

No “cookie cutter rules”: best practice for social care staff in supporting autistic adults with relationships and sexuality

Claire Bates and Rose Matthews

Abstract

Purpose – *The purpose of this study is to explore the support needs surrounding intimate relationships and sexuality of autistic adults accessing funded social care in England.*

Design/methodology/approach – *Semi-structured interviews with 15 autistic adults who were accessing funded social care examined their support needs surrounding intimate relationships and sexuality, with subsequent data analysis using reflexive thematic analysis.*

Findings – *Four themes were generated: Help at hand, but not too close for comfort, No “cookie-cutter rules”: personalised, inclusive approaches, Playing it safe, not leaving it too late, and Autism-informed education and support.*

Practical implications – *The authors produced an online learning module for social care staff in England on best practice in supporting autistic adults without learning disabilities with relationships and sexuality.*

Originality/value – *To the best of the authors’ knowledge, there has been no other UK-based research published to date on the social care support needs of autistic adults without learning disabilities surrounding relationships, gender and sexuality.*

Keywords Relationships, Sexuality, Gender, Autism, Social care, LGBTQ+

Paper type Research paper

Claire Bates is an Honorary Research Associate at the Tizard Centre, University of Kent, Canterbury, UK and Manchester Metropolitan University, Manchester, UK. Rose Matthews is an independent Autistic Researcher, York, UK.

Introduction

Many autistic adults see intimate relationships as crucial in terms of practical and emotional benefits and quality of life (Barnett and Maticka-Tyndale, 2015; Dewinter *et al.*, 2017; Strunz *et al.*, 2017; Mason *et al.*, 2018). In the Care and Support (Eligibility Criteria) Regulations (2014) for England’s Care Act (2014), “developing and maintaining personal relationships” is an eligible support need in social care assessments, alongside assistance with daily tasks, personal care and independent living. However, HM Government (2021) overlooks relationships and sexuality, despite autistic people raising these in consultations (Huysamen *et al.*, 2022). A systematic review (Huysamen *et al.*, 2022) reveals that almost all health and social care publications ignore autistic adults’ relationship and sexuality needs. *The Core Capabilities Framework* (CCF) (Skills for Health, 2019), co-produced with autistic people, is the sole exception, but this is underused, perhaps because it is not embedded in mandatory staff social care training in England. Existing research on autistic adults’ dating support needs only relates to individuals who have a co-existing learning disability (McCarthy *et al.*, 2020).

Autistic people report difficulties when forming and sustaining relationships, leading to heightened anxiety in intimate situations compared to non-autistic adults (Dewinter *et al.*, 2017; Hancock *et al.*, 2020; Sala *et al.*, 2020; Yew *et al.*, 2021). They highlight specific

Received 25 May 2023
Revised 28 September 2023
24 January 2024
Accepted 20 February 2024

The authors are grateful to the participants and advisory group members for contributing to this research.

challenges such as unclear expectations and not knowing how to meet people or develop relationships (Strunz *et al.*, 2017). Confusion around social norms, cues and typical romantic communication can heighten anxiety (Barnett and Maticka-Tyndale, 2015).

Research on autism and relationships has tended to focus on autistic: non-autistic relationships (Wilson *et al.*, 2017; Lewis, 2017). Yew *et al.*'s (2023) systematic review highlights how such studies tend to pathologise autistic behaviour, seeing it as a problem that requires fixing. Research suggests that communication differences, stigma and social isolation make autistic people more vulnerable to sexual victimisation and intimate partner violence (Brown-Lavoie *et al.*, 2014; Pearson *et al.*, 2023). As yet we do not have research evidence on distinctions between autistic: autistic and autistic: non-autistic relationships.

A higher percentage of autistic individuals identify as LGBTQ+ (Dewinter *et al.*, 2017; Strunz *et al.*, 2017) or question their gender identity (George and Stokes, 2018) than in the general population. "Autistic sexual minorities experience a 'double minority' status that complicates identity formation and increases vulnerability in sexual relationships" (Lewis *et al.*, 2021, p. 2324). The same study suggests that psychological support to understand and express sexual identity may benefit self-acceptance, and practical support can reduce sensory and social challenges (*ibid.*).

Dewinter *et al.* (2017) emphasise the importance of relationship and sex education (RSE) for autistic people focusing on developing relationship skills, understanding sexual diversity and fostering sexual identity development. However, existing provision frequently fails to address the needs of both LGBTQ+ and heterosexual autistic people by ignoring social aspects of sexuality and diverse sexual orientations (Barnett and Maticka-Tyndale, 2015).

Most research on autism and intimate relationships involves individuals from outside the UK who do not access social care (Hogan and Micucci, 2020; Sala *et al.*, 2020), or explore autism specific RSE programmes (Rothman *et al.*, 2022; Crehan *et al.*, 2023). Despite compelling evidence of challenges and risks, there has been no research to date on what support, if any, autistic adults who access social care, want from staff with relationships and sexuality. This study explored the lived experiences of autistic people to identify themes and create a targeted training module for social care staff in England.

Method

Advisory group

A seven-member advisory group of autistic adults was recruited through adverts on social care networks and social media. To be eligible applicants had to be an autistic adult with experience of accessing funded social care in England (location restricted by funding requirements). Online meetings with the lead researcher (PI) and research assistant (RA) confirmed eligibility and provided opportunities to ask questions. All eligible applicants were invited to join. Online advisory group meetings were held at intervals to discuss accessibility issues, develop participant recruitment materials, create the semi-structured interview schedule and produce the training module for social care staff.

Participants

In this exploratory qualitative study, we used purposive sampling (Palinkas *et al.*, 2019) to select autism support organisations, through which we sent recruitment information to potential participants. Inclusion criteria were that participants had to live in England (funding requirement), be aged 18 or over, be autistic (diagnosed or self-identified), access funded social care and be able to interact in English (verbally or via text).

Fifteen autistic adults were recruited (see Table 1 for demographic information). Participants' ages ranged from 27 to 58, with diverse sexual identities and gender expressions. Over 80%

Table 1 Participants' demographics

Ref	Age range	Gender	Ethnicity	Living/support arrangements	Sexual orientation	Relationship status
P1	25–35	Trans female	White	Own home/PAs	Lesbian	Single
P2	55–64	Female	White	Own home/PAs	Pansexual	Married (cohabiting)
P3	45–54	Male	Black/white British	Own home/PAs	Heterosexual	Relationship (cohabiting)
P4	25–35	Male	White	Own home/staff visit	Pansexual	Single
P5	25–35	Non-binary	White	Own home/PAs	Bisexual	Single
P6	35–44	Non-binary	White	Own home/PAs	Gay	Single
P7	25–35	Female	White	Own home/PAs	Heterosexual	Single
P8	45–54	Male	White	Own home/PAs	Gay	Single
P9	25–35	Male	White	Supported living/24 h staff	Heterosexual	Single
P10	25–35	Female	White	Supported living/24 h staff	Heterosexual	Relationship (non-cohabiting)
P11	35–44	Male	White	Supported living/staff visit	Heterosexual	Single
P12	35–44	Male	White	Own home/staff visit	Heterosexual	Relationship non-cohabiting)
P13	25–35	Male	White	Own home/staff visit	Heterosexual	Engaged (non-cohabiting)
P14	25–35	Non-binary	Not stated	Supported living/24 h staff	Unclear	Single
P15	35–44	Male	White	Own home/staff visit	Gay	Single

Source: Authors' own work

identified as white British. Two participants who disclosed mild learning disabilities in addition to being autistic during the interview were included.

Procedure

Both researchers are neurodivergent (the RA is autistic), with extensive experience of working within social care and conducting qualitative research. Each researcher conducted one-to-one online interviews with a sub-group of participants (PI: 8, RA: 7). Prior to the interview, the researchers met participants individually online to discuss the study, check their eligibility, answer questions and gain informed consent. Several applicants were ineligible (not based in England and/or not accessing social care). Eligible participants could choose to be interviewed online, by telephone or via email and were offered accommodations for inclusivity (e.g. turning off cameras, receiving the interview topic areas in advance and taking breaks whenever needed). One participant chose a phone interview, and another preferred email. The remaining 13 participants chose online Teams or Zoom interviews.

Semi-structured interviews were recorded and transcribed. Interviews focused on the support participants had received or wanted from social care staff surrounding relationships and sexuality, addressing four main areas:

1. support with dating or romantic or sexual relationships;
2. support with gender or sexuality;
3. preferences for accessing information on relationships and sexuality; and
4. anything else the participant wished to share.

Questions were open-ended, and prompts developed by the advisory group were used flexibly to identify topics participants wished to discuss.

Interviews lasted approximately 1 h, and the email interview took place asynchronously over several weeks. Participants were offered a £20 voucher to acknowledge their contribution. Ethical approval was granted by the Social Care Research Ethics Committee (ref: 311451).

Our orientation was “big Q” and “fully qualitative” (Kidder and Fine, 1987), and our realist approach was underpinned by standpoint epistemology (Legault *et al.*, 2021). This reflected our positionality as neurodivergent researchers, and our commitment to addressing epistemic injustice by centring views of autistic people with experience of using funded social care.

Analysis

We chose reflexive thematic analysis (RTA) because of its flexibility and suitability for exploratory qualitative research, combining insights from neurodivergent participants, advisory group members and researchers (Braun and Clarke, 2021, 2022, 2023). Our analysis reflected the neurodiversity paradigm, which sees neurodivergence in terms of differences not deficits, acknowledging autistic strengths and the disabling effects of belonging to a poorly catered for neurominority (den Houting, 2019).

We followed the RTA process outlined by Braun and Clarke (2022, p. 6):

- data set familiarization;
- data coding;
- initial theme generation;
- theme development and review;
- theme refining, defining, and naming; and
- writing up.

In the data set familiarisation stage, we immersed ourselves in interview transcripts and audio recordings, consciously reflecting on how our positionality and subjectivities impacted analysis. Initially, each of us independently coded the interviews we had conducted and transcribed, including semantic and latent meanings. The second researcher then added their comments and insights to the coded transcript. In a series of joint reflexive conversations, we explored both of our perspectives to develop richer insights. Rather than seeking to identify objective truths, we recognised that our interpretations were necessarily subjective (Braun and Clarke, 2023, 2022, 2021).

When generating themes from the interview data we also drew on our own lived experiences of being autistic/neurodivergent and working in and/or accessing social care. Draft themes were discussed in a series of advisory group meetings where reflections of an ethnically diverse group of autistic people further enriched our analysis and interpretation. This iterative and collaborative approach allowed us to develop a more nuanced understanding of the social care needs of autistic individuals regarding relationships and sexuality.

Results

We generated four themes from the data describing the kind of social care support autistic participants wanted with relationships and sexuality.

Help at hand, but not too close for comfort

Social care staff were seen to play a vital role in providing informal support with relationships and sexuality by our autistic participants. They generally welcomed the accessibility and comfort of staff who worked with them providing informal support:

Just being available for any questions [...] like you know the appropriacy of having a girlfriend over and [...] just generally how things are sort of progressing in my relationship. (P11)

Participants particularly valued staff being available to talk through any issues they were unsure about:

I think as with most of the population, googling things often raises more questions than it answers, so you need someone experienced in the area of sex, gender and autism to check things with. (P6)

Almost all participants found social norms and unwritten rules about relationships confusing and welcomed support from staff to reduce anxiety and discomfort:

Sometimes you have to be aware that autistic people are not gonna know the unwritten social rules of going on a date. (P9)

[My PA] helped explain why it's not always obvious to other people [I'm non-binary] and how to get round it, so I'm more comfortable being me. (P2)

Participants highlighted the diverse roles social care staff took on, from providing practical assistance with setting up dating profiles, to giving advice on consent:

[...] staff supported me to set up an online dating app [...]. They helped me write the things down on like the description about myself page to help me sort of support me to write that gave me some ideas about what I could, but maybe what's not such good ideas. (P9)

I just spoke to my last PA and she was just telling me that everybody is different it's like talking to that person that you're having a relationship with about things to do with what you can and can't do and just things to do with touching and things, it's speaking to that individual person really, so it's learning as to how to do it really. (P1)

However, several participants were unable or unwilling to discuss intimate matters with people close to them:

I do bring it up [with friends] and one of them, well a few of them will go 'No stop!' They just don't have that need to talk about those things like I, or if they do have a need, it's not something they want to discuss among friends. (P2)

In such circumstances, staff could be effective informal mentors, providing information, emotional support and practical guidance. But some participants found talking to staff about relationships and sexuality too close for comfort and preferred to access support in a separate space:

I suppose that specialist sexual autism service would be great. Because it's kind of, like sometimes it's helpful and beneficial to have something that's sort of non-personal because you know, you can be too close to people to talk to sometimes about things. (P11)

There was no consensus about the optimal proximity of support, what mattered was having a choice.

No “cookie-cutter rules”: personalised, inclusive support

Participants emphasised the importance of social care staff having non-judgemental attitudes, being trained in understanding autism and providing information in varied formats for accessibility. They wanted staff to foster open conversations about relationships and sexuality and underscored the importance of non-judgemental, sex-positive attitudes. A trusting relationship was essential for effective support:

When you talk about relationships and sex and sexuality it's a big thing not a lot of people would be comfortable to talk about it, so it's got to be someone who is comfortable about it who you trust. (P1)

Two participants said that they were less likely to be open with social care staff if they feared being judged, and another participant described being in an abusive relationship and feeling anxious about disclosing this:

It took me quite a while to be truthful with my support worker about it because I was scared that I was gonna get judged about the relationship I was in. (P10)

There was unanimous agreement on the need to train staff to understand that autistic people are uniquely individual, not homogenous. Participants wanted staff to use a personalised approach:

Every autistic person is a very individual person just like everyone else. There are no one-stop-shop cookie cutter rules that every autistic person is like this, so you must know that. (P8)

One participant's support staff had been trained to work in empowering ways:

It's about respecting the people you support's decisions. That's a big thing that I think people need training around is actually, you're making the choice to see this person and that's your choice. (P9)

Participants stressed that training should highlight individual preferences and information processing needs:

I think I would prefer a support person to talk with me first and then just leave me to it afterwards. (P4)

Some participants valued reading with space to reflect, while others preferred to listen to information, highlighting the importance of varied options:

I like mixture of formats, so for me the most helpful, I like books, so I like reading books a lot. (P8)

I'm one of those autistic people who prefers to have information broken down, because so much information can overload my brain [...] so if I were to get support with relationships and all that information would have to be broken down for me. (P4)

Several participants wanted staff to communicate using straightforward and direct language regarding sex and relationships. Staff were not always explicit enough due to embarrassment or fear of saying the wrong thing:

Be open, honest and clear. Don't use jargon and NT [neurotypical] babble. As that often confuses me and I lose tracks of the conversation and important points. (P6)

The findings highlighted the need for staff to be person-centred, working with an individual autistic person to decide how best to meet their relationship, gender or sexuality needs.

Playing it safe, not leaving it too late

Participants described considerable safety concerns, emphasising the need for proactive support, which had either been non-existent or which had failed to meet their needs. Participants who had previously been abused within an intimate relationship feared recurrence, while others feared they might become victims. Every participant had experienced some kind of bullying or abuse, which sometimes included mate crime (Pearson *et al.*, 2022).

Participants stressed the importance of a preventive approach, with one person suggesting the social care budget should be used to foster positive self-perception and healthy relationships. Participants wanted proactive support, to reduce the likelihood of getting into unhealthy or abusive relationships, e.g. by helping them to spot early warning signs. Funded social care was typically only put in place after abuse had occurred:

The social care budget in my opinion would be best used as a preventive, would be best used to have someone feel good about themselves and their life and relationships before they get into a situation where they need counselling or Victim Support. (P8)

Some participants had theoretical knowledge about unhealthy or abusive relationships but found it difficult to apply this to real-life situations. They wanted support to help them make these connections:

I find it hard to transfer skills, like I can have a really good conversation about safety around relationships and that kind of thing, but it doesn't always translate into reality. (P7)

Another recurring theme was the need for guidance on navigating online dating safely. There was a strong narrative regarding internet dating being unsafe, which restricted dating opportunities:

I heard horror stories on dating apps and that kind of thing, and I didn't feel safe enough to do that. (P7)

Some safety concerns were gender specific, with male participants expressing fears about financial abuse in online dating:

I kept getting messages, the same messages and it wasn't happening. People kept scamming me, luckily I cancelled my card. (P3)

Female and non-binary participants were more concerned about the risk of sexual abuse; one participant felt that attending workshops run by a dating agency had enhanced her self-knowledge and sexual safety:

I learnt some other things about myself, my potential to be overly trusting, and [um] some other things, which highlighted to me some of the issues that I've had over many decades, with regards to other relationships, in particular about putting myself, not meaning to put myself, [um] at risk, but ending up very vulnerable in many, many situations over many years. (P2)

Several participants stressed the positive impact of psychological support on their ability to form healthy relationships after experiencing abuse. This helped them avoid being held back by trauma, underscoring the importance of social care staff knowing how to signpost individuals to therapy when needed:

And because of her [therapist], because I think mainly because I was working with her [therapist] like I felt it [relationships] was possible for me, because after I left, the relationship was like, that's it. Like intimate life is over. Like I'm not I don't think I'll ever be able to and sort of date again. (P5)

Participants wanted support with relationships and sexuality to be practical not purely theoretical. Guidance needed to be applied to real life situations, considering the context and any gender specific issues. Participants wanted to be empowered to navigate relationships safely from the start. Without appropriate information and support, they risked coming to harm (as a victim or alleged perpetrator of abuse) or getting stuck in a platonic relationship by playing it too safe.

Autism-informed education and support

Participants stressed that it was crucial for relationships and sexuality support to be centred around autistic perspectives, experiences and preferences. Traditional education had often only covered basic topics (e.g. pregnancy, contraception and sexually transmitted infections), neglecting sexual and gender diversity:

I also think the whole 'sex' thing was whizzed through along with contraception and just made to sound scary and confusingly complicated, always split along gender groups and the assumption that you like the opposite sex." (P6)

This heteronormative and binary bias resulted in gaps in sexual knowledge, e.g. what gay sex consists of, and diverse gender expression. This was especially significant given autistic people are more likely to identify as LGBTQ+ compared to non-autistic people (George and Stokes, 2018):

[...] the school and that [...] was mostly focused on straight relationships and most, it was mostly straight heterosexual things. (P14)

The only relationship workshops for autistic adults in England are provided by specialist dating agencies and a few social care providers. Several participants had found such workshops helpful as they addressed issues not covered adequately in school, such as boundaries and consent:

I get so excited about seeing people that [...] I go to hug somebody, and I won't let go, and it sounds awful, but I am just enjoying that hug so much I just want it to last forever and I squeeze really tightly as well. (P2)

However, several participants raised concerns that existing workshops were aimed at people with learning disabilities and highlighted the need for autism specific support:

If there was autism-centred support that would be great, on sex on relationships, on drinking, on sex, on gender identity, on sexuality. Rather than 'Oh, we've got, we've got, we're a non-stop shop of everything. (P11)

Participants wanted relationship education to be delivered in a variety of formats to accommodate different needs and preferences: small groups, one to one or a combination:

I think it needs to be a mix of individual and group. I'm often mute around people I do not know and just coping with the social interaction can mean I forget to listen and so end up stressed. I need someone who knows me to answer my questions and help me find information. (P6)

Participants felt strongly that any such education should be developed and delivered by people who were either autistic themselves or who had a good understanding of autism and would not impose neurotypical norms:

I don't want professionals who will come in and fix me and that space doesn't necessarily have to be autistic led. It just has to be led by a professional who will understand them and won't try to fix them. (P5)

A safe shared space for autistic people to meet and explore relationships and sexuality with staff and/or peers was seen by most participants as beneficial:

If there were the sort of places to sort of openly talk about relationships and how to have a successful relationship and someone who understands of like exactly what you're going through then that would be [phone rings]. (P11)

I would like to have trained autistic peer support workers, or a specialist autistic-related sexual support, hang-on, staff or professionals who have lived experience of autism, so I would say those three, provided they are very autism aware would be the top for me. (P2)

Most participants saw benefits in both professional and peer support but wanted all providers to be appropriately skilled in autism, relationships and sexuality.

Discussion

This exploratory study of the social care needs of autistic adults in England surrounding sexuality and intimate relationships suggests that social care staff could play a positive role, provided they have appropriate expertise and tailor support to accommodate individual needs and preferences. To our knowledge, no previous research has explored the role of social care staff in supporting such needs.

A limited number of organisations, mainly within the social care or charitable sector, currently provide education and support with relationships and sexuality for autistic individuals, with hardly any statutory sector provision. Social care staff in England who support autistic adults with sexuality and relationships generally lack sufficient training (Bates *et al.*, 2020), confirmed by a subsequent study (Huysamen *et al.*, 2022). Our participants expressed a strong need for relationships and sexuality support and proposed its inclusion in UK social care assessments, even if immediate assistance is not required. They also wanted such support to be offered by post-autism diagnostic support services.

Participants emphasised the distinctiveness of their needs as autistic people without co-existing learning disabilities and resented being described as "people with learning

disabilities and/or autism” which commonly happens in the social care literature (Huysamen *et al.*, 2022). The support participants wanted mirrored the CCF guidance, co-developed with autistic people (Skills for Health, 2019), which is seldom integrated into social care commissioning.

Most participants wanted the opportunity to access autism-specific relationship support to fill gaps in their knowledge. They thought that autism and relationships experts, trained peer support workers or (less commonly) social care staff should provide this. They agreed with Bertilsdotter Rosqvist and Jackson-Perry (2021) that any such support must be autism-affirmative, avoiding “coaching” individuals into adopting neurotypical behaviours and masking autistic traits.

The CCF states that social care staff should be able to “support and facilitate the delivery of person-centred/age appropriate and autism specific sex and relationships education across the lifespan, including support in recognising healthy and unhealthy relationships and online risks and issues” (Skills for Health, 2019, p. 54). However, social care staff are seldom trained to support sexuality and intimate relationships. Educational programmes for autistic adults do exist (Rothman *et al.*, 2022; Crehan *et al.*, 2023), but social care staff may not know how to access them or feel sufficiently skilled to deliver them. Research suggests that the effectiveness of RSE programmes depends partly on delivery over an extended period (Ragaglia *et al.*, 2023; Crehan *et al.*, 2023), and not-for-profit organisations may struggle with this due to resource constraints.

Our participants emphasised the importance of being assisted by staff with appropriate expertise. The social care sector in England lacks mandatory training in relationships and sexuality, often leaving staff untrained and with limited resources (Bates *et al.*, 2020). There is an argument for RSE for autistic people to be commissioned as part of UK social care and provided by specialist organisations, to increase sexual safety and wellbeing. The primary day-to-day support desired by autistic participants centres on informal conversations with social care staff. They seek environments where they can openly discuss relationships and sexuality without judgement and receive practical assistance (e.g. setting up dating profiles) or emotional support (e.g. resolving conflict). Negative, risk-averse attitudes among social care staff regarding sexuality hinder discussions with the people they support (Bates *et al.*, 2020). Autistic people do not always have “vanilla” sexual tastes, so open-mindedness is essential (Pearson and Hodgetts, 2023).

The freely available training pack produced as an output of this study, spotlights the necessary support for autistic individuals, addressing their preferences and the attitudes and values they require from staff. Social care staff can also access resources from projects like Supporting Autistic Adults Intimate Lives to better support autistic individuals (Autlives, 2023). Access to peer discussion in a supportive atmosphere, a concept echoed by Crehan *et al.* (2023), is also desirable. Social care organisations could play a role in co-developing and supporting such spaces for autistic people, seeking specialist input where necessary.

Social care staff must be mindful that autistic individuals are more likely to identify as LGBTQ+ than their non-autistic counterparts, with a higher prevalence of gender diversity and dysphoria, especially among autistic women (George and Stokes, 2018; Kallitsounaki and Williams, 2023). Non-binary participants in our study found defining their sexuality challenging, which impacted relationships, and they wanted ongoing support, with the option of seeing specialist counsellors. Autistic LGBTQ+ adults encounter additional challenges in finding partners and expressing their sexual needs, and all our LGBTQ+ participants reported inadequate RSE (Herrick and Datti, 2022). While Hogan and Micucci (2020) noted some autistic individuals feeling stigmatised within the LGBTQ+ community, our participants highlighted the scarcity of spaces for queer autistic women and non-binary individuals to explore their gender and sexual identities. Social care staff should be aware of LGBTQ+ organisations that provide

accessible social groups for neurodivergent people, and therapists, and help people to access these if desired.

This study of the social care needs of autistic individuals in England surrounding sex and relationships highlights the need for supportive attitudes and spaces. Suggestions for tailored sex and relationship support underscore the need to proactively enhance sexual safety and well-being. Such support needs to be integrated into social care planning, with staff trained to meet autistic individuals' diverse needs surrounding intimate relationships and sexuality. Our findings suggest a need to commission RSE tailored for autistic adults within social care support in England. Inclusive workshops or one-to-one sessions could address gaps in traditional education, and promote Care Act principles by preventing harm, supporting well-being, improving sexual safety and reducing loneliness.

Limitations and future research

Despite recruitment in urban and rural areas in England, including multicultural cities, 13 participants were white, and only one participant was non-British, limiting insights into social care needs of autistic people from minority ethnic communities. This may reflect barriers that people from minoritised ethnic groups face in accessing social care ([Greenwood *et al.*, 2015](#)) and being recognised as autistic ([Tromans *et al.*, 2021](#)). The omission of sexuality and relationship needs of autistic individuals from social care needs assessments was clear from our study, and a further funding proposal has been submitted to explore this.

Practice implications

Social care staff should proactively establish whether autistic adults want information and/or support with relationships and sexuality. If they do, staff should identify their specific needs and ensure support is available. Assistance must be provided in a non-judgemental, autism-affirming manner, respecting individual differences. Social care staff should be well-informed and trained in addressing the challenges faced by autistic individuals in this domain. Familiarity with local and online services is crucial for connecting individuals with appropriate resources. Workshops and individual support provided by social care staff or charitable organisations must adopt a neuro-affirmative approach, recognising the effects of stigma, prejudice, abuse and enduring trauma, and being mindful of how the double empathy problem affects communication ([Milton *et al.*, 2022](#)). Organisations should always acknowledge the higher likelihood of autistic individuals being part of the LGBTQ+ community and provide tailored support for people with non-cis, non-heterosexual identities, including signposting to specialist services and support groups.

Conclusion

Almost all our participants wanted to develop or sustain satisfying intimate relationships but faced challenges such as lack of technical sexual knowledge, limited opportunities to make connections with potential partners, lack of social confidence, stigma, trauma from past abuse and accessibility issues. This left many of them feeling hopeless and stuck, unable to make new romantic connections or progress to sexual activity in existing relationships.

Participants who had struggled with RSE at school had significant knowledge gaps which continued into adulthood. They sometimes filled these with unreliable information from informal sources (e.g. television shows). Available relationship and sexuality support was extremely limited and often designed for autistic adults with co-existing learning disabilities.

Lack of support for relationship and sexuality needs had increased the risk of exploitation and abuse as well as denying individuals the chance of romantic and sexual fulfilment. Specialist support was typically only provided to our participants after they had experienced harm, emphasising the importance of proactive approaches by social care

staff. Participants stressed the need for staff to be trained to have open, non-judgemental, unembarrassed discussions about relationships and sexuality and to be aware of services to connect them with. Trusting relationships with staff were regarded as crucial for the exploration of sensitive personal issues. Some participants found this too close for comfort and preferred support to be provided at a distance.

Our findings demonstrate the importance of providing support in an autism-centred, affirmative way, reflecting the diversity of gender expression and sexual identities within autistic communities. Staff must be equipped to recognise the impact of stigma, trauma and social exclusion and respond appropriately to unique individual circumstances, preferences and needs. It should not be assumed that social care staff are confident or competent to provide such support without appropriate training and expertise.

References

- Autlives (2023), "Supporting autistic adults intimate lives (SAAIL)", available at: www.autlives.com/ (accessed 20 January 2023.)
- Barnett, J.P. and Maticka-Tyndale, E. (2015), "Qualitative exploration of sexual experiences among adults on the autism spectrum: implications for sex education", *Perspectives on Sexual and Reproductive Health*, Vol. 47 No. 4, pp. 171-179, doi: [10.1363/47e5715](https://doi.org/10.1363/47e5715).
- Bates, C., McCarthy, M., Milne Skillman, K., Elson, N., Forrester-Jones, R. and Hunt, S. (2020), "Always trying to walk a bit of a tightrope: the role of social care staff in supporting adults with intellectual and developmental disabilities to develop and maintain loving relationships", *British Journal of Learning Disabilities*, Vol. 48 No. 4, pp. 261-268, doi: [10.1111/bld.12320](https://doi.org/10.1111/bld.12320).
- Bertilsdotter Rosqvist, H. and Jackson-Perry, D. (2021), "Not doing it properly? (Re)producing and resisting knowledge through narratives of autistic sexualities", *Sexuality and Disability*, Vol. 39 No. 2, pp. 327-344, doi: [10.1007/s11195-020-09624-5](https://doi.org/10.1007/s11195-020-09624-5).
- Braun, V. and Clarke, V. (2021), "Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches", *Counselling and Psychotherapy Research*, Vol. 21 No. 1, pp. 37-47, doi: [10.1002/capr.12360](https://doi.org/10.1002/capr.12360).
- Braun, V. and Clarke, V. (2022), *Thematic Analysis: A Practical Guide*, Sage Publications, London.
- Braun, V. and Clarke, V. (2023), "Toward good practice in thematic analysis: avoiding common problems and be(com)ing a knowing researcher", *International Journal of Transgender Health*, Vol. 24 No. 1, pp. 1-6, doi: [10.1080/26895269.2022.2129597](https://doi.org/10.1080/26895269.2022.2129597).
- Brown-Lavoie, S.M., Viecili, M.A. and Weiss, J.A. (2014), "Sexual knowledge and victimization in adults with autism spectrum disorders", *Journal of Autism and Developmental Disorders*, Vol. 44 No. 9, pp. 2185-96, doi: [10.1007/s10803-014-2093-y](https://doi.org/10.1007/s10803-014-2093-y).
- Care Act (2014), Available at: www.legislation.gov.uk/ukpga/2014/23/section/13 (accessed: 20 January 2024.)
- Care and Support (Eligibility Criteria) Regulations (2014), available at: www.legislation.gov.uk/ukdsi/2014/9780111124185 (accessed 20 January 2024).
- Crehan, E.T., Yang, X., Dufresne, S., Barstein, J., Stephens, L., Dekker, L. and Greaves-Lord, K. (2023), "Adapting the tackling teenage training sex education program for autistic adults in the US: a pilot study", *Journal of Autism and Developmental Disorders*, Vol. 12, doi: [10.1007/s10803-023-05962-3](https://doi.org/10.1007/s10803-023-05962-3).
- Den Houting, J. (2019), "Neurodiversity: an insider's perspective", *Autism*, Vol. 23 No. 2, pp. 271-273, doi: [10.1177/1362361318820762](https://doi.org/10.1177/1362361318820762).
- Dewinter, J., De Graaf, H. and Begeer, S. (2017), "Sexual orientation, gender identity, and romantic relationships in adolescents and adults with autism spectrum disorder", *Journal of Autism and Developmental Disorders*, Vol. 47 No. 9, pp. 2927-2934, doi: [10.1007/s10803-017-3199-9](https://doi.org/10.1007/s10803-017-3199-9).
- George, R. and Stokes, M.A. (2018), "Gender identity and sexual orientation in autism spectrum disorder", *Autism*, Vol. 22 No. 8, pp. 970-982, doi: [10.1177/1362361317714587](https://doi.org/10.1177/1362361317714587).
- Greenwood, N., Habibi, R., Smith, R. and Manthorpe, J. (2015), "Barriers to access and minority ethnic carers' satisfaction with social care services in the community: a systematic review of qualitative and

- quantitative literature", *Health & Social Care in the Community*, Vol. 23 No. 1, pp. 64-78, doi: [10.1111/hsc.12116](https://doi.org/10.1111/hsc.12116).
- Hancock, G., Stokes, M.A. and Mesibov, G. (2020), "Differences in romantic relationship experiences for individuals with an autism spectrum disorder", *Sexuality and Disability*, Vol. 38 No. 2, pp. 231-245.
- Herrick, S.J. and Datti, P.A. (2022), "Autism spectrum disorder and sexual minority identity: sex education implications", *American Journal of Sexuality Education*, Vol. 17 No. 2, pp. 257-276, doi: [10.1080/15546128.2021.2002225](https://doi.org/10.1080/15546128.2021.2002225).
- HM Government (2021), "National strategy for autistic children, young people and adults: 2021 to 2026".
- Hogan, M.S. and Micucci, J.A. (2020), "Same-sex relationships of men with autism spectrum disorder in middle adulthood: an interpretative phenomenological study", *Psychology of Sexual Orientation and Gender Diversity*, Vol. 7 No. 2, pp. 176-185.
- Huysamen, M., Kourti, M. and Hatton, C. (2022), "A critical overview of how English health and social care publications represent autistic adults' intimate lives", *Critical Social Policy*, Vol. 43 No. 4, doi: [10.1177/02610183221142216](https://doi.org/10.1177/02610183221142216).
- Kallitsounaki, A. and Williams, D.M. (2023), "Autism spectrum disorder and gender dysphoria/incongruence. A systematic literature review and meta-analysis", *Journal of Autism and Developmental Disorders*, Vol. 53 No. 8, pp. 3103-3117, doi: [10.1007/s10803-022-05517-y](https://doi.org/10.1007/s10803-022-05517-y).
- Kidder, L.H. and Fine, M. (1987), "Qualitative and quantitative methods: when stories converge", *New Directions for Program Evaluation*, Vol. 1987 No. 35, pp. 57-75.
- Legault, M., Bourdon, J.N. and Poirier, P. (2021), "From neurodiversity to neurodivergence: the role of epistemic and cognitive marginalization", *Synthese*, Vol. 199 Nos 5/6, pp. 12843-12868, doi: [10.1007/s11229-021-03356-5](https://doi.org/10.1007/s11229-021-03356-5).
- Lewis, L.F. (2017), "We will never be normal: the experience of discovering a partner has autism spectrum disorder", *Journal of Marital and Family Therapy*, Vol. 43 No. 4, pp. 631-643, doi: [10.1111/jmft.12231](https://doi.org/10.1111/jmft.12231).
- Lewis, L.F., Ward, C., Jarvis, N. and Cawley, E. (2021), "'Straight sex is complicated enough!': the lived experiences of autistics who are gay, lesbian, bisexual, asexual, or other sexual orientations", *Journal of Autism and Developmental Disorders*, Vol. 51 No. 7, pp. 2324-2337, doi: [10.1007/s10803-020-04696-w](https://doi.org/10.1007/s10803-020-04696-w).
- McCarthy, M., Milne Skillman, K., Elson, N., Bates, C., Forrester-Jones, R. and Hunt, S. (2020), "Making connections and building confidence: a study of specialist dating agencies for people with intellectual disabilities", *Sexuality and Disability*, Vol. 38 No. 1, pp. 3-18, doi: [10.1007/s11195-020-09619-2](https://doi.org/10.1007/s11195-020-09619-2).
- Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J. and Parr, J.R. (2018), "Predictors of quality of life for autistic adults", *Autism Research*, Vol. 11 No. 8, pp. 1138-1147, doi: [10.1002/aur.1965](https://doi.org/10.1002/aur.1965).
- Milton, D., Gurbuz, E. and López, B. (2022), "The 'double empathy problem': ten years on", *Autism*, Vol. 26 No. 8, pp. 1901-1903, doi: [10.1177/13623613221129123](https://doi.org/10.1177/13623613221129123).
- Palinkas, L.A., Horwitz, S.M., Green, C.A., Wisdom, J.P., Duan, N. and Hoagwood, K. (2019), "Purposeful sampling for qualitative data collection and analysis in mixed method implementation research", *Administration and Policy in Mental Health and Mental Health Services Research*, Vol. 42 No. 5, pp. 533-44, doi: [10.1007/s10488-013-0528-y](https://doi.org/10.1007/s10488-013-0528-y).
- Pearson, A. and Hodgetts, S. (2023), "'Comforting, reassuring, and [...] hot': a qualitative exploration of engaging in bondage, discipline, domination, submission, sadism and (SADO)masochism and kink from the perspective of autistic adults", *Autism in Adulthood*, doi: [10.1089/aut.2022.0103](https://doi.org/10.1089/aut.2022.0103).
- Pearson, A., Rees, J. and Forster, S. (2022), "This was just how this friendship worked": experiences of interpersonal victimization among autistic adults", *Autism in Adulthood*, Vol. 4 No. 2, pp. 141-150, doi: [10.1089/aut.2021.0035](https://doi.org/10.1089/aut.2021.0035).
- Pearson, A., Rose, K. and Rees, J. (2023), "I felt like I deserved it because I was autistic': understanding the impact of interpersonal victimisation in the lives of autistic people", *Autism*, Vol. 27 No. 2, pp. 500-511, doi: [10.1177/13623613221104546](https://doi.org/10.1177/13623613221104546).
- Ragaglia, B., Caputi, M. and Bulgarelli, D. (2023), "Psychosexual education interventions for autistic youth and adults – a systematic review", *Education Sciences*, Vol. 13 No. 3, p. 224, doi: [10.3390/educsci13030224](https://doi.org/10.3390/educsci13030224).
- Rothman, E.F., Graham Holmes, L., Caplan, R., Chiang, M., Haberer, B., Gallop, N., Kadel, R., Person, M., Sanchez, A., Quinn, E. and Wharmby, P. (2022), "Healthy relationships on the autism spectrum

(HEARTS): a feasibility test of an online class co-designed and co-taught with autistic people", *Autism*, Vol. 26 No. 3, pp. 690-702, doi: [10.1177/13623613211069421](https://doi.org/10.1177/13623613211069421).

Sala, G., Hooley, M. and Stokes, M.A. (2020), "Romantic intimacy in autism: a qualitative analysis", *Journal of Autism and Developmental Disorders*, Vol. 50 No. 11, pp. 4133-4147, doi: [10.1007/s10803-020-04377-8](https://doi.org/10.1007/s10803-020-04377-8).

Skills for Health (2019), "Core capabilities framework for supporting autistic people", available at: www.skillsforhealth.org.uk/wp-content/uploads/2020/11/Autism-Capabilities-Framework-Oct-2019.pdf (accessed 15/09/2023.)

Strunz, S., Schermuck, C., Ballerstein, S., Ahlers, C.J., Dziobek, I. and Roepke, S. (2017), "Romantic relationships and relationship satisfaction among adults with Asperger syndrome and high-functioning autism", *Journal of Clinical Psychology*, Vol. 73 No. 1, pp. 113-125, doi: [10.1002/jclp.22319](https://doi.org/10.1002/jclp.22319).

Tromans, S., Chester, V., Gemegah, E., Roberts, K., Morgan, Z., Yao, G.L. and Brugha, T. (2021), "Autism identification across ethnic groups: a narrative review", *Advances in Autism*, Vol. 7 No. 3, pp. 241-255, doi: [10.1108/AIA-03-2020-0017](https://doi.org/10.1108/AIA-03-2020-0017).

Wilson, B., Hay, S., Beamish, W. and Attwood, T. (2017), "The communication "Roundabout": intimate relationships of adults with Asperger's syndrome", *Cogent Psychology*, Vol. 4 No. 1, doi: [10.1080/23311908.2017.1283828](https://doi.org/10.1080/23311908.2017.1283828).

Yew, R.Y., Samuel, P., Hooley, M., Mesibov, G.B. and Stokes, M.A. (2021), "A systematic review of romantic relationship initiation and maintenance factors in autism", *Personal Relationships*, Vol. 28 No. 4, pp. 777-802, doi: [10.1111/per.12397](https://doi.org/10.1111/per.12397).

Yew, R.Y., Hooley, M. and Stokes, M.A. (2023), "Factors of relationship satisfaction for autistic and non-autistic partners in long-term relationships", *Autism*, Vol. 27 No. 8, pp. 2348-2360, doi: [10.1177/13623613231160244](https://doi.org/10.1177/13623613231160244).

Further reading

Douglas, S. and Sedgewick, F. (2023), "Experiences of interpersonal victimization and abuse among autistic people", *Autism*, doi: [10.1177/13623613231205630](https://doi.org/10.1177/13623613231205630).

Corresponding author

Claire Bates can be contacted at: claire.bates@choicesupport.org.uk

For instructions on how to order reprints of this article, please visit our website:
www.emeraldgroupublishing.com/licensing/reprints.htm
Or contact us for further details: permissions@emeraldinsight.com