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Acknowledging Autistic Adults' Intimate Lives in Health and Social Care Policy: Analysis and Recommendations

Introducing SAAIL

Supporting Autistic Adults' Intimate Lives (SAAIL) is a qualitative research project based at Manchester Metropolitan University that explores how adult social care in England can better support autistic adults to enjoy fulfilling intimate lives. SAAIL is funded by the NIHR School for Social Care Research.

Summary

Autistic people face more social barriers to, and experience greater anxiety around, intimate relationships than the general population in our majority neurotypical society. This leads to increased loneliness and social isolation. National health and social care policies and publications should recognise these inequalities and help service systems to reduce them. We systematically analysed a cross-section of English national health and social care publications to investigate how they represent and prioritise autistic adults' intimate lives. Our key findings are that most publications do not adequately and proportionally recognise or prioritise autistic people's intimate lives compared to other aspects of social life and participation. Rather, they focus on the risks associated with sex and relationships and overlook autism-specific intimacy needs. Our key recommendations for policy-makers are: recognise that autistic people with and without learning disabilities may have autism-specific intimacy needs; recognise the need for sex and relationship education and support across the whole lifespan; and make changes to policy-making processes so that autistic people's expressed concerns surrounding their intimate lives are not written out of health and social care policy.

Why intimate lives matter

Intimate relationships are an important aspect of most adults' lives. Positive intimate relationships mitigate loneliness, act as a protective factor against the risk of suicide, and improve people's mental health and well-being. Research shows that most autistic adults want to engage in romantic and/or sexual relationships. However, they experience greater social barriers and anxiety around intimate relationships than the general population. In our majority neurotypical society, normative social cues, romantic scripts, and neurotypical patterns of flirting and communicating present difficulties or elicit anxiety for autistic people. These factors, along with different sensory needs and experiences, can result in autistic people avoiding intimate relationships, which contributes to loneliness and social isolation.

Loneliness and social isolation among autistic people in the UK have both been exacerbated by the COVID-19 pandemic. According to the National Autistic Society's (NAS) Left Stranded report (2020)¹, autistic people were seven times more likely to be chronically lonely during the first wave of the COVID-19 pandemic than the general population.

Context

National health and social care policies and publications produced by the Department of Health and Social Care (DHSC) and its Arm's Length Bodies (ALBs) play a crucial role in highlighting the inequalities faced by autistic people and guiding service systems to reduce them. The National Strategy for Autistic Children, Young People and Adults: 2021 to 2026² – the Autism Strategy – underpins the government's approach to

¹ National Autistic Society (2020). *Left stranded: The impact of coronavirus on autistic people and their families in the UK*. <https://s4.chorus-mk.thirdlight.com/file/1573224908/63117952292/width=-1/height=-1/format=-1/fit=scale/t=444295/e=never/k=da5c189a/LeftStranded%20Report.pdf>

² HM Government (2021). *The national strategy for autistic children, young people and adults: 2021 to 2026*. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004528/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf

improving autistic people’s lives. The joint ministerial foreword to the strategy states that, “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). However, it is silent on an important aspect of autistic people’s lives: their intimate relationships. Given the challenges that autistic adults face with loneliness and isolation, the omission of intimate lives is striking.

Research aims

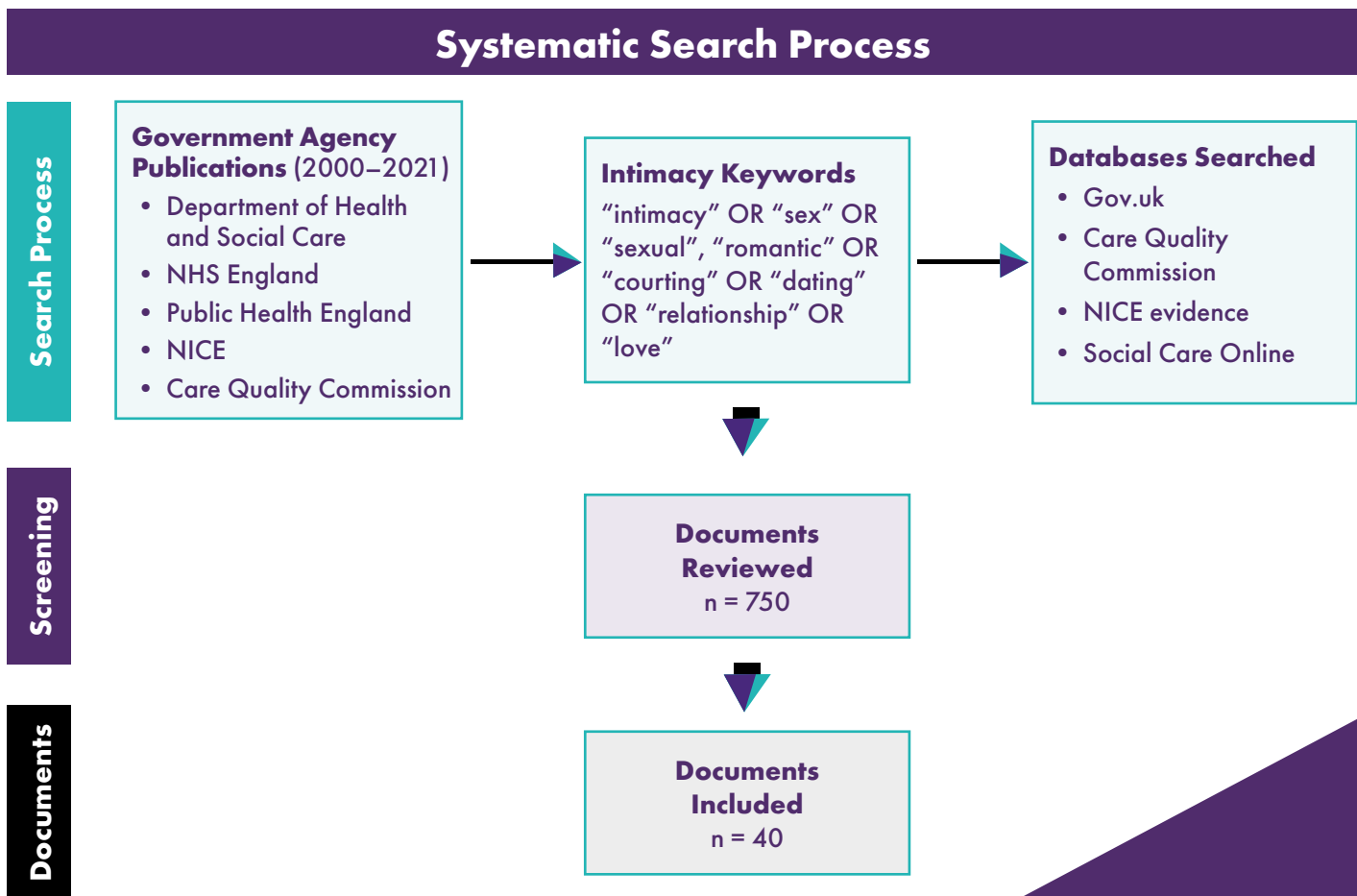
Prompted by these silences within the Autism Strategy, we systematically analysed a cross-section of English national health and social care policy and guidance documents to present an overview of how autistic adults’ intimate lives are represented and prioritised within them.

Method

We employed a systematic document analysis to identify publicly available documents published by English national health and social care agencies between 2000 and 2021 that reference

autism and intimate lives. Our search included documents (and guidance on webpages) published by the Department of Health and Social Care (and its predecessor, the Department of Health) and the following ALBs: NHS England (NHSE), Public Health England (PHE), the National Institute for Health and Care Excellence (NICE), and the Care Quality Commission (CQC). These all play key roles in health and social care service provision and access, commissioning, and regulation throughout England.

After a screening process, 40 policy and guidance documents containing specified autism and intimacy keywords were analysed. Of these documents, 62.5% (n=25) pertain specifically to supporting autistic people (autism-specific documents), such as the Autism Strategy. The remaining 37.5% (n=15) are documents that include but are not solely about autistic people (autism non-specific documents) and are mostly guidance documents that relate to supporting people living in supported housing and residential care settings.



Key findings

A failure to recognise intimate lives proportionally

We found that autism-specific documents identify and prioritise many aspects of autistic people's social lives, such as participation in the workforce, community involvement, recreational activities, and relationships with parents and carers. However, they do not include similarly weighted discussions about intimate relationships, sex, marriage, or parenthood. There is also a failure to recognise the need for support with intimacy-related transitions like moving in with a partner or starting a family, in contrast to the emphasis on supporting autistic people's transition into work. This failure to recognise intimate lives proportionally in health and social care documents reinforces stereotypes about autistic people, and implies that romantic relationships, sex, or starting a family are not important aspects of autistic people's lives.

Overemphasising risk

Clinical guidance documents emphasise the risks involved in intimate relationships for autistic people, with little focus on the benefits. These documents describe autistic people as either vulnerable to exploitation and abuse or as being at a high risk of sexual offending themselves. The guidance focuses on practitioners' responsibility to mitigate risks, but not on their responsibility to also support autistic people to access and enjoy intimate relationships. When risks are emphasised disproportionately, or in the absence of positive discussions around sex and relationships, this reinforces common tropes about autistic people as victims or perpetrators of sexual violence. This contributes to the marginalisation and social exclusion that autistic people experience and encourages risk-averse way of approaching sex and relationships within health and social care.

Autism-specific needs are overlooked

The documents do not regularly mention autism-specific intimacy needs, e.g., those related to sensory needs, communication differences, or social anxiety. Many documents discuss autistic people and people with learning disabilities in one breath – the phrase "autistic people/and or people with learning disabilities" is common – as though all intimacy needs are the same for people with learning disabilities, regardless of whether or not they are autistic. The specific needs of autistic people (with and without learning disabilities) are overlooked in these documents.

No state commitment to supporting autistic people's intimate lives

Our analysis revealed that there are no concrete government commitments or implementable plans to provide support for autistic people's intimate lives. Moreover, the responsibility for delivering support surrounding intimacy for autistic people is consistently displaced from the state onto the third sector. Community colleges, user-led and voluntary support groups are repeatedly described as already providing this support for intimate lives, while there is no commitment of resource from the government that would enable these organisations to provide these services effectively.

Stakeholder concerns around intimate lives are lost in the policy-making process

To date, the government has published three versions of the Autism Strategy: in 2010, 2014, and 2021. Numerous documents are also associated with each strategy, including public consultation documents and government responses. None of the published public consultations contain any questions about intimate lives. This omission limits the evidence that can be collected to recognise and assert intimate lives as a policy concern. Despite this, people consistently raised priorities around intimate lives in their responses to open-ended consultation questions. However, these were not acknowledged in the government's official responses to public consultations and ultimately do not appear in the Autism Strategy. This demonstrates how autistic people's concerns surrounding their intimate lives are written out of the policy-making process.

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 around sex and relationships as adults.

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

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