

Starting Conversations to Support Intimate Lives

A guide for social care professionals

About SAAIL

Supporting Autistic Adults' Intimate Lives (SAAIL) is a research project exploring how adult social care in England can better recognise and support autistic people around sex and relationships. Find out more at <u>www.autlives.com</u>

Intimate lives matter. We know that positive intimate relationships are good for our mental health and wellbeing and can help combat loneliness and isolation. We also know that autistic people experience higher levels of loneliness and isolation.

However, SAAIL has found that:

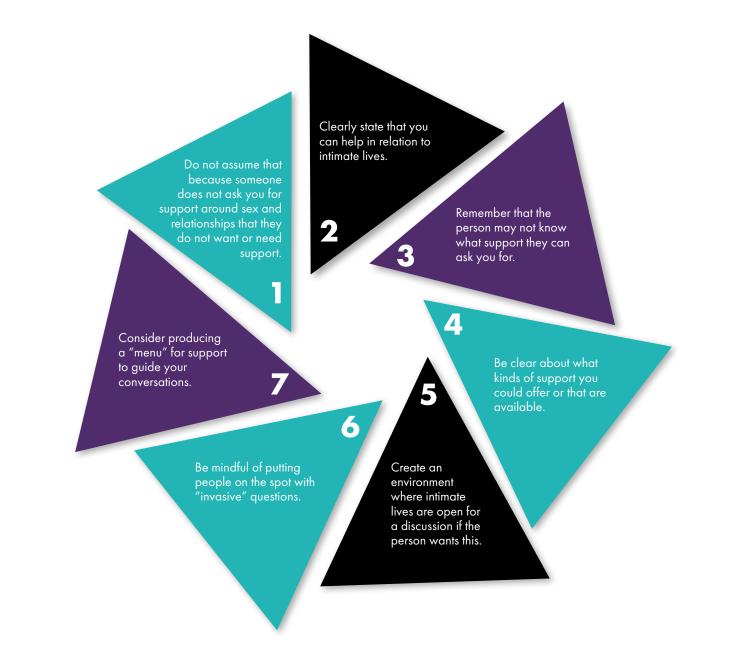
- Social care professionals and policy-makers in England are not putting autistic people's intimate lives on the social care agenda.
- The Government's five-year Autism Strategy, created to improve all aspects of life for autistic people by 2026, does not mention support for intimate lives.
- Most of the autistic people we spoke to have received no or unsatisfactory support around sex and relationships from social care professionals in England.
- Discussions around sex and relationships are usually missing from post-diagnostic support and from social care assessments.
- Professionals are not speaking to autistic people about support for sex and relationships, they are not letting them know that they can be supported in this area, and they are not asking them what they can do to help.

We want this to change. We want to see intimate lives "on the menu" for support within adult social care. As a social care professional, you can be part of this change by making some small adjustments to how you start conversations about support needs with autistic adults.

We provide 7 considerations for you on the next page.

"The Government's latest fiveyear Autism Strategy, created to improve all aspects of life for autistic people by 2026, <u>does not</u> <u>mention support for intimate lives</u>"

7 considerations for professionals who support autistic adults



Do not assume that because someone does not ask you for support around sex and relationships that they do not want or need support.

Many autistic people we interviewed said they would not bring up the topic of sex and relationships with a social care professional even if they needed support. This is because sex tends to be a taboo subject, and they were not sure whether it is appropriate to ask for support, information, or resources.

2

Clearly state that you can help in relation to intimate lives.

When you discuss the possible areas where someone might need support in their daily lives – like work, housing, transport, and personal relationships – remember to specifically include romantic and sexual relationships as an area that's open for discussion.

By doing this you put support for intimate lives "on the menu": you acknowledge that sex and intimate relationships are a part of life and a legitimate social care issue.

Remember that the person may not know what support they can ask you for.

Because sex and intimate relationships are so seldom spoken about in health and social care settings, many autistic people said that they did not know how different professionals (i.e., social workers, occupational therapists, personal assistants) could support them. They did not know what would be within different professionals' remits, or what support they have a right to ask for. Take, for example, Neo, who is unsure what her social worker's role in supporting her would be:

"I have a social care package and social worker. I don't really understand what is and isn't my social worker's role so it's hard to even know what [support] fits." (Neo, woman, queer, 32)

Be clear about what kinds of support you could offer or that are available.

Having never been offered support around sex and relationships before, the person is unlikely to be able to imagine what that support might look like for them. You should give them clear and specific examples of what kinds of support and resources they could access.

Create an environment where intimate lives are open for a discussion if the person wants this.

Not all people will want support around their intimate lives at all times. However, the people we spoke to said that they do want professionals to provide a safe and trusting environment where they would feel comfortable to discuss or ask for support in this area if they want it. For example, Swimboy says that professionals must:

"Create a safe consensual, respectful environment where the topic of intimacy and needs can be discussed if the autistic person wants to have such a conversation. If so, enable the discussion to happen in a space and format that is comfortable and accessible to the individual... Always give well defined options and always presume competence." (Swimboy, 46, Transmale)

Be mindful of putting people on the spot with "invasive" questions.

Because we live in a society set up according to neurotypical people's needs and expectations, many autistic people find themselves in social situations that feel unpredictable or that they are unprepared for, causing them distress.

Many autistic people say that they may need time to process information or their emotions, or to understand and articulate their own needs. They do not want to be caught off guard by an unexpected question from a professional.

For example, JR247 explains:

"I think [I would not want] anything that would put me on the spot, anything that is sudden or done without fore warning." (JR247, woman, bisexual, 21)

Based on what our participants have told us we suggest that social care professionals:

- Do make it clear that the topic of intimate lives is up for discussion if a person wishes to talk about this.
- Do not put someone on the spot or catch them off guard by asking very specific or "invasive" questions that they may not have been expecting to discuss in detail.
- Always create an environment where the person feels prepared, safe and in control within the conversations you are having.
- Consider producing a "menu" for support to guide your conversations.

We suggest creating a menu document to guide your conversations around needs and support. This will help you to open up discussions about intimate lives in a way that allows the person safety, choice, and control.

On the next page we explain how you can do this.

"I think [I would not want] anything that would put me on the spot, anything that is sudden or done without fore warning." "Create a safe consensual, respectful environment where the topic of intimacy and needs can be discussed if the autistic person wants to have such a conversation."

How to produce a menu for support that includes intimate lives

- Write a list of the broad areas where you could offer or facilitate support. Always include romantic and sexual relationships alongside all other areas.
- Provide the person with the menu before you meet, to consider in their own time. This gives them time to process the information and to think about and articulate what they may need. This allows people to feel prepared, safe, and in control within the conversation.
- The menu could allow the person to steer the conversation, to pick and choose the areas they would like to prioritise for support and the areas they don't want to talk about now. People's needs change over time, so you can return to the menu with them later if that's applicable to your role.
- Everyone processes information and would like their needs met in different ways. If applicable, the menu could contain options for how the person would like to receive support around a particular area, for instance having a one-to-one conversation or accessing online resources by themselves. You can see an example of this menu below.

Sex and relationships-specific example menu





The Principal Investigator for the study is Dr Monique Huysamen, Manchester Metropolitan University.

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