

Resources available:

Intellectual Disability Australia, as the 'news voice' of ASSID, is committed to providing membership with up to date information about available resources. Already this year IDA has covered 'Taking Care of Me', a program developed by The Illawarra Disability Trust to promote skills for women with intellectual disability in identifying violence and in seeking supports to deal with the issues. We have also published details of the West Australian Disability Service Commission's 'Feel Safe' program, designed to enable adults with disability develop skills in dealing with potentially abusive situations. Below is the background and the outline of 'Living Safer Sexual Lives', a program of workshops that were the outcome of a project that listened to the stories that people with intellectual disability told about their own lives.

Living Safer Sexual Lives

Kelley Johnson, Patsie Frawley, Lynne Hillier and Lyn Harrison, Australian Research Centre in Sex Health and Society, Latrobe University.

From Research.....

In spite of changes in the way people with intellectual disabilities are perceived in our community, issues of sexuality and relationships remain particularly problematic for them. *Living Safer Sexual Lives* is a three year Victorian Health Promotion Foundation funded action research project which has sought to address how people with intellectual disabilities view these issues. During the first stage of the project twenty five people with intellectual disabilities told their life stories, with a focus on sexuality and human relationships, to experienced qualitative researchers. In the second stage 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.

Rationale

The project developed from consultations between the researchers and representatives from service provider and advocacy organisations. During these consultations the following concerns were expressed.

- People with intellectual disabilities were perceived as experiencing barriers and problems in leading safe sexual lives.
- There was little opportunity for people with intellectual disabilities to discuss sexuality and relationships.
- There was often little consultation with people with intellectual disabilities in relation to decisions made about their sexuality and human relationships.
- Current research had failed to place sexuality and relationships in the broader context of the lives of people with intellectual disabilities.
- People with intellectual disabilities are vulnerable to sexual abuse or exploitation. Research findings have revealed that women (and to a lesser extent) men are more likely to experience sexual abuse than other

groups in the population and to be vulnerable to sexually transmissible diseases (Brown and Turk, 1992; Carson, 1994; Millard, 1994; Cambridge and Brown, 1997; McCarthy, 1999).

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.

Key findings (from the stories):

- Stories were complex, emotional, passionate, painful and joyful. They were accounts of adults struggling with huge issues around sexuality and relationships. For example Kevin and Hannah live in a special accommodation house where, after a struggle they have been able to share a room. Kevin wants to live more independently but says:
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.
- Many people led secret sexual lives which sometimes exposed them to abuse and risks. For example Elaine lived at home with her parents and had been involved in several long term sexual relationships. However she had never once been able to have sex at home with any of them. This had led her into situations where she had been both sexually and physically abused.
- Some people led very unsafe sexual lives. Secrecy made it more difficult for people to be safe. Hussein had been sexually abused at the age of 13 and had sex with men on a casual basis. He did not use condoms and was very afraid that his family or worker would find out about his hidden life.
- Many wanted long term relationships. All of the people in the group expressed strong desires for a close long term relationship with someone. For most this was a dream which had been unfulfilled. For example Shaughan says:

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.

- Some people were isolated and had experienced repeated rejections by other community members. 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.

- Almost all of the men and women in the group had been sexually abused at some time. For example Neville had lived for twenty years within an institution. He said that staff at the institution told him that sex was fun and then "jumped into bed with me." However when he tried to form a relationship with a woman living at the institution he was punished and never saw her again.
- People lacked information about sexuality and human relationships. Even when people had been given sexuality education they often found it embarrassing or irrelevant. So Hussein who had an active sexual life comments:

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?

Conclusion

The stories which people contributed to the project have increased our understanding of the place of sexuality and relationships in the lives of people with intellectual disabilities. In particular the stories reveal how sexuality needs to be seen in the broader context of someone's life. Efforts to protect people by service providers and families in many cases left them vulnerable to sexual abuse or to a denial of their rights to a safe and pleasurable sexual life. The lack of power and information to make informed choices by this group of people reflected their relative powerlessness in other areas of their lives.

References

- Brown, H. and Turk, V. (1992). Defining sexual abuse as it affects adults with learning disabilities. *Mental Handicap*. 20(2) 44-55.
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- Carson, D. (1994). The law's contribution to protecting people with learning disabilities. In J. Harris and A. Craft (Eds). *BILD Seminar Papers No. 4: People with Learning Disabilities at Risk of Physical or Sexual Abuse*. Kidderminster: BILD.
- McCarthy, M. (1999). *Sexuality and Women with Learning Disabilities*. London: Jessica Kingsley.

Millard, L. (1994). *Between ourselves. Experiences of a women's group on sexuality and sexual abuse*. In A. Craft (Ed). *Practice Issues in Sexuality and Learning Disabilities*. London: Routledge. 159-176.

.....To Practice

The life stories contributed by 25 people with intellectual disabilities to the *Living Safer Sexual Lives* Project formed the basis for the development of a range of different resources designed to assist people with intellectual disabilities to live safer sexual lives. The resources consist of:

- A one day workshop for service providers which uses he stories to focus on issues such as values and attitudes, safety and rights has now been developed and trialled with more than 200 service providers across the state. A manual for the workshops is now complete in draft form.
- A four week set of workshops for women with intellectual disabilities has been developed, trialled and evaluated in both city and country areas.
- A family workshop of two hours has been developed and trialled.
- A set of stories has been prepared for publication as plain English booklets for people with intellectual disabilities. These deal with major themes arising in people's lives. Two publishers have indicated interest in publishing the booklets.
- A video of three of the stories has now been produced.

1. Service Provider Workshops

The workshops have now been trialled with more than 200 service providers across Victoria and internationally. Participants have included staff at Supported Employment Services, Adult Training and Support Services, accommodation services, and community visitors. Workshops have been run in both rural and city areas.

The evaluation provides evidence that the workshops challenged service providers to reflect on their values and beliefs through the stories. They then began 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.

Continued on next page

- recognising that the sexuality of people with intellectual disabilities is not "something different" to that experienced by the rest of the community.
- treating people with intellectual disabilities with respect, privacy and dignity and using this way of working to solve problems which may arise.
- acknowledging that you cannot deny the sexuality of this group.

The workshops provide a unique basis for working with service providers. We believe that from this basis 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.

2. Family Workshops

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

These workshops were developed slowly over the 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 even in shortened form 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 shown repeatedly through these workshops.

3. People with Intellectual Disabilities Workshops

Eight workshops have been run with women with intellectual disabilities. Thirty eight women have been participants. The workshops for women with intellectual

disabilities have revealed very positive and energetic responses to the stories and activities. The evaluation has shown that the sessions seem true to the life experiences of the women. Further they offer a space and opportunity for women to be treated as adult learners who bring their own experience and skills to address issues which are important to them. Providing the workshops over time allows for a climate of trust and equality to be developed. However it is also apparent from the evaluation that the facilitators of these workshops require considerable skills in working with people with intellectual disability, confidence to respond flexibly to diverse needs and sensitivity in dealing with intimate experiences. In these workshops there is an adult exchange of questions, queries, replies, thoughts and feelings. They are not contrived.

Conclusion

The experience of running the workshops over time has been both challenging and exciting. On the basis of this experience we believe that they offer a new way of working with people on sexuality and relationship issues. In particular the workshops offer an opportunity for organisations to provide education to families, service providers and people with intellectual disabilities simultaneously and within a common framework. This offers real possibilities for change. We are currently developing the workshops further and they are now available to organisations and groups working with people with intellectual disabilities.

If you would like further information contact:

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Email: a.mitchell@latrobe.edu.au ◆

March Edition of IDA

to include:

- ★ Details of the 2000 conference
- ★ Controversy over reports
- ★ Review of 'Moving On without Parents'
- ★ Pics of ASSID members enjoying themselves (yes, the evidence exists)

AND MORE....

Changing your address?

Let Wendy at the Secretariat know!

Contact: **Wendy Grant**

ASSID Secretariat
University of Newcastle Union
PO Box 18,
University of Newcastle, Callaghan NSW 2308
Phone: 1800 644 741 Fax: 02 4921 7151
Email: scwbg@alinga.newcastle.edu.au

Wendy will update the database and you will continue to receive all the benefits of ASSID membership.

Publications and Reports Available

Parents with a disability in the NSW Children's Court.

This report found that almost one quarter of all cases before the NSW Children's Court in care and protection matters were parents with a disability. Furthermore care and protection workers typically put parents with a disability into the "too hard" basket. Concerns of workers were more about potential for harm than alleged or substantiated abuse.

The Court's reliance on expert opinion further disadvantages these parents, who are assessed by diagnosis rather than parenting performance. The majority of children of parents with intellectual disability were made state wards. The absence of suitable support services results in more invasive actions than would be the case if assistance was available to parents in the community.

The report is available from David McConnell or Gwynnyth Llewellyn at the Family Support and Service Project, Faculty of Health Sciences, University of Sydney, PO Box 170, Lidcombe NSW 1825
G.Llewellyn@cchs.usyd.edu.au or
D.Mcconnell@cchs.usyd.edu.au.

(Thanks to Gwynnyth Llewellyn)

Making a Statement: Barriers Facing Women with Intellectual Disabilities when Making a Statement about Sexual Assault to the Police.

This report, by the Intellectual Disability Rights Service in NSW, is the product of an study involving in-depth interviews with police officers and sexual assault workers in the greater Sydney area. *Making a Statement* gives further weight to evidence that women with intellectual disability face enormous barriers in completing a victim statement that has forensic value. The report concluded with recommendations as to how these barriers might be diminished. The study and report were supported by funding from the Dept of Corrective Services, Victims of Violent Crime Grants Program.

Copies of the report available from IDRDR,
Level 1, 128 Chalmers St, Surry Hills, 2010.
Phone: 02 9318 0144,
Fax: 02 9318 2887 or
Freecall: 1800 66 66 115

Victorian Department of Human Services: Management of Services for People with an Intellectual disability.

The Victorian Auditor-General tabled a report in Parliament recently on a performance audit examining the Department of Human Services' management of services for people with an intellectual disability, including:

- resource allocation processes
- safeguards to protect the rights of people with an intellectual disability
- quality of services provided
- adequacy of monitoring arrangements and accountability mechanisms.

The audit focused particularly on case management, day programs and shared supported accommodation.

Copies of the report are available from the Victorian Auditor-General's Office on 03 8601 7000 or www.audit.vic.gov.au or Information Victoria 03 1300 366 356.

(Thanks to Anita Tang) ♦

New Publication

Some Observations on Several Enduring and Decisive Leadership Challenges In the Field of Disability

Michael J. Kendrick PhD

The Queensland branch of ASSID is proud to announce the publication of a new monograph.

Some Observations on Several Enduring and Decisive leadership Challenges in the Field of Disability was originally delivered at the Queensland State Conference by Michael Kendrick in July 1999.

Kendrick discusses such topics as:

- Establishing Shared Vision, Values and Moral Purposes
- Strengthening the Voice and Influence of Persons with Disabilities
- The Work of Improving the Quality of Life for People with Disabilities within Communities"
- Challenging and Transforming the Relevance of Already Established Services
- Strategic Investments in the Renewal and Evolution of the Field

ASSID (Qld) is proud to make this publication available for the price of \$5.00 per copy.

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