

SEX & RELATIONSHIP FACILITATION PROJECT FOR PEOPLE WITH DISABILITIES - (SARFP)

Introduction

In 1999 the author met with a number of disabled sexuality activists in Sydney, Australia and we co-conceived a project which is not dissimilar to 'Surrogacy' as understood by International Professional Surrogates Association (IPSA) but is geared specifically to the needs of people with disabilities of all sexual orientations. 'Surrogacy' however, is a very widely interpreted concept and outside the US has a fairly negative press in the sex therapy world. We have been struggling for a new name and *The Sexual and Relationship Facilitation Project for People with Disabilities* is our current working title.

The project aims to promote the development of disabled people's self-esteem including feelings about their body and enhancing body awareness and to help develop skills and confidence in forming sexual and emotional relationships if this is their goal. We believe it is fine to be celibate and single, if it's by choice. However, ableism, body fascism, and economic disadvantage are key social factors that cause many disabled people to remain single and isolated against their will. Many people with disabilities only experience of touch is when it is functional and/or intrusive – people are poked and prodded, and rarely stroked and caressed. Yet research has clearly demonstrated the how vital affirming, gentle, loving touch is to physical and emotional well being.

The project will offer a highly flexible and responsive user-led service that helps disabled people achieve well being, personal competency and satisfaction in the last frontier of our civil and human rights fight to participate equally in society. We've fought for equality in terms of access to the built environment, to education and employment now we want our rights to love, form relationships, and have sex with ourselves and with other people. This is going to be challenging not only for society to deal with, but for disabled people too. Anne Finger states: "Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about - and formulate strategies for changing - discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction." [Finger, 1992: 9]. A great many disabled people and organisations have difficulties around notions of our being sexual, and forming relationships. We have been excluded from most of the dominant socialisation processes that help teach and prepare people for love, sex and intimacy.

In this project we envisage disabled people getting access to skilled therapeutic help to work on whatever issues that impede them in developing a sound sense of self with regard to feelings about their body and self-esteem. Developing self-confidence in this arena may well lead to working on finding and maintaining sexual and emotional relationships. Work on self-esteem and body image issues, education about human sexuality and its implications for their particular impairment, acquisition of dating and relationship skills, learning more about their body and its sensual sensitivity. Where appropriate and in certain circumstances the work may also include specific sexual experiences. [However, in the UK, we would not be permitted to actively assist in genital contact leading to orgasm.]

Why is this necessary?

As stated earlier, opportunities have been rare for disabled people to learn about love, sex and relationships:

- Lack of physical and financial access to where the rest of society work and play has meant we are disadvantaged in opportunities to meet people and acquire sexual and relationship skills through practice and normal socialisation processes. Life in residential institutions or with our families is often policed to ensure we don't develop intimate relationships.
- Lack of positive role models and low self-esteem generated by shame about our bodies from the messages we receive from those around us, can create psychological barriers as great as any in the built environment to our believing in our capacity to participate in sexual relationships. Many disabled people have never experienced loving sensual touch. Our experience of touch is being poked and prodded in having our most basic personal hygiene needs met. We may not know what kinds of touch feel good on our differently formed bodies.
- We are often excluded from sex education lessons, rather than given some education geared to our specific needs and situations. We may need for example to learn about specific positions which would enable us to give and receive sexual pleasure, ways of managing pain and spasm, how to deal with the physical adaptations which enable us to function in the world but which may become obstacles in sexual relationships.

Previously funded work on sexuality and disability has usually been centred on problematised notions of sexuality – mostly the prevention of sexual abuse. These have been either helping disabled people

recognise and report sexual abuse, or funding schemes to manage *Troublesome Sexual Expression in Persons with Developmental Disabilities* as we have seen in conferences around the world.

Our work would be presented in a more positive way; it is about empowerment and enabling disabled people to improve their confidence and self-image although much of the recent previous work could be achieved through less problematised approach. For example it is anticipated the Facilitation Project will be working with a great many disabled people who have experienced sexual abuse, and part of their recovery programme will be about undoing the damage caused and working on prevention of further abuse through positive self-esteem and self-empowerment. It is envisaged we will also be working with people on issues of sexual frustration and inappropriate behaviour. However, at our core, will be beliefs about empowerment, compassion and self-actualisation through peer-led education and support working with trained allies.

Training for Facilitators

It is proposed that two groups of people be trained to assist disabled people. The first would be Sexual Lifestyle Assistants (SLA), these workers could be involved in helping consenting sexual partners have sex, this may include tasks like assisting with positioning the partners or helping fit a condom and being available to help if people got into painful positions. If the disabled person didn't have a partner, the SLA may help facilitate meeting other people (cruising and chatting up), and they may become involved in helping purchase sex toys, etc. The other group would probably be known as Sexual and Relationship Facilitators and these would take on the training and therapeutic tasks in helping raise self-esteem and the acquisition of relationship skills and may facilitate direct, positive sexual experiences. This work would be closest to 'Surrogacy' as understood by IPSA. Disabled people and their allies would specifically train both groups, and both SLA's and the Sex and Relationship Facilitators would include disabled and non-disabled people providing the services we would actively encourage facilitators of all sexual orientations and gender identities. Choice and flexibility are central.

It is envisaged that this training could be on a modular basis with increasing complexity of tasks and learning and students would build on previous knowledge, experience and skills. Accreditation of Prior Learning would ensure a flexibility to progress through the training tailored to the student's needs. Draft and outline working course curricula form Appendix 1.

It has been suggested that we would find interest amongst a variety of groups for training as Sexual Lifestyle Assistants and Facilitators: personal care workers, nurses, sex workers, and counsellors and body oriented therapists (masseurs etc).

Individual Assessment of Service Users

It is envisaged that disabled people approaching the service for help would receive a detailed individual assessment, which would seek to explore their previous experience and knowledge and co-create some personal goals and objectives for their particular situation.

The service user would then be assigned an SLA and/or Facilitator(s) who would then work with the disabled person on these goals, and the work would be monitored and supervised by regular three way meetings between the disabled person, the supervisor ('assessor') the facilitator(s).

Funding

This is THE most problematic area we can think of. Who is going to pay for all this? We should be applying for Government/State funding out of the Health and Social Service budgets. We will support our claim to these funds under pre-existing Anti Discrimination legislation. It may be best to locate the management of such a service in the non-profit voluntary sector so that maximum flexibility is given to service development and responsiveness to changing needs.

Research and development grants may be available for small-scale pilot projects via Universities and sympathetic Trusts and Charities.

Where might this happen?

This sort of project would work well throughout the world and we currently know of no similar project anywhere. Limited specialist service provision for disabled people exists in various small pockets. For example individual professional sex surrogates working with therapists in California and a few other states in the US have experience of working with disabled people amongst their clientele. In the Netherlands and Denmark the state runs a dedicated licensed brothel for disabled peoples needs. However, what is being proposed here is a concept that individuals and groups of disabled people and their allies could take on and set up in their own location. Developing the concept as best fits the specific demands of their own location. Currently, most interest in the development of a project like SARFP seems to be located in Australia, with various active groups in both Sydney and Melbourne exploring sexual empowerment issues.

Random Ideas for Development

There are many ways to garner support and interest for SARFP:

Some people may be interested in running a short training session for therapeutic masseurs and body workers in offering sensual touch workshops for disabled people. This could be followed by workshops offering disabled people experiences of sensual touch and helping people learn more about what feels good on their differently formed bodies

In other locations, it may be appropriate to offer an existing course on health and social care a module of sexuality and disability with the aim of educating students about some of the specific issues in disability sexuality.

Elsewhere it may be possible to find some sex workers who would be interested in meeting some disabled people and learning more about how to meet their needs.

Somewhere else we might explore training counsellors or nurses in promoting self-esteem work for people with disabilities.

Wherever we get an opportunity to push the boundaries back further and realise this goal of developing a dedicated service for disabled people to develop their sexual and relational selves we should do so, always moving towards the goal setting up a dedicated Facilitation Project for PWD's.

Setting up networks for support and development

Interested parties are invited to network and support each other in their ideas for service development through an e-mail discussion listserve. An email discussion group has been set up. To subscribe e-mail: SARFP-subscribe@egroups.com

It is hoped that people will develop local based activity groups of supportive individuals interested in working towards setting up a Sexual and Relationship Facilitation Project in their own locality and to stay in touch with others through the listserve. We see funding for a building where Facilitation work can be based as essential to co-ordinate many of the activities that can take place.

APPENDIX 1

SEX AND RELATIONSHIP FACILITATOR TRAINING FOR PEOPLE WITH DISABILITIES DRAFT COURSE SYLLABUS

2 levels of courses: (Cert. & Diploma)

Probably validated by a university or further education college, for people wanting to specialise in working with disabled people's sexuality.

Understanding the social context of disability

Working with clients who need info in alternative formats and/or use alternative modes of communication such as makaton, or working with interpreters, etc (who may even be parents of the client).

Attitudes to and appropriate language around disability/people with disabilities

Residential care

Access

Parental roles

The economics of disability

Basic understanding intellectual, cognitive, physical, sensory and psychiatric disabilities

Anatomy & Physiology (how impairments affect sexual functioning)

Human Sexual Functioning and the Sexual Response Cycle

Understanding psychosexual dysfunctions and specific treatments for PWD's.

Strategies for assisting in neurological deficit

Sensate focus and massage techniques including basic aromatherapy principles

Use of sex aids and toys for PWD's

Implications for and specific difficulties around safe sex for people with disabilities (e.g. impossibility of accessing customised latex gloves for those who's disability affects shape of hands, using condoms/dams with limited hand function, or less reach etc.)

Tantric techniques – using sexual energy, enhancing 'dominance transfer'.

Social and dating skills

Enhancing self esteem

Basic listening skills

Communication skills including flirting and dating/relationship skills for people with specific impairments

Contracting and negotiating skills

Assertiveness training

Understanding the use of Internet in disabled people's dating

Safe handling and lifting techniques

Helpful positions for facilitating sex

Bowel and bladder management

Working with survivors of abuse

Recognising abuse

Working with survivors of sexual abuse

Preventing abuse

Gender Issues and Sexuality

Cultural Issues and Sexuality

Lesbian, gay, bisexual and transgender awareness

Ethical and Professional Issues

Facilitator self care, support and supervision

Facilitator and Client Emotional Attachment managing professional boundaries

Legal issues of sexual and relationship facilitation

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