Learning Disability Practice

Stonewalled: supporting LGBT people with learning disabilities express their sexual and gender identities.

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Abstract

The aim of this paper is to develop an understanding of supporting people who identify as LGBT and who have a learning disability through alignment of lived experiences and an exploration of the existing literature. Evidence indicate barriers to people with learning disabilities obtaining and maintaining loving relationship, this is particularly the case for those identify with an LGBT community.

A twitter chat, and subsequent exploration of the literature indicate themes in UK policy and legal frameworks, influenced by series of complex ethical issues, pertaining to concept of intersectionality – that of unique discrimination experienced by those who identify with a combination of minority groups.

The results prompt considerations for further research to underpin practice development and education programmes to support people in developing their sexual identity, linked to further research to document this progress.

Keywords :
Learning Disability, LGBT, Intersectionality, Twitter chat

Introduction

For many people with learning disabilities, loving relationships are unattainable (Bates, 2018). Evidence of barriers such as risk aversive practice can limit the formation of loving and sexual relationships and create a negative impact on an individual's self-esteem, sense of belonging and mental health (DH, 2009; Stacey & Edwards, 2013; Bates 2018; 2019).

The Government Equalities Office (GEO) LGBT action plan (GEO, 2018) acknowledges that despite advances in equality, LGBT people continue to face significant barriers in society. It found that physical, mental, sexual health, and wellbeing outcomes are generally worse for LGBT people than the rest of the population (GEO, 2018). Pairing these findings with the evidence of multiple forms of discrimination for LGBT people with a learning disability (Abbot & Howarth, 2005; Wilkinson et al, 2014; Bates, 2018) presents a compelling argument for greater support and training. This paper outlines the process of harnessing new media to explore the topic with interested parties (Robinson & Dowling, 2018) as a foundation for a commentary on current literature.

While the authors recognise the breadth of identities within the LGBT+ community, within the context of this paper the term LGBT will be used, exploring the experiences of lesbian, gay, bisexual and transgender people (Stonewall, 2019), rather than the wider experiences of communities such

as those who identify as queer, non-binary and intersex and other identities that may be considered under the LGBT+ umbrella (University of Bristol, 2019)

Main text

Online conversations provide space for discussions and debate, reflection and learning with an intention to impact on attitudes, perspectives and ultimately practice (Moorley and Chinn, 2015). Increasingly, Social media is recognised as an arena in which professionals and researchers can engage with a range of subjects and understand the lived experiences of individuals, however the potential bias that is created through increased familiarity with specific social media platforms, those who engage with this format and researcher experience of the explored phenomena must considered (Salmons, 2020). Through facilitated bi-weekly conversations WeLDNurses have enabled a range of topics, through discussion with the facilitators, a discussion on exploring LGBT identities was arranged, following this a brief exploration of the literature was conducted to identify any themes across both the lived experiences of people and also within the evidence base.

While the aim of this paper is not to provide a systematic review of all existing literature exploring the intersection between learning disabilities and LGBT identities, the principles of literature searching were applied.

The following search terms were used "Sexuality", "Sex", "learning disability" and "Support", on Scopus database. No articles prior to 2000 were included within the thematic analysis, due to significant changes in social policy and legislation across the UK for both people with learning disabilities and LGBT people in that time frame.

Results

The WeLDNurses chat (Robinson & Dowling, 2018) attracted 22 participants, including parent carers, and a range of nurses from students to consultants. A transcript of the conversation was generated (Robinson & Dowling, 2018), along with a wordcloud (figure 1). A word cloud provides a visual representation of themes within a body of text creating an accessible method of engagement beyond statistical analysis (Bletzer, 2015). Through later analysis of the transcript informed by the auto-generated word cloud; a number of themes emerged:-

- How to support LGBT people
- Educating carers and supporters
- Ethical and legal issues and understanding of legal frameworks

An exploration of the literature identified themes more broadly under which the above discussion points could be comfortably housed, it is these broad themes that will inform the discussion moving forward;

- Ethical implications
- UK Context including legal and policy

- Research and practice development
- Intersectionality

Figure 1 WeLDNurses LGBT Chat Wordcloud (Robinson & Dowling, 2018)

Discussion

UK Context

The World Health Organisation (2006) conceptualises sexuality as a multidimensional construct which includes; sex, gender and intimacy. Which can be expressed through; attitudes, behaviours and relationships throughout a person's life span. Adults with learning disabilities present with the full range of gender identities and sexual identities which occur in the general population (Parkes et al., 2009; Bates, 2018). Regarding adults with learning disabilities who identify as lesbian, gay, bisexual and transgender (LGBT), there is both historic and recent evidence of negative attitudes and stigma surrounding them (Abbott & Howarth, 2006; Cambridge, 2013; Bates et al., 2016; Bates, 2018; Maguire et al., 2019), with services responding inappropriately to their needs and many services considering sexual choice and sexuality to be a taboo topic (Wilkinson et al., 2014; Bates, 2018). In 2018 the Government Equalities Office (GEO) released its LGBT Action Plan; this follows a national survey of LGBT people, open to anyone who identified as having a minority sexual orientation, gender identity or those with variations in sex characteristics (GEO, 2018). It asked questions regarding the experiences of participants living in the UK and the public services they have accessed, including education, health, safety and employment. With more than 108,000 responses it became the largest survey of its kind in the world (GEO, 2018). They found that the UK had made great advances in supporting LGBT people, however, they recognised that despite these advances' LGBT people continue to face barriers (GEO, 2018; Bates 2018; 2019). Commissioned research by the National Institute of Economic and Social Research (2016) found evidence of health inequalities of

LGBT people in comparison to heterosexual people. The research also found higher rates of mental health problems amongst LGBT people which include; suicide, self-harm, anxiety and depression.

Policy context

In 2001, Valuing People (Department of Health (2001); a government white paper, aspired to develop opportunities for people with learning disabilities in Britain to from relationships, including those of a sexual nature. However Valuing People Now (Department of Health, 2009, DH) discovered a lack of progress, with people with learning disabilities continuing to lack relationships, friendships and continue to experience isolation (DH, 2009; Stacey & Edwards, 2013; Bates, 2018; 2019). Additionally, the Family Planning Association (2008) found that people with learning disabilities were denied the support to pursue sexual relationships. Bates (2018; 2019) identified that people with learning disabilities have; a desire to have a partner who they love and who loves them, that love is important, specifically companionship and the support a loving partner can provide.

Legal framework

The Human Rights Act (1998) incorporates the right to express one's sexuality and to be free from discrimination on the ground of sexual orientation, while the *Equality Act (2010), protects those who identity as LGBT.* However most significantly is capacity legislation – Mental Capacity Act 2005 in England and Wales and Incapacity Act 2000 in Scotland –which is key to services and providers when working with adults with learning disabilities, this includes discussions and decisions related sex and sexuality.

Sexuality and sexual abuse must not be treated as interchangeable concepts. It is utmost importance that we respect the agency and autonomy of people with learning disabilities to have fulfilling sexual experiences and relationships providing we are confident in their capacity to consent to these, and to protect themselves from unwanted sexual encounters (Craft, 1987).

When discussing risk aversive practices alongside this legalisation it is important to distinguish that the person is not being treated as unable to decide merely because decision could be considered unwise. Allowing a person with a learning disability, who may be vulnerable, to make decisions regarding their sexual expression and relationships, can be testing for services and providers (Bates, 2018; 2019; Maguire et al., 2019). However, this complexity ought not preclude the person of their right to choose and to learn from the decision.

"The intention of the act is not to dress an incapacitious person in forensic cotton wool, but allow them as far as possible to make the same mistakes that all other human beings are at liberty to make and not infrequently do" (EWHC 50, 2013, cited in, Bates, 2018, p.27).

With this point in mind it is important that services and providers are given the right information to be able to support their individuals through these experiences rather than preventing them from

doing so (Bates, 2018; 2019; Maguire et al., 2019). Additionally, for people to have the information and the capacity to decide, they must be given all the relevant information, understand the information, and retain the information for long enough to come to the decision (Parkes et al., 2009).

Ethical implications

Love and Belonging is cited by Maslow (Maslow, 1943, cited in Bates et al., 2016) as essential in order to achieve self-esteem and self-actualisation. Love in its many forms is an important aspect of life for people, including those with learning disabilities; with sexual expression, sexual relationships, marriage and children being a natural expectation of a person's life experiences (Cambridge & Mellan, 2000; Abbott & Howarth, 2006; Mental Welfare Scotland, 2011, Bates et al., 2017). Belonging to a community can improve health, happiness and self-esteem (Bates et al., 2017; Bates, 2018). Additionally, it is widely known that sexuality encompasses a range of experiences which contribute to a person's self-identity (Abbott & Howarth, 2006; Bates et al., 2016; 2017, Bates, 2018; Maguire et al, 2019). It is felt that further work exploring communities and this sense of belonging could be beneficial in the future. The creation of these will support people with learning disabilities further and in turn allow their identities to flourish.

Research and Practice Development

In the past evidence has indicated the use of pharmacological interventions in the hope of reducing sexual expression (Puri & Singh, 1996, cited in Cambridge 2013; Bandri & Robertshaw, 1998), while current research showing positive developments, exploring the equal rights of people with learning disabilities and their right to explore their sexuality (Bates et al., 2017; Bates, 2018; 2019; Maguire et al., 2019). However, despite this progress, a sense of belonging and loving and sexual relationships remain unattainable for many people with learning disabilities (Bates, 2019; Maguire et al., 2019).

Abbott & Howarth (2006) found that staff did not feel confident to be able to support their individuals with learning disabilities with personal relationships and sexuality, with Maguire et al (2019) concluding that support workers may inadvertently express negative and limiting discourses about the sexuality of adults with learning disabilities. There is historic and current presumption that issues regarding sex and sexual identity should not be raised by those supporting but should wait until it comes from the person (Abbott & Howarth, 2006; Thompson, 2011; Cambridge, 2013; Maguire et al., 2019). However, research by the Social Care Institute for Excellence (2017) found that many people with disabilities including learning disabilities are not open with their support workers about their sexual identity. It was said that this was due to fear of judgement, intolerance and discrimination (SCIE, 2017). Although some individuals who had revealed their sexuality to their supporters said they felt more relaxed 'in their own skin' and were able to get the right support, not all shared participants had shared these positive experience (SCIE, 2017; Bates, 2018).

To challenge some of these issues the LGBT Health and Inclusion Project (LGBT HIP) led by Switchboard (2019) was created to promote LGBT health and wellbeing in the Brighton and Hove area. Since it began in 2012 the LGBT HIP has researched the experiences of the LGBT community surrounding health and social care. Although limited to a small geographical area, the findings correspond with the findings within the LGBT Action Plan (GEO, 2018) In addition, Switchboard (2019) found there was a lack of accessible information which, under the Equality Act (2010), is a requirement for all services, including those who support people with learning disabilities. Furthermore, they discovered practical barriers, for example; communication, social isolation and accessing LGBT events and groups can be difficult for adults with learning disabilities if not provided with the appropriate support (Bates et al., 2017; Bates, 2018; Switchboard, 2019). There are also concerns regarding risk aversive practices; these are practices in which services restrict their individuals from experiencing relationships and sexual avoidance (Bates, 2018; 2019; Maguire et al., 2019).

The National Development Team for Inclusion (2016) systematic review identified that support workers and family carers struggle to find the balance between protecting their individuals from potential abuse and empowering them to realise their sexual expression, with the Department of Health (2009,) finding that services was more likely to restrict the opportunities for sexual relationships rather than support. It is clear that there is still a reluctance from support workers to support adults with learning disabilities to express their sexuality through sex and relationships (Cambridge, 2013; Bates et al., 2016; 2017; Bates, 2018; Maguire et al., 2019). Tindall (2015) highlights evidence of relationships being restricted by staff; this could be due to staff following strict safeguarding practices. In addition, there is a fear of 'getting it wrong' and a worry that the individuals are vulnerable to abuse (Abbott & Howarth, 2006; Bates, 2018; Maguire et al., 2019), therefore discouraging relationships (Thompson, 2010).

Cambridge (2013) believes a tension exists between protection and empowerment when regarding the sexuality of people with learning disabilities. Safeguarding processes and procedures are important to both the wellbeing of individuals and the providers who support them on a daily basis (Cambridge, 2013; Tindall, 2015). However, in concordance with the DH's (2001; 2009) findings, some of the decisions made to protect an individual can make them less safe and serve to protect the decision makers instead (DH, 2001; 2009; Tindall, 2015). With people with learning disabilities no longer living in institutions and living in smaller or individual homes there is a reliance on other to support accessing the community and making these decisions as well as partaking in these decisions (Abbott & Howarth, 2006; Tindall, 2015; Bates 2018; 2019; Maguire et al., 2019), there is evidence to suggest that relationships are being restricted by staff (Bates et al, 2017; Bates, 2018).

Intersectionality

The concept of intersectionality was defined by Crenshaw (1989) as a theoretical model for considering how an individual's social and political identities might mix to cause new types of discrimination, in this case the combination of having a learning disability, and identifying as part of the LGBT community. There is evidence to suggest that mental health services are often perceived as discriminatory towards LGBT people, the LGBT action plan (GEO, 2018) suggests that for transgender people there is evidence of pathologisation (attributing mental health problems to their transgender status) in concordance with evidence of diagnostic overshadowing for people with learning disabilities (GEO, 2018). Additionally, the higher rates of mental health problems for people who are LGBT were found to be due to discrimination and prejudice within society (GEO, 2018). Evidence of health inequalities and mental health problems in the wider community (DH; 2001; 2009; Foundation for people with learning disabilities, 2008) demonstrates it is also important to recognise the need for appropriate support for people with learning disabilities who identify as LGBT.

For LGBT people there is a significant need for a sense of community in order to reduce social inequalities, barriers and support good mental health (Formby, 2012; NIESR, 2016; Bates, 2018). Walkerdine & Studdert (2011) and McKenzie (2012) states that there is an importance of communities of identity and with that, the sense of belonging which is significant for marginalised or stigmatised groups. A feeling of belonging for people who are LGBT can come from the shared experiences such as; stigma, prejudice, inequality or discrimination (Formby, 2012) and additionally, through diversity within the communities such as; age, disability, ethnicity and gender. Leading to a feeling of acceptance and the desired sense of belonging. Furthermore, Weeks et al (2001) highlights the roles of friendships and 'families of choice' for people who are LGBT which leads to asserting and supporting a positive individual and collective identity (Weeks et al., 2001; McKenzie, 2012; Formby, 2012). For people with learning disabilities who are LGBT accessing these communities will be challenging through lack of accessible services and appropriate support (Switchboard, 2019; Bates, 2018), this can lead to social isolation.

Limitations

The aim of this paper was to provide and understanding and align the lived experiences of participants with the existing evidence base, this process has not been without its limitations, a more thorough literature search using a broader database set may have yielded a higher number of articles (Grewal, Kataria and Dhawan, 2016) which may have implications for the outcome of any analysis, furthermore, the inherent bias of use of social media (Salmons, 2000) means that those unfamiliar with the platform may not have been able to contribute effectible and there voices may have note been heard.

Considerations

For staff and services to provide appropriate support for people with learning disabilities regarding their sexuality they must have the right; policies, guidance, knowledge and training in place (Maguire et al., 2019). Services must design policies to facilitate the provision of supporting surrounding sex and relationships for their individuals with learning disabilities (Abbott & Howarth, 2006; Bates et al., 2016). According to Cambridge (2013) policies & education must be informed by the experiences of those involved, as they have the right to safe, consenting and consensual sexual expression (Abbott & Howarth, 2006; Cambridge, 2013; Bates et al., 2016; Bates, 2019), encouraging positive risk taking, which is essential for love and relationships to flourish (DCA, 2006; Bates et al., 2016; 2017, Bates, 2018). Additionally, will ensure the provision for access and engagement in social activities is also at the forefront (Abbott & Howarth, 2006; Cambridge, 2013; Bates et al., 2016; Bates, 2018).

Bates et al (2016) asserted the importance of support staff and the role they play in supporting their individuals to fulfil their romantic needs, which is still believed today (Bates, 2018; 2019). Evidence also indicates the importance of staffs role supporting the individual, including reflecting on their own values and beliefs and challenging the preconceptions of others (Thompson, 2010; Cambridge, 2013; Bates, 2018; Maguire, 2019). As such awareness training of recognising, supporting and empowering their individuals with their sexuality, sexual identity, sexual experiences and relationships is recommended. This should be informed by the individual's experiences (Cambridge, 2013; Tindall, 2015; Bates et al., 2017; Bates, 2018), supporting the development of empathy and positive regard for an individual's wishes. Additionally, it will help combat negative self-image and low self-worth, giving a sense of self-actualisation and a feeling of belonging (Bates et al., 2017; Bates, 2018; 2019). Furthermore, it will target the mental health inequalities for people with learning disabilities who are LGBT (Bates 2018; GEO, 2018; Maguire et al., 2019).

Allied to this educational opportunity it would be beneficial to understand more about the intersectional experience of people with learning disabilities who identify with the LGBT community, both quantitatively, to identify inequities, while also hearing the narrative experiences from people themselves which can help educate others.

Conclusion

This paper identifies some significant ethical and legal implications for ensuring that the LGBT community of people who have learning disabilities can have their rights supported and maintained in the UK, and explores the complexity of combinations of social and political identities in the form of intersectionality and the implications for learning disability nursing practice.

Considerations are made for educational and practice development and it is identified that further research in the area is needed to better understand the inequalities and inequities for this cohort, and developing leadership through the sharing of narratives by experts by experience to inform education for carers and supporters.

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