

# **SAAIL: Supporting (?) Autistic Adult's Intimate lives.**

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# Growing, Developing and Learning

About me: Researcher in sexual and reproductive health and justice, Manchester Metropolitan University, UK.

Sexualities, sex work: for a social justice lens.

Using this space as an opportunity to grow develop and learn.

# Outline of Presentation

- Initial research about paying for sexual services
- Motivation for doing this research
- Introducing SAAIL
- Your input, suggestions, advice

# Dating, flirting, hook-ups, relationships in a neurotypical society

Interviewed all sorts of people about their experiences of paying for sex.

Dating in a heteronormative society with **neurotypical dating scripts and norms**:

Indirect “signals” “playing games” “hard to get” “hints” “vibes” “non-verbal” cues

This is difficult for neurotypicals but can really be exclusionary and isolating for autistic people.

I wanted to hear about autistic people’s experiences of dating, relationships, and how this tied into paying for sexual services:

# Primary study: intimacy and paying for sex

20 Participants Identified as autistic who had paid for any kind of sexual services

- UK: 11
- USA: 4
- South Africa: 2
- Netherlands 2
- Greenland: 1
  
- Ages early 20's to late 70's
- Mostly white, mostly cis men
- Identified Range of sexual identities: Heterosexual, gay, queer, bisexual (spoke about paying for sex from people of a range of genders)

# Some Findings: Flirting

Many participants said they had trouble understanding flirting or were not able to pick up when others were flirting with them.

Rather, they needed honest, direct communication and **explicit consent**.

# Challenges: Flirting

“I didn’t realise when someone was flirting. I was on a Tinder in September in Iceland and she knew I was autistic because I told her. Before we kissed, I asked her, ‘is it okay if I kiss you?’ where in the movies no one ever says that, the music starts and the violins and stuff. And then she gave her consent and stuff like, so it was very vocal because otherwise I would not know how to do it”. (Pilip, 33, Greenland)

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

# Challenges: doing the wrong thing

Many participants spoke about being 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. (More self-aware than most people I have interviewd)

**The explicit consent process involved in sex work relationships provided safe spaces**



# Safe spaces with clear boundaries

**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, are we, ah, there's less control...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, UK)

# Vicious Cycle of Anxiety and Avoidance

Anxiety at a young age (about getting it wrong or a bad experience). Avoidance. Lack of experience (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

# Breaking the cycle: Feeling Desired

I remember saying “Thank you for making feel human like for the first time in my life, making me feel human and desired”

...After that first moment umm my world view changed completely, where I felt more confident about how I look and what I want to look like to people not get into negative preconceived notions about myself.

...After that experience I was able to go on my first date with someone err outside all that, I went on three successful dates (Tony, 24, USA)

# Silences and gaps in support about sex

**UK Participants all said that no support they received (if any) ever directly addressed sex and intimacy**

**“I think that I think it is necessary to kind of have a discussion about sexuality and autism, I think, because um, a lot of the tools like when you search for how to have a relationship and stuff like that might, even autism organisations, talk about how to go on a date and how to approach someone to ask them out on a date or something like that but it doesn’t go further than that because we also need, you know, guidance on how to do the actual intercourse and stuff”. (Pilip, 33, Greenland)**

# Stigma and Misunderstanding

For many, their biggest concerns were around others' ignorance around autism rather than their own issues.

Trouble on dating apps: after disclosing autism (but felt they should disclose) they were ghosted

**They wanted others to be more informed about autism and neurodiversity**

# What did this study tell us about autistic adults' intimate lives?

Paying for sexual services was one coping strategy for addressing the challenges participants faced around dating, intimacy while autistic in a neurotypical, heteronormative society.

In the new study I focus in intimacy in general. I want to know more about all these challenges, and **how autistic people think society needs to adapt to be more accessible.**

**Better representations** of autistic adults' intimate lives in all its diversity

I wanted to hear from a much **broader group of people:** people who identify as women, queer people, non-binary, ethnic minorities, men, trans

# **NEW STUDY**

## **SAAIL: Supporting Autistic Adults' Intimate Lives**

Funded by National Institute for Health Research (NIHR) School for Social Care Research : 

Study exploring all autistic people's diverse experiences of what they define as Intimacy, sex, relationships. (not just sex work)

With the remit of improving adult social care in England  
(Broad definition of social care)

# Silence around autism and intimacy

Intimate and sexual relationships can play an important role in social support, overall mental health and wellbeing and can help **combat loneliness and isolation**.

They can also be closely tied into

- Sense of identity,
- sense of community,
- Intersect with many other aspects of everyday life

But yet there is largely silence around the importance of addressing sex and intimacy in thinking about supporting autistic people



# Silence around intimacy and Autism

Almost complete silence in UK gov health and social care policy about supporting intimacy, sex and relationships for autistic people.

Very little research except for “problematic” or “deviant” sexualities or research that reproduces assumption that all autistic people are asexual.

Very little support through organisations, charities focusing on sex, intimacy and relationships, sexual health.



HM Government

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

# Let's Normalise Sex & Disability

#UndressingDisability

[Learn About Our Campaign in BSL](#)

## Enhance the UK Undressing Disability Hub

**Did you know – Disabled people have sex & they like it?**

Yep. Shocking though it may seem, disabled people are just like, well, everyone, really. Sex is important. We all want to be loved, we all crave a bit of intimacy from time to time and like it or not, we are sexual beings. Take sex out of the equation and we will quickly start to feel insecure and unattractive. How we judge ourselves is inextricably linked to how we think others perceive us. This is a problem because (and this isn't much of a secret) disability isn't seen as sexy.



What we do

# Supported Loving



## What is Supported Loving?

For people with learning disabilities finding love is often more than just chemistry – it can come down to getting the right support from your staff.

[Read more →](#)



## Supported Loving events

Find all the upcoming Supported Loving events here. This includes national and regional network meetings, webinars, our reflective learning groups and training courses for people with learning disabilities and professionals.

[Read more →](#)



## Supported Loving toolkit

The Supported Loving network has produced a series of guides to help support people with learning disabilities with issues around sex and relationships.

[Read more →](#)



## Supported Loving blog

Supported Loving is attracting interest from many different people – read what they are saying in their blogs.

[Read more →](#)



## Podcasts & webinars

Watch or listen to all our Supported Loving podcasts and webinars discussing issues around sex, relationships and good support for people with learning disabilities.

[Read more →](#)



## Further resources & training

Find more resources for support and information on love, sex and relationships.

[Read more →](#)

# SAAIL: Supporting

Focusing on autistic adults who do not access support through learning disabilities channels or other channels

- Sex-positive study
- Explores experiences of dating intimacy relationships
- Differences, strengths, challenges
- How sensory differences may play out
- How can autistic people feel supported in society to have fulfilling intimate lives

**We want to speak to people who belong to: Kink, LGBT, Queer communities, minority groups, married people, polyamorous relationship configurations, single people, heterosexual people, parents, older people etc.**

# The Team

Monique Huysamen

Peter Baimbridge: Salford Autism <http://www.salfordautism.org.uk>

**Salfordautism - autistic people  
doing it for themselves!**

Marianthi Kourti: Research Associate

Chris Hatton: Prof social care



# Research Design: Three Main Aims

## Three Main Aims:

- **What** are autistic people's experiences around intimacy and relationships, and **what** support and resources around intimacy, sex and relationships they would like to see
- Identify **Who** the stakeholders who can inform, support and facilitate these changes are;
- To work with stakeholders to generate an understanding of **How** to go about developing resources and setting up structures that can facilitate these changes.

# Research Design Three Main Tasks

1. Stakeholder Mapping
2. Qualitative Interviews and focus groups
3. Participatory Stakeholder workshops

# 1. Stakeholder Mapping

Who are the people, organizations, structures that are already working in or providing support in the area of autism and intimacy?

- Which organizations, people groups could be mobilized to support changes?
- Who would be affected by changes?

*Do you have any suggestions for organizations in England?*



## 2. Centring Autistic Voices through qualitative research

### Individual Narrative Interviews with autistic people

- About their experiences and their intimate lives
- Particular challenges?
- What they wished they had known?
- Support received/not received
- What would they like to change?

Recruitment: Recruit people from all walks of life. *Do you Any suggestions?*

Interview methods: As diverse as possible face to face, WhatsApp, email, Zoom, phone. *Any other suggestions?*

# Focus groups

Taking themes from individual interviews and presenting them to groups

Groups help with data analysis

- Sharing collective experiences
- How would you like the representation of autistic people's sexualities in society to shift?
- How can society be more accessible and supportive of autistic adults' intimate lives?

# Focus groups

Focus groups: In person, online, and asynchronous focus groups

Asynchronous groups: Chat room style discussion, participants can choose their own groups, or join anonymous one, respond in their own time over a month. Set their own agenda

# 3 Participatory Workshops

Workshops with stakeholders: including autistic people, autistic-lead organisations, and other organizations, policy makers

Working with the knowledge generated from research and own expert and lived experience

Co-analyse research and co-produce:

2 Digital toolkits: 1 for Autistic People and 1 for NTs

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FOR YOU

# My questions and challenges

- What kinds of questions would you like us to ask about autistic adults intimate lives?
- What are your suggestions for recruiting participants who might not be reached by twitter or social media?
- Do you know organisations who are already doing this important work?



# My questions and challenges

- What are your suggestions for interviews and focus groups? What are more creative ways of getting people to share their stories
- How can we do this research and better represent autistic people's intimate lives and NOT stigmatise or patronise autistic people? Social model of disability
- Would you like to be involved or follow the study's progress?

**For input or to get involved  
Please get in touch!**

[m.huysamen@mmu.ac.uk](mailto:m.huysamen@mmu.ac.uk)

**Twitter: @monique\_huy**

@Autlives (new project twitter)

Newsletter to come



A close-up photograph of human skin, showing a smooth texture and a warm, golden-brown tone. A soft shadow is cast across the skin, creating a sense of depth and highlighting the contours of the body.

**Please get in touch!**

**If any person or organisation would like to support, collaborate or participate in the workshops or in any part of the project, please get in touch!**

**M.Huysamen@mmu.ac.uk**

## **SAAIL: Autism, Intimacy, sex, pleasure**

What are autistic people's experiences of sex, intimacy, relationships, and pleasure?

What do they want and need?

How do they want resources/services delivered?

### **INTERVIEWS and FOCUS GROUPS**

How do health and social care policies talk about autism and sexuality? (if at all)

What services and support already exist? What does not exist?

### **DOCUMENT ANALYSIS**

Who can effect change? Who will be affected by change? Who can support? Who can be an ally?

Who can inform?

### **STAKEHOLDER MAPPING AND ENGAGEMENT**

How do we make the changes?

What resources can we make available? What's next?

### **3 x STAKEHOLDER WORKSHOPS**

### **DIGITAL TOOLKITS**