ACCESSIBLE SUMMARY

- Some men with learning disabilities have a sexual fetish which may present a support challenge for staff or carers.
- Sexual fetish in people with learning disabilities is often ignored, seen as pathological or associated with risk.
- It is possible to support sexual fetish in person-centred ways which respect individual rights and informed choice.

SUMMARY

This paper reports on a psycho-educational intervention associated with the sexual fetish of a man with mild learning disability and autism which centred on his use of nappies and baby paraphernalia. It outlines the nature and expression of his sexual fetish and the risks perceived to be associated with it and describes the approach developed to support him, including the aims which underpinned the work and the methods and processes employed. It was found that a person-centred psycho-educational approach from a rights based perspective achieved important changes in his life and self-esteem and helped challenge assumptions about his sexual risk. The paper also reflects on the organisational location of this work and identifies the applied learning for supporting the sexual fetish of people with learning disabilities, of value for informing sex education and sexuality support for people with learning disabilities more widely.

KEYWORDS gender, learning (intellectual) disabilities, male and female sex lives, sexuality

INTRODUCTION

A number of long-standing tensions are evident in the constantly developing discourse on the sexuality of people with learning disabilities. Uppermost is the tension between protection and empowerment (Cambridge et al. 2003). This is exemplified in the responsibilities of services to protect people from sexual abuse and exploitation through safeguarding procedures (No Secrets, Department of Health 2000, 2009a) and to promote individualised and
person-centred support in line with a rights perspective and the goal of social inclusion (Valuing People, Department of Health 2001, 2009b). This tension is evident in policy, sex education and individual support and has been described as the balance between individual rights and service responsibilities (McCarthy and Thompson, 1996). It is particularly evident in work and support relating to sexual abuse and sexual offending (Brown & Thompson 1997; Lindsay 2002; Murphy et al. 1995) and HIV risk management (Cambridge 1997, 2001) as well as occurring in relation to everyday sexual behaviours such as masturbation (Cambridge et al. 2003).

Particular sexual behaviours and sexual identities have remained less visible on the margins of sexuality work, including homosexuality (Abbott & Howarth 2005; Cambridge 1997; Cambridge & Mellan 2000; Thompson B, 1994; Thompson D, 1994, 2001; Wheeler 2005), stylised sex and sadomasochism (Cambridge & Mellan 2000) and cross-dressing and trans-sexuality (Allen 2003; Wheeler, 2005; Wilson 2006). The sexual fetishes expressed by some men with learning disabilities have consequently been relatively under-explored and discussed in the practice literature. Although they may be particularly visible when they occur, there is no evidence to suggest that they are particularly different to those which some men without learning disabilities may express. In relation to this relative visibility, Cambridge & Brown (2006) have observed that:

‘Self-presentation of sexuality is forged at the interface between fantasy and reality and requires constant editing. People with learning disabilities find this a difficult skill, resulting in the disclosure of sexual thoughts and fantasies that others keep hidden, with their sexuality consequently becoming pathologised’

Moreover, the sexuality of men with learning disabilities tends to be relatively highly controlled and policed by care staff or families, often being under constant scrutiny, subject to judgement and linked to deviancy, as is usually the case, for example, with cross-dressing (Cambridge 2010; Cambridge & Mellan 2000; Wilson 2006), rather than seen as a consequence of denied access to women’s clothes. They also note that stylised sexual behaviours such as sadomasochism (Butt & Hearn 1998; Thompson B, 1994; Thompson D, 1994, 2001) are more likely to be perceived or associated with violence and dangerousness than with consenting or reciprocal sexual expression. Indeed, there are examples where the presentation of sexual fetish by men with learning disability has been met with wholly medical responses – Puri & Singh (1996) report the successful use of pharmacotherapy with pimozide on a man with a learning disability who cross-dressed, and El-Badri & Robertsaw (1998) report the use of brain scans for two men with learning disabilities who displayed foot fetishes.

Background

An interim account of this case study and the related individual work was provided by the author at an international learning disability conference (Cambridge 2008), generating much discussion and interest. This response, together with a desire to promote the sexual rights of people with learning disabilities and to make the sexual fetish of men with learning disabilities more visible, represents key driving factors behind the development of a more complete account of this work and related issues. This has been constructed from experience of the individual work conducted with the man and mediated dialogue with his service, with the publication of generalised learning agreed prior to undertaking the work. Anonymity in name, location and organisation has also been preserved to safeguard confidentiality. Without a research component to this work, ethical approval was consequently not required.

The particular sexual fetish that forms the basis of this case study, the work undertaken and the general lessons identified was expressed in the form of a ‘baby’ fetish, involving the use of nappies for masturbation and the collection of various baby paraphernalia by a man with mild-to-moderate learning disability and autism. He was supported by a formal residential service for people with learning disabilities in a small group home with two other men with learning disabilities.

A particular associated complexity and support challenge was also his production of ‘scrap books’ comprising images of babies in nappies cut out of regular magazines but annotated in sexually explicit and violent ways, hence the concern about his sexual risk to babies and children. The scrap books had always been taken away from him when they were discovered and his use of nappies variously discouraged and prohibited, although there was indirect evidence that the explicitness of the images he expressed in his production of scrap books had been progressively increasing over time.

Although there was no history of sexual offending, the man was consequently supervised whenever he went outside the service, presenting a serious restriction to his liberty. His service manager was keen to reduce his supervision, this also being an expressed wish of the man himself. My involvement was also, therefore, a part consequence of the desire to resolve the dilemma relating to the restriction of his liberty.

Method and principles

The conduct and approach to this work was informed by a number of key principles, namely to:
1. advocate on his behalf for his right to the safe sexual expression of his fetish
2. place his sexual rights at the forefront of the work and the outcomes sought
3. be honest and open to him and other relevant parties about the issues that surfaced and resolution strategies
4. be nonjudgemental about his sexual fetish
5. seek to provide good and informed information and advice
6. seek to resolve conflict and strive to reach the least restrictive outcome for him
7. seek to skill and empower the manager and staff of his service to recognise and respond to his rights and to work positively and constructively with him

Individual sessions lasted for approximately one hour, usually followed by mediated dialogue and discussion with his service manager. Sessions were chronologically planned in advance, although he or his manager could also request sessions based on the evolving support situation. The individual sessions occurred in clusters over a three-year period. The man had repeatedly refused to discuss his scrap book with his psychiatrist, but indicated that he would speak with the author of this study following a sex education group, which had been established and run by the author.

‘In working therapeutically we must be prepared to tolerate the fact that there is no cure for... organic impairments. The best we can hope for is that secondary and emotional disabilities are diminished, thus contributing immeasurably to someone’s quality of life’ (Hollins 2003, p. 197).

The individual work with the man followed a psycho-educational approach, based on providing information and advice and using the same principles as, for example, sex education (McCarthy & Thompson 1996). This is designed to assist the person make more informed choices about their sexual expression, whilst at the same time acknowledging the complex reasons, in this case for the man’s sexual fetish and his experience of disability as a child and in services. For example, information about choices and positive suggestions for change were provided, with the implications and consequences of different choices discussed. He was also encouraged in a nonjudgemental way to disclose his thoughts and wishes regarding his sexual interests and experiences. These were then placed in a wider social context and interpreted with him in relation to his living situation and contact with his family. He was also advised about his rights to safe and private sexual expression and his responsibilities not to produce sexually offensive material, as well as the nature and consequences of sexual offending. Where there were conflicts between them, he was encouraged to consider possible resolution strategies. This was therefore a complex role that included education and advocacy, with the latter progressed through a support agreement developed through mediated dialogue and negotiation with the man and his service manager.

A professional independent advocacy stance was possible because my role was detached from managerial responsibilities, thus strengthening professional capacity (Henderson & Pochin 2001; White & Harris 2001). My nonjudgemental approach to his sexual fetish, for example, combined with positive regard and empathy in relation to his experience of disability and rejection, enabled me to advocate effectively on his behalf. This person-centred approach placed him and his interests at the centre of my individual work and the wider work with his service and those around him. The values that underpinned this work are therefore close to the characteristics to the core conditions of therapy – congruence, unconditional positive regard and empathy – (Thomas & Woods 2003) and modern psychotherapeutic approaches to working with people with learning disabilities (Cottis 2009; Frankish & Terry 2003; Willner 2005).

‘When using a person-centred approach there are core conditions that are considered essential in promoting change. As supporters, workers, nurses or social workers we are clearly not therapists; nevertheless, the knowledge and use of the core conditions is both relevant and recognisable and should underpin our work’ (Thomas & Woods 2003, p. 153).

As a Gay man, I have some experience of social marginalisation and was well positioned to identify with and have empathy for his experience of marginalisation in relation to his minority sexual interests. Having had a member of my family who had Downs, I was also emotionally attuned to his experience of disability and rejection (Howe 2008). I believe these factors helped ensure my work remained relevant to his lived experiences and expectations. The work also developed a systemic approach by connecting with his wider service and support system (Dallos & Draper 2000), acknowledging that the parts of this system required connecting in coherent and meaningful ways if the work was to have a lasting and positive impact on his life. For example:

1. direct and frequent liaison with his service manager
2. work with his support staff in relation to the consistency of the day-to-day support relating to his sexual fetish
3. involvement in case reviews, including those with his care manager and family (maintaining his wishes for some things relating to his sexual fetish to remain confidential)
4. risk assessment and management work alongside his psychiatrist
5. the provision of supporting information for referral for forensic risk assessment to a national organisation working therapeutically with people with learning disabilities

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Process and issues

An overview of the processes and issues surfacing from the individual work is now provided. The wishes of the man and the service manager did not all conform, although there were significant shared wishes. The man wanted to be able to buy and use nappies, to have rubber sheets and pillowcases, to keep scrap books, to look after his nephews, not to be supervised and to have other baby paraphernalia. His manager sought resolution of the challenges the man’s sexual fetish had brought, including the use of nappies and not having to deal with any more scrap books. He also wanted the man to be more aware of the consequences surrounding any disclosure of his sexual fetish, better understanding the importance of confidentiality, reduce any risk there might be of his sexually offending and to consider reducing his supervision.

The work started by discussing his scrap book, and he disclosed through writing (as he was reluctant to speak words which he associated with negative responses) that he would like to have access to nappies and baby wipes, adding that when he had bought these in the past, they had been taken away from him. He explained that he wanted to use them in his bedroom at night during masturbation on his rubber sheet and plastic pillowcases. He was afraid staff would find out, was deeply ashamed of his interest and was aware of the importance of privacy.

When discussing why he wanted to wear nappies, he responded that this made him feel safe – as a baby, he did not need to worry about the bad things in his life like his disability and the trouble this had caused him. He was assertive in voicing his wishes and often wrote letters to me requesting changes in his support plan (see description of his written agreement below). His service manager and psychiatrist, whilst concerned that he should have maximum liberty, were also aware of the necessity to manage any risks that might be associated with his sexual fetish. Although these were primarily signalled by his production of scrap books, it was not possible to separate out his sexual fetish from the function the scrap books potentially served, although the scrap books also likely connected to his early childhood experiences of rejection and his low self-image as a man with a learning disability. His mother reported that when he had lived at home, he sought access to nappies and would sometimes use dirty nappies if that was all he could find. The advice given to her at the time was to make sure that access to such things was denied, and when she reported that he had then tried to use pillowcases and other items as a substitute, her observations were dismissed.

From a human rights perspective, he clearly has the right to express his sexual fetish in private, as other men with similar fetishes enjoy. Through mediated dialogue with his service manager, a person-centred written agreement was established. This was person-centred because it was built from work with the man where he was able to identify the things he wanted in his life in relation to expressing his sexual fetish, including the opportunity to purchase nappies and use them in private in his bedroom. The agreement consequently facilitated him to purchase his own nappies, with the support of his manager, with a monthly limit. It also referenced the monitoring of their use through a diary kept by the man, with progress regularly reviewed between the man and his service manager and periodically between me and the service manager. Factors considered included the frequency of nappy use, interpreted in the context of the expressly recorded views of the man himself about this, whether inappropriate disclosure had occurred and whether that man had been disposing of his used nappies appropriately.

It was also agreed that he would not make or keep other scrap books, with the link between these and his supervision similarly made explicit. Boundaries relating to confidentiality and the disclosure of his sexual fetish were also outlined in the written agreement, reflecting the man’s desire that his interest was kept secret from other staff, service users and his mother. He also took responsibility for locking away his baby paraphernalia in a cupboard in his room during the day and took responsibility for disposing of his used nappies in black polythene bags in the main rubbish bin. It was also agreed that he would only engage in his fetish during the evening and night when this did not distract from other planned activities.

Assessing progress in relation to such complex support issue is difficult and primarily qualitative and subjective, given the nature of the work and the aims and values that underpinned it. However, central to such an assessment should be the man’s expressed well-being and views about this. A number of years on, some difficult behaviour which he had displayed had diminished, and the greater autonomy and control he has developed in his sexual life had resulted in him periodically opting out of his interest. He had also become more articulate and vocal about his rights and wishes and less reluctant to discuss his sexual fetish when appropriate to informing his person-centred support plan.

Some factors are easier to identify but also require careful interpretation in relation to progress. For example, there was also an incident when he had unwittingly but inappropriately disclosed his sexual fetish to someone outside the service, although this experience provided important learning for him and his support plan. During the individual work, he also disclosed a past incident of sexual abuse, which was reported through local adult protection procedures (Department of Health 2000, 2009a). His involvement in the investigation served to acknowledge his experience and empower him to take greater account and control of his feelings. This can therefore be viewed as a positive outcome. The fact that he had not sexually offended could also be
offered as a positive outcome, but needs to be interpreted on the basis of his history of non-offending.

The organisational outcomes from the work also remain somewhat conflicted. A major restraint to his liberty and his expressed desire to have more independence was seen to be his assumed risk to babies and children, emanating largely from his scrap books but also from unsubstantiated observations on his client record from a previous placement. Resolution of this conflict was sought through referral for a forensic risk assessment to a national organisation working therapeutically with people with learning disabilities. Funding for this was eventually gained from the local adult social services department through lobbying in conjunction with his psychiatrist. However, this work was not able to discount such a risk as a consequence of fantasies disclosed during psychotherapy and his inability to demonstrate empathy and feelings for others, with the possibility that his fantasies might have escalated and he might have offended had this not been contained through his supervision. Continued supervision in conjunction with the development of social opportunities was recommended. This was a disappointing outcome, especially as the care manager from his placing authority had been pushing for supervision to be lifted in relation to the restriction of his liberty.

Unresolved concerns include the function of the scrap books, namely whether these were expressing a hatred of himself and his disability or a violent sexual interest in children. For this reason, his expressed wish to have a ‘dolly’ which he can take to bed with him was not granted because of concerns that the doll might function as a sexual rather than nurturing object. The function of his sexual fetish also remains unclear, namely whether it is an expression of a potentially dangerous behaviour or represents regression to a safer childhood. Indeed, it is not possible to ascertain whether removing the scrap books or allowing an expression of sexual fetish is likely to increase or decrease any sexual risk, although it is unlikely that there is no connection between his fetish and the images expressed in the scrap book.

**Values, observations and learning**

In developing individual work supporting the sexual fetish of men with learning disabilities, advice and support should be based on the principle that men with learning disability have the same rights as other men to express a sexual fetish. However, conditions include the sexual expression being legal, consenting and private and considerations include appropriate support and guidance to express his sexuality and sexual fetish appropriately and legally (Brown & Thompson 1997).

Underpinning aims should include the importance of the man recognising the social context of his behaviour, including the fact that such a specialist and intense sexual interest is unusual and that its discovery by others is likely to result in negative consequences, such as ridicule. In parallel, the man’s right to express his sexuality safely and appropriate should be constantly reinforced in non-judgemental ways which demonstrate positive regard and empathy for his feelings and acknowledgement of his likely experience of rejection and often humiliation. Boundaries to confidentiality and disclosure will also be important to establish.

It should also be acknowledged that what might be appropriate in one cultural context might not be acceptable in another and that not everyone charged with supporting people with learning disabilities is likely to agree with the positive support of sexual fetish because of their personal values or faith beliefs. Consequently, people who do not adhere to a rights-based approach to supporting the sexual fetish of men with learning disabilities should not be expected to provide such support directly.

The rights-based person-centred model described in this study offers such an approach, and it has been possible to identify the essential core conditions to promoting change. The work should start with and be informed by the experience and wishes of the individual. It should also recognise that they have a right to safe and consenting sexual expression, in this case the private expression of a sexual fetish with appropriate support. This requires empathy and positive regard for the person’s experiences and wishes to help combat negative self-image and low self-worth.

Such work is also most likely to succeed and affect change when combined with psycho-educational methods and implemented through a professional advocacy stance. The former are best placed to empower the man to make more informed choices in his sexual life and facilitate positive support from staff and services, with the latter providing more independent and objective mediation between the different interests at stake, thus maintaining the connection between person-centred work and systemic intervention.

When conducting such work, it is also important therefore to assess the capacity of the management and support system to progress such interventions and sustain positive change. This may require some direct work with the staff group and with developing-related policies, procedures and guidelines within the service to promote consistent responses and agreed courses of action (Cambridge & McCarthy 1997). It will also be important to acknowledge the considerable role emotions play in decision-making in such support contexts (Brown 2011).

It should be anticipated that access to specialist and often expensive resources such as psychology, psychotherapy and forensic risk assessment is likely to prove difficult. Not only are such resources scarce, but they are unlikely to provide immediate answers to risk management dilemmas. However, they offer a potentially valuable role for validating or challenging the assumptions that might underpin work
supporting the sexual fetish of men with learning disabilities, informing risk management, helping the person deal with deeper-rooted psychological issues and helping identify longer-term support goals.

As with all sexuality work, it remains important to consider the relationship between sexual behaviours and past or present sexual and other forms of abuse. Evidence on the sexual abuse of people with learning disabilities (Brown et al. 1995; Cambridge et al. 2011; McCarthy & Thompson 1997) demonstrates a high incidence and prevalence of sexual abuse to men as well as women with learning disabilities, suggesting the requirement to be alert to this possibility and the potential of post-abuse work when supporting the sexual fetish of men with learning disabilities.

References

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