

Living Safer Sexual Lives

Final Report

Kelley Johnson, Lynne Hillier, Lyn Harrison* and Patsie Frawley

Australian Research Centre in Sex, Health and Society
La Trobe University

***Deakin University**

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Melbourne, Australia: La Trobe University, Australian Research Centre in Sex, Health and Society (ARCSHS).

Tel: +61 3 9285 5382

Fax: +61 3 9285 5220

Email: arcshs@latrobe.edu.au

<http://www.latrobe.edu.au/www/arcshs/>

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Acronyms

AMIDA - Action for more independence and dignity in accommodation

ARCSHS – Australian Research Centre in Sex, Health & Society

ATSS – Adult Training & Support Service

CRU – Community Residential Unit

DHS – Department of Human Services

DSTU – Disability Services Training Unit

LSSL – Living Safer Sexual Lives Project

OPA – Office of the Public Advocate

Reinforce – a self advocacy organisation for people with intellectual disabilities

VAC – Victorian AIDS Council

VALID – Victorian Advocacy League on Intellectual Disability

VCOSS – Victorian Council of Social Services

VUT – Victorian University of Technology

Executive summary

Living Safer Sexual Lives was a three year Victorian Health Promotion Foundation funded action research project undertaken at the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University. The project was established to gain an understanding of how people with intellectual disabilities saw their sexual lives and relationships and to develop interventions from the research that would assist them to lead safer sexual lives. It began with a series of consultations between the researchers and representatives from service provider and advocacy organisations that revealed the following concerns:

- barriers and problems which people with intellectual disabilities face in leading safe sexual lives.
- lack of opportunity which people with intellectual disabilities have to talk about sexuality and relationships.
- lack of consultation with people with intellectual disabilities about sexuality and human relationships.
- failure of research to place sexuality and relationships in the broader context of the lives of people with intellectual disabilities.

The project was undertaken in two stages.

Stage 1: The research phase

The project established a reference group representing people with intellectual disabilities, service providers and advocacy organisations. Twenty five people with intellectual disabilities told their life stories, with a focus on sexuality and human relationships, to experienced qualitative researchers. The story-tellers were from both rural and urban areas and their ages ranged from 19 to 57. At least three meetings were held with each story-teller. The stories were audio-taped and transcribed using only the story-teller's own words. They were then typed up and taken back to the story-teller for checking.

The findings from the research phase of the project revealed that people with intellectual disabilities lead diverse sexual lives and that their desires and many of their experiences reflect those of other adults. The stories were complex, emotional, passionate and joyful. They were accounts of adults struggling with issues around sexual expression and relationships. The stories revealed that many of the story-tellers led secret sexual lives because of negative attitudes towards their sexuality by those around them. In some instances the secrecy of their relationships had led to vulnerability and sexual abuse. Many of the story-tellers told of unsafe sexual lives because of lack of information about sexuality and relationships, poor or non-existent sex education and vulnerability to sexual exploitation. Almost all of the story-tellers reported some form of sexual abuse. This had occurred in a variety of living situations: institutions, independent or supported living in the community or while they were living with their families.

Many of the story-tellers wanted a long term relationship. Some had struggled against community attitudes to achieve this. However not all of the stories were negative. Some were accounts of the joy in finding a partner and in becoming a parent.

Almost all of the story-tellers told of isolation and of rejection by others in the community. There were few opportunities for them to develop relationships or to find safe means of sexual expression.

It became clear that the attitudes and values of those around them was a key factor in deciding the kinds of sexual lives the story-tellers led. Families were often concerned at the possible exploitation of their son or daughter, while service providers balanced uneasily between a knowledge about rights and duty of care.

Stage 2: From research to practice

In stage 2 of the project the stories were used to provide people with intellectual disabilities, families and service providers with workshops and resources designed to help people with intellectual disabilities to live safer sexual lives.

Two workshop modules were developed which used the stories as a basis for exploring issues such as values, attitudes and duty of care and rights. Although the workshops were designed to be implemented separately with families, people with intellectual disabilities and service providers they used similar content and processes. This enabled an integrated approach to sexuality and relationships within a specific organisation or locality. The workshops were innovative in that they were based on the real life experiences of people with intellectual disabilities, focussed on values, attitudes and relationships rather than sexual behavior or problems and were guided by adult learning principles. The workshops were trialled across Victoria with more than 200 service providers, 40 families and 38 women with intellectual disabilities. A process evaluation was carried out and revealed that the workshops were regarded very positively by participants. A workshop manual is being developed for publication.

Information resources were also developed during stage 2 of the project. The stories were designed as booklets in plain English for use with people with intellectual disabilities. Three videos of stories were produced in which actors with intellectual disabilities read stories.

The project also provided input into forums on sexuality and disability and into a discussion paper that made recommendations for state government policy review on sexuality and disability.

Finally work was commenced in exploring how people with intellectual disabilities might find more social opportunities.

The lived experience of people with intellectual disabilities in relation to their sexual lives has not been well documented. The failure by service providers and policy developers to take account of how this group of people see their lives has, in our view, led to the continuation of stereotypical views of people with intellectual disabilities and their sexuality. For many of the story-tellers in this project the values and attitudes of those around them not only prevented them from leading fulfilling sexual lives they also left them vulnerable to abuse and to unsafe sexual practices.

This report documents the findings from the *Living Safer Sexual Lives* project and examines some of their implications for policy and practice. This report is in three parts. Part 1 of the report describes how the research was undertaken. Part 2 discusses the research findings. Part 3 describes how the research was taken into a practice or action stage.

The stories told to the researchers by people with intellectual disabilities¹ were the core and focus of the research and for its outcomes. In this report we have used extracts from the stories to illustrate and to demonstrate the findings. However part of the underlying rationale for the research was the belief that sexuality and relationships were part of ‘the whole story of someone’s life.’ Consequently while the stories have been fragmented to some extent in the body of the report we have also included six of the stories as introductions to the different parts of the report.

The format of this report

The report has three complementary layers:

1. Stories – stories from the participants are throughout the report.
2. Summary information – larger font plain language summaries are at the beginning of each chapter.
3. Body of the text – comprises the bulk of the report.

¹ Names and identifying information of the story-tellers have been changed to protect their privacy.

Recommendations

RECOMMENDATION 1:

Organisations working with people with intellectual disabilities should consult with them in a meaningful fashion in the development of research and policies which have impact on their lives.

RECOMMENDATION 2:

Government and funded non-government day and accommodation services should be strongly encouraged to develop policies in human relationships and sexuality for their consumers. Support from the Department of Human Services (DHS) should be made available for this to happen. DHS Provider Management and the Quality Improvement Branch should be included in new policy development in these areas by ensuring that, as required by Disability Services Self-assessment System, individual needs are met (Standard 2) in the areas of sexual health and human relations and consumers are free from abuse and neglect (Standard 9).

RECOMMENDATION 3:

An independent comprehensive review of existing human relations educational options for people with disabilities and care providers should be undertaken to identify best practice and shortfalls in the system.

RECOMMENDATION 4:

That an integrated health promotion program should be developed as part of the DSTU training strategy for the future to develop learning outcomes for care providers on sexuality and education that includes a focus on health, duty of care, attitudes and values.

RECOMMENDATION 5:

That sex and relationship education should be developed in a way that will provide families, care providers and people with intellectual disabilities with a consistent and integrated form of education. Providing training on an organizational basis so that families, care providers and people with intellectual disabilities associated with the organisation receive simultaneous education is in our view more effective than a more fragmented approach.

RECOMMENDATION 6:

That a training package should be offered by DHS for families to assist them in understanding and accommodating the sexuality of their children.

RECOMMENDATION 7:

That training on rights, attitudes and values should be offered consistently as part of sex education programs for people with disabilities.

RECOMMENDATION 8:

Financial support should be given by DHS to support and extend innovative human relationship and sexuality programs.

RECOMMENDATION 9:

That DHS policy initiatives reflect a cultural shift that clearly articulates the position that health and relationships of people with disabilities are health promotion issues.

RECOMMENDATION 10:

That DHS, OPA and VAC begin discussions as to the development of training modules to assist people with a disability to lead safer sexual lives.

RECOMMENDATION 11:

That DHS should undertake a health promotion campaign around sexuality and relationships issues with key advocacy groups to provide forums for change and increased opportunities for people with disabilities to lead safer sexual lives. That an integrated community education/public information strategy be developed for groups within the disability sector and for the broader community.

RECOMMENDATION 12:

That an action research project be funded by the DHS to investigate current provision of social opportunities for people with intellectual disabilities on a regional basis with a view to identifying best practices in this area and developing new initiatives.

I am an actor and I'm good looking and I can speak for myself

Gina Mason

I can't really remember most of my childhood. My mum had a lot of kids. I grew up in a rough kind of relationship with my family. I don't remember much 'cause I was on so much medication. I was always on tablets as a child.

Mum said I was out of control as a child, attention seeking. I don't know what it was but that's what they always said to me. As a child I never grew up in a normal healthy way. There was always someone watching me.

I went to a school at the corner from my mum's house. One day, I don't know what happened, but the teacher, she did something to me. She slapped me with a ruler and so I stabbed her in the hand with the scissors. And I never went to school after that and she ended up in hospital.

Mum was a slut basically. She was never there for us. My real father, she shot him because her friend Nell and my father Harry were having sex. When my mum found Nell with Harry, they were in her bed. So she got a gun and shot him and he got away from her which was good, but left with a hole in his arm, so he didn't leave on a good note. After my father left she married my stepfather.

The best thing that I can remember about my father is that he used to take us out. My stepfather never took us out. He was always too tired or something. My father used to take us out in his boat and he had motorbikes in the back yard. He loved kids, my father.

I was on drugs until I was older than 10. When I came off it I started remembering all of the bad things. When I was coming off the drugs I realised she just wrecked me, wrecked my whole life you know. One time I got the bashing of my life. I was black and blue, and my mum made my brother help her, and she raped me with a broom. And for punishment they'd make me eat chilli and also in my cereal they'd give me chilli. I didn't have a birthday until I left home, so that's how I never remember things.

My stepfather abused me. He loved me as a child but he later used to abuse me. If my mother wouldn't give him sex, he'd turn to me or my older sister.

When I was small, my brothers and sisters got pocket money, but not me. Once my brother gave me a sherbet lolly and my mother found out and belted me. I don't remember being a bad kid but she had a lot of childhood problems herself. She told us a lot about her childhood.

Every Thursday and Friday night mum would have parties all night and you'd just blend in with that. Play spin the bottle. Mum'd have guys over and sleep with them. She'd have a 23 yr old over and have sex with him. He'd go home and she'd bring another guy in. Sex was just like that.

One day I ran away. My older sister's husband came into the caravan and raped me, and that was my last option. When I left home that day I went on a swing and I stayed on the swing all day saying, 'I'm a good girl, I'm not a bad girl, I'm a good girl, I'm a good girl.' And I was swinging and I was tired. It got dark and I was still on the swing. I fell asleep on the park bench. When I woke up I was dirty and bleeding and a lump on my arm from my mother. She hit me with a knife. I was like a jungle girl. I had a blue dress on and no shoes. I used newspaper to wrap around my feet with string for shoes. An old copper found me and took me to the cop station. They took me back to my mum's house. I was scared. I was like a crushed leaf. The police woman was holding me up. My mum said, 'We don't know her, we don't want her in this house. Take her away.'

They took me back to the cop station and I slept. They promised not to lock me in. I was scared and the first aid lady fixed me up. I stayed there till the next day when they put me in a house. And I never looked back. I stayed with different workers and that and I tried to get my life together. And I went to school but it didn't work. I didn't do nothing for about 4 years. I was on the pension trying to get my head together.

There's a movie about a women's camp, an old movie in colour. A young woman used to always get bashed and raped and she committed suicide. I did the opposite, I just went bang. I'm going to survive this and move on. I took my spirit. I think there was an angel behind me.

I went to Footscray and I joined the Women's Circus and I never looked back. Then I worked with people with a disability and they said, 'Would you like a job in a special theatre?' I had to talk to my workers about it and they liked it.

When you come from a background of hate and abuse you become obsessed with one thing. I'm obsessed with being the spastic little mental retard daughter and I've got to try to get over that. And I go to my counsellor and I say, 'Am I this little spastic retard stupid slut?' And she says, 'No' and I say, 'Then why do I feel like that?' And she says, 'Because it's in your brain and it's in your system.' And I try not to be that person and I want to not be that person but I can't not do it. It's horrible because I'm trying to be this calm person and I can't. I know I've come a long way but still I just feel really bad. I've been smoking heaps so it could be that. Like some nights I only smoke because I don't want to feel angry.

This is what I believe, personal how I feel. Women who have had things done to them see. They are always afraid to go through their life. I'm not afraid any more. I can face the world. And if you knew me when I was 16 or 17 you wouldn't have known me here today. Before I was just this frightened little girl.

I survive by going to counselling. I actually rely on my counselling a lot to keep me on the right track. If I don't go to counselling I feel I'm not on track. I feel like I'm going to get angry but I'm holding back. I feel like I want to get so pissed off, but I have to hold it back

because I might aim it at the wrong person and that's why I want to get back to counselling.

There was no messages about safe sex. If my stepfather couldn't get sex or my brother in law, they would come to me. The message was, 'come here'. Or if Mum was asleep they'd say, 'Stay right there.' They'd get a towel with nothing on underneath and take me into the bedroom. They'd say, 'Your mum told me to punish you now,' chuck me on the bed, hand over mouth, 'I'm going to do it my way.'

My step father got this book out and he used me as his object to show me. He would open the book to a certain page and show me. He was naked and he used himself as an object. He would say, 'Sit on top of me,' and stuff like that. He would tell me to watch him come, and when he had finished to clean him up and stuff like that.

The kitchen is so strong to me. I remember being in the kitchen buttering bread or something, and my stepfather would pull down my pants and do what he wanted, and I'd do nothing, but inside it was killing me. I was crying. When he finished I'd have a shower and go to bed. Oh Yuck!

When I ran away I went to a woman at the Women's Hospital. She said, 'What do you know about sex?' And that's when I got into trouble. I told her everything that happened the way my father used to show me. And she was shocked and said, 'That's not what you show a person.' And I said, 'Yes you do.' And I was touching her and she got another woman in because I was frightening her

because I didn't know. I started crying and then I told her what had happened. I went there for three months. She says, 'You're not going to touch me today are you?' It was so hard.

She helped me with safe sex. She gave me those square yellow things. She said go home and masturbate and so on. And I thought, 'Oh wow, a much better way to learn.'

She had this big dick and a condom and put it on. Yuck. I knew I was gay but I had only kissed women at this stage. I hadn't actually loved a woman.

I've known for a long time I love women. I didn't think about it. It was like I woke up, and it was like a new sparkle in my life. A new life. I just got sick of being a slave girl and I thought, 'My mother doesn't like me but I'll find a woman who does.' I just knew when I was about 16 or 17. Melissa Etheridge has been important for me. She has balls. I like her music. Her voice is like water, like the ocean. 'Prisoner' was always my favourite show. The women were beautiful. I knew there were good women. I slept with a girl when I was 17 but we didn't have sex. The first woman I had sex with was the woman I'm with now, Cathy. She is the one who taught me to relax when I had sex. I'd have a bath and candles and then, 'Wow oh Wow! What a wonderful thing!'

Cathy and I were made for each other. She looks after me. I can't read and write very well and she helps me. She has been there from the start. She is always there for me. Loving a woman is like loving everything you want in life. I've never liked a man in my

whole life. I think to me loving a woman is like loving yourself. Women have a lot more than men. Honesty, open and caring. And their bodies! Oh yeah their bodies!

Sometimes I don't want to be myself. I can be someone else. Melissa Etheridge. 'But who am I?' I ask myself. I don't know yet. I know I am an actor and I'm good looking and I can speak up for myself.

Things are going well here, but how long is it going to last? I'm always acting, so how can I know who I am? I've learned a lot from my story and I can help others with it.

It doesn't worry me much

Luigi Favoloro

My name is Luigi and I live at Burnside in Brunswick. I've been there seven months. The place where I'm livin' now is my favourite place because people there understand me. They understand how I feel. I share my room with another person. The person that I share with is all right. He doesn't *really* worry me really. It's too many people living in one house. They get aggro. If there's something wrong they get upset. They yell, slam doors. I get a little bit scared. Something might happen. A fight might break out.

I've worked in several workshops, different workshops. The work there was too easy for me. After the workshops, I went to a job doing cleaning. Factories. I liked it because the job was easy to do. Cleaned when the factory was shut. Now I'm unemployed. So I'm lookin' for another job.

My closest friend is Neville. I've known him for about 15 years. Sometimes I see him once a week. Sometimes, twice a week. We watch TV, have a cup of coffee. We might go out. Go out. The city. Look at the shops. If one of us wants to go to a movie, we go to a movie.

Sarah is a girl that I like. I met her at school years ago. We go out. Sometimes she wants me to go to her place. Sometimes she'll

come to my place. She lives at Bundoora. I catch public transport to see her. The bus. And I have good friends where I live.

I have actually got a mum and dad. I've got two brothers and one sister. I see them sometimes. We just talk. Go out. We do a lot of things. I don't get much time these days. I don't get much time to see them. My mum and dad are Italian. I speak Italian.

When I was a child I lived at home with mum and dad. They used to fight every now and again. They used to fight. Problems at work, problems elsewhere. I got scared. I would go for a walk or something, or go in the city or something.

I had a bike, to ride around on. A bike. That was good. I went to Ferndale Special School. I was happy and sad. I used to have reading and writing. That was good. Tuesday we'd go for a swim at the City Baths. There were bad things. Fighting at school. Fighting. The big boys. I felt no good. I don't know why really. Frightened. They might hit me yeah.

Since I was 16 I went to different places. Different hostels. Special accommodation. I went to other places when I was 16. I felt a lot calmer. Because with the family they used to fight a lot, scream a lot, and see, a lot of Italian people right, they fight a lot. They fight and that's not my style, that's not my scene. That's why I left home because of arguments, fighting....

I lived in three or four institutions. Ferngrove when I had the breakdown. It was a bit scary. If you bang a cup they locked you

up. Some good things and some bad things. We were walking along with each other, that was good. And the bad part was the staff. They grab you and they'd lock you up for one night lock up. For just swearing, and swearing at them, arguing with them.

I was put into another institution but it was a boy's home. No good things there. The bad thing was too much staff. They wasn't very nice. They used to get upset with you, and they used to get upset. Send you to your bedroom. It was OK in the morning.

I was put in Pinewood when I was about 13. Because I used to run away from home and school. Because my dad got divorced. Some years ago he got divorced. And I've been tryin' to get hold of me real mum. And my mum and dad put me out of the house. Because of things I didn't do.

In these institutions there was sex. Between the staff and the residents, I got told. But I wasn't gonna have sex with them. I'd tell them. I'd tell them to go away. They wanted to stick their dicks up the bum. I felt no good. It was a little bit scary saying no to them. Feel horrible. Locking me up one night. The next day let out. Next day. No staff that I liked.

I can't remember how I learned about sex.

Toilets is the place where sex happens. Most of the time that's the place where it takes place. Sometimes men come up to me. They want sex off me. Sometimes they give me things. One guy gave me about \$10.00 because he wanted sex. I had to masturbate him.

I felt okay about that. Because at the time I didn't have a girl friend. I'd rather have sex with a girl. A girl's got a good touch. Wouldn't have sex with men if I had a girlfriend. I keep things with men private to myself.

I like to get a girl of me own and we can have a bit of fun together. I met a girl a long time ago. She wanted to have sex with me. Because she wanted to. Then I wanted to. So we sat there and talked. And then after that she wanted to have sex with me. So I said, 'Alright, let's have sex, both of us.' We did lots of things. We both had sex. It was a good thing. We both had sex. It was nice. Still see her.

I know nothing about AIDS. But plenty of people have talked about it. You have to buy condoms at the chemist. They are for your thing, you know your dick. They stop sperm to come out. I don't know why. Good question that.

Part 1 - Living Safer Sexual Lives: Action Research

Part 1 of this report explores why and how the research was undertaken. The decision to undertake research which involves an exploration of intimate and private aspects of someone's life is not one to be undertaken lightly. In this instance it appeared justified because of concerns about the sexual safety of people with intellectual disabilities, their support for the project and a commitment by the researchers to action oriented research which would ensure outcomes designed to assist people with intellectual disabilities to lead safer sexual lives.

Chapter one

In the *Living Safer Sexual Lives* project we set out to understand better how people with intellectual disabilities see their relationships and sexuality. We began by talking with people with intellectual disabilities, service providers and advocates. They all thought that this research was important because often people with intellectual disabilities are not heard about issues which affect their lives. Service providers and families are often very anxious about sex and relationships. There are many reasons for this. Sometimes this is because of the way people with intellectual disabilities were seen in the past. Some people were put in institutions because of fears that they would be a danger to themselves or others because of sexuality. As more people with intellectual disabilities have come to live in the community families and service providers have become anxious that they may be sexually abused or hurt. And sometimes service providers and families do not realise that relationships and sex are important for people with intellectual disabilities.



Sexuality and intellectual disability : Current context

This report describes the work carried out by the *Living Safer Sexual Lives* project.

This three year project has involved researchers working with people with intellectual disabilities to document their life stories. Each story was written with a strong emphasis on sexuality and relationships. The stories have since been used to develop:

- innovative workshops with service providers, families and people with intellectual disabilities
- information for people with intellectual disabilities
- policy development and
- action strategies to assist people with intellectual disabilities to lead safer sexual lives.

This chapter explores why we decided to undertake this project. It grew out of concerns of researchers, service providers, advocates and people with intellectual disabilities themselves who met to discuss sexuality issues. They were concerned with a number of different issues: the consequences of the regulation of sexuality for people with intellectual disabilities, the absence of that group's voice in published literature, and the evidence that this group of people were more likely to be subject to sexual abuse than other groups in the community.

Regulating sexuality and disability

Sexuality today is highly plastic. It represents a huge field of potential desires and is invested with many different meanings. Sexuality is the object of intense cultural fascination. It is also highly contested.

Its contestability opens the way for numerous strategies aimed at defining and regulating what the sexual comprises.

(Harding, 1998; p.1)

Our sexual freedom is enjoyed only within narrow bounds defined by government regulation, law and community 'morals' and values. In our communities heterosexual sexuality remains the most uncontested form of sexual expression. Gay

men and lesbians continue to find their sexuality challenged or marginalised. But the regulation of these groups relates to sexuality itself. There are other groups in our society where sexuality is negated, marginalised or regulated because of the inherent characteristics of the group. For example older people, children and people with physical disabilities are subject to particular social prescriptions and proscriptions in relation to their sexuality. Moreover for many of these groups socially sanctioned sexuality will be or has been part of their lives. However, this is not the case for people with intellectual disabilities.

The reasons for the marginalisation and regulation of the sexuality of people with intellectual disabilities are both historical and contemporary and are closely related to eugenics arguments prevalent early this century, to the fears associated with the increased rights of people with intellectual disabilities and to prevailing attitudes towards people with intellectual disabilities.

A danger to society

As part of the eugenics movement people with intellectual disabilities were constituted as posing a threat to the social fabric of society and to its future genetic survival (Trent, 1994; Rose, 1979; Wolfensberger, 1975). Within such a framework this group of people was seen as sexually threatening both because of characteristics attributed to them such as immorality, anti-social propensities and lack of productiveness and because of the belief that they would have many children who would themselves have disabilities. The consequences of the theory led to the institutionalisation of many people and to their sterilisation (Trent, 1994; Rothman, 1990).

While eugenics has lost its force in its original conceptualisation, it can still be heard in the recent debates about the nature of intelligence and its social implications (Fraser, 1995; Hernstein and Murray, 1996; Jacoby and Glauber, 1996), in some of the expressed anxieties and fears of service providers and families about the sexuality of people with intellectual disabilities (McCarthy and Thompson, 1995; Rose and Jones, 1994), and in the emerging debates about genetic engineering (Bailey, 1996).

Increasing freedoms

The last 20 years has seen a change from a medical discourse of disability in which people with intellectual disabilities were seen as sick or as patients to be cared for and protected, to a rights one in which they are recognised as citizens. As a consequence of this change, more people with intellectual disabilities now live in the community, are engaging in paid work and are living relatively independently (Beyer, 1995; Fitton and Willson, 1995; Johnson, 1998; Taylor, Bogdan and Lutfyya, 1995). However in spite of these changes the issue of sexuality remains particularly problematic for both people with intellectual disabilities and for those who are connected with them. Ironically it is problematic in part because of the increased freedoms which people with intellectual disabilities now have. Such freedoms have increased anxieties among carers about the possibilities of sexual abuse and exploitation and have raised controversial issues of duty of care for service providers.

Prevailing attitudes

Shakespeare (1996) comments:

Policy and provision around disability often neglect to consider sexuality as one of the basic human needs. While housing, transport, education and other needs are dealt with, albeit inadequately, consideration of social and sexual factors is not high on the welfare agenda. Disabled people in day centres or residential homes are often denied privacy, or the opportunity to form emotional or sexual relationships. This failure to prioritise matters which are highly significant to most adults, reflects a failure to consider disabled people as fully human.

(Shakespeare, 1996; p.87)

McCarthy and Thompson (1995) attribute this neglect of sexuality by service providers to 'failing to acknowledge the reality of people with learning difficulties sexual lives' and 'by being ill informed or even ignorant of wider debates on sexual behaviour and gender' (McCarthy and Thompson, 1995; p.278).

In this project we were interested in exploring with people with intellectual disabilities how they saw their sexual lives and relationships and how they experienced the regulation of their sexuality. We were also interested in discovering the consequences of such regulation for individuals.

Sexual abuse and exploitation

Research findings have revealed that women and (to a lesser extent) men with disabilities are more likely to experience sexual abuse than other groups in the population and to be vulnerable to sexually transmissible diseases (Carson, 1994; Johnson, Andrews and Topp, 1987; Millard, 1994; Senn, 1988; McCarthy, 1999; Brown and Turk, 1992; Turk and Brown, 1993).

These findings have increased the anxiety of some carers sometimes leading them to ignore the issue of sexuality or to take protective measures in relation to individuals and in some instances, provide sex education. They have also raised questions about why such abuse can continue to happen in an environment where service providers are so concerned about the issues.

This project aimed to reassess how people with intellectual disabilities themselves saw issues of sexual abuse and exploitation. We were particularly concerned to identify the level of information that this group of people had about safe sexual practices and the extent to which they could put such practices into effect.

The lack of a voice

The research evidence reveals that there are few publications which give a voice to people with intellectual disabilities about their sexuality and relationships. The small amount of in-depth qualitative research available from the perspective of people with intellectual disabilities has been mainly carried out in the United Kingdom, Thompson (1994; 1997) and Cambridge (1996; 1997) have undertaken research primarily with men who have sex with men, and McCarthy (1993; 1999; McCarthy and Thompson, 1994; 1995) has explored the meanings of sexuality for women. The people involved in this research have come primarily from institutions, hostels and family homes and have been referred to counselling services because of difficulties relating to sexual behaviour or experiences. The views of people with intellectual disabilities who have not been referred for counselling have not generally been known.

Although making an important contribution to the field, the English research has not sought to place sexuality in the broad context of people's lives. Further, there has been no research in Australia which has sought to explore sexuality and intimate relationships from the perspective of people with intellectual disabilities.

We believed it was important to hear the voices of people with intellectual disabilities directly in talking about sexuality and relationships. Previous research undertaken at ARCSHS revealed that stories told by marginalised groups often differed from the perspectives of those concerned with regulating them.

***Living Safer Sexual Lives* project: Background**

Sexuality and relationships are sensitive areas of discussion for all of us. They can be even more so for groups who are marginalised and devalued in society. Working with people with intellectual disabilities raised further issues about informed consent, decision-making and communication. We were also committed to developing tangible outcomes from the research. These issues and concerns informed the conceptualisation of the goals for the project and led us to formulate (with the reference group) a set of key principles which would guide its progress.

The goals of the *Living Safer Sexual Lives* project

The goals for this research emerged from discussion with people with intellectual disabilities, service provider organisations, and advocates. The *Living Safer Sexual Lives* project aimed to use life stories contributed by people with intellectual disabilities to provide the following:

- A contribution to the understanding of the lives of people with intellectual disabilities and the society in which they are living with a particular focus on sexuality and relationships.
- Workshops which would be based on real stories and would aim to assist people with intellectual disabilities to live safer sexual lives.
- Workshops for families and service providers which would educate them about how people with intellectual disabilities saw their sexuality and relationships.
- Accessible resources which would give people with intellectual disabilities information about safe sexual practices and resources.

- Policy input to improve the policies and practices currently in place.
- Other activities as dictated by the findings from the stories and work of the reference group for the project.

Guiding principles

To ensure that we achieved these goals and because of the sensitive nature of the research we began with a set of principles which would guide, inspire and sometimes frustrate us throughout the research process. In the first instance these were formulated by the researchers but were later revised and added to by means of the reference group, during the project.

- Fostering partnerships between the academic institution and community based organisations working with people with intellectual disabilities was a priority.
- The participation of people with intellectual disabilities was essential to the project.
- Unwaged workers and story-tellers were to be paid for their contributions to the project.
- Story-tellers were to be supported emotionally and psychologically in telling their stories.
- The researchers involved in story gathering were to be supported emotionally and structurally in work which we knew would be emotionally and ethically demanding.
- The research was designed to minimise possible emotional, psychological or physical harm to people participating in it.
- Sexuality was to be placed in the wider context of an individual's life and not seen as something separate.
- The researchers and those participating in the project designed it in the awareness of the sensitive and intimate nature of sexuality.
- The stories contributed to the project should be in the participants' own words.
- The project should be based on the stated needs of people with intellectual disabilities.
- Action should accompany the research and be directed at changing unjust or oppressive policies, practices and social structures and at increasing the knowledge about sexuality of people with intellectual disabilities.

Conclusion

The research discussed in this report sought to fill some of the gaps in our knowledge of how people with intellectual disabilities see their own sexual lives and developed strategies to assist them in having more fulfilling and safer sexual expression and relationships.

Chapter two

Living Safer Sexual Lives happened in two stages. In the first stage we set up a reference group representing people with intellectual disabilities, service providers and advocates. We believed that it was very important that people with intellectual disabilities were involved in the project. So we used plain English in the reference group meetings and minutes and made sure that unwaged workers were paid for their time. In the first stage of the project the reference group helped to find 25 people who told their life stories to the researchers. They also helped with designing advertising and with the kinds of questions we might ask. After we found the 25 people (whom we have called the story-tellers) the researchers met with each person at least three times and the stories were sound taped. Then they were written up and taken back to the story-teller.

We knew that some of the stories people with intellectual disabilities would tell us might be sad or painful. We made sure that they could get help and counselling if they needed it. After we listened to each story each of the researchers met with another researcher to talk about the story. This stage of telling and gathering stories took a long time. At the end of this stage we had 25 stories.

In the second stage of the project we used the stories in workshops to provide information about sexuality and relationships to service providers, families and people with intellectual disabilities. This stage is described in Chapter 5.



How the research was done

Living Safer Sexual Lives occurred in two stages. The first was concerned with supporting 25 people with intellectual disabilities to tell their stories, then writing them and returning them to the story-tellers for consideration. The second stage was concerned with using the stories to design action strategies to assist people with intellectual disabilities to live safer sexual lives. This chapter is concerned with how we went about undertaking the first stage of the research. (For an account of the second stage see Chapter 5).

The reference group

At the beginning of the project a reference group was established to assist in its development. Representatives from self advocacy rights organisations and service provider groups were included (See Appendix 1). The reference group for the project met regularly, at two monthly intervals throughout the project. Changes were made to meeting procedures to ensure that they were as accessible as possible.

In particular all agendas and minutes were in plain English and large type face, reference group members could talk with a researcher between meetings, the chair person was required to ensure that each person had a chance to speak, all unwaged workers who were members were paid and meetings were practically focussed and reasonably casual in style.

The reference group provided guidance, criticism and support throughout the twelve months of the research phase. In particular they:

- helped to design the story telling sessions held between researcher and participant
- assisted in finding people who wanted to contribute
- identified language about sex which was clear and relevant and not offensive
- designed the advertising, ran recruitment, interviewed researchers on radio and advertised the project through advocacy organisations
- resolved ethical issues involved in working with people with intellectual disabilities; and

- conveyed forcibly what people felt comfortable and uncomfortable with.

Over time some members left the reference group but at the end of the three year project there remained a large group of enthusiastic members including people with intellectual disabilities, who had been with the project from the start. One reference group member commented:

The LSSL researchers genuinely attempted to involve people with an intellectual disability in the project. This is, unfortunately, still quite rare. I strongly believe that there should be 'nothing about us, without us'.

And that people with disabilities have a real expertise to share – an expertise that is often under-utilised, even when we do get a seat at the table.

Too much jargon, difficult to understand meeting procedures, inaccessible minutes, power imbalances - they make it hard for people with disabilities to contribute. In the LSSL project these barriers were kept to a minimum.

(Reference group member with a disability)

Designing the research: Towards participatory action research

This research was based on a participatory action research model (Grundy & Kemmis, 1981; Kaplan & Alsup, 1995; McTaggart, 1997). The literature on Participatory, Action and/or Participatory Action Research (PAR) is extensive and a review of this literature is not possible or necessary here. Rapoport describes action research as:

A type of applied social research differing from other varieties *in the immediacy* of the researcher's involvement in the action process...[It] aims to contribute both to the practical concerns of people in an immediate problematic situation and to the goals of social science by joint collaboration with a mutually acceptable ethical framework (1970, in Foster, 1972, p. 532).

Kaplan and Alsup are much more prescriptive in identifying the core components of Participatory Action Research as including: '...active and democratic community participation, non-traditional power relations, use of critical theory, emergent design, praxis, a focus on empowerment, and science as a tool for change' (1995, p. 41).

In this common definition community members are involved from start to finish, from defining the problem to disseminating results. Kaplan and Alsup echo a strong theme in the literature (see Hall, 1979 for example) in seeing this approach as

particularly suited to research with minority groups. *Living Safer Sexual Lives* included elements of both these definitions. Sometimes we were not able to include people with intellectual disabilities fully within the research because of the sensitivity of the topic, the smallness of the world in which people with intellectual disabilities live, methodological difficulties and the nature of the disability experienced by some participants. Finally we sometimes did not include people fully because we were unsure of how to do it at the time.

Sandra Hollingsworth has described collaboration as ‘...a complex and unpredictable swirl of power relations, and of constantly changing selves’ (1998, p. 56) and over time the knowledge and skills of all participants in the research increased. Our collaboration was very different at the end of the project compared to its beginnings (see Harrison et al, 2001).

However people with intellectual disabilities, service providers and advocates were involved in all stages of the research. People with intellectual disabilities were also involved in writing and editing the stories and in making decisions about what would be included in the long and short versions of the stories. They supervised the development of booklets coming from the project and participated as paid actors in the videos (see Chapter 5).

Living Safer Sexual Lives was particularly concerned to move research into action and practice. We began the research with a commitment (and with funding) to develop practical outcomes. The work arising from the research is described in chapter 5.

Designing the discussions

Talking about sex with a stranger is not easy and it is particularly difficult to do when sexual abuse or negative attitudes have dominated sexual experience. There was also a power imbalance between the story-gatherer and the story-teller. Consequently a lot of time and work went into designing the methods for gathering stories.

Story-tellers met with a researcher at least four and sometimes five times. The length of each meeting was negotiated by the two people concerned. Sometimes the

meetings were relatively short (1-2 hours) and sometimes they lasted for half a day or more. Not all of that time involved discussion. Other activities, for example shared travel, a meal, coffee or a walk were often included.

A set of core questions were designed in collaboration with the reference group. We encouraged people to talk about their lives generally, their childhood, families, work, social lives and accommodation. They discussed how they found out about sex and the kinds of relationships they had had (if any) including the good and bad experiences. These discussions were audio-taped and the researchers kept journals.

People telling their stories were encouraged to initiate themes and discussions which flowed across many different topics in any one session. Researchers could engage in discussion, answer questions and be self-disclosing to the point where they felt comfortable. (The same safeguard was made very explicitly to story-tellers). (For a more detailed account of this approach, see Johnson, 1998).

Finding the story-tellers

Finding story-tellers proved to be one of the most difficult parts of the first year of the project. We had thought on the basis of the enthusiasm of the reference group that it would be easy to find 24 people (12 men and 12 women) who were sexually active and able to give informed consent and who would like to talk with us about their sexual lives. We sent out advertisements through advocacy organisations. We went on radio programs for people with disabilities. We spoke to groups in colleges and advocacy organisations. Our reference group members used their networks to locate people. Of these the last three strategies proved to be the most successful.

There were a number of reasons for our difficulties:

- It is difficult for anyone to discuss sex and relationships and for some people with intellectual disabilities the taboos about doing this make it even more difficult.
- It was difficult for many people to go through the barriers to find us without assistance from someone else. For example they had to ring us and talk with us about the project.
- While some workers and advocates were very supportive of the project, others were not. When some people did want to participate and were able to give their

consent they were sometimes prevented by parents or by workers. When this happened we withdrew.

- Some people had had very bad sexual experiences and they did not want to discuss them.

In the end 12 men and 13 women contributed their stories to the project (for details of the story-tellers see Chapter 3).

Supporting the story-gatherers

Three women and one man undertook the task of supporting people to tell their stories. The women worked only with women story-tellers and the man worked only with men. All of them were experienced in working with people with intellectual disabilities and had some experience in working on issues about sexuality and relationships. An evaluator was part of the research process.

Two training days were developed by the researchers to support the story-gathering process. We used written materials about oral history research to assist us in developing a common approach. The training days were also used to resolve individual concerns about the project and to explore ethical issues of concern to all the researchers.

The researchers worked in pairs to monitor and support each other. After each discussion or encounter, the researcher would contact his/her partner and debrief. This was particularly necessary because many of the issues raised in interviews were upsetting and sometimes frightening. The researcher's partner would also read the transcript of the discussion or encounter and offer feedback, ideas and comments before the next discussion.

Each researcher kept a journal of the story telling sessions. This was shared with their partner and was then included in the research data.

Supporting the story-tellers

Story-tellers were known only to the researchers and they had the right to withdraw at any point in the process. One person did so. A preliminary interview was held with each potential story-teller to talk about the project. An advocate could be present at this interview if the person with a disability wished. Each person was given time to think about their involvement between the initial interview and the first discussion. Because we knew that some people would find it difficult to talk about sexuality, or would recall abusive issues which had remained unresolved, we gained the support of a sexual counselling service which guaranteed us immediate counselling for anyone who needed it. Funding for this was provided in the research budget. No-one in the research wanted to take up this offer. Story-tellers also had phone numbers for a contact person for the project.

Care was taken by the researchers at the end of each session to check if the story-teller was comfortable about continuing and was not feeling upset by the content of the session. We made sure that the session did not end on an upsetting note and were careful to finish the conversation with an issue about which the story-teller felt confident and reasonably happy.

Writing the stories

Transcripts were made from each story telling session by the person working with the story-teller. We believed it was important that the transcription be done by the researcher or with his/her involvement both because of the intimacy of the topic and because sometimes people were very difficult to understand.

The length of the transcripts for each session varied from 15 to 80 pages depending upon the people involved. Once the transcripts were complete stories were written from them.

Three researchers were involved in the story writing. The stories remained in the words of the story-teller. Only minor grammatical changes were made to transfer from an oral to a written form. Texts were shifted in order to give the stories coherence for a reader but no other changes were made. Identifying information about the story-tellers were changed to ensure their privacy. Two versions of each

story were written. One was a longer version that included more detail of the person's life. The shorter version was designed for people with intellectual disabilities and for use in the workshops developed from the research. In the action phase of the research the shorter versions have been used.

When the stories were in draft form they were circulated to the reference group for discussion. A series of workshops with the reference group was held over a period of three months. At each workshop reference group members would be asked to comment on four stories. They analysed the content of the stories to ensure that they made sense to new readers and were not repetitious. Themes emerging from the stories were discussed and possible strategies for the action stage of the project were developed. Finally one member with a disability became a paid co-researcher editing the stories for clarity, repetition and representation. The stories were then given back to story-tellers for final comment and approval. No story-teller withdrew from the project at this point and the changes made by them to the stories were minimal.

Conclusion

While the research sought to be participatory in nature and to give a voice to people with intellectual disabilities about their lives the question remains: Whose story is it?

The researchers commented:

The stories were/are central to the process. There were concerns all the way along about not doing violence to them – maintaining their integrity. There will always be problems with representation because you can't just present them as is. Also we categorise them, choose titles from the text, shorten them *etc.* This inevitably changes them. They are however still authentic in the sense that both the story contributors and other people with an intellectual disability recognised themselves in the stories. The stories were never jointly owned. Contributors had a choice about adding to or changing their story or withdrawing it. However there was never any intention that we would not have final say over what was to be done with it.

A self-advocate involved in the reference group commented:

Whose story is it? The researchers, and those of us, who helped edit the stories, made lots of decisions – what would be included in the written stories? What would be left out? How much would we fix people's grammar? Would we add words to make the stories clearer? How would

we change the stories to make sure people couldn't be identified? What name would people be given? Where would we say they lived and worked? And so on.

The people who told us their stories could have been more involved in shaping the written versions. Some people may not have wanted that – but people should have been given the choice I think.

Participation and the ownership of research material remain contested issues. *Living Safer Sexual Lives* tried to approach these issues as honestly and as ethically as possible.

You're in my world

Vicki Mulholland

I live at Dawson St. It's nice. Four people live there. Jim, Mary and Josie. Can't stand Mary and Jim. Josie's all right. There's staff. Rachel Jones, Naomi and Vronnie. I smacked Vronnie's face. I don't know why. Something on me mind made me do it. I was feeling angry. Dawson St is the best place.

Do nothing during the week. Go to women's group, I don't know what we do. Talk about things. Can't get a job. I'm on a pension.

I went to Morris House. I was sick. They used to look after me. Make sure no-one hurt me. The police sent me. I was lifting up me dress. Wanted sex.

Mum and dad are all right. Me brother took the house. Me brother lives with mum and dad. The brother that was in gaol. Bernard, Blue. And there's Eric. I can't go back home. Blue's there and I'm frightened. I can't go and visit mum and dad when he's there. He used to hit me. Punched me on the back. He still hits mum and dad. He gave Eric a black eye. He used to knock dad around, Blue. He hit dad. That makes me upset. I reckon they should get a restraining order. I'm angry about Bernard. It's pretty rich when you can't go out and see your mother, 'cause your brother's there.

Bernard's not allowed near me. The police told mum. Last year he threw a knife at me. Last Christmas when I went out there. I told

Fiona O'Reilly. She's a policeman here. He threw the knife at me back. I'm frightened to hit him. He's strong. He gave Eric a black eye. He knocked mum and dad over. They'll ring the police if he comes round.

Eric lives with me mum and dad. In my bungalow. That used to be my bungalow. Eric took it from me.

It was all right growing up in Ripley. I got a lump. When I was a little baby the nurse dropped me. And me hip's bigger than the other hip. People called me Hoppy. Sylvia knew about it. They used to call me Hoppy. I went to central school. Ripley Central School. Had friends there. Sarah Wilson. She's married now. I used to go swimming by meself when I was a kid.

I found out about sex by meself. In me mind. I went to a home when I was 14, I lifted up me dress in Nixon St. Just playing on me mind. It was something to do. Wanted sex. The police came along and took me to a home in Tallis, a Girls home. I don't remember what happened there.

I was fourteen when I found out about sex. The first time was at home. Ronnie Tallis. The boy Tallis. He raped me. And a white man.

He put his dick up my vagina. He said, 'You bitch.' I didn't tell the police. I told mum and dad. They didn't say anything. He hurt me.

Some men used to hurt me down below. They used to grab me hard. Aborigines used to shove bottles up me. It hurt. I had sex with them. They had condoms. The Aboriginal women belt me and shove a beer bottle up me. They took me \$50 and bought beer and smokes and I never even got beer or a smoke out of it.

Mike Thomas. He was a nice man. I miss him. I lived with him. He used to sleep with me in the nude. He used to give me sex. He put his penis up me. He used to wear condoms. Yeah. He used to give me sex. I never told mum and dad about Mike. They didn't like him. They didn't want me to marry him. I wanted to. He didn't want to. He left me and went back to Carrington. He left me.

I had two children. The Welfare took them. I had one when I was 17. No, one when I was 19. Show bloke done it to me. And when I was 27 an Aboriginal interfered with me. The Welfare took 'em. I haven't seen them. They'll never find my kids. I had two babies. I had one from the show bloke and one from the Aboriginal bloke. Tommy Baker. He was nice but he was an aboriginal though. He wasn't nice to me. He took all me clothes off and gave it to me. He's dead now.

I lived at home. Mum and dad didn't want the baby. Dad might like the white bloke, the white child. He don't want the half caste. I felt awful 'cause I had a half caste baby. Half caste baby. He was a boy. Gave the first baby a hug but not the second. I miss them. Sylvia don't want me to have another baby. I can't have another baby because my periods have stopped.

Sylvia won't let me have sex. No-one will give it to me. I like it. Haven't had sex for a long time. No-one will give it to me. I can't bring men home. Sylvia might get to know. She wouldn't say anything. I might get into trouble. It's up to Sylvia what I do.

Sylvia said, 'When you get angry, go in your bedroom.' I go in the bedroom and shut the door. 'Come out when you're not feeling angry.' It works. I wouldn't hurt you. You're in my world. Sylvia is the most important person in my world.

I know what stops you having a baby. Condoms. Who's going to buy me them? I heard about AIDS. It's a germ. It kills you. Get it off men. If I have sex I have to have a condom. Sylvia gave me condoms and she taught me how to put them on. But I've got no-one to give it to me.

I've got small dreams

David Warren

A car accident happened when I was 10 weeks old. I flew out of the car. One side of the brain got damaged. I mean hit, and the other side got damaged. So right down the left hand side, my eye, my arm and my leg have been damaged.

I am a painter in an arts company. We did two exhibitions a year. The company's for people with intellectual disabilities. I've only been there for six months. I work at the pub voluntary. Behind the bar. I do another part time job as well. Smith's Engineering. I do reception there.

I have a few friends but I'm always contacting them, they're not doin' the same, they're not doin' the same to me. Meaning I've got friends, yeah, but it's always: 'Give me a phone, give me a phone.' It's always on their terms not on mine. And it's not often people drop around and say, 'Oh I felt like droppin' in. Oh let's do something.' People talk to me at the pub but it's only just a conversation. But you can see sometimes it is difficult to keep a conversation going. I know what to try, you know what you want to say, but it's kind of hard to put it into words.

I've got this flat and people say to me you know, 'Who's the relative that died?' But I just sort of saved up. And people go, 'How

old are you?' And they think that you're older because you own a place.

I meet women through school and through activities and that. I've had a girlfriend. No sex, touching, yeah, but not sexual. I've had a relationship but I've never like had a sexual relationship. We see each other, hug and kiss and that was about all.

I mean that sort of relationship. Cuddle. With me it doesn't go any further than that. I think, 'That wasn't the right person' or I think that we weren't suited for each other. Because it's hard to find someone suited for you in a relationship. I enjoy people's, females' company. I liked their friendship. I don't really think about having sex with someone, but when I do I know it'll be good.

I was thinking of going to a massage parlour but it's over a hundred dollars, and I reckon sex, it depends on the human being, but I reckon sex is free instead of buying it. I've always wanted to try and experience sexual relationships but it hasn't been the time or I haven't found someone.

I see my family on and off. Let me say that it's sort of hard to have a disability in the family, when you're trying to be like them and you can't. It feels like with my father and brother that whatever you do it feels like you've done something wrong. So I'm always apologising which I don't need to.

I went to a few primary schools and I went to the special school, just to see the difference. But because I'd been brought up in a

usually normal environment, I actually went down, because the education there was easy.

I learned about sex through school, but no one actually knew. No one actually told me about it but I asked a teacher. The teacher didn't know what I was talking about. I didn't know how to put it into words. I sort of left it for a while and then I went to another school where they did sex education, but that was only one or two lessons. I could find out about sex by going to the library, or book stores. I could talk to friends, but I don't know. When I was young I tried to speak to my doctor about sex, but he didn't understand and I was almost in tears, like, like he say, 'Talk, talk, talk,' but you just can't get it out.

I don't put my hopes up too high because I know that they won't come true. I wish they could come true. I wish I could drive a car. Driving a car is sort of freedom for you isn't it? There's a dream that I'm going to do soon because I want to. I want a joy flight in one of those tiger moths. I'm going to do that. I'd like to get married some day, but I haven't met anyone yet. It's difficult to do that. I used to have high hopes and then that's been crushed, so I have small dreams. I've got lots of small dreams.

Part 2 : The stories

The stories were central to the research project and are central to this report.

We believe strongly that the stories should be read and thought about holistically. Too often the lives of people with intellectual disabilities are fragmented. Their IQ is measured by tests. Their past is often not known by those around them. They may be known in one way by the people working at their CRU and in another way by the people at their employment or day programme. There are few opportunities for them to be known as a 'whole person.' Yet our research has revealed the need to understand the way in which different aspects of a person's life interact with and reflect each other. In this part of the report we will use fragments from other stories with the proviso that each story should be regarded as an entity and is a complex statement about hopes, dreams, joys, desires, fears and pain.

We have scattered six stories throughout the report. The stories are best read aloud. However their strength and power are also apparent when they are read alone and silently.

We ask you as readers to treat these stories whether whole or fragmented, with respect. They reveal intimate and often painful parts of an individual's life. They took great courage to tell.

Chapter three

Twenty five people with intellectual disabilities told us their life stories. They talked about many different things in their lives but they all told us something about sex and about their relationships. We think it is very important that sex and relationships are seen as part of how people live their lives. The story-tellers were all very different people. Some lived in the city and others in the country. Their ages ranged from 25-60. Some of them had lived in institutions although all of them now lived in the community. Some of the story-tellers were married or lived with their partner. Others were looking for a close relationship with someone. One man was gay and one woman was lesbian. Almost all of the men and women talked of having bad sexual experiences in the past. But not all the stories were sad or painful. Some people told very joyful stories about their lives and relationships.



About the story-tellers

Twenty five people with intellectual disabilities contributed stories to this project. We have given their pseudonyms in Appendix 2 at the back of this report because we believe it is important that even in a disguised fashion they are recognised as individual story-tellers.

Our focus in this research was both on hearing the stories and reporting them as a whole for each individual. But in doing so we found that there were common themes and experiences for this group of people. There were also important differences which reflected age, gender and life experiences. It is difficult to sum up the characteristics of the group without making them 'subjects' rather than participants.

The characteristics described below indicate only that the group of people who told their stories were diverse. They may have all carried the label of intellectual disabilities but their experiences in childhood and adulthood were very different. The research findings are more powerful because common themes and experiences were revealed even in such a diverse group.

In summary 12 story-tellers were men and 13 were women. Their ages ranged from 25 to 60. The oldest person was a woman with a range of different experiences including separation from her family at a young age, institutional life, and a movement back into the wider community later in life. The youngest story-teller was David Warren whose story introduces this part of the report.

Seventy five per cent of the story-tellers lived in Melbourne. Twenty five per cent lived in rural areas or on the fringes of the city. It was difficult for us to obtain access to people in the country because of the effort required in contacting us. However networks and increasing knowledge about the project led to story-tellers from a number of rural areas coming forward. In some instances this required considerable travel by the researcher and involved more intensive story telling sessions.

Twenty five per cent of the story-tellers came from non English speaking backgrounds. However all told their stories to us in English. Although we wanted to

include people who had arrived in Australia more recently or who did not speak English we decided that the ethical issues involved were too difficult to solve.

Using interpreters and discussing sexually explicit experiences with someone in another language and from another culture seemed to be fraught with dangers for the story-teller.

Twenty per cent of the story-tellers lived independently, either alone or with a friend. Two people were buying their own accommodation, however most people were renting their accommodation. Eighty per cent lived in supported accommodation of one sort or another. Some lived in hostels, or special accommodation houses, others lived in community residential units.

No-one in the group was currently living in a large institution although four men and one woman had spent part of their lives in them. We decided on reflection not to include people currently living in large institutions because of concerns about confidentiality.

One man identified as gay and one woman identified as lesbian. Over half the men had had sexual intimacy with men and four women had experienced sexual intimacy with women.

One man and three women had children. They had managed to keep their children with them. In the other instances the children were removed by authorities and had not been seen by their mothers since. Vicki Mulholland in her story speaks movingly of this experience.

Seven of the men spoke of having experienced sexual abuse at some time in their lives. Eleven of the thirteen women stated that they had experienced some form of sexual abuse. Of course in interviews this kind of language was not used and the stories of sexual abuse were told in the context of past relationships and childhood experiences. In some instances the story-teller recognised that the situation was abusive and painful. In others it was not seen as such and we are inferring abuse from the details of the story.

Conclusion

People with intellectual disabilities are often treated as though they are one homogeneous group. Our story-tellers revealed great diversity in life experiences. Their stories reflect both the difficulties which people had experienced in leading full adult lives and the ways in which they had managed them. They are powerful and moving stories of people who were living adult lives which were circumscribed by those around them.

Chapter four

The stories which people told to us were very important. They showed people with intellectual disabilities as adults struggling with very big issues about sex and relationships.

Important things they said were:

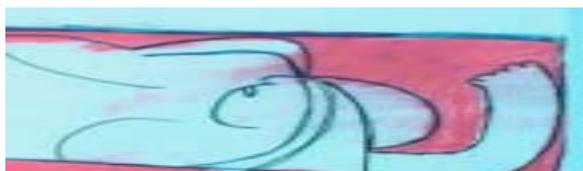
Sometimes the story-tellers led very secret sexual lives because of the attitudes of the people around them. For example they could not have sex at home, they had to go to the beach or the bush or someone else's home. This sometimes meant that people got abused.

Story-tellers told us that they were not always treated fairly about sexuality and relationships. Some story-tellers had been abused by service providers or families, some people could not talk about sex or get information about it, some people had to really struggle to live together. Because people did not always have good information about sex and relationships they did not have safe sex and so were at risk of getting diseases such as HIV/AIDS.

Some people did have very good relationships or they were living happy lives. It is good to celebrate this.

Men and women story-tellers had much in common. But there were some differences. Men found it easier to talk about sex than women. Women talked more about bad sexual experiences they had had. Some men found it easier to have sex with men because of the difficulty of finding a woman partner.

Many of the story-tellers were lonely and had felt rejected by other people. There seemed few ways in which they could meet other people with whom they could form relationships.



What the stories told us

It is difficult to summarise the findings from this research because of the complex layers each story demonstrates. Fragmenting the voices of the story-tellers reduces the power of the messages they convey. Drawing out themes and examples is in many ways simplistic and does not do justice to the stories themselves. In our view it inevitably does violence to the ways in which sexual experience reflects wider life experience and in turn shapes the individual's life. However it is impossible in a short report to include all the stories in full. We hope to do this through the publication of plain English booklets. In this chapter we explore some of the key themes which emerged from the stories and examine the social and policy implications of these themes.

Key themes emerging from the stories were:

1. Diversity and similarity. Diversity within the lives of the story-tellers and similarities between needs and desires of this group and other adults.
2. The issues of rights and sexuality.
3. The hidden nature of people's sexual lives.
4. Celebration of sexuality and relationships.
5. Gender issues.
6. Loneliness and rejection.

1. Diversity and similarity. Diversity within the lives of the story-tellers and similarities between needs and desires of this group and other adults.

People with intellectual disabilities are frequently constituted as other or different by members of the community. McCarthy (1999) describes two such stereotypes.

As soon as a historical view is taken, it is apparent that strong stereotypes prevailed. The first of these was the stereotype of people with learning disabilities as being 'eternal children.' Because of their limited intellectual capacity, people with learning disabilities were considered to forever have the mind of a child. They were associated with child-like interests and pursuits and often treated as if they were children (Craft and Craft, 1983; Kempton, 1972). In contrast to this image was the other stereotype of people with learning disabilities as potentially dangerous. This was based on the idea that they were unable to control themselves and historically it had sometimes also been believed that they possessed a 'super-human' strength so they could not easily be controlled by others (Hattersley et al 1987).

(McCarthy, 1999, p.53).

Such views have implications for how the sexual lives of people with intellectual disabilities are constructed by those around them. They may be seen as uninterested in sexuality or relationships, unable to sustain them or initiate them or they may be seen as indiscriminately promiscuous and dangerous to the community.

The stories we gathered in this research revealed a very different picture of the lives of people with intellectual disabilities; one that revealed adults who were struggling with issues of love, passion and desire.

For example Kevin and Hannah lived together in a 'special accom'. They were unable to leave it because Hannah's guardian did not wish her to do so. However Kevin would like to have a home of his own. He comments:

We asked her brother about moving out. He doesn't want us to live in a house. He wants her to live in special accommodation all her life. So I'll spend my life with her there.....One thing: I'm hoping to marry Hannah one day. Yeah. Hoping to.

For Kevin and Hannah the most important thing was to be able to stay together.

Other story-tellers revealed their desire for a long term relationship with someone loving and gentle. Shaughan who is gay comments:

I'd like to have a boyfriend and do something together. I'd like to share feelings with him. I'd like to find a caring, loving sort of man.

Vicki (see Chapter 3) mourns her lost children whom she never expects to see.

Some people spoke openly of their enjoyment of sexual expression either alone or with someone else. So for example Angela, a young woman, comments:

He's loving and understanding and caring. It's good, kissing. I like it. Mum said it's alright, kissing. It feels special when you're with the other person that you love. I sometimes touch myself and I like to do that. I've never talked about it at home, mum'd have a fit. It's okay as long as mum and dad don't see you. I touch my vagina and sometimes my breasts. It feels really good to do, so I do it.

Story-tellers were involved in relationships, they were seeking them, or they were exploring avenues for sexual expression alone or through massage parlours or social contact. Their views about sexuality and relationships were as diverse as other members of the community. For some people sexual expression and gratification were important, for many, relationships were seen as central to their lives. Some of the story-tellers were heterosexual, some identified themselves as lesbian and gay, some were single, seeking a partner, others had found a loving relationship. Some people were struggling with issues around parenthood, deciding either to have children or to remain childless. The issue was central for some of the storytellers, for others it was less important.

The stories powerfully supported Valerie Sinason's view that people with intellectual disabilities do not have 'emotional disabilities.' As a psychoanalyst working with people with intellectual disabilities she has written movingly of the struggles of her patients to be heard as people through societal views about disabilities (Sinason, 1992). Their needs for intimacy, sexuality and for relationships are expressed in the same fashion as other adults. This is not however the whole story. As the other sections of this chapter show, people's sexuality was shaped by particular circumstances in which they lived.

2. Rights and sexuality

In response to the neglect of services in addressing the sexuality of people with intellectual disabilities and consistent with the rights discourse which has assumed such importance in their lives Craft (1987) suggested six rights which should form the basis of service practice and policy in relation to sexuality. A similar set of rights inform the objectives of the Department of Human Services Human Relations Policy. Below these rights are discussed in the light of our findings.

2.1 The right to grow up i.e. to be treated with respect and dignity accorded to adults

The stories revealed that there was a continuing struggle by people with intellectual disabilities to be accepted as a sexually mature adult. For example 35 year old Kevin

lived in supported accommodation in the community and had fallen in love with Sarah who also lived in the house. He said:

We loved each other that much, and we wanted to have sex. We had to ask permission from staff. They got a bit funny but afterwards they said we could move in. They didn't like us going to bed together because I was havin' sex that's why. Before we shared our room, a staff member knocked on the door and found us together. She said, 'Get into your own bed.' I didn't like her that much doin' that. Because we're two adults and she should have let us do it.

This story revealed the failure of staff to consider Kevin and Hannah as adults deserving respect and dignity. The staff, perhaps concerned about issues of duty of care, denied the couple privacy and forbade their sexual expression, seemingly without discussion.

2.2 The right to know, i.e. to have access to as much information about themselves and their bodies and those of other people, their emotions, appropriate social behaviour, etc as they can assimilate

The stories reveal that sexuality was overlaid with silence, shame and guilt as well as, in some instances, pleasure. Knowledge was gained primarily from friends, brothers and sisters or neighbours, or lovers and much more infrequently from parents. Some people did tell of sex education classes at school but there was a tendency for the memories of these to be fragmented or perceived as embarrassing or irrelevant in real life.

Hussein, in his story recalled his memory of sex education, told of his lack of knowledge and questioned the researcher.

Well I remember at school we had some lady coming in, forget what she was talking to us about and she showed us condoms, some different condoms and how you open them and that. And how to tie them up when you're finished and that and to throw them away. But it was yucky, sticky and one of me friends started blowin' it up and poppin' it. Nobody told me about me body and AIDS. When you're young and you get older your body changes and that and your voice. I don't know about HIV or AIDS what does that mean?

When you have sex with someone, sperm comes out. Whereabouts is it in your body? I didn't know your body can produce that. Can it?

Many of the story-tellers showed an alarming lack of knowledge of safe sexual practices which is hardly surprising given their life experiences. Hussein who was an

active participant in having sex with men said that he never used condoms because they were yucky. Kevin said women did not like condoms so he did not use them. He believed it was safe as long as the woman washed frequently. Luigi said that he had unprotected sex with men to supplement his pension but only when he didn't have a girlfriend. Neville had acquired many of the myths about HIV/AIDS which led him to feel extremely anxious about any contact with other people.

You can get it from cars or buses. Someone can have HIV and you go sitting in the bus in that seat or tram after the person's been in it. You don't even know. Anyone can catch it. Anyone can catch it, homosexual or not. Eating out of rubbish tins, picking up any dirty stuff and so on you get HIV. I can't work out why you get it from homosexuals. Perhaps you could get it from people who are not homosexual. Anyone could catch it. Through having a relationship, kissing, stuff like that. Kissing and hugging and stuff like that.

The failure to provide people with accurate, relevant information about sexuality and sexually transmissible diseases led them to engage in unsafe sexual practices or in the case of Neville, to withdraw from any close contact with other individuals.

2.3 The right to be sexual and to make and break relationships

Being sexual is not a right, rather it is integral to being human. The right to express oneself openly sexually is however another matter entirely. And it was this right and the desire for relationships which were dominant themes in the stories.

Some of the men in particular had proved to be creative in their search for sexual expression. Tom who at 38 lived at home and characterised himself as a bit of a rebel, went to massage parlours on a regular basis.

The receptionist comes to you andtells you the prices and that and then the different girls come and you pick a girl you know. We had sex together...

He has also tried dating clubs where he lost his money and did not gain a relationship and bought magazines which he read in privacy away from his mother.

However Tom has never had a permanent relationship with a woman and says:

Well I was thinking more or less about how to get a girlfriend you know. What do I have to do sort of? And what places do you have to go to get a girlfriend? And how do you approach them? All that sort of thing? And I was wonderin' if you could help me in that regard.

Women too found it difficult to establish the right to sexual expression or to form relationships. Some were told from an early age that these were not issues which would form part of their lives.

For example Elaine comments:

Oh well I asked mum if I could get married you know, before I was going with anybody. I said to mum, I think I'll get married one day. She said 'over my dead body.' I said 'why?' I said 'why not?' I said 'if I find a nice man.' She said it wouldn't work out. I said 'why wouldn't it work out?' Said 'you and dad got married and had beautiful kids. Why can't I do the same?' She said 'sorry.' They didn't want me to make love anyway.

2.4 The right not to be at the mercy of the individual sexual attitudes of different care-givers

The stories revealed the lack of power by the story-tellers in asserting a right to their sexuality in the face of care giver opposition.

This was particularly true for people who had lived in institutions where heterosexual behaviour between residents was prohibited with the threat of heavy punishment for infringements. However there were exceptions to this prohibition.

Neville says:

Staff in St Thomas', [a large institution for people with intellectual disabilities] they started to tell me about sex. They said it was good. It was lovely. 'You won't get sick or anything. Nothing will happen.' And then they started to come into my bed, mucking around with me and with some of the other residents to do the same. Get me to do the same to them and stuff like that. It was scary. It wasn't very nice. If you tell them to get out they'd probably drug you up on drugs, and say that you'd been playing up and all this type of thing. And they'd lock you up for a week and stuff like that, in St Thomas'.

When Neville tried to form a relationship with a woman living in the institution he was severely punished. He learned that abusive sexual relationships were condoned but that other relationships were forbidden.

Elsie, aged 53, was raised by nuns who told her nothing about sexuality; rather she found out bits of information from friends and an older sister. She then found herself at Hillside [a large institution] where she experienced her first sexual encounter in the bushes in the grounds. She told no-one about this and spoke also of the

prohibitions which stopped people from forming open relationships and drove them into secrecy.

2.5 The right not to be sexually abused

The stories endorsed the findings of other research about the high incidence of sexual abuse of people with intellectual disabilities. Such abuse was reported by eleven of the women and by seven of the men. It occurred within institutional settings, in supported accommodation in the community and when people lived at home with their families. It was often unreported because of the prohibitions around sexuality or because the person did not see it as abuse.

Hussein, aged 22, who lived at home with his parents in what seemed to be a close family situation recounts his first sexual encounter.

I was thirteen. Well it was someone from the same street as us. I was going for a walk. And I snuck in quickly when they weren't looking. Into the guy's house. And he let me in. He didn't tell on me. And we did it together. And then we talked and then we, he showed me his penis. And when he showed me I showed him mine and I touched his. And he got, what's the word?...when you get carried away?... And he said. Don't tell your parents, it's a secret.

Hussein was actively involved in having sex with men on a regular basis. However his sexual life remained highly secret from his family and from service providers.

Gina experienced a childhood and adolescence of sexual abuse before running away from home and gradually discovering a new life and a warm caring relationship with another woman. She comments about her early experiences:

There was no messages about safe sex. If my stepfather couldn't get sex or my brother in law, they would come to me. The message was, 'come here'. Or if Mum was asleep they'd say, 'Stay right there.' They'd get a towel with nothing on underneath and take me into the bedroom. They'd say, 'Your mum told me to punish you now,' chuck me on the bed, hand over mouth, 'I'm going to do it my way.'

2.6 The right to humane and dignified environments

Peoples' stories repeatedly emphasised that they had found it difficult to gain acceptance for their sexuality. Although those who were leading relatively independent lives in the community in their own homes had been able to create an

environment which gave them a measure of peace and dignity, it seemed that for people who were living in services this was hard to achieve.

People talked about having sex on beaches, in the bushes, outside, in cheap hotels, or in other people's houses. They spoke of constant unsympathetic surveillance and fear of being found out by those around them.

Perhaps the most poignant statement of all comes from Derek.

At Hillside there's a mortuary where they keep the dead bodies right. Behind that mortuary there's an old shack. Behind that old shack is another old building. Myself and a female went for a walk down behind there and we started talking.....She took a liking to me and we became friends and then she started rubbing my back.....

Derek and his partner were discovered by staff at the institution, were punished and never saw each other again.

3. The hidden nature of people's sexual lives

The lack of rights to a safe sexual life experienced by the story-tellers and the prevailing negative attitudes towards their sexuality by those around them led to hidden sexual lives. It was clear from the stories that for many of them the struggle for intimacy and for sexual expression happened in silence or were made more difficult by those around them. The silencing of sexuality seemed to be due to the fears of families and service providers. Discussion of sexuality by people with intellectual disabilities was regarded as inappropriate by many of those around them because it was labelled a 'private' not a 'public' issue. This enabled service providers and families to deny the issue until it was perceived as a problem. This attitude made it difficult for people to obtain information from others about 'normal' sexual expression. For example David comments:

People with intellectual disabilities should be taught about pregnancy, diseases. Anything that's sort of to do with the body I reckon. When they say the do's and don'ts, meaning like what's normal, what's normal for everyone else, then that's cool. I think people with disabilities think it's different, that other people don't feel it as well.

For some people, the silence led to a secret sexual life leaving them vulnerable to abuse and to exploitation. Elaine who had led an active sexual life for twenty years

and had been involved in several long-term relationships had never gone to bed with someone in her own home. Her parents would not allow it. She had had sex on beaches, in the bush and in her partner's flat. On at least two occasions she had been physically or sexually abused. She could not discuss either of these occurrences with her parents. Hussein had been sexually abused at the age of 13. He had an active sex life with men whom he met on the street. His explicit enjoyment of sex was coloured by a terror that someone would find out. His family knew nothing of his sexual life.

In some instances the silence which was designed to protect 'vulnerable' people led to abuse or to them finding sexual pleasure in unsafe ways.

Hussein comments:

I have had a girlfriend. We went out together and we talked and that, me and my girlfriend and we kissed and that, and get to know each other, and she knows me. We haven't had sex together. She goes, her parents will find out and so will mine. Like to have sex. But only if she has her own room, and her flat mate goes to work, and you've got the house to yourself. Then it's okay. When you're living with your folks, it's hard. She said when her folks go away, and you've got the house to yourself.

But it's a bit hard when you've got to stay with your uncle or your cousins, or they stay with you, or one of the neighbours, you know. Sometimes it's easier with men.

The silent prohibition of sexual expression did not stop people with intellectual disabilities from having sexual lives. It did increase their vulnerability, and it increased the possibility that their sexual lives would be unsafe. They were not able to talk about sex within the context of their own social lives and sex education was experienced as abstract and disconnected. Their sexual lives became 'abnormal' because of the silence of those around them. Such silence was not passive but was seen as actively prohibiting sexual expression and desire. Essentially it excluded them from the possibility of being present in the lives of people with intellectual disabilities. When sexual expression, desire or relationships surfaced, they were often regarded by those around the person with intellectual disability as a cause for concern and for 'treatment'.

4. Celebration of sexuality and relationships

While many of the stories told to us were bleak accounts of lack of rights and sexual abuse, there was also a great deal of joy expressed by some people in their relationships and sexuality.

For example Gina after a childhood history of physical and sexual abuse speaks with joy of her current relationship.

Cathy and I were made for each other. She looks after me. I can't read and write very well and she helps me. She has been there from the start. She is always there for me. Loving a woman is like loving everything you want in life. I've never liked a man in my whole life. I think to me loving a woman is like loving yourself. Women have a lot more than men. Honesty, open and caring. And their bodies! Oh yeah their bodies!

Such descriptions were not idealised. Story-tellers involved in relationships were aware of their positive and negative aspects.

Alicia describes her marriage in such terms:

I got married about, in April and I got married at St. Leo's. Our anniversary is coming up soon in April. Five years now. It was a happy day, I was very happy. I like being married. Rob's got some disabilities. We were at special school together. We help each other, shopping and things like that, budgeting. Budgeting and that stuff. Sometimes we do things together, sometimes not. Sometimes we fight but not real fighting because marriage is all about fighting. But we get together again. Sometimes we argue, I argue and Rob argues.

I think every couple argues sometimes. It's not normal if you don't. We go our separate ways. Then we get back to normal. Sometimes you need space, to do your own things sometimes and I like space. He wants me to do everything with him and sometimes I like to stay home. We have a commission house. We live on the highway. We dream if we've got plenty of money to build a house. We talk about it a lot really. We talk about our private stuff, things I don't tell any one else. If I want to tell him something I tell him. I can tell him anything.

Hussein who found it difficult to talk about most areas of his life, became very articulate when he discussed his enjoyment of sex with a man met in a toilet. He says:

He said, 'Do you want to go somewhere and do it?' I said, 'OK, I don't mind.' And that's what we did. He said, 'We'll go to my friends house and we can do it there.' I said, 'OK.' So I went there, upstairs to the room. He took his jacket off, his shoes and socks off, his watch, undid his belt, pulled

down his pants and take them off, took his jumper off. We started touchin' each other at the same time. I pulled his undies down, he pulled my ones down. We got carried away. He couldn't stop and I kept goin'. We kept on going and he came about 4 times. I did too. He came on me and I came on him, about four times and he did it to me. I didn't have any condoms. He had a few in his pocket.

Celebration or even acceptance of the sexual lives of people with intellectual disabilities is not usual by those around them. Sex education, information and advice are usually given in relation to 'a problem.' This approach by service providers and families makes it difficult for people with intellectual disabilities to have a positive view of themselves as sexual people. By not teaching them that sex and relationships can be good and can be enjoyable we leave them vulnerable. If they only hear about the risks and dangers they have no benchmark against which to judge actual sexual experiences. Consequently unsatisfying or abusive sexual encounters can be treated by them as the norm.

5. Gender issues

Men and women who told their stories shared many things in common. They were interested in finding ways to lead positive sexual lives. Many wanted a loving relationship with another person and struggled to find this. Almost all of the story-tellers had experienced some form of sexual abuse.

However there were also suggestions of gender differences in experiences which sometimes shaped the way men and women lived their lives. The men in the sample spoke about the physical aspects of sexuality more openly than the women.

For example Hussein was explicit both about the nature of the sexual acts in which he was involved and about his enjoyment of them. Women found it more difficult to be explicit. For example common kinds of comments included: 'He did it to me in the bushes', 'we made love', 'he touches my breasts'.

Such reticence may be the result of different prohibitions for men and women about sexuality and reflect similar styles of language in the wider population (Hillier et al, 1999). Men also seemed more active participants in their sexual lives while women saw themselves as having sex done to them, sometimes with little choice.

Women did not talk very much about masturbation or about sexual pleasure. Rather they focussed on the relationships they had experienced or wanted.

The majority of both men and women in the group had experienced some form of sexual abuse during their lives. Two of the men reported abuse from former women partners. However abuse from partners was more frequent in the lives of women. This may be due in part to the failure of sex education to focus on the rights and responsibilities of relationships and how to deal effectively with conflicts. Men who had sex with men reported instances of abuse consistent with findings from overseas research (Cambridge, 1996; 1997; MCCarthy and Thompson, 1994; 1995). In part this seemed to be because of a power imbalance between the parties. Often such encounters occurred through meetings in toilets or public places and frequently the other partner was not a man with an intellectual disability.

Abusive sexual experiences had led some men to reject their own sexuality. Neville says:

A sexual relationship is a relationship that's what you call it. Having sex you would um.....It would probably be bad. You've got to have a shower. You've got to clean yourself you know.

If you have a shower in the morning and you go out again and you meet someone like a homosexual or something and you come back and you've got to have another shower again, you know. It's no good you know. After you've been in someone's behind with your penis or in a girl's....you know what I mean? You get all dirty from doing it. You got to have a shower, clean yourself up afterwards you know. It's dirty and smelly and that's not very good right. I can't remember [having sex when it didn't feel dirty]. It was some time ago. I think it was clean at that time you know. It was when I was made to have sex.

Similarly some women in the group had decided not to seek a sexual partner because previous experiences had been painful or abusive. Sarah, a single mother caring for her child with the help of her mother, comments:

I'm not having anything more to do with men in my whole life. I'm going to be on my own the rest of my life with Mary.

Three of the women revealed that they had been attracted to or involved with another woman in a sexual way. Two spoke of this with embarrassment and anxiety.

'I was scared I might be lesbian' while one identified strongly with being lesbian and was involved in a positive relationship with another women. Only one of the men identified himself as 'gay'. However a majority of men revealed that they had had some experience of sex with another man. The reasons for the difference between genders in relation to this issue seem to be complex. For some men it was the result of institutional experiences.

For example Derek comments:

You've got one guy punching you, another guy kickin' you and another guy pullin' your hair out. They didn't do it to anyone else. It was about sexual issues with men. And I was the one who copped it all and I didn't like that treatment. I thought this is ruining my life, what the hell is goin' on? I sort of had to stand up.

I was ah....the best way to cut a long story short was to do something about it, so the second time I reported it, so that they had to notify the Mental Hygiene Authority and they thought the best way for me is not stay there any more because they didn't like the way I was being treated. So I had to move from there to Hillside.

Some men found that sex was 'easier with men'. It was much more difficult to find a private space with a woman.

Some men found it easier than women to find some form of sexual expression. For example two of the men went to massage parlours. The cost of this however prevented them from going very often. And they found their way there only through chance acquaintance with someone who would take them (in one instance a regular taxi driver) or by telling those around them where they were going. Others rejected the idea of 'paying for sex'. Some women found sexual expression more difficult; masturbation was either disliked or unacknowledged and often other forms of sexual expression was highly restricted or forbidden by those around them.

Both men and women were far more similar in their desires than we expected. A longing for a long term relationship, desire for children and concerns about how to achieve a satisfying sexual life were consistent and strong themes. Both men and women experienced great obstacles in achieving any of these goals.

6. Loneliness and rejection

The movement towards inclusion of people with intellectual disabilities in the community has led to new opportunities and greater choice in many areas of their lives.

However many of the story-tellers expressed great pain at continued rejection by others. They also revealed a loneliness and a yearning for close and intimate relationships.

David says:

I think one thing I'm missing here is friendship. Either male or female it doesn't matter. Either a male or a female friend, I don't mind. I prefer something like companionship. Just someone else in the house. Either a male as a good friend or a female as a good friend, it doesn't matter. But I think that human beings need companionship no matter what. Whether you're a male or a female. I hate [loneliness]. I mean it's not something I would throw a party for!

Relationships were few and far between and often remembered with warmth and yearning. Neville remembers with great vividness his last relationship with a woman:

[I had a girlfriend] many years ago. About six years ago. [We didn't have sex]. We just put our hands around and had a few kisses you know. And she left me, 'cause another guy wanted her. He had two girlfriends and he wanted her too and I never see her. She never come back and I rang her up and she couldn't talk to me anymore because this other guy was there. I'd love to [have done more] but I don't think she wanted it. Just be friends that's what she wanted. Just take her out. Things like that. Go for walks she liked. [I would have liked] just a sexual relationship you know. Like other people do you know. But you have to know the girl for a long time, get to know who she is and stuff. Do what I like, you know, quiet and understanding.

The sadness and yearning for a lost relationship, one that was struggled for and valued is shown in Darren's story. Darren threatened his fiancée with a knife and she left him. The pain remained. He mourns for her:

I do miss her. Oh I really miss her, oh I know I can cook, but I know I can cook but I really miss her cookin' Oh bein' with her and watchin' TV and stuff like that. Oh goin' shoppin' with her. Goin' for a drive with her mum, stuff like that. Touching or cuddling? Oh we cuddle, yeah I miss that stuff

too, cuddlin' and kissin'. I miss that stuff too.....I miss, miss, miss having' sex, sex with Simone. Havin' sex and havin' fun with her.

Story-tellers did talk of a social life. Going to the pictures, to coffee shops, to the 'pub' or to clubs. But they remained outsiders. David spoke of his efforts to approach a woman and the pain of repeated rejection. Women spoke of their hopes of relationships and the disillusionment of finding that they had been 'used for sex.' Some women paid their sexual partners part of their pensions either for sex or as 'loans' which were never repaid.

In our efforts as a community to include people with intellectual disabilities there has been a strong movement towards normalisation. Service providers have sought to ensure that people are taken to places which are used by others in the community and sometimes relationships between people with intellectual disabilities have been discouraged because they are perceived as leading to 'devaluing' of the individuals. Similarly social occasions which would allow people with intellectual disabilities to meet together are often regarded as a form of segregation and are thus devalued.

However for the story-tellers there was a lack of opportunity in their lives to meet others with whom they might form intimate and long lasting relationships. It is very difficult for people with intellectual disabilities to form friendships with people without this label. It is even more difficult for them to form sexual relationships. Neither services nor families have been able thus far to provide many places where people with intellectual disabilities can meet safely and with enjoyment and where the possibilities of such relationships can be explored.

Conclusion

Fragmenting the stories gives only a snapshot of the lives of the story-tellers. The picture is a somewhat bleak one brightened in part by the relationships which some people have managed to develop and sustain and by the very real joy and happiness which some people have expressed. If, as Freud said, the meaning of life is love and work, we need as a community to be much better at finding a safe way to give people the freedom to form relationships and to be sexual. This would involve a community committed to the real inclusion of people with intellectual disabilities and to the removal of barriers which prevent sexual expression.

I like being married

Alicia Rodriguez

I'm twenty-seven. My mum and dad come from Spain, and I was born here. My mum died in 1990 from cancer. My relationship with my dad is pretty good. I'm happy. We just like being together. Dad and Rob get on well. We live near dad 'cos he helps me. I'm pretty happy really. When I got married I was scared leaving dad. I thought how could I manage living out of home? I told my dad and he said I would be fantastic. He lives near me anyway. I have two sisters and one brother, one nephew and four nieces. My sisters are a bit older than me. My sister helps me a lot. We talk, go out. My grandparents and other relatives are overseas. My dad sometimes gets letters from his cousin. I sometimes spend time with my Godmother. They're overseas now. She helps me...thinks what I need. I would ask her advice if I needed it. And my Godfather. Mum and dad made all the decisions when I was growing up. I didn't ever feel any different. Sometimes people don't want to talk to me because of my disability. I've got friends, two girlfriends, and we sometimes go out for meals, talk and all that. Sometimes I visit them.

I had a blood test and the results come back that I was sick. I have tests whenever I see my doctor for diabetes. I'm supposed to eat pasta and stuff, but I forget. I go to the diet clinic and they tell me things about hypos and how to treat it and what to eat and all that. Me and my sister go shopping. She helps me buy the right things. I have to be sensible now I've got sick.

Mum said, 'Be careful and don't rush it, and don't get pregnant. It's really easy to get pregnant. You don't have to get pregnant, there's pills.' And to do the safe sex. Girls get their period, and I panicked. It was at Geelong Special School and I told the PE teacher and she said, 'Don't worry, girls get their periods.' When I was 15 I started. Mum said, 'Don't worry, girls have it.' I don't know why. I haven't had any discussions or classes about safe sex and relationships.

I got married about, in April and I got married at St. Leo's. Our anniversary is coming up soon in April. Five years now. It was a happy day, I was very happy. I like being married. Rob's got some disabilities. We were at special school together. We help each other, shopping and things like that, budgeting. Budgeting and that stuff. Sometimes we do things together, sometimes not. Sometimes we fight but not real fighting because marriage is all about fighting. But we get together again. Sometimes we argue, I argue and Rob argues.

I think every couple argues sometimes. It's not normal if you don't. We go our separate ways. Then we get back to normal. Sometimes you need space, to do your own things sometimes and I like space. He wants me to do everything with him and sometimes I like to stay home. We have a commission house. We live on the highway. We dream if we've got plenty of money to build a house. We talk about it a lot really. We talk about our private stuff, things I don't tell any one else. If I want to tell him something I tell him. I can tell him anything.

We went to P&O for the cruise, we were on the cruise together. Vila, all the islands, Mystery Island and French Island. We want to go on another cruise but it'll take a long time to save the money. I want to see the jungle at Africa.

I can't have kids because my ovaries stopped growing. I found out by my doctors. Because I've got diabetes and really small hands and small feet. I wouldn't like a child. I can't cope with little ones, I can't chase after them. Babysitting my nieces and nephews is enough. I like them and all that but they are really hard to look after. It's hard enough just being myself. I couldn't look after another person, especially a baby. Rob understands. We sort of planned to have a family.

I never talk about sex. I don't really like it. I don't know why. It's embarrassing. We don't have sex much. I don't need it and he doesn't either. We like to cuddle. We have the same ideas about things like that. I like things to be calm and not too much fuss. I don't like seeing people kissing and hugging in the street and that. Rob and me we know each other a long time, since school and that, so we just like to be together to do things together and that. He gives me presents, flowers, makes me breakfast in bed. Someone said that I had a man in a million. Sometimes I get him things and presents and that.

I'll spend my life with her

Kevin Ryan

There was about 14 of us in the family but I haven't met them since I was about 3 or 4 years old. I might contact one or two of them on the phone, but they don't ring me back any more. My father had too many kids that's what it was. Couldn't look after them all. We all went into homes and that. I was lucky. I was adopted out. It felt good to have someone who loved me, and things like that.

I went to a special school because I was a bit deaf and I couldn't speak and I had two calipers on my legs when I was a baby. That's why I was a bit slow. I'm still a bit slow but I'm a lot better than I have been. I haven't stuttered for a long time. I'm starting to stutter but not as much.

I live in a special accommodation now. Before, I lived with my grandmother. My grandmother passed away this year. I was crying, yeah. At the respite houses they looked after me and were sorry for me. And they made me happy and that when I went with them. I been a different person since I had them to comfort me after her death. Like a family. It's goin' to be funny this year, because this is the first year I'm going to be without her, because I had Christmas with her last year. So this year's going to be funny without her. She was 88. So when my grandmother died her house went to her girlfriend. That's why I came here. I didn't have anywhere else to live.

I like it here but one day I'd like to leave. In a couple of years I'd like to leave. I'd like to get a cheap house, 'cause I'd like to get an Alsatian. We had a dog here but the staff got a bit funny about it. I'm vegetarian 'cause I don't like animals gettin' killed. Sometimes we have barbeques and some days we have roasts. It's a bit of a problem. Staff are okay. Sometimes they tell you to get to the room and that, they don't like you spending time in the kitchen. I come back here to my room.

I do building. And we do gluing, blu tack, you know, we do that. This year I started work. I love it because of meeting new friends. I'm happy about that. That's what I started a job for, because I sit at home all the time doing nothing. Just sitting home with old people all the time. I get a wage. I get \$415.00 but I don't see it, it goes to, oh I can't think of the name, oh the Trustees. They pay here.

Sometimes I go to the city on Saturdays. Sometimes I go to pet shops and look at snakes and lizards and that. And sometimes I go out and buy something to eat. And what else do I do? I go down shops lookin' at space stuff and things like that. With Hannah, my girlfriend, we go to the shops. Myers, clothes shops and that.

I don't see my friends from work much. They've got other friends, they don't ask me out. It doesn't worry me. I've got Hannah so it doesn't worry me. I got another mate here, Mike. He goes to the same work, so I've got him too, so that's the main thing.

I met her last year. Her name is Hannah. She's 36. A really nice person. A lovely person. I haven't been so *happy* since I met her. I met her at the special accommodation here. I was living with two guys here before we moved into the room together. We loved each other *that much*, and we wanted to have sex. We had to ask permission from staff. They got a bit funny but afterwards they said we could move in. They didn't like us going to bed together because I was havin' sex that's why.

Before we shared our room, a staff member knocked on the door and found us together. She said, 'Get into your own bed.' I didn't like her that much doin' that. Because we're two adults and she should have let us do it. We didn't like it, so we left one night and we had sex somewhere. When we came back they had a talk to us and they said, 'You can move into a room together,' into the room.

Well we'd been goin' out together and about seven days after that I said, 'Do you want to have sex?' And she said, 'Yes.' I asked her if I could do things to her and she said, 'Yes.' The first time I slept with her, I went to bed with her, and I took my clothes off and I put my penis into her. Yeah. It was quite good. I enjoyed it.

When you put a penis in the vagina it's called sexual intercourse. That's what you call it. Normally I love just foreplay. Yeah. Hannah and I have sex every Saturday night.

Because I work all the time and get tired. And sometimes she goes to sleep and that. And that's why we do it Saturday. We spend more time together on Saturday. I want to have sex all the time, I

asked her last night, 'Want to do it tonight?' She said 'No, Saturday. Just wait.' The only one I want to spend all my life with is Hannah, I love her that much. I don't want to lose her. I pamper her, look after her, take her tea to her, take her food, take her out, buy her flowers, chocolates, take her away sometimes for the weekend, things like that.

I'm not afraid of STDs because she hasn't had sex with many men. Mainly slept without having sex, yeah. I don't have any diseases because I've looked at my penis a couple of times but I haven't seen anything on it.

She can't have children because she's had her womb taken out because she didn't want children. She made that decision. We'd talked about having children but she said, 'I don't want any children.' It doesn't worry me because I like being with her very much. I love her and that's the main thing.

We asked her brother about moving out. He doesn't want us to live in a house. He wants her to live in special accommodation all her life. So I'll spend my life with her there.

She's on tablets and that, she gets a bit funny sometimes. And that's probably why he's worried about her.

I haven't had sex with men because I prefer to do it with Hannah. One guy asked me. I said 'No'. I prefer to do it to a woman. One thing: I'm hoping to marry Hannah one day. Yeah. Hoping to.

Part 3 : From research to action

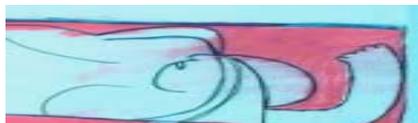
Living Safer Sexual Lives was planned as action research from its beginning. As the research process developed, consideration was given to possible outcomes in an ongoing way by the researchers and the reference group. We were concerned to make sure that the stories contributed to the research were used to develop, implement and evaluate a range of strategies which would assist people with intellectual disabilities to live safer sexual lives. The chapters in this part of the report document the action arising from the research and draw some conclusions about the nature of action research and the factors which can facilitate and/inhibit its success.

Chapter five

After we had gathered the stories and talked about them in the reference group we had to decide how to use them. We ran workshops based on the stories with 200 service providers around Victoria. We also ran workshops with families and with people with intellectual disabilities. The workshops were different to sex education classes. We gave people a safe space to talk about their feelings and their desires. We tried to find ways to link the stories with what people had experienced. We also turned some of the stories into booklets which people with intellectual disabilities could read. And we videotaped three of the stories.

We also knew that service providers have to do what government policy tells them to do. So we gave information to the Department of Human Services which we hoped would lead to better information and guidance for service providers.

And we started to think about how people with intellectual disabilities could have more chances to meet with people. We hoped that by doing these things the stories would help people with intellectual disabilities to lead safer sexual lives.



Taking action based on research

Living Safer Sexual Lives was not only a research project. We were also concerned to take action from the research in order to assist people with intellectual disabilities to lead safer sexual lives. At the beginning of the project we thought that this might involve the development of a peer education project. However as the complexity of the issues affecting the lives of people with intellectual disabilities became more apparent we realised that there needed to be a more comprehensive and diverse approach. With the assistance of the reference group a number of different strategies were developed. These were:

- The development, implementation and evaluation of workshops for people with intellectual disabilities, families and service providers using the stories as a basis.
- The development of information resources for people with intellectual disabilities.
- Collaborative work with the Office of the Public Advocate and other organisations in preparing a policy document for the Department of Human Services.
- Discussions with advocacy organisations and service providers about the need for more social opportunities for people with intellectual disabilities.

This chapter briefly describes each of these outcomes.

1. Taking action on workshops

The 25 stories produced during the *Living Safer Sexual Lives* research phase were used as the basis for developing a series of workshops for people with intellectual disabilities, families and service providers. Two modules were developed with different time frames for each group. The modules focussed on attitudes and values towards sexuality and relationships and on 'having rights and being safe.' The workshops were similar in structure and content for each group. They all had the following characteristics:

- They used the experience of members of the group in an activity to explore perceptions of the sexual lives of people with intellectual disabilities.

- They used some of the stories provided by the story-tellers to generate discussion of issues such as attitudes and values, beliefs about duty of care, safe sex and rights. In some workshops the stories were read aloud by participants in small groups, in others they were read by the facilitator or a video of the story was used.
- They avoided prescriptions or advice about what to 'do' in favour of facilitating discussion of the issues among participants.
- They provided a safe place for participants to examine some of their experiences, fears, anxieties, hopes and joys.

The workshops adopted an innovative approach in that they:

- Used the stories contributed by the story tellers in the research as a means of providing information and beginning discussion about sexual and relationship issues;
- Were similarly designed for people with intellectual disabilities, service providers and families. We were aware that sex education often occurred in a fragmented way. Sometimes family received support, at other times staff at a CRU or ATSS would be provided with in service education. People with intellectual disabilities were likely to receive such education either at school or on a problem centred basis. We hoped that some organisations would adopt the workshops for use by all three groups and that this might assist change in the lives of people with intellectual disabilities;
- Treated all participants as adult learners. The workshops used structured activities based around the stories to provide a safe and stimulating space in which people could discuss issues around sexuality and relationships. Participants drew on their own experiences as well as input from the facilitators in order to explore their values and attitudes; and
- Focused on issues of key concern and interest. The content of the workshops was based on the themes and issues which were dominant in the stories. Facilitators were also guided by the specific concerns of participants in a particular workshop.

A workshop committee was formed from the reference group which assisted with the design of the workshops and provided assistance in developing resources for it.

The workshops were developed, implemented and evaluated over an eight month period in 2000. An evaluation report documents the responses of the different groups to the workshops (Johnson, et al. 2000). This chapter provides a summary of the evaluation.

The evaluation of the workshops indicated that they were extremely useful to families, service providers and women with intellectual disabilities. Workshops for men with intellectual disabilities are currently being implemented and an evaluation of these workshops is not yet available.

1.1 Service provider workshops

The workshops were trialled with more than 150 service providers across Victoria. Participants included staff at supported employment services, adult training and support services, accommodation services, and community visitors. Workshops were run in both rural and city areas.

The evaluation provided evidence that the workshops challenged service providers to reflect on their values and beliefs through the stories and to use these reflections to set a framework for informed, aware and thoughtful responses to the issues that arise for them when working with people with an intellectual disability around sexuality. More particularly the workshops assisted staff to respond more appropriately to people with intellectual disabilities by:

- Becoming aware of the fact that the sexuality of people with an intellectual disability is more about sexuality than disability and it is not a 'behaviour' that has to be managed.

Comments from some service providers included:

I will be more aware of this issue on my visits.

We need to meet together as a staff on a regular basis and talk about our views about sexuality and relationships. It's difficult to help our employees if we aren't clear ourselves.

We need to think about why we do things.

- Recognising that the sexuality of people with intellectual disabilities is not ‘something different’ to that experienced by the rest of the community. For example:
This could have been me.
People with intellectual disabilities have sexual rights the same as any other person.
- Treating people with intellectual disabilities with respect, privacy and dignity and using this way of working to solve problems which may arise. For example:
I will listen more to what people tell me.
- Acknowledging that you cannot deny the sexuality of this group creates more problems than it solves. For example:
It’s really important to deal with people sensitively. We could wreck this guy’s life if we did the wrong thing.

The workshops provide a unique basis for working with service providers and should be the core of a more developed programme of sexuality and relationship education. Existing courses and modules provided by other agencies, for example, sexual assault or sexual abuse may be added depending upon the needs of particular groups and agencies.

1.2 Family workshops

Four workshops have been run for families with 42 people attending in all. Two workshops were carried out in Melbourne and two in a country area.

These workshops were developed slowly over six months. They proved more difficult to shape than those for service providers and required much more reflection about content and process. More substantial changes were made to them over time. However, it is clear from the questionnaire responses to the last workshop that families found the workshops a challenging and useful process. The need for workshops that can assist families to face their fears and anxieties and to become more proactive in helping family members with disabilities to learn positively about sexuality, relationships and sexual rights and safety has been demonstrated repeatedly through these workshops.

Comments from some of the families graphically illustrate their responses to finding a safe space in which to explore their anxieties.

It [the workshop] raises a lot of questions which we have to cope with. Really need a person we can ring up to solve some problems.

Very interesting and created awareness and we are not alone with problems. Made me think more about what Julie [pseudonym] thinks.

Loved it - very thought provoking about my own sexuality [beliefs] and what I say to Ian [pseudonym].

1.3 People with intellectual disabilities: workshops

Eight workshops were run with 38 women with intellectual disabilities. Two workshops were conducted in a rural area and six in an inner Melbourne education centre.

The workshops for women with intellectual disabilities provoked very positive and energetic responses to the stories and activities. The evaluation demonstrated that the sessions related to life experiences of the women. Further they offered a space and opportunity for women to be treated as adult learners who drew on their own experience and skills to address issues which were important to them. Providing the workshops over a period of six weeks allowed for a climate of trust and equality to be developed.

However it was also apparent from the evaluation that the facilitators of these workshops required considerable skills in working with people with an intellectual disability, confidence to respond flexibly to diverse needs and sensitivity in dealing with intimate experiences. In the workshops there was an adult exchange of questions, queries, replies, thoughts and feelings. They were not contrived. The verbal members of the groups responded enthusiastically with the following comments:

Video helps to explain things, informative.

You get to know about yourself and feel better, interesting.

Pretty good stuff. All the stuff. Kiss boys and that! (laughs).

Learning more about safe sex that we don't already know.

Learn all good things to do with a boy friend like pictures and having dinner.

I hope we get more groups.

Implementing and evaluating workshops for men with intellectual disabilities has proved to be a difficult problem logistically. There has been less interest by agencies hosting workshops for men around sexual issues. This may be because service providers are more concerned about women's vulnerability and see sex education as 'problem focused' and aimed at developing protective behaviours. On the other hand men's sexuality is constituted as either unproblematic or as something to be contained rather than explored. Previous experience by Family Planning Victoria (personal communication) has also revealed that men are more reticent about attending group workshops on issues about sexuality. We have also found it difficult to find a man who is able to be a facilitator with men with intellectual disabilities. However the workshops for men have been prepared and implementation and evaluation are proceeding.

2. Taking action on information

Information resources were needed for the workshops. We also believed that these would be used independently by people with intellectual disabilities, families and service providers to assist them in talking about issues about sexuality and relationships. Two different resources have now been prepared:

- Three videos of the stories have been made with people with intellectual disabilities reading the stories. These people were paid actors and not the original story-tellers.
- A set of booklets is currently being prepared for publication. These booklets are designed around particular themes; for example 'Dreaming about Sex',.

2.1 The videos

Three videos were produced during the project. These were designed for the following reasons:

- It is often difficult for people with intellectual disabilities to access written material. Videos provide an interesting and useful way of both giving information and beginning a discussion.

- Sometimes it is difficult for families and/or service providers to discuss sexual issues in relation to people they are close to. It is easier to begin such discussions from a safe distance. The videos provided a means of both personalising the issue and distancing it.
- Few people with intellectual disabilities have opportunities to see their stories (or to hear or read them). The videos provided a means by which other people's stories could be disseminated and discussed.

It was not possible to ask the story-tellers to read their own stories. However other people with intellectual disabilities were employed to read the stories. The videos were produced cheaply and focus on the story and the story-teller with few props. They have proved to be a powerful resource in the workshops.

2.2 The booklets

A resources committee was established from the reference group which assisted in the development of a booklet prospectus. This is currently under consideration for publication. Sixteen stories were chosen for inclusion in a set of eight booklets. Each booklet is designed to be read independently from the others although they can also be used as a series. The booklets vary in length but on average are approximately 4000 words in length. The booklets include an introduction to the topic and the stories, two stories and a conclusion which consists of feedback from people with intellectual disabilities who have read the stories. The themes for the booklets are:

- Dreaming and Thinking about Sex and Relationships
- Being Together
- I'm a Man and I have Sex with Men
- Talking and Thinking about Babies
- Hurting and Surviving
- Sex is not Always Safe
- Being Married
- Running My Own Life

It is envisaged that the booklets will be accompanied by illustrations which tell the story enabling those without reading skills to follow the narrative.

3. Taking action on policy

Members of the reference group for the *Living Safer Sexual Lives* Project were concerned at the issues raised by the stories which had policy implications. Of particular concern were the following:

- relationships between service providers and clients;
- lack of clear policy and guidelines from the Department about sexuality and relationships and resulting confusion about rights and duty of care;
- the lack of knowledge of safe sexual practices by people with intellectual disabilities.

Such concerns were exacerbated by the work experiences of some reference group members outside of the project. For example community visitors were concerned at the lack of information available to people with intellectual disabilities about sexuality and the Office of the Public Advocate was concerned with people who were perceived to be at risk of having HIV/AIDS. They were also concerned with the lack of guidance and support offered to service providers on the issues of sexuality and relationships. The Department of Human Services policy on sexuality and relationships (Intellectual Disability Services, 1995) appeared dated and contradictory. A review was to be held of this policy and of two other relevant policies (Reporting Allegations of Physical and Sexual Assault to the Police and the Disability Services HIV+Guidelines) and the reference group believed that information from *Living Safer Sexual Lives* could provide useful input into this review.

As a result of these concerns the Office of the Public Advocate organised a forum of representatives from relevant organisations to discuss issues around sexuality and disability. The *Living Safer Sexual Lives* Project was involved in the forum and collaborated to produce a discussion paper to be submitted to the review of the Department's policy (Office of the Public Advocate, 2000)

The document adopted a health promotion model to sexuality and relationships. It defined sexual health promotion as:

The holistic process of enabling individuals and communities to increase control over the determinants of sexual health, and thereby managing and improving it through their lifetime.'

(Winn, 1996)

It made a series of recommendations which focussed on education of service providers which would include 'a focus on health, duty of care, attitudes and values', the need for education on sexuality and relationships for families and people with intellectual disabilities. A number of discussions have since been held with the Department of Human Services staff involved in the review and new or revised policies are now in train.

4. Taking action on social opportunities

Of particular concern to the reference group members was the dominant theme in the stories of loneliness and rejection. A subcommittee was formed to examine what might be done to increase social opportunities for people with intellectual disabilities. A member of the reference group took responsibility for organising a forum to discuss this issue in September 2000. Service providers and people with intellectual disabilities attended the discussion. It was agreed that while some local governments and services were providing social opportunities these were fragmented and often unknown to people with intellectual disabilities in the region. The need for better information about what was available and how well it worked was stressed at the forum. There was also a stated need for better means of information which could reach people with intellectual disabilities, their families and service providers. It was agreed that little could be done without further funding. Currently we are exploring funding possibilities to enable a person with disabilities to undertake work on this issue.

Conclusion

The research stage of this project proved to be time-consuming and challenging for all those involved in it. The second stage of *Living Safer Sexual Lives* was an innovative approach which moved research into practice. It involved the movement of the work from the research to action involving people with intellectual disabilities in the community and to those who worked directly with them. In doing this the reference group proved to be central. Representatives on the reference group came

from organisations which were concerned with issues about sexuality and relationships. They were concerned at the findings of the research and excited by the possibilities for policy development and education which the stories revealed. The work of the reference group did not finish with the research phase. Members became involved as paid editors and actors in developing the stories and in producing information resources. They provided a network of organisations which began to use the workshops and assisted in their evaluation. They initiated actions of their own, particularly in relation to policy issues, which drew directly on the research and took it to another stage.

We believe that the work of the reference group provided a vehicle by which research could be used directly to promote changes which could assist people with intellectual disabilities to lead safer sexual lives.

Chapter six

The research was exciting and challenging for everyone. We wanted to include people with intellectual disabilities in all of the important decisions about the research and its outcomes including being on the reference group, editing stories and checking processes. We were guided by a number of principles:

- that the voices of people with intellectual disabilities are important and should be heard.
- that people with intellectual disabilities are the experts on their own lives including love, sex and relationships
- that sexuality is a normal part of everyone's lives - including people with intellectual disabilities
- that research about people with intellectual disabilities should be guided by them

To support these principles, meetings and materials were in plain English and large print. We wanted to learn from the experiences of people with intellectual disabilities and we tried to use their wisdom at all stages of the project.

We know that there is still a lot to be done to make the sexual lives of people with intellectual disabilities safe and to have their sexual lives acknowledged by the community.



Conclusion

This research was exciting and challenging for all those people who were involved with it. We finish this report with some recommendations which we hope will mean that the findings from the research will help people with intellectual disabilities, service providers and families get better information about sex and relationships. We believe that it is only when people have good education and a chance to explore their attitudes and values that people with intellectual disabilities will lead safer sexual lives.

This has been a very personally challenging project. Challenging because this was a project that many thought could not be done and for good reason - we hit brick walls at many stages - getting funding, having people believe that it was worthwhile, dealing with the hard issues of ethics and consent and then finding people to be involved. But it has also been a joyful project which has moved me deeply on many occasions eg. meeting people who had been dealt a rough hand but who were living their lives with integrity and determination to be the best they could be. Seeing the stories emerge and realising that these were an incredible gift with the power to change people's lives. Awareness of the responsibility that we had to these storytellers to use the stories for change. I don't know that I would want to repeat the experience but I am grateful for it because it has taught me many lessons. I have had the chance to reflect on my ways of being in the world both professionally and personally.

(Lynne Hillier, researcher, *Living Safer Sexual Lives*)

I believe the Living Safer Sexual Lives project was absolutely groundbreaking. Often, people with an intellectual disability are seen as asexual. Either that, or our sexuality is seen as a problem; one that workers and families need to deal with. Our own experiences, good and bad, our own voices –they're just not heard. Living Safer Sexual Lives changed that. People were given a chance to tell their own stories – and those stories are now being used to change people's attitudes towards relationships, sex and people with intellectual disabilities. I'm glad I was part of the process.

(Ria Strong, reference group member, *Living Safer Sexual Lives*)

It seems a long time ago since the first discussions about this project. I have travelled, lived overseas and been involved in other work projects during this time. The stories have gone with me; carried in bags on computer disks and most particularly in my head. At times I have felt despondent at the difficulties involved in working on such intimate and sensitive issues; anxious that our research project could perpetuate the stereotypes of difference rather than challenging them. Then as the stories began to take shape excitement rose. For here were stories of people's lives, coherent, articulate and reflective. Sometimes the words stumbled, sometimes there were long pauses and sometimes there were difficulties in hearing. But the stories were there. I have spent twelve months using the stories with service providers, families and workshops. I have seen people acknowledge that it is a privilege to have read them and I have seen how the power of stories can shift and change our attitudes to others. I have learned much from this project: about people with intellectual disabilities, about the power of words and voice and much about myself. It has been exciting work.

(Kelley Johnson, researcher, *Living Safer Sexual Lives*)

This project necessitated meeting the men I interviewed on four occasions to hear their stories and learn about their lives. From the onset I found this arrangement difficult. I was employed to come into the men's lives for calculated reasons - to extract information so the project would have rich material and in my own mind to gain credibility for being a 'talented' interviewer. I also found that over the course of the meetings most of the men bonded with me (and I with them). This resulted in much angst around whether I had a right to come into their lives in such a measured way knowing that after the last meeting I would probably not see them again. Parts of this still remain unresolved for me. However, I am convinced that the men wanted their stories heard. They wanted others to know what had happened to them, no matter how painful or difficult to recall, in the hope that the lives and experiences of people with an intellectual disability worldwide would become better. I was constantly amazed at the determined, systematic and tenacious way the men approached telling me their stories. Equally, I was amazed at the insights some of them had gained through their experiences and with their capacity to move on.

I suspect parts of the *Living Safer Sexual Lives* project will stay with me forever. The infectious laughter of two of the men I interviewed, the humour of another (particularly when taking the 'micky' out of me), the desperate circumstances of yet another, and so on. I thank all of the men I interviewed and share their hope that the lives and experiences of people with an intellectual disability everywhere will be better as a result of this project.

(Phil Nott, researcher, *Living Safer Sexual Lives*)

Although much of my research before joining the project had been with marginalised groups and had a strong social justice focus, I had never before worked with people with an intellectual disability. One of my roles in reference group meetings was to record proceedings. During this process my interpretations, and even the formatting of minutes, were constantly challenged by those members with an intellectual disability. In this context I was forced to examine the taken for granted and 'walk a mile in someone else's shoes' and it was a challenging, sobering and life changing experience. I feel privileged to have had the opportunity to work on this project and to have listened to the marvellous, sad but also uplifting experiences of research participants and reference group members. The stories still make me cry. One of the most satisfying experiences for me was to see the research move into an action phase and to see all of our hard work have an impact on the quality of life of many people with an intellectual disability, as well as their families and care givers.

(Lyn Harrison, researcher, *Living Safer Sexual Lives*)

This research proved to be challenging and exciting for all those involved in it. When it began the researchers were confident about the need for it because of extensive consultation with relevant organisations and groups. However we were also conscious that working with people with intellectual disabilities meant that the research process would have to be flexible and sensitive in its approach. To achieve this we adopted a number of strategies. These included:

- A reference group which would participate actively in the design and implementation of the process.
- Training for all researchers on issues about disability and sexuality.
- The use of a peer review process throughout the gathering of stories which enabled story gatherers to debrief with each other and identify key themes.
- The use of strategies which would assist the continuing involvement of people with intellectual disabilities in the research such as regular meetings, the use of plain English and large print in minutes and agendas and opportunities for a variety of different kinds of involvement.
- Opportunities for counselling for story-tellers and opportunities to comment and change their stories.

As we moved into the second stage of the process more people became involved. A skilled workshop facilitator was employed to assist in the development of workshops

and organisations represented on the reference group began to take the initiative in developing the ideas and themes arising from the stories. Outside organisations began to use the stories to inform their own work and policies. The year 2000 was very exciting. We travelled the state with the workshops, designed a process evaluation and developed a series of exciting information packages for people with intellectual disabilities. Simultaneously policy development work was happening and work was begun to look at how to broaden social opportunities for people with intellectual disabilities.

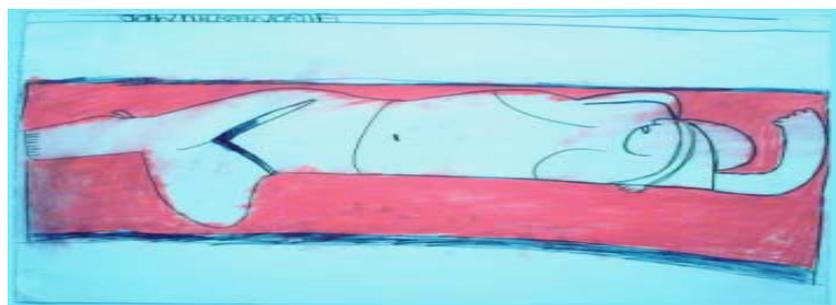
As researchers this entire process was demanding and exciting. We worked from a number of assumptions which informed the work and we believe provide a useful framework for other research with people with intellectual disabilities. These were:

- A commitment to moving from research into action. Early work on this project had revealed that people with intellectual disabilities had little access to information about safe sexual practices and relationships. To undertake research, write a report and hope that someone would use the findings did not seem to us to be enough. The second stage of the project was firmly based on findings from the research and enabled us to move into an action phase.
- The needs of people with intellectual disabilities were to drive the research. This was important in both stages of the work. The implications of this principle became most apparent in the workshops where the stories were seen to be central to the education of people with intellectual disabilities, families and service providers.
- Ensuring the continuation of the learning from the research. We were concerned that at the conclusion of the research there should be ways for the learning from it to be used by other organisations. One representative from a community organisation which was a partner in the project was involved in the development and implementation of the workshops and trained to use them. Others have continued to promote the project through work directly with those using their services or have continued to promote its findings in policy development work.

Plans are underway to publish the stories as booklets for people with intellectual disabilities and to write a book which will use the stories to examine issues of sexuality and disabilities.

No research project can achieve everything within its time frame and now at the conclusion of *Living Safer Sexual Lives*, there remain outstanding issues which in our view require further work and commitment from relevant organisations within the state. Accompanying this report are recommendations which we hope will form the basis for further work to assist people with intellectual disabilities to lead safer sexual lives.

At the conclusion of this research we are more aware than ever of the work that needs to be done in order for the sexual lives of people with intellectual disabilities to be acknowledged by those around them. Without this acknowledgement and an acceptance that people with intellectual disabilities have the right to relationships and to sexual expression, we believe that it will be difficult to support them to lead safer sexual lives. We believe that the stories contributed to this research and the outcomes which eventuated from them will help in this process.



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Appendix 1

Living Safer Sexual Lives Reference Group 2000

Ms Patsie Frawley
ARCSHS

Mr Alan Robertson
VALID

Dr Lyn Harrison
Deakin University

Ms Chris Reynolds
DHS

Dr Lynne Hillier
La Trobe University

Ms Anne Rudowski
Family Planning, Vic

Mrs Amanda Hiscoe
AMIDA

Ms Jacqui Schultz
Office of the Public Advocate

Ms Debbi Holopainen
VUT

Ms Chris Scott
VALID

Dr Kelley Johnson
La Trobe University

Ms Marilyn Shepherd
Community Visitors

Ms Chris Jennings
VCOSS

Ms Ria Strong
AMIDA

Ms Lea Kewish
Consultant

Mrs Janice Slattery
AMIDA

Ms Karleen Plunkett
Women's Health West

Mr Luke Stone
Reinforce

Appendix 2

Pseudonyms for participants:

Alicia Rodriguez

Angela Hamstead

Elaine Webster

Gina Mason

Hannah Booth

Jan Waters

Marilyn Roscoe

Mary Stevens

Margaret Crowley

Molly Hope

Ruth Simpson

Sara Standish

Vicki Mulholland

Adam Driscoll

Darren Walters

David Warren

Derek Housemann

Hussein Damianis

Kevin Ryan

Luigi Favoloro

Neville McDonald

Richard Sayers

Shaughan Taylor

Tom Harris

Vlado Mecier