Living Safer Sexual Lives: Research and Action

**ABSTRACT**

In spite of changes in the way people with learning disabilities are perceived, issues of sexuality and personal relationships remain particularly problematic for them. Living Safer Sexual Lives was a three-year Australian action research project which sought to address how people with learning disabilities view these issues. During the first stage of the project, 25 people with learning disabilities told their life stories, with a focus on sexuality and human relationships, to experienced qualitative researchers. In the second stage of the project, these stories were used to provide people with learning disabilities, families and service providers with workshops and resources designed to help people with learning disabilities to live safer sexual lives.

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**INTRODUCTION**

The need to find ways of translating research into action seemed particularly important to us as we began a study to look at how people with learning disabilities saw their sexuality and relationships in Australia. Previous research had revealed that people with learning disabilities were vulnerable to sexual abuse (Brown & Turk, 1992; Millard, 1994; McCarthy, 2000) and sexually transmitted infections (McCarthy & Thompson, 1995; Cambridge, 1997; Thompson, 1994). Given this knowledge, it seemed irresponsible to undertake research that did not have practical outcomes.

Further, in Australia there had been no qualitative research designed to document how people with learning disabilities saw their own sexuality or what kind of assistance they wanted in order to lead safer sexual lives.

Such research has the potential to develop interventions arising directly from the views of people with learning disabilities. Sexuality and relationships are sensitive topics to most people, so if people with learning disabilities were to give life stories to the project, then it was important to be sure that their contribution was not simply of 'academic interest' (McCarthy, 2000); the participants in the study had a responsibility to ensure positive outcomes.

Recognition of these issues early in the research enabled us to plan interventions from the research. The funding obtained for the project included money for an action stage. Over the three years of the project we retained the same researchers and the same critical reference group. We were also able to include in the research people who were skilled in community development and education. Consequently we were able not only to undertake

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qualitative research with people with learning disabilities, but also to use the research to develop, implement and evaluate strategies designed to help them lead safer sexual lives, raising parallels with action research. Participatory action and/or participatory action research (PAR) has been variously defined. 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, p532).

Applied research falls within this definition and Kaplan and Alsup are more explicit in seeing action research as focused on the ‘empowerment’ of groups who are marginalised, defining 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, p41).

In practice, Living Safer Sexual Lives fell somewhat between these two definitions. It did seek to empower the people involved in it, but there were limits to their participation at different points in the project (Harrison et al, 2002). We did focus on the need to translate the research findings into strategies and actions that would assist people with learning disabilities to lead safer sexual lives.

However, unlike some action research, this occurred in two clearly marked stages. One was concerned with the research and the other with action, the two not really occurring simultaneously. Despite such limitations in methodology, Living Safer Sexual Lives proved to be an exciting and innovative project, with very positive outcomes both for participants and for promoting systemic change.

This paper outlines the two stages of the project and explores how it made the transition from research into action.

**Living Safer Sexual Lives: The Project**

The project developed from consultations between the researchers and representatives from service provider and self-advocacy organisations. These affirmed the lack of voice by people with learning disabilities about sexuality and relationships, the barriers and obstacles they experienced around sexuality and relationships and concerns about their lack of knowledge of safer sexual practices. As a result of these consultations, Living Safer Sexual Lives sought to fill some of the gaps in our knowledge of how people with learning disabilities see their own sexual lives and to work with them to find strategies which would assist them in having more fulfilling and safer sexual expression and relationships.

**Aims**

The aims of the project were:

- to identify key issues around sexuality and relationships for people with learning disabilities
- to place sexuality and relationships in the broader context of the lives of people with learning disabilities
- to develop, trial and evaluate workshops and other resources based on stories contributed by people with learning disabilities to assist them to live safer sexual lives.

**Methodology**

Living Safer Sexual Lives involved two stages: research and action. The research involved the contribution of 25 stories by people with learning disabilities. The second stage used the research to develop, implement and evaluate strategies which were designed to assist people with learning disabilities to lead safer sexual lives. Throughout both stages of the research, a critical reference group made up of representatives from self-advocacy, advocacy and service provider organisations advised on the research design and process.
Twenty-five people with learning disabilities contributed life stories, each over at least three extended sessions, to researchers with experience in qualitative research and in working with people with learning disabilities. The ages of the story contributors ranged from 25 to 60. There were 12 men and 13 women. The stories were taped, transcribed and written in the person's own words. Each story was taken back to the story teller for approval. Two versions of each story were written: the first, a short story in plain English, the second, a longer, more complex version.

Both versions of each story were workshopped by the reference group to ensure clarity and to determine how best to use it.

**FINDINGS FROM THE STORIES**

The stories were complex, emotional, passionate, painful and joyful. They were accounts of adults struggling with huge issues around sexuality and relationships. In this paper the focus is not on the complexities of individual stories (for a detailed account of this, see Johnson *et al*, 2000b) but rather on the key themes identified by the researchers and the critical reference group. These formed the basis for the action stage of the project:

- attitudes of service providers and families which presented obstacles to people with learning disabilities leading sexual lives or developing relationships
- lack of accurate information about sexuality available to people with learning disabilities
- lack of clear policies and guidelines for staff working with people with learning disabilities
- loneliness and isolation experienced by many of the story tellers.

**Attitudes and values of service providers and families**

The stories revealed that many of the story tellers had experienced great difficulties in leading active sexual lives or forming relationships. Reasons included poverty, isolation and previous bad sexual experiences. However, a key theme centred on the attitudes and values of service providers and families. Many of these other interests either ignored sexual and relationship issues or treated them as a problem. In some instances, they prevented the development of a relationship. For example Elaine Webster lived at home for 30 years. She was involved in a relationship with Peter for almost 15 years.

'Well I just asked mum and dad if I could get married to Peter. And me mum said "No". I was nearly 30. Me mum said "You've only got one hand, you can't cook, you can't do ironing, you can't do anything". I said "Well, I'll find a nice man". I said "He will do it". Mum said "No".'

The silence about sexuality and relationships and various prohibitions encountered led many of the story tellers to have secret sexual lives. This left them vulnerable to abuse and unsafe sex. Eleven of the women story tellers had experienced some form of sexual abuse, as had eight of the men.

**Lack of information**

People with learning disabilities lacked information about sexuality and relationships. Even when they had been given sex education classes, they often found them embarrassing or irrelevant. Hussein who had an active sexual life commented:

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

Neville believed that he could catch HIV/AIDS, from 'bus seats', 'cups', being close to someone who had it, kissing and eating from rubbish bins. He had stopped having any kind of sexual life because he couldn't 'remember having sex when it didn't feel dirty'.

**Lack of clear policies and guidelines**

The barriers and obstacles which people experienced in relation to sexuality seemed due partly to a lack of clear policies and guidelines for service providers and carers. Even when they existed, they were often not known by people with learning disabilities. For example, Kevin and
Hannah lived in a special accommodation house and had been together for more than 12 months. They found it very difficult to share their room.

Kevin said:

‘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 don’t that. Because we’re too 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’.

It is not possible to know from this story why staff took the action they did. However, an analysis of current government policies on sexuality and relationships (Intellectual Disability Services, 1995) revealed that the existing policy provided contradictory and ambiguous advice to staff about the issue, and in some instances prohibited staff from providing information to people with learning disabilities about sex. This fostered a service provider culture of caution and prohibition.

Loneliness and isolation

Nine of the story tellers wanted an intimate relationship with someone else. The three who did not want a relationship had been badly hurt by previous relationships or had adopted a lifestyle of transitory relationships. For most of those who wanted a long-term relationship, this was an unfulfilled dream. For example Shaughan said:

‘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’.

Many of the story tellers led isolated lives and had experienced repeated rejections. For example, David, a young man living alone in the community, commented:

‘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’.

The four themes identified by the researchers and the critical reference group formed the basis for the development of a series of interventions in Stage 2 of Living Safer Sexual Lives.

On to action

Stage 2 of Living Safer Sexual Lives began with the formation of four planning committees developed from the critical reference group. Each planning committee took responsibility for developing interventions around one of the research themes. This section of the paper describes the outcomes.

Towards changing attitudes and values

It was apparent from the stories that workshops and education were needed for service providers, families and people with learning disabilities. It was decided that the workshops should be designed to be used with each of these groups. The workshops use a common framework and materials, adapted to meet the needs of different groups of participants. They use the lived experience of people with learning disabilities, revealed through the stories, as a focus to provide an ‘experiential learning’ environment for each group of prospective participants. They are unique in that they focus particularly on attitudes and values, treat sexuality and relationships as a part of everyone’s life, not as a problem, and recognise all participants as adult learners.

The workshop committee designed aims for the workshops and a set of guidelines to ensure that the workshops were implemented ethically and that the stories were treated with respect. Three modules were developed for a two-day workshop, focusing on values and attitudes, being safe and having rights, and policy development.

Each module uses the stories to initiate discussion about these themes and to highlight common issues recognised by the workshop participants. Some activities are also used to assist participants to develop their own responses to these issues. A manual (Frawley et al, 2001) and a ‘train the trainer’ workshop have been developed and trialled.
The workshops were developed, implemented and evaluated over an eight-month period with more than two hundred service providers, sixty families and fifty people with learning disabilities across Victoria (Johnson et al, 2000). After each trial the workshops were modified. They have now been used successfully in Australia, New Zealand and Iceland. The responses to the workshops have been overwhelmingly positive from all three groups of participants.

Written evaluations from participants suggest that the workshops challenge the existing values and attitudes of families and service providers and provide a safe and creative space for people with learning disabilities to explore issues of sexuality and relationships.

Towards better information
A series of eight plain-English booklets with two stories in each booklet were designed. Each booklet focuses on a particular theme, for example Being Together or I'm a Man and I have Sex with Men. Members of the resources committee chose the stories for each booklet. People with learning disabilities were paid consultants to the booklet design. Their discussions of the stories provide a commentary at the end of each booklet.

A video of three of the stories was made with people with learning disabilities reading the stories. All story readers were paid for their work. Two members of the critical reference group were story readers on the video. The video is used as part of the workshops, although it can also be used independently.

Towards new policies
The Office of the Public Advocate (an ombudsperson for people with disabilities in Victoria), which was represented on the critical reference group, took responsibility for organising a forum with agencies concerned with sexuality and relationship issues and with people with disabilities, to discuss current government policies. As a result of the forum, a discussion paper was written (Office of the Public Advocate, 2000) recommending that sexuality be regarded as a health promotion issue for people with disabilities, urging more sensitive and informed policy development and stressing the need for adequate education for people with disabilities, families and service providers. The discussion paper was submitted to the relevant government department. Consequently four members of the Living Safer Sexual Lives reference group are now representatives for their own organisations on the government working party which is developing a new policy on sexuality and relationships.

Towards breaking down loneliness and isolation
This issue proved to be the most difficult and least successful strategy of the project. Three members of the critical reference group organised a forum to discuss strategies to increase the social opportunities for people with learning disabilities. Very few people attended, although it was advertised widely. The forum concluded that there needed to be a funded project that would appoint a person with a disability to gather information about available social activities, disseminate it and explore new ways of providing people with social opportunities. Funding has not yet been obtained for this project. The reasons why this part of the project proved so difficult are not easy to identify. The prevailing negative attitudes in the community about the sexuality and relationships of people with learning disabilities, the long-term nature of establishing new social opportunities and the limited time frame of Living Safer Sexual Lives are possible factors.

CONCLUSION
Living Safer Sexual Lives was an innovative action research project which sought to establish a new paradigm for working with people with learning disabilities on sexual and relationship issues. It was concerned to place these issues within the wider context of people's lives and to seek the contribution of people with learning disabilities in exploring the issues. The stories contributing to the research were retained in the story tellers' own voice and used to assist the critical reference group in
developing strategies which were relevant to people with learning disabilities.

The workshops, information and policy which were developed during the action phase of the research have proved to be significant steps in providing people with learning disabilities with opportunities to lead safer sexual lives. It is disappointing that to date our efforts to increase the social opportunities of this group of people have met with less success.

Of equal importance with the content of the study were some of the process issues. The critical reference group developed into an active promoter of the project. The members became advocates, co-researchers, editors and actors as the project developed. Funding was obtained to ensure that all unwaged workers involved in the project were paid. This was seen as highly significant by people with learning disabilities who participated in the project. As the project came to an end, the critical reference group members have continued to work on the issues arising from the project. The work is not yet over.

References


