



ORIGINAL ARTICLE

'May we please have sex tonight?' – people with learning difficulties pursuing privacy in residential group settings

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Accessible summary

- Everyone has the right to privacy and relationships.
- Some people who live in group homes are not allowed to be private with their partner.
- We will explain how this makes us feel.
- We will say what should change.
- Parts written in 'bold' font are in plain English. Read them to find out more.

Summary

Many residential group settings for people with learning difficulties do not provide individuals with the private space in which they can explore their sexual relationships in a safe and dignified manner. Lack of agreed private spaces seriously infringes the individual's human rights. Many people with learning difficulties who lack privacy have no other option but to escape to isolated public or semi-private spaces to be sexually active. This places individuals at risk. It is suggested that self-advocacy driven policy guidance must be developed which must require residential services to review their practice to ensure that they accommodate residents' need for privacy, whilst supporting them to lead safe sexual relationships.

Keywords *Privacy, residential services, self advocacy, sexual abuse, sexuality, relationship policy*

Introduction

This paper is concerned with privacy and sexual relationships. People with learning difficulties have traditionally been excluded from discussing these issues. We hope that this paper will encourage policy makers and practitioners to consider our concerns, while we also hope to help other people with learning difficulties to gain the courage to speak up for their rights to privacy and relationships.

This paper was composed jointly by a researcher and a self-advocacy group. **Sections written in the words of the self advocates are presented in the bold font.** People with learning difficulties may wish to read only these sections, which are more accessible than the sections that were written by the researcher, although pictures are not used to aid understanding. It is therefore recommended that individuals receive assistance with reading and understanding these sections, should they require it.

This paper begins with some notes on terminology. Next the methodology of the research on which this paper is based is described. A brief outline of historical conceptualisations of the sexuality of people with learning difficulties and of the ideologies that shaped residential services is provided, before the rights of this population to sexual lives under current legal and policy frameworks are outlined. Then it is discussed how lack of privacy and a number of practical issues in residential group settings affect personal safety and restrict the autonomy of people with learning difficulties. The paper concludes by discussing ways in which change may be achieved.

Terminology

Like most other self advocacy agencies (e.g. Central England People First 2000), the self-advocacy group that is involved in writing this paper has chosen to be referred to as 'people with learning difficulties'. In contrast to the term 'learning disabilities', which is used amongst UK professionals (e.g. Department of Health 2001, 2007), the term 'learning difficulties' emphasises that people are *able* to learn once *difficulties* in the learning process are overcome (Harris 1995). In line with the social model of disability it emphasises that the barrier to learning is not merely located within the individual experiencing difficulties, but within his or her social environment (e.g. Oliver 1990). Disabling barriers include inaccessible language or restrictions that are placed on people who are labelled to have learning difficulties.

Self advocates determine the course of their own lives (Goodley 2000). They speak up and take responsibility for themselves; they stand up for their rights, make choices and strive towards independence (People First Workers 1996). Self-advocates represent the interests of all people with learning difficulties. In short, self advocacy is a practice that contests oppression (Dowse 2001).

When using the term 'residential group settings' this paper refers to any residential group arrangement that does not present a family unit or a group of friends who initiated the set up of their residential arrangement and have thus negotiated ground rules amongst themselves, without the interference of others. 'Residential group settings' include residential homes and independent living groups. They include large and small establishments that house a minimum of two people. Support staff are typically present 24 h per day.

Methodology

This paper is the outcome of a participatory research project; hence it is based on an alliance between a researcher and people with learning difficulties. Participants were involved at all stages of the project, from defining the problem to disseminating results (Walmsley & Johnson 2003). An alliance between researcher and participants is crucial to facilitate the inclusion of people with learning difficulties in

research (Chappell 2000). While people with physical impairments may require technological aids in order to carry out their own research, most people with learning difficulties require the assistance of non-disabled allies to access research and complex theory and to enable their views, concerns and theorisations to find their way into print (Walmsley & Johnson 2003).

Four focus group discussions were conducted with 15 self-advocates during a service user consultation on the formulation of a local relationship policy for working with people with learning difficulties [see NHS Lothian (2004) for an example of such a policy]. The group identified the issues discussed in this paper to be of particular importance and decided to share their concerns with a wider audience. What started out as research that was in danger of being service-led, enquiring about best practices within current provisions, evolved into what Aspis (1997) would consider to be a true self-advocacy project: The self-advocates involved in this research do not only wish to negotiate existing provisions, they also recognise the importance of fundamental change to what is currently available.

The self-advocates who were involved in the research gave their informed consent to and asked for their concerns to be publicised. To ensure confidentiality of research participants, all data presented in this article has been anonymised. However the group chose to be acknowledged as a contributor to this paper. The implications that this has for confidentiality have been discussed and participants decided nevertheless to be acknowledged as co-authors. The self-advocacy group has been consulted throughout the writing of this paper, to ensure that individuals' concerns are reflected adequately. Social services managers and the writers of the local relationship policy are informed of the outcomes of group work. Ethical approval for this work has been granted by an appropriate ethics committee.

Historical context and rights

Historically the sexuality of people with learning difficulties was conceptualised through two contrasting stereotypes. On the one hand, they were seen as 'eternal children', as innocent and asexual. To protect their 'natural innocence', information about sexuality was withheld from this population. 'Any signs of sexual interest or arousal were ignored, repressed or misunderstood' (McCarthy 1999:53). On the other hand, people with learning difficulties were also portrayed as sexually deviant, as sexually menacing and promiscuous, as having urges that are beyond their capacity to control. They were seen as over-sexed and as a potential sexual threat to others (McCarthy 1999; Parmenter 2001; Ryan & Thomas 1987). In the UK eugenic assumptions contributed to the reasoning for segregation of people with learning difficulties in residential institutions, which was legally enacted by the *1913 Mental Deficiency Act* (Weeks 1989).

'Traditionally, disabled people have been viewed as passive, unable to cope with normal social relations and dependent upon others' (Finkelstein 1981, p. 59). Professional practice grew on the basis of the social exclusion of disabled people and led professionals into a set of practices which have become barriers in disabled people's lives (Finkelstein 1981). Illich (1977) claims that the way in which traditional services were set up was beneficial to professionals, who were able to control and manage the lives of disabled people. However, they prevented people with impairments from exercising their full rights and responsibilities as citizens. In the 1960's a group of people with physical impairments who resided at the Le Court Cheshire Home in Hampshire began to demand control over their own lives. They asked for the freedom 'to choose our own bedtimes, drink alcohol if we chose, freedom for the sexes to relate without interference, freedom to leave the building without having to notify the authorities, etc.' (Hunt 1981, p. 38). Later on many of these residents managed to move into their own homes in the community and they became convinced 'that community-based alternatives to residential homes [are] an essential component of regaining the citizenship rights of disabled people' (Finkelstein 1991, p. 23). The demands of the disabled people's movement, the emergence of the normalisation principle (Nirje 1992), economic considerations and other influences resulted in the deinstitutionalisation and community living movement (Parmenter 2001). However for many people with learning difficulties moving into community-based settings meant to move from large institutions into smaller independent living groups, where rules and regulations that were set out by non-disabled professionals continue to impact on their lives.

Today the UK government is committed to enforce the human rights of people with learning difficulties. The White Paper *Valuing People* (Department of Health 2001) is underpinned by the principles that this population must be included in mainstream social life and that their rights, choices and independence must be promoted. *Valuing People Now* (Department of Health 2007) continues to build on these principles. People with learning difficulties have the right to respect for private, home and family life [Human Rights Act 1998, Article 8(1); United Nations 2006, Article 22]. The *Convention on the Rights of Persons with Disabilities* (United Nations 2006) directs state parties to:

Take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others (Article 23).

Such and other recent legal, policy and practice developments have resulted in positive changes, but there continues to be a need for further developments in order to enable

people who reside in larger residential services and smaller independent living services to exercise their right to privacy and to lead autonomous sexual lives. This paper draws attention to the fact that not all the people with learning difficulties who were involved in writing this paper can take their right to privacy for granted.

Our homes have rules that do not allow our partners to sleep in our bedrooms. But there should be ways around them. Especially couples who have been together for a long time are upset by those rules. We want to do in our home whatever we like to do. That is what other people do. We want privacy and a right to sexual lives.

Pursuing privacy in residential group settings

Adults who have reached the legal age of consent to sexual activity, which is 16 in the UK for both homo- and heterosexual activity [Sexual Offences Act 2003, section 10.c(i)], may choose to be sexually active. Sexuality has a central place in cultural understandings of the boundaries between childhood and adulthood (Waites 2005). Disabled people are however often excluded from the rights and responsibilities normally associated with adult social status (Priestley 2003). In respect to sexuality people with learning difficulties are often kept in a permanent state of adolescence as social constraint causes their sexual activity to be secretive and rushed.

At [...] they used to say: 'Don't kiss your boyfriend here. Go behind the wall'.

At [...] they used to send couples behind the shed.

We went into the car park.

Research conducted by McCarthy (1999) confirms that sexual activity of people with learning difficulties in institutional settings takes place outdoors or in isolated semi-private places indoors (e.g. in unused rooms). Rushed sexual activity 'behind the wall' allows little space for careful negotiations of personal boundaries. Consequently individuals have limited time to consider whether they consent to a proposed sexual act and to communicate their decision. Inevitably this places them at risk. Many incidents of sexual violence against people with learning difficulties are perpetrated by a known and trusted person, 'in the context of an ongoing, often intimate relationship' (McCarthy & Thompson 1996, p. 206). Combined with our knowledge of the high incidence of sexual violence against this population (prevalence figures range from around 10% to 80%; Cambridge 2007), these factors must make us alert. The self-advocates suggest a simple solution to balancing personal safety and personal rights:

We want our partners to be allowed in our bedroom. We want to be private and safe. Then we could call for help if we need to. We would be comfortable. We would be able to take time and enjoy each other.

However some family members or carers may hinder the relationship of a person with learning difficulties.

Sometimes carers will say that a person is unable to make decisions about privacy and relationships. This is bad. You should have your own choices and make your own decisions. You should be treated as an adult. If you have no choices, you have no rights. Staff should step back and let people make their own decisions.

Some people with learning difficulties are deemed to lack the capacity to make decisions about sexual activity (Sexual Offences Act 2003, section 74). The Sexual Offences Act (2003) does not define capacity. The Mental Capacity Act (2005) is underpinned by the principle that 'a person must be assumed to have capacity unless it is established that he lacks capacity' [Section 1(2)]. Lack of capacity can only be established in relation to a particular decision and only after 'all practicable steps to help (a person to make a decision) have been taken without success' [Section 1(3)]. This implies that people with learning difficulties must in the future receive suitable information about sexuality and support with interpersonal relationships, in order to enable an appropriate judgment about their capacity. If these measures are taken, it is likely that it will be established that many people with learning difficulties, who were in the past assumed to lack capacity, do in fact have the capacity to make decisions about sexual relationships. The Mental Capacity Act 2005 furthermore directs that 'a person is not to be treated as unable to make a decision merely because he makes an unwise decision' [Section 1(4)].

Everybody has their own choices and opinions and everybody can make their own decisions. Some relationships work out, some don't. But the person with learning difficulties should be able to try to make it work.

Being allowed privacy in one's bedroom is not just about sex. Privacy is also an important factor in personal relationships. Not all conversations between couples can be held in public or semi-private spaces.

A couple should have a chance to get to know about each other and to talk to each other in private.

Some self-advocates report that they are not allowed to invite any person who is not a staff or family member to their bedroom. The following personal accounts describe what happened when individuals disobeyed these rules:

My boyfriend once went to my bedroom. Staff came and checked on him. They asked: 'What are you doing here?' and told him to leave.

Once I was in this hostel. I was in a bedroom with this man and we were watching the television. Staff came in and told me off. We weren't doing anything. We were just watching the television. They misunderstood. They would not allow us to be in his room together after that.

When you went to your room they checked on you every two minutes.

They [...] removed the locks on the doors.

Carers in these situations may have been concerned with the personal safety of the individuals involved, but where, if not in one's own bedroom, can a person seek privacy? Some of these examples date some time back and services may have improved for the better, but others are recent examples from people whose sexual relationships are suspected to be unsafe by staff. One member of the group does not understand that this is the reason for staff discouraging privacy, even though when we asked, staff claimed this has been explained. We must conclude that this was not explained in a way that enabled the individual concerned to understand the staff's concerns. It might also be worth asking whether those safety considerations cannot be attended to. Attempting this is after all a legal requirement under the Mental Capacity Act (2005) [Section 1(3)].

When talking about privacy in more general terms, the self-advocates in the focus group felt that people who cannot lock their bedroom door especially lacked privacy because 'anyone can walk in'. Others complained that:

Some people just walk into my room without knocking. It's annoying. Sometimes I'm decent, sometimes I'm not decent.

Lack of privacy in one's own bedroom consequently affects people on a daily basis and extends to a broad range of situations, of which lack of privacy in sexual relationships is only one aspect. Being private is even harder for people who share bedrooms. One member of the focus group has only recently been allocated her own room. She remembers what it felt like to share:

I shared my bedroom. I wasn't my own boss then. I didn't have my own space. I could not be private at all.

If you share your bedroom it may not be possible to be intimate and have your partner sleep in your bedroom. A further obstacle for many people who live in group homes is the fact that they sleep in single beds. Some single beds are very narrow and there might not be the space to allow another person to sleep in the same bed. All the people in

the focus group who live in group homes sleep in single beds and they do not know anyone in their homes who has a double bed, with one exception:

One of the lads sleeps in a double bed, but that is because he kept falling out of a single bed with fits. I slept in a single bed. Everyone else is in single beds. No one thought about us having double beds.

This quote indicates the fundamental tension between service priorities and the priorities of those using services: A medical reason may serve to justify the purchase of a double bed for a person, but whether some people would wish to have a double bed to make space for their partner to sleep over is rarely discussed. Whether people are allowed some private time in their bedroom with their partner during the day varies:

It depends who is on. Sometimes I am allowed in [girlfriend's] bedroom.

In those cases individuals are dependent on the goodwill of staff members who will overlook written or unwritten rules. Such change is only temporary. It does not take the power away from individuals who represent institutions (Aspis 2002).

The way forward?

We contacted the Commission for Social Care Inspection (2007) to enquire whether they believe that individuals who live in residential group settings can have their partner stay overnight in their bedrooms. We were asked to consider the following points:

- the contractual agreement between the individual and the service provider;
- the use of an independent advocate;
- the facilities in the home and what safeguards can be put in place for other people who may be living at the home;
- the role of staff in supporting all the people living at the home and the person wanting to stay over;
- the service user guide and statement of purpose should provide information about what arrangements are and can be put in place to support people wishing to use their private space to see someone privately;
- before a couple is allowed privacy, an assessment should establish that this is a fully consenting relationship.

As we have stated earlier on, we disagree with the last point: We believe that people with learning difficulties can and should make their own decisions about relationships. We do not agree that all of our relationships have to be formally assessed by professionals.

In respect to the other points that were raised, these are complex issues. It is unrealistic that individual people with learning difficulties can follow these procedures by themselves. Even if one person would succeed to establish the

right to have a partner stay overnight in his or her bedroom, this would not benefit others in the same situation. For permanent or long-term change it is necessary that rules, policies or legislation change (Aspis 2002). One of us lives in a group setting in which the policies have changed:

My boyfriend is allowed to be in my bedroom. All of us have panic alarms in our rooms. We can call the carers if we need to.

We think this is good. All homes for people with learning difficulties should work like that.

Living in a home that provides privacy in such a way should be the norm, not a privilege. Policies should consequently change to ensure that a right for privacy can be realised in any setting, so that people who live in residential group settings do not continue to be disadvantaged.

The rules that say who can and cannot sleep in someone's bedrooms are written in the policies of group homes. We don't even know the person who made those rules! We want to speak to the person who made the rules so that we can change the rules.

Professionals call us 'service users'. We and our social services departments pay for the service we receive in our homes. In return we ask to be able to have some choices and control over how that service is delivered to us.

If we look at national policy developments we can see that our concerns have moved onto the agenda. *Valuing People* (Department of Health 2001) merely stresses that '[g]ood services will help people with learning disabilities develop opportunities to form relationships, including ones of a physical and sexual nature' (section 7.39, p. 81). The White Paper does not name support with sexual relationships as a key target for local or central government action. *Valuing People Now* (Department of Health 2007) on the other hand lists 'a focus on relationships when planning with people about their own lives, including personal and sexual relationships' (section 2.3.4, p. 14) amongst the priorities for action.

Most services have progressed in recent years. Men with learning difficulties who participated in Yacoub & Hall's (2008) study, for example, stated that services were generally supportive of their relationships, but that this had not always been the case. Despite some positive developments then, *Valuing People Now* (Department of Health 2007) acknowledges that currently 'insufficient consideration [is] given to personal relationships in individual planning and care management processes' (section 12.3.1, p. 57). It is suggested that positive risk taking should be a part of people's lives (ibid). Allowing for privacy and allowing for people to try to make their relationships work without interference from others would constitute positive risk taking. In order to ensure that more people with learning

difficulties in the UK can claim their right to privacy in their own bedrooms, each local area should have a relationship policy that directs how these rights should be enforced. People with learning difficulties must have a central role in writing the policy. But as long as enforcing a relationship policy is an option, not an obligation, people who reside in some areas will continue to miss out.

Conclusion

There are many more things that need to be said about privacy, relationships and people with learning difficulties who live in residential group settings. For example we have not written anything about the specific difficulties gay or lesbian people may experience. That is because nobody in our focus group identifies as gay or lesbian and we do not know what difficulties this group would face. Would staff attitudes be different? Would people find it harder or easier to be private in a relationship? Furthermore we have been talking about relationships between two people with learning difficulties and we have not asked how things might be different if a non-disabled person would want to sleep in the bedroom of his or her partner who lives in a residential group setting. Nonetheless we believe that we have raised some important issues.

We argue that it is not possible to stop people from being sexual by barring privacy. Lack of privacy means that people often have no choice but to be sexually active in public places. Sex is often unsafe and rushed. Consequently we believe that the safest way of responding to the sexual needs of people with learning difficulties is to create safe spaces that allow for privacy. This is of particular importance for people who continue to live in residential group settings, where privacy is even harder to achieve. Only consistent policy guidance that makes our rights explicit can ensure that being allowed the privacy to lead fulfilling sexual lives becomes the norm, not a privilege.

Maybe the issues discussed in this paper are not that new. As far back as in the 1960s residents of the Le Court residential home articulated concerns about lack of control over their own lives. Disabled people in Britain as a whole have benefited from the struggles of such groups of disabled people who speak up for their rights, but for us some issues have remained unresolved. We want to help to further challenge the rules and regulations that affect our private lives. This paper sets out to facilitate this process.

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References

- Aspis S. (1997) Self-advocacy for people with learning difficulties: does it have a future? *Disabil Soc*, **12**: 647–54.
- Aspis S. (2002) Self-advocacy: vested interests and misunderstandings. *Br J Learn Disabil*, **30**: 3–7.
- Cambridge P. (2007) Editorial. *Tizard Learn Disabil Rev*, **12**: 2–3.
- Central England People First (2000) *Who are we?*. Central England People First, Kettering, UK. Available at <http://www.people-first.org.uk/whoarewe.html> (accessed 4 June 2008).
- Chappell A.L. (2000) The emergence of participatory methodology in learning disability research: understanding the context. *Br J Learn Disabil*, **28**: 38–43.
- Commission for Social Care Inspection (2007) *Homepage*. Available at <http://www.csci.org.uk/> (accessed 4 June 2008).
- Department of Health (2001) *Valuing people: a new strategy for learning disability for the 21st century – white paper*. London, HMSO.
- Department of Health (2007) *Valuing people now: from progress to transformation – a consultation on the next three years of learning disability policy*. London, Department of Health.
- Dowse L. (2001) Contesting practices, challenging codes: self advocacy, disability politics and the social model. *Disabil Soc*, **16**: 123–41.
- Finkelstein V. (1981) Disability and the helper/helped relationship. A historical view. In: Brechin A., Liddiard P., Swain J., editors. *Handicap in a social world: a reader*. Sevenoaks, Hodder and Stoughton in association with the Open University Press: 58–63.
- Finkelstein V. (1991) Disability: an administrative challenge? (The Health and Welfare Heritage). In: Oliver M., editor. *Social work: disabled people and disabling environments*. London, Jessica Kingsley Publishers: 19–39.
- Goodley D. (2000) *Self-advocacy in the lives of people with learning difficulties: the politics of resilience*. Buckingham, Open University Press.
- Harris P. (1995) Who am I? Concepts of disability and their implications for people with learning difficulties. *Disabil Soc*, **10**: 341–51.
- Human Rights Act 1998*. London, HMSO.
- Hunt P. (1981) Settling accounts with the parasite people: a critique of 'A Life Apart' by E.J. Miller and G.V. Gwynne. In: Union of the Physically Impaired Against Segregation (UPIAS), editor. *Disability challenge (1)*. London, UPIAS: 37–50.
- Illich I. (1977) Disabling professions. In: Illich I., Zola I.K., McKnight J., Caplan J., Shaiken H., editors. *Disabling professions*. New York, London, Marion Boyars: 11–39.
- Mental Capacity Act 2005*. London, HMSO.
- McCarthy M. (1999) *Sexuality and women with learning disabilities*. London, Jessica Kingsley Publishers.
- McCarthy M. & Thompson D. (1996) Sexual abuse by design: an examination of the issues in learning disability services. *Disabil Soc*, **11**: 205–17.
- NHS Lothian (2004) *Making choices keeping safe – policy and practice guidelines on relationships and sexual wellbeing when working with people with learning disabilities*. Edinburgh, NHS Lothian.
- Nirje B. (1992) *The normalisation principle papers*. Uppsala, Sweden, Centre for Handicapped Research, Uppsala University.

- Oliver M. (1990) *The politics of disablement*. London, Macmillan Education.
- Parmenter T. (2001) Intellectual disability – Quo Vadis? In: Albrecht G., Seelman K., Bury M., editors. *Handbook of disability studies*. London, Sage Publications: 267–96.
- People First Workers (1996) *Speaking out for equal rights workbook 2*. Buckingham, Open University Press, People First and Mencap.
- Priestley M. (2003) *Disability: a life course approach*. Oxford, Polity.
- Ryan J. & Thomas F. (1987) *The politics of mental handicap (revised edition)*. London, Free Association Books.
- Sexual Offences Act 2003*. London, HMSO.
- United Nations (2006) *Convention on the rights of persons with disabilities*. New York, United Nations General Assembly.
- Waites M. (2005) *The age of consent: young people, sexuality, and citizenship*. Basingstoke, Palgrave Macmillan.
- Walmsley J. & Johnson K. (2003) *Inclusive research with people with learning disabilities – past, present and futures*. London, Jessica Kingsley Publishers.
- Weeks J. (1989) *Sex, politics and society – the regulation of sexuality since 1800*. 2nd edn. Essex, Longman Group Limited.
- Yacoub E. & Hall I. (2008) The sexual lives of men with mild learning disability: a qualitative study. *Br J Learn Disabil*, Advance access published article online: 19-Feb-2008 (doi: 10.1111/j.1468-3156.2008.00491.x).