



SAAIL

Supporting Autistic
Adults' Intimate Lives

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[www. autlives.com](http://www.autlives.com)

A participatory study exploring how adult social care in
England can be better at

Supporting Autistic Adults' Intimate Lives

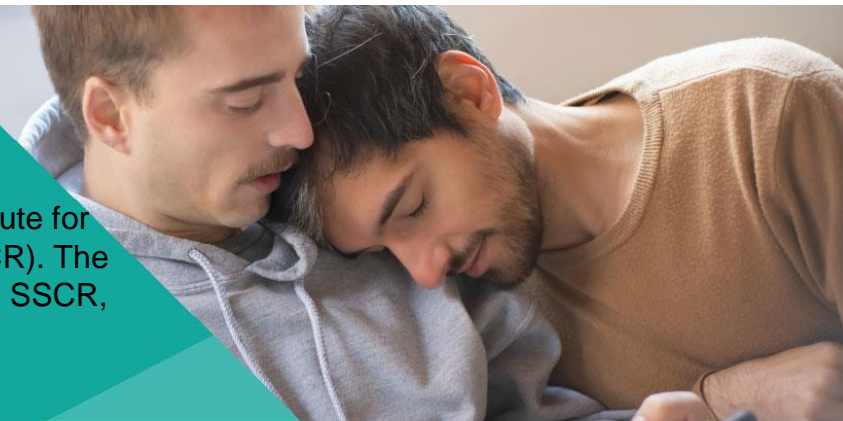
Focusing on autistic adults without learning disabilities



www.autlives.com



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Neurodiversity

Sees neurocognitive diversity as natural, valuable and needed.

“Neurodiversity may be every bit as crucial for the human race as biodiversity is for life in general...” Harvey Blume

“Biological diversity of all kinds is essential to the survival of an ecosystem—so why should neurological diversity, which is one aspect of biological diversity, be any different”.

What drives SAAIL

Navigating sex and relationships in a “neuro-normative” society

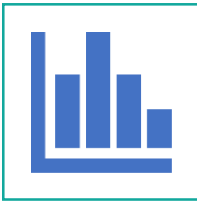
In our society, neurotypical and heteronormative dating and communication – “flirting”, “hints”, “playing hard to get” indirect language, subtle body language – present barriers for autistic people.

It can be hard for everyone – many autistic people find themselves isolated and excluded from participating in intimate relationships.

The humanising potential of recognising intimate lives

Denying people the opportunity to have closeness, intimacy, fun, pleasure, connection, and touch, and be recognised as sexual beings is profoundly dehumanising.

SAAIL Methods



Policy Document
Analysis



Interviews



Focus Groups



Workshops

Autism and Intimacy

National Policy Document Analysis



Policy documents fail to recognise intimate lives proportionally.

The Autism Strategy is silent on intimate lives.



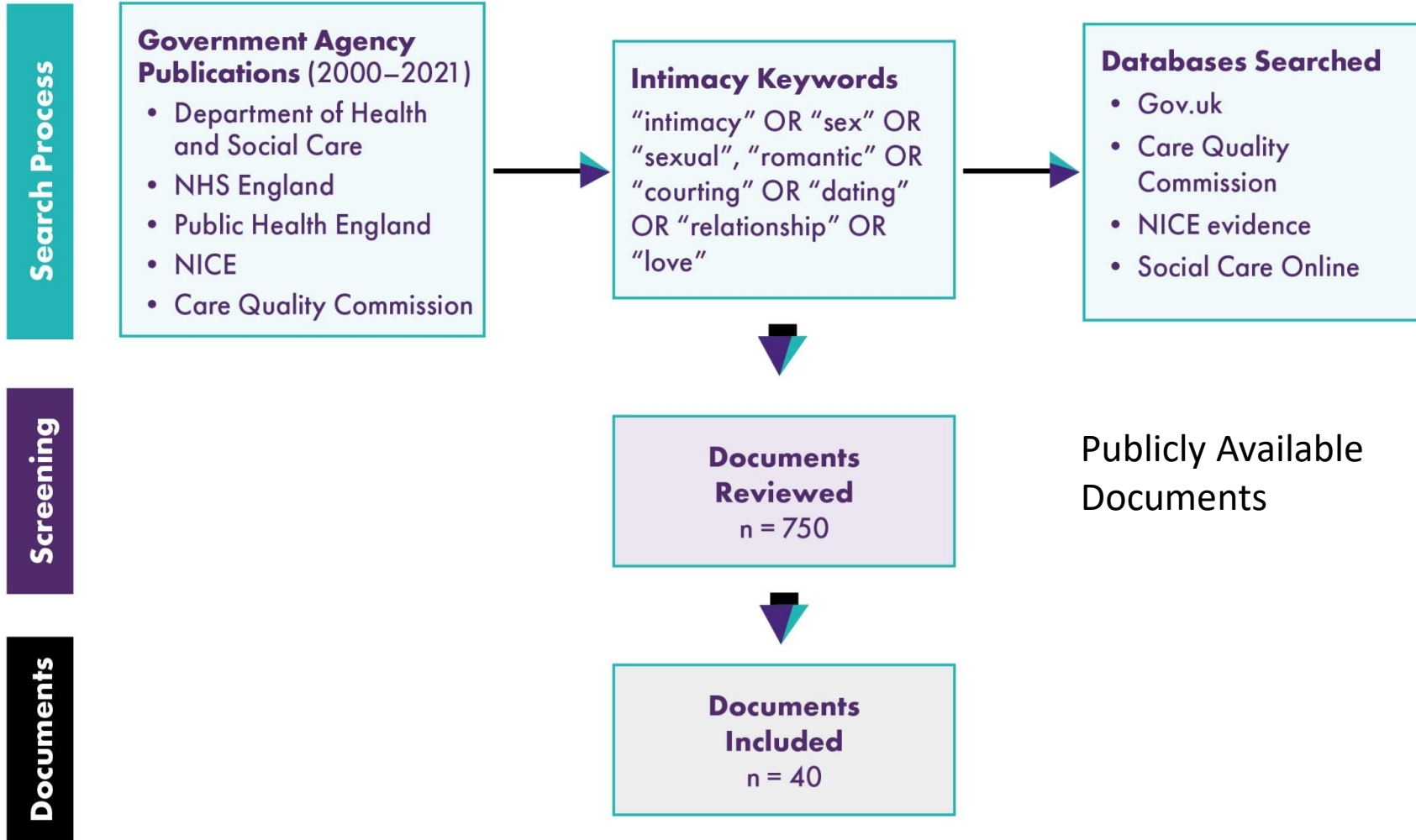
HM Government

The national strategy for autistic children, young people and adults: 2021 to 2026

Intro: “over the next 5 years, we want to create a society that truly understands and includes autistic people in all aspects of life” (p. 7).

But it is silent on an important aspect of autistic people’s lives: their intimate relationships.

Systematic Search Process



A failure to recognise intimate lives proportionally

- All other aspects of social life are mentioned (work, housing, community engagement, carer and family relationships) except from sex and relationships.
- A big emphasis on work/employment.
- Work mentioned over 40 times, love and relationships: 0.

“The predicament around loneliness and intimacy was in retrospect probably about half of my mental health crisis at university.”

(aut_amo, male, 37, heterosexual, white)

Emphasis on risk

- An emphasis on risk in the absence of discussion of the positives and the value of supporting intimate relationships.
- Reinforce infantilising stereotypes and damaging discourses.
- These discourses position staff's responsibility around mitigating risks, rather than actually supporting intimate lives.

Recommendations

Proportionate acknowledgement of intimate lives in policy documents

Our central recommendation to policy-makers is to give intimate lives space and recognition within future national health and social care policy and guidance publications. Support for intimate lives should be addressed in a way that is proportionate to other important (and not neglected) aspects of social life. Policy-makers should adopt holistic approaches that value autistic people's participation and inclusion in all aspects of life, including intimate relationships.

Present balanced representations of risk

Include balanced representations and considerations of autistic people's intimate lives which recognise but are not driven by considerations of risk. The responsibilities of health and social care professionals set out in these documents should extend beyond discussions of risk mitigation and incorporate responsibilities to support autistic people's right to participate in fulfilling intimate relationships.

Include autism-specific needs around intimacy

Policy and guidance documents must:

- Address the challenges and disparities faced by autistic people, who are a very diverse group. This includes support around managing and negotiating sensory needs in relationships, communication differences, and the impacts of social anxiety on intimate lives.
- Recognise that autistic people with learning disabilities living in supported accommodation with other people with learning disabilities may have support needs around intimacy that are additional to those related to learning disability.
- Recognise that autistic people without learning disabilities also face significant barriers to forming and maintaining intimate relationships and may also need, benefit from, and be eligible for resources to support their intimate lives.

A "whole life" approach to supporting intimate lives

Health and social care publications should recognise the importance of autism-specific sex and relationship education and support across the whole lifespan. Sex and relationship education, resources, and support should not only be considered for autistic children and adolescents. Many people only receive an autism diagnosis in adulthood. Many autistic people want age-appropriate resources and support

Ensure policy-making processes reflect autistic people's priorities

We have a set of recommendations to improve the policy-making process:

- Directly involve autistic people through genuine consultation, co-production, and co-authorship at all stages of the policy-making process, from consultation to final publication.
- Public consultations should include questions that ask autistic people directly whether they have needs or priorities regarding support around intimate relationships.
- Public consultations should include open-ended questions and qualitative data collection methods. These allow autistic people's own agendas to feed into the process. Where only closed-ended quantitative responses are collected, consultations are limited to generating evidence on priorities that policy-makers have already set, and these seldom include intimate lives.
- Policy-making processes should incorporate monitoring and accountability mechanisms that ensure that the priorities raised by autistic people during public consultations are not written out of the final documents.

Consult the Core Capabilities Framework for Supporting Autistic People

We recommend that the Core Capabilities Framework for Supporting Autistic People (2019) is read by anyone involved in producing or reviewing autism-specific national health and social care guidance and policy. This document satisfies all the recommendations set out in this brief. The principles, values, and processes underpinning the framework offer a set of good practice principles upon which future national health and social care publications can build.

Read the Core Capabilities Framework:
bit.ly/CoreCapabilities



The full research article is available Open Access here: (forthcoming)

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

To offer feedback or suggestions around taking our recommendations forward, please contact us:

Email: m.huysamen@mmu.ac.uk

Visit: autlives.com/feedback

Twitter: twitter.com/Autlives



Read our
summary here



Policy Brief: suggestions to ensure intimate lives are included in future autism policy and guidance that autistic people are involved in policy-making processes.

Interviews and focus groups

63 People took part
in SAAIL

In-depth interviews:

- 25 participants
- Online, in-person, text, phone



Online focus groups:

- Forum-style, text based
- Participate in own time and pace
- Entirely autistic spaces
- 46 participants
- 5 groups



A very diverse group: Gender and sexual orientation

Ages 19–67 (average 39)

Many Adult DX/realisation

(They used their own labels)

Genders	
Female	18
Male	20
Non-Binary	1
Trans non-binary/femme	2
Genderqueer	1
Questioning	2
Trans male	1
Agender	1

Sexuality	
Heterosexual	20
Lesbian	3
Gay	3
Bisexual	7
Pansexual	4
Queer	3
Undefined	1
Questioning	1
Pomosexual, Veggiesexual, Autisexual	1
Lesbian but with bi/pan tendencies	1
Gray Ace	1
Biromantic asexual	1

53% of all participants identified as something other than cisgender and heterosexual

Relationship status	
Single	27
In a relationship	9
Married	5
Engaged	1
Separated	2
Dating	1
“Undatable”	1

A very diverse group: Race and ethnicity

Race/Ethnicity	
White British	13
White European	4
White British/Irish	1
British	1
White American	1
White	4
White Jewish	1
Celtic	1
Mixed/British African	1
British African	3
Black British	3
Black	4
Black Carribean/White	1
Black American	1
African American	2
White Asian	1
Middle Eastern	1
Mixed	1
Mixed, Somali/English	1
Mixed, White British/Black Caribbean	1

41 % of SAAIL participants identified as black or as being part of a minority ethnic group

Being black and autistic

“As a Black woman I’ve always felt quite fetishized in the world of sex and dating. I realised I was autistic quite late in life but have always felt like a bit of an oddity. I think in future the impact on my intimate life is that I can imagine feeling like a curiosity or taboo experience more so than just being an individual that someone wants to connect

with.” (Petty_LaBelle: 33, Female, Heterosexual, Black Caribbean/White)



Common challenges: Most related to living in a society not responsive to autistic people's needs

- Anxiety
- Sensory needs
- Lack of trust in others (being let down in the past) and lack of trust in their own “instinct”
- Fear of rejection
- Trauma
- Age, and feeling inexperienced
- Lack of information for older adults
- Alexithymia and knowing and communicating own boundaries
- Fear of being taken advantage of, past experiences of trauma
- Low self-esteem and self-worth
- Perceived lack of sexual experience / knowledge
- Stigma/people’s ignorance, and societal assumptions
- Infantilisation by HSC providers and others
- Mental health (in both directions)
- Other physical conditions and disabilities
- Hypermobility

Indirect language and social cues in our society

Causing immense anxiety, about getting signals and messages wrong and crossing boundaries accidentally

“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)

“If things aren’t explicitly communicated, it makes life so much harder for autistic people...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)

Autistic communication leading the way for clear consent and boundaries

“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 it’s so rule based, 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)

Vicious Cycle of Anxiety, Avoidance, Shame

Negative early social experiences with peers or rejection → anxiety about getting it wrong → avoidance of early dating, flirting, experimenting → missed early sexual/dating experiences → perceived lack of experiences compared to peers → shame and avoidance of intimacy → perceived lack of sexual experience in adulthood → avoidance.

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

"I'd really gotten through all of my 20s without any more relationships. Erm, so **rather than sort of gaining experience and confidence, I'd felt more and more ashamed, and more and more like even if someone did find me attractive it would be such a disappointment** for them because of such a lack of experience, if we did ever have sex that erm... I just couldn't really see a way forward, you know... and I was, you know, depressed quite often as well and had a lot of kind of general social anxiety. So I sort of felt around the end of my 20s like I just don't understand how I can hope to meet someone else. So this was actually quite, you know, painful really. Because, you know, my body and soul wanted these kinds of relationships so much." (Fred: male, 38, heterosexual, mixed race)

Challenges with knowing and communicating own boundaries and needs: Alexithymia

Alexithymia is trouble with being able to know, process or express what you are feeling in the moment.

I've been so programmed to mask, and spend so much energy and intellect trying to read people, and meet their expectations, I simply lose touch with my own needs far too easily!!! It's like a delayed reaction. My instant reaction is the one I've learned, the socially accepted reaction, and then it takes me a while to actually process what happened and feel my own response to it! (Anne, female, 49, bisexual, white).

Sometimes leading to autistic people having their boundaries crossed.

Consent, boundaries, and Alexithymia

“Also always give space and time to those who might at present be uncertain of their needs. This is a big one for me as due to alexithymia I can be confused by my own feelings, or find it difficult to understand my needs and desires.” (Swimboy, trans male, grey ace, mixed race)

Sensory needs and differences

- Many typical spaces where people meet and “hook-up” (like bars) are not autism friendly

“And often meet ups in ‘going out’ places (e.g., bars) can be hard - no activity to focus on/aid conversation, loud sounds, competing sounds, sensory overwhelm...” (Bigcatgirl69, Trans non-binary/female, 28)

- Sensory needs and differences: touch , pressure, sounds, textures, smells.
- “In my experience sex is something of a sensory nightmare,” Anon
- Normative living and sleeping arrangements are not conducive to supporting sensory and other needs, so people felt relationships were out of their reach

Embrace difference

Participants wanted other autistic people to know there is no one correct way to do sex and relationships, do what feels affirmative, safe and pleasurable for you and your partners.

Normative ideas about how to do relationships can be exclusionary.

“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, 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)

We don’t need to stick to idealistic, ableist, heteronormative ways of doing relationships.

Sensory Joy

“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)

Kink, BDSM, paid sex

Can be autism friendly: Spaces where communication, consent and boundaries are inherently clear.

Spaces to explore sensory needs in non-judgmental environment

Sensory Joy

Kink, BDSM

"I think the nice thing about the [kink] dynamic is it's in control... because you've discussed what you want that dynamic to be, how you want that dynamic to be...It gives that sense of control, that we don't get, particularly as autistics ... it's almost a relief because you can relax into a dynamic you understand... It's being aware of yourself, being open and honest with yourself, and with others...It can be difficult at times, particularly if you don't know how you feel yourself. I struggle with alexithymia. So it does mean that recognising and interpreting emotions and feelings, and what the input is telling me, is really really difficult. And then it's really, really hard to then discuss that with someone else. But [kink] gives me a space where I don't have to go and find the right way of discussing that with someone else. I can just go, "I'm enjoying something, I don't know what it is, but this needs to... get more intense... stop... do something else." ... it just gives that flexibility to be what it is." (Meg, 36, agender, Pansexual polyamorous, white)

We asked autistic people about support and found that:

- Health and social care staff are not asking autistic people about their intimate lives, and how they can help.
- Conversations about sex and relationships are missing from social care assessments, post-diagnostic support, care plans, and just about every other health and social care interaction interaction.
- Almost all participants said they have had no, or completely unsatisfactory support around sex and relationships – despite a genuine need.

We asked autistic people about support and found

People had very diverse views on what they wanted support to look like, but:

- Choice
- Control
- Dignity
- Respect
- No infantilisation

Create an environment where intimate lives are open for discussion, but be mindful of putting people on the spot.

“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)

Towards a menu of support: Choice and control in discussions about support needs.

- Always make sure intimate lives are “on the menu” alongside discussing other forms of support, like housing, work, etc.
- Written information/options that people can consider and process **in their own time before they meet with you.**
- Everyone learns and processes information differently: Options which allow autistic people to be in control and to choose and opt in or out.



Toolkit for professionals: How to start conversations about supporting intimate lives

How health & social care professionals can start conversations about supporting intimate lives



<https://www.autlives.com/menu-for-support>

Autism and Intimacy Digital Toolkits / Resources



Toolkit for Autistic Adults

Coming soon

Presenting the main themes and topics emerging from our interviews and focus groups with autistic people about their intimate lives. Toolkit aims to normalise experiences, challenges and differences, and help autistic people better articulate their needs. We also share tips, strategies and resources that SAAIL participants have found valuable when navigating their intimate lives.

[Toolkit Here](#)



Toolkit for Providers

Coming soon

Resources on how health and social care providers can better support autistic adults' intimate lives.

[Toolkit here](#)

An ever-evolving online resource:

- One for autistic people
- One for health and social care providers

Based on:

- SAAIL findings
- Stakeholders' input and expertise
- Existing resources

www.autlives.com



Consent and communication

We live in a neurotypical majority society where flirting and communication around...

[Read more](#)

[View Toolkit](#)



Managing rejection

Past negative experiences with interpersonal relationships can lead to ...

[Read more](#)

[View Toolkit](#)



Alexithymia and intimacy

Understanding more about Alexithymia and how it might impact your intimate life.

[Read more](#)

[View Toolkit](#)

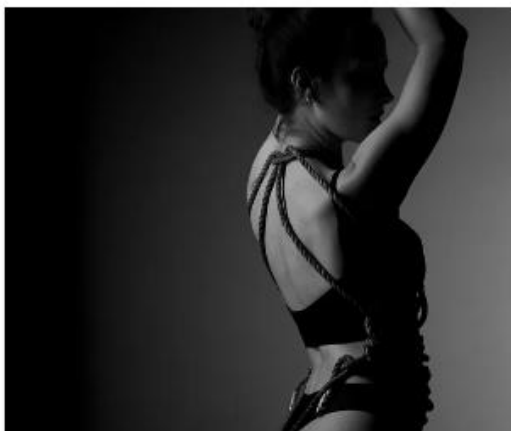


Symptomatic hypermobility and neurodiversity

Download the SEDS Connective toolkit on Hypermobility, neurodiversity, and ...

[Read more](#)

[View Toolkit](#)



Exploring BDSM, Kink, and other sexual spaces

Find out more about BDSM, Kink and these spaces and communities. Some of ...

[Read more](#)

[View Toolkit](#)



Paid sexual services

Some information on paying for sexual services.

[Read more](#)

[View Toolkit](#)



Being autistic and queer

We share some of what autistic people had to say about navigating gender an...

[Read more](#)

[View Toolkit](#)



Online autism and intimacy resources

A list of our favourite podcasts, networks, and resources about autism and intimacy.

[Read more](#)

[View Toolkit](#)



Helping you to put intimate lives on the "menu" for support

A practical toolkit to help Health and Social Care professionals to include ...

[Read more](#)

[View Toolkit](#)



Symptomatic Hypermobility and neurodivergence

Download the SEDS Connective toolkit on Hypermobility, neurodiversity, and ...

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Policy recommendations

Our policy recommendations

[Read more](#)

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Learning disabilities and intimate lives

A link to the incredible Supported Loving toolkit. Everything you need to know ...

[Read more](#)

[View Toolkit](#)



Paying for sexual services

Paid sexual services can provide a safe



Skills for Care: Supporting personal relationships in the social care workforce



A list of dos and don'ts for health and social care providers



Acknowledging the diversity among the autistic people you support



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