



# BMJ Open Explaining reproductive health inequalities among people with intellectual disabilities: a meta-narrative review protocol

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## ABSTRACT

**Introduction** People with intellectual disabilities experience health inequalities at a greater level than their non-disabled peers. Notably, while general health status is starting to receive some attention, the reproductive health and rights of people with intellectual disabilities continue to be understudied from a policy and research perspective. The objective of this review is to elucidate the complex interplay between individual, social and structural factors that influence reproductive health outcomes for this population. The findings will be used to develop a theoretical framework to explain how and why reproductive health inequalities persist for people with intellectual disabilities and to identify gaps in the knowledge base to inform future research on this topic.

**Methods and analysis** A six-stage meta-narrative review will be undertaken to synthesise the available evidence that seeks to explain the reproductive health inequalities experienced by people with intellectual disabilities and the factors contributing to these inequalities. The protocol for this review was developed in accordance with the Realist And MEta-narrative Evidence Syntheses: Evolving Standards publication standards, and the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocol guideline is completed to ensure transparency.

**Ethics and dissemination** This meta-narrative review protocol does not require formal ethics review because it will be based on published studies. The findings from this review will be submitted to a peer-reviewed journal and presented at national and international conferences. We will also produce our findings in a range of accessible and easy-to-read formats.

**PROSPERO registration number** CRD42024495199.

## INTRODUCTION

People with intellectual disabilities experience health inequalities at a greater level than their non-disabled peers.<sup>1–5</sup> Notably, while general health status is starting to receive some attention, the reproductive health and rights of people with intellectual disabilities continue to be largely ignored or understudied from a policy and research perspective due to social, cultural and normative

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ A six-stage meta-narrative review will be undertaken to synthesise heterogeneous literature from multiple paradigms, allowing for a pluralistic exploration of the topic.
- ⇒ The review will follow the Realist And MEta-narrative Evidence Syntheses: Evolving Standards guidelines and Preferred Reporting Items for Systematic Review and Meta-Analysis Protocol standards, ensuring a transparent and systematic approach.
- ⇒ Conceptual saturation will be prioritised over the quantity of data, focusing on depth of understanding rather than an exhaustive review of the published literature.

reasons. People with intellectual disabilities experience many obstacles when trying to access reproductive healthcare and information. These gaps can lead to limited choices when it comes to having children and worsening health problems that could have been prevented.<sup>6</sup> For example, people with intellectual disabilities often do not get the right support when experiencing menstrual health issues.<sup>7–10</sup> People with intellectual disabilities also face many challenges in exercising their reproductive rights and making informed decisions about their bodies and reproductive health—this is often influenced by the lack of policy or clear guidance in this sphere.<sup>11</sup> Indeed, this has been propagated throughout history with this population being subject to coercive practices, such as involuntary sterilisation or forced contraception, without their consent.<sup>12 13</sup> People with intellectual disabilities do not always receive appropriate care before or after having a baby, which can lead to problems during pregnancy and childbirth, negatively affecting both the mother's and baby's health.<sup>14 15</sup> On becoming parents, people with intellectual disabilities are also disproportionately affected by child removal

by the state compared with people without intellectual disabilities.<sup>16</sup>

WHO defines reproductive health as: 'A state of physical, mental and social well-being in all matters relating to the reproductive system. It addresses the reproductive processes, functions and systems at all stages of life. Reproductive health, therefore, implies that people are able to have a responsible, satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so'.<sup>17</sup>

While reproductive health, as defined here, promotes a holistic and positive state of well-being, population and public health approaches have tended to focus on pregnancy-related 'morbidity' as this relates to outcomes, such as rates of abortion and teenage pregnancy. However, it is argued that a 'deficit' or 'problems-based' approach largely overlooks the social determinants of health—such as gender inequalities, violence, discrimination and stigma, which play a significant role in determining reproductive health outcomes.<sup>18</sup> We would add here that systems of ableism which serve to disadvantage people with intellectual disabilities are rarely considered in this context.

The historical context of research and practice related to the health and rights of people with intellectual disabilities has undergone significant evolution, marked by shifts in societal attitudes. As the mid-20th century progressed, ethical concerns surrounding eugenics grew (eg, involuntary sterilisation), leading to a re-evaluation of practices. The development of the reproductive rights movement in the latter half of the century was to play a pivotal role in reshaping societal perspectives on reproductive health and bodily autonomy.<sup>19 20</sup> Running parallel to this, the late 20th and early 21st centuries saw the emergence of the disability advocacy movement, where disabled advocates began challenging traditional medical models that pathologised disabilities and instead embraced the social model of disability, emphasising the role of societal barriers in disabling individuals.<sup>21</sup> The emergence of the social model of disability aligns with a broader rights-based approach to health that places a significant emphasis on human rights irrespective of disability. In the context of reproductive health, a rights-based approach, anchored in international human rights legislation, such as the UN Convention on the Rights of Persons with Disabilities upholds the principle that people with intellectual disabilities have the fundamental right to make choices about their reproductive lives.<sup>22</sup> This encompasses the right to access comprehensive information, healthcare services and support necessary for informed decision-making.

In the contemporary landscape, however, concerns persist about the potential for modern eugenic practices in the context of reproductive control, particularly through the use of contraception. While contraceptive technologies are essential tools for empowering individuals to make informed choices about their reproductive lives, there is a risk that these tools may be misused

or disproportionately applied in ways that perpetuate discriminatory practices.<sup>23 24</sup> In addition to the published research on this topic, RE, AK and NM recently undertook a yearlong engagement project about the capacity to consent to long-acting reversible contraception (Foundation for the Sociology of Health and Illness (FSHI) Research Grant Development Award: Capacity, context and consent: a codesigned exploration of 'capacity' through the provision of long-acting reversible contraception (LARC) (Grant no: 061221)), which identified that people with intellectual disabilities may face subtle pressures or societal expectations to limit their reproductive choices, raising ethical questions about the intentions behind such practices.

These experiences of discrimination and abuse (both historical and contemporary) negatively impact the reproductive health and rights of this most marginalised group. In general, there is a gap in the evidence base regarding the experiences of people with intellectual disabilities in relation to reproductive health, but also the structural systems of oppression that serve to (re)produce these health inequalities. This individualised and decontextualised approach limits understanding of this topic.

As far as we are aware, no previous study has sought to address this complex area, therefore, this meta-narrative review shall seek to elucidate the complex interplay between individual, social and structural factors that influence reproductive health outcomes for this population. We argue that a meta-narrative approach is ideal for synthesising heterogeneous literature on a topic which has been previously explored from different paradigms using diverse research methodologies. The findings of this review will be used to develop a theoretical framework to explain how and why reproductive health inequalities persist for people with intellectual disabilities and to identify gaps in the knowledge base to inform future research on this topic.

### Aim of the protocol

To describe a protocol for a meta-narrative review which will synthesise the available evidence on the reproductive health inequalities experienced by people with intellectual disabilities.

The specific review questions are

1. What research (or epistemic traditions) have considered the reproductive health inequalities experienced by people with intellectual disabilities?
2. How has each tradition conceptualised the topic, and what methods did they use?
3. What theoretical propositions are present in these narratives for how and why these reproductive health inequalities persist?
4. What changes have been observed in the meta-narratives, and what has been the stimulus for these changes?
5. What insights can be drawn by combining and comparing findings from different traditions?

**Table 1** Six guiding principles of meta-narrative reviews<sup>25</sup>

Principles	Definition	Application in this review
Pragmatism	The included information should be driven by usefulness to the intended audience.	The aim of this review is to understand the main paradigms or epistemic traditions that have sought to explain the reproductive health inequalities experienced by people with intellectual disabilities. In a diverse field of research and practice, articulating the complementary and conflicting approaches to understanding the problem across multiple disciplines is critical to attaining coherence and developing theory.
Pluralism	The topic should be considered from multiple perspectives.	We will explore the current evidence across various disciplines including sociology, medicine, law and public health.
Historicity	The included information should be presented according to its development over time.	The history/genealogy of the different epistemic traditions will be analysed using bibliometric methods. Landmark documents will be recorded and traced to study the evolution of the paradigms.
Contestation	Any conflicting information should be used to generate higher order insights.	Differences between the conceptualisations of intellectual disability and explanations of the reproductive health inequalities experienced by this group in terms of theory, methods and approaches to the problem will be highlighted.
Reflexivity	There should be continual reflection on the review findings.	The protocol will be updated to reflect the changes to the process as findings emerge. Any changes to the review that were initially planned will be described and justified in the final report.
Peer review	The review findings should be presented to an external audience for feedback.	The emerging findings will be communicated with the patient and public involvement group and at academic conferences.

6. How does the meta-narrative approach improve the understanding of reproductive health inequalities for people with intellectual disabilities?

## METHODS

The protocol was methodologically designed using the Realist And Meta-narrative Evidence Syntheses: Evolving Standards publication standards<sup>25</sup> and Greenhalgh *et al's*<sup>26</sup> methodological guidance regarding, planning, searching, mapping, appraisal and synthesis. The Preferred Reporting Items for Systematic Review and Meta-Analysis Protocol guidelines have been included for complete transparency.<sup>27</sup> The protocol is registered at the International Prospective Register of Systematic Reviews (registration number: CRD42024495199) and supplementary files are registered on Open Science Framework: <https://osf.io/eu4t3>.

Meta-narrative reviews are a growing and increasingly important approach towards qualitative and mixed-methods systematic reviews that enable the synthesise of heterogeneous information that has been explored from different paradigms.<sup>25</sup> The six guiding principles of the meta-narrative review—*Pragmatism, Pluralism, Historicity, Contestation, Reflexivity* and *Peer review*—are integrated into the review process as articulated in [table 1](#). Given the historical changes in societal perspectives on intellectual disability, sexuality and reproduction, the meta-narrative review approach will enable the researchers to identify, articulate, synthesise and interpret the diverse literature regarding reproductive health inequalities and people with intellectual disabilities.

## Phase 1: mapping the literature

We will commence with a preliminary ‘territory mapping exercise’, to broadly discern various research traditions embedded in diverse bodies of literature that have engaged with the subject of interest. The initial efforts to comprehend the topic may extend beyond casual perusal of existing literature to include consultations with experts and stakeholders, with a specific acknowledgement of Patient and Public Involvement in this context.

[Table 2](#) outlines five paradigms on intellectual disability and reproductive health—legal and rights-based frameworks, the medical model, sociological theories, social work and social care and public health (these will be further refined and developed as part of the iterative process during the mapping phase).

In this phase, we will develop a set of parameters for each paradigm. For example, we will define the characteristics of each paradigm based on their definitions and/or conceptualisations of intellectual disability and the conceptual/theoretical frameworks used by each paradigm to explain the reproductive health inequalities experienced by this group; the methodologies used, and the solutions suggested (eg, the policies, practices or activism proposed to address these issues). These parameters will be used as a guide to search for data on the dimensions of the multiple paradigms in each publication. We will apply the set of parameters to assign each piece of included publication to its corresponding paradigm(s).

## Identifying landmark works

The mapping phase includes identifying landmark works that formed the foundation for the paradigms and were recognised by scholars in the field as highly influential

**Table 2** Mapping of initial intellectual disability and reproductive health paradigms

	Legal and rights-based frameworks	The medical model	Sociological theories	Social work and social care	Health inequalities
Main concept	Focus on issues of mental capacity in the context of legal frameworks and human rights	Focus on individual characteristics/deficits	Social model of disability, feminist theory, and reproductive justice frameworks	Historically paternalistic, focus on 'fitness to parent' and risks to vulnerable individuals	Focus on health inequalities/social determinants of reproductive health
Related disciplines and fields	Law, human rights, psychology, sociology	Medicine, nursing, psychology and allied health professions	Sociology, disability studies, Gender studies.	Social work and social care research	Public health, health, epidemiology, population health

in shaping subsequent research and practice. They can be conceptual papers or reports, or empirical studies that form a model for future work in the paradigm. To corroborate this, we will use triangulation, incorporating citation metrics data and insights from bibliometric network analysis. The following inclusion criteria will be applied to identify the landmark sources:

1. Is the paper part of a recognised research paradigm, that is, does it draw critically and comprehensively on an existing body of scientific knowledge and attempt to further that body of knowledge?
2. Does the paper make an original and scholarly contribution to research into the topic area?
3. Has the paper subsequently been cited as a landmark contribution (conceptual, theoretical, methodological or instrumental) by competent research in that tradition?
4. Is the paper an exemplar of a recognised research paradigm and its parameters? The review team will independently score and nominate landmark sources according to the above criteria. Discussions will be held with external experts to attain consensus.

## Phase 2: searching

### Search strategy

The main objective of the search is to collate a comprehensive set of literature to capture the diversity of research traditions and paradigms on the topic of intellectual disability and reproductive health. In order to achieve the right balance between thoroughness and precision (and in keeping with the MNR method), we incorporate the notion of saturation, a concept borrowed from qualitative research methodologies. Saturation refers to the point at which gathering additional data ceases to yield novel information. Given the objective of this meta-narrative review, which is to advance knowledge and formulate theories, the search process will cease when no further theoretical contributions are anticipated. In contrast to reviews that prioritise accumulating as much information about a particular topic as possible, our review highlights the achievement of conceptual saturation in the identified literature during the evaluation or synthesis phase. If the review team determines that additional studies would only result in marginal changes to findings, saturation will be considered attained.

The search will take three main strategies: (a) a double-sided snowballing search, (b) a search in electronic databases using search terms and (c) an additional hand search. Search strategy (a) will include a forward search of all papers that cite the landmark work identified in the mapping phase, and a backward search that collects the literature included in the reference list of these papers. Search strategy (b) will involve a search using keyword search terms, and will be conducted in relevant multidisciplinary scientific databases, including SCOPUS, Web of Science, MEDLINE, CINAHL Complete, PubMed, Embase, and PsycINFO SocINDEX with full text and topic-specific databases, including NHS evidence, Social Care Online, Public Health England and LexisNexis. A subject librarian was engaged at the developmental stage of search strategy (b) and with the primary author (AK). The SPIDER framework was used to develop the search strategy (table 3). The search is comprised of two key concepts: reproductive health inequalities AND people with intellectual disabilities. In search strategy (c), an additional hand search of key journals and publications by key organisations will be conducted to maximise comprehensiveness.

Our search strategy (table 3) was developed using an adapted version of Mann *et al*<sup>18</sup> three-pronged approach to reproductive health, incorporating three distinct but related categories of reproductive health: pregnancy-related, non-pregnancy-related and sex-related.

## Phase 3: selection and appraisal of the literature

### Eligibility criteria

Publications to be included in this review will be limited by language (English) and publication types (journal articles, reviews, books, book chapters, editorial and opinion pieces, reports and case law commentaries). All study designs, including empirical and non-empirical studies, and all publication years will be considered for inclusion. The topic of the paper must explicitly focus on reproductive health inequalities and people with intellectual disabilities and must address one or more of the conceptual, theoretical, methodological or instrumental dimensions on this topic. The WHO definition of 'reproductive age' spans the interval between age at menarche and age at menopause (15–49 years).<sup>28</sup> However, for this review, we have decided to not exclude papers based on



**Table 3** Scopus search strategy using the SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) framework

Sample	#1 Intellectual Disability	"Intellectual* Disab**" OR "Cognitive disab**"OR "learning disab**"OR "development* disab**"OR "mental handicap"OR "mental retard**"OR "intellect* handicap"OR "cognitive impair**"OR "intellect* impair**"OR "development* impair"OR "special needs" OR "Subnormal**"
Phenomenon of interest	#3 Repro justice	"Reproductive rights"OR "Reproductive *justice"OR "Reproductive health"OR "Reproductive health inequalities"
	#4 non-pregnancy related	"menstrual health"OR menstruat* OR "menstrual disorder"OR "abnormal uterine bleeding"OR dysmenorrhea OR metrorrhagia OR amenorrhea OR "premenstrual syndrome"OR "premenstrual dysphoric disorder" OR endometriosis OR menopaus*
	#5 pregnancy related	contracept* OR "birth control"OR "family planning"OR "pregnancy planning"OR "unintended pregnancy"OR abortion OR pregnancy OR childbirth OR labor OR labour OR "prenatal care"OR "antenatal care"OR "maternity services"OR "maternity care" OR fertility
	#6 sex related	Sexuality OR "sex* relationship"OR "sexual abuse"OR "sexual violence"OR "sexual coercion"OR "sexually transmitted disease**"OR "sexually transmitted infection"
Design		n/a
Evaluation		n/a
Research type		n/a

an age-range criteria. This is because precocious puberty is more common in children and young people with intellectual disability, and this may mean that certain procedures and medications are used earlier in this population.<sup>29</sup>

### Screening of papers

The final set of papers to be included in the review will be compiled in EndNote and exported to Covidence to be screened for inclusion in the review. Two reviewers will screen the title and abstract of each publication to decide inclusion in the review. Any disagreement will be resolved by consensus.

### Appraisal

It is an inherent property of paradigms that each will endorse a different set of standards for assessing the quality and risk of bias of studies. Criteria to assess the quality and risk of bias will be taken from the paradigms included in the review, particularly from the landmark papers that have been accepted by the paradigm as authoritative. The publications, now classified to one or more paradigms, will be assessed against the corresponding quality criteria. The included publications will be critically appraised for methodological quality using the Mixed-Methods Appraisal Tool (MMAT)<sup>30</sup> for peer-reviewed journal articles and the Authority, Accuracy, Coverage, Objectivity, Date, Significance (AACODS) checklist<sup>31</sup> for grey literature. To ensure consistency, all reviewers will discuss the applicability of MMAT and AACODS tools and assess a sample of full-text publications. Publications not included in the sample will be independently assessed by two reviewers. If all reviewers agree, publications that have been assessed as low quality may be excluded from the analysis.

### Phase 3: data extraction

The extracted data from the final set of included publications will then be coded according to relevant conceptual, theoretical, methodological and instrumental concepts. Details of the coding system will be determined by the review team. In the context of a meta-narrative review, the extracted data elements contribute to the narrative detailing the evolution of research on a given topic within a specific tradition over time. It is not possible to provide a definitive list of data to extract at this stage. Nevertheless, the alignment between the research question and the nature of the extracted data should be evident and may include:

- ▶ Bibliographic metadata (eg, author, publication year, title and publication type).
- ▶ Antecedent traditions from which this literature originated; underlying philosophical assumptions.
- ▶ Formulation of research enquiries and their framing; conceptual and theoretical considerations.
- ▶ Preferred research methodologies, study designs and criteria for assessing quality.
- ▶ Influential figures (such as prominent scientists or commentators) and pivotal events (such as conferences) in the development of the tradition; seminal empirical or theoretical investigations.
- ▶ Noteworthy discoveries and their impact on subsequent research; and central debates and points of contention within the tradition, including connections with or deviations from other traditions.
- ▶ Characteristics of interdisciplinary approaches (interdisciplinary, multidisciplinary, or transdisciplinary).

We will use the NVivo qualitative data analysis software to efficiently organise and code the data. Using NVivo software for qualitative coding will also allow us to refer back to the original data and transparently track the collaborative process. The reviewers will independently

extract data, and the coded data will be examined to ensure inter-coder reliability. All data will be stored in the approved research data storage system provided by the lead author's institution and handled in accordance with the institution's data management standards and guidelines.

A supplementary bibliometric analysis using the dataset of the final set of articles will be conducted to map the genealogy of citations and the author network analysis. The findings will visualise clusters of researchers and relationships between publications. These visualisation data will provide information to triangulate the different paradigms and research traditions. The main outputs from this phase include a codebook with the descriptions of the codes, an NVivo project with coded data of the included literature, the development of the quality assessment criteria for each paradigm and the bibliometric network analysis.

#### Phase 4: analysis and synthesis

In this stage, our objective is to chart the meta-narratives found within each paradigm. Specifically, we will concentrate on delineating the fundamental concepts, theories and methodologies distinctive to each tradition. Throughout this process, our aim is to elicit both the similarities and differences of the findings from different research traditions and consider the reasons for the differences.

The process for building these unfolding meta-narratives will follow the principles of interpretivist analysis. This shall include immersion in the data by repeated reading and/or analysis of coded data; prioritising reflexivity and discussion among reviewers, to consider how each new data item fits with an emerging picture of the whole; and checking where appropriate that the account is considered valid by experts within the designated research tradition. The incorporation of both quantitative and qualitative traditions and data into the meta-narrative may be necessary, where a clear exposition and rationale for the chosen analytic methods to consolidate and summarise data with a specific tradition will be highlighted.

Moving to the synthesis stage, the focus will be on comparing and contrasting the meta-narratives. This will entail identifying and analysing how different traditions have conceptualised the topic, encompassing variations in philosophical and epistemological positions, theoretical frameworks and used methodologies. High-order data, such as differences in findings between meta-narratives, will be subject to interpretive analysis to glean deeper insights into underlying assumptions or methodological variances across research traditions. Key areas for exploration guiding this phase will include understanding the conceptualisation and methods employed in each tradition, exploring commonalities and tensions in the research findings across paradigms elucidating overall key findings and their implications and pinpointing gaps to direct future research endeavours.

#### Patient and public involvement

The motivation for the development of this review arose from an FSHI-funded research development project, which engaged with over 80 people across the United Kingdom. Many of whom were people with intellectual disabilities, who described experiences of coercion and abuse in their own reproductive lives. These are long-standing problems which negatively impact the reproductive rights of people with intellectual disabilities. The (original) topic of this project was about 'capacity to consent' to the use of LARC. However, what transpired through this process was that for people with intellectual disabilities, this specific focus on LARC was not meaningful. Instead, a combination of reproductive health topics was desirable for address including getting pregnant, discrimination related to parenting (and the intersection with other forms of discrimination, for example, LGBTQ+-phobia) periods, (forced) sterilisation and child removal. The tendency to 'sweep under the carpet' reproductive and sexual health topics was identified specifically through partnership work with Inclusion North experts who devised and delivered a workshop as part of our engagement and consultation within this project. This systematic review is a direct response to this structured period of engagement and consultation whereby we recognise the need to be led by the concerns and perspectives of people with intellectual disabilities and therefore have adapted our research development plan to reflect this input.

#### Ethics and dissemination

This meta-narrative review does not require formal ethics review because it will be based on published studies. The findings from this review will be submitted for publication in an Open Access reproductive health-related health journal, for example, *BMJ Sexual and Reproductive Health*. We will also present the findings at national and international conferences and produce our findings in a range of accessible and easy-to-read formats.

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**Contributors** AK designed and drafted the protocol. RE, NM and MJM played prominent advisory roles. All the authors supported the review conceptualisation. AK is the guarantor.

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**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

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