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Doing the Wild Thing: Supporting an Ordinary Sexual Life for People with Intellectual Disabilities

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Abstract

For many people who are called disabled, having this label means to be excluded from the experience of 'an ordinary sexual life'. For those who are called intellectually disabled exclusion from experiences of any kind of positive sexual life is almost universal. This article explores how some people with intellectual disabilities have sought to open up pathways towards accessing experiences of sexual expression as a way to move forward towards being able to integrate a concept of sexuality into their lives. Two support workers are interviewed. Both are employed by a Human Services organization in Aotearoa, New Zealand, which provides long term support for people with intellectual disabilities. Their comments reveal that access to successful instances of sexual expression for people in this group are currently only available those who are articulate enough and persistent enough to keep trying until they succeed. Barriers to success are isolated and some wider issues surrounding what changes might positively affect this group are discussed.

INTRODUCTION

Recognition that issues of sexuality, sexual expression, love and desire are integral to the physical, emotional and spiritual well-being of the lives of people with disabilities has been slow to get to the top of political and social agendas. In the lives of people with intellectual disabilities, these issues still struggle for positive formal recognition of any kind in Aotearoa/New Zealand.

The reason for this is not that these two groups have no wish for active and positive growth and development in these areas. Disability advocates have strongly indicated (Shakespeare 2000) what academic research has also found, that all disabled people who are able to contribute to this discussion report wanting and needing to experience dating, intimacy and sexual interaction. What they lack are the opportunities, social skills and the self-esteem to actively pursue these options.

People with disabilities generally do not access information about sexuality from the same sources as most of the general population. Whereas most within this population receive information from parents, friends and other sources, people with disabilities are most likely to receive information about sexuality from other sources only (McCabe 1999). Findings in academic literature make it clear that people with intellectual disabilities have lower levels of sexual experience than people with disabilities who, in turn, experience lower levels of sexual experience than people from the general population (McCabe 1999).

Formal sexuality education for people with intellectual disabilities continues to focus on biological issues at the expense of socio/cultural factors (Brown 1994) despite challenges that many of the issues connected with sexuality and sexual expression are not just issues of sexual functioning, but are issues deeply imbedded in those of a more complex psycho-sexual nature (Jacobson 2000).

For all disability groups the inclusion of desire in sexuality education curricula remains controversial (Tepper 2000) and it is particularly hard to access formal evaluations of educational courses that contain this and other important elements. As Davies (2000) remarks, formal research into providing sexuality education covering effective cruising and flirting strategies for people with disabilities have yet to be developed. However, difficulties involving the level of risk-taking necessary to be able to deliver this kind of educational programme for people with intellectual disabilities means that much valuable work may well have been "...stifled for fear of repercussions and controversy..." (Mellan 2001).

People with intellectual disabilities and very high support needs are often denied even access to any formal sexuality training offered. Thus, this group lacks not only the opportunity and social skills to engage in meaningful sexual experience, but the basic information about how to do it as well. As McCabe remarks "These findings clearly need further exploration to determine why this situation exists..." (2001:168). Much of the small amount of innovative educational work started in response to findings such as these is reported as having been done for and by gay men in response to the challenge presented by HIV/AIDS (Thompson 2001). Education relating to sexuality for lesbian women with intellectual disabilities remains almost non-existent (McCarthy 2001:16).

These findings need to be set alongside more disturbing reports that note the concerns expressed by many parents, care-givers and support people connected with people with intellectual disabilities about an extremely high level of heterosexually and homosexually abusive activity found amongst at least some people in this group (Thompson 2001).

For people termed 'non-disabled', issues of gender permeate all experiences of sexuality and sexual expression and what is viewed as 'appropriate' behaviour filters through these lenses. Being viewed as 'disabled' interrupts this dynamic. Gender is subsumed under disability and gender issues are experienced through the context of disability (Tepper 1999). However this filter does not entirely preclude people with intellectual disabilities being subject to dominant discourses about sexuality in positions where their sexual 'need' is recognised. That these discourses prioritise culturally stereotypic notions of 'masculine' and 'feminine' sexual responses has been noted (Chivers and Mathieson 2000). However, at a deeper level, the lack of perceived right to a sexual life accorded by the wider community to this group renders problematic how even stereotypically driven representations might be actioned. In addition it may also enable any community obligation to provide what 'appropriate' behaviour entitlement for males and females might allow for, to languish (Fiduccia 1999).

This lack of right also enables the space for negative community attitudes to influence assessments of what might be possible, sexually, for people with disabilities and, in particular, assessments about sexual possibilities for people with intellectual disabilities. Of all the problems this group encounters in their dealings with the wider community, negative attitudes towards their emotional and sexual needs are probably the most widely entrenched and the least likely to be the subject of overt discussion (Katz, Shemesh and Bizman 2000). This group's close family members often share these wider community attitudes (Schwier and Hingsburger 2000).

Thus, at one level people with disabilities are treated as if they were asexual (Shakespeare 2000), yet at another attempts by member of this group to express individual sexualities are often treated with either amusement or anxiety by support staff. The relationship between adults with intellectual disabilities and support people has not been extensively researched (Ramcharan and Grant 2001:352). Existing studies suggest that these relationships are often complex, involving more than just physical or practical care and support. In addition they can take on a particular importance for those who are supported. Support people can play a central role in the lives of the people with intellectual disabilities who may have few other close emotional relationships (Mattison and Pistrang 2000). The boundaries of these relationships may not always be clear to either party and each may have a different interpretation of it.

In individual cases, where the issue of sexuality is taken seriously, having to establish the capacity to be able to consent to an action of sexual expression faces a significant proportion of people with intellectually disabilities. Kennedy and Neiderbuhl (2001) isolate eight criteria that are considered 'absolutely necessary' to ensure that the ability to give a decision based on informed consent to an action of sexual expression is present.

The individual can say or demonstrate 'no'; when given options an individual can make an informed choice; an individual knows that having sexual relations can result in obtaining a disease; an individual can differentiate between appropriate and inappropriate times and places to engage in intimate relations; an individual can differentiate between a male and a female; an individual can recognise individuals or situations which might constitute a threat to h/er; an individual will stop a behaviour if another person tells h/er 'no' (Kennedy et al. 2001: 506).

Often issues facing people who are severely or profoundly disabled and unable to communicate easily are left out of theoretical discussions and their support needs in this area remain unmet (Paparestis 2001). It has been suggested that caregivers and well meaning professionals can often inadvertently end up creating 'prisons of protection' (Koller 2000:25) rather than creating environments to promote empowerment for people with intellectual disabilities who need high levels of support. For this group, the criteria for establishing consent itself can become an insurmountable barrier. Yet if the potential for enhancing the sexual experiences of this group remains in the too hard basket, the risk is left open that any person with an intellectual disability might fall into the position of playing "...hostage to the needs dictated by a wider principled consensus..." (Ramcharan et al. 2001:357).

Perhaps this is not as much a risk that might happen as what, in everyday life, does happen. As Brown (1994) points out, those who constitute the 'wider principled consensus' may not be so keen to engage in actively supporting people with intellectual disabilities in even stereotypic sexual roles. Thus, beneath the rhetoric of empowerment and inclusion that surrounds this group, is there a deeper recognition that access to an ordinary sexual life for all but a select few of those with an intellectual disability, is to remain firmly off limits? This article provides the space to begin to explore some aspects of this question.

INTERVIEW METHODOLOGY

Two people who work for a human services organization who support people with an intellectual disability in a wide variety of residential and vocational settings were interviewed. Many of the People Who use Services (PWS)[1] this organization supports live in group homes consisting of between three and five residents. Many PWS have histories of living in isolation from ordinary community services and activities through prior experiences of large-scale institutional care. Others have come from family homes with a history of attendance at schools and vocational settings largely segregated from access to wider community venues.

One of the interviewees is employed as an advocate working with PWS who are involved in the self-advocacy movement, People First. The other is employed by the human services organization as a sexuality trainer. This position involves facilitating workshops for support people as well as working directly with groups and individual PWS in the sexuality support area. Both interviewees have prior experience as key support workers for a person with intellectual disabilities.

In Aotearoa/New Zealand support services for PWS are very small by international standards. The interviewees have been chosen because they are unique in this country in the support positions they hold. These interviewees were also chosen to address the problem connected with the validity of proxy responses that might be given by parents or close caregivers (Hensel: 2001). Although closely connected to the lives of people with disabilities, neither of the two interviewees are currently employed as support persons. Nor are the interviewees either family members of, or caregivers for, a person with an Intellectual disability.

Utilising conventional research methodologies has proven difficult to implement with some people with intellectual disabilities. Carrying out interviews with individual members of this group without support is not always possible. It has sometimes been necessary to rely on reports from carers and relatives to compile data. However this way forward has been seen to hold more promise for objective rather than subjective indicators (McCabe 2001:318). Issues of sexuality and sexual expression are as much subjective as they are objective. The interviewees chosen also represent an acknowledgment that to canvas the views of users of support service who are intellectually disabled in isolation may run the risk of failing to tease out the complexities of interactions among the support people who are an integral part of the physical, social and economic well being of this group (Ramcharan et al. 2001).

Following a postmodern approach (Sarup 1989), both interviewees are positioned so as to be able to comment, subjectively, on the influence of families, service structures and communities on PWS experiences in this area. As such they are interviewed as journalistic 'reporters' (Ramcharan et al. 2001:351), although not unbiased, of the incidents and experiences which contribute to the complexity of the quest PWS face for ongoing and satisfying experiences of sexual expression. The data is written up so as to include as much of their 'reportage' as possible.

Question Areas

Interviewees were asked to comment on trigger questions based on aspects of their observations of the sexual lives of PWS. These aspects include PWS' successful access to pathways towards experiences of sexuality and sexual expression; barriers that might have impeded PWS from gaining access to experiences of sexuality and sexual expression and information that PWS are given about sexuality and sexual expression. To conclude the interview, interviewees were asked to comment on what they saw as future possibilities for PWS in this area.

ANALYSIS

Access to Experiences of Sexuality/Sexual Expression

Interviewees' responses to questions revealed that pathways open to PWS to access experiences of sexuality and sexual expression remain difficult to access. However, both interviewees were able to recall the following examples of cases where these issues had at least reached discussion point.

Example 1

In this example Jane[2] describes a series of events she became involved in while supporting a PWS in his residential home.

Jane "...there was a man I used to support and he decided he wanted to have a sexual relationship with his girlfriend and they came to me for advice on how to do that....and at the time his family were really against it so I had to try and work with him, and with the family...because the parents wanted to withdraw him from services if he was supported to have a sexual relationship. They believed that he wasn't responsible enough to, well they thought that there shouldn't be sex outside of marriage, so he said oh well I want to marry...and they said he wasn't responsible enough to be married so that was sort of it... Later he and his girlfriend came to me and said, we had sex... (pause) ...and I'm like did you use a condom and they said no we don't know what a condom is. So I ended up getting a condom and a carrot and showing them how to put the condom on the carrot, then he told me afterwards that they hadn't had sex, he just wanted to know how to use the condom..."

Jane did not know what further outcomes developed in this case as she moved away from this residential service shortly afterwards.

As this example shows, although the couple mentioned had yet to achieve physical intimacy by the time Jane left the home, it is possible to imagine that this could become a realistic option for them in a not too distant future. However it seems very likely that support workers, organizational managers and family members would not know about it. It is also possible that if the two PWS had known how to use a condom in the first place, this relationship may not have come to the attention of family members or organizational staff so quickly.

Example 2

Mary cited this example from an area of work she was currently involved in.

Mary "...an older man um...who is in the process of coming out. He's very definite, and he has a very good understanding about what being gay is all about. His mother told him that he wasn't gay and so he proved her just now non-gay he could be. He had sex with a woman that he works with. After he had done that he dialed the emergency services...(111)...and said that they had to come quick because he'd just done something he shouldn't have. And he was just in complete turmoil...but he has been so persistent with that, that what's happening for him now is that the staff are supporting him to be able to come out as a gay man ... "

Currently support is ongoing for this person.

As Example 2 shows, a physical expression of sexuality was achieved, yet the circumstances surrounding this incident empowered neither the PWS discussed or the other PWS involved. Although information about how to achieve sexual expression must have been known to the PWS, it is very hard to view this encounter as the end result of an independent choosing of his own pathway to sexual expression through a negotiation of consensual sex with a partner. It is equally as hard to view this encounter as a positive avenue for the other person involved. However this experience was pivotal in opening up avenues of support towards experiences of the kind of sexual expression that the PWS did want to pursue. No comment was made about what the outcome for the other person was nor about the level of ongoing support offered to her.

Example 3

In a different support context, Jane recalled the case of two PWS who were offered the opportunity of a sexual relationship with each other at their local day service.

Jane: "...and it had a couch that was used by a couple and people there knew about it and shut the door and let this couple use that room because they weren't allowed to do it at home or anywhere else. That was the family that said so...so they used to go to the daybase... "

I: "...did everyone at the daybase support that or? ..."

Jane: "...I'm not sure if everyone knew what was going on. I know both the CSW's (community support workers) there did, and I know they ended up getting told that it wasn't acceptable because it wasn't the appropriate place for that to happen...because it was a day service and people should get a motel basically if they really had that need..."

Jane didn't know whether the suggestion of a motel room had been actioned or not.

Example 3 indicates that physical intimacy had been achieved by the couple and the support by at least one support person surrounding these two PWS gives some hope that they will be able to find another venue to further the physical aspect of their relationship. Whether consideration of other venues would include either of the two people's own homes remains unclear as does the commitment by organizational management to work towards changing the attitude of family members. Having management backing would help a more formal recognition of the nature of the couple's relationship to become an aspect of service delivery for these two PWS. However there was a reflection about the presence of a biological need, which might keep open possible pathways for this couple in the future.

Example 4

This example was connected to a problem that had arisen in the residential home Jane was working at. Concern had been raised about the sexualised elements of a PWS's behaviour, which had been taking place outside his house.

Jane: "...a young guy I used to support used to take his penis out and play with it on the trampoline...he found it difficult to have relationships with people... he had echolalia...but he obviously had a sex drive...so his mother ended up at a lifestyle planning meeting and said OK what are we going to do about sex for him? Shall we be hiring a sex worker or is someone here comfortable with teaching him how to masturbate? ..."

No direct action was taken as a result of the outcome of this meeting.

Example 4 reveals what might be possible with the positive input of a key family member. In this case the issue stalled over the necessity for this PWS to be shown how to masturbate, an organizational issue rather than a family matter. At this point in the interview Jane started to talk about another aspect of the topic. She was later asked if she could remember anything that had happened as a result of the meeting she had described. She could not remember any details but said that the idea that another service user the young man had been able to form an emotional bond with might become a potential future partner for this person was raised. No more direct action was explored.

Example 5

Another instance involved a support worker facilitating access to an experience of sexual expression for a PWS.

Jane: "... I know of one case where a house account was used to pay for a sex worker for somebody...and the particular staff person lost their job over it because it was seen as an inappropriate use of (organizational) funds..."

I: "...and that telling came from..."

Jane "...their CSM (the support worker's manager)."

Here the example reveals that the involvement of a sex worker can be utilised to provide a supportive role and offers a clear possible avenue towards a means of sexual expression for some PWS. However it remains open to question as to whether what prompted the support worker to take the action he did was addressed or solved. Did the action taken produce the results the support worker thought it might? Did the PWS gain any useful knowledge that he might have been able to use later on to form a more intimate relationship? This example also shows what can happen to support workers who become involved in this area of support without organizational approval.

Sexual 'Success' - What It Takes to Get You There

Mary "...so the pathway is really, really limited... if you can go and access it yourself...then it'll work... If you are someone who doesn't communicate verbally and you have a significant disability...(pause)... then your pathway's shot..."

As all the examples outlined show, PWS who become successful in this area are likely to be ambulant, articulate and knowledgeable. Successful PWS need to possess a large degree of resourcefulness and possibly be prepared to exhibit a certain amount of antisocial and what might be seen as underhanded behaviour to achieve their aims. Being able to talk about the possibility of marriage is a useful tactic to employ as is to talk about the possibilities of becoming involved in a gay relationship. Having information about how to have sex is a key element underpinning success as is the courage to withstand negative responses from close family members and from organizational staff.

Conducive support surroundings are also extremely important. Having access to a private place away from public scrutiny is a vital ingredient in the quest for a successful long-term outcome. Success in many cases will also require the active involvement of at least one support person who may have to be prepared to risk their job to assist the process. While behaviours termed antisocial, yet which clearly express sexual 'need', are viable routes, these behaviours are best displayed within an environment where the idea of sexual 'need' is already established.

Thus to be sexually successful it is useful to be male, young, and perhaps to be pursuing a gay lifestyle. As well as these criteria having access to a partner, who may or may not be willing, and who will possibly be a sex worker enhances probable success. And, as all the examples reveal, the kinds of access strategies that produce successful results call for displays of persistence and determination by three key agents - PWS, support people and family members.

BARRIERS TO ACCESS/SUCCESS

1) Socio/Environmental Barriers

Living in a supported service environment was commented on by both interviewees as constituting a major barrier to PWS engaging in any kind of sexual expression and establishing sexual relationships.

For the majority of young New Zealanders, rites of passage from adolescence to adulthood involve leaving the family home and going flatting. For the non-disabled, flatting offers the opportunity to experience freedom from family constraints, to take on a more adult role and develop an intimate couple bond away from the scrutiny of family and friends. Opportunities to form and deepen intimate relationships become more possible at this time. When PWS enter a supported residential home these opportunities are very rarely made available.

Mary: " ... there really isn't a pathway that is followed, its not part of our service provision... We support people to do the basic needs things of eating and drinking or keeping warm and we put the sexuality stuff...separate to what we're supposed to do... "

Sometimes even the creation of opportunities for couples of any sort to meet socially can become a logistical nightmare.

Mary: "...like if you want to ask someone out? ... how do you reach date night? Book? ... Well, like I'll pick you up about seven in a transit van and they'll be six of us and we'll need to be back by nine because it's staff changeover..."

In the event of this dating hurdle being overcome, bedroom environments are not set up to encourage the building of intimate relationships. For Mary, this drawback represented more than just an inconvenience for PWS.

Mary: "...I think people are incarcerated... it's really basic stuff like people having to sleep in single beds so your ...(pause)...and its not even about having sex so much as it is about being an adult and even the word single bed, you know, gives you again the sentence to be single..."

Status descriptions ascribing socio/sexuality status to individuals are not widely used in the service organization. When descriptors are used by support people to identify work areas, they are usually based on perceptions of biological sexual qualities, often highlighting biological gender when the gender is male.

Mary: "...they don't even make it onto the label of spinster or bachelor. Don't even make it to that. That's how sort of asexualised they are. We never refer to any of the services that we have where all men live. We never say I work with a group of bachelors or a group of single guys... its like, I work in a male house or group full of males, or I've got five...or I've got two that I look after..."

Displays of behaviour within residential setting which are viewed as sexually driven are deemed 'inappropriate' and treated as a matter for specialist behavioural intervention.

Mary: "...you can't come home and take your clothes off and watch TV and fiddle with your bits... that results in an incident report and, you know, that sort of carry on. There's just not the freedom to be who you want to be. And I think that we use the word appropriate and inappropriate far too much... "

I: "What do those words mean to you?"

Mary: "...when I hear inappropriate, it means that someone's having a good time and we're trying to stop it! ....if it's appropriate then it's something quite out of the ordinary that none of us would ever do because we'd find it incredibly boring ...(laughs).

2) Support Person Barriers

All the examples noted show that support people are central to PWS ability to successfully access pathways to any kind of sexual expression, yet working within this supportive role can be extraordinarily difficult.

Jane: "...in the case with the guy (Example 1) if he and his girlfriend went and had sex and she got pregnant or whatever... the family would have been on me like you wouldn't believe, and probably my manager as well..."

As well as having to juggle family and organizational concerns, having to note incidents of sexualised behaviour in incident reports must detract from the possibility of support people being able to give positive feedback to PSW about their aspirations in this area. From the perspective of the PWS, what might be seen as policing of behaviour must affect judgements about how trustworthy with personal information support people are capable of being.

Individual personal belief systems can either enhance or inhibit how far support people are able, or willing, to go.

Jane: "...I can think of a person that I know and he is gay, and he wanted to explore his sexuality ...one support person was saying that she was not willing to support him, for it was against her beliefs...and another support person went and got him the phone number of the gay hotline, and helped him to ring it..."

As both interviewees note, the position of key support person continues to be characterised by a lack of influence and power to bring about positive outcomes for PWS in this area. Actions support people might want to take can be compromised through fear of promotional compromise or job loss.

Mary: "...and then they have the organization saying hey you need to behave as a paid employee, ...so it's the agency that you tend to respond to. Then you can't be a pure advocate for someone ...and say well I'll support you in your decision absolutely because I know I won't, cause I've got a mortgage..."

Both interviewees also mentioned anxiety over repercussions as constraining levels of support when support people lacked the organizational power of a senior management role themselves or lacked access to this power through the support of a sympathetic manager.

3) Family Member Barriers

Mary: "...I can't think of how people have gone out and overcome most of the barriers other than taking the risk of loosing their family... and people have lost family connections because they've wanted to get married..."

Lack of support from key family members creates almost insurmountable difficulties for PWS who would like to have an ongoing sexual life. The examples given uncover how influential family members are in the lives of the PWS, in the support positions of those who work with them, and to the running the organization as a whole. Where the examples given do not present a family member's point of view the assumption that no close family members retains contact with the PWS concerned is easy to make. On the other hand the family may have already cut off contact with their family member as a result of their persistence with this issue. Both positions are a reality for some PWS who live in residential homes.

Although not directly spoken about by either interviewee, it can also be assumed that negative messages from family members must be one of the hardest emotional barriers for any PWS to overcome. This is exemplified by the case outlined in Example Two.

Mary: "...for him to function as he wants to be, he needs to identify with being gay and to have this man sitting in front of me crying when I said to him well what do you want to have happen in your life, he just sobbed and said I just want to be a gay man..."

For some older PWS who do not seem interested in wanting an active sexual life, the reality may be that they have accepted that it is just not worth the effort to begin to access pathways towards sexual expression because of this emotional pressure.

However not all family members will display negative responses in all cases.

Jane: "...the two examples I gave you (Examples #1, #4) that was the same house I worked in but here was one family saying there's to be no information...and another parent saying how do we do this? ... "

Yet it is noteworthy that where the positive and affirming support was offered, the PWS was a young man.

Negativity expressed by parents in the examples outlined lead to the conclusion that most of the positive messages the PWS in the examples shown had received about issues of sexuality and sexual expression which had enabled them to keep moving forward came from sources other than close family members.

ACCESSING INFORMATION

Both interviewees reported that PWS they knew about were able to gain access to information about issues of sexuality and sexual expression.

Mary: "...Yeah basic stuff about people having knowledge about where everything is and how it looks and those sorts of things..."

In the opinion of the interviewees, access to information relied on a number of things including parental consent to their son or daughter attending sessions. What PWS might have learned from educational sessions they attended was difficult for one of the interviewees to comment on.

Jane: "...I think it (the educational session) showed photos of genitalia. Is that how you say it? You know, photos of..."

I: "...Of sexual organs?"

Jane: "Yeah, and what's good touching and bad touching..."

This information could certainly provide a useful starting point for discussion, yet it is hard to envisage how an educative programme that ends at the point of good and bad touching would enable anyone to become knowledgeable about the interplay of physical and social intimacies that captures the diversity of human sexual responses. It is also hard to think about how being shown pictures of sexual organs might possibly make any PWS eager to proceed on to any experimental stages.

For Mary it remained unclear how much PWS might have been able to gain from some of these educational sessions.

Mary: "...Women have thought that they have had hen's eggs inside them. You know, you've talked about your eggs do this, and your eggs do that, well we've just assumed that people have understood..."

Information such as this should also only provide a starting off point. For Mary the need for hands on experiences was also seen as vital.

Mary: "...people have to do kind of inappropriate things to get what they want. So they have to grab a support person's breasts because they haven't felt one before and they look bloody good and it's a shame that they have to do that to support people. There should be a whole range of breasts that they can grab. Appropriately, with a lover..."

Sessions which start to explore the complexities of intersections between disability and sexuality are also seen as fundamental.

Mary: "...how to function and be an individual ... how to be really comfortable with your skin ...a lot of people haven't seen their bodies in a mirror and yet they're supposed to keep these things safe...I guess a whole lot of stuff around self esteem and celebrating your gender and identity. What you like about your masculinity and what you like about your femininity... the whole concept of beauty is not embraced in disability...the affirmation and the, the absolute exhilaration that can happen when you fall in love with someone. It would be terrible to go through life and not to have had that experience..."

For Jane educational issues would involve not only educating the PWS but the organization, the family and the wider community as well.

Jane: "...not just PWS's but other people in their lives ...and resources as well. There needs to be resources available, plain English stuff, pictorial, accessible information, and the education to try and help facilitate that change of attitude out there in the wider community, and in our organization...and the family need support to begin to accept the decision than their son or daughter may want to.... you know what I mean. Yeah."

GOING BEYOND THE BARRIERS

Given the difficulties these two interviews uncover, it is possible to offer some suggestions about what might need to change in order to look beyond the constraints currently inhibiting the PWS ability to actively explore issues of sexuality through practices of sexual expression.

Changing Environments/Changing Attitudes

Private places should be made available in residential homes for people who live in them who want to be in couple relationships. However this change would require an attitudinal shift on the part of the support organization and family members as much as an environmental change within residential homes. Jane cited the example of another couple

Jane: "...who were caught in a public toilet at a Polytechnic. Again because they had nowhere else to go to have sex, so they found their own private place where they had a door to shut..."

Although it might be difficult for some to understand how a public toilet in an educational institution might be viewed as a private place, perhaps having a door to shut that gave some guarantee of remaining shut lead to a feeling of security that was not available to this couple anywhere else.

Later on in the interview Jane discussed a case study that had been prepared by a senior member of the organization to facilitate a group discussion about this issue at a committee meeting of the national governing body of the organization. This governing body comprises senior organizational members, representatives of parental groups and PWS representatives.

Jane: "...at the discussion group the National Committee had about sexuality they were given some case studies...and one of them was that there were two PWS's who were caught in the bathroom engaging in sexual behaviour.... What should the CSW (Community Support Worker) do? Should they tell the parents or whatever? ...and the six People First (National Self-Advocacy group) presidents sat down and they went through the case study and one of them said "well, what was the staff doing in the bathroom anyway?" ... This guy was quite upset...he said if the staff came in while I was in the bathroom and having sex and broke it up, I'd be very upset...and they went back to the National Council and said 'we want to know what the staff were doing there in the first place'... And I thought good on you, yeah...(laughs)..."

Educational Programmes

More innovative education programmes for this group need to be developed, implemented and evaluated. As well as being information gathering sessions about biological issues, these programmes should also be slanted towards the development of individual socio/sexual skills . This kind of educational experience is vitally important for some PWS as using the resource of responses of family members or the wider community as a means of education into what are deemed 'appropriate' socio/sexual responses cannot be relied on.

For Jane, the barriers facing PWS who would like to access information from outside of the organization was a particularly strongly felt issue.

Jane: "...the attitudes of health professionals... when I would support people to go to the doctor, often doctors really didn't understand Intellectual Disability, they would talk to me and leave the person out...I even once got told I didn't need to bring this particular man... that's just archaic..."

Her support of the young man used in Example #3 also points to the lack of possibilities for some PWS to be able to capitalise on the presence of family, friends and the wider community as an educational reinforcer of appropriate behaviour in this area.

Jane: "...He didn't realise...he hadn't picked up all the social cues throughout his life, that that's something you do in private, whereas maybe people without an intellectual disability ...might pick up on cues of people looking a bit odd if you touch yourself there, some of the people might not pick up on that stuff and might not always be told directly until it happens..."

Through these educational programmes it might become possible to assist some PWS to become teachers for other PWS who are signaling that they want an avenue for sexual release, yet for whom too much anxiety and stress would accompany going to unfamiliar places and being intimate with people who are strangers to them.

Sex Workers

Formal access to sex workers needs to become a clear option available to all PWS. For those with severe and profound disabilities this move represents their best hope of access to assisted sexual expression in the near future. Currently the debate surrounding this issue is on going and vigorous, particularly in relation to the involvement of workers in the sex industry to enable PWS to gain hands on experiences. However this initiative has some drawbacks.

Mary: "...in terms of solutions for people, I think probably we would support men going along to a sex surrogate ...its not something we would look at for a woman."

I: "...it's probably the most contentious issue at the moment. Is it?"

Mary: "...Yeah it is and probably the most tragic ones too. I mean it would be exciting to pay to have sex outside of own relationship...(laughter)... It adds a different dynamic to it but if that's all you ever have to do... one group I worked with, the staff were all for this man going along to a sex worker on a regular basis to have an orgasm... Yet when we talked about applying for funding for him to get a friend they all thought that that was really mean. To pay to get a friend. I think both options are quite mean really...."

Supporting Support Staff

It is clear from the comments the two interviewees made that support people working alongside PWS do not receive enough support themselves to be able to function effectively in this aspect of their role.

Jane: "...(about the experience of the PWS in Example 1)"... my personal belief was that hang on, this guy is 28, I had absolutely no doubt in my mind whatsoever that...it was consensual, but I was told that I needed to just hold off until the parent situation got sorted out. So that went against my beliefs...."

The lack of any coherent organizational policy[3] makes the task of supporting PWS in this area no easier.

Jane: "...When I talk about a policy and procedure that sounds so sterile...(laughs).... But what I mean is guidelines as a CSW (Community Support Worker) so that...when a situation like that comes up you know really clearly what your role is...this is what I'm saying..."

However neither policy statements nor service guidelines may fully address some of the more difficult to isolate emotional dimensions support work in this area can raise.

Mary: "...I can see how people with disabilities fall in love with us, because we don't have disabilities. We are always positive, we can drive cars, we can get money out of a wall...we can do a whole lot of stuff. We're an attractive option..."

Developing an interactive relationship between a support person and a PWS involves trust and degrees of emotional comfort. For some support people these emotions may blur some aspects of the physical boundaries necessary to maintain the role of organizational support person.

Mary: "...this male person with an Intellectual Disability had been sexually abused by, well she'd had sex with this man."

I: "This was a staff person?"

Mary: "Um Hm. So the staff person was female. The person with an ID was male. Everyone joked about how she had had an affair with him. If that staff person had been male then it would have been called abuse. So that kind of appropriate applies amongst staffing groups, and I guess in society as well..."

Towards the Future

For Jane, the future included a society where PWS could begin to enjoy the same freedoms currently available to every citizen in Aotearoa/New Zealand.

Jane: "... In a totally ideal world, all people with intellectual disabilities are embraced as part of the community, the same as other people are... people have the same access to information, health professionals are aware of how they can support people...and a real culture within our organization, and within the community, that it's OK to look at how to support people with their sexuality..."

For Mary the future showed possibilities for provision being made for PWS to talk openly about issues relating to a more holistic notion of sexuality and sexual expression.

Mary: "...hopefully Jonny (a PWS) can talk about what he wants and it will start the conversation rather than him having to do it through behaviour. Hopefully that will be a part of what we provide, for people to talk about their sexuality, their self esteem and their identity. That might change. Whether Jonny gets his rocks off is an extra bonus...."

As the information reveals, the road toward these two futures appears long and further more beset by issues that raise more questions than they outline solutions.

The difficulty the interviewees had in being able to access sexual 'success' stories illustrates the point that sexuality and sexual expression are not easy concepts to pin down. The interview questions themselves left any definition of these two concepts unstated, yet as the examples noted show the notion that these two concepts might include bodies acting in certain prescribed ways defined as appropriate to surrounding conditions became a key assumption for both interview discussions. As Mary suggests sexuality should be viewed as an holistic concept the celebration of gender, esteem and individual identity. If definitions of sexual 'success' were to be constructed within these broad parameters, what might practical examples of these expressions of successful sexual practices look like?

Proscribing ways of enacting sexual success to include gay male bodies is a move forward from more traditional assumptions about what bodies are allowed to do. Yet how women are positioned within the interview stories suggests an adherence to some ideas that trail what even less than liberal notions might hold as possible, sexually, for women who live in the twenty first century. At an organizational level, prioritising experiences for sexuality and sexual expression for women PWS appears to be an issue that has, for the moment, been sidelined. If issues of sexuality and gender difference were to be enhanced rather than downplayed, how might actions leading to instances of positive sexual success for women be prioritised and enacted?

None of the examples discussed include the experiences of PWS with very high supports needs. The example that did include a PWS with high support needs (Example 4) resulted in no action on his behalf being taken. At present, ordinary notions of what sexuality and sexual experience might look like do not begin to address the issues that might present barriers for PWS from this group. What might sexual 'success' stories look like when the physical and emotional realities of those who are severely and profoundly disabled start to actively be taken into account?

Many assumptions are made about individual capacity when discussing sexual issues and this group including assumptions about the capacity to produce verbal or equivalent comments. Assumptions such as these should not be made lightly, yet they continue to form the cornerstone from which supportive action becomes possible. What might sexual success for PWS look like if the idea that all members of this group will, in the near future, be able to speak for themselves about this issue is no longer a baseline assumption?

Kennedy et al.'s scale of 'absolutely necessary' expects individuals to know what places for sexual expression are deemed 'appropriate'. Having this knowledge should allow these places to be made available to PWS who display an understanding of this concept. As issues currently stand there is no guarantee that this will happen for PWS who understand the concept and who use the services of this human services organization. What might practices of sexual success look like for PWS when ordinary definitions of private places for the purposes of sexual expression are acknowledged and facilitated by individuals working at every level of the organization?

Yet perhaps the most fundamental question these interviews uncover lies within the interplay of connections between the individual, the family, the support organization and the wider community. If the emotional, social, cultural and physical interconnections experienced by these groups were to be laid open, actively acknowledged and directly worked through by all participants, what might an 'ordinary sexual life' for a PWS really look like?

Endnotes

1. People who use services (PWS) is the term people with intellectual disabilities who are associated with this human services organization have asked to be used to describe them.
2. The names of both interviewees are pseudonyms.
3. This policy is currently being developed.

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