

# There's no disability in women's hearts

Count Me Two:  
A Project about Sexual Health for Women  
with an Intellectual Disability

Final Report

Prepared by  
Women's Health Goulburn North East 2002

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**WOMEN'S HEALTH**  
GOULBURN NORTH EAST

Women's Health Goulburn North East (WHGNE) was established in July 2000. Previously known as NEWomen, Women's Health Goulburn North East is the government funded, specialist women's health service for the Goulburn Valley and North-East Victoria.

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# Background

The work of Women's Health Goulburn North East is developed within a framework that views health and wellbeing from a holistic, social perspective. Both the Ottawa Charter and the Jakarta Declaration inform this framework. The World Health Organisation describes health promotion specifically as the '...process of enabling people to increase control over, and to improve their health' and 'health is seen as a state of complete physical, social and mental wellbeing, not merely the absence of disease or infirmity'.

*Count Me Two*, an action research project undertaken from September 2001 - September 2002, has sought to discover barriers to sexual health and to identify or develop strategies that potentially improve sexual health for women with intellectual disability. The work has been conducted in Wangaratta in partnership with women with intellectual disability, service providers and training providers.

Over the past twelve months the project has moved through these phases:

- 1 Contact with service and training providers and formation of the reference group.
- 2 In consultation with the reference group and based on an understanding of issues identified in broad research, a research plan was developed.
- 3 Advertising the project and inviting participation.
- 4 Focus group interviews and individual interviews were conducted between January and April 2001.
- 5 In response to sexual health issues raised by one group of participants a young women's health group was designed and trialled. Women participating in the group named it 'Groovy Chicks'.
- 6 In response to sexual health issues raised by the second group of participants, we provided education and information specific to participant interests in six sessions.
- 7 Evaluation.

# Literature Review

Women's Health Goulburn North East has responsibility for the project titled "Sexual Health and Women with an Intellectual Disability". Sexual health encompasses the following areas and concepts: puberty and body development, menstruation, reproductive health, menopause, breast health, social skills, socio sexual development and expression, relationships, decision making skills, rights and responsibilities, information seeking skills, self care, protective behaviours and health maintenance. One objective of the project is to identify the aids and barriers to women with an intellectual disability in relation to access to appropriate sexual health information, education, service and support. This paper provides discussion and summary of these aids and barriers to women with an intellectual disability enjoying sexual health as identified through a literature review. It forms one dimension of the work that will be undertaken in an effort to understand sexual health issues for women with an intellectual disability. Discussion will begin with locating the experiences of women with intellectual disability as a disadvantaged group in western society. Barriers to sexual health will be considered and while they are presented as discrete topics for consideration, links between them are strong and these links should be drawn. Potential aids to sexual health will be explored and together with the identified barriers will form the basis of conversations with women with intellectual disability (and significant others) to check their relevance and gain clarity about a way forward in a local context.

Women with a disability occupy a position of marginalisation in Australia (Chenoweth 1997). Life for these women includes experiences of exclusion and powerlessness in which the definition 'disability' becomes all encompassing and other important aspects of being such as womanhood and sexuality are denied (Chenoweth 1997, Meekosha 1999, Hastings 1998, Swift 1998, Rappaport 1998, Atkins 1998). Women with a disability are less likely to be employed than other women, men with disabilities and the remaining population. Women with a disability are less likely to receive vocational rehabilitation or work ready programs, earn less than their male counterparts and live in poverty at a higher rate than men with disability. Furthermore, women with disabilities are less likely to receive appropriate health services such as breast and cervical cancer screening programs, bone density testing, menopause and incontinence management. Women with disabilities are more likely to be unlawfully sterilised than men with disabilities. 90% of women with an intellectual disability have been sexually abused and 68% of women with intellectual disability will be sexually abused before they are eighteen years old (Women with Disabilities Australia c. 2001 & Women's Health West c. 2001). Women with intellectual disability are likely to live in segregated care (Women with Disabilities Australia c. 2001 & Women's Health West c. 2001). From this location, women with intellectual disability face significant barriers to enjoying sexual health.

One of the barriers women with an intellectual disability face is that the community have created and believe in mythology that differentiates them from other women. The mythology includes two dimensions: one is the notion that this group of women are eternally child like and the other is that they are asexual. When a woman is seen to be eternally child like she is denied access and pathways to adult roles and rights (Johnson, Hillier, Harrison & Frawley 2001). Without an adult social life, opportunities to meet people, make friends, form relationships and exercise choice in relation to intimacy or marriage, the woman's ability to express her sexuality is limited (Johnson et al 2001). Also associated with this aspect of mythology is the notion that women need protection.

In an environment of protection women are not able to take the risks associated with becoming sexually active and forming relationships. Furthermore, from this perspective she is likely to be deprived of information and education about sex and sexuality (Chenoweth 1997). Another aspect of mythology is that a woman who has an intellectual disability is asexual (Chenoweth 1997). From this construction she is seen and understood as a virtuous and innocent being or, if sexually active, as promiscuous and depraved (Chenoweth 1997, Atkins 1998). This aspect of mythology has implications for partners who are then seen as saints or losers (Atkins 1998).

Women with an intellectual disability are not provided with the information and education that will assist them to develop sexual identity and be capable of making informed choice about sexual expression (Johnson et al 2001, Shakespeare et al 1996). Sexual development is part of physical and emotional development and sex education acknowledges, respects and affirms this aspect of a woman's being (Fegan Rauch & McCarthy 1993). Lack of sex education has an impact on a woman's well being beyond sexual choice and expression. Women are left to endure feelings of confusion about their sexual desires, needs and health in a world of silence. This lack of sex education negatively influences the woman's ability to feel good about herself and to have confidence expressing herself as a sexual being (Centre on Disability Studies 2001, Hastings 1998, Shakespeare et al 1996). Lack of sex education also leaves women vulnerable to abuse (Chenoweth 1997). Women who have not been informed of their sexual rights, and provided with information about sexual activity and relationships of equality are not in a position to protect themselves or seek support when they experience violence and abuse (Chenoweth 1997, Johnson et al 2001).

Members of the broad community and caregivers hold fears that sex education will encourage sexual activity (Johnson et al 2001). For people with disability to become sexually active is seen as a 'dangerous' development (Shakespeare et al 1996). Society expects women with disability to be passive and to comply with mythological images of asexuality and eternal childhood, as mentioned previously (Atkins 1998). Fears and anxieties are embedded in a complexity of layers including religious beliefs, cultural mores, law, values and eugenics (Johnson et al 2001, Fegan et al 1993). These fears are imposed on women with intellectual disability in such a way that their right to sexual expression and personal happiness are seriously compromised (Meekosha 1999).

In some cases, this includes illegal sterilisation of women. Women with disabilities have been sterilised for three purposes. These are for the prevention of pregnancy, the avoidance of the need to manage menstruation and eugenics (Hastings 1998). When control over a woman's autonomy is exercised in this way, she is not only affected physically. The sterilisation affects her self-image, self-esteem, hopes and dreams. It affects the whole of her womanhood (Hastings (1998). Sterilisation is unlawfully performed on young girls in Australia (Brady & Grover 1997). It is clear that this process is not only unlawful, but also immoral, discriminatory and violent (Chenoweth 1997, Hastings 1998, Brady & Grover 1997).

While it has been mentioned that women with an intellectual disability are likely to live in segregated settings (as residential care facilities are), it is also likely that many service providers have stopped segregated activities (Hinsberger 1991). Careful consideration of competing ideologies is necessary to broaden our understanding of the impact of segregation on women with intellectual disabilities. It appears that residential facilities provided for people with intellectual disability are understood by service providers to be

'community based' and therefore not segregated. At the same time these residential facilities are provided to a target group i.e. people with intellectual disability and people who take up residence within them do not have choice about whom they live with or who works in the residence (Rotering, Scott & Quinn 2001). Disability service providers are also likely to advocate for women with an intellectual disability to be included in activities provided within the general community and oppose groups set up specifically for women with intellectual disability, naming such groups as 'segregated' (Chenoweth 1997, Hinsberger 1991).

The debate about segregation originates in Wolfensbergers' theory of normalisation and with the emphasis Wolfensberger placed on community participation and inclusion (Hinsberger 1991). These principles remain relevant. They also raise questions. If people with intellectual disability are going to develop friendships and intimate relationships with whom will that be? Will it be with able people who at this stage exclude them from participation in society at many levels? Will it be with other people with intellectual disabilities (Hinsberger 1991)? If we ask ourselves the question, "Who do I socialise with, form friendships and intimate relationships with?", what is the answer? When we oppose women with intellectual disability gathering together and gathering with men with intellectual disability we contribute to their social isolation and violate a basic human right. We all have the right to choose the people we socialise with and form relationships with.

Further to the subject of human rights, another barrier to sexual health is the lack of autonomy women with intellectual disability experience in residential settings (La Fontaine 1999). Managers take decisions about daily living in the 'best interests' of the resident. It can mean a loss of decision-making, risk taking and personal freedom for residents. Another debate is evident here: autonomy versus duty of care (La Fontaine 1999). Women with disabilities want self-determination and this must be given weight during the course of this debate (Atkins 1998). It is essential that the voices of women with intellectual disability be heard. (Moore, Beasley & Maelzer 1998, Rotering, Scott & Quinn 2001).

Another barrier to sexual health for women with an intellectual disability is prejudicial and discriminatory treatment in matters of child protection (McConnell & Llewellyn 1998). McConnell & Llewellyn (1998 p. 36) inform us that

"False presumptions, inadequate legal representation, parents' vulnerability and culturally biased views on what constitutes family and parenting competence are among the factors accounting for this."

Women with intellectual disability who are parents have reported that they live under scrutiny and in fear that their children will be removed (McConnell & Llewellyn 1998). Service providers report that they find it challenging to meet the needs of parents with intellectual disability as they lack knowledge about parental ability. Alternatively, service providers that have expertise in disability report a lack of skill to work with family support and child protection matters (McConnell & Llewellyn 1998). This gap in service provision is experienced as a lack of family support and as heightened vulnerability in terms of parental rights by women and men with intellectual disability.

As indicated by discussion thus far 'disability' is in itself a major barrier to the sexual health of women with an intellectual disability. Separate to the real constraints a woman faces from a location of poverty and lack of power, it is apparent that we (the broader community, families and service providers) relate to women with an intellectual disability

first, and perhaps only, through her disability. We fail to relate to her as a woman, as a woman with hopes and dreams, as a woman who would like an opportunity to take a place in society through the assumption of roles that give life to sexual expression such as partner, lover, wife and/or mother (Chenoweth 1997, Meekosha 1999, Hastings 1998, Swift 1998, Rappaport 1998, McConnell & Llewellyn 1998, Atkins, 1998). Intellectual ability is only one aspect of a woman's being and physical, sexual and emotional ability need to be considered (Johnson et al 2001).

Once we begin to consider the ability of women with intellectual disability, we can find aids to their sexual health. Information and sex education should be provided to women with intellectual disability as a matter of routine (Johnson et al 2001). Information should be comprehensive and provide opportunities for women to understand the physical, emotional and interactive aspects of sexual life (Fegan et al 1993). Additionally, families and service providers should be offered information and education about sex and sexuality. The Australian Research Centre in Sex, Health and Society, a faculty of Health Sciences, La Trobe University, have developed workshops for this purpose. They are titled, 'Living Safer Sexual Lives' and are an outcome of the research recently conducted by Johnson et al ( 2001).

Women with intellectual disabilities should have the opportunity to become peer educators (Cooper & Temby 1995, Shakespeare et al 1996, Johnson et al 2001). Shakespeare et al (1996 pp. 32) inform us that "When young people with learning disabilities were asked who would be good people to help disabled people to learn about sex, other disabled people came on top of the list". When women are trained and employed to fulfil health professional roles, health education provided will be much improved (Cooper & Temby 1995).

Social opportunities for women with intellectual disability (and men with intellectual disability) must be broadened. Loneliness is one of the major battles fought by people with intellectual disability (Hinsberger 1991, Johnson et al 2001). Girls with disabilities have few opportunities to interact with peers in a social setting (Centre on Disability Studies). Increasing social opportunities for women with intellectual disabilities will enrich lives, reduce loneliness, reduce vulnerability and provide the place from which sexual health can be developed.

Finally, it is time to find the space in local settings where families, service providers and members of the community can sit with women with intellectual disability and engage in conversations about the debates identified in this paper. Let us talk to each other about autonomy versus duty of care. Let us talk about segregation and community participation. Let us find a way forward that addresses the issues of loneliness and powerlessness faced by women with an intellectual disability.

# Methodology

Feminist action research was the approach used for this project. Yoland Wadsworth (1998 p. 11) explains action research, "It is action which is researched, changed and re-researched, *within* the research process by participants". Initially, a literature review was conducted to provide a summary of the barriers to sexual health faced by women with intellectual disability and to locate our local work within the parameters of broader research. Strategies to improve sexual health were also searched for. Using the literature review four conversation themes were developed for use in semi-structured focus group or individual interviews.

The themes are titled *womanhood, social life, information/education and health*. For each theme, women were asked what has been good/or helpful, what has been tough/ or painful and what could be done to make their experience better.

For sampling, assistance was sought. Many participants on the reference group offer services to women with intellectual disability. Their help was enlisted: they talked about this project with women they worked with and identified women who were interested in participating. Another service, North East Support and Action for Youth, referred women with whom they had contact and who were interested in participating. The risk associated with sampling through participant networks was that women would feel an obligation to participate. Special attention was dedicated to explaining to women that participation was a choice. At this point two women opted out of the focus groups. Two groups of women participated in focus group interviews and four sessions were conducted with each group. Two women opted for individual interviews. In total, seventeen women chose to participate. Women were aged between eighteen and sixty-eight. Two women lived independently with partners, one lived independently with a friend, six lived in community residential units and eight lived with their family. Pseudonyms are used throughout this report.

Focus groups are considered to be less intrusive than individual interviews. It is plausible that we may have missed gathering very personal information from respondents who may have felt uncomfortable sharing such experiences and feelings in a group setting. One to one interviews may have elicited much more information. However, the choice we made to collect data primarily through focus groups was informed by our understanding that focus groups minimise power differentials. It was critical to do this, as the relationship of researched to researcher was already steeped in power relations. We therefore chose to value a method that was empowering to the women more highly than a method that yielded full and comprehensive data collection.

At each of the four focus group interview sessions one of the four themes was raised for discussion. A note taker recorded input from the women. A copy of these notes was provided to each participant at the beginning of the following focus group session to provide an opportunity for participants to validate or amend the data. Additionally, at the beginning of the following focus group session, discussion of the previous weeks focus group content was facilitated as a means of gaining validation and checking for accuracy of understanding. This additional method of seeking feedback was necessitated by our

knowledge that some participants are illiterate. We were confident women understood this process as we observed lively interactions between them about the content of previous sessions. In summary, women were encouraged at each focus group session to provide further information if they wished to do so, to change information that did not accurately reflect their contribution or to delete information they were not happy to have included.

True to action research it was our intention to respond to the interests and needs of those who participated. *Groovy Chicks* was a young women's health group that met for eleven weeks between April and July 2002. As a response to the second group of participants six sessions were planned for delivery between June and August 2002.

Qualitative data was analysed by searching for themes and patterns. These themes and patterns were organised and used to report findings (Ezzy 2002: Miles & Huberman 1984). Direct quotes are included to give a sense of the lived experiences of the women who participated and to serve as testimony to the interpretations and conclusions drawn (Berg 1989: Reinhartz 1992).

The reference group provided critical review of the research plan through ongoing discussion of informed consent and ethical issues relevant to the project. Through this discussion we agreed that:

- 1 The project should maximise the rights of women at every stage: their views will be given priority (Moore, Beazley & Maelzer 1998).
- 2 We anticipated that accounts of sexual abuse and violence may be given in interviews. We included Upper Murray Centre Against Sexual Assault and Central Hume Domestic Violence Outreach Service in this project so that they were well informed and could support women on an as needs basis. We secured their commitment to this work. Furthermore, we chose focus groups as one means by which women were not left on their own with the content of an interview, but had the support of their peers with whom they have ongoing contact.
- 3 We acknowledged the difficulty of maintaining confidentiality in our small community. Although we left out names and identifying information, this may not be enough to protect participants (Bell 1999). Participants were given an opportunity to review the notes pertaining to each focus group and to change details in a way that would maintain their privacy.
- 4 We would check with participants if we had accurately recorded their views when the notes were offered for review.
- 5 Consent. We explained to the women what we'd like to know, what we planned to do with the information provided, who funded the project and why we were doing it (Bell 1999: Liamputtong, Pranee & Ezzy 1999). We agreed to check for understanding and restate any aspect of the work that needed clarification. We checked for understanding again. Women could then consent to participation. However, we would also offer women the opportunity to consent or withdraw their consent with each conversation theme. Participants would be informed of their right to refuse in total or to some parts of the conversations we initiated.

Peer debriefing was another strategy utilised to strengthen credibility of the work (Lincoln & Guba 1985). At Women's Health Goulburn North East the research group meets monthly. During these meetings data was analysed and discussed as a means with which to build greater depth of understanding of participant contributions.

The limitations of this work must be acknowledged and I present myself to you as a fourth year social work student with limited knowledge and experience to bring to the project. As mentioned peer debriefing has been one of the measures taken to build credibility for the data; it has also been the location of supervision and support. Further, the limitations are with time. We had one year to conduct this work in its entirety and I worked part time. With more time this report, particularly the links between data analysis and discussion would have been strengthened. Also, we wish to acknowledge bias that was generated through the sampling technique. Asking assistance from gatekeepers has meant that the majority of women who participated have accessed Department of Human Services Human Relations Program. We understand that this affects data and purport that the picture generated is more optimistic than it would be for women who have not accessed that service. Finally, we acknowledge that at planning stage participation of women with intellectual disability would have improved the design by strengthening relevance and inclusion.

# Interviews with Women

Pseudonyms are used throughout this report.

## Womanhood

The women inform us that no one has talked with them about forming relationships and what to expect of relationships. Nor have they had opportunities to talk about falling in love or going out with someone. When information and opportunities such as this are missing women are left alone with their experiences without the support they need to navigate hardship and without the joy of sharing the details of how love and intimacy feels. Nor are women able to protect themselves from violence and abuse when they don't have information about it and information that locates their experience beyond that of an individual (Chenoweth 1997: Johnson, Hillier, Harrison & Frawley 2001).

## What's tough about being a woman: Violence

When conversation was generated about the hardship of being a woman, the first issue raised was violence. It was raised in each participant group and each interview. A number of women reported physical, sexual and verbal assaults (Please note throughout this report that *italicised quotes* represent the views of one participant. Therefore, in this section, for example, five participants report violence). The following excerpts from conversation exemplify various forms of violence:

*He flogged me up and so now I want to take it slow. Drugs too. Now I'd leave straight away if someone hit me. I lost the baby because of the hitting. Broken arms. Black eyes. I told Mum I was moving furniture. Mum didn't believe me. She knew. I tried to get out of that relationship. Wound up in a home for women... a refuge.*

*I'm too scared to have sex. When I was nineteen my cousin raped me. My Mum and Dad didn't help. No one helped me. I was only nineteen. There was blood all over the bed.*

*She yelled at me that my breath stank (participant crying). When she yells at me I walk away. She follows me yelling. I go to my room and close the door. She doesn't follow me in there.*

*He touched me here (breasts) and there (vagina) and I didn't like it. I said NO but he didn't stop touching me and it made me feel sick.*

*In my relationship everything is falling down like one heap. It's getting worse each day. He gets really stroppy 'cos he's got no money. It's terrifying - it's really terrifying 'cos I just couldn't cope with him getting stroppy and him hitting me. I want to get out of the house as quickly as possible. It's like living in fear. It's like during the wartime.*

Our immediate response to the issue of violence was to hear the women's stories. We let women know violence is an issue faced by many women and they are not alone. We encouraged the women to explore how they've survived violence and what supports have been useful. We sought to discover whether the women have been able to access formal support through domestic violence and sexual assault services. Only one woman reported her use of domestic violence services by accessing the women's refuge. We provided information about support services and how to access them. Broadening women's knowledge of support services and how to access them is one of our central concerns. Locally, Upper Murray Centre Against Sexual Assault and Central Hume Domestic Violence Outreach Service have participated in this project and demonstrate both their commitment and their knowledge and skills when working with women with intellectual disability. However, their ability to provide education to women is limited by service demand and resource allocation.

### **Recommendations:**

- 1 Improve access to formal support services in response to experiences of violence by including a description of services and what they can provide in sexual health education sessions. Follow this up with a visit to the service providers' agency so that women can locate it physically and imaginatively. Provide women with the Women's Health Goulburn North East card that lists domestic violence service providers and their telephone numbers.**
- 2 Provide information about safe and healthy relationships with which women can scrutinise their personal experiences. This information should be provided at the transition from adolescence to womanhood.**
- 3 Improve resources allocated to sexual assault and domestic violence services for the purpose of delivery of information about healthy relationships to women with intellectual disability.**

## What's tough about being a woman: Grief and Loss

Women talked about the sadness they feel when they lose contact with someone they love: a friend, a partner or someone in their family. When institutions closed women became separated from men or women they loved and didn't have opportunities to keep up their relationships. Struggles to keep up contact with family and friends continue today. Women rely on workers and family to transport them to social events and to open their homes to visitors in a welcoming way that encourages friendships to endure and blossom. Loneliness has an enormous and negative affect on people with intellectual disability (Hinsberger 1991: Johnson, Hillier, Harrison & Frawley 2001). Of course if we love we suffer grief and we can all expect to feel such sadness in the course of our lifetime. Some of the quotes provided exemplify grief we can all expect.

*Only one boyfriend took me places. The others didn't care. One was psycho and went off with another girl when he said he'd take me. I feel depressed. I see how men are to treat a lady. My sister has a nice man. They're a rare species aren't they? I'm going to up my antidepressants to 3.*

*Breaking up is hard. It's sad. We're having a break. We're going out with our*

*friends instead of being together a lot. In a month we'll be friends like when we first met. It was hard because we niggled each other a lot.*

However, women with intellectual disability suffer a form of grief that is distinctive. It is grief born from lack of information and control, grief that is imposed by the way that we (service providers and families, society), arrange care and fail to include women in full discussion and decision-making. Some examples cited below illustrate this type of grief.

*If I could go anywhere I wanted to go I would go to Melbourne to see my sister.*

*My sister didn't know I was shifted from the institution. She went looking for me and couldn't find me.*

*When I left the institution I didn't get to contact my boyfriend ever again. I don't know where he went.*

*I didn't get to see my friend Barney again. Don't know where he went.*

*I wish I could turn back time and have a parent to guide me through the years. When I met dad everything changed. It was good.*

### **Recommendations:**

- 4 Include discussion of grief and loss in women's health groups.**
- 5 Structural change to the community residential unit model that enables people to choose who they live with. Women will then be able to choose to live with friends rather than without them.**

## What's tough about being a woman: Pressure from men

Closely related to violence, women told us about the pressure they experience from men to comply with their wishes. Sometimes the women are interested in a romantic relationship that includes going out together, being sexual in some ways but not having sexual intercourse. When we talked about this issue in women's lives they let us know they want more opportunities to talk about men, relationships and how to say No.

*Guys can be nasty. They can be jerks. They want one thing: sex. When we're not ready.*

*My boyfriend wants a child and puts pressure on me. I am not ready for a child and I told him.*

*Guys crack it if you say No.*

*Girls like hugging and kissing, but don't like more touching than that sometimes.*

*I've learned to be more cautious. Experience has taught me that. I've learned to think 'I'm better off without you'.*

*Guys get what they want and give you the flick the next day. You lose them. They go with someone else. Someone who will (have sex).*

*When guys put the pressure on for sex I can stick up for myself. Say No. I can fight.*

### **Recommendations:**

- 6 Women are provided with opportunities to explore healthy relationships and to develop assertive communication skills. This should be included in sexuality education at each delivery through the life cycle. It is critical at the transition from adolescence to adulthood.**
- 7 Offer men opportunities to explore sexual health and healthy relationships.**

### What's special about being a woman: Love, sex, romance

When the women talked about the special experience of womanhood their first stories were of love, sex and romance. They asked, 'Do men get these feelings too?' and 'Maybe men get nervous too?' It seems that women have had few opportunities to explore their feelings and extend their exploration to finding out about men's feelings. Mystery surrounds the notions of sexual feelings, love and men. Of all the conversation themes and sub-themes, women were most animated and interested in this aspect of their life experiences and hopes. Planning to be with someone special, imagining how life will be with them, imagining independent living and having babies were talked about and dreamt about. There is no disability in women's hearts.

*It's good now - my boyfriend - I have a place to live and do what I want to do. We want a house of our own and he wants his own business - a nursery - we keep our own money. He has his and I have mine. We both want to go slow. We don't want children 'til I'm in my 30's - he will be late 30's - he wants to be 35 - the 30's are right for me.*

*Meeting boys....Getting together with boys in the night time.*

*It's all right with John he's all right - (big smiles). It's a special friendship. He came round to visit and have lunch at the weekend. He rang last night and will come over on the weekend. (The women who share house with her share the excitement of this romance too).*

*My boyfriend drives around and picks me up. We go to his house and watch movies or next door to the neighbours.*

*My heart raced when he drove in the driveway. I wanted to hug and kiss him.*

*I have a special friend Keith.*

*I get butterflies in the belly.*

*I have romantic dreams.*

## **Recommendations:**

- 8 Extend opportunities for women to be together and explore their diverse experiences of womanhood and sexuality, including finding out more about men. This can happen in a women's health group that meets on an ongoing and regular basis. Furthermore, increasing opportunities to be out together socially will correspondingly increase women's opportunity for experiential learning.**

## What's special about being a woman: Our bodies

Closely connected to love, sex and romance conversation moved to consideration of women's bodies. Women were very interested in the special potential of womanhood: motherhood. Motherhood is socially contested for women with intellectual disability. Only one of seventeen participants in this research is a mother, though many expressed their interest in babies. McConnell and Llewellyn (1998) report that people with intellectual disability who are parents live under scrutiny and in fear that their children will be removed. If women are to realise their dreams of having babies, current gaps in service provision must be addressed. Workers with the skills and knowledge to support women with intellectual disability as they learn to prepare for motherhood and then learn how to parent are missing in our service system (McConnell & Llewellyn 1998). In this conversation women also explored the expression of their womanhood through presentation of their bodies by choosing clothes and make up that felt good for them. While responses are verbally minimal, women smiled a lot when contemplating the special parts of being a woman, and were very attentive listening to each other's views.

*We can choose to have babies or we can choose not to. There is no pressure either way: to have babies or not to have babies.*

*Our bodies.*

*We have periods.*

*It can be a joy. Like to have babies.*

*The vagina is a special part of the body men don't have. And breasts.*

*Babies. I would like to have a baby. (Three other women agreed they would like to have a baby).*

*We can wear jewellery and make up. I like to. Fingernail polish and shopping. It's good to go clothes shopping.*

## **Recommendations:**

- 9 Adult education include contemplation of family planning and preparation for motherhood according to the interests of the women.**
- 10 Creation of a specialist team who can respond to the needs of people with intellectual disability who wish to become or who are parents. This team will believe in the rights of people with disability to be parents and will**

**advocate for them within the system. The team members will be multi-disciplinary and will have knowledge and skills related to disability, parenting, family support and the legal system.**

## Social Life

### What's hard about social life: Loneliness

The impression we have gathered from hearing women's stories is that there are real limitations around having, developing and preserving friendship. The idea of having visitors for themselves was one that seemed puzzling to the women. We didn't hear stories that told us of social interactions that the women experienced as rich, though as mentioned in *Womanhood*, the depth of affection expressed for special friends is sure. It seems there is a lack of social life and groups of friends to be with. Keeping up connections with family who live a distance from the women is also a problem raised in women's accounts of their social life.

*It's not often I have a social life. During the day I go out and talk to friends. I wasn't allowed to have a social life when I was young. I was around twenty when I left Mum's care. Mum kept shutting me out from friends.*

*I want to see my sister. She lives in Melbourne. Haven't seen her for a long time. She couldn't come last Christmas.*

*We only visit friends when we're in town - we have to ride our bikes - it's twenty-five kilometres.*

*I don't go out very much. I stay home and do some cooking.*

*Other than (workplace) I don't have a social life. I used to ring people: they didn't want to know me 'cos I'm slow. I used to hang out with drug addicts because they were the only ones who I thought cared. They used me for money. I don't see them now. (he) comes around and stirs up my feelings. I've got my family and animals. I'm glad of that.*

For women who live in community residential units, some restrictions are related to resources. Others are harder to understand.

*Go out with staff for shopping and stuff. Sometimes there isn't a car to go anywhere. A bus comes to pick people up to go to programs. Staff tell you what you can go to and what's on.*

*Staff decide where I go. I have to go with the staff. I'm not allowed out by myself. We never get to talk about what we will do.*

### **Recommendations:**

#### **11 Social life is valued and women are provided with the support and**

**opportunity to broaden their social experiences. Volunteer Friends and Interchange are programs all women have the right to know about and be part of.**

- 12 Alternatives to the existing arrangements of care are researched and a trial arranged which includes the concept of women (and men) led accommodation services.**

What's good about social life: What we like. What we'd like to try.

When talking about what was good about social life we gathered some stories of what women like to do. Some were expressed as current experiences and some as hopes. Hopes are as humble as going to the movies and very achievable.

*Haven't tried going to the movies, only been once before, a long time ago. I would like to go again one day and will ask if I can.*

*That's what I want in my life: love and attention, friends and family.*

*It's good seeing different people all the time. I see different people at the different programs.*

*I would like to go to the beach.*

*I would like to try going to the movies.*

*Just going out more would be good. Anything.*

*I go out for tea, go to the movies. I like music. I love singing. I go Christmas shopping. I go out with my boyfriend. He is at my old school now. Chinese is my favourite food.*

*I go out with friends or stay home with my dog. I see my cousins. I miss my boyfriend. We used to go to movies and parties every weekend but now we're not together.*

*Hang out with friends. Watch videos. Catch the train and go to my friends' houses.*

*I go out to Dad's friend's farm and watch the truck. I like bowling in Wodonga and catch a bus to get there. I go to the movies with friends and the Pizza Hut. Or to Wodonga ten pin bowling.*

### **Recommendations:**

- 13 Further to previous recommendations about women joining groups such as Volunteer Friends, consideration of the extension of the use of**

**volunteers in the disability sector is warranted as a means to help women realise their social goals and as a means to reduce isolation.**

## Health

There was a lot of silence during this conversation. The subject didn't generate interest and our impression was that the women were not accustomed to thinking about health choices. To stimulate conversation we suggested to women that choices might include whether to choose a male or female doctor, what clinic to attend and whether to take someone with you or go alone.

### Getting health care from doctors

Doctors are talked about positively in a broad sense. Women mentioned liking their doctors, feeling relaxed, feeling trust and being happy to visit.

*In a way my doctor suits me... He is the one my sister and Mum go to. Everything has gone wrong so I go to him. I trust him.*

*I'm calm, relaxed and like to know what's going on when I go to the doctor.*

*My carer takes me to the doctor. I like having her with me. I've got a caseworker too.*

*Mum takes me to the doctor. I go to a woman doctor. She's pretty good. She checks my disability... my ears and feet. I have blood tests. It is not about me as a woman. Of course I am a woman, but she doesn't talk to me about it. I am happy to visit the doctor.*

*I take Mum to the doctor. I talk for myself.*

*Mum takes me and she talks to the doctor.*

*Haven't been to the doctor for a good while now. Sometimes go up to my doctor; he's nice.*

However, they also report that doctors don't initiate the provision of information about pap tests, breast checks and menstruation. One participant raised the subject with her doctor:

*I asked the doctor about pap smears and breast checks. It was uncomfortable to start with but OK.*

*Doctors don't talk to us about sexual health.*

There is an indication from some women that they would not raise sexual health questions with their doctor.

*Mine always asks at the end if I have any problems. That's good. I say No. I wouldn't feel comfortable asking him about pap smears and I wouldn't talk to him about breast checks. (Others nodded agreement)*

## Pap Tests

Without fail, the women screwed up their faces when the subject of pap tests was raised. They tell us they haven't talked about pap tests before. The exception is two young women who have talked with their mothers. Some young women do not want to talk with their mothers about pap tests and sexual health. Women asked questions about pap tests such as whether pap tests hurt, what happens and when you need to have one. Responding to questions formed the bulk of the discussion. Women did not have information about pap tests, nor have most women had a pap test.

*Pap smears sound uncomfortable. They sound like they will hurt.*

*I had a pap smear a long time ago. It hurt.*

Participants who live independently have sought pap tests.

*Yeah, I've had a pap smear - debating whether to have another one - I had a female doctor up there - down here I've got a male doctor. I need a female doctor though. (Place) was good - there was a health centre there- and we could have pap smears, get condoms, everything. I can't get to the family planning clinic at night.*

The Family Planning Clinic in Wangaratta is open 5.00 p.m. - 8.00 p.m. every Thursday evening and an extra clinic is currently offered on the last Monday of every month. Demand for service is high and the clinic is currently booked four weeks in advance. The clinic bulk bills for service. There is a small charge for contraceptive supplies.

*Pap tests are OK. I've had 2 or 3. I'm not very keen on pap tests. They hurt, feel uncomfortable, are really especially annoying. You have them when you're sexually active. It is very hard to have a pap test but sometimes you've got no choice.*

From the focus group discussions, it appeared there were very few women accessing pap tests. We collated responses to two questions as to whether each woman has had a pap test or intended to have a pap test. As shown in Table 1, only three women have had a pap test. Two women intend to have a pap test in the future. They are not the same women who have had one. Such low levels of screening for cervical cancer are a serious issue for women's health and warrant the development of a health promotion response.

## COUNT ME TWO

### CERVICAL SCREENING SURVEY

| AGE | HAVE YOU HAD A PAP SMEAR?           |                                     | DO YOU INTEND TO HAVE A PAP SMEAR?  |                                     |                                     |                                     |
|-----|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|
|     | YES                                 | NO                                  | YES                                 | NO                                  | DON'T KNOW                          | NO ANSWER                           |
| 18  |                                     | <input checked="" type="checkbox"/> |                                     | <input checked="" type="checkbox"/> |                                     |                                     |
| 20  |                                     | <input checked="" type="checkbox"/> |                                     | <input checked="" type="checkbox"/> |                                     |                                     |
| 25  |                                     | <input checked="" type="checkbox"/> |                                     | <input checked="" type="checkbox"/> |                                     |                                     |
| 18  |                                     | <input checked="" type="checkbox"/> |                                     | <input checked="" type="checkbox"/> |                                     |                                     |
| 27  |                                     | <input checked="" type="checkbox"/> |                                     |                                     | <input checked="" type="checkbox"/> |                                     |
| 21  |                                     | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> |                                     |                                     |                                     |
| 51  | <input checked="" type="checkbox"/> |                                     |                                     |                                     |                                     |                                     |
| 18  |                                     | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> |                                     |                                     |                                     |
| 18  |                                     | <input checked="" type="checkbox"/> |                                     |                                     |                                     | <input checked="" type="checkbox"/> |
| 62  |                                     | <input checked="" type="checkbox"/> |                                     | <input checked="" type="checkbox"/> |                                     |                                     |
| 45  |                                     | <input checked="" type="checkbox"/> |                                     | <input checked="" type="checkbox"/> |                                     |                                     |
| 66  |                                     | <input checked="" type="checkbox"/> |                                     | <input checked="" type="checkbox"/> |                                     |                                     |
| 48  | <input checked="" type="checkbox"/> |                                     |                                     | <input checked="" type="checkbox"/> |                                     |                                     |
| 45  |                                     | <input checked="" type="checkbox"/> |                                     | <input checked="" type="checkbox"/> |                                     |                                     |
| 21  | <input checked="" type="checkbox"/> |                                     |                                     |                                     | <input checked="" type="checkbox"/> |                                     |
|     |                                     |                                     |                                     |                                     |                                     |                                     |
|     |                                     |                                     |                                     |                                     |                                     |                                     |
|     |                                     |                                     |                                     |                                     |                                     |                                     |
|     |                                     |                                     |                                     |                                     |                                     |                                     |

Client demographics provided by Department of Human Services (30.9.01) indicate there are 69 women with an intellectual disability, aged between 18 and 80 living in the Rural City of Wangaratta Local Government area. Of the sample survey, 13 women are residents of the Rural City of Wangaratta area. This is almost one fifth of the local population.

## Breast Care

The idea of breast checks was easier for the women to talk about. We talked about the breast van visiting Wangaratta at the moment. Some women had noticed it in the Safeway car park. While women had more knowledge of breast checks only one woman reported having a breast check, even though six women are over forty five years old, and are of an age where breast checks are recommended. Women with intellectual disability access breast screening at lower rates than the general population (Durvasula & Beange 2001). Research indicates that women with intellectual disability don't fare well in the health care system, one that offers care that is asked for and fails to suggest preventive health care such as blood pressure monitoring and breast checks (Durvasula & Beange 2001). Locally, workers from accommodation services concur, reporting that blood pressure checks are not routine, nor are breast checks or pap tests.

*There's that ad on TV about mammograms. 'Have a bloody breast check'. Mum talked to me about it too. (Another woman agreed she had seen the advertisement too.)*

*I've seen a diagram that describes breast checks and how to do it. It was a poster in a shower at my friend's place.*

*The new lady doctor gives a breast check.*

*I don't know about breast checks.*

*The doctor does breast checks but don't know what for.*

*You have breast checks to see if you have cancer.*

## Information and Education.

Women with an intellectual disability are not provided with the standard of information and education that will assist them in the development of their sexual identity and assist them to be capable of making informed choice about sexual expression (Johnson et al 2001: Shakespeare, Gillespie-Sells & Davies 1996). Locally we conclude that information and education opportunities are few. Women have informed us through each of the conversation themes that no one has spoken to them about their sexual health or that the information they have is limited. Access to accurate information would empower women considerably.

## Access to Information and Education: what's been helpful

It is important that all women receive accurate information about sexuality. It is information that should assist her to understand her body and to make informed choice about caring for her body and relating with others.

Women had access to education at Year 6 level and were prepared for the onset of their menstrual cycle and menstrual hygiene. They learned this information from their mothers, from their teachers in the classroom and from doctors. One woman mentioned learning about pap tests from television. Only one participant referred to sex and safe sex. She talks about sex with her mother. Mothers are most frequently mentioned with reference to information and education.

*We learned a little bit at school in Year 6 - periods, tampons, and stuff like that - but I learned all that from Mum. If I wanted to know something now I would go to my older sister.*

*We learned about menstruation - getting the monthlies at school in grade six. We saw a video.*

*Mum gave me one of those talks -*

*I went to the women's clinic when I lived in (place). I had a woman doctor there. I was only young and she told me about periods and pap smears. She helped me through a lot.*

*I learned early. We had sex education at primary and tech school plus Mum took me to the doctor. My brother got married and had a baby. I went to (child's) birth. Plus animals, seeing their births, seeing suckling. And other people, not just family. I know about pap tests from telly.*

*Talk about sex all the time with Mum and having babies, being tested. Safe sex.*

## Access to Information and Education: what's been unhelpful

Some information has been misleading.

*Sex is yuk. It is very rude to talk about sex. My sister has a boyfriend. She said it is yuk and all boys have worms and they'll give you worms if you let them kiss you.*

Some has been dangerous. One woman was taught self-defence during her secondary school years and used it when her partner was being violent to her with disastrous results.

*I never learned about safe relationships - all we learned at high school was a bit of self-defence but not anymore - that's how I broke my arm couldn't break his grip - trying to do what they taught me. No, they never taught me anything. Just*

*self-defence.*

#### **Recommendations:**

- 14 Sexual health education is delivered consistently to women with an intellectual disability across the life cycle. Education should be delivered pre-adolescence, at transition from adolescence to adulthood, during early adulthood and at mid-life to ensure that information is repeated, thus increasing its availability to women and ensuring that information specific to the stage of the lifecycle is offered in more detail at the time it is most relevant.**
- 15 Women gain information from their mothers. Support and information should be made available to mothers to ensure they have accurate information and encouragement as they assist their daughters to prepare for womanhood and adulthood.**

### **What could be better: Women's Recommendations**

Women had a range of ideas about improving their sexual health. These ideas flowed from the question offered at each focus group session, "What could be better?"

- 1 Men's Participation: Opportunities for Men.** In focus groups and individual interviews, women stated they would like more respect from men, less pressure and would like men to participate in health education so that they too learn about healthy relationships. If the men had opportunities to explore the nature of healthy and happy relationships, perhaps there would be a correlating decrease of pressure and increase of respect for women? This does not address the broader influences on men's behaviour, though locally it provides a point of action the women think would be helpful.

*Boys get it easy. More respect from them would be good.*

*No peer pressure. Do this, do that. "We've done it. Why can't you?" They want me to do unsafe things.*

*It would be good for guys to learn too - they need to know the same things we know.*

- 2 Independence.** The variety of ideas women offered for ways that life could be better are impressive. Women want opportunities to increase their independence and to be represented politically.

*I want a job - maybe at the pub. (Employment agency) help me - they are going to get me a bar course - I'll get a big certificate - so I can work. Yeah.*

*I want a mobile phone and a car and a driver's licence. I could ring Mum and*

*change times. I could go for a drive and meet people.*

*Going out more would be a good change. Getting to go places by myself. (This statement generated agreement from four other participants).*

*More women in government. To get things women want and need.*

- 3 Learning about women's health.** Women indicate interest in learning opportunities that are ongoing and include peer education. One participant emphasises her isolation with experiences of sexual assault and domestic violence and sees a women's health group as a place where she can learn and get support.

*Mum never went through it (sexual assault and domestic violence) and that's why she didn't teach us or know to talk to us about it. My boyfriend doesn't want me to talk about it. He doesn't want to hear it. Yeah. I would like to learn: just all of it... women's health.*

*Getting monthlies is so painful. What else can I do?*

*We need to know more about pap tests and breast care.*

*Having a session once a month to talk about women's health (Group of eight participants agreed this is a good idea)*

*Getting information from each other.*

*Do men get these feelings? (Feelings we get: sadness and disappointment in relationships) Maybe men get nervous too? It would be good to be able to talk about these things.*

*It would be good to have a box to put questions in and then talk about them on women's health days.*

- 4 Improving social and recreational life.** Ideas for improving social life appear to be very actionable. The women describe constraints to their social life in terms of restriction on resources, such as not having access to transport every weekend and if one person in the household can't manage an activity such as walking, that restricts the possibilities for the whole group. They tell us too that getting out for an activity that they want to do and others may not want to do is not usually possible on the weekends.

*I would like to go to the pictures. I have asked (worker) if I can go to the pictures but I haven't gone yet.*

*It's fun at the pool for water aerobics. I want to go to the beach.*

*Picnics in the park would be good.*

*I like going walking. It's a bit hard because not everyone can walk so well.*

# Interviews with Service Providers

When the project began last September, I set out to meet the workers who were involved in service provision or training, to introduce myself, introduce the project and invite people to join the reference group. I hadn't developed an action research plan at that stage and intended to return to participants for 'interviews'. The conversations we had about sexual health were so rich that I asked the group for permission to use them. It also seemed sensible, given time pressures on everyone to make use of our time in this way. Permission was granted on condition that workers were not identified by name or organisation. We talked about the worker's understanding of the barriers to sexual health for women with intellectual disability and strategies they knew of or could suggest that improved sexual health.

## Barriers to Sexual Health

### **Lack of access to education/information re sexual health for women with intellectual disability.**

Workers reported that women do not have access to education and information. There are two aspects of this issue to consider. One is that sex education and information is missing from women's lives. The second is that sex education is not provided in a consistent way. This is an issue that affects all young people and is not confined to our local environment. Sex education is contested in our society. Some schools provide comprehensive sex education and others do not (Dunn 2002). A curriculum offered statewide accompanied by training for teachers is yet to be offered in Victoria (Short 2002).

*Sex education has not been offered as a standard educational unit for children and young people with intellectual disability. This leaves them vulnerable.*

*There is a lack of a consistent approach to providing information and education to women re sexual health.*

*Education for women should begin pre-menstrually and continue throughout life. This is not the case now. Education for young women is so important: so that they develop the skills and knowledge to enjoy their sexual health; so that the trauma of separation from babies is not endured. Education needs to include basics such as time, place, discretion and safety.*

*The women do not know enough about their sexual health. For example, they do not know about sexually transmitted disease, pregnancy and the right to sexual safety.*

*Young people are not provided with good sex education. Sex education needs to be provided through relevant communication tools: compic and electronic communication boards.*

## **Lack of access to education/ information for workers.**

Workers in residential and day activity settings, including managers, apply their own cultural and generational perspectives to decision making with regard to sexual health for women. Workers are entitled to opportunities to explore sexual health and develop greater understanding of their role in the context of the setting they operate in.

*Staff bring cultural and personal perspectives to sexual health. We cannot assume that staff have adequate knowledge of sexual health and must endeavour to teach in a way that is non-threatening and enables staff to teach clients in a non-threatening way.*

*Residential care workers lack the support, ongoing training and opportunity that would assist them to fine-tune their understanding of the fine line between duty of care and individual rights.*

*Training re human relations and sex is offered as a response to issues rather than as a matter of ongoing professional development.*

*We need a base qualification to raise our awareness and knowledge of sex education and know that we are providing good information when asked questions: not repeating our own ignorance.*

*There is no basic standard at TAFE where workers are taught human relations. Workers lack knowledge re women's sexual health.*

*There is a lack of expertise in our organization to support people to develop their sexuality.*

*Health care professionals need training and education so that their skills and understanding meet the needs of women with intellectual disability.*

## **Loneliness**

Workers inform us that women have few opportunities to enjoy a social life. They do not have the chance to enjoy adult autonomy.

*The right to form and maintain relationships is limited for women with an intellectual disability.*

*There is a lack of opportunity for friendships to develop and for social opportunities.*

*Women are vulnerable when they are lonely.*

*Parents sometimes refuse their daughter the right to have relationships and sometimes friendships. In one example, the family believe everything their*

*daughter needs is available through the family and actively discourage her when she tries to form friendships.*

*Parents are often very fearful about the development of relationships and ask staff to separate their son/daughter from anyone they are showing romantic interest in.*

## **Exploitation and Compliance**

Some men exploit women with intellectual disability. Furthermore, women with intellectual disability may be unaware of their entitlement to access domestic violence and sexual assault services. One worker aptly described the experience of exploitation and compliance observed amongst women with intellectual disability as an amplification of problems all women face. This is one aspect of the problem to consider.

*Women with intellectual disability comply for people to like them, to be seen to do the right thing. They will be available sexually when they really don't consent to please others. Women have not learned they have the right to say No.*

*Women are taught to trust adults and do as they are told without question. This has a negative impact on their ability to make choices and to protect themselves.*

*Males tend to knowingly exploit women with intellectual disability.*

*Able men, some of the local drinkers, exploit the women, demand sex on their terms.*

## **Sexual Abuse**

Sexual abuse is an issue that was reported by about half the women who participated in this project. Service providers report a range of experiences and views associated with sexual assault. Some women are not seen as competent and therefore an investigation does not take place. Alternatively, when a report of sexual assault is followed up it has implications for the woman that may be difficult for her to navigate such as not being believed or being removed from home for safety sake. The affect of childhood sexual assault can be seen in abusive adult relationships. Furthermore, there is a view that women who have lived in institutions have experienced sexual relationships as abusive.

*Often sexual assault is not investigated because women with intellectual disability are not seen as competent. When a woman discloses sexual assault and seeks help she is moved from her home. As the offender is usually known to the woman and often lives with the woman this is how her re-location happens. It happens to keep her safe or because significant people refuse to believe her.*

*For some women, childhood sexual abuse means that they find a sense of belonging and acceptance in abusive relationships and think that's what being a*

*woman is about.*

*There are some women who have abusive histories. Women who have lived in institutions have, in my view, been sexually active and experienced sex as abusive.*

## **Institutionalisation**

Women who have lived in institutions have not had the same opportunities to participate in the community, to enjoy family life and to broaden social connections. Social skills we take for granted, are learned over a lifetime in a community environment. Today, living in the community, mainly in community residential units, life is happier. However, the effects of institutionalisation remain.

*Women who have lived in institutions find it hard to make friends. They have fewer social skills and lack foundation knowledge about the types of social choices they can make.*

*There is a noticeable difference in social skills between those who live at home and those who have lived in institutions. Those who have lived at home have much better social skills.*

*The women who have lived in institutions are very rigid when it comes to sexuality. It is common for them to form intimate non-sexual relationships with each other. They meet each other's emotional needs and avoid men.*

## **Health Care**

Women are related to through their disability and their womanhood is ignored or forgotten (Chenoweth 1997, Meekosha 1999, Swift 1998, Rappaport 1998, Atkins 1998). This has serious consequences for their health care. Workers providing direct care in accommodation services inform us of similar concerns. Their views add weight to this issue.

*Some doctors in the region see no need for women with intellectual disability to have pap smears no matter what age they are.*

*Doctors believe women with intellectual disability don't need pap smears and regard informed consent as a difficult issue to negotiate. Doctors regard women as not sexually active and therefore not needing sexual health care. So one barrier is relating to women as non-sexual and another is fear.*

## **Rights are ignored**

Service providers inform us that a number of barriers exist to women's ability to enjoy sexual health. When women express interest in their sexual life, a relationship or having children they may face opposition from their families and workers. This opposition should be understood in broad terms. One participant pointed out that society conveys the message that sex for women with intellectual disability is taboo. This is the context within which families and workers live and care for women. Within this context, women's rights to self-determination are ignored.

*Sexual life is not theirs to choose. Relationships are a no no for women.*

*It is hard for women to state their needs in relation to sexual health because families don't see they are 'women' and often take the view that sex should not be one of the concerns for them. Also, disability workers (residential and day placement) place barriers to people taking up sexual rights. Workers worry about what will happen and try to prevent things happening. Workers are concerned about duty of care and being held accountable for pregnancy.*

*One woman in her 30's has frequently expressed her wish to find a partner, marry and have kids. She compares herself to me and tells me how lucky I am to have these opportunities. Her family would not accept the idea of helping her daughter to bring these dreams to life and is very protective of her daughter.*

*Community attitudes. Women with intellectual disability are not seen to have a right to sexual life. Society broadly and families specifically will say it is not OK for women to have sex.*

*Often parents don't want to acknowledge the possibility that their son/daughter will be sexually active and become suspicious or hostile about the motivation of workers who seek to intervene.*

## **Strategies used to improve sexual health - Current Practice**

Women have access to some programs that make a positive contribution to their sexual health. There is a women's group that meets each Friday. Advocacy has been better utilised by the disability sector to improve women's health experiences, Upper Murray CASA has developed a course that aims to support parents, teachers and caregivers and assist them to strengthen their support and understanding of women. Victorian state policy, particularly since 1997, has improved social conditions for women living in residential setting. Significantly, families are named as one of the most important supports and resources within which women and men develop a strong sense of themselves and are able to enjoy sexual health.

*There is a women's group that meets every Friday. It provides space for women.*

*The government sector has become better at acting as advocates. It consults*

*with and uses advocacy groups, Disability Advocacy Information Service (DAIS) and Office Public Advocacy (OPA). It is more capable as advocate and, for example, can challenge doctors and health practitioners more adequately.*

*Supportive families make a big difference to the well being of young women.*

*We have found female doctors really good and they will take the time to develop a relationship with a woman with intellectual disability in order to meet her health needs. For example, female doctors might have two or three consults before the pap smear, paying attention to relationship and preparation. Community health nurses are willing to give the time to women with intellectual disability.*

*Family support. Those families that have been able to accept and promote the sexual health of their son/daughter have made a very big difference to the potential happiness of their son/daughter.*

*Upper Murray Centre Against Sexual Assault has developed an eight-week course that is available to parents, teachers and caregivers. It is about relationships, teaching protective behaviour, safety and vulnerability. It caters for 12 - 14 participants and comes from the view that participants are experts in their own lives. This course could be available more often with extra funding.*

*Supportive families. They provide better foundations for their sons and daughters. They provide the type of education that helps them to make choices and know what they're doing. They enable women to be independent and strong.*

*Since the Victorian Standards were put in place in 1997 life has improved for women and the changes are noticeable. Social life has improved and holidays are planned for women living in residential settings. It is wonderful to see. At the time a lot of dollars were devoted to education of staff to support ongoing change. We need more education for staff.*

## **Recommendations**

- 16 Conduct the Living Safer Sexual Lives workshops in Wangaratta to offer all workers, families and people with an intellectual disability an opportunity to consider sexuality, values and attitudes.**
- 17 Offer the Living Safer Sexual Lives workshops at appropriate times, venues and cost to enable access for all who wish to attend.**
- 18 DHS to negotiate with TAFE to include human relations modules in the Certificate IV course for workers.**
- 19 DHS to acknowledge the particular vulnerabilities of women with an intellectual disability in terms of violence and sexual assault through improved educational opportunities and support for the women and their families; through targeted strategies for increasing safety; and through increased education and personal development opportunities for men, available in small local communities.**

**20 WHGNE to work with CASA and Family Violence Network to implement strategies to ensure women with an intellectual disability are aware of their right to a safe sexual life, and their entitlement to access domestic violence and sexual assault workers.**

# Interviews with Direct Care Workers.

Direct care workers were contacted by managers and offered opportunities to participate in this project. Managers provided names and contact numbers of potential participants. All prospective participants were contacted and provided with a description of the project and of informed consent.

Five workers participated in this project. We acknowledge that this is a very small sample and the validity of the work represented here must be questioned. The rationale for presenting an analysis sourced from such a small sample can be explained. First, we present it to honour the contribution made by the five workers who took the time to share their views with us. Secondly, we present it because we know direct care workers are very significant to women with intellectual disability and have a substantially important role to play. We wish to acknowledge the importance of their work and their views. Three participants work in accommodation services managed by non-government organisations and two work in accommodation services managed by the Department of Human Services. Three opted for individual interviews and two opted to interview together. Notes were kept at the interviews, typed, organised and returned to participants for their review. The purpose of this was two-fold: one was to check that the notes accurately reflected what had been said and secondly, it was an opportunity for participants to remove any information they considered identifying or to add information as they wished.

I spoke with many workers who chose not to participate in the project and frequently they expressed the view that sexual health is not relevant to their work. This provides a clear indication of the need for further education. The workers who participated emphasised the importance of education and their lack of opportunity to explore and understand sexual health. Their views add weight to the assertion that further education is indicated.

## Health. Barriers to health and doctors

Workers report that the women they work with do not have access to the same standard of care that women without disability can expect. Their view is that doctors do not understand the needs of women with an intellectual disability and work with them reluctantly. They recommend that education be provided for doctors.

*Doctors need greater expertise and understanding of clients with intellectual disability: especially when there are behavioural problems and a client is difficult to work with. They are not keen to take on patients with intellectual disability.*

*Medical practitioners are apprehensive especially when dealing with non-verbal behaviour. How much training do doctors have to work with people who have a disability? Training is important.*

Furthermore, workers indicate that doctors do not provide preventative health care.

*Doctors respond to specifics and neglect routine health care like blood pressure, weight and pap tests. People might slip through in terms of breast care.*

*There is a gap between ideals and practice with regard to health care. Care is not driven by GP's. The health care is not working. They only check basics like BP on request. Male doctors don't check for women's menopausal symptoms: just give instructions. They have whinged about giving women pap tests to me. Pap tests: how do you get them? Some women go to a female doctor. That's OK. Trust is essential. One person: one doctor, but you wait a long time for appointments and it is difficult to see the right doctor. Breast checks don't happen: to my knowledge, No. On request the doctor might but not as part of health care. And women with intellectual disability don't get reminders for pap tests.*

*An improvement of care, especially of assessment of depression is important.*

### **Recommendations:**

- 21 General practitioners have access to this information through the North East Division of General Practitioners with accompanying professional development.**

## **Health. Barriers to health and women**

Workers express their concern that some women do not comprehend the purpose and procedure of breast checks and pap tests. They are also concerned about the sexual health needs of women who may not have been sexually active. For some women seeing a doctor is frightening.

*Pap tests are intrusive tests and potentially frightening: cognitive understanding has to be considered, as does the special needs of women who may not have been sexually active. Breast checks don't happen monthly: women may not have been taught to self-examine plus self-examination may not be accurate (the view of two workers).*

*Women fear doctors, particularly male doctors.*

*To the best of my knowledge no one has had a pap test: because the women would not understand.*

### **Recommendations:**

- 22 Resources are made available to community health nurses to visit community residential units and provide information for women and direct care workers about pap tests and breast care.**

## **Barriers. Incongruence, Fear, Values and Attitudes.**

The complexity of issues faced by workers is palpable in these accounts of barriers to sexual health and accentuate the dilemma's that exist when a diverse range of values

and beliefs are to be navigated.

*Most of the women are on the Pill. None are sexual though! We don't want them to breed. The community would die of fright if you encouraged anyone to take a partner. The asexual myth is alive and influential. Families view their sons and daughters as 'children' and as asexual.*

*For one woman, parents won't provide consent for a pap test and breast check, yet they placed their daughter on the pill when she was young.*

*Staff are offended by nudity. For example, if someone makes a dash from the bathroom to get underwear or something. It is not house members who are offended. But there is no opportunity for education. Priorities don't get to sexual health.*

*One of the tensions workers must navigate is the environment: that is the local and rural context of the work. Workers relate not only to the client but also to their family and their networks. Sometimes there is a need for someone to walk the path of rights with a client. This role isn't easy for staff in accommodation services to take on because they must preserve a working relationship between the service, client and family. Another tension is that parents have a difference of knowledge and understanding of the rights of their son or daughter. Any discussion of their son or daughter's rights is likely to be emotional. Also, the sheltered lifestyle is a problem. People mix with the same people through life at home and at work. Intimacy and affection is an issue for people who are single, rather than as an issue that is disability specific. Where does the single person seek and receive affection?*

*It is hard for women to have optimum sexual health experiences given the difficulty of placement. People go to available placements. It doesn't mean it is a suitable living arrangement: or use of resources. Managers know this and listen to us, support us, but the resources limit things. Knowing there was consent between partners would be difficult. We don't have people doing sexual expression. If clients did have sexual relationships there would be some dilemmas to sort through around decision-making. For example, if Yes becomes No at some point during intimate contact, how will that be understood by the other partner who has an intellectual disability? Sometimes the issue is understanding the person and their desires when language doesn't match what they want to do.*

#### **Recommendations:**

- 23 Advocates are available as a matter of routine for women with intellectual disability who live in accommodation services, have an ongoing relationship with the individual assisting her to reach her goals and responding to issues as they arise.**
- 24 Education for workers.**
- 25 Rural access teams are informed of the community attitudes that have a negative affect on women's lives in our local environment.**

## Barriers and workers' education.

Workers clearly indicate a strong interest in education about sexual health. This education has been missing in Certificate IV and in professional development opportunities. Workers identified that in an educational setting teachers were uncomfortable with this topic.

*Sexual expression and education about sexual health is missing from learning modules in Certificate IV. There was no mention of sex and when there was there was great discomfort in the teachers. I've never seen a sexual health seminar offered. If there was one the supervisors would get to go and the staff would be left out. Education is the foundation for improving rights for people with intellectual disability. Target the GP's and accommodation teams. It would be good to get a newsletter... re sexual health and other issues of interest. Informal learning would help.*

*Staff need training. We don't get much training that helps to understand and differentiate between behaviours. Staff need education to look at the broad picture. For example, if a client puts their arm around a person and buries their head in their bosom: is this sexual behaviour or affection? It needs to be understood properly. Lack of training and recognition are prominent problems. Staff do not have enough training re sexuality and that is the bottom line.*

*Professional development is important for workers.*

### Recommendations:

- 26 Strengthen links between workers in accommodation services and workers from community based organisations in order to increase informal learning opportunities. For example, workers from services such as community health centres, women's health, sexual assault services and domestic violence services can be invited to attend staff meetings and provide information about sexual health and sexuality.**
- 27 Locate and offer sexual health seminars for workers in their local environment. For example, the Living Safer Sexual Lives Workshops, can be offered.**
- 28 Sexual health is offered as a distinct module in Certificate iv.**

## Barriers and workers environment

Since 1992 the Victorian State Government has created a contract state, one in which the focus is on outputs rather than inputs and on task rather than process (Muetzelfeldt 1994). This changes the way work is measured and what type of work will be judged valuable (Muetzelfeldt 1994). The past decade has been one that has seen a trend to hierarchical work arrangements and one that rewards individuals working to produce specified outcomes, rather than those who work together based on shared values (Muetzelfeldt 1994). Direct care workers must manage the challenge of a work

environment that straddles the public and private domain (Parkin 1989). Locally, workers are experiencing tension through the dualistic demands of their work environment, both in terms of the influence of arrangements by the State over the past decade and in terms of the public private domain. If workers are less available for 'hands on' work and name this as a problem, women and men living in the houses must surely feel the effect.

*Computers. Outings and hands on work has diminished with higher expectations of paper work: managers understand but the current trend is to greater legal accountability. Everything has to be down. Our motivation is to work with people not paper work.*

*Computers. Staff spend more time at the computer than with clients. The workload has increased. Staff are expected to be computer skilled and some find it difficult. The pressure on the supervisor has become big over the past few years: huge workloads. Many have resigned. It seems supervisors are kept busy at meetings and don't have any time for clients.*

Workers also take the view that women's health in community residential units is affected by the knowledge and skills of direct care workers, and that recruitment of workers with the appropriate knowledge and skills is difficult. Furthermore, they indicate that caring for staff through support and through the creation of a diverse range of work opportunities would improve morale and therefore retention of skilled workers. Their views provide very good ideas about the re-arrangement of current work practice that could improve conditions locally.

*Staff recruitment and selection. We don't have a good selection of people to be staff and casual staff. They need to find ways to improve staff selection and the interview process. They need to know themselves how to conduct an interview, including the courtesies that help prospective staff to feel welcome and relaxed. The process from application to interview to selection is too long: six months usually and you lose good people in that time. The work is demanding; appropriately trained workers are essential. It is very hard to stay motivated in this field; people get bored and lose motivation. Staff members need opportunities to vary their work: even by the opportunity to take on projects, or vary their responsibilities, such as taking on responsibility for individual planning programs. I wanted to have such opportunities and discussed my interest but it never eventuated. Supervision has gone. Haven't had access to supervision for yonks. When we did, no one said "You're going OK. You've done well". And there is no interest taken in the person when they're not doing well and appear stressed. Let the whole staff learn all the roles and be multi-skilled. It is important to teach people to improve their living skills: this is neglected. Multi-discipline teams would help.*

*Communication could tighten up. Going back to the one house/one staff model will help. We told them it wouldn't work when they were starting it. The government doesn't listen to workers. Staff are very protective and trying to do the right thing. Some staff shouldn't be employed but it is difficult to recruit. Most staff have Certificate IV. Part time is a problem. We've lost a lot of good people*

*because they need full time work and rosters could easily be changed.*

## **Recommendations:**

- 29 Review the current community residential model taking into account the views of direct care workers. Conduct further interviews with direct care workers to investigate the validity of views presented here.**

## **Strengths of current practice.**

Workers recognise and acknowledge the importance of sexuality in the lives of women they work with. Sexuality is after all, a part of women's being on a daily basis, and relevant to the work of direct care workers.

*Romance is part of women's lives. Usually friendship is romanticised in idealised ways such as those portrayed on television. Some people with intellectual disability are married.*

*The women I work with are in their twenties and thirties. Two have expressed their interest in having babies. They are selective about who they talk to about this heart's desire. Romance is centred on favourite television characters. It is quite like being 'madly in love'. The women love weddings, babies; expressions of relationship and love. There are no real opportunities to have partners. One of the women really wants a sexual experience.*

Workers use referrals to the human relations programs when they are aware of the need for extra support for the people they are working with.

*If we had issues first we'd talk as a team, then with our team manager and then we'd call the Human Relations Program: Paula. When we had a man and a woman sharing a unit and needed to teach privacy Paula worked with that.*

*Paula is called in response to a failure of strategies used by workers and/or as an alternative provider for clients. If there are issues re sexual expression the teams call Paula and work together (the view of two workers).*

## **Strengths in the environment.**

For women with financial resources beyond those provided by the State there are significant gains in social opportunities and the attendant personal developments. When utilised, the community health nurse provides an accessible and personal health care environment in which women have had a positive experience of pap tests. Community living has provided family and social environments that have positively contributed to personal development of women with intellectual disability. When parents can access support groups the benefits of education and action become visible.

*For some women, there is money from family or inheritance. This changes life*

*opportunities considerably and annual leave can be organised nicely. For example, the person can go on holiday without staff and really have a break.*

*The pap test experience has been good. The community health nurse is used and she is great. She caters for each person's needs with great care.*

*Support groups for parents are positive. They provide avenues for parents' voices and education opportunities.*

*There is a noticeable difference for clients who have not been institutionalised. It makes a difference to have family support. And there are changes: younger parents have more early support and knowledge. This should mean improved experience of life for people with intellectual disability.*

*In this region there is one example of good health care. The doctor attends house meetings monthly and builds relationships with the clients.*

**Recommendations:**

- 31. Workers across the disability sector indicate that families and community life make a noticeable difference for women with intellectual disability. Increase opportunities for families to access sexual health information and explore their values. Specifically, begin by offering the workshops designed and run by La Trobe University, Living Safer Sexual Lives.**

## In a Nutshell: a summary discussion of findings

Women have no disability in their hopes and dreams: they hope to be related to first as women and aspire to belong to family and friendship circles that include opportunities for them to have partners and for some, to become mothers. Women with intellectual disability do not have access to the freedom of choice, education, support and social participation that enables these hopes to be seen to fruition. Education is missing and this is an issue that demands immediate attention. Education can be delivered at transition stages in the life cycle. It is apparent that preparation for adolescence with a focus on menstruation is one aspect of sexual health education that has been delivered locally. Future education opportunities should also include education when women reach transition from adolescence to adulthood with a focus on healthy relationships, adult education that includes family planning and preparation for motherhood where indicated, cervical and breast health and at mid life we should offer women the opportunity to discover more information about menopause.

Importantly, we must find ways to work that will strengthen women's ability to embark on a journey that leads to full and free lives. We need families and direct care workers to accompany women on this journey. We need the support of the Department of Human Services to trial alternative models to the community residential unit model as it exists today and to provide ongoing education for direct care workers. Education is needed in the health sector, particularly for general practitioners, from whom we want initiation of preventative health care for women with intellectual disability. We anticipate that in future greater numbers of general practitioners are confident about providing care for women that includes discussion of sexual health, cervical screening, breast screening and family planning.

There are some services in place locally that support the sexual well being of women with an intellectual disability. We emphasise the importance of the two local programs, Volunteer Friends and Interchange. These programs work to strengthen social opportunities for women and men with intellectual disability. It is vitally important in today's society that support such as that provided by these programs is available to provide a beginning for the establishment of social connections between people in our community. The rural access programs are equally important, working to build community capacity to be inclusive and envisioning a community that includes all people. Ovens and King Community Health Service offer a weekly women's group. This provides opportunities for women to explore sexual health according to their interests and with the support of community health workers. These activities in our community make a positive contribution to the sexual health of women with an intellectual disability.

In the Hume Region the Human Relations Program works to expand community awareness and understanding of issues relating to sexuality and disability. It also provides counselling and education to people with an intellectual disability. This service is highly valued by local workers and is seen to make another positive contribution to the sexual health of women with an intellectual disability.

Upper Murray Centre Against Sexual Assault works very actively to support women with an intellectual disability and have extensive experience providing group work to young women. The group that gathered this year has focussed on self-esteem, relationships, sexuality and sexual health.

We can continue to build on the strengths of good practice highlighted here to further diminish the barriers to sexual health identified in this action research project. In order to realise the changes in the lived experiences of women that reflect our vision for the future we can recruit services from existing community based organisations, we can rearrange current resources and structures so that women experience greater freedom of choice and improved access to education and we can commit further resources to provide the infusion of energy that will generate further change. The recommendations summary provides a guide to the specific actions that will sustain the change envisaged.

## The Pilot: *Groovy Chicks*

At reference group we discussed the design of the pilot, *Groovy Chicks*. We used information gathered from the first group of participants, with whom focus groups were completed in February 2002. Melissa Habermann, who works with the Futures for Young Adults Program, based at Ovens and King Community Health Service, participated equally in the design, development and delivery of the work. We designed *Groovy Chicks* according to the expressed interests of the women who were aged between eighteen and twenty eight years. We would not have anticipated providing education about period pain without their contribution. Nor would we have appreciated the questions they raised regarding pap tests and condoms. So their input to the program guaranteed relevance and explains the high participation rate. Six young women opted to participate in the pilot and only one young woman missed one session. This is a very high level of commitment.

We will describe the program to you by presenting the weekly outline and the guest speakers (all mainstream). At each session, I was present to facilitate evaluative conversations in readiness for adjustment of the program to meet participant needs. At most sessions Melissa and Colleen Davis, teacher at Goulburn Ovens Tafe were present. Both Melissa and Colleen have ongoing relationships with the young women through their roles, and they participated to provide support outside the program for the women and also to build trust between families and the project. Jackie Coupe attended as a Certificate IV student and to build a relationship with the young women in preparation for art and celebration activities. The importance of generating relationships was given strong emphasis. The group objectives developed are included for your review. Then we will provide the evaluative feedback women offered along the way and the evaluation gathered as a finale to the work when we met for our art and celebration day at our final and eleventh session. In conclusion we will present a description of our learning as facilitators. In summary, recommendations for future sexual health education delivered to young women at transition from adolescence to adulthood or in early adulthood will be listed.

|   |  |
|---|--|
| <b>The Plan</b>   | <b>Presenter:</b>  |
| <b>Week One.</b> Monday 15 April<br>Group Agreement and Objectives.<br>Period Pain. How to manage period pain | <b>Melissa and Kerry</b>   |
| <b>Week Two.</b> Monday 22 April<br>Breast Care. Video and discussion   | <b>Jodie Finlayson</b> , Breast Care Nurse.<br>Wangaratta Base Hospital.   |
| <b>Week Three.</b> Monday 29 April<br>Pap Smears. Hearing all about them                                      | <b>Diane Hourigan</b> , Community Health Nurse,<br>Ovens and King Community Health Service                           |
| <b>Week Four.</b> Monday 6 May<br>Pap Smears. Visit to Diane's rooms  | <b>Diane Hourigan</b>  |
| <b>Week Five.</b> Monday 13 May<br>Healthy Relationships  | <b>Lynne Allen</b> , Domestic Violence Outreach,<br>Central Hume Support Service                                     |
| <b>Week Six.</b> Monday 20 May<br>Healthy Relationships   | <b>Lynne Allen</b>   |
| <b>Week Seven.</b> Monday 27 May<br>Back to Period pain. Exercise and diet                                    | <b>Melissa</b><br>(Lynne unavailable)  |
| <b>Week Eight.</b> Monday 3 June<br>Youth Health Access Workshops   | <b>Megan Gerrish</b> , Youth Worker, North East<br>Action Support Youth<br><b>Rowena Mann</b> , General Practitioner |
| <b>Week Nine.</b> Monday 17 June<br>Youth Health Access Workshops   | <b>Megan and Rowena</b>  |
| <b>Week Ten.</b> Monday 24 June<br>Healthy Relationships  | <b>Lynne Allen</b>   |
| <b>Week Eleven.</b> Tuesday 2 July<br>Celebration and art<br>Evaluation                                       | <b>Jackie Coupe</b> , Community Artist<br><b>Kerry and Melissa</b>   |

## **A statement of principles and values to inform and guide our work.**

- Every woman will be respected for who she is, how she chooses to live and what she believes in.
- We will support the well being and growth of each of us.
- We will encourage each other to talk about things that are close to our heart.
- We will work together to make our lives what we want them to be.
- We will work in a way that makes us feel equal to each other.
- We agree that what we talk about in the group is private and will not be talked about outside the group.
- Each woman is in charge of her own life and will decide what action she wants to take. If she wants support to take action with any issue in her life she can seek it within the group.

# GROOVY Chicks

## What we want to get from this group

- Feel better about ourselves
- Have fun
- Get to know people
- Get to know services
- The chance to talk
- Feel more confident
- More Knowledge

## Evaluation Week Three

### **What was good about last week? (Breast health)**

- Learned a lot from the video
- The video was good: the people were disabled in our way, similar to us
- Being shown the breast X ray on the video. It is a good idea
- Feeling the lumps was good. (This relates to the 'breasts' Jodie brought in for women to look at and feel).
- The video was good.
- Finding breast lumps

### **What could have been better about last week?**

- The room could have been bigger
- More time to explore what we're learning
- Time to talk at the end

### **If we need more time at the end how do we get it?**

For women who travel

Creative ideas

Sleepovers at friends

Getting home another way?

## Evaluation Week Four

### **What was good about last week (pap smears):**

- It is good to know a 'nice' nurse (Diane)
- Diane explained things well. She talked slowly and did not "blubber on"
- The breast screen van is at Safeway (in the carpark). The group members would like to have a look inside. The women who work in the van would be happy for the group to visit.
- One person is thinking of having a pap test

### **What did we learn?**

- About the instruments used in pap tests
- What the inside of our vagina looks like (a donut, you can't see in there)
- Your vagina stretches when you have children
  - can do exercises to make the muscles stronger (pelvic floors)
  - when you are busting to do a wee, sometimes you can't and might have some wee come out before you go to the toilet
  - how do boys hold on? They have different anatomy.

### **What else would you like to learn?**

- Would like to watch the video "Paps I Should...". We will try and watch it next week. If we don't, we will find another time to watch it.

### **Ideas to make the session better?**

The group did not have any ideas on making the session better. It must have been perfect!

## Evaluation Week Five

### **What was good about last week (visit to Diane's office):**

- Diane's a funny lady (good sense of humour)
- Melissa liked being a "model" for Diane
- Good to see Diane's rooms

### **What did we learn?**

- About the instruments used in pap tests
- Learnt about using condoms properly
- Know we can go to Diane if we want more information

### **What else would you like to learn?**

- Would like to watch the video "Paps I Should...". We will find another time to watch it.

### **Ideas to make the session better?**

The group did not have any ideas on making the session better.

## Evaluation Week Six

### **What was good about last week?**

(Lyn's session about healthy relationships)

- We talked about our feelings
- The faces explained our feelings. Emotional faces.
- Finding the feelings that we had most: lovestruck, happy, satisfied, bashful.
- Learned how we feel
- We thought about lots of relationships, like with boyfriends, brother and sisters, mothers and fathers, and friends.

This conversation included the things we learned.

### **What else would we like to learn or talk about?**

- What to do about relationships you can't get out of
- Finding ways to get out of relationships
- Confusing relationships
- Talking in relationships
- Saying "No"
- When people/boyfriend react to us saying "No" like when they get angry.
- Telling someone something they mightn't like to hear.

## Evaluation Week Ten

### **What was good about last week (with Megan and Rowena: sexual health)?**

- Showing us the injection; it lasts three years
- Showing us the big condom; it is a female condom
- We saw the diaphragm
- We talked about men getting excited
- And women getting excited: the opposites
- It was good: we talked about orgasms
- Getting excited about seeing friends
- Privacy: when it is ok to kiss and when it isn't

### **What could have been better about last week?**

- Nothing. We got it.

### **What did we learn last week?**

- About good condoms... the winnie the pooh ones don't work! The fancier the condom the less reliable it is.
- To look at the due date on the condom
- Don't use condoms that have been kept in wallets. They get hot and don't work anymore.

## Final evaluation Week Eleven

### **What we did, whether it was useful or not**

- Things you didn't know, learn before, you know now
- Learned heaps of things

### **Why did you come to this group?**

- It was fun
- 'Cos Sue and Kristy were coming. I like being with Kristy.
- To enjoy being with my friends and to be with Julie
- 'Cos all my friends were coming.

### **What did you hope to get out of it?**

- New experiences
- Normally you don't have classes like this, hardly any. This is a chance to talk about what you feel
- Experiences
- To know my breasts

### **What did you think at your first meeting?**

No answers.

### **What have been the best things about coming to the group?**

- I got up on the table. I was the model.
- Today: Fun. Jackie's taught us a lot and everyone's having fun.
- Making my necklace
- Everything just being open, for me I could never say anything, now I can talk to people and get help when I'm not sure. I know where to go to get help.

### **What has been difficult about coming to the group?**

- Nothing
  - No
- Others in the group shook their heads in agreement: nothing.

### **Have your learning and support needs (worked out in the first group) been met?**

- Yes
  - Sexual health, yes
- Nods all around.

**If yes, what were they and how were they met?**

- Yes. All of it was important. Now I can go home and say I had a bad day today. I used to keep it to myself.
- Yes. Everything.
- Yes. Learning about the breasts.
- Yes. Noticing the breast van.
- Yes. How to put on condoms.
- Yes. About condoms. It's good to learn heaps of things.

**If no, what were they and what went wrong or didn't happen?**

No responses here.

**What has changed for you since you have been part of the group?**

- Don't know.
- It's changed my life. I can... I like it... the new things I know.
- Knowing where Diane is at O & K.
- Knowing what the ducks bill is and about pap tests.
- Everything's changed.... In my self... relationships didn't work out before... now I'd rather be friends until later on and see what I want.

**Would you recommend the group to friends?**

- Yes (x 6)

**If yes: what would you tell them?**

- See Kerry
- Don't know
- Because they might want to learn about sexual health
- If they're in a situation where they can't figure out why it's happening - I'd tell them to come along to a women's health program and you'll get it sorted out. You'll get support and help.

**Any other ideas or comments or things you'd like to tell us?**

No responses here.

**Thank you for sharing this with us. We will use your ideas.**

## Talking about *Groovy Chicks*.

We (two mums, two young women, Melissa and Kerry) met to talk about Groovy Chicks. We wanted mums to have an opportunity

- To hear about the information Groovy Chicks had access to
- To be able to ask questions
- To identify their interests or needs
- To present the poster for everyone to view and tell us how they felt about it.

We heard from mum's that their daughter's confidence had grown significantly through their participation with Groovy Chicks.

We also heard that they want this opportunity available in the future for young women they know who haven't had the chance to join in this time and for young women as they become adults.

When we explored the work we noted that it did not extend to sexual pleasure through aids such as vibrators. One mum had thought it might.

The young women informed their mums of things they'd learned and remembered from the eleven weeks Groovy Chicks met. Their recall of detail was excellent.

We talked about babies. One of the young women had wanted a baby about eighteen months ago. She borrowed the plastic baby that cries from Deb at Department of Human Services. She changed her mind about babies.

## As facilitators we learned

- That *Preparation Focus Groups* serve several functions. The work is *woman led* and this is an empowering experience for women. It enables content to reflect their interests and needs and becomes personally relevant to participants. Once the content is personally relevant, participants are engaged and committed to an ongoing program.
- We found the first session needs to be dedicated entirely to the group agreement and generating an understanding of privacy or any other important concepts developed in the group. While we had allowed the time to develop the group agreement we had also scheduled a small session on period pain for the first session and this was unmanageable.
- We found the breadth of the program was unmanageable in ten weeks. The topic “Healthy relationships” was very important to participants and warranted more time.
- Our impression was that *access to services* was improved by three aspects of the work. First, speakers came from a range of programs and the women have therefore met them and have their contact details. Secondly, one activity delivered by the youth health access workers taught young people to consider where to go for help with specific issues. Finally, we visited four venues from which services work so that women knew where they were. This *tour* greatly helped the women to conceptualise where people and services were located.

### Recommendations:

- 32 “Healthy Relationships” is offered as a ten week group work program facilitated by a community health worker and with guest speakers from domestic violence, youth services and sexual assault services as indicated by the expressed interests of the young women.**
- 33 Sexual health subjects such as menstruation, pap tests, breast care, contraception and sex information should form another ten week group work program. If this is facilitated by a community health worker, guests can present to the group similarly to the Groovy Chicks arrangement.**
- 34 Young women who have participated in the two programs and are interested in becoming peer educators are offered the opportunity to train with the community health worker and act as employed facilitators for future programs.**
- 35 If one program was offered one year and the other the next, a two - year cycle would be created and young women could access them as they enter adulthood or when they become interested.**

# Older Women's Health

The second group of women who participated in focus groups were aged between forty-eight and sixty-eight years of age. Their interests were significantly different than the young women. Since most of the women indicated they have not had a breast check or a pap test and that they don't know much about this aspect of their sexual health care we were keen to provide information. Further, some of the women had indicated they would have liked to have babies and were interested in knowing more about what it's like for women to have a baby. We were keen to offer the women peer education because it improves access to health education and is one of the preferred options indicated by people with disability (Shakespeare, Gillespie-Sells & Davies 1996; Cooper & Temby 1995). Finally, we offered the women an opportunity to meet Sharon Lovett, who co-ordinates Volunteer Friends locally. This group of women were keen to have a broader range of social activities than they currently enjoy. Thus responses were provided that included:

- Power On. Women's Health West's *Peer Education Program* for women with disabilities. This team delivered information about pap tests and breast care using a video, prepared information and discussion.
- A visit from a woman with intellectual disability who is a mother. She talked about being a mother through these points:
  1. Having a baby; What was scary. What was good
  2. What it's like now: Now my child is school age
  3. What it's like to be a parent and to have responsibility
  4. Having a partner.
- A visit from Sharon Lovett and a discussion of Volunteer Friends. An opportunity to join and plan for future social events.

A description of how the women found these activities was generated through an evaluative conversation.

## Evaluation Week 2 Power On

- I knew Daisy at the institution.
- I remember the video about the pap test. The speculum went into the vagina.
- Pap tests are to find something wrong with you. I am too frightened to have a pap test.
- Leeanne showed us the breast care brochure and pointed to the breast examination picture.

Evaluative feedback from the facilitator of the women's health group.

- We missed out on asking Daisy what a pap test was like for her.

- The apron: the symbolism was too remote. The breasts were coloured so brightly.

### **Evaluation Week 3 Guest Speaker about being a mother.**

- I love babies. (In response to the photos shown of guest speaker's baby when newborn). Followed by a long conversation about babies.
- It was good. Yes. Living independently. I think about it.
- I can't live independently because of epilepsy. I need someone to look after me.
- It would be good to live by myself in a flat. I can imagine it. I do cooking on Wednesdays. It's good to talk about babies.
- I liked talking about babies. Yeah. I'd like to try living with friends. Making my own tea would be good. I'd need help to get meals.
- I felt a bit nervous. My hands got nervy. Sometimes I get up in the morning and it is cold. That's all right. I'd like to nurse a baby.

# Recommendations Summary

- 1. Improve access to formal support services in response to experiences of violence by including a description of services and what they can provide in sexual health education sessions. Follow this up with a visit to the service provider's agency so that women can locate it physically and imaginatively. Provide women with the Women's Health Goulburn North East card that lists domestic violence service providers and their telephone numbers.**
- 2. Provide information about safe and healthy relationships with which women can scrutinise their personal experiences. This information should be provided at the transition from adolescence to womanhood.**
- 3. Improve resources allocated to sexual assault and domestic violence services for the purpose of delivery of information about healthy relationships to women with intellectual disability.**
- 4. Include discussion of grief and loss in women's health groups.**
- 5. Structural change to the community residential unit model that enables people to choose who they live with. Women will then be able to choose to live with friends rather than without them.**
- 6. Women are provided with opportunities to explore healthy relationships and to develop assertive communication skills. This should be included in sex health education at each delivery through the life cycle. It is critical at the transition from adolescence to adulthood.**
- 7. Offer men opportunities to explore sexual health and healthy relationships.**
- 8. Extend opportunities for women to be together and explore their experiences as women, including finding out more about men. This can happen in a women's health group that meets on an ongoing and regular basis. Furthermore, increasing opportunities to be out together socially will correspondingly increase women's opportunity for experiential learning.**
- 9. Adult education will include contemplation of family planning and preparation for motherhood according to the interests of the women.**
- 10. Creation of a specialist team who can respond to the needs of people with intellectual disability who wish to become or who are parents. This team will believe in the rights of people with disability to be parents and will advocate for them within the system. The team members will be multi-disciplinary and will have knowledge and skills related to disability, parenting, family support and the legal system.**
- 11. Social life is valued and women are provided with the support and opportunity to broaden their social experiences. Volunteer Friends and**

- Interchange are programs all women have the right to know about and be part of.
12. Alternatives to the existing arrangements of care are researched and a trial arranged which includes the concept of women (and men) led accommodation services.
  13. Further to previous recommendations about women joining groups such as Volunteer Friends, consideration of the extension of the use of volunteers in the disability sector is warranted as a means to help women realise their social goals and as a means to reduce isolation.
  14. Sexual health education is delivered consistently to women with an intellectual disability across the life cycle. Education should be delivered pre-adolescence, at transition from adolescence to adulthood, during early adulthood and at mid-life to ensure that information is repeated thus increasing its availability to women and to ensure that information specific to the stage of the lifecycle is offered in more detail at the time it is most relevant.
  15. Women gain information from their mothers. Support and information should be made available to mothers to ensure they have accurate information and encouragement as they assist their daughters to prepare for womanhood and adulthood.
  16. Conduct the Living Safer Sexual Lives workshops in Wangaratta to offer all workers, families and people with an intellectual disability an opportunity to consider sexuality, values and attitudes.
  17. Offer the Living Safer Sexual Lives workshops at appropriate times, venues and cost to enable access for all who wish to attend.
  18. DHS to negotiate with TAFE to include a core sexual health stream in its human relations course for disability workers.
  19. DHS to acknowledge the particular vulnerabilities of women with an intellectual disability in terms of violence and sexual assault through improved educational opportunities and support for the women and their families; through targeted strategies for increasing safety; and through increased education and personal development opportunities for men, available in small local communities.
  20. WHGNE to work with CASA and Family Violence Network to implement strategies to ensure women with an intellectual disability are aware of their right to a safe sexual life, and their entitlement to access domestic violence and sexual assault workers.
  21. General practitioners have access to this information through the Royal College of General Practitioners with accompanying professional development.

- 22. Resources are made available to community health nurses to visit community residential units and provide information for women and direct care workers about pap tests and breast care.**
- 23. Advocates are available as a matter of routine for women with intellectual disability who live in accommodation services, have an ongoing relationship with the individual assisting her to reach her goals and respond to issues as they arise.**
- 24. Education for workers.**
- 25. Rural access teams are informed of the community attitudes that have a negative affect on women's lives in our local environment.**
- 26. Strengthen links between workers in accommodation services and workers from community-based organisations in order to increase informal learning opportunities. For example, workers from services such as community health centres, women's health, sexual assault services and domestic violence services can be invited to attend staff meetings and provide information about sexual health and sexuality.**
- 27. Locate and offer sexual health seminars for workers in their local environment. For example, the *Living Safer Sexual Lives Workshops*, can be offered.**
- 28. Sexual health is offered as a distinct module in Certificate iv.**
- 29. The current community residential model is reviewed taking into account the views of direct care workers. Conduct further interviews with direct care workers to investigate the validity of views presented here.**
- 30. Workers across the disability sector indicate that families and community life make a noticeable difference for women with intellectual disability. Increase opportunities for families to access sexual health information and explore their values. Specifically, begin by offering the workshops designed and run by La Trobe University, Living Safer Sexual Lives.**
- 31. "Healthy Relationships" is offered as a ten week group work program facilitated by a community health worker and with guest speakers from domestic violence, youth services and sexual assault services as indicated by the expressed interests of the young women.**
- 32. Sexual health subjects such as menstruation, pap tests, breast care, contraception and sex information should form another ten week group work program. If this is facilitated by a community health worker, guests can present to the group similarly to the *Groovy Chicks* arrangement.**
- 33. Young women who have participated in the two programs and are interested in becoming peer educators are offered the opportunity to train with the community health worker and act as employed facilitators for future programs.**

**34. One program is offered one year and the other the next to ensure that a two- year cycle is created and young women can access them as they enter adulthood or when they become interested.**

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