Continued from page 3

Parents can mistakenly believe they are keeping their children safe, but in actuality it can make them more vulnerable. "It is better to walk like you're comfortable in your body."

However it can be difficult to be comfortable in a body that refuses to be easily managed. Complicated periods, spasms and incontinence, for example, can make it hard to develop a positive body-image. This can make accessories, such as clothes and hair colour, all the more important. "For me, my image was about people noticing what I looked like before my disability", says Philip Patston. "I wanted people to get more of a sense of who I was."

Clothing choice can be complicated. "When you're disabled, clothing becomes something that's practical, not fashionable", says Philip Patston. "It's about what's easy to get on and off." He also points out that it is less likely that a young person with a disability will choose their own clothes.

In Kirsty Pillay's experience, parents do want their kids to feel good about who they are and can be excited about them developing their own body image, because it's tied up with them establishing their own identity and self-esteem. It's well-known that a key to being attractive and being desirable is being happy with yourself and your body. .

However there can be an almost subconscious "lack of expectation that disabled people will look good", says Philip Patston, which is compounded by the lack of positive role models in the media. For young people with a visible disability it can be difficult to reject dominant images of what society decrees is beautiful. Young women are particularly under pressure, as they are more likely to be judged on outward appearances.

Relationship qualities

"Communication, trust and understanding," are often key qualities young people with a disability look for in a relationship, according to Kirsty Pillay, from her teaching experience as an FPA Educator. "They are concerned about feeling safe." Philip Patston agrees, noting that every person he has been involved with has had a quality that allows them to look past the impairment. Could this mean that people with a disability are more likely to be in sincere and meaningful relationships?

Philip Patston is unsure, having witnessed a range of relationships, including the stereotypical 'saint' and 'deviant' arrangements. But he does concede that "disabled people can often make relationship choices based on 'knowing I can trust somebody before I fall into bed with them'".

"There's a communication you have to have, for example in getting help to take your shoes off. This can help build intimacy because you're laughing, getting to know each other better." But this can also be a passion-stopper, Philip Patston acknowledges wryly.

"I met a guy at a café and had to decide whether to ask the café guy, who I knew, or this new guy to help me with my wheelchair. I had the choice to either 'play independent' or to bring this person, who I didn't know well, and show them what my life entails. It's a balancing act – if you do it too early you can freak the other person out – if you leave it too long you risk stifling the intimacy about being honest about who you are."

There are no statistics relating to how many people with a disability develop relationships with other disabled people. But there are observable trends in the pressure on disabled people to have relationships with non-disabled people. "It used to be that, "if you can make it with a non-disabled person, you've made it", declares Philip Patston. "Sexuality is the last bastion of acceptance."

Even today, people with a disability are more likely than others to find their relationship under scrutiny. "Disabled people have to be better than any of us in their relationships – have to prove themselves", says Claire Ryan. They may have to prove there is "consent" and it can even extend as far as pressure to sign a contract promising to treat their partner well. Philip Patston agrees, saying, "If you're disabled your relationship has to be good and healthy – happy all the time".

Claire Ryan refers to a "movement of disabled people 'coming out' as being sexual". Such a 'coming out' is not a spontaneous event, but the result of a life-long process of learning and growing socially and sexually. What a parent does now to teach their child about caring, respect, self-esteem and intimacy will impact on their child's self-image, values, and ability to have fulfilling relationships as an adult.

Update on Respite Facilities in Auckland

Three new services are:

- The Laura Fergusson Trust (Greenlane). 3 beds available. For people over the age of 16 who have severe physical impairments.
- Creative Abilities (Beachaven). 3 beds available. For people over the age of 16 with Autism and severe intellectual impairments.
- The Open Homes Foundation (Howick). For children under 16 with Autism and severe intellectual impairments.
- Need more information? Contact Peter Druskovich at Taikura Trust.

EVENTS

NEEDS ASSESSMENT & SERVICE COORDINATION

HOW CAN FAMILIES & DISABLED PEOPLE BE BETTER INFORMED & GAIN FROM THIS PROCESS?

THURS 22 SEPT
OVER 16 YEARS
7 pm
VENUE: ST COLUMBA CENTRE
40 VERMONT STREET, PONSONBY
For people/caregivers who access NASC and who are over 16 years of age.

WED 28 SEPT
UNDER 16 YEARS
7 pm
VENUE: ST COLUMBA CENTRE
40 VERMONT STREET, PONSONBY
For families who access NASC for children who are under 16 years of age.
Phone PFRC to register. Numbers ltd.

ROCKET DAY
HOSTED BY PARENT & FAMILY RESOURCE CENTRE
SUN 20 NOV
11 am - 1.30 pm
ROCKET PARK, MT. ALBERT

AUSTRALIAN SOCIETY FOR THE STUDY OF INTELLECTUAL DISABILITY CONFERENCE 2005
10 - 13 OCTOBER
WAIPUNA HOTEL & CONFERENCE CENTRE MT WELLINGTON
The New Zealand Branch of the Society is hosting its 40th annual conference. Conference theme: "Out of the Ordinary? Creativity, co-operation, collaboration."
For more information visit
www.assid-conf05.org.nz

RISING TO THE CHALLENGE
WELLINGTON
9 - 10 NOVEMBER
A sumposium to advance state of the art practises in supporting families & young people where behaviour presents as challenging. Register with Standards Plus.
Phone 262 5374

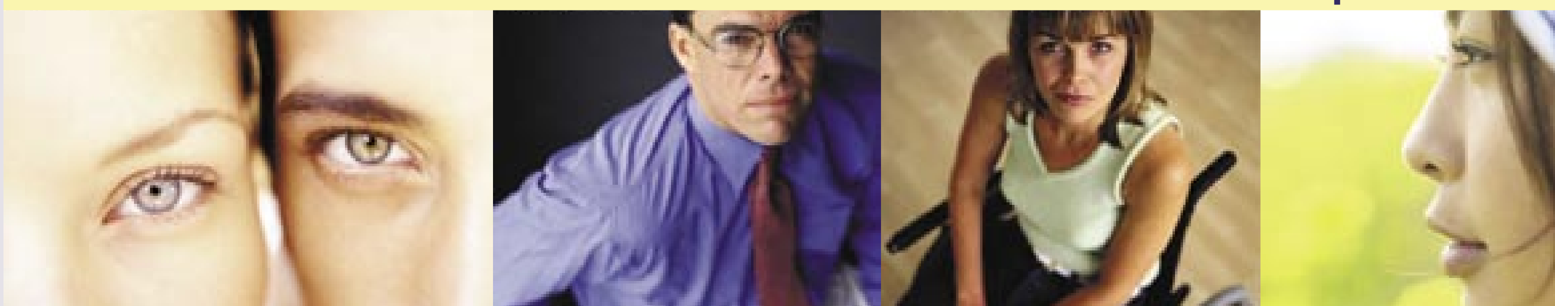
NEXT EDITION: Needs Assessment & Service Co-ordination

Disclaimer
The views and suggestions in this newsletter are those of individual contributors and are not necessarily supported by the Parent and Family Resource Centre Inc. If you find errors in this publication – great, it means you are reading it!

Share your news
Send us your news and views, conference / meeting dates and reports, successes and suggestions, your child's or your own artwork or poetry. Celebrate your world by sharing it with others in the PFRC Networker. Just contact us at the Centre.

NETWORKER

September 2005



THIS ISSUE
- ★ RESPITE Update
- ★ PARENTING Tips
- ★ RACHEL Grows Up
- ★ DISABILITY & SEXUALITY
- ★ NEW TEAM on board
- ★ EVENTS

DISABILITY & SEXUALITY

Acknowledging the Essence of Self

Tammy Ewing takes a look at current issues

"There's nothing like someone being attracted to you" says Claire Ryan, Relationships and Sexuality Advisor at IHC. Such simple words; words that make you smile with their simple truth: This experience of attraction recognises and validates your sexual self – the integration of your physical, emotional, intellectual and social being.

"Sexuality is an integral part of the personality of everyone – man, woman and child. It is a basic human need and an aspect of being human that cannot be separated from other aspects of human life", is the definition offered by the World Health Organisation (WHO).

Likewise, IHC maintains that "relationships and sexuality are a fundamental part of everyone's sense of self and their connection to the world", with sexuality encompassing self-image, self-esteem, relationships and choice-making.

Although sexuality has so many positive connotations, for parents with a child with a disability it can be a topic fraught with anxiety.

Facing those fears

"Some parents can feel nervous talking with their child about sexuality issues," says Kirsty Pillay, an Educator at the Family Planning Association (FPA), which can mean they miss out on acknowledging this part of their child's identity. Whether weighted-down with fatigue or a fear of the unknown, it is easy to slip into the myth that: if we talk about it, they'll want to do it.

Upon unwrapping the topic of sexuality, Philip Patston, entertainer and owner of Diversity Works, says there is "a lot of fear about: What will happen if my child is sexual? – Will they be hurt, abused, or hurt someone?" The good news is that Kirsty Pillay says that research indicates that if young people are educated and informed, "they're more likely to delay first sexual experiences and to use methods to protect themselves from unplanned pregnancy and sexually transmitted infections".

However theoretical information can be very different from the knowledge gained from experience. Kirsty Pillay says, "Parents sometimes have a fear of their child's vulnerability, but it is important to acknowledge that their sexuality is an important part of who they are." Philip Patston (37), who has cerebral palsy, thinks that some parents procrastinate in accepting their child's sexuality, almost believing they hold the reins on their child's sexuality. "But "it's doing it that makes you ready".

Continued on page 2

the new team

Sometimes I just can't resist a challenge and accepting the position, as Manager of PFRC was one of those times. I am excited about the challenges that this new position presents and the enormous opportunities to lead change for families. I bring to this role experience in NASC management, Provider Development, Needs Assessor and Service Co-ordinator. Amongst other experience, I led a parent support organisation for nine years.

You will be aware that there is another change of staffing at PFRC however there are some great seminars planned for the next couple of months and we hope to see you at one of them. The new team is Denise Gledhill (Community Advisor), Karen Nicol (Community Advisor and Admin Support), Shannon Thompson (Receptionist and Admin Support) and Kerin Baker (temp. receptionist). The new team brings a wealth of experience and knowledge and are all committed to upholding the aims of the PFRC and, developing the Centre further.

Bridget Snedden. Manager

Continued from page 1

Explaining further, Philip Patston advises: "All parents are protective, but when the child is disabled you need to "actively let go" whereas in a normal situation it would happen "organically". This process of 'letting go' is all the more difficult when the young person remains heavily reliant on their parents for support, resources and transport.

As parents acknowledge their fears it is important they recognise that their children will have fears of their own, even if they aren't vocalised. Philip Patston knew early on that, "It wasn't going to be the same for me. Would I be attractive? Would I be a burden?" At the same time as exploring his own feelings, Philip Patston was considering what his parents might be feeling: "I always felt there was an assumption that it was going to be more difficult for me to be in a relationship."

In facing these fears, parents also confront the envisaged future they have, consciously or subconsciously, been developing for their child. This illuminating experience can be either uplifting or disheartening for the parent. Although Philip Patston didn't live in accordance with his parent's vision, "it was great that they had a vision for me, because lots of parents don't have a vision".

Changing philosophies

In the past the philosophy was about "care" not "support", says Claire Ryan, Relationships and Sexuality Advisor (IHC), and has been working in the disability sector for about 20 years. "It was about containing people; about living in a nice home with nice meals." Philip Patston agrees that disabled people were, and sometimes still are, seen as eternal children.

The new philosophy is about "teaching about self-esteem and sexuality intertwined", says Kirsty Pillay, as both contribute to feeling good about yourself. After a process of consultation, IHC put together a Relationships and Sexuality Policy.

The policy illuminates ways in which professionals can understand and support an individual's needs, including privacy, education, establishing relationships and self-growth.

Increasingly parents are wondering what underlies their child's behaviour – disability or adolescence. Under the new philosophy, parents are placed in the precarious position of managing difficult behaviours, such as masturbation in public, as well as taking on a parental obligation to give positive messages about sexuality.

Addressing safety issues

In order to teach their child about being safe with their body, parents need to show respect for their child's body. Personal or intimate care is an area where mixed messages can easily arise.

> "Your sex life is not as hidden."

The focus on giving "care" needs to be alongside an acknowledgement and respect that their child is going through puberty, advises Kirsty Pillay. She advocates for openness, such as, "respecting an individual's body and explaining and asking before touching."

Likewise Claire Ryan stresses the need for disabled young people to have control over their bodies. "If you're showering someone and they're naked and you're not, there's a huge power difference". She points to the paradox of the stereotypical "Pleasure Police, who stop people wanting to be sexual and yet will invade their bodies in other ways."

Parents of a child with a disability are right to be overly protective – it's a well-known fact that people with a disability are more likely to be sexually abused, says John Hibbs, a sexuality educator and counsellor. The responsibility of parents is even greater when it's considered that many parents may be involved as carers far into their children's adulthoods. "Mum and dad will often know about their child's sexuality for the rest of their lives", says Claire Ryan.

"Your sex life is not as hidden," agrees Philip Patston. For example, if the parents are the chauffeurs and event organisers, it can be difficult for a teenager with a disability to develop a life that is private and separate. More importantly, a lack of close friendships can lead to parents becoming the foremost confidantes on personal and sexual issues.

One way of protecting a daughter from pregnancy is through contraceptive methods, such as tubal ligation or a contraceptive pill or injection. Dr Christine Roke, National Medical Advisor (FPA), says it would be usual to expect to try medical means of contraception before the decision for sterilization.

However the choice for contraception, while ostensibly about preventing pregnancy, can also be about caregiver convenience, says Claire Ryan. Periods and erratic mood shifts can be difficult for a stressed parent, and similarly distressing

A mother positive about the future

When Jackie Vallance glimpsed her 14 year-old daughter absorbed with applying lip gloss in front of the mirror, she felt happy and reassured – Rachel was growing up.

Rachel's bedroom is one of marked contrasts – dolls lovingly tucked up with bedcovers on the floor and posters of The Lord of the Rings' stars and the Olsen twins on the walls.

Jackie's efforts to ensure Rachel has a positive self-image have paid off. By encouraging Rachel to choose her own clothes and take responsibility for herself, Rachel has become self-confident, socialises well in diverse settings, and "believes she's good at everything".

Underlying Jackie's motives is a belief that "if you have a positive self-image, you're not making unsafe choices". Because Rachel has Down Syndrome, which makes her characteristically friendly and eager to please, Jackie does worry about the risk of her being sexually abused.

However she has the same vision for Rachel as for her older sister – "eventually a sexual relationship, get married…" To begin with, Jackie plans to cultivate potential relationships in the Down Syndrome community – "they will have things in common" - , through such subtle means as regularly visiting family friends with teenage sons.

Whether or not Rachel has a relationship with someone with a disability, Jackie believes a strong relationship will form between the two families as well. Rachel will need support over the years, acknowledges Jackie, but her future will be influenced by attitudes today – "It's all about what you expect".

"sexuality is the last bastion of acceptance"

Quote by Philip Patson pictured to right

for a young person with a disability, particularly if compounded with incontinence or an intellectual disability. In Christine Roke's limited experience with young people with a disability, the choice for a hysterectomy is about "both managing menstrual hygiene and preventing pregnancy" and is not used for contraception alone.

Many adult women with an intellectual disability have had hysterectomies, acknowledges Claire Ryan. Anecdotal evidence indicates that sterilization is given much more consideration than in the past. It is being acknowledged that, not only is it difficult for any parent to predict how their teenager will develop and what their capabilities as an adult will be, sterilization could be seen to contravene their child's rights.

Sexuality and rights

Young people have legal rights concerning access to information, behaviour and medical treatment. The Contraception, Sterilisation and Abortion Act (1977) allows for young people under the age of 16 to be given contraceptive information, services and prescriptions. Objective 9.1 of the New Zealand Disability Strategy expands on this, stating: "Support disabled people in making their own choices about their relationships, sexuality and reproductive potential."

The Care of Children Act provides for people over 16 to consent to their own medical treatment. This is then negated by the Contraception, Sterilisation and Abortion Act, which gives the authority to a parent or guardian of a female to, "if that female is mentally subnormal and it is considered in the best interest of the female to do so, administer any contraceptive to that female". The same notion that there can never be 'informed consent' allows parents to make the decision for sterilization.

Agencies, such as IHC, are keen to promote widely-accepted rights of disabled people. Rights discussed in their Relationships and Sexuality Policy include, "All people have the right to make their own decisions about their bodies"; "Everyone has the right to develop relationships and to determine the nature of these relationships" and "All people have the right to express their sexual feelings".

More controversial is the idea that disabled people have a right to state-subsidised sexual services. This is based on the premise that sexuality (and the act of sexual intercourse) is a basic human need, as defined by WHO. Currently there is no overt subsidy of the services of prostitutes. However the New Zealand Prostitutes Collective liaises with disability agencies, such as IHC, and is able to recommend prostitutes trained in disability issues.

Sex Education in Schools

Sex education is part of the Health and Physical Education curriculum, which is compulsory up to year 10. Schools have loose guidelines on what material is to be included and parents are able to ask that their children be excluded from sex education classes. The fundamental issue is ensuring that the content is suitable for young people with a disability.

Kirsty Pillay gets many calls from schools and parents, primarily concerned about ensuring that young people with a learning or intellectual disability can understand what is being taught. To simplify concepts, Kirsty Pillay uses dolls and visual materials to support teaching topics such as, "Good touch, bad touch", "Personal safety and boundaries", "Safer relationships" and "Public and private places and behaviours".

With increased mainstreaming, sex education has largely become normalised to young people with a disability. Parental attitudes, on the other hand, are very diverse. John Hibbs describes parents as being along a vast continuum, "from relaxed to very uncomfortable". In this way, the school environment, with its opportunities to socialise with peers, is an ideal setting to learn about sexuality.

"Friends and peers play a large role in the messages and learning a young person receives about sexuality and relationship issues", says Kirsty Pillay. "They make meaning together." Similarly Claire Ryan says, "Young people need to talk with their peer group – not just mum and dad". She believes there is not enough "natural forming of friendships" and that bigger peer networks are needed, particularly in secondary school.

> "Friends & peers play a large role in the messages & learning a young person receives about sexuality."

Body image

When asked what fashion differences might typically be observed between adolescents in a special unit and adolescents in a mainstream class, Claire Ryan admits that the students with a disability would likely be less 'cool-looking'.

Continued on page 4

10 Tips for Parents

1. Encourage your child to talk about feelings and express themselves
2. Use your own diverse relationships to positively model how to relate to others
3. Puberty can begin early – make sure your child is prepared for bodily changes
4. Make the most of any opportunity to talk about sexuality issues, for example when watching TV, and answer questions openly and honestly
5. Find out what sexuality education the school is providing and support it at home
6. Try to avoid giving out negative ideas of sexuality, even in the tone of your voice
7. Teach your child that they 'own' their body, and only they can decide who touches it
8. Encourage your child to make decisions and take responsibility for themselves
9. Use regular strategies to build your child's self-esteem and support them to develop a positive body image
10. Remember that teaching your child about sexuality is not a one-off discussion – it's a life-long journey!