



SAAAIL

Supporting Autistic
Adults' Intimate Lives

Workshop 1

Dr Monique Huysamen

Manchester Metropolitan University



Thank you for your coming!

Aims for today:

- Share some of SAAIL's processes and findings with you
- To put our heads together and think about developing our online “toolkit” and other strategies for using the understanding and data generated from SAAIL

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

Supporting Autistic Adults' Intimate Lives

Focusing on autistic adults without learning disabilities

NIHR | School for Social
Care Research

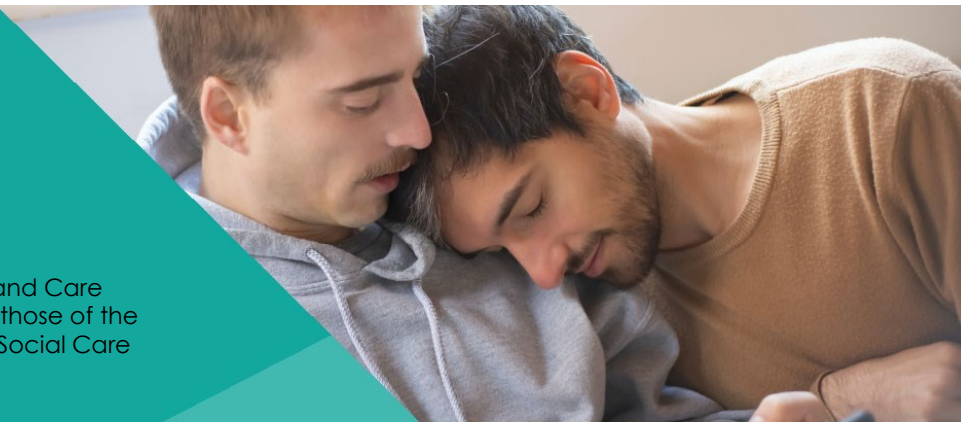
Funded by National Institute for Health and Care Research

autlives.com



m.huysamen@mmu.ac.uk

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What drives SAAIL

Navigating sex and relationships in a “Neurotypical” 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.

Normative ways of “doing” relationships.

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

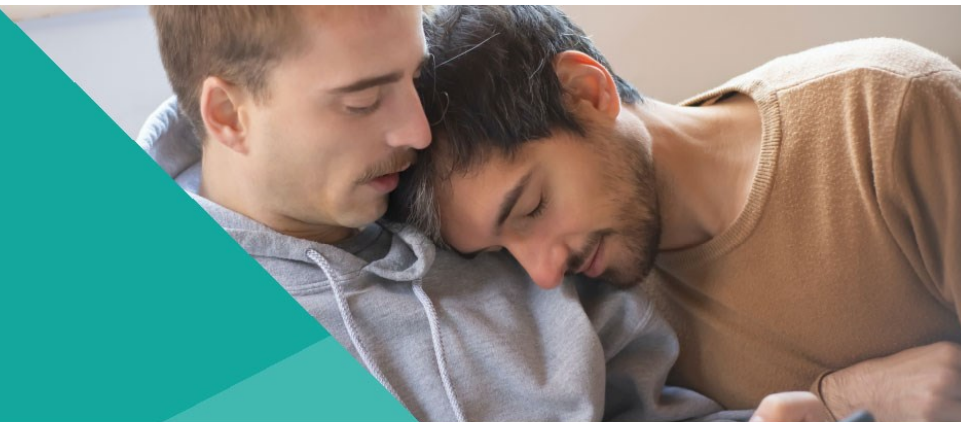
The humanising potential of recognising intimate lives

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



SAAIL

Aims:

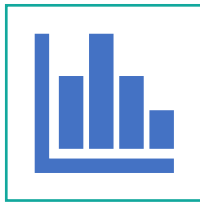
- Represent autistic people's intimate lives in all their diversity (smash stereotypes and misperceptions).
- Understand the challenges autistic people face around intimate lives in our neurotypical society.
- Develop an understanding of how autistic people think health and social care can better support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



We know that autistic people:

- Are interested in sex and/or intimate relationships (most) ✓ 
- Experience more anxiety, barriers, and challenges around intimate relationships ↑
- Have more negative experiences with dating and relationships ↑
- Experience more loneliness and isolation ↑
- Get almost no autism-specific support around relationships ↓ 

SAAIL's Methods



Policy Document
Analysis



Interviews



Focus Groups



Workshops

“I’m up for workshops, think tanks, exploratory sessions any time any place in any format that works for all participants autistic, NT, allies, researchers, funders in one glorious pick ‘n mix.” (Mammakiz, 58, Female, Pansexual, White British)



Autism and Intimacy

National Policy Document Analysis



Government National Health and Social Care Policy and Guidance Documents

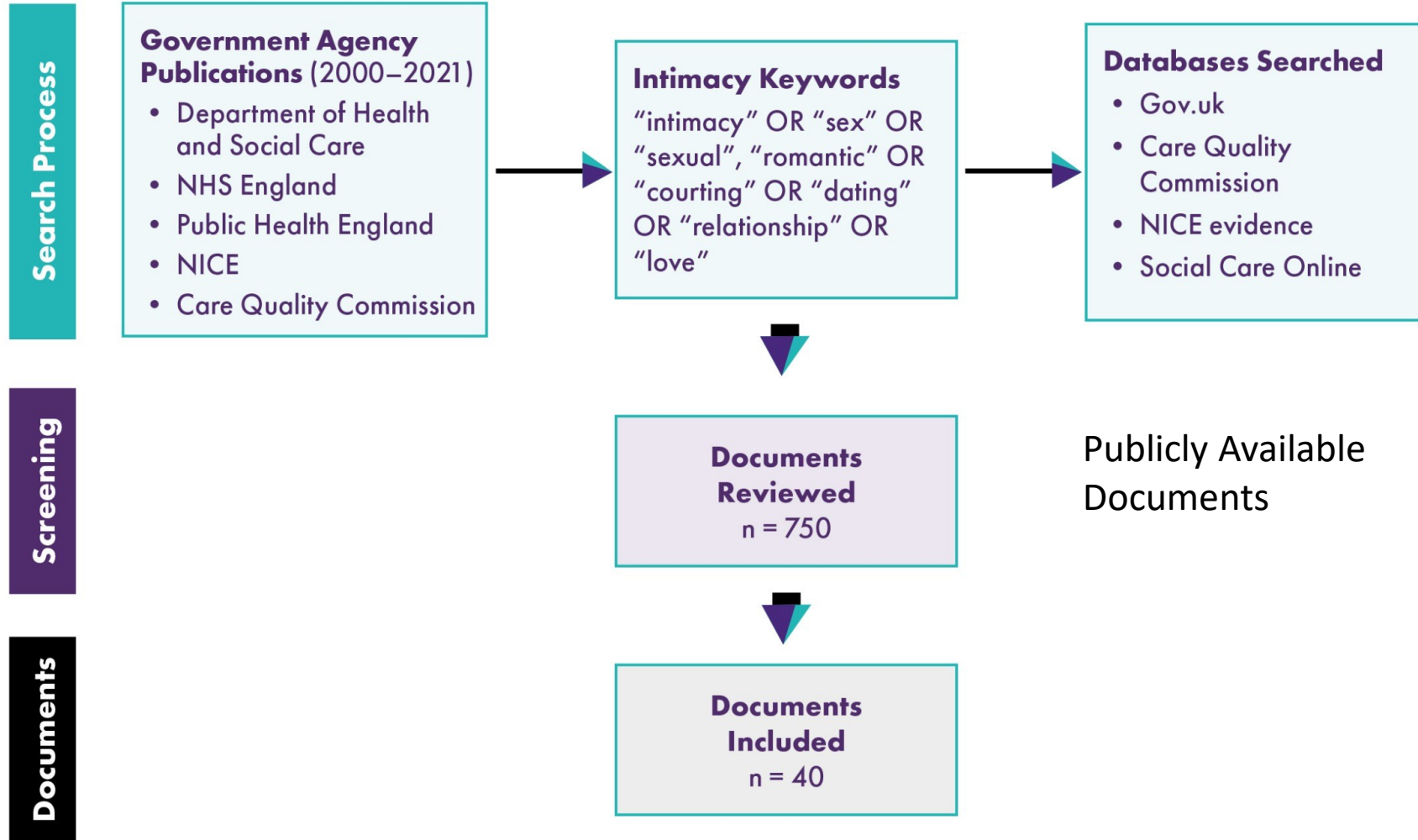
Understanding the “top level”

E.g. Autism Strategy and Care Quality Commission guidance

This is important because:

- They set the priorities for funding and what “counts”.
- They ultimately guide and shape support people receive on the ground.

Systematic Search Process



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.

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.
- **Are intimate lives a “non-issue” for social care?**

“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)

Intimate lives ignored in the policy-making process

Each Autism Strategy (2010, 2014, 2021) involves a public consultation process.

No consultations included a question about intimate lives.

How then do you generate evidence and understanding?

When intimate lives are raised, it does not make it to policy

Autism-specific needs are overlooked

“Learning disabilities and/or autism.”

Documents discuss autistic people and people with learning disabilities in one breath, as though all intimacy support needs are the same.

Emphasis on risk

- An emphasis on risk in the absence of discussion of the positives and the value of supporting intimate relationships.
- This means staff's responsibility is around mitigating risks, rather than actually supporting intimate lives.
- CQC documents include emphasis on “eradicating mixed-sex accommodation” in some settings as a way to ensure safety.

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.

Research Article



A critical overview of how English health and social care publications represent autistic adults' intimate lives

Monique Huysamen¹, Marianthi Kourti², and Christopher Hatton³

Abstract

Autistic people face more social barriers to, and experience greater anxiety around, intimate relationships than the general population in our majority neurotypical society, leading to increased loneliness and social isolation. National health and social care policies and publications should recognise these inequalities and guide service systems in reducing them. In this paper, we employ a document analysis design to analyse a cross-section of English national health and social care publications to investigate how autistic adults' intimate lives are represented and prioritised in these publications. Most publications do not adequately and proportionally recognise or prioritise autistic people's intimate lives. They focus on the risks associated with sex and relationships and overlook autism-specific intimacy needs. They prioritise participation in the workforce while renouncing government responsibility for supporting intimate relationships which can reduce loneliness and alienation. We offer recommendations to ensure that health and social care publication processes better recognise intimate lives.

Keywords

autism, critical social policy, intimacy, open data, relationships, sexuality

Interviews and focus groups

63 People took part
in SAAIL

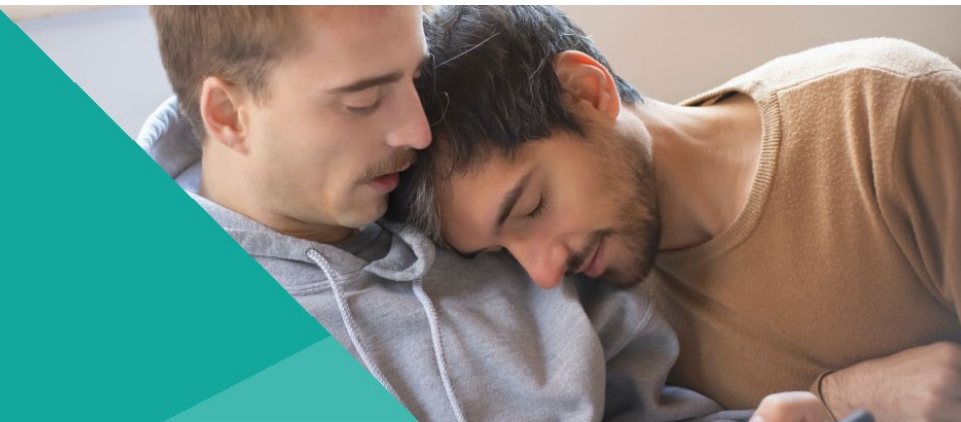
In-depth interviews:

- 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

What does this mean for how we think about supporting autistic adults' Intimate live?

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)

Findings: Barriers to intimate lives



Trouble with flirting

- Not knowing when someone is flirting with you, not know knowing how to flirt with someone else.

“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)

- Small talk on dating sites and apps feels inaccessible.

→ Leaving participants feeling excluded and isolated

Indirect language and social cues in our society

Causing immense anxiety, lack of confidence, and avoidance behaviour:

“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. ‘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)

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 sensitivities and needs during sex (touch, smell, pressure etc.)

“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 reach

Other common challenges:

- 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 and rejection sensitivity
- 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

Tips: 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.

“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.

“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)

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

Autism and Intimacy Digital Toolkits / Resources



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We want toolkits to:

1. Normalise “usualise” a wide range of autistic people's experiences so that they see themselves in other's narratives and realise they are not alone.
2. Signpost people to helpful existing resources.
3. Pass on any tips and advice from participants and other autistic people.
4. Provide practitioners with as much advice on providing support at the intersections of autism, sexual orientation, and gender identity, etc.

Inspired by the Supported Loving Toolkit



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Masturbation

The following toolkit page explores the topic of masturbation and how to effectively support an individual to engage in this activity, safely and legally.

[Read more](#) →



Online dating

When it comes to using the internet, technology or something like online dating, there should be a choice to use it or not, but choice should always be informed.

[Read more](#) →



Pornography

Many adults enjoy viewing pornography, and most is legal to view. However, this page explores some of the challenges that may arise when supporting someone.

[Read more](#) →



Rights vs risk

This toolkit page is about balancing the rights of individuals we support, to explore their intimate lives with the management of any associated risks.

[Read more](#) →



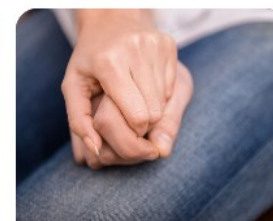
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Aids and equipment

People have a right to support around their sexuality, which includes finding appropriate equipment and aids to facilitate sexual activities.

[Read more](#) →



Capacity to engage in sexual relations

Here at Supported Loving, one of our most frequently discussed topics is mental capacity regarding sex. Staff are often uncertain about this topic and this page aims to provide clarity.

[Read more](#) →



Challenging values, attitudes and organisational culture

It may be necessary to challenge attitudes towards the relationships of people who access support.

[Read more](#) →



Contraception

Research shows there is need for clear accessible information and advice about contraception, and the need for inclusive sexual health services.

[Read more](#) →



Sex positive sexuality and relationships training

People with support needs have the same rights to have intimate, sexual and romantic



Sexual rights

Sexual rights are human rights related to sexuality. These rights are often an under-acknowledged area of sexuality and relationship support, but are very important



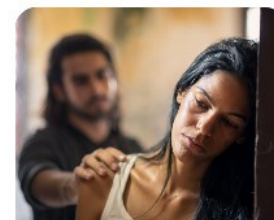
Sexual violence

This toolkit page is about sexual violence and how sexual violence can affect people with learning disabilities and autistic people.



Sexuality and gender identity

Everyone has the right to information about gender and sexuality and to get good support to express themselves.



Domestic abuse

People with learning disabilities are three times



Harmful sexual behaviour

Adults and children with



Having conversations

Uh, oh. Someone wants to talk



Housing and supporting relationships

<https://www.choicesupport.org.uk/about-us/what-we-do/supported-loving/supported-loving-toolkit>



Managing rejection

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

[Read more](#)

[View Toolkit](#)



Consent and communication

Being in touch with and communicating your own needs and boundaries and ...

[Read more](#)

[View Toolkit](#)



Mental health and intimacy

Participants share how their intimate lives are linked to their mental health

[Read more](#)

[View Toolkit](#)



Symptomatic hypermobility, neurodiversity, and intimacy

Coming soon

[Read more](#)

[View Toolkit](#)



Embrace difference: Doing relationships your way

Participants give tips on letting go of conventional ways of doing sex and ...



Being autistic and queer

Many of our SAAIL participants said that "normative" gender or sexuality labels ...

[Read more](#)



Sensory differences and needs

New theme coming soon

[Read more](#)



Existing online resources, organisations, and service providers

Find our list of relevant YouTube videos, ...

Toolkit break-out sessions

See Padlets

Managing rejection

Or

Autistic and queer

Consent and
communication

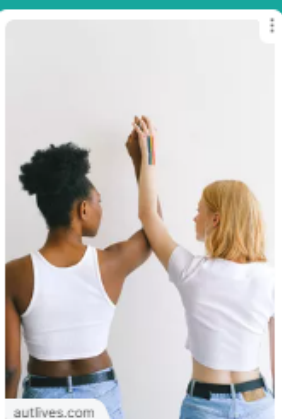
or

Putting intimate lives on the
social care “menu”



An opportunity to engage with the data

Managing Rejection Toolkit



Toolkit for autistic people | SAAIL: Supporting Autistic Adults' Intimate Lives

Click on the image to go to our website for the detailed toolkit on managing rejection

0 Add comment

How to use this Padlet

Have a look through the information and quotes and add your thoughts in the comments.

This Padlet has been designed to give you an opportunity to engage with our data, and invite you to help us build the toolkits.

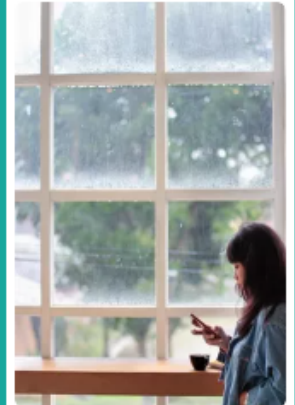
We've provided some information, quotes from participants, and our thinking.

Reading the Padlets before the workshops might give you some more discussion points.

Feel free to read as much of this as you like, and add your

Rejection, anxiety, avoidance, lack of sexual experience, shame

A vicious cycle



Negative early social experiences with peers >>> anxiety and 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

0 Add comment

"[If I met someone in a bar] probably are looking for someone who is good at whatever kind of sex people have in casual hookups and I'm unlikely to be and don't have that experience to draw on. So it would probably be humiliating." (Anon38, male, 28, heterosexual)

Lack of experience

0 Add comment

The kind of support people spoke about wanting

0 Add comment

"How to deal with the reality of likely being far less sexually experienced than any potential partners, and what knowledge would help compensate for the mismatch in experiential knowledge. There seems to be an attitude, probably quite understandable, that people my age wouldn't want to have to teach their new partner how to have sex as if he's a bumbling virgin teen. So what can that person learn/practice in order to take that burden off their more experienced partner?" (Anon38, male, 28, heterosexual)

0 Add comment

"There must be Autistic sex therapists and counsellors out there who could run programmes for all ages but in particular help out people who are diagnosed late with that awful feeling that they missed out on a helluva lot of fun and games in previous decades". (NedNerd, 54, questioning, heterosexual, white)

Rejection sensitivity

0 Add comment

The support autistic people want for managing rejection

"How do we prepare for rejection, even after showing ourselves in a good light? How do we stop rejection from preventing us moving on? Do we need clear advice on what things might be improved to make ourselves more attractive, desirable and confident, and what things it is better to accept and hope a potential partner also accepts?" (NedNerd, 54, questioning, heterosexual, white)

0 Add comment

Tips from participants about managing rejection

"I realise that I looked to professional help precisely when I wanted help in relationships or after a rejection...There was a single session after someone had broken up with me. The therapy had to focus on my self-worth around relationships because it was the single theme I'd brought to focus on. The result was that the therapists encouraged me to see the relationship ending as not final or damning: I would have other lovers in future (they were right fortunately)." (NedNerd, 54, questioning, heterosexual, white)

"The one" thinking

The idea that somewhere out there "the one" exists – the one person in the world who was made for you or is right for you – is a myth. This kind of thinking can make rejection feel even more painful.

Some of our participants described experiencing this kind of "the one" thinking. Because they were often misunderstood or had many negative experiences, when they met someone they clicked with it felt like their only chance at a relationship. In these cases, rejection could feel like a disaster.

0 Add comment

We love



Revealing Your Crush | Together - Sexpo

0 Add comment

"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

Breaking the cycle of avoidance/inexperience

Paid sexual services as an option?

In our previous study, some autistic people said that paid sexual encounters with an experienced professional (sex workers, sexological bodyworkers, surrogates, etc.) was a valuable way to gain the sexual and intimate experience in a non-judgemental environment. This helped them to feel more confident in other intimate situations.

0 Add comment

What do you think about this as an option for supporting people around their intimate lives?

Should we cover it in our toolkits? We know that, unfortunately, organisations like COSRT deem this kind of work unethical.

How can we support professionals to feel comfortable supporting this as an option?

Do you have written or recorded materials we could add to our toolkits for professionals which sets out any legal requirements and considerations?

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TLC Trust
tlic-trust.org.uk

Resources

Rejection Sensitive Dysphoria

IDENTIFYING YOUR TRIGGERS

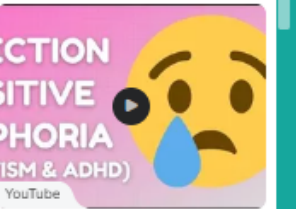
READ MORE AT BLACKGIRLLOSTKEYS.COM



10 Coping Skills For Rejection Sensitive Dysphoria

0 Add comment

We love



What causes Rejection Sensitive Dysphoria in AUTISM and ADHD

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Resources for Rejection Sensitivity

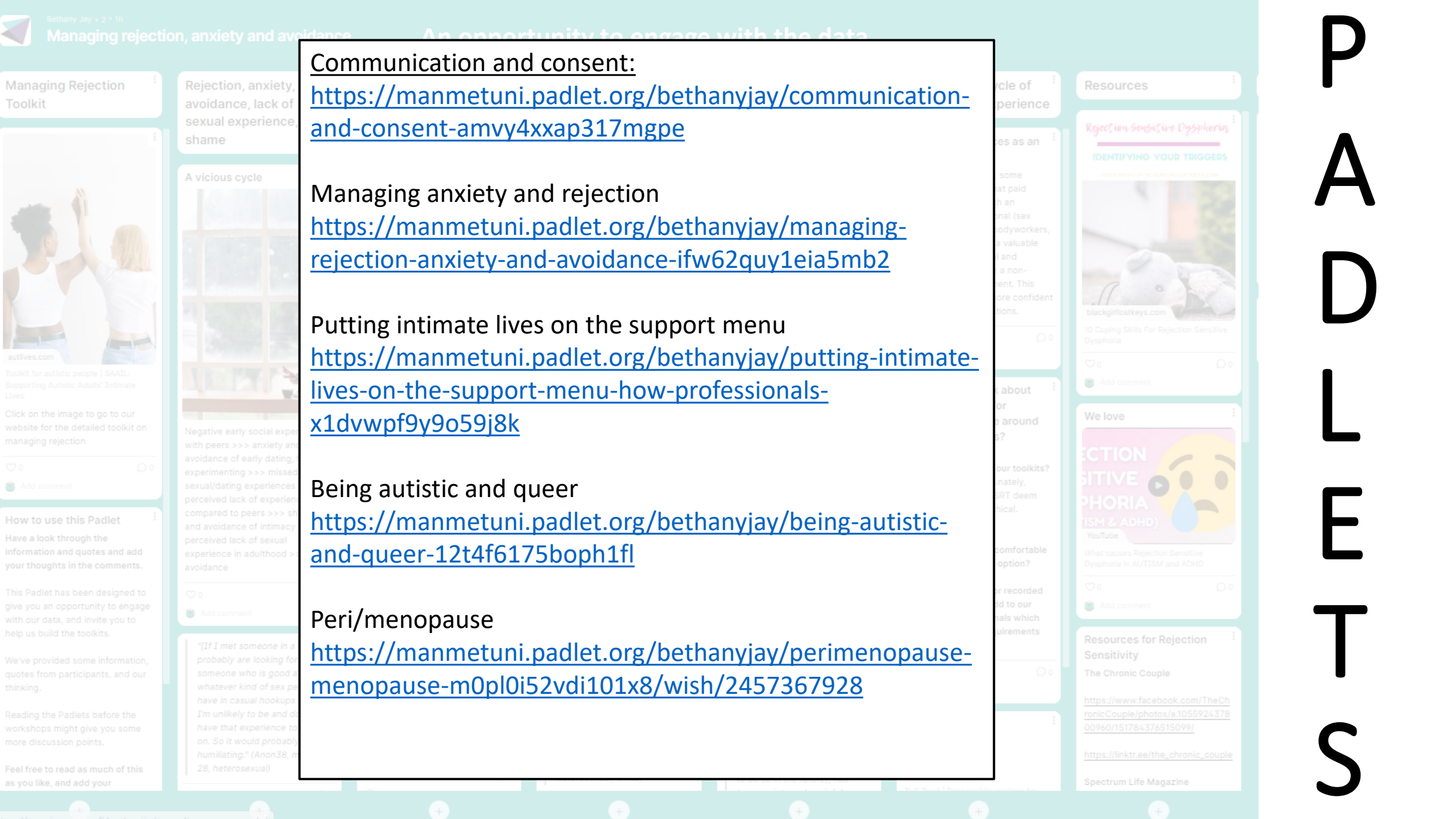
The Chronic Couple

<https://www.facebook.com/TheChronicCouple/photos/a.105592437800960/151784376515099/>

https://linktr.ee/the_chronic_couple

Spectrum Life Magazine

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Communication and consent:

<https://manmetuni.padlet.org/bethanyjay/communication-and-consent-amvy4xxap317mgpe>

Managing anxiety and rejection

<https://manmetuni.padlet.org/bethanyjay/managing-rejection-anxiety-and-avoidance-ifw62quy1eia5mb2>

Putting intimate lives on the support menu

<https://manmetuni.padlet.org/bethanyjay/putting-intimate-lives-on-the-support-menu-how-professionals-x1dvwpf9y9o59j8k>

Being autistic and queer

<https://manmetuni.padlet.org/bethanyjay/being-autistic-and-queer-12t4f6175boph1f>

Peri/menopause

<https://manmetuni.padlet.org/bethanyjay/perimenopause-menopause-m0pl0i52vdi101x8/wish/2457367928>

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Toolkit break-out sessions

Managing rejection

Autistic and queer



Theme 1: Managing rejection:

A vicious cycle: rejection, avoidance, and perceived lack of experience

Vicious Cycle of Anxiety, Avoidance, Shame

Negative early social experiences with peers >>> 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)

Finding ways to break this cycle of anxiety-avoidance-shame

Paid sexual services as an option?

Some autistic people have found that paid sexual encounters with an experienced professional sex worker is a valuable way to gain the sexual experience they needed, but in a non-judgmental environment where the person could support their sexual exploration.

Opportunities TLC Trust/Outsiders Trust

Organisations: COSRT don't condone

What are the challenges and limitations? Please discuss

Rejection Sensitivity

Some of our participants spoke about dealing with rejection sensitivity, and some mentioned the term Rejection Sensitivity Dysphoria (RSD).

Nobody likes rejection, however, people with rejection sensitivity can't shake off rejection easily when it happens and it can trigger an overwhelming trauma-like emotional response.

“Most of the autistic people I know act like I'm crazy when I talk about the trauma I have from romantic rejection” (RandomVirus: male, 25, gay, white)

“I think I still have PTSD as a result of it, as it was so intense and so long lasting!” (aut_amo, male, 37, heterosexual, white)

Rejection Sensitivity symptoms:

- **Anticipating rejection.**
- Experiencing rejection as **extremely painful** and traumatic.
- Overly high standards for yourself.
- Feeling easily triggered toward guilt or shame.
- **Isolating yourself or avoiding flirting or dating as not to be rejected.**
- Displaying **strong feelings and sometimes anger or aggressive behaviour toward those who you believe have rejected you.**
- Frequently feeling an uncomfortable physical reaction due to being misunderstood.
- Self-esteem that is entirely dependent on what others think
- Frequent and intense ruminating after a social interaction (**replaying situation over and over in your head**).
- Feeling like a failure because you haven't lived up to other people's expectations.
- Obsessive thought patterns.

Understanding these responses to rejection

Can be very helpful for the person with rejection sensitivity and for those around them to understand the person's strong reaction, and also to be cautious with their feelings.

For the person, understanding why their feelings are strong can be really validating.

We provide tips and numerous great resources on the website.



Rejection sensitivity: Thinking about support and toolkits

Is the term useful in thinking about support for autistic people?

Does it seem relevant to you as an autistic person

“How do we prepare for rejection, even after showing ourselves in a good light? How do we stop rejection from preventing us moving on?” (NedNerd, 54, questioning, heterosexual, white)

Theme 2:

Being autistic and queer

This theme is to discuss anything related LGBTQI+ issues, resources and support for autistic people

When labels don't quite fit

Many of our participants (a little less than half) identified as cisgender and heterosexual.

But more than half of our participants did not feel these labels or identities best represented them. Many identified as queer or using a myriad of other labels (as shared before).

Some just weren't bothered with labels of any kind at all

"I'm queer but labels are hard. Like 'not straight' is about as accurate as I've got."

Using labels to navigate an already-exhausting system

“I describe myself as heterosexual for ease and because a label doesn’t really make a difference to me, it doesn’t affect who I am... in practice, I’m probably pansexual.”

“I know I said in the introductions that I’m gay, but I only said that because that’s the checkbox-type answer that most people will understand without me having to go into details.”

Realising I was autistic

For some participants, realising that they were autistic later in life prompted them to explore and reconsider their sexual orientation and what they wanted and needed from sex and intimate relationships.

“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)

This points to the importance of sex education and resources at all ages for autistic people

Are autistic people more likely to question or reject normative gender and sexual orientation labels?

“I think autistic people are more likely to identify with other sexual identities because we are used to being outside the “typical” and because we see the nuances, detail and meaning behind the terms.” (Petty_LaBelle, woman, 33, Black Caribbean/White)

“I think [autistic people are] more gender questioning, for sure (but not necessarily in a dysphoria way). **Maybe more likely queer, or maybe just more used to being ‘out’ in other ways**, so LGBTQI+ is just another label too. When your life is full of labels I think it makes you question some that you’re default ‘given’. Also our experiences of things like emotions can often be different (alexithymia) so why not other experiences. If internal experiences are less concrete there will naturally be more question markers, I think.” (Neo, 32, female, queer)

LGBT Organisations

Many participants felt that LGBTQIA+ organisations were a good place to seek support and resources around gender and sexuality.

Even when these organisations do not have autism-specific support, they often work in open, flexible and understanding ways that embrace difference. These organisations are used to supporting people who do not feel that they fit into society's normative ways.



Home > Young People > Exploring Identity > Sexual Orientation (LGB+)

★ ADD TO FAVOURITES

[PROUD TRUST SEXUAL ORIENTATION \(LGB+\) TOOLKIT](#)

[PROUD TRUST GENDER IDENTITY \(T+\) TOOLKIT](#)

Toolkit break-out sessions 2

Consent and communication

Putting intimate lives on the “menu” for social care



Theme 1: Consent and Communication

Trouble with communicating with neurotypical people

"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)

Anxiety about getting signals and messages wrong and crossing boundaries accidentally

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)

The double-empathy problem

Many of our participants wanted people to understand this theory.

Double empathy problem theory suggests that both autistic and non-autistic people struggle to empathise with each other, because of their different experiences of the world, rather than just autistic people lacking the ability to empathise.

Damian Milton

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

Challenges with knowing and communicating their own boundaries and needs

Alexithymia

Alexithymia is not knowing or being able to express what you are feeling.

“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)

Alexithymia

Struggling to communicate boundaries.

Some participants described not being able to explain their feelings when their boundaries were crossed. Instead, they described feeling "weird" or "strange" and only realising days or week later.

Alexithymia

“I find it so very hard to reject people’s advances!! 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!** Sometimes, I freeze in the moment, because my gut is telling me I’m not sure, but I don’t actually know at that precise moment what I do want. I think this is why I like dating apps, and why I like to chat for quite a long period of time, intensively, before meeting. I have more time to process how I feel.” (Anne, female, 49, bisexual, white)

“I felt violated, I really felt violated. Just three days later, but I didn’t at the time, it took me three days to get to that point.” (Derek, male, 38, heterosexual, Vietnamese-British)

Solutions

Spaces where boundaries are clear and explicit

Kink BDSM communities

Paid sexual encounters

Theme 2: Putting intimate lives on the “menu” for support

We asked about support and found:

- HSC staff are not asking autistic people about their intimate lives, and how they can help.
- Intimate lives are missing from post-diagnostic support, from social care assessments, and just about every other HSC interaction.
- Almost all participants said they have had no, or completely unsatisfactory support around sex and relationships.

“I think, if I had had access to appropriate sex education as part of the post-diagnostic support I did not receive, this would have helped me to keep safe and hopefully, to understand that there are other people in the world that see sex in the same way as I do.” (Mammakiz: 58, Female, Pansexual, White British)

We asked about support and found:

- Don't assume that because an autistic person doesn't ask for support around sex and relationships that they don't want or need it.
- Most participants said they would not feel comfortable ask about sex and relationships outright – even though they wanted it.
- If no one presents it as an option, why would people feel they could bring it as a need, like housing or employment.

Participants had clear ideas about what they want and need from HSC staff and practitioners

HSC providers 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. This could mean, virtual spaces such as online, text, email, in-person, multi-media options, video, recorded messages etc. Always give well defined options and always presume competence.” (Swimboy, 46, Transmale)

HSC staff to be clear about how they can support

HSC staff should clearly state that they can support intimate lives and what kinds of support they can offer

“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, female, queer, 32]

Many participants said they would not know what to ask a particular professional for, what is in that professional’s remit, what would be within their rights to ask for.

Should staff be asking outright about sex and relationships?

Some participants said yes, but others said no.

Important to create an environment where intimate lives are open for discussion, but be mindful of putting people on the spot with very direct questions.

“I think health and social care professionals should provide support and let us know what is available. They should make it easy for us to divulge personal information if it’s relevant, but they shouldn’t be “asking” as this would put pressure on us.” (AutCroc8, nonbinary, lesbian, 44)

“No, I don’t think they should ‘ask’ but be open to questions that someone may have. **Maybe have it noted down somewhere that this topic is open to discussion.**” (L07, man, heterosexual, 22)

“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

- Firstly, always make sure support for intimate lives is “on the menu”/the agenda for support 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.
- An actual menu can be useful – and has worked.
- Options which allow autistic people to be in control and to choose if they feel comfortable, but not catch them off guard.





Feedback and Reflection from the First Workshop

Language & Terminology

- Ensuring that the toolkit is accessible for all ages
- Ensuring that language acts a facilitator not a barrier
- Recognising that new terminology can open the door to new understandings



Co-produced SAIL Autism and Intimacy Glossary

Contact Cedric: link in chat and
Padlet

Recognise that different people can
have different definitions for the
same term

<https://rochdale.gn.apc.org/index.php/s/grwC2maBpyGZzGB>

ASC 'Autistic Spectrum Condition', a slightly friendlier term than ASD

ASD 'Autistic Spectrum Disorder', a term often used within medical researchers and the health service to mean autism

asexual A person of any gender or sexual orientation who experiences little, or no, sexual attraction. Asexual people may still experience other types of attraction, such as physical or romantic attraction (The word has a different meaning in biology, for instance plants that have asexual reproduction.)

assertiveness being able to clearly and specifically ask or refuse or accept, knowing that you are responsible for yourself and not trying to control anyone else. This is another skill that can be learned with practice and by recognising yourself as an equal to others. Useful in both establishing sexual consent and in continuing friendships and relationships.

attraction (basic definition time) the state of wanting to be physically close to someone who holds your attention

autisexual a new, unusual and so not a fully defined [word](#): having or referring to a sexuality that is affected by being [neurodivergent](#). An [autisexual](#) person may not want or be able to describe their own sexuality in conventional categories that are typically used. [auti-](#) is a prefix used about autistic people, in for example [autigender](#).

autism it's complicated

autosexual feeling sexual attraction or excitement about yourself rather than other people, or not responding sexually in encounters with other people. Not necessarily related to *auto-erotic* practices, which are carried out by one person on their own.

awkwardness autistic people may come across as awkward and/or be very aware of their own awkward behaviour in social and romantic situations, perhaps because they are [dyspraxic](#) or trying to juggle awareness of their inner state with attention to other people and other distractions (see [monotropism](#)). Saying or doing the wrong thing can make you even more anxious, but a bit of disclosure of apology can help. Awkwardness or weirdness may have been excuses to bully or mock you, but if someone likes you, your awkwardness won't put them off.

BDSM Bondage, domination and [sado](#)-masochism, often involving dressing up and acting out

LGBTQIA+ Organisations

LGBT support organisations tend to be more inclusive generally, because they are used to diversity, but it would be useful for LGBT support organisations to be more intentional about being autism inclusive.

“Some LGBT organisations might worry that they're 'stepping on the toes' of organisations that support autistic people, but this is rubbish – it's the job of LGBT support organisations to be inclusive of everyone.”



We need LGBT orgs to be intentional about supporting autistic people AND autism-specific orgs to be intentional about supporting gender and sexual orientation.

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)

Whatever toolkit you develop there has to be a focus on addressing inequalities. If you have that **within the main toolkit**, that should enable people to think about specific issues around like the quote you gave, which is around intersectional discrimination and things like that. **So I think if it’s separate, sometimes it will be forgotten.**

Embrace difference and alternative ways of “doing” sex and relationships

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

“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.

Models of healthy (neurodivergent) relationships? A challenge for toolkits

“Models of healthy relationships are needed.”

“We [proud trust] also have like a safer person project which focuses more on what healthy relationships look like.”

We need resources that provide good models but are also not prescriptive, limiting, and reproduce normative ideas:

Do these resources exist?

Can you recommend them?

“for those with questions about physical sex say, are there general-purpose sex manuals or sites that are reasonably non-prescriptive, explanatory, reassuring and generally autistic-friendly?”

Consent

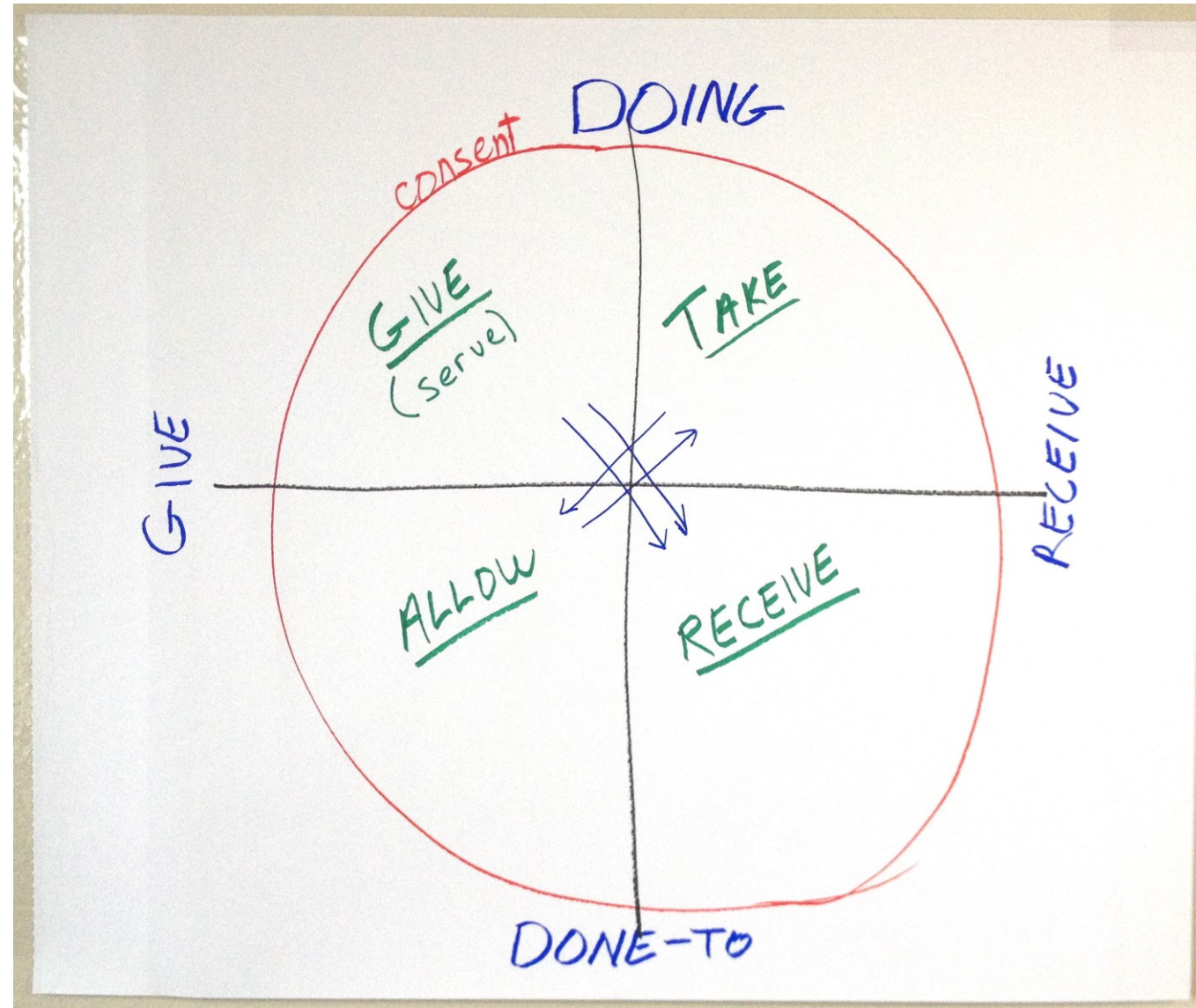
- Consent is an “everybody issue”
- There is a massive learning gap in universities on consent
- As a child, consent isn't gained when hugging family members etc. This teaches faulty models of consent
- “Growing up, individuals are taught consent with a neurotypical viewpoint”

Wheel of consent

“Consent is more complex than yes or no. Delving into consent is important. What does it mean? Who is it for? What will it lead to? It is only when these questions are answered that fully informed consent can be given.”

The Wheel of Consent is a new way of moving through the world, including intimate relationships.

This tool views consent as something that needs to be practiced and relearned.



Betty Martin

Discussion topic

Peri/menopause: What would a toolkit look like?

One of my inquiries at the moment around intimacy and autism, is about menopause and as a menopausal woman and a woman in her 50s, I'm finding it incredibly difficult.

Menopause is when I discovered sex toys and all their wonders. It took some pressure off sharing an overheated confused body with another person

It's horrifying to see women trying to cope It's horrifying to see women trying to cope with frustrations around HRT. Why it's not working for them. Queries not being answered

Broader reproductive health and justice

“How to deal with clinical appointments that cover intimate anatomy women and men. Information you need particularly when procedures are invasive, cervical smears, coil fitting, prostrate examination.”

- Pregnancy, perinatal
- Support around abortion
- Contraction (support and pressure)



Monique Huysamen

Autlives.com

Twitter: @autlives

m.huysamen@mmu.ac.uk

