



SAAAIL

Supporting Autistic
Adults' Intimate Lives

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Outsiders Trust Presentation



A qualitative study exploring how autistic adults' intimate lives can be supported by adult social care in England

Focusing on autistic adults without learning disabilities

Funded by National Institute for Health and Care Research

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autlives.com



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SAAIL

Aims:

- Produce representations of autistic people's intimate lives in all their diversity (smash stereotypes and misperceptions)
- Understand the challenges autistic people face around intimate lives in our neurotypical society
- Develop an understanding of how autistic people think health and social care can better support intimate lives



Qualitative interviews and focus groups

Interviews:

25 participants

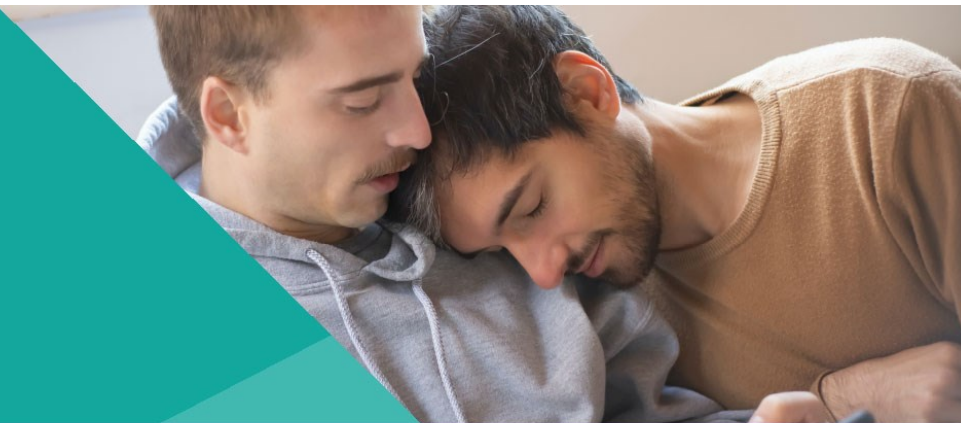
Semi-structured, narrative

Online, in-person, text, phone

Focus groups:

48 Participants

- Asynchronous text-based
- Entirely autistic spaces
- Participate in own time and pace



Focus groups:

Participants incredibly diverse: Participants do not speak for all autistic people

- Ages 19 – 67
- Most diagnosed in adulthood

Genders	
Female	18
Male	20
Trans non-binary femme	1
Non-Binary	1
Trans non-binary/female	1
Genderqueer	1
Questioning	2
Trans male	1
Agender	1
Not provided	1

Sexuality	
Heterosexual	20
Lesbian	3
Gay	3
Bisexual	7
Pansexual	4
Queer	2
Unknown	1
Undefined	1
Questioning	1
Pomosexual/ Veggiesexual/ Autisexual	1
Lesbian but with bi/pan tendencies	1
Gray Ace	1
Biromantic asexual	1
Not Provided	1

Diagnosis Type	
Formal	38
Self	6
Self, formal pending	2
Not Provided	2

Relationship Status	
Single	27
In relationship	9
Married	5
Engaged	1
Separated	2
Dating	1
Undatable	1
Not Provided	1

Before SAAIL

Study exploring autistic men's experiences of paying for any sexual services

20 Participants

- UK, USA, South Africa, Netherlands, Greenland
- Ages early 20's to late 70's
- Mostly white, mostly cis men
- Range of sexual identities and spoke about paying for sex from people of a range of genders

Navigating sex and relationships in a Neurotypical Society

In our society neurotypical and heteronormative dating scripts, “flirting”, “hints”, indirect language, subtle body language and patterns of communication present barriers for autistic people.

Normative ideas about doing relationships seldom are accommodating to sensory differences, preferences and needs. (*Amatonormativity*)

Many autistic people find themselves isolated and excluded from participating in intimate relationships.

Vicious Cycle of Anxiety and Avoidance

Anxiety at a young age (about getting it wrong or a bad experience). Avoidance. Lack of experience as adult. Anxiety about inexperience compared to peers. Avoidance. Isolation and loneliness.

Left many people feeling completely isolated and excluded from dating, intimacy and sex.

Paying for sex offered and opportunity to break that cycle. So can positive relationships

Indirect language and social cues in our society

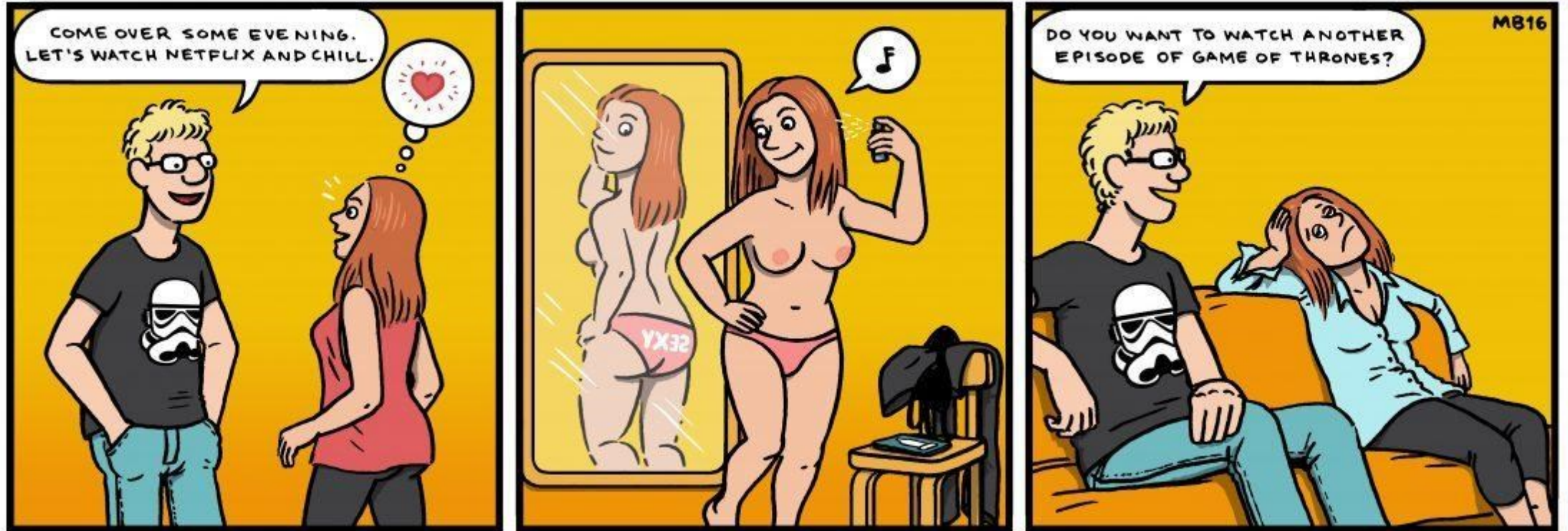
“It’s almost like, like there’s things like these unwritten rules, you know, I sometimes find it difficult to read body language, and, you know, reading between the lines”.

(Edward, man, heterosexual, 45)

“I find there is so much subtext and implied meanings and a need for mind reading with neurotypical people. Flirting is just really alien to me. It can be really exhausting to have that disconnect in communication styles and I find non-autistic people I’ve had relationships with are actually not very good at communicating what they really mean and what they really feel, they are too conditioned to almost speak in riddles and I’ve found people get frustrated with me when I haven’t been able to solve the riddle of what they really meant when they said or did something completely unrelated!” (Petty_LaBelle, woman, 33)

“So I would say it's like... going into a dark room looking for a black cat when you're blindfolded.” (Kimberly, woman, heterosexual, 63)

Indirect language



Credit: <https://comics.sexpo.fi/en/sarjis/proposing-sex/>

The double-empathy problem

Damian Milton

Whilst autistic people can struggle to process and understand the intentions of others within social interactions, research increasingly shows that problems are in both directions. Both non-autistic and autistic people struggle to empathise and understand each other.

Rather than having autistic people have to try to bridge this gap, we should all be trying to “do” sex and relationships in a way that works, and is safe, pleasurable, and affirmative for everyone

Credit: <https://www.autism.org.uk/advice-and-guidance/professional-practice/double-empathy>

Challenges: Trouble with flirting

- Knowing when someone is flirting with you

“By the time I figure out what the other person’s intentions are it’s either too late or, you know, the moment’s passed”. (Derek, 38, man , heterosexual)

- Knowing how to flirt
- Small talk on dating sites and apps

Leaving participants feeling excluded and isolated

Anxiety around “Doing the wrong thing”

Worried being misunderstood, doing or saying the wrong thing, being perceived as disrespectful, or misunderstanding consent.

Some worried about coming across as patriarchal or sexist accidentally.

Some participants avoid sex and relationships because of this anxiety.

Autistic participants repeatedly asked for clear Communication

Yeah, if things aren't explicitly communicated, it makes life so much harder for autistic people. 'Cause so much is not explicitly communicated. And some of it could be so easily. So it's just constantly feeling like, "Oh, I've screwed up again, I know I've messed up, I'm not quite sure how. But I'm going "Oh, I missed that. If they'd said that, this never would've happened," you know....It's exhausting and it's anxiety provoking as well. 'Cause it leads to that kind of hypervigilance and masking. And they're just not healthy or sustainable.

(Fred, man, 38, heterosexual)

Safe spaces with clear boundaries

The explicit consent process involved in sex work relationships provided safe and predictable spaces.

Strip clubs: It's also a place where the rules are very, very clear and ... umm... as long as I'm willing to accept those rules you know, I know exactly where I stand, so if I want a dance from a girl I'll ask for a dance... because it is clear cut there's a sense of control whereas, if I'm in my local pub and there is an interesting young lady, it is much, much, much more nebulous as to are we going to be friends is there something else...I mean in a strip club environment...we socially agree to exchange one for the other and then we all stick to the rules (Mike, 45, man, heterosexual)

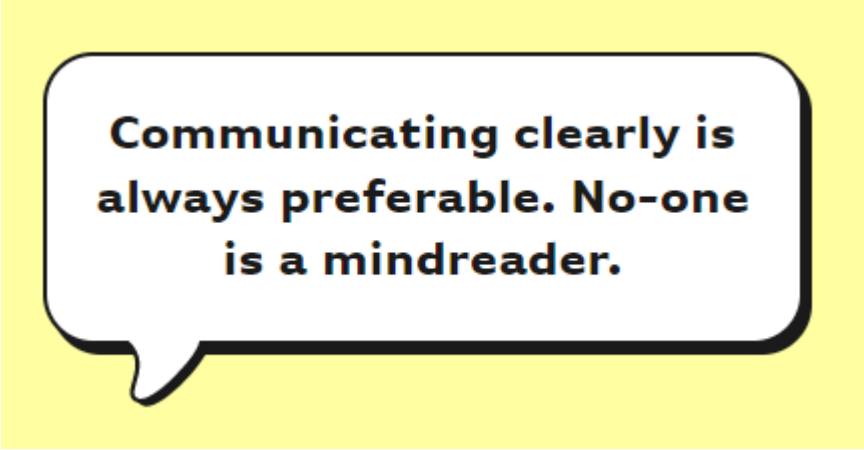
Consent and boundaries: Neurodiverse communication leading the way

I think that actually, the idea of consent – the boundaries, communication tools, all these things. Actually I think autistic people may actually be better at them, because of, they are so, it's so rule based, it's so uh, it makes sense, it's logical, it's rational, it's, uhm, very clear communication. It's blunt. And so I think that because of this it makes more sense to an autistic person, just literally ask someone, can I kiss you? Or can I hug you? Than like, you know, 500 levels of mind reading (Jay, 25, Trans-masculine, bisexual)

Clear Communication, consent and boundaries

Autistic people need clear explicit communication to feel safe and confident in dating and flirting.

But everyone, neurotypical and neurodiverse, could benefit from being more direct about their desires and boundaries.



**Communicating clearly is
always preferable. No-one
is a mindreader.**

Some other challenges autistic people mentioned

- Some participants shared about developing intense feelings for and focused interest in another person.

Advice: Seeing what you get back from people

I'd say with the autistic people I've known they've expected to be in contact a lot more often, a lot more frequently than neurotypical people have. And I think it's great if you're somebody who's quite intense and loves that, or if you're with somebody where it matches, but if you're not, if it's not matching it feels overwhelming and a bit intrusive I'd say. So it's about learning how to match somebody's intensions there. **And I think that can be done by seeing what you get back from people, you know, are they responding to all of your messages, you know, with equal enthusiasm?** Or are you not hearing from them for three weeks? Until you're the one who always has to initiate otherwise they don't reply to you at all, that kind of thing. (Jess, 30, woman, pansexual)

“the one” thinking and Rejection

I am now in a long term heterosexual relationship, but sexuality, particularly the lack of sexual experiences (and lack of prospect of being able to do so in the future), has been an intensely painful experience for many years at the start of my adulthood. At the time, it seemed as though I had found ‘the one’, she wasn’t interested, and if I couldn’t establish a relationship with this woman, who seemed to understand me really well, it seemed I wouldn’t ever be able to do so. This was the main cause leaving my degree course, and caused severe depression. I think I still have PTSD as a result of it, as it was so intense and so long lasting. (Aut_amo, 37, man, heterosexual)

“the one” thinking

The heteronormative myth about “the one” who is right for you may cause unnecessary anxiety when forming relationships. As a result, you may place a lot of expectations and hopes on one person.

Credit <https://comics.sexpo.fi/en/sarjis/revealing-your-crush/>

Rejection sensitivity

Some autistic participants spoke about heightened rejection sensitivity, causing a great deal of pain and distress from romantic rejection.

Rejection experienced as a traumatic event

Past negative experiences, leading to fear of rejection

Important to keep this in mind when you are dating and flirting with others, anyone could experience this. Be empathetic.

Almost all people have been rejected in their relationships at some point in life.

- If someone says they are no longer interested, believe what the person says to you about their feelings.
- Do not reflect too long on what you could do differently or how you could change the other person's mind.
- Although rejection may feel devastating, the situation gets easier with time.
- You have the right to feel sad and seek help if the grief feels overwhelming

Credit: <https://comics.sexpo.fi/en/sarjis/revealing-your-crush/>

Anyone has the right to change their mind any time

Often people change their mind about having sex, after they have already said they wanted to have sex, or during sex. It is never too late to say no and to change your mind. Even if it feels hurtful at the time, you have to respect someone's decision and move on.

The same goes for flirting and talking online. If someone stops talking to or "ghosts" you, you need to respect and try to move on.

Sometimes after you have proposed sex or agreed to it, the decision no longer feels good and you may want to stop in the middle. Your partner also has the right to decide in the middle of sex that they don't want to continue. This decision must always be respected.

Credit: <https://comics.sexpo.fi/en/sarjis/proposing-sex/>

Other considerations: Delayed processing

Many participants said it took them longer to process a social interaction, and to know how to respond.

Not all participants felt that they were always fully aware of their own needs in the moment.

Many participants felt that were more likely to be taken advantage of by others.

Embrace difference

There is no one correct way to do sex and relationships, do what feels affirmative, safe and pleasurable for you and your partners.

We don't need to stick to ableist, neurotypical, heteronormative relationships conventions and styles.

“Realising I was autistic allowed me to see lots of parts of myself more positively including the sensory, sensual, sexual, romantic and emotional”. (Zel, 42, gender-questioning)

“I manage better with intimacy when there are spare beds, rooms to hop into it. There are times when everyone is uncomfortable in their own bodies with fatigue, worries, medical conditions that would cover allergies. Then we get into the issue of sleeping surfaces, duvets, pillows and air temperature, windows open or shut. I find there's more excitement created if there is less expectation on sharing the same bed every night” (Purple Queen, 67, woman, Pansexual)

How does this relate to dating, flirting and meeting people online?

- Always use clear communication, say – in words – what you want and need. And always say what you don't want.
- Don't assume everyone understands your indirect ways of communicating. Some people may be confused by your indirect communication even though it seems obvious to you.
- Understand that people might take what you say literally.
- Understand that some people experience rejection intensely, be empathetic in your interactions.
- Try and avoid “the one” magical thinking

- Check whether your frequency of communication matches the other persons'
- If you think something you say may be sexist, racist, transphobic, or offensive, check first.
- Anyone can change their mind about flirting or having sex, at any point. They can change their mind about chatting online. Try not to dwell on it or take it personally. But it is ok to feel hurt, seek help or support if you need it.
- Understand that some people have less experience with relationships
- This, and other experiences, may lead to lots of anxiety around sex and relationships. Be empathetic.

“Be silly. Be honest [and direct]. Be kind.” — Ralph Waldo Emerson

Autism and Intimacy Digital Toolkits / Resources

An ever-evolving online resource co-produced at a series of two workshops

One for autistic people

One for health and social care providers

- Based on these findings and stakeholders' input
- Existing resources

Can you contribute?





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