Between a rock and a hard place: The problems and practices of professionals and care workers supporting autistic people with regards to their sexual autonomy, capacity and decision making[1]

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Abstract.

This article presents findings from a research project that examined the problems of professionals and care workers who work with autistic people in dealing with issues of sex and sexuality in their day-to-day work with service users. The research explored what professionals and support workers feel they can or should do when providing support for people whose intellectual disability or mental condition makes their sexual consent—being informed, competent and free from coercion—legally unreliable.

As desexualising prejudices about people with disabilities recede, staff and their organisations are left with no guidance as to how to support service users with regards to the realisation of their sexual desires and the expression of the sexual identities. The law is unhelpful, in that the 2003 Sexual Offences Act and the 2005 Mental Capacity Act make contradictory demands of settings in terms of the criteria for consent and its absence.

Despite contradictions in the law and the absence of national guidelines, the overarching finding from the data is that staff are sensitive to the needs and desires of their service users, and have developed an inclusive ethos and display positive attitudes in supporting the people they work with regarding to their sexuality. However, the contradictory demands of the SOA (2003) and MCA (2005) presented staff with a dilemma: On the one hand, staff and the organisations they work for have statutory duties to safeguard the people they support, but at the same time, they also work in a strengths-focused way to support individuals to live a full and fulfilled life, which includes a recognition of their sexual desires, orientations and identities. At the core of staff concerns are judgements of the competence and comprehension of the service user, complicated by the difficulty of assessing competence, and recognising that competence is neither easily measured nor consistent amongst service users.

Introduction

What should professionals and support workers do when providing support for people whose cognitive or mental condition makes their sexual consent—being informed, competent and free from

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coercion—legally unreliable? This article presents findings from a research project that examined the problems of professionals and care workers working with autistic people[2] in dealing with issues of sex and sexuality in their day-to-day work with service users.

In England and Wales, the legislative framework for supporting vulnerable adults, and specifically the 2003 Sexual Offences Act and the 2005 Mental Capacity Act, make contradictory demands of settings in terms of the criteria for consent and its absence. Under S.1(2) of the 2005 Mental Capacity Act, "A person must be assumed to have capacity unless it is established that he lacks capacity," and S.1(3) states that "A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success."[3] However, capacity to consent to sex is not defined in the 2003 Sexual Offences Act, and under S.30 it is a criminal offence to engage in "Sexual activity with a person with a mental disorder impeding choice,"[4] where the extent of the impediment to choice resulting in criminalisation is not specified.

The Care Quality Commission, the independent regulator of health and social care services in England, has recently published guidance on relationships and sexuality in adult social care services (2019). It provides some examples of how capacity to consent to sex might be established through, for example, assessing individuals' knowledge of the mechanics of sex, their awareness of the potential consequences of sex and, crucially, their understanding that they have a choice in whether they say "yes." This is certainly a step in the right direction, but it fails to address the fact that attitudes towards sexuality are not neutral: they are formed over time, and are socially and culturally contingent. Assessing the capacity to consent to sex takes place in a context where individuals are considered *a priori* to *lack* capacity because of constructions of autism as a deficit characterised by "impairments" in social communication and interaction. Further, capacity is dynamic, continually moving according to mood, environment and context.

The findings from this research demonstrate that staff, whilst committed to empowering and enabling the people they support, struggle with the practicalities of how to do that against a backdrop of legal ambiguity, an absence of appropriate training, and vague, if well intentioned, guidance from regulatory bodies.

Autism and sexuality

Despite the growing body of research into the causes and effects of autism, as well as greater recognition of the specific support needs of autistic people, autism continues to be understood largely within a medical framework, underpinned by a deficit model exemplified in the triad of impairments (Milton, 2012; O'Dell *et al.*, 2016; Woods *et al.*, 2018). Although seen to vary in severity, the triad of impairments assumes that all autistic people are impaired with regards to social and emotional interaction, social communication and language, and flexibility of thought/imagination.[5] In large part, the deficit model of autism contributes to the perpetuation of myths and stereotypes about autistic people's sexuality, and this continues to be an under-researched area, with the effect that relatively little is known about their sexual identities, desires and relationships. According to Stokes and Kaur

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[2] Throughout the article, identity first language will be used rather than person first language, which assumes that "autism can be separated from the person" (Sinclair, 2013)[2]. Although there is considerable debate over which term to use, research indicates that autistic people prefer identity first language (Kapp et al, 2013). The term Autistic Spectrum Conditions (ASC) will also be used in place of the more common but limiting term Autistic Spectrum Disorders.

[3] https://www.legislation.gov.uk/ukpga/2005/9/section/1

[4] https://www.legislation.gov.uk/ukpga/2003/42/section/30

[5] https://www.nhs.uk/conditions/autism/

(2005: 266) “This may be because persons with autism are regarded as sexually immature, or the presence of socioaffective deficits is considered to render sexuality irrelevant.” The sexuality of people with developmental disabilities and cognitive differences, including autism, is seen as simultaneously absent and present. Although usually assumed to be absent because of stereotypes and misconceptions that have desexualised autistic people, its presence is problematized, because it is deemed inappropriate or improper.

Sexuality, which includes but is not limited to sexual expression, sexual and intimate relationships, sexual desires, orientations and identity, is recognised as a positive and affirming feature of human life. The World Health Organization (2010) identifies sexuality as “a central aspect of being human,” and the World Association for Sexual Health’s (WAS) *Declaration of Sexual Rights* recognises that “sexuality is a source of pleasure and wellbeing and contributes to overall fulfilment and satisfaction.”[6] The declaration further states that “sexual rights are grounded in universal human rights” (*ibid*.) and, as such, are predicated on the “freedom, dignity, and equality of all human beings” (*ibid*.). Sexuality is understood to refer to constructions of “blurred description” and distinction, comprising personal and social identities, relations, orientations, behaviours and practices subsumed by pleasure and desire but rooted in physiological and psychological responses (Moore and Reynolds 2018: 8-9). Conventionally, they are recognised through genito-centrism.[7]

Despite the centrality of sexuality to an individual’s wellbeing, there are some groups of people whose sexuality is denied and/or subject to such surveillance that they cannot be said to exercise sexual freedom or autonomy over their bodies because of assumptions that have systematically desexualised them, and resistance to seeing them as sexual subjects.[8] Older people, young people and those with disabilities are notable examples of this, as are autistic individuals.

Attitudes towards autism and sexuality should be understood in the broader context of attitudes towards disability and sexuality. Historically, and, to a lesser extent contemporaneously, disabled people have been viewed as asexual, lacking in sexual interest and unable to form and maintain intimate, sexual relationships. Sexuality has been seen as something that is harmful to disabled people because of fears that they are more susceptible to abuse and exploitation, and therefore as something that they need to be protected from. Considerable energies have been invested in developing laws and policies designed to protect disabled people from sexual abuse and exploitation, and yet there has not been a concomitant investment in providing sex education so that disabled people are better equipped to make informed choices regarding their sexuality and to recognise potentially abusive relationships. Significant progress has been made with regards to inclusion of disabled people in many aspects of social life, due in large part to the emergence of the social model of disability, which posits that disability should be thought of not as an individual phenomenon, but rather as a social, and socially contingent, category. Yet the recognition of disabled people’s sexuality continues to lag behind the wider inclusion agenda, and there are still desexualising myths and misunderstandings about disability and sexuality that act as barriers in the realisation of their sexual rights (Esmail *et al*., 2010; Gougeon, 2010; Abbott, 2013; Abbott and Howart, 2007; Burns and Davies, 2011; Lŏfrgen-Mårtenson, 2004, 2008). There are similar stereotypes and misconceptions about autism and sexuality that shape the lived experiences of autistic individuals.

Sexual development is a complex process that is shaped by physical, social and psychological/emotional factors. Autistic children physically develop in much the same way as their

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[6] http://www.worldsexology.org/wp-content/uploads/2013/08/declaration_of_sexual_rights_sep03_2014.pdf

[7] For an extended discussion of conceptual understanding of sexuality, see Weeks (2010, 1-45)

[8] For a discussion of desexualisation, see Moore and Reynolds (2016)

neurotypical[9] counterparts and reach puberty at a similar time. Like non-spectrum children, autistic children can experience sexual response as early as 24 hours old and engage in “rhythmic manipulation of genitals similar to adult masturbation […] at 2.5 to 3 years of age” (Urbano *et al.*, 2013: 430), even though this is not understood as sexual by children. In other words, the capacity for sexual desire and behaviour is determined by chronological age and not cognitive ability or difference (Tissot, 2009). However, because of desexualising assumptions and the prevalence of a deficit or impairment model of autism, this behaviour is frequently ignored, repressed or classified as “inappropriate.” Autistic children can be denied access to sex education, which in turn prevents them from understanding their behaviour as sexual and from developing a sexual identity (Tissot, 2009). Although ostensibly done in the name of protection, the lack of sex education for autistic children leaves them more vulnerable to becoming victims of sexual abuse (Koller, 2000) and at greater risk of committing sexual offences (Stokes and Kuar, 2005) because of limited knowledge about the contexts in which sexual behaviour should take place.

There continues to be a scarcity of academic research on autism and sexuality, and what is known still tends to be based on the views of parents, carers and professionals rather than the experiences of autistic people themselves. However, what research there is indicates that many autistic individuals do have sexual desires and express an interest in forming relationships and getting married (Newport and Newport, 2002). Not only do autistic people begin to form sexual desires in early puberty at the same time as their neurotypical counterparts, but some research also suggests that they “have levels of sexual interest comparable to those of the general population” (Nichols and Blakeley-Smith, 2010: p. 73). Research findings show that masturbation is a part of the sexual repertoire of both men and women, and that there may be higher incidence of homosexuality, bisexuality (Hellemans *et al*. 2007; Byers *et al.*, 2013; Gilmour *et al.*, 2012) and gender nonconformity (Dewinter *et al.*, 2013) amongst autistic people compared to neurotypical population samples. In light of these findings, a number of commentators have suggested that effective sex education for autistic people is required (see, for example, Danson, 2015; Hellemans *et al.*, 2007; Stokes and Kaur, 2005; Stokes, Newton and Kaur, 2007). However, the lack of accessible sex education material, combined with support staff’s duties to safeguard the people they are working with, means staff are often anxious about raising sexuality issues. For support staff working in England and Wales, this is further exacerbated by the contradictory demands of the Sexual Offences Act 2003 and the Mental Capacity Act 2005.

Research aims and methods

The research was conducted in partnership with an autism specialist charity in the north of England, which supports over 2500 individuals across a range of services, including Registered Supported Living, community resource centres and outreach. They also run various Social Enterprises offering work experience for autistic individuals.

The research explored what professionals and support workers feel they can or should do when providing support for people with respect to their sexuality and to understanding the value of training programmes, guidance documents and codes of conduct, in both day-to-day work with service users and in the development and implementation of organisational policies.

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[9] The term ‘neurotypical’ or ‘neurologically typical’ refers to individuals who are not diagnosed as autistic or as having an intellectual/developmental disability. It is used in preference to ‘normal or ‘typical’ to challenge “the assumption of a non-autistic ‘norm’ [which] is, in conventional understandings, unquestioned and naturalised” (O’Dell *et al.*, 2016: 168).

The study used a mixed methods approach, comprising 65 questionnaires, 44 qualitative interviews and six focus groups. Participants were drawn from samples ofthe charity's (hereafter referred to as "the charity") workforce across seniority, roles and geographical locations. Participants were recruited through the charity, where the aims and objectives of the research and invitations to take part were cascaded via service area managers. Participation was entirely voluntary.

The research was funded through a Research Investment Fund award by Edge Hill University (RD/Moor/14). Ethical approval for this project was granted by the University, and the data were collected in compliance with the University's Framework for Ethics.

This article reports on the findings from the questionnaires and interviews. Fuller details of the methodology are available in the report published with the charity (Moore and Reynolds, 2017).[10]

Research Findings

Despite contradictions in the law and the absence of national guidelines, the overarching finding from the data is that most staff working in the organisation are sensitive to the needs and desires of their service users, and have developed positive approaches for supporting the people they work with regarding to their sexuality. However, the contradictory demands of the SOA (2003) and MCA (2005) presented staff with a dilemma. The 2003 Act emphasises the need for meaningful consent to a sexual act, and states that to engage in sexual activity with a person with "a mental disorder impeding choice" is a sexual offence.[11] The 2005 Act is based on enabling people and recognising their capacity to make decisions, notwithstanding possible limits to that capacity. On the one hand, staff and the organisation they work for have statutory duties to safeguard the people they support, but at the same time, they also work in a strengths-focused way to support individuals to live a full and fulfilled life, which includes a recognition of their sexual desires, orientations and identities. At the core of staff concerns are judgements of the competence and comprehension of the service user, complicated by the difficulty of assessing competence, and recognising that competence is neither easily measured nor consistent amongst service users. Four themes emerged from the study, which reflected both the positive and progressive work being done by the charity, as well as areas for further work and reflection.

Recognition of rights, equality and satisfaction

One of the strongest themes to emerge was a commitment to the recognition of rights and equality for autistic people that corresponded with the organisation's core values and commitment to service users. There was a consensus that the equality and rights of autistic people should be extended to issues of sex and sexuality. For example, 83.1% (n=54) of questionnaire respondents stated that they thought the service users they worked with desired a sex life, and qualified their opinion with statements like:

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[10] The report can be downloaded from https://www.edgehill.ac.uk/socialsciences/files/2018/03/the-problems-and-practices-of-professionals-and-care-workers-working-with-clients-who-are-sexually-active-but-not-legally-able-to-consent-to-sex-report.pdf

[11] https://www.legislation.gov.uk/ukpga/2003/42/section/74 and https://www.legislation.gov.uk/ukpga/2003/42/section/30 respectively

> *"Sexual desire is a normal and healthy part of one's life."*
>
> *"Just because someone is deemed to have a 'disability,' why does this dictate that they shouldn't or cannot have a sex life."*
>
> *"Some service users I have supported self-stimulate sexually, and others have verbally expressed a wish to develop sexual relationships with other individuals."*

However, equality was not simply seen as being the same as neurotypical conceptions of equality. Autistic people's satisfaction of their sexual needs and desires involves complex issues of sexual orientations and behaviours, emotional expression and needs, and interpersonal relationships, which may look very different to neurotypical and normative constructions of sexuality (Hendrickx, 2008). Assuming that service users' sexual identities, desires and needs necessarily mirror those of neurotypical people can be as harmful as assuming that they have no sexual interest (*ibid.*).

This means that when service users do express an interest in being sexual and/or having a relationship, staff actively ask what that means to them. As one questionnaire respondent stated *"It's unclear whether all of the people I work with would like a sexual relationship with another person but they do get pleasure from their own bodies. Their desired relationship with another person could be different to culturally typical ones."* There was a recognition, therefore, that these issues are nuanced and demanding, but also essential if principles of rights and equality are to be respected:

> *"I think we don't have the conversation with people with autism about sex because we just can't imagine for a minute how they would fit in to our lived experience of sex but actually, maybe the person with autism's lived experience of sex would be completely different to what mine's is."*
>
> *"I think everyone has the right to access [sex]. It's ensuring they are safe, they have a fully informed understanding of what they are accessing. ... Whether it's watching porn or masturbation or having a girlfriend or stuff like that. That's where we come in, to build on that understanding. It's got to be very small steps and reflecting back to ensure that what you've spoken about, that little bit, that information has been retained. It's like a building block so you can build on to it. Because the biggest thing about that to me is their vulnerability.*

There was a clear awareness that equality and rights are mediated by the service user's understanding of what form of rights and equality they desired and how their particular sexual needs and sense of satisfaction could be met. This extends to an understanding that service users might have different understandings of their sexual needs and how they might be satisfied, and these might be different from the understandings staff might routinely have from their own life experience:

> *"...it takes me back to what a person understands [sex and sexuality] to mean, and what's important for them as well. It's not just that people would say that because this person has a right to a sex life then we pursue that and go down that avenue when that might not be what sex means to them, what intimacy means to that person ... that person most definitely has the right to explore sexuality how they want to explore it really."*

This elides with findings from previous studies that indicate that support staff, in general, have positive attitudes towards disability and sexuality (Bazzo *et al.*, 2007; Cuskelly and Bryde, 2004; Yool, Langdon and Garner, 2003). Whilst some earlier research findings have suggested that homophobic and/or heterosexist attitudes are present in care staff (Grieve *et al.*, 2009; Parkes, 2006; Swango-Wilson, 2008), the participants in this study demonstrated a recognition that autistic people have diverse sexual orientations. All of the questionnaire respondents agreed or strongly agreed that "Adults who are able to consent should be supported to live in a same-sex relationship if they so desire." The acknowledgement that autistic people can have same-sex desires and should be supported to realise these desires is particularly important. As Löfgren-Mårtenson (2008: 23) notes, sexuality has symbolic meanings, and how we understand our sexuality is shaped by "how we think about ourselves, how we relate to others, and how others think and relate to us." When support staff recognise and respect sexual diversity, autistic people who have same-sex desires are provided with safe environments and increased opportunities to express their sexuality.

However, this recognition gets variable responses from different stakeholders. Where autistic people's sexuality departs from heterosexual desires, they are seen as being more challenging to families who might be concerned about sexual behaviour or expressed preferences, than they are to staff who find their commitment to service users' quality of life and safeguarding create competing tensions. Particularly where sexual orientation is concerned, staff recognised the complexity of the balance of accepting declarations of sexual orientation and its reception in families who might see it is a matter of misunderstanding.

> *"I have worked with a gentleman that openly has said that he was homosexual and his partner, from that point of view, really struggled with it because she said 'I don't think, I don't think he knows that,' but it was very clear that he was Asperger's*[12] *and he was very clear about his sexuality and I would never question that. Like, his mother was trying to say 'Oh he doesn't understand it' and I don't think he is because it was very clear in my opinion that he understood and he was making it clear 'I'm a homosexual man,' you know."*

Recognition of the sexual desires and behaviours of service users yields a complex set of concerns for staff: balancing quality of life against care and safety; family concerns against taking seriously service users' expressed desires; judgements of the appropriateness of service users' sexual behaviours; and judgements of the extent to which service users understand the orientations and desires they express as theirs. These contradictions provide a terrain within which decision-making is framed, and the heteronormative and desexualised framings of sexuality in respect of autistic people tends to create a bias that staff have to be constantly aware of and are often ill-prepared to respond to.

Safeguarding and managed risk taking

Amongst our questionnaire respondents, 84.6% (n=54) viewed supporting service users with regards to their sexuality as an important part of their job. However, because autistic people may struggle to understand the social conventions around sexuality or may never have received any sex education because of the stereotypes associated with autism, establishing "appropriate" contexts within which to display sexual behaviour appeared to be the most common type of support offered. Establishing

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[12] Recent changes to both the Diagnostic and Statistical Manual (DSM-5) and the International Classification of Diseases (ICD-11) have changed to the diagnostic criteria and condensed a range of autism profiles into one category of 'Autism Spectrum Disorder' and 'Autism', respectively. Where participants are referring to Asperger's, they are talking specifically about people they support how received their diagnoses before these changes.

"appropriate" boundaries for sexual expression is not unproblematic, however, and some participants were concerned that rigid distinctions between public and private space, where sexual behaviour takes place only in the latter, can inadvertently create difficulties for the service user:

> *"[If they] then just decide to, you know, drop their pants and start wherever they are, wherever that might be, and then it's just, it's inappropriate so guided even to maybe the toilet area which again is not really ideal because they might transfer that to outside in the community, so that's where, we're increasing vulnerability there unwittingly."*
>
> *"Our issues are more, is sort of like, helping them know when is it appropriate to touch themselves and where that's, when it's appropriate."*

These concerns highlight the importance of clear communication. Many participants reported that they wanted to increase dialogue about sexuality with their service users, and that those conversations needed to be proactive rather than reactive. Participants also saw increased dialogue about sex and sexuality as having other positive, but less obvious, consequences. Engendering a culture that facilitates open discussions about sexuality allows staff to ask service users about the motivations for their behaviours. This includes asking them what they are looking for from a relationship but also asking questions to identify behaviours that appear to be sexual in appearance but are not sexually motivated.

> *"I have observed at times that people supported will actually display sexual behaviours but the function isn't actually seeking sexual stimulation but actually the person has learned that if I display these behaviours it clears the room really, really quickly. So, that's not seeking that stimulation, that pleasure that fulfilment that's actually seeking alone time if you will and people accessing the space."*
>
> *"Someone might just touch someone and it's deemed as inappropriate but there wasn't a sexual intent to that."*
>
> *"We have lots of people that want to hug and things like that and people say 'Oh, you shouldn't let him hug you' but it depends what that hugging means to that person. Is it sexual need? Is it a sensory need? Is it a tactile need?"*

Questions over the "appropriateness" of the nature, timing or location of sexual behaviours highlights the importance of understanding autistic sexuality within the context of, what has been referred to in the literature on intellectual disabilities as "counterfeit deviance." First coined by Hingsburger, Griffiths and Quinsey (1991) and only recently used in relation to autism, the term denotes those sexual behaviours that transgress socially sanctioned norms and, therefore, may appear to be deviant, but are in fact a product of "lack of sexual knowledge or social skills, or social naiveté" (Nichols and Blakeley-Smith, 2009: p. 85). It is not inevitable that autistic people will engage in what is considered "inappropriate" sexual behaviour, despite the differences they have in social communication compared to neurotypical people, and inappropriate sexual behaviour cannot simply be attributed to a diagnosis of autism. Rather, it can be seen as a consequence of lack of access to sexual information and again highlights the pressing need for sex education for autistic children and adults who are unlikely to have received it when they were children (Boucher, 2014). Sexual behaviour characterised as counterfeit deviancy, like object fetishism, can also be the result of physical and environmental hypo- or hyper-sensitivity experienced by many autistic people (Kellaher, 2015). Thus, sensory satisfying behaviours, like hugging, or stroking hair, skin or material like leather, or crossdressing, may be initiated to meet a sensory, rather than sexual, need.

> *"He would touch somebody's arm, not in a sexual way and that didn't matter if it was male or female. It was just he wanted some affection or just that stimulation and it didn't depend on if it was male or female, or service user or staff member."*

Whilst a number of participants expressed the view that increasing communication about sexuality and promoting positive sexual behaviour would have the effect of enhancing service users' quality of life, the contradictory demands of the 2003 Sexual Offences Act and the 2005 Mental Capacity Act, combined with the individual and organisational duty to safeguard the people they support, presented staff with a dilemma. The ethos of the charity and the work undertaken with individual service users is designed to empower them to make choices over their life and foster their independence. However, exercising greater decision making over increased areas of their life can inevitably lead to greater risk-taking.

> *"... in the line of work that we're in as being a service provider, I suppose the difficulties we have is that you sort of tend to be very risk aware ... so it's all around risk assessments, I suppose, with us and managing risk and the vulnerability of the people that we are supporting so I think that's where the dilemma comes in for us as staff members when we are supporting people within this area."*
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> *"I think, supporting people with autism isn't about eliminating risks, but supporting them to understand the risks in some way, and supporting them to do things as safely as possible. ... Other than that I think it's about leaning your own boundaries or other people's boundaries in a safe and consenting way and obviously consent with people who may understand things in a different way than we do can be tricky..."*

Such dilemmas can present themselves in all areas of service users' lives where they are developing their independence, whether that is in relation to the food they eat, the people they choose to socialise with or how they spend their money. However, the areas of sex and sexuality leave staff in a particularly vulnerable position, which is exacerbated by the absence of clear national and local guidance, and the lack of clarity over what their personal and organisational role is in supporting service users.

These concerns reflect the complexity of how staff understand their responsibilities to service users whilst equally understanding their own risk and discomfort in addressing sexual issues, and the requirements of the law. This balance is at the core of staff perceptions of the rights and responsibilities, which they see as creating some potential difficulties with service users, other staff and families, and in the scope and limits to their role in sexual matters:

> *"What is my duty of care in a situation where you are with someone, on support but he's then making a decision to engage in some form of sexual activity with another?"*
>
> *"So, consent and stuff like that and a lot of service users do access, you know, porn and that sort of thing but to be able to help them through that, to be able to make sure that the stuff they are watching, it might be an uncomfortable thing to do, but to make sure they're not watching something that could be damaging to them or anyone else they might have a future relationship with."*

Issues of comprehension and competence

At the core of staff concerns are judgements about the competence and comprehension of the service user. This starts with the difficulties of giving advice, and extends to trying to give guidance or make meaningful and sensitive interventions whilst simultaneously respecting intimacy and privacy. This is complicated by the difficulty of assessing competence, and recognising that competence is neither easily measured nor consistent amongst service users. Over and above that, competence is not simply a medical measure, but one related to mood. As Herring and Wall (2014) note, capacity cannot be measured simply on the basis of whether an individual understands factual information or whether they are cognisant of the possible consequences of their decisions; it "is not simply a matter of comprehension, but it is a matter of judgement and emotion" (*ibid*.: p. 626).

> *"You can't just go in there and assess someone's capacity and say 'Oh yeah, they've got that.' It's an ongoing process that requires a very skilled staff team, which requires investment and so I think we should be using the capacity framework on a daily basis and at this point I'm not really sure how much we do do that and I think we almost go 'Well, that person lacks capacity.' Full stop. So, we complete it but then how often do we revisit it? ... Sometimes that judgment about a person's capacity that was taken four years ago is still informing the life and life experiences that they're having today."*
>
> *"Capacity for me is actually understanding 'What are the implications of what I am doing here? Am I actually understanding why I am doing it and what might be the result of it?' So, that means if there isn't capacity I might not realise that what I am doing is wrong, not just for myself but maybe I am being made to do something and I don't realise it's wrong."*

Part of staff concerns is that in recognising service users' sexual rights, they are concerned that they bring the service user, who may be vulnerable, into potential harm. Balancing an enthusiasm for the service user to live a full life has to be tempered by the need to safeguard:

> *"What I've got to be careful of is not to get carried away with [the idea] that they have the right. Obviously it could be an 18 year old girl who's expressing her need to go out and have a sexual relationship, but she could be putting herself in danger by going to a nightclub on her own in Liverpool and looking out to have sex off someone ... it's the sexual transmitted diseases she could pick up ... mental capacity is important. But again it's how you support her emotions and her need for that desire. It's getting it right but if she hasn't got that capacity to keep herself safe, she's got the right to make the decision, it's all about positive risk but what danger is she putting herself in if she doesn't. It's important!"*
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> *"... Yeah as long as the right support and management is in there. It's not saying No' she can't have these, she can't have sex, of course she can. She's still, the body still works!"*

Staff concerns over comprehension and capacity with regards to sexual decision-making are undoubtedly shaped by the competing demands of the Sexual Offences Act 2003 (specifically sections 30-33) and the Mental Capacity Act 2005: contradictions that are exacerbated by the fact that they fall under very different areas of law and, as such, serve different functions and have different goals. The Sexual Offences Act 2003 falls under criminal law and is used retrospectively to determine whether an individual had the capacity to consent to a sexual encounter. Its focus is on a particular event in the past and any measure of capacity is related to that particular event. On the other hand, the Mental Capacity Act 2005 falls under civil law and is prospective in that it makes judgements about an individual's capacity to consent to sex in the future. The distinction between criminal and civil law illustrates another distinction between issue-specific and situation-specific capacity or the question as to "whether the person understands at a general level the nature of sex or … whether a person has capacity to consent to sex with a particular person at a particular time" (Herring and Wall, 2014: p. 621), with the MCA adopting the former approach and the SOA adopting the latter. However, despite these distinctions, both laws, or relevant sections of them, apply only to individuals with disabilities and, in particular to those with cognitive and intellectual disabilities. This manes that they are required to demonstrate a higher threshold of capacity than people without disabilities, where no proof of capacity is required (Arstein-Kerslake, 2015). Further, under the MCA, assessment of capacity for decision-making is not just predicated on the ability to understand and retain information pertinent to decision-making and then utilise that information to weigh up the pros and cons of making that decision, it involves normative judgments as to whether a person is using and acting upon information in what the assessor determines as "the right kind of way" (Banner, 2012: p. 1040).

Some staff, particularly support staff, also expressed concerns as to how far their understandings and concerns are taken in relation to professional judgements, and particularly those relating to diagnoses of mental capacity and incapacity.

> *"You do worry how seriously we're taken in terms of we're just the support staff, we're just, you know. We're actually the people that have worked with, in my case with some of the gentlemen I still work with them nearly fifteen years down the line, you know. So it is kind of strengthening who we are, placing value on what it is that we do. I'd like to think we're getting better at that, you know, arguing our case for the person rather than the professional just going 'Oh, no. I've done it. I've assessed their capacity'."*

This quote illustrates the tensions in and barriers to multi-agency working. Although designed to facilitate greater information sharing between professionals in order to safeguard vulnerable people, multi-agency teams continue to be beset with difficulties as a result of lack of clarity over roles and responsibilities, as well as different, and at times competing, organisational and professional cultures. In the context of determining capacity under the MCA "many practitioners are still unclear who completes capacity assessments and who determines best interests" (Stevens, 2013: p. 88).

Clarifications, guidance and training

The issues of competence, understanding of roles and responsibilities, and balancing supporting service users' quality of life with duty of care and safeguarding all point to the importance of good advice, guidance and training for support staff. Although 76.9% of questionnaire respondents said that they had some experience or a lot of experience in relation to service users and difficulties they might have with issues of a sexual nature, only 38.5% (n=25) felt that they had enough knowledge about sexuality and sexual issues to be able to discuss issues of a sexual nature with the people they support, and only 18.5% (n=12) had received sexuality training. The absence or paucity of such training was a concern of some staff:

> *"... I think [this] has had an impact on the staff that I've worked with, that's been the head down, 'We don't talk about this. We don't,' and I suppose ... the fact that [we] don't have clear guidance that we can say to the staff that this is what we can do, this is where your role begins and ends it does become a topic where they just go 'No, we're not going there' and they will put their hands up and say 'I'm not talking about that. I'm not, you know, that's not my area' or they don't feel comfortable wanting to talk."*

> *"It can be difficult because of the guidance, the guidelines and everything, there aren't actually any, I don't think there are any set guidelines as to what people can and can't do with service users and I think that's where staff can struggle in the fact that, you know, obviously you've got the law and the policy around law and things like that but to actually support what's appropriate for service users and what staff feel can be right or wrong and then it's staff who are worried about 'Well, if I say this, will I get into trouble for saying it?' So, it can be really difficult. I think there's a lot of grey areas."*

There is a sense in which some staff are clearly concerned that an absence of guidance and advice leaves them vulnerable. Equally, there is an awareness that some training simply addresses the issues of liability and organisational priorities:

> *"You have to make your own interpretation on it but sometimes that can be on dicey ground in case you give across wrong information to be honest. There's no legal document or guideline to say that you should say it this way. It's just, it's a free for all really. I could go and give any piece of information I want even though it might be incorrect. There's no guideline or monitoring on it."*
>
> *"I've been on training which is really about making sure you don't do the wrong thing and create problems for the organisation, it's not really training about the best thing to do, the thing that is most helpful. It's safeguarding the staff and the organisation and the interested person at times too, but that's a bit different from helping."*

Part of the training agenda that staff identified is an awareness of the need for service users' sex education. 90.7% strongly agreed or agreed with the statement "Sex education for adults with autism has a valuable role in safeguarding them from sexual exploitation." Similarly, 60.9% (n=39) of questionnaire respondents strongly agreed (20.3%, n=13) or agreed (40.6%, n=26) with the statement "Sex education for adults with autism should be compulsory" and 62% (n=40) strongly agreed or agreed that masturbation should be taught to adults with autism as an acceptable form of sexual expression.

> *"Sex education extends to giving service users specific advice on how to achieve satisfaction, so for example in respect of porn, though this raises issues about where boundaries lie in facilitating sexual behaviour."*
>
> *"Does a person know how to masturbate and how to achieve a finish because a person might be masturbating but they never reach that end, that orgasm and then you think "Well that never ever finished so that person might actually seek something else to meet that need."*

There is a recognition amongst staff that guidance and training, whilst useful in itself, should primarily be facilitative of continuing and constructive communications between staff and service users. There is an awareness that a standardised "tick-box" guidance would not be appropriate.

Given that autism impacts on individuals in ways that are unique to them, it is not surprising that majority of participants identified the diversity of conditions on the autistic spectrum as a barrier to supporting their service users with regards to sex and sexuality, and to providing training in order to meet this end. Not only are there several conditions on the autistic spectrum, the manifestation of those conditions varies significantly. Autistic people see, hear and feel the world differently to neurotypical people. Some autistic people may experience difficulties in the area of communication, having trouble in understanding what another person is saying to them and/or struggling to express their own thoughts and ideas. Other core features of autism can include rigidity in thinking, finding the interpretation of culturally specific social conventions challenging, and sensory sensitivity, where both hyposensitivity and hypersensitivity can exist in the same person.

> *"We have somebody who communicates through film and you might find that when it comes 'round to Valentine's Day his choice of films, his communicating has a more romantic tone and this sort of thing, and he might be talking about flowers and things like that."*
>
> *"The more high functioning, the Asperger's ... there is a possibility that they can form a relationship; they might have children depending on what their social skills are like. I've worked with guys, a lot of guys who want a girlfriend to have sex because that's what happens on TV, that's what happens on* Coronation Street*, and realistically life isn't like that, you know there's a process but it's how they see things. This is the sign of literal thinking, what they see, what they want."*
>
> *"I feel that maybe, just because someone is not able to verbally say to you 'this is what I need it to be' doesn't mean their instinct to know that 'my body's wanting me to do something' or 'my body's reacting a certain way' doesn't mean that they can't respond to that instinct, do you know what I mean?"*

In addition to the diversity of conditions on the Autistic Spectrum, a diagnosis of autism frequently sits alongside co-morbid conditions, including Attention Deficit Hyperactivity Disorder (ADHD), dyslexia, dyspraxia, epilepsy, learning disabilities and mental ill health. These comorbid conditions can compound the difficulties autistic people experience in terms of communication and cognition, which in turn can make it harder for staff to discuss issues of sexuality with their service users and provide appropriate support.

> *"If you're potentially looking at a service user who also has a learning difficulty or learning disability and ... if he's having a relationship with a person who doesn't, so vulnerable adult with non-vulnerable adult could raise issues."*

Differences in communication and thinking do act as barriers to both service users expressing their sexual needs and to staff supporting them. They also present challenges to developing appropriate training and guidance around sexuality. However, the uniqueness of each service user and their autism can also be the foundation for providing individualised, positive and proactive services.

> *"So, it's about being person-centred and giving the information but supporting that person to succeed with it. ... It's about having a history about that person. It's about knowing what works and doesn't work. It's about knowing how they learn and perceive. It's about knowing their triggers and de-escalate. It's about knowing THEM individually."*

Alongside this focus on communication and constant engagement, staff have ideas as to what would best support them in their work, which includes sexual awareness, open-ended discussions of orientations and desire, and the joining of issues of competency with constituent issues such as vulnerability.

Conclusion

What this research project indicates is that a fine-grained understanding of the issues of autism and sexuality has evolved amongst the staff within the charity, and there is a strong will to support this within management and supervision roles through, for example, the development of a sexuality policy and a commitment to future training. It is all the more noteworthy and commendable that such an ethos has developed within a context of a lack of both legal clarity and national practice guidance over how the contradictions of the Sexual Offences Act (2003) and the Mental Capacity Act (2005) can be negotiated by those organisations working with autistic people and supporting them with regards to their sexuality. Although focused on just one organisation, it is reasonable to assume that other organisations have similarly good intentions, and therefore the research findings and conclusions to be drawn from them are relevant for all organisations operating in this vacuum.

Although this research focused on staff experiences and perceptions, they identified that better sex education for autistic children and adults would improve their situation and better position them to support the people they work with. One interviewee went so far as to suggest that sex education is even more important for "somebody who's possibly vulnerable than it is for someone who's got the capacity to make an informed choice or at least understand the outcome, possible outcomes." However, sex education in isolation is not sufficient to adequately equip autistic people to engage in sexual decision-making and protect themselves from sexual exploitation. It must move beyond the biology of reproduction and the mechanics of sex, and acknowledge the ways in which autism can shape an individual's sense of their own sexuality. To do this effectively, sex education must be developed in such a way that it encourages children and adults to develop a deeper understanding of their autism and what that might mean in relation to sexual desires, experiences and relationships (Hatton and Tector, 2010). This has been recognised at a national level, with changes to the delivery of Sex and Relationship Education in schools in England and Wales due in 2020[13], and at an international level, evidenced, for example, in the World Health Organization's standards for sex education in Europe (2010), which calls for a positive and holistic approach to sex education. However, the standards of the WHO remain aspirational and, in practice, sex education continues to reflect heteronormative and biomedical understandings of sexuality.

Similarly, staff working with autistic people require training that addresses key areas of concern highlighted by this research, such as sexuality awareness, diversity in sexual orientations and behaviours, managing risk, and balancing empowerment with the duty to safeguard, as well as key issues to consider in relation to law and policy. Again, this training needs to reflect the diversity of autistic experience, and the impact this can have on the development of an individual's sexual identity.

However, without clear national guidance on how staff working with autistic people, specifically those with the power to make assessments about capacity under the MCA, should support individuals with respect to their sexuality, practice can only ever be partial, uneven and localised to specific organisations. The inconsistencies and contradictions in the legislation concerning capacity result in confusion over how to assess capacity in relation to sex, whose responsibility it is, and whether the assessment should adopt an issue or situational approach. The differential standard of capacity that people with cognitive disabilities and differences are required to demonstrate under the MCA means that they are invariably treated differently to neurotypical individuals. This is a direct breach of Article 12 of the Convention on the Rights of Persons with Disabilities (2007) which states that signatories "shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." The United Kingdom ratified the treaty in 2009, and yet the current legal

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[13] https://researchbriefings.parliament.uk/ResearchBriefing/Summary/SN06103

framework for assessing capacity undermines Article 12 and the commitment to equal legal capacity for disabled people.

In this analysis, progressive ethos and best practice might be said to develop within organisations and service provision almost *in spite* of the legal, cultural and knowledge-specific contexts to supporting autistic people. That leaves the possibility of practice based on prejudice or pathology, or simply underdeveloped understandings and knowledge, guiding those who seek to support autistic people, which would have a direct impact on their quality of life. It certainly places considerable burdens of stress and lack of clarity on those practitioners who seek to provide support. As long as this continues, and professionals work in an environment of confusion and ambiguity over how best to support managed risk-taking, the sexual rights of autistic people, which are fundamental human rights, will not be realised.

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