated the early years of deinstitutionalisation and the policy and practice that accompanied it (Johnson et al , 2005) advocating for people with an intellectual disability to have full human rights, 'valued roles' in places and spaces occupied by people without disabilities and to lead a 'normal life'(Nirje, 1985; Wolfensberger, 1972). Normalisation as formed by Scandanavian theorists Nirje (1985) and Bank- Mikkelson (1980) had a strong focus on equality and rights,

however the North American approach formulated by Wolfensberger (1972) has been criticised for its focus on changing the person with an intellectual disability to 'fit in', or its use of deviancy theory rather than rights (Culham & Nind, 2003). Some research suggests that despite the aspirations of inclusion and equality embedded in normalisation and rights based approaches the experience of people with an intellectual disability is they live their lives in "small action spaces...and on the outer fringes of the daily round [of community]", where they have at best had "limited spatial presence" (Laws & Radford, 1998). Others note this has led to people being "known well by no one" (Bigby, 2008) and becoming "the ultimate other[s]" of society because of "...a presumed inability to reason, exert agency and so be part of a modernist society (Parr & Butler, 1999). This 'othering' it is suggested is due to deeply held beliefs about intellectual impairment and capacity and the impediment of intellectual impairment to full citizenship whereby the perceived incapacity that is associated with intellectual disability frames people with an intellectual disability as 'not like us' (Bigby et al, 2012; Johnson, et al, 2004; Stainton, 2001). Goodley & Runswick-Cole (2014) suggest that the disability that stems from these views does not only lead to social exclusion but could also be seen as the basis for violence against people with an intellectual disability including hate crimes (p.2) and other experiences of discrimination.

Hall & Kearns (2001) who looked at social geographies of inclusion of people with an intellectual disability suggest "...the preparedness of a community to accept, as well as affirmatively respond to their [people with an intellectual disability] presence may be [a] more potent determinant of inclusion" (Hall & Kearns, 2001, p. 242). Other research agrees arguing that people with an intellectual disability need to be 'seen', (Milner & Mirfin-Veitch, 2012) and be visible where they are and for who they are, or "under their own terms" (Hall, 2004, p. 304). This understanding of inclusion is clearly outlined in the New Zealand research by Milner & Mirfin-Veitch (2012) and strongly reflected in the title of this work "I am here".

Self-advocacy through the self-advocacy movement of people with an intellectual disability has been an important way for people with an intellectual disability to be seen and to have their voices heard, particularly on issues relating to community living and deinstitutionalisation (Frawley, et al, 2012; Frawley, et al, 2013). In Australia however there has been limited success creating a place for people with an intellectual disability 'at the table' of public policy. Efforts continue to be experienced by people with an intellectual disability as tokenistic and result in people with an intellectual disability not being 'seen' in both generic and disability policy (Frawley, 2008; Frawley & Bigby, 2011). More needs to be done to make people with an intellectual disability and their experiences visible and to advocate for them and their experiences to belong in public policy. As Hall & Kearns (2001) suggest though this may need an affirmative response to overcome the particular experiences of oppression, marginalisation and exclusion experienced by people with an intellectual disability in comparison to the general population and in some areas like sexual abuse, in comparison to people with other experiences of disability. Rights based policy, while building the foundation for inclusiveness has not achieved it. Inclusion it is argued is a "...journey or process of continual societal adjustment" that requires the

"...the preparedness of a community to accept, as well as affirmatively respond to their [people with an intellectual disability] presence may be the more potent determinant of inclusion" (Hall & Kearns, 2001, p. 242).

'differences' experienced by and of people to be made visible (Culham & Nind, 2003 p. 66). Ballard (1995) argues then that "...for inclusion, difference is ordinary".

French (2009) suggests the need for a substantive equality framework to be applied to rights to enable inclusion and full expression of equal rights. This he argues requires both targeted approaches and an equal voice and presence in generic or universal approaches to combating discrimination and exclusion. The United Nations Convention on the Rights of People with Disabilities (UN, 2008) aims for this by advocating for 'everyday citizenship' (Duffy & Perez, 2014) where this means creating equality by recognising and responding to diversity. It aims to do this by aligning the rights of people with a disability with those of the community and by establishing new collective rights that specifically highlight the inequities and social vulnerability experienced by people with disabilities because of their experience of disability. These include the community inclusion right expressed in Article 19 and the right to freedom from violence, exploitation and abuse in Article 16. They highlight that without particular attention to the experiences of people with disabilities, and in relation to community inclusion and violence and abuse, particularly people with an intellectual disability the global rights to inclusion and safety will not be achieved. These articles make it clear there are differences in the life experiences and experiences of disability for people with a disability and these need to be seen and taken account of to gain full expression to their human rights and full social inclusion.

Violence, abuse and intellectual disability

One area where the experiences of people with intellectual disability differ markedly from the general population and from people with other experiences of disability is the incidence and prevalence of abuse. Research suggests that people with disabilities have a 50% higher chance of experiencing violence and abuse (Hughes et al, 2012) and 90% of people with an intellectual disability will experience sexual abuse (Frohman, 2002). As with other groups who experience violence and abuse at high rates, in particular women, it is understood that the reasons for violence and abuse in the lives of people and particularly women with intellectual disabilities are intersectional and systemic and that gender and disability based imbalances of power and control are at the heart of the problem (Brownbridge, 2006; Sobsey, 1994; WDV, 2014). Despite the remarkable statistics and the socio-ecological understanding and framing of abuse of people and in particular women with disabilities that is emerging through research and advocacy, very little has been done in mainstream violence and abuse prevention research or practice to consider how to address or prevent such abuse. Less still has been addressed through disability research and practice and even less from a cross sector or intersectional perspective that brings the disability, abuse prevention, women's sectors together around prevention of violence and abuse of people with an intellectual disability (Mikton & Shakespeare, 2014b).

Prevention of violence has become a public health priority for government and a focus for communities through policies and funding programs internationally and nationally led by the World Health Organization through the 'World report on violence and health' (Krug et al, 2002). Meanwhile, the disability sector has begun to question how best to safeguard people with an intellectual disability, in particular within disability services as a result of increased public awareness of violence and abuse in these settings (Coulson-Barr, 2012) and in preparation for the full implementation of the National Disability Insurance scheme (NDIS, 2014). However the strategies and approaches that are emerging still fail to connect strongly with the mainstream or with public health prevention frameworks (Mikton & Shakespeare, 2014a). Those that do are aiming to bring 'prevention science' into disability prevention strategies and to bring the mainstream and disability

sector together in this work (Coulson-Barr, 2012; Fitzsimons, 2009; Frawley & Bigby, 2014; Frawley, Slattery, Stokoe, Houghton, & O'Shea, 2011). Research suggests however, there is still a dearth of knowledge about the effectiveness of such strategies and programs (Barger, Wacker, Macy, & Parish, 2009; Mikton & Shakespeare, 2014b).

Preventing violence and abuse: taking account of people with an intellectual disability

Despite a common theoretical base for understanding disability, violence and abuse and the high rates of violence and abuse, and in particular sexual abuse experienced by people with an intellectual disability, it is not clear to what extent mainstream 'whole of community' primary prevention programs have:

- 1) recognised that people with disabilities are increasingly part of mainstream communities and therefore included a focus on behaviour and attitudes towards people with a disability in the community or in organisational change, educational or awareness raising programs they undertake
- 2) reached out to collaborate with and include people with disabilities in the design and implementation of programs and
- 3) tailored programs such as awareness raising to be inclusive of participants with an intellectual disability (Frawley & Bigby, 2011)

Mikton & Shakespeare (2014a) in their review of disability violence and abuse prevention research and approaches to prevention highlight that the intersection of the disability and violence prevention field needs more attention. They recommend a public health approach that: (1) defines the problem conceptually and numerically (2) investigates why the problem exists by determining risk and protective factors and using these in prevention work (3) devising approaches using information gathered from the previous strategies and evaluating their outcomes (4) scaling up effective approaches, disseminating knowledge about them and determining their costs and cost effectiveness (p. 2). Currently in Australia there is an increased effort in this area which has been led by research and advocacy from the women with disabilities sector (WWDA, 2013; WDV 2008; 2014). This research and advocacy has worked from an intersectional perspective and has aimed to build knowledge about the extent of the problem and to inform policy and practice, in particular through first person accounts by women with disabilities. Continued efforts from these groups are focussing on the first and second strategies outlined by Mikton & Shakespeare above, with a particular focus on quantifying and qualifying the problem of violence and abuse of people and particularly women with disabilities. Less work is being undertaken to develop, implement, evaluate and scale up prevention strategies, however some government departments and disability peak organisations have begun to develop frameworks to inform prevention (Coulson-Barr, 2012; NDS, 2014; Nucleus, 2002; Queensland Government, 2014), although much of the focus of these frameworks is on risk reduction and service responses.

The 'Adopting mainstream approaches...' research reported here (Frawley & Bigby, 2011) aimed to develop an understanding about how people with an intellectual disability could be taken account of and included in mainstream prevention through the extension and 'scaling up' (Mikton & Shakespeare, 2014) of a targeted cross sector abuse prevention model for people with an intellectual disability; *Living Safer Sexual Lives: Respectful Relationships* (Frawley, Slattery, Stokoe, Houghton, O'Shea, 2011). The research built on the cross sector partnerships developed in three

sites through this model to look at the ways people with an intellectual disability could be known, acknowledged, taken account of and included in violence and abuse prevention.

Living Safer Sexual Lives: Respectful Relationships

Prevention of violence and abuse of people with an intellectual disability, in particular sexual assault has been an important focus of the work of a small group of researchers internationally (Fitzsimons, 2009; Frawley et al, 2011; Hollomotz, 2009; Mansell & Sobsey, 1995; Sobsey, 1994). Sobsey's work in the early 1990s urged researchers, practitioners and policy makers to consider the social ecological basis of abuse of people with an intellectual disability and to develop multi-layered approaches to prevention. This approach aligned with mainstream approaches and sought to shift the focus from protection to prevention. Despite the growing evidence base for this approach primarily through the work of Sobsey and later others (Fitzsimons, 2009; Frawley, et al, 2011; Hollomotz, 2009), a review of sexual assault prevention programs for people with an intellectual disability by Barger et al, (2009) found that too few used 'prevention science', many still focussed on individualised approaches and few were evaluated for effectiveness. This review called for an overhaul of programs for people with an intellectual disability including the development of comprehensive, cross sector approaches that included people with an intellectual disability in the planning and delivery of sexual assault prevention programs (Barger et al, 2009).

Living Safer Sexual Lives: Respectful Relationships (LSSL:RR) (Frawley, et al, 2011) is a violence and abuse prevention model that reflects Barger's recommendations. It uses a systemic prevention framework bringing the community and disability sectors together, is comprehensive going beyond the teaching of a set of 'rules' for self-protection and it includes people with an intellectual disability in the development and delivery of the peer education program. The model has four components: a respectful relationships education program that is co-facilitated by peer educators and sexuality and relationship professionals; a learning partner approach that encourages participants to share their learning with an advocate or support person to strengthen support for the learning; sector development through training community professionals to work as co-facilitators of the program alongside the peer educators and through the cross sector planning groups; and research and evaluation to build the evidence. This model is depicted in Figure 1.

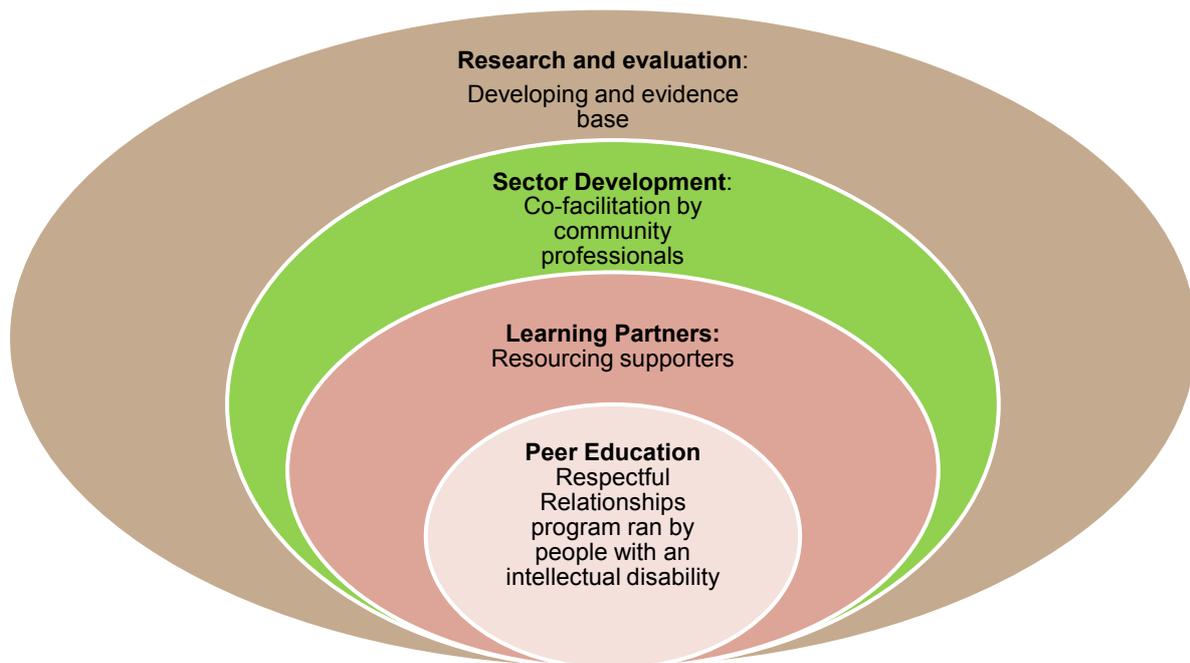


Figure 1: LSSL:RR Model (Frawley et al 2011)

The peer education program consists of four sessions, each with a theme drawn from the *Living Safer Sexual Lives* stories (Frawley, Johnson, Hillier & Harrison, 2003); Talking about sex and relationships – Molly’s story; Having rights and being safe – Angela’s story, Respectful Relationships – Kevin & Hanna’s stories; and Men and respectful relationships – draws on all three stories (Frawley et al 2011). These stories were gathered in the original *Living Safer Sexual Lives* research (Johnson, et al, 2001). This project worked with 25 people with an intellectual disability to develop awareness and action on the sexuality and relationship rights of Victorians with an intellectual disability through their life stories (Johnson, Hillier, Harrison & Frawley, 2001).

The LSSL:RR model was piloted in five sites in Australia from 2009 to 2011. It was funded by the Australian Government’s policy on reducing violence against women and children (reference) and was the only program funded with people with a disability as the target group. The model evaluation found there were three core enablers to its success; (1) cross-sector engagement of professionals from mainstream community services and disability services who came together to plan, promote, and implement the model, (2) belief in the capacity of people with an intellectual disability to be involved and the importance of their involvement in program planning and as educators, and (3) an understanding of the prevention framework that underpinned the model. The key inhibitor to the success of the model was ‘gatekeeping’ by community professionals, disability advocates and disability services where they questioned the capacity of people with an intellectual disability to be leaders in prevention work and where they did not identify this work as ‘core business’ for their organisation (Frawley, Barrett, Dyson, 2012). While research has not been undertaken on the effectiveness of the program in bringing about changes to individual or collective experiences of violence and abuse, program participants report that involvement in the program has changed their own understanding about their rights in relationships, their knowledge of local services and their resolve to strive for respectful personal, intimate, social and support relationships (Frawley & Bigby, 2014; VicHealth, 2014). Furthermore, peer educators report feeling more confident, empowered in their own relationships and identify as role models for prevention of abuse (Frawley & Bigby, 2014).

Research approach

Three sites where the LSSL:RR model was being implemented were engaged in the current study to look at how a targeted model like LSSL:RR fits with broader mainstream work on prevention and how people with an intellectual disability were acknowledged, taken account of and included in the prevention of violence system in these sites. The research questions were:

- What account do mainstream primary prevention programs take of people with intellectual disability?
- How can mainstream programs be influenced and shaped by the experiences of people with intellectual disability?
- What are the most effective ways to ensure these programs are relevant to and take account of abuse and violence against people with intellectual disability in the work they do?
- What are the obstacles for people with intellectual disability in accessing targeted and mainstream awareness raising programs and how can these be minimised?
- What is the role of specialist primary prevention programs targeted at people with intellectual disability in resourcing mainstream programs to take people with intellectual disability into account?

This study was based on a Participatory Action Research (PAR) approach (Rappoport, 1970). Central to PAR is the generation of research ideas by people affected by the issues and follow through collaboration between those people and academic researchers in carrying out the work (Kindon, et al., 2008). People with an intellectual disability and community professionals involved in LSSLRR model were consulted during the development of the research proposal and put forward a 'working idea' that approaches to abuse prevention need to be developed to enable their experiences to be taken account of in programs. The scaling up of LSSLRR was seen as one way these groups could do further work in the prevention of violence and abuse of people with an intellectual disability. They wanted to do more to ensure this model was sustained and some had already begun developing local strategies to achieve this. The vulnerability of this targeted model however was evident; it was difficult for these groups to access funding and despite connections with mainstream prevention services through links to the program by the co-facilitators, most expressed some concern that this model was operating in isolation from mainstream prevention of violence models.

Action research groups

Three case study sites were established based on their expressed interest in doing further work in this area. Each case study was in a locality where a nucleus of interest in thinking about abuse prevention for people with intellectual disability remained from the earlier LSSL: RR program. In all sites people with an intellectual disability were involved in some aspects of the study – in particular through their roles as peer educators in the LSSL:RR program and the program network groups in their local areas. Action research groups were established in each site growing from and including the LSSL:RR networks. The establishment of these groups and the ongoing work with them was the key research activity in this study.

Each group was comprised of representatives from a range of organisations in the local area that had (a) been involved in the establishment of the LSSL:RR model in the locality and /or (b) were involved in working with people with an intellectual disability and /or (c) were involved in violence and abuse prevention or response work and/or (d) were involved in community or sexual health.

Participation in work associated with establishing or maintaining the LSSL:RR model was the way into this study for some organisations and individuals. Most of these people had been trained as co-facilitators in the program and after the training maintained involvement in the local network that focussed on sustaining the program in their area. Some others joined the action research groups after they had completed the survey that was conducted as part of this study (see data collection below).

The following table lists the action research group members for each site identifying their roles, organisations and/or basis for involvement.

Table 1 Action research group members per site

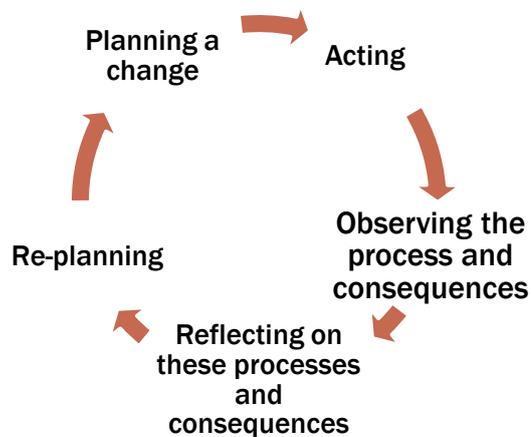
Site 1 N=8	Site 2 N= 11	Site 3 N=14
CASA (2) - 1 Manager, 1 counsellor/advocate (trained LSSL:RR co-facilitator)	CASA (3) - 1 Manager; 1 Counsellor/Advocate; 1 project worker	CASA (2) - 1 manager; 1 Counsellor/Advocate (trained LSSL:RR co-facilitator)
Community Health (1) - 1 Men's health project worker	Government Disability Service (2) - 1 Behaviour support practitioner (trained LSSL:RR co-facilitator); 1 Outreach support coordinator	Community Health (3) - 1 manager; 1 Women's health nurse; 1 Men's health nurse (both trained LSSL:RR co-facilitators)
Disability NGO (1) - Day services support worker (trained LSSLRR co-facilitator)		Gender diversity awareness service (1) (trained LSSL:RR co-facilitator)
Women's' Health (2) - 1 manager; 1 project worker	Local Government (2) - 2 Rural Access workers (1 trained LSSL:RR co-facilitator)	Women's Health (2) - 1 manager; 1 project worker (trained LSSL:RR co-facilitator)
Youth Health Service (1) - Sexual health nurse (trained LSSL:RR co-facilitator)	Family Violence Service (1) - Family violence worker	
Person with an intellectual disability (1) - (trained LSSL:RR peer educator)	Self-Advocacy organisation (3) - All trained LSSL:RR peer educators	Community Disability Service Organisation (3) - 1 manager; 2 community project workers (trained LSSL:RR co-facilitators)
		People with an intellectual disability (3) - Trained LSSL:RR peer educators

Membership of some of the groups changed over the course of the project. Sadly two members of two different sites passed away and in all sites some members had a more focussed and consistent involvement than others. In other sites new members joined at different stages based on the development and focus of the groups. While the groups were seen as action research groups by the University researchers, the group members identified as being members of the local LSSL:RR network whose main role was sustaining and growing LSSL:RR. These two aims were able to be combined through the work of the LSSLRR network groups. These dual aims were outlined in a discussion paper that was distributed early in the study in each site (see Box 1 below).

The aim of the research group is to discuss and plan for strategies and approaches that can build a focus on inclusion of people with an intellectual disability in mainstream violence and prevention work and to strengthen the work of LSSL:RR as a targeted program that can work to build a focus on violence and abuse prevention for people with an intellectual disability. How the group does this is up to the members.

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Facilitation and input will be provided by LaTrobe University researchers using a Participatory Action Research (PAR) approach (Kemmis & McTaggart, 2000 p. 595). This can be summarised as:



Planning Change - In this research the planned change is to build a focus on disability in mainstream violence and abuse prevention work and to strengthen the place of people with an intellectual disability in this work.

Acting – This will be what the group decides to do

Observing the process and consequences – This is what the LaTrobe University researchers will do by attending meetings; looking at and discussing what the group develops and does

Reflecting on processes and consequences – The group facilitated by the researchers

Further action – developed by the group with input from the researchers

This discussion paper formed the basis for the dual work of the action research groups/LSSLRR network groups over the course of the study and provided a framework for data collection and analysis in the action research groups.

Data Collection

A number of approaches were used to gather data about inclusion of people with an intellectual disability in violence and abuse prevention approaches in the three case study sites. This data was analysed throughout the study and used to inform the work of the action research groups.

- A survey of local government and other community organisations to identify the range of primary prevention programs in the locality, the extent to which they have taken account of

people with an intellectual disability, their views on the relevance of doing so and their interest in joining a research/program network to progress this work (58 surveys distributed across three sites – Site One 18, Site Two 30; Site Three 20; 24 completed)

- Semi-structured interviews with a sample of professionals involved in local programs/prevention strategies to gain their perspectives on how they have or can take account of people with an intellectual disability. (21 interviews: Site One 5, Site Two 10, Site Three, 6)
- Focus groups with people with an intellectual disability in the local areas to gain their perspective on involvement in primary prevention programs and activities in their local area¹ (N participants 13: Site One 1, Site Two 5, and Site Three 7)
- Final stage focus groups with the action research network groups.

Data Analysis

Qualitative data was the main data collected in this study while some quantitative data was gathered in the survey of abuse prevention workers. This quantitative data was analysed using SPSS and was reported on using *descriptive (summary) statistics* such as percentages of respondents responding in a certain way and other measures of data spread. All qualitative data including that gathered through the survey was recorded and coded using NVivo 10. An interpretative approach to the qualitative analysis was used to understand the participant's experiences. Some broad codes were defined to inform the more in-depth analysis of the data based on the interview transcripts. This draws on approaches used in constructivist Grounded Theory (Charmaz, 2003). The first and second authors had regular meetings to discuss the coding process and the themes and revised these as the analysis progressed.

Study sites: an overview

The following provides a brief background of each site and an overview of the key activities of the action research groups from when the groups formed to participate in this study (November 2012) until the completion of the study (September 2014). The site names and other identifying information have been removed. The analysis of the approaches used in each site, factors that impacted on their participation and the outcomes are discussed in the findings section of this report.

¹ In S2 the focus group also included the community professionals involved in running LSSLRR

Site 1 (S1) : Establishing LSSL:RR 2009 - 2011

Site 1 was a LSSL:RR pilot site between 2009 and 2011. A local planning group was established in 2009 with representation from DHS Disability Services, two Non-government disability day services, the Centre Against Sexual Assault and a youth health service. This planning group was coordinated by the DHS representative who was a designated health promotion worker in the disability services division. During the pilot phase meetings were held over a 12-month period to promote the program, coordinate its development and support its delivery. Information sessions were held at two disability organisations for people with an intellectual disability to introduce the program and to recruit participants for the upcoming programs. These information sessions also outlined the model and recruited staff to be trained as co-facilitators. One person with an intellectual disability from the local area was already involved in the program working as a project worker with LaTrobe University, she continued as a peer educator in this site. Two other peer educators were trained from one of the day services and four co-facilitators; 1 DHS, 1 youth health service, 2 disability day services. Two groups participated in the LSSL:RR programs in the pilot phase of LSSL:RR. After the pilot phase of the program one of the disability day services coordinated the delivery of a third program for 10 people with an intellectual disability. No further programs have been conducted in this site.

Participation in the research (2012 – 2014)

The current study was an opportunity to re-connect the network of people and organisations which had been involved in the LSSL:RR pilot program and to identify others in the local area working in prevention of violence around the question of prevention approaches which could include people with an intellectual disability. When the group was re-formed in November 2012 both the LSSL:RR program and a focus on prevention involving people with an intellectual disability had ceased in this site. The reasons put forward for this included; movement of people from positions where they had a role in LSSL:RR, in particular the cessation of the health promotion role in DHS disability services; trained peer educators moving onto full time employment or other activities leaving only one trained peer educator in the area; lack of funding to support ongoing work and the organisations questioning their capacity to justify this work in their work roles. There was also a view that disability services in the local area were uncertain about their future approach to this kind of work in light of the introduction of the National Disability Insurance Scheme (NDIS).

Despite the lack of current activity the group agreed that involvement in the study would be a benefit to the region and act as a catalyst to regain a focus on prevention of violence and abuse and improved sexual health for people with an intellectual disability.

Through the survey three new members were recruited to the action research group and the following violence and abuse prevention activities/strategies were identified: a cross government working group on violence and abuse prevention; family violence and sexual assault network meetings; preventing violence against women as a key priority of the regional women's health organisation; month of action activities coordinated by a cross-sectoral working group.

Aims and Actions

The group agreed on the following broad aims

- develop a new focus for LSSL:RR and use this as a springboard to develop community awareness and mainstream program awareness of inclusion of people with an intellectual disability in violence and abuse prevention;
- identify key mainstream violence and abuse prevention initiatives planned for 2013/2014 and use the research network to create links between people with disabilities and disability organisations in these initiatives;
- promote and support participation of people with disabilities in public awareness campaigns.

The group met three times during the study. They developed links with the Month of Action planning group in the region and one organisation received funding to develop, implement and evaluate a school based violence and abuse prevention program in a local special school. This organisation also developed and ran a sexual abuse prevention program in a mental health facility following an incident of abuse.

Site 2 (S2): Establishing LSSL:RR 2009 -2011

Site 2 was a LSSL: RR pilot site from 2009-2011. A local planning group was established with representation from DHS Disability Services, Local Government Rural Access, DHS Disability outreach service, Centre Against Sexual Assault and a self- advocacy organisation. During the pilot phase meetings were held over a 12-month period to promote the program, coordinate its development and support its delivery. Information sessions were held at two disability organisations for people with an intellectual disability to introduce the program and to recruit participants for the upcoming programs. These information sessions also outlined the model and recruited staff to be trained as co-facilitators. Seven peer educators and five co-facilitators (DHS Disability services x 3; CASA; Rural Access worker) were trained to run the program locally. During the pilot phase the local educators ran three groups. The self-advocacy organisation had a waiting list for new programs. Between the end of the pilot phase and the beginning of the current research four peer educators dropped out of the program and five groups were ran by the remaining peer educators and co-facilitators.

Participation in the research (2012 -2014)

The LSSL:RR network in this site had continued to meet regularly since the completion of the pilot phase and had developed Terms of Reference for the group with an aim to be the central contact point for the program locally, to further develop the program and to strengthen it. The group had a renewed focus with the return of one key member after a period of leave. The group saw the research as an opportunity to support their aims and to connect more strongly with mainstream violence and abuse prevention work in the region.

The survey at the beginning of the study found there was a strong focus on prevention in the region through government funding for a whole of region strategy, however the LSSL:RR group had missed out on opportunities to participate in the planning for this and another organisation had received funding through this strategy to develop and deliver a prevention of violence program to women with disabilities. Meanwhile the LSSL:RR group had applied for funding to enable more peer educators and co-facilitators to be trained and had missed out on this funding. Despite this the group were now ready to connect with the other work in the region and agreed to: invite a representative from the funded prevention strategy to join the LSSL:RR group and to apply for brokerage money available through this strategy to strengthen LSSL:RR or to develop a component of LSSL:RR that could meet an identified need of the strategy eg a men's group.

Aims and Actions

The group already met quarterly and decided that these meetings would continue with a dual focus; strengthening LSSL:RR in the region and working as the action research group for the study and as such they would consider how to connect with mainstream work in the region. One of the organisations employed a project worker to support these aims.

This group achieved the following outcomes during the research: received funding to train three new peer educators and eight new co-facilitators; established the CASA as the new auspice organisation for LSSLRR; broadened representation on the group to include representatives from community health and two new local government rural access workers and had LSSL:RR identified on two regional plans; sexual health and violence and abuse prevention.

Site 3 (S3) Establishment of LSSL:RR (2011 – 2014)

In 2011 a non-government disability service developed LSSL:RR in this site by providing funding for 4 peer educators and 7 co-facilitators from six organisations to be trained to run the LSSL:RR program. . Leading on from this a network was formed to enable ongoing promotion and delivery of the program in the area. This network comprised three peer educators and the trained co-facilitators from Community Health Services, CASA, sexual health, women's health, gender diversity awareness service and a non-government disability service. The group had ran three programs since being trained in 2011. When the network were approached to participate in the study in 2012 they had already began to consider how to integrate LSSL:RR into other work in sexual health and abuse prevention in the region and how to embed and sustain LSSL:RR as the key targeted program for people with an intellectual disability in the region. From 2012 to 2014 the program was delivered to 41 individuals (24 women, 17 men) in three locations; one provincial city and two rural areas.

Participation in the research (2012 – 2014)

Despite reporting the program had been well received and that it was identified in the region as a key relationship and sexuality program for people with an intellectual disability, the network had difficulty recruiting any other disability organisations to the network and had difficulty promoting the program to these services. In contrast, the mainstream organisations involved in the program reported that it had become their key program for this target group and they were promoting it as the 'program of choice' to disability organisations making referrals for sexual health and relationship education for people with disabilities. These mainstream organisations noted the program was good to run and that the involvement of the co-facilitators was supported by their organisations which recognised t this work was enabling their services to be known by people with disabilities and be linked up with other mainstream and disability services in the pursuit of prevention of violence. The peer educators reported that being involved in the program had been 'very satisfying' and for one peer educators she had not expected it to "...make her feel so powerful". At this stage it was clear the LSSLRR program was reasonably well recognised in the region, was operating and this had been made possible through both the support of the auspice organisation- a non-government disability service, and through all organisations supporting the involvement of their staff 'in kind'. It was also evident the peer educators were at the centre of the program in the region and were being supported to stay involved through the network.

Aims and Actions

The key aim for this group was to involve managers from the participating organisations to get a stronger 'buy in' and to ensure the model would be formally recognised and supported to make it sustainable and to have it recognised in both mainstream and disability organisations. In October 2013 the network convened a meeting to look specifically at the question of "how the program can be embedded and sustained in the work of partnering agencies" (meeting notes 161013). Managers of the organisations already represented in the LSSLRR network attended; the aim was to consider their organisational commitment to the program and what they as managers perceived was possible in terms of further developing LSSL: RR, embedding it in their services and linking it to other work in the prevention of violence and related work in the area. Their aims were: to promote the model through disability, sexual health and prevention of violence conference presentations and applying for research and program awards; connect peer educators to other women with disabilities programs and leadership opportunities and to include the model on organisational and regional work plans.

The work in this site has led to the group presenting at one disability advocacy conference, two regional sexual health conferences, one preventative health conference and a prevention of violence conference; inclusion of LSSL:RR in a sexuality educators university course DVD; development of a promotional DVD, inclusion of LSSL:RR in the community health service work plan and inclusion of a disability organisation on the regional sexual health network.

Findings: violence and abuse prevention including and taking account of people with an intellectual disability

Public policy framework

Central to this study was the question, “What does it take for people with an intellectual disability to be taken account of and included in violence and abuse prevention?” The research presented at the beginning of this report makes it clear this group need to be taken account of and included in violence and abuse prevention; they are at much higher risk than the general population of all forms of violence and abuse in particular experiences of sexual abuse, and this risk is socially determined.

Disability and human rights advocates and advocacy organisations in Australia have been doing their part in raising the issue of abuse of people with intellectual disabilities as a social problem. Annually since 2008, the Victorian Office of the Public Advocate through its Community Visitor program and research has reported about the violence and abuse in residential services and have made it clear that people with disabilities and in particular people with cognitive disabilities are not safe in these services (OPA; 2008 – 2014)². The Victorian Disability Services Commission has published a report on safeguarding people with disabilities in services (Coulson-Barr, 2012), National Disability Services have followed up on work undertaken in 2002 by the Commonwealth Government (Nucleus, 2002) with the Zero Tolerance project (NDS, 2014) and and the NDIS implementation has included a working group on safeguarding people with a disability from violence and abuse (NDIS, 2014). While these efforts are important there is still a disjuncture between the mainstream and the disability sectors in terms of the way abuse of people with an intellectual disability is understood, responded to and efforts to prevent it (Mikton & Shakespeare, 2014).

Institutionalisation and institutional approaches, the isolation of people with an intellectual disability from society and the closed nature of disability services are common themes relating to the violence and abuse experiences of people with intellectual disabilities. However, as community inclusion researchers highlight the social exclusion of people with an intellectual disability has not stopped with the closure of large institutions; they write about the “asylum without walls’ (Hall & Kearns, 2001) referring to being ‘in’ but not ‘part of’ society. This ‘invisibility’ from society, not having a social or political presence is still a key factor in the lives of people with an intellectual disability and is connected to their experiences of social exclusion, inequity and increased risk of violence and abuse.

Public health policy has a role to play in changing this. Despite reports that people with disabilities have not previously been prioritised in public health (VicHealth, 2014) public health frameworks and in particular preventative health and violence and abuse prevention frameworks provide an important template for inclusion of marginalised groups through approaches that are inclusive (VicHealth, 2014; Victorian Government, 2014). *Healthy Victoria Together* (Victorian Government, 2014) the framework for preventative health in Victoria for example has the following features: a socioecological systems approach, co-creation and co-production of knowledge, capacity building, and creation of multiple healthy environments, leadership for prevention and developing and sustaining partnerships locally and statewide. This framework does not highlight or focus on

² For a full list of OPA publications including Community Visitor reports go to <http://www.publicadvocate.vic.gov.au/research/255/>

particular population groups; rather it encourages an inclusive approach that can support the involvement of targeted approaches to cater for particular groups. This is evident in its aim to develop ‘leadership for prevention’ which notes that “leadership in prevention...can come from anywhere within the system” and that “leadership may emerge from...within sectors that, while not traditionally involved...have an important contributions to make” . This study took an action research approach to see how this might work in the area of violence and abuse prevention and a population group with a significant need for prevention of violence and abuse; people with an intellectual disability who through Living Safer Sexual Lives: Respectful Relationships had begun to be leaders for prevention.

What does it take? : five components for inclusion

Answering the question, “What does it take?”, this research has found five components that were evident in the three case study sites outlined earlier in this report and where the work of the action research groups was effective in achieving their aim of including and taking account of people with an intellectual disability in local violence and abuse prevention work. These components are depicted in Figure 2 and discussed in detail in the following section.



Figure 2 Components of inclusion: violence and abuse prevention

Reasons for exclusion

The findings of this research show that from the perspective of disability-specific and mainstream service providers there are number of real or perceived barriers to the development and implementation of an inclusive model of primary prevention of violence and abuse. Any model must seek to overcome these real and perceived barriers.

Survey results of disability services and mainstream community professionals working in the abuse sector gave some indication of the perceived barriers to inclusion of people with an intellectual disability in violence and abuse prevention. Respondents were asked to indicate whether they agreed or disagreed that certain factors were barriers to inclusion of people with an intellectual disability in violence and abuse prevention. Lack of resources was the most commonly cited barrier by 86.4% with lack of contact with or awareness of the experiences of people with an intellectual

disability being cited by 54.5% and 63.6% respectively. Sixty eight percent believed that specialist knowledge and skills were needed to include people with an intellectual disability and 54.5% thought that specialist services were needed. A further 18.2% reported that staff believed people with an intellectual disability did not need to be involved in violence and abuse prevention.

A first step to addressing these barriers is instilling the notion that preventing violence against people with intellectual disabilities is an essential part of the services delivered by both the mainstream and disability sectors. When neither sector acknowledges their responsibility they do not provide the 'great service' to which their clients are entitled. Interviews with community professionals found gaps in both sectors' acknowledgement of the problem.

Violence against women is a good example where you have crisis response providers who know they are not providing a great service for people with disabilities and you have disability service providers not being well enough connected with crisis [services] and the underlying argument for both of those is this is not our core business. Site 1(Com Health)

A number of the interviewees suggested that their organisation lacked the time to meet what they regarded as the additional support needs of clients with disabilities reflecting the views put in the surveys about lack of resources;

I've certainly worked in the community sector and the local government sector and I know how scarce resources are and I certainly take that as, certainly for my work now, I take that very much as an issue around that impacts on the way people approach things Site 1(Com Health)

Organisations were busy with crisis work and sometimes found it difficult to allocate resources towards primary prevention of violence and abuse;

...it has always been considered really important but probably difficult with the huge demand of seeing clients, there's always massive waiting lists and finding the time to put the time and energy into preventative kind of work... Site 3 (CASA)

Others were concerned that they or their organisations lacked particular skills and knowledge needed to work with people with intellectual disabilities in the area of violence and abuse prevention, seeing instead that this was knowledge held by particular individuals who were mostly working outside their organisations;

And I mean it takes a lot of time I think and I think that's one of the difficult things about selling a program as it were, into an organisation of any sort is, unless there is already groundwork there or unless they are really open and ready for it, it can be really difficult I think for an organisation to pick it up...Site 3 (Dis Serv)

Normal staff which would be ideal but we just didn't have anyone with the right skills at the time that was coming up...Site 3 (Wom Health)

I think the problem you have with a project worker or with specific resources that are attached to something is it then becomes very much perceived as being that person's thing. Site 1 (Wom Health)

In seeking to overcome this barrier and build the capacity of organisations to work in the area of violence and abuse prevention, interviewees identified the need to make sure that staff felt comfortable and confident about working with people with disabilities when they might not have done so before;

I want people to do this work and if the way to get them to do the work is to talk about it in a way they are comfortable with, then let's do that. Site 1 (Wom Health)

I think sometimes people think they are not equipped .. and they may not be, but sometimes they are and don't realize they are...and [they] think I'm not quite sure how I have to operate here to make this work and I might look like an idiot if I say something wrong or if I try and explain in really simplistic terms or whatever it might be but I suppose they just have to let go of that.

I guess a lot of people have difficulty communicating with some people with an intellectual disability. Site 2 (CASA)

I think it is for me again, the sense of incompetence or lack of confidence is around again that delivery, the communication, delivering information in a format that is appropriate to that individual, there is a real hesitation, self doubt I guess you could call it. Site 2 (Dis Serv)

For some, there were strong feelings within their organisations which went beyond concerns about how to work effectively with people with intellectual disabilities and were about resistance to their participation in any programs and services. Issues about the sexuality of people with intellectual disabilities challenged some staff and the broader community;

We've got a bit of moral panic about you people over here so therefore we will do what we can to control the way in which you participate. Site 1 (Wom Health)

There's still and you would be aware there's still the whole to do thing around people with intellectual disability and sexual activity and stuff like that, that's a concern, some people, some families don't recognise that it exists in their kids or whatever or don't want to talk or know about it. Site 2 (Com Health)

Adding another layer to attitudes about sexual abuse and violence preventative work with people with intellectual disabilities was commentary from interviewees describing an attitude of denial about the demand and the need for such programs by some managers and staff within organisations;

One service there was a CEO there who said look I've been working here for 35 years and I've never come across any client that has experienced family violence and she said that in front of her staff. Site 2 (Dis Serv)

...a lot of people seem to have an attitude that because the people with disabilities are supervised, the family supervises them when they are at home and when they are not at home, they are at the day centre so they're always supervised therefore they are safe, there's that sort of attitude. Site 2 (Dis Serv)

Because the other thing that people talk about is we don't have contact with people with intellectual disability. If they came in the door, we'd do something about it. Site 2 (Com Health)

One interviewee suggested that attitudes about violence and abuse of people with intellectual disabilities both within the community and in services are only part of the problem. There may be a structural issue in the way that services are delivered, managed and measured which limits their availability to some vulnerable groups;

Well I wonder whether some of it is about being entrenched in what you have to do so it is about the way you approach the work and some of that is obviously driven by reporting requirements and organisations that do have those very, you will deliver 30 X by 30th June, they do have those constraints upon them but what you do find is there are some organisations that allow a lot more scope for exploration of that idea than others... Site 1 (Wom Health)

Sometimes, getting prevention programs to 'fit' within the way services are provided to people with disabilities created a barrier to their development and delivery;

[I said]... let's work with some organisations that work with people with disabilities to fit them ...which was great until we got to the point where people couldn't fit it into their idea of how they packaged disability support and interestingly enough that was where it fell over. Site 1 (Wom Health)

Making people with intellectual disabilities aware of the availability of services was also raised as an important issue. Perceived difficulties in getting the message out to prospective service users was frustrating for providers;

I think it is a lot deeper than just being able to operationalise it, it is about being able to get the message out to that individual who's got a disability, and following through. Site 2 (Com Health)

Service provider interviewees outlined a of perceived or real barriers to the implementation of a model of primary prevention of abuse and violence some of which are related to the ways in which services deliver programs to their clients and how these are resourced and managed. Other barriers are attitudinal and seem to relate to an unfamiliarity or apprehension about working with people with intellectual disabilities in spite of a strong recognition of the importance of both disability and mainstream organisations working to meet the needs of this group.

Survey respondents when asked about addressing the real or perceived barriers to inclusion overwhelmingly noted the need for more contact between disability services and mainstream services and networking between specialist and mainstream providers of abuse prevention, 95.5% respectively. The need for increased public awareness about abuse of people with an intellectual disability was the second most cited approach to address these barriers with 90.9% of respondents noting this as a necessary approach. Eighty six percent noted the need to provide more information about abuse of people with intellectual disabilities in mainstream reports and research, training for staff and access to knowledge about abuse of people with an intellectual disability and abuse, and increased resourcing to all programs to enable inclusion. These suggestions highlight the need for more visibility of people with an intellectual disability within the violence and abuse prevention sectors.

A strong foundation: LSSLRR 'it ticks all the boxes'

Overcoming some of the barriers to the implementation of programs and services which address the needs of people with intellectual disabilities requires creative and pragmatic approaches on the part of disability and mainstream organisations.

Making the rights and quality of life of people with intellectual disabilities part of the organisational 'culture' was the key for one interviewee;

When you talk about rights, that's certainly there and part of the culture of the agency, the recognizing, you know UN convention on the rights of people with disabilities under DVA and all of those sorts of rights based things but I guess for this agency too there's been a very strong emphasis on quality of life and that whole framework and so it sits within that framework and within recognizing the isolation of people with disability often and wanting to support people to develop connections and relationships... Site 3 (Dis Serv)

The 'Living Safer Sexual Lives' program provided a framework for working with people with intellectual disabilities and was a strong foundation for some organisations. The program offered a chance to 'mobilise' scarce resources and allow the organisation to 'contribute';

So I think in a way we, (inaud) of a chance to support the program Living Safer Sexual Lives because we could, with a small amount of money, contribute to something that we didn't have, we didn't have more money to put into it I suppose so it enabled us to do that with just mobilizing of resources, make it available but didn't take us away from doing other things we were doing so the fact that it was a shared thing was helpful, that someone else was leading it gave us a chance to contribute. Site 3 (Com Health)

Changing the way service providers think about people with an intellectual disability was an important outcome of their involvement with the LSSL program;

I think doing the training [as a LSS:RR co-facilitator] just really got me thinking in a different way. Site 3 (CASA)

Offering an example of a model that could be built into the core business of organisations LSSL:RR was seen by interviewees as providing a way to make violence and abuse prevention programs accessible and sustainable;

It would seem to me that a model like Living Safer Sexual Lives could just be kind of incorporated into things that other people were doing so it didn't just become, it becomes something you do every year or every time you get a new client group but you would just build it into the system and things that you do. Site 1 (Wom Health)

The design of the program was mentioned by many of the interviewees as being accessible and enjoyable for participants;

It is much more experimental in a way like with the activities and getting up and moving around, it's not just sitting there and being lectured to and so therefore it makes the whole experience much more meaningful. Site 3 (Com Health)

I would hope that anybody who heard about it would think what a great idea, isn't that fantastic, wonderful way of being able to give peer educators, what a great opportunity for

them and also how important that is for the whole group and great it is for us to be able to say okay we do want to talk about this part and know more about it than what I do. Site 3 (CASA)

And I never feel I give the model enough credit in how I explain it....It just ticks all [the] Site 3 (Com Health)

It has certainly met a need and emerging needs were certainly there in terms of, from my perspective as a clinician it really met my need in terms of being able to learn about, well to learn with more credibility around people with disability in terms of the stories and what they experience and then putting that into context of daily life. Site 3 (Com Health)

It is reassuring for service providers to be able to tap into a developed framework in doing primary prevention work in the area of violence and abuse prevention;

...there is somehow some work or awareness or understanding that there are tools that can be used and picked up, I mean the Living Safer Sexual Lives, the package is a perfect example of that. Site 2 (Local Govt)

...it is too hard for us to develop that ourselves because it is so much about, in seeing Living Safer Sexual Lives in operation, we see so clearly how it works, understand how it works because of the way it has been structured and that and the whole process that's gone on, that's been a long process obviously, developing Living Safer Sexual Lives and then developing the Respectful Relationships component. Site 3 (Dis Serv).

Living Safer Sexual Lives: Respectful Relationships was a 'known' model in all three sites and had been tried and tested. Seventy percent of those who participated in the survey had some knowledge of LSSL:RR before the research, of these 70% had been directly involved through co-facilitation training and 30% had heard about it through a colleague. All three sites developed aims and approaches to sustain and grow, or 'scale-up' LSSL:RR through this study. Two succeeded in this; Site 2 gained funding to train more peer educators and co-facilitators thereby growing their network to include more community organisations and people with an intellectual disability and strengthening their capacity to both run programs and participate in local violence and abuse prevention work; and Site 3 promoted LSSLRR through conference presentations, linked it to a rural sexual health and research initiative and through their network group to local sexual health policies and strategies. Site 1 however did not run any more LSSL:RR programs or further develop it during the research. They put their efforts into adapting and implementing a sexual abuse prevention program for young people with an intellectual disability in a special school using their knowledge and skills from previous work in LSSL:RR to inform this program and to run a further program in a mental health facility.

The LSSL:RR model, a targeted violence and abuse prevention model with a peer education respectful relationships program incorporated had some role in forming a foundation on which further work could be developed to include people with an intellectual disability in violence and abuse prevention work. All three sites developed their knowledge and skills in working with people with an intellectual disability and their connection to people with an intellectual disability as leaders for prevention through LSSL:RR. Two sites have continued to grow and develop this model as a way of linking LSSL:RR to mainstream prevention work and had linked people with an intellectual disability directly to mainstream violence and abuse prevention work through this model.

Beyond 'moral panic': Recognising prevention of violence and abuse of people with an intellectual disability as core business

Recognition that people with intellectual disabilities need to be taken account of and included in violence and abuse prevention programs within mainstream and disability organisations was strong in all three sites. Eighty-six percent of the community professionals surveyed had considered how to or had included people with an intellectual disability in their work and 14.3% considered that existing violence and abuse prevention work had taken account of people with an intellectual disability. The majority of respondents who had taken account of and included people with an intellectual disability cited LSSL:RR as the way they had done this. These community professionals were an informed, experienced and engaged group of professionals; 67% had worked for more than one year in positions relating to violence and abuse prevention and/or response and over 90% had undertaken specific training in violence and abuse prevention including the Common Risk Assessment Framework (38%) and 17% had completed the VicHealth preventing violence and abuse of women course. Eight percent noted LSSL:RR co-facilitation training as training in violence and abuse prevention they had completed. Overall there was a strong recognition of the need to address violence and abuse in the lives of people with an intellectual disability;

...it is fair to say they have a harder time standing up for themselves in that situation than those without intellectual disability. Site 1

Sometimes mainstream service providers need to respond in creative ways to what is for some a new and challenging experience working with clients with intellectual disabilities;

I'm an advocate I suppose so I try and promote it but not everyone is going to identify that is what is needed or maybe it is not appropriate always to do an intake, risk assessment in the office, that we might have to go somewhere else, it may be the carer is around all the time and they are the perpetrator and how are we going to sit down and do a risk assessment with this woman when the carer is always there so we have to be more creative about how we're going to do that rather than try and speak to the woman, the carer answers and, because obviously it's a voluntary service so to try and sit with the woman by herself, where she feels safe enough to talk about things. Site 1

Others noted the need to adapt approaches and resources to suit the needs of particular clients;

You've got to provide information in small chunks and appropriate to the person's communication and processing capacities, that you may need to work with that individual for a longer period of time. Site 2 (CASA)

I think we are working with people and it is just being respectful of the difference and enhance and strengthen areas where the person needs that extra support. Site 2 (CASA)

For some, experience had led to a change in perspective and a loss of some of the mystery and uncertainty about working in violence and abuse prevention with people with intellectual disabilities;

As soon as people have that interaction with individuals then that mystery goes away and there's a realization that actually a lot of time the approach can be a very human approach, it's not necessarily a disability specific approach. Site 2 (CASA)

In mainstream services an acknowledgement at the most basic level that there was a need to make services available for all people was an important first step;

*...it doesn't matter who they are, anybody potentially can be a victim of sexual assault
Site 3 (CASA)*

A change in the way disability services think about violence and abuse prevention was evident in some of the interviews beginning with the introduction of a more consultative approach with service clients; asking them what they would like and what they need;

...we're very open to altering programs and our input to suit the people, the audience, the clients who are wanting that service. Site 2

Making connections to mainstream services and links to advocacy and self-advocacy groups had changed the way some disability services were working and as a result they had been able to change some of the 'moral panic' about educating and empowering people with intellectual disabilities about (sexual) violence and abuse and advocate for more accessible services to better meet their needs.

Power of partnerships trumps all: cross sector and cross profession

Organisations were seeking to work together in service planning and delivery in order to establish partnerships which would improve access to services across sectors for people with an intellectual disability. The LSSL:RR model had brought organisations together in the three sites to work on and promote violence and abuse prevention that included people with an intellectual disability. These cross sector network groups were operating prior to the research in the case study sites and grew in size and cross sector representation during the study. In each site there was at least one representative from a disability organisation, CASA, and community health/health service. In total across all three sites during the research phase there were seven members from CASA, four from community health/health services, six from disability organisations/services, four from women's health, seven people with an intellectual disability, two from family violence services, two from local government and two from youth/gender diversity services. This represents 33 people from 16 different organisations including one self-advocacy group. These groups are a strong example of cross-sector and cross-professional partnership.

For one organisation it was important to be a part of a consortium of providers in order to share resources and improve access for clients;

...that organisation includes a range of different community sector organisations ranging from youth services and crisis support through to disability support, residential care, respite care, registered training (inaud), employment services so it is quite a broad, they have a broad number of organisations underneath them but as much as we want to talk about what we do to them we also want to understand what they do so we can feed that into the work we do as well. Site 1 (Com Health)

This kind of collaboration and communication between providers can help to ameliorate the lack of resources in both the mainstream and disability sectors;

To me the power of networks and partnerships can trump availability of resources because people, through that exposure to others will actually have a different way of thinking about how they approach their work. Site 1 (Wom Health)

We want our organisation to be bringing people along not waving fists at people about them not having done what we expect them to do because I think once people understand what it is that you are asking of them, you can have a much better conversation about what it is that you want to win. Site 1 (Wom Health)

Connections between organisations can build capacity in regions;

We prefer to make connections with a whole lot of, probably similar to yourself, other agencies that are working in and around a whole variety of areas around health promotion and make those connections around capacity so that can be (inaud) training, professional development, leadership, advocacy, it could be any, networking, any number of things around building capacity within the region. Site 1 (Com Health)

Some interviewees noted that they saw the development of partnerships to be more difficult for disability organisations than for mainstream services, perhaps because they may have thought of themselves as something other than a 'community' organisation;

And it is about our organisation seeing itself as a community organisation in the same way that [a]Community Health [service] is but for some reason in the disability sector we've come to think of ourselves as not part of the community because we are trying to send everybody out into the community Site 3 (Dis Serv)

Being proactive and seeking out people and organisations with expertise and resources had been helpful to a number of interviewees from disability services and in turn enabled their clients to access specialist support.

Persuading disability organisations and their staff to change the way they see themselves and to build partnerships with mainstream services was an important step towards strengthening existing violence and abuse prevention work in the regions as well as implementing primary prevention programs such as LSSL:RR.

It has to be a committed approach to be able to spend the time doing a thing of value and developing those relationships. Site 1 (CASA)

Organisations were working together to create a 'good space' to deliver programs and services;

I only wanted to make the point and you already know but there is such a good space for us to work together across the sector and we need to make it happen because there is a need, hopefully we will make it happen with time, a bit of money and initiative I think. Site 1 (Wom Health)

The power of partnerships to improve access to mainstream services and break down some entrenched negativity about disability was an important step forward;

I do really see the benefits of linking the disability and the mainstream services together, I think it is only going to strengthen the support out there for those that require such a service, I think it

has broken down the barriers around disability... I think they are people with different needs as we all have. Site 2

Champions and drivers – they get it

The implementation of an inclusive model of primary prevention of violence and abuse requires the involvement of champions and drivers; committed individuals within both mainstream and disability organisations who understand the need for such a model and are committed to overcoming some of the barriers which may make its development difficult.

Champions include some leaders of organisations;

I think that the organisation has been extremely dedicated as trying to recognise the importance of the issue to the people we're working with ... that combination that has allowed it to do some of these things but I think certainly primarily in that is the position and dedication of the leadership in the organisation (Site 3 CASA)

The commitment from my organisation has been right there. (Site 3 CASA)

I think that commitment has been really good and the ability to find, [organisation's] ability to find groups and then the support for that...(Site 3 Dis Serv)

Others acknowledged that their role and that of their service had changed as a result of their commitment to working in this space with people with disabilities through LSSL:RR;

It's a shift from saying we're delivering a service to we're advocating for something (Site 2 CASA).

The creation of roles within organisations with specific responsibilities relevant to the development and delivery of programs was also important;

I think that [worker] has created this role of community development officer and I think that would continue. (Site 2)

Creating networks of like-minded individuals had provided opportunities for champions of violence and abuse prevention to share resources and strengthen their efforts;

I interact with [worker] so she sits around the table with the Women's Health Services so even in that group, we have [worker] the multicultural women's health service, and to both of them we say how do we best get value or work with, how do we best collaborate, they have great knowledge and understanding of the issues and needs of their population groups...(Site 1)

Prevention of violence and abuse had become a part of the practice of organisations together with an acknowledgement of the need for both mainstream and disability organisations to engage in community development work alongside their reactive or crisis service provision;

I suppose it is something we've always been very conscious and aware of, that there needs to be more of it and part of our funding is based that we do some community development or community work and that's around doing, providing education, running workshops, professional development workshops and providing that kind of education I suppose and

also even when I first started there were, schools would often ask us to come in and talk to the kids about protective behaviours and things so we've always been, and it has always been considered really important but probably difficult with the huge demand of seeing clients, there's always massive waiting lists and finding the time to put the time and energy into preventative kind of work which we all know it's much better to do the preventative work and then hopefully you don't have to do the...Site 3 (CASA)

A number of the interviewees also talked about the role of people with intellectual disabilities as champions of violence and abuse prevention. As peer educators, advocates and self-advocates, people with intellectual disabilities had played an important part in driving change in the level of commitment to prevention programs on the part of organisations but also in altering some long-held negative perceptions about the need for such programs.

It has certainly met a need and emerging needs were certainly there in terms of, from my perspective as a clinician it really met my need in terms of being able to learn about, well to learn with more credibility around people with disability in terms of the stories and what they experience and then putting that into context of daily life. (Site 3 Com Health)

They are outspoken and speak with conviction about their life experiences (Site 2, Com Health)

They are quite passionate about, and they take every opportunity. (Site 2, Com Health)

The use of peer educators was cited by a number of interviewees as the feature they most appreciated about the LSSL program;

Look the pride that the members [peer educators] have in what they've achieved and what they are doing and that's really evident, the pride in their achievements and feeling of equality and they speak about that, they speak about feeling like we're all working together, it's not a you and us situation. Site 2 (Local Govt)

...we'd been talking about Living Safer Sexual Lives and how important that has become and the things that have come out of that, recognizing the value of the peer educators and what they've gained from it... Site 3 (Dis Serv)

The training, development and use of peer educators has made the rhetoric of the involvement of people with disabilities in decision making and service provision a reality in some organisations;

I wonder if the organisation knows what it has done, that, because there's a lot of talk about people with disability being part of decision making and we see it in reference groups for organisations or councils or in a kind of an obvious structured way...that's important, we're not saying that's not important but I don't think the organisation recognises what it, how it has been able to develop essentially those peer educators and the potential there has been to have roles that are far reaching. Site 3 (Dis Serv)

There's always that need for prompts and whatever but participating and really understanding why it is important for people with a disability to do the program, that just comes through time and time again Site 3 (Com health)

For some service providers, hearing the voices of people with an intellectual disability speaking

about violence and abuse was a challenging experience;

I think initially, because it was so unusual to have someone come and facilitate something who has an intellectual disability, kind of, a bit of maybe discomfort but I think it was, the team walked away thinking gee okay. Yeah. Everything he was saying was valid and important. (Site 3, Com Health)

Hearing issues explained from the perspective of a person with an intellectual disability had made a strong positive impression on this worker;

Because they are talking from their own point of view I guess, and I think staff noticed that, actually more than any other way because they're actually now listening to someone who has an intellectual disability that you notice that actually I haven't heard someone speak about these issues with an intellectual disability before so then they might start thinking, maybe I need to start considering that more. (Site 3, Com Health)

There were benefits for the peer educators and the service provider in working together to deliver the Liver Safer Sexual Lives Respectful Relationships program within this region (Site 3). A greater level of community awareness and a change in the way that some workers within service organisations regarded the value of input from people with intellectual disabilities was an important step in establishing a strong foundation for implementing a successful and sustainable violence and abuse prevention program.

People with an intellectual disability interviewed noted some very important outcomes for themselves in their roles as peer educators and as program participants. Peer educators said;

It has made me more confident Site 3 (Peer educator)

I didn't think it would make me feel this powerful Site 3 (Peer educator)

We can help share stories and learn from each other. Site 3 (Peer educator)

It helps them (program participants) when I share a bit about myself. Site 1 (Peer Educator)

Peer educators in all three sites had promoted the program and their work at a range of conferences including a national self - advocacy conference, a regional prevention of violence conference, a regional sexual health conference, a Statewide preventative health conference and in one site LSSL:RR was the springboard for the Centre for Excellence in Rural Sexual Health (Melbourne University) one day forum. Three peer educators were also involved in the development of a promotional DVD for LSSL:RR (CERSH, 2013) which has now been shown at a number of forums. This DVD was developed as an additional resource for the group after they had contributed to a sexual health educators DVD resource developed by Deakin University (Ollis & Harrison, 2013). Their story of being peer educators has also been included in the VicHealth resource 'Enabling health: Taking action to improve the health of people with a disability' (VicHealth, 2014).

Participants of the LSSL:RR program also benefited from their involvement in LSSL:RR;

I liked the stories [used in the LSSL:RR peer education program]...I can relate to them Site 3 (Participant Focus Group.)

I liked going to the group because at the time I had trouble with my ex...so annoying...so it was good to go and hear what other people knew. Site 3 (Focus Participant Group)

I had been to other women's groups years ago...it was good to do it again and to relate to it...to have this experience again. Site 3 (Participant Focus Group).

“It has sprung tentacles” : linking, integrating, normalising and embedding

For many of the interviewees, involvement individually or through their organisation in the LSSL:RR program had been the beginning of a broader interest in and commitment to a model of primary prevention of violence and abuse. This involvement had ‘sprung tentacles’; reaching across organisations to create links and share resources and developing and embedding new skills and practices in working more effectively to meet the needs of people with intellectual disabilities;

My involvement in this little program has really sprung tentacles all over the place and a lot of people would have heard about this program through other avenues and so then we talk about yes I'm one of the co facilitators and how does it work and how does it go. Site 3 (Com Health)

The importance of making the work done so far sustainable and embedded in work practices of organisations was emphasised by this interviewee:

Certainly for people to recognise the value of it ...it's interesting because in some ways taking time you risk losing the impetus and urgency for something so it is possible for things to trail off but at the same time taking time with it, it is that work flow, I think it is more successful in, as you say, embedding it or making sure that it continues beyond just one thing.(Site 3, Com Health)

I suppose what I'm thinking about and what we're trying to do here in [region] is consider the sustainability of the Living Safer Sexual Lives Program and/or another model or a hybrid or whatever that means that the work continues, the work with people with intellectual disability around rights and prevention of violence and [promoting] safe, happy relationships continues. (Site 2, Local Gov)

Having a developed model was helpful in integrating knowledge about violence and abuse prevention into services and programs;

It would seem to me that a model like Living Safer Sexual Lives could just be kind of incorporated into things that other people were doing so it didn't just become, it becomes something you do every year or every time you get a new client group but you would just build it into the system and things that you do.(Site 1, Wom Health)

Again, services and individuals in partnership were the key to integrating ideas and knowledge about prevention into the everyday practices of mainstream and disability service providers;

I suppose I only wanted to make the point and you already know but there is such a good space for us to work together across the sector and we need to make it happen because there is a need, hopefully we will make it happen with time, a bit of money and initiative I think (Site 2, CASA)

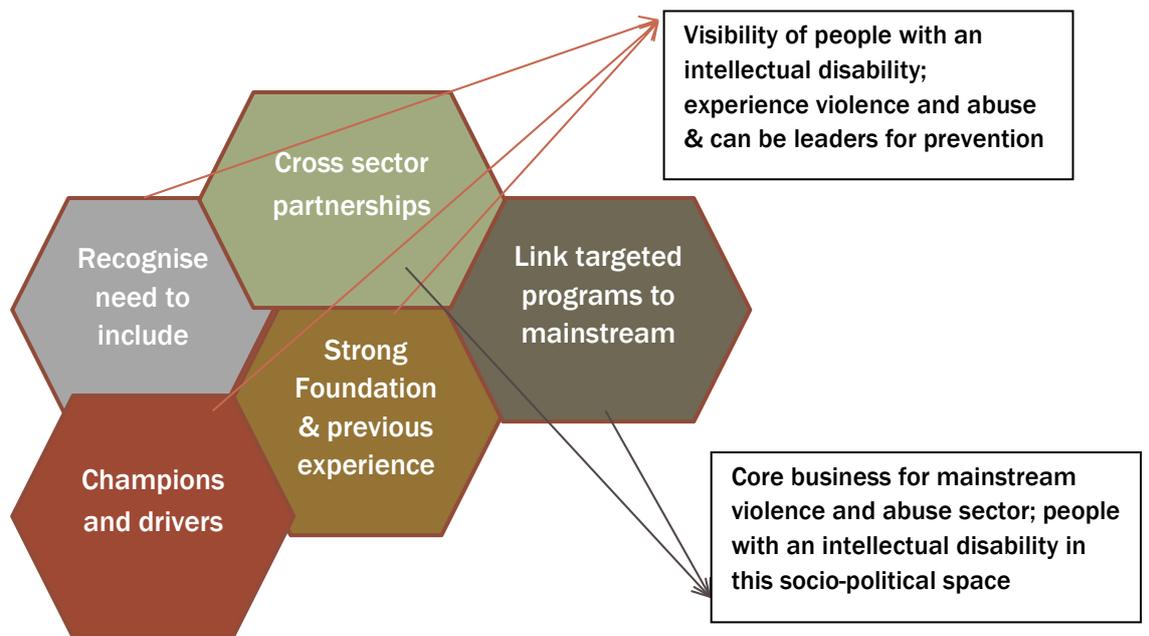
I think it is about communication and identifying pertinent people from organisations to take a responsibility, a role and to grow (Site 3, Com Health)

Discussion

This research sought to develop an understanding about what it took for people with an intellectual disability to be included and taken account of in violence and abuse prevention work. It did this by working closely with three sites where cross sector networks had established a nucleus of interest and activity in this area of work through the LSSL:RR violence and abuse prevention model for people with an intellectual disability. At the centre of this work was a broader question about inclusion of people with an intellectual disability in society as equals, on their own terms and in social and political spaces where they might previously have been absent and where, as this research argues they are needed. It also asked what this kind of inclusion might be able to do to curb the current unacceptable and possibly un-imaginable rates of violence and abuse, in particular experiences of sexual abuse, in the lives of people with an intellectual disability.

The research has found that there is a way of bringing people with an intellectual disability into the social, political and practice space of violence and abuse prevention, described in this report through the five components depicted in Figure 1. It has not however been able to link this in any way to prevention of violence and abuse. It is ironically both a strength and a weakness of some preventative approaches that they are systemic and ecological. Within such approaches many components within and across systems need to be addressed in order to bring about positive change and this change is hard to measure. It will take time and as Mikton & Shakespeare (2014) note a concerted quantitative and qualitative research effort to determine the current size of the problem and the effectiveness of current strategies in reducing and impacting upon this social and public health problem.

Bringing people with an intellectual disability into the space of violence and abuse prevention has been achieved in this research in these three sites. What has been reported about their work and their outcomes does speak to the bigger question of inclusion. As community inclusion researchers cited earlier in this report have noted "...those less visible, less obviously marginalised, in particular intellectually disabled people...are likely to receive less attention" (Hall & Kearns, 2001 p. 240), unless they are seen and 'affirmatively responded to' recognising the 'dual notion' of the lives of people with an intellectual disability as similar to and different from other people in the community and other people with disabilities. The LSSL:RR model and peer education program makes people with an intellectual disability more visible in the violence and abuse prevention 'space' and affirmatively responds to them in violence and abuse prevention work. Through the research this model has been used to advocate for both sustaining this 'exclusive' program and through it building inclusion into the mainstream violence and abuse prevention sector. This process is an important step in building a presence and increasing the visibility of people with an intellectual disability in a socio-political space where they have been previously absent. Figure 2 below indicates how each of the components put forward in this research links to the goals of visibility and access or being 'taken account of' that can support inclusion.



Further research and community development work is needed to continue the work undertaken in this study and through the LSSL:RR model to understand inclusion of people with an intellectual disability in violence and abuse prevention and more broadly their social inclusion. This work can 'elevate' their needs and life experiences in such a way that will ensure their participation and inclusion in the social, economic and political spheres of society but also to do real work to address the barriers they continue to face which entrench their health and wellbeing inequity and social exclusion. Ensuring that they are seen, and recognising the call 'I am here' (Milner & Mirfin- Veitch, 2013), is an important step towards a community in which people with an intellectual disability can be counted, taken account of and included as everyday citizens who matter socially, politically, personally and who should be included in approaches that seek to address their experiences of disadvantage.

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