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Responding to masturbation in supporting sexuality and challenging behaviour in services for people with learning disabilities

A practice and research overview

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Abstract Masturbation is frequently referenced as a key issue for supporting the sexuality of people with learning disabilities, yet the subject has received little attention in the professional and academic literature. This article provides an overview of masturbation in relation to service responses and user support in sexuality work in learning disability more widely, drawing in evidence and experience from sex education, clinical work and staff training. Issues such as gender, sexuality, culture and consent are addressed and some of the commonly held myths and assumptions about sexuality and masturbation are challenged. The discussion and related suggestions are designed to be of value to service managers and practitioners, particularly those involved in sexuality work and one-to-one support.

Keywords challenging behaviour; masturbation; rights; sex education; sexuality policy

Introduction

There is a long discourse on the sexuality of people with learning disabilities and the development of protective and empowering support and education based on an increased awareness of sexual abuse and risks (e.g. Brown and Thompson, 1997; Brown et al., 1995; McCarthy and Thompson, 1996) and the articulation of rights and education agendas (e.g. Brown,
1980; Craft, 1983; 1987). The related research and practice debates have focused on emerging themes including HIV and homosexuality (Cambridge, 1997; 2001a); the sexuality of men (Cambridge and Mellan, 2000; Thompson, 2001); capacity to consent and consent to touch (Brown and Turk, 1992; Murphy and Clare, 1995); and the sexuality and sexual health of women with learning disabilities (McCarthy, 1998; 2001), including menstruation (Rogers, 2001) and the menopause (McCarthy, 2002a). These and related literatures in sexuality have shifted the agenda for sexuality in learning disability from one characterized by pathology and suppression to one centred on rights and empowerment, despite a continuing recognition of the prevalence of sexual abuse.

Despite this paradigm shift, relatively little attention has been paid to one of the commonest sexual behaviours, namely masturbation. This is particularly surprising as it is also the most frequently referenced presenting issue for referral to sex education for men (much less frequently, women) with learning disabilities (McCarthy, 1996) and repeatedly surfaces in staff training and clinical work (Cambridge, 2001b; Cambridge and McCarthy, 1997). Concerns are seen to centre primarily on five key and sometimes interrelated themes:

1. The person is considered to be unable to masturbate properly, usually meaning that it is thought they are unable to reach orgasm/ejaculate.
2. The person does not know how to masturbate, usually meaning that they have been observed rubbing their penis or vagina, generally through their clothes, against people or objects.
3. The person is doing it too much, usually meaning that the duration or frequency of the masturbation is such that staff consider that the person is losing out on social opportunities at home or in the community.
4. The person is inappropriately masturbating, usually meaning that they are masturbating in public or shared spaces in services, causing difficulties for staff or other service users.
5. The person is using inappropriate objects or means to help them masturbate, usually meaning that they are using objects not intended to aid masturbation which could hurt them.

Commonly, staff relate explanations or hypotheses they have developed to help them understand the behaviours they observe. An example is linking unsuccessful masturbation with frustration, leading to challenging behaviour (e.g. Sheppard, 1991). Challenging behaviour may also be directly linked to masturbation, such as inappropriate sexual behaviour, which may include masturbation in a public place, self-stimulation through sexual rubbing against another person or the inappropriate use of pornography.
to aid masturbation. Self-injury may be linked to the use of inappropriate or dangerous objects by the person to aid sexual self-stimulation or masturbation. In such situations it may be hypothesized that their removal may lead to aggression or other challenging behaviours. Complex causal linkages may therefore be constructed between masturbation, as it presents itself or is perceived to be a problem, and challenging behaviour, so it remains important to ensure that masturbation and sexuality per se are not pathologized in any debate.

Overlying such considerations are issues of gender and sexuality. Masturbation is generally reported to be much more of an issue for men with learning disabilities than for women (McCarthy, 2002b). More widely it has been observed that the sexuality of men with learning disabilities is seen as relatively pathological, with a range of sexual behaviours such as homosexuality having historically reinforced such perceptions owing to homophobia (Cambridge, 1997; Cambridge and Mellan, 2000). Conversely, it has been observed that the sexuality and sexual experiences of women with learning disabilities have remained relatively hidden (McCarthy, 1999; McCarthy and Thompson, 1998). Lesbian sex, for example, is virtually invisible in services for people with learning disabilities particularly compared with the relative visibility of homosexuality between men. Such observations are mirrored in relation to referrals to sex education in services for people with learning disabilities (McCarthy, 1996) and discussions in staff training in sexuality and learning disability (Cambridge and McCarthy, 1997).

The remainder of this article examines these issues and offers interpretations and explanations for the commonly reported difficulties associated with masturbation, with suggestions for supporting service users in masturbation and supporting staff to respond effectively.

Why masturbation is often seen as a problem

One of the main explanations for this is that masturbation is a common and frequently occurring sexual behaviour, regardless of intellectual ability. It is therefore not surprising it is often visible in services for people with learning disabilities and is consequently perceived to be a problem, regardless of related considerations such as the neglect of sex education, lack of privacy in services themselves or failure to recognize differences in culture or ethnicity (Baxter, 1996; Malhotra and Mellan, 1996; Senker, 1997). We construct and organize social and physical space and support in services for people with learning disabilities in ways where communal and collective spaces such as living rooms, bathrooms and toilets often merge along the public–private continuum with shared or individual spaces such as...
bedrooms (Parkin, 1989) or in ways which are fundamentally ethnocentric. By and large, private space and culturally appropriate space are at a premium. In residential services someone may have their own bedroom, but its use may be discouraged during the day, there may be no locks on bedroom doors, and staff and other service users may not respect privacy. This is why simple messages such as a right to privacy and respect and the importance of gender in some intimate care interaction have received prominence in some educational materials (e.g. Cambridge, 1996; Cambridge and Carnaby, 2000a; McCarthy and Cambridge, 1996). Private spaces in day services or services for people with profound and multiple learning disabilities are even scarcer, and the only places available for someone to masturbate may be the toilets, which may sometimes not even have private cubicles or locks on doors.

In addition to the tendency to disrespect or disregard privacy in services for people with learning disabilities, there is also a tendency to desexualize and to deindividualize people with learning disabilities (Carnaby, 1997; 1999). This can mean that ordinary sexual behaviours, when they do surface, are interpreted as inappropriate. Masturbation, exposure of the body and homosexual tendencies were, for example, crudely referenced as behaviour problems on the Adaptive Behaviour Scale (Nihira et al., 1974, referenced and discussed in Felce et al., 1994).

**How best to respond**

The first steps are to clarify and accurately describe the actual behaviour and its social and physical context. Five key sets of questions can be asked about the actual behaviour, evidence and context (McCarthy and Thompson, 1998), the answers to which can be formulated into an agenda for individual work:

1. What is the actual behaviour or form of sexual self-stimulation? For example, is the person rubbing themselves against objects or touching their vagina or penis directly?
2. How do staff respond to the behaviour, and are responses consistent? For example, do some staff or staff responses seem to be more effective than others?
3. Does the behaviour (masturbation) vary between places or settings? If so, what factors might explain this variation?
4. Is there a daily or temporal pattern to the person’s masturbation? If so, what might this suggest? Are there times when this does not appear to be a problem? If so, is there a ready explanation for this which might help formulate an intervention?
Is this a new behaviour which has recently surfaced or been observed, or has it been going on for some time? If it seems durable, what interventions have already been tried out and how successful have they been in modifying the behaviour?

Depending on the individual situation or behaviour, more detailed questions may also be helpful to ask and seek to answer, for example:

• For a woman, does she directly stimulate her clitoris, vagina or breasts, and is this done above or beneath clothing?
• Does she seem to achieve satisfaction, whether through orgasm or not?
• For a man, does he get an erection, does he get his penis out and use his hand, and does he ever ejaculate?

Answers will provide precision about describing different forms of self-stimulation and masturbation which may have only been loosely described or labelled in the past and consequently aid the design and planning of interventions.

For both women and men, a series of secondary questions are also likely to prove useful, in particular:

1 Does there seem to be a particular stimulus or co-factor, for example a particular place, contact with a particular person or association with a particular care activity, such as changing a continence pad? If so, such associations may need to be mapped and understood in more detail in terms of their cause or function.

2 Is the masturbation part of a wider repertoire of attention seeking behaviours or other challenging behaviours such as self-injury? If there appear to be links, then the underlying functions of the masturbation and other challenging behaviours will need to be clearly articulated and understood.

3 Is there any suspicion or evidence that the person may have experienced sexual abuse in the past or is currently at risk of sexual abuse or exploitation? If so, and especially for people with very limited verbal communication, touching their genital area may be their only way of drawing attention to something having happened to that part of their body.

Answers to these questions will help place the behaviour on a continuum between sexual arousal, self-stimulation and masturbation, which will inform the response. They will also help develop and test hypotheses about the link between masturbation and other stimuli or challenging behaviours or the function of the behaviour itself which may be more than self-stimulation. In some cases, it may be necessary to collect additional
information to help decide on the function of the masturbation and clarify the attribution if it is a challenging behaviour, for example using a simple but widely recognized ABC (antecedent, behaviour, consequence) approach to understanding setting conditions and triggers as part of behaviour analysis (e.g. Murphy, 1994).

In many cases it will also be important to check out some even more basic but often overlooked possibilities, particularly in relation to situations where the woman or man is considered to be unable to masturbate effectively. For example:

- Does the person have a vaginal, penile or urinary tract infection?
- Are there any signs of a skin irritation or condition, such as thrush or eczema?
- Could having an erection cause pain for the man, as with a very tight foreskin?
- Is the person on any form of medication which could reduce their ability to masturbate or their libido, such as anti-psychotic medication?

Whilst we may not always be able to understand why a person behaves in a certain way, if we accept the premise that the person will usually have a reason for what they are doing, the challenge for carers and support workers lies in working out the reason. The importance of such a response has been clearly stated:

> addressing inappropriate masturbation successfully relies on an understanding of what the behaviour communicates about that person, or what purpose the inappropriate masturbation may be serving for them. If this understanding is lacking, approaches tend to be oppressive and punitive. (Walsh, 2000, p. 29)

In trying to understand a person’s sexual behaviour, staff need to be encouraged to reflect on their own beliefs and values about sexuality. We draw on a range of models and sources for this, including our cultural backgrounds, subjective feelings ('gut reactions'), beliefs about how common or uncommon a certain type of sexual behaviour is, our understanding of the law, and so on. The models of ‘normality’ people hold can be influential in determining our responses and staff need to be helped to recognize that many of us make distinctions about what we think is ‘normal’ or ‘abnormal’ on an instinctive and subconscious level, rather than as a result of considered reflection.

Finding out more about a person’s motivations and purposes will obviously require careful and respectful observation. Intimate and personal care or help with washing or bathing can sometimes provide such opportunities (Cambridge and Carnaby, 2000a). If a person is able to discuss such
matters, then private and respectful conversations can help. However, in many cases if staff already consider someone is unable to masturbate effectively, then they are likely to hold similar information or observations to support their concerns or will have collected evidence indirectly. It will remain important to check such evidence at staff meetings or case reviews in order to validate any assumptions or interpretations as a first step to planning responses or deciding on what additional information may be needed to inform any intervention. Considerations likely to surface from such work include links with activities and levels of meaningful engagement. If people lack meaning in their lives they are more likely to engage in self-involved behaviours which serve the purpose of relieving boredom or frustration, than in interesting and enjoyable activities. Similarly, if they have been denied structured sex education they are more likely not to have been given clear messages about masturbation being a normal and enjoyable activity, either on your own or with a consenting partner, or about the importance of privacy.

**Policy and practice guidelines**

Two caveats need to be referenced at this point in the discussion. The first relates to the role of sexuality policies in services for people with learning disabilities (Cambridge and McCarthy, 1997). Most such policies make a point of referencing service users’ rights to information about sexuality, and services’ responsibilities for providing sex education and support for sexuality, including masturbation. The second concerns the ways individual or group sex education work is organized.

Individual educational interventions need to be agreed and referenced in the person’s individual plan (Carnaby, 2002). This may need to involve the multi-disciplinary or community team, care manager and service manager, depending on supervision and line management arrangements and the nature of outside support being provided for the service user. This has obvious implications for an individual’s confidentiality and rights to privacy and these need to be weighed against the benefits of sharing such sensitive information about an individual (Downs and Farrell, 1996). It will also be important to identify the aims of the work, how these relate to the teaching, how the teaching will be undertaken, who will conduct the work and where it will take place. Similarly, group educational interventions, such as women’s or men’s sex education groups, require careful planning, supervision and management (Cambridge and McCarthy, 1997; McCarthy and Thompson, 1998). In short, both forms of sex education require the unambiguous allocation of worker led responsibility, within an individual or service-level action plan and outcomes.
Commonly reported problem areas

Attempts to masturbate during intimate or personal care are frequently reported, especially in services for people with profound and multiple learning disabilities, for whom a discourse on sexuality has been initiated (Downs and Craft, 1997). Such situations may be the only time someone has access to the sexual parts of their bodies (Cambridge and Carnaby, 2000a) and so are easily understandable, but they do raise particular adult protection concerns (Cambridge and Carnaby, 2000b). However, there are a number of ways staff can respond, such as leaving someone in a safe and comfortable place to allow them to explore their own bodies in private and giving them a positive response verbally or through other forms of communication (Ware, 1996) that the behaviour is allowed and valued.

Where an individual is masturbating in a communal area and it is not thought that they are doing it deliberately to offend others, the role of staff would be to sensitively guide the person to his or her own private space (usually a bedroom). If this behaviour occurs in a day service setting, then strictly private space is unlikely to be available and the best option available (such as the toilets) may have to be used. Clearly, there are other instances where consideration must be given to the possibility, or likelihood, that the person knows what they are doing is wrong and indeed that they are doing it deliberately to offend others or gain attention. Good guidance on working with men with learning disabilities with unacceptable and difficult sexual behaviours now exists (Thompson and Brown, 1998) and such materials can help formulate service responses.

If a man is deemed to be masturbating too much or ineffectively, it is sometimes suggested that chemical responses using medication designed to suppress the male sex drive (such as Androcur) will help the situation. However, without the person’s informed consent, which in the case of someone with a profound or severe learning disability would be very unlikely, then this is not a realistic or ethical option to consider. In addition to the ethical problems, there is the question of effectiveness, as experience suggests that men who take this medication may still experience sexual feelings and attempt sexual activity (either alone or with a partner), but are unable to reach orgasm. This can then exacerbate the problem it was trying to solve. Rather, support staff need to be asking whether the individual concerned is having enough ‘private’ time. For example, if appropriate and safe, is he being given time to relax alone in the bath or shower, or have time to rest in bed when not actually sleeping, without wearing pads or restrictive clothing?

Similar dilemmas occur, for example, with managing the risk to people who use inappropriate or dangerous objects to masturbate. Vaginal or anal
insertions of certain objects pose a clear risk and necessitate action on the part of staff. There will clearly be a strong case in terms of risk management to protect the person by removing the dangerous object. However, in terms of the person’s rights and in interests of providing a supportive response, there would also be a case for replacing the object with a safe alternative, such as a specially designed sex aid or similarly shaped object.

Taking sex education forward

A range of possible educational responses for helping teach someone to masturbate effectively or in an appropriate place can be considered (McCarthy and Thompson, 1998):

- talking to the person, using unambiguous terms
- discussion using photographs or line drawings (for example Cambridge, 1997; McCarthy and Thompson, 1998)
- using a sex education video, where actors or puppets demonstrate masturbation (for example FPANSW, 1993; WLHPA, 1994)
- demonstrating on a model vagina or penis
- directing them or taking them to an appropriate place when they start to masturbate
- introducing modification, such as lubrication or a sexual aid if an inappropriate object is being used
- physically directing a person’s hand when they are trying to masturbate (for example Shelton, 1992).

Two overriding principles are relevant here. The first is informed consent, and the second is that the least intrusive methods should always be tried first. The most important practical consideration will therefore be to tailor the educational response to the person’s cognitive capacity and known sexual experience. Issues of consent for and the design and targeting of educational interventions underline why it is important to have these agreed in the person centred plan (Department of Health, 2001) and to adhere to basic principles of consent (mirroring those developed for sexual activity itself by Brown and Turk, 1992, and others). These would need to take account of the person’s sexual experience and their understanding of the planned intervention. However, consent can be more difficult to put first when service responsibilities for care and the protection of vulnerable adults (Department of Health, 2000), possible legal constraints (Gunn, 1996; 1997) or the risk of negligent practice or assault (Cambridge, 2001a) are part of decision making.

Some of the difficulties of matching resources to needs are reflected in
the range of off-the-shelf educational resources available. For example, videos which use puppets to demonstrate masturbation (WLHPA, 1994) are sometimes considered to create an additional conceptual barrier, namely the difficulty of the person relating the puppet on the video to self. Conversely, there may be a reluctance on the part of the educator to use sexually explicit educational material or images (such as those on masturbation using actors in FPANSW, 1993), on the basis that the service user might misinterpret these or simply because the educator finds using such material difficult.

When considering options, concern within services often returns to whether such interventions, if successful, will then lead to the person spending too much time masturbating, as they may have learnt how to do it well and effectively. Although there is little evidence that this happens in reality, if such outcomes occur, then it will be necessary to revisit considerations of engagement in activities more widely.

Another important reference issue at this stage is often the practice and adult protection boundary between education and what has been euphemistically coined ‘hands-on’ intervention. Providing information and education in response to an assessed need is clearly the right thing to do, but the question of how to do this effectively may present a challenge. Whilst it might be rational to suggest, in a particular agreed case or situation, that staff should guide a person’s hand, this is not the same as, for example, placing a man’s hand on his penis or a woman’s fingers on her clitoris, and simulating masturbation for the person. The latter interventions will rarely or ever be appropriate, owing to confounding issues of consent and experience on the part of the service user and the feelings, motives and rights of staff. Indeed, these interventions are highly likely to be defined as abusive under adult protection procedures. For similar reasons intimate and personal care interventions are informed by considerations of consent to touch (Cambridge and Carnaby, 2000b) where hand over hand contact and indirect cues to consent such as body language and non-verbal forms of communication are utilized. However, it also needs to be recognized that there are often no absolute boundaries on issues such as ‘hands-on’ interventions (Shelton, 1992), a reality mirrored in sexuality work more widely, where previously ‘taboo’ issues such as access to paid sex by men with learning disabilities have recently been discussed (Cambridge, 2001b).

The cultural appropriateness of educational method, image or message is also an important consideration. For example, it has been observed in safer sex education that images which may be culturally appropriate to a gay identified man may not be culturally appropriate to a man with learning disabilities who has sex with men (Cambridge, 1997). Cultural
appropriateness in relation to race and ethnicity has also been discussed in relation to sexuality work and sex education in learning disability (Baxter, 1996; Malhotra and Mellan, 1996; Senker, 1997) and is also relevant to anti-oppressive practice more widely (Baxter et al., 1990; Karmi, 1996; Shah, 1998). However, it is worth noting that few, if any, of the major world religions take a positive view of masturbation (Thomson, 1993). That is not to say that there is no value in consulting specialist advisers on cultural matters relating to the education of people with learning disabilities about masturbation. Experience suggests that this may be very useful and sometimes a very pragmatic and helpful approach may be taken, but there may also sometimes be conflicts with user rights as articulated in law or in sexuality policies.

Considerations for working with men with learning disabilities

An issue which often emerges when undertaking sexuality work with more able men with learning disabilities concerns the use of pornography, which is often used as part of masturbation or an aid to masturbation. Difficult political and practice arguments surround the use of pornography, such as situations where the man may have bought this himself or been given it by other men he has met (Cambridge and Mellan, 2000). Staff may object to its presence in bedrooms and the man has responsibilities to use it appropriately and in private. However, in situations where it is used in shared spaces or for masturbation in non-private places, the man will need to be given clear messages that this is unacceptable.

For more able men with learning disabilities who may be having sex with men outside their service (Cambridge, 1997), it will be particularly important to present consenting masturbation and mutual masturbation as positive sexual behaviour in the context of safer sex education, counselling about HIV or assertiveness work. Men with learning disabilities who engage in masturbation in public sex environments will be less vulnerable to exploitation or sexual abuse and more able to escape assault or arrest than those engaging in other, more involved forms of sexual contact. However, the reality of sexual encounters in such situations will often mean that masturbation is the initial stage of a sequence of sexual behaviours which may lead to very unsafe sex, and safer sex education will need to acknowledge such connections and risks (Cambridge, 1999).

Masturbation is popularly considered to be almost a preoccupation for adolescent boys in the general population and clearly the enormous physical and hormonal changes that take place during this time in a young person’s life can lead to a very strong interest in masturbation and indeed
other sexual activities, for girls as well as boys. Yet the needs and feelings of adolescents with learning disabilities are often overlooked (Rowitz, 1988), despite the fact that they will largely be undergoing the same physical changes, with the disadvantage of less formal and informal sources of sex education and support than other young people.

**Considerations for working with women with learning disabilities**

One of the main considerations for working with women with learning disabilities on masturbation issues is how little we know about women’s experiences and their feelings and needs related to this sexual activity. There are few avenues for women with learning disabilities to talk about masturbation and, even when provided with respectful opportunities to do so, most women with learning disabilities find it extremely difficult and embarrassing (McCarthy, 1999). This is not surprising given the double standards and strong social taboos which still exist for all women in talking about the sexual pleasure they can give themselves (McNeil, 1992). This issue is made more complex for women with learning disabilities given the negative feelings and lack of pleasure and pride they often take in their bodies (McCarthy, 1998).

However, if appropriate opportunities can be made to discuss masturbation (and experience suggests that for many women with learning disabilities, this will be need to be on an individual basis, owing to the embarrassment factor in group settings), then there is much that could be gained from it. If women with learning disabilities can be helped to understand that masturbation is normal and widely practised amongst most women (Hite, 1976), then they may feel less embarrassed and negative about their own experience of it. In turn, they may learn what kinds of sexual touch they do and do not enjoy and this can only help in any subsequent sexual activity they have with a partner. As evidence suggests that many women with learning disabilities do not get much, if any, pleasure from the sexual activity they engage in (McCarthy, 1999), then this would clearly be of benefit.

**Concluding remarks**

Masturbation is one of the commonest and potentially most harmless forms of sexual behaviour, enjoyed by women and men alike, sometimes solely, but more often as part of a wider sexual repertoire. Most people also masturbate throughout the majority of their lives. Considering this reality, services for people with learning disabilities have been slow to empower
service users to enjoy masturbation and to support them to masturbate effectively and in appropriate ways and places. This is sadly often reflected in the responses of service users themselves to masturbation, reported from individual and group sex education (Cambridge and McCarthy, 1997; McCarthy and Thompson, 1998), where it attracts negative interpretations and associations with guilt and shame.

This inheritance reflects decades of neglect in relation to sexuality, rooted in a values system in which people with learning disabilities are socially and culturally marginalized and economically excluded, and where services are still largely segregated and fail to acknowledge the heterogeneity in the population of people with learning disabilities. Recent policy initiatives (Department of Health, 2001) have stressed the importance of individualized and person-centred services and of social inclusion, and almost two decades on from the influential work of Craft (1987) and Brown (1980) we are now in a service culture where adult protection policy (Department of Health, 2000) and management and practice in sexuality can move forward in more empowering as well as protecting ways. A starting point is how we respond to masturbation in productive and empowering ways.

References


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