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Review Article

# The A3ReAcH (Autistic, ADHD and AuDHD research accessibility in healthcare) framework: Principles for inclusive healthcare research with autistic, ADHD and AuDHD individuals in radiography and medical radiation technology

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## ABSTRACT

**Background:** Autistic, ADHD and AuDHD individuals are often excluded from healthcare/radiography research due to inaccessible methodologies and systemic biases, perpetuating well-documented health inequalities. While researchers can recognise this, they may be unequipped to address it effectively. This narrative review introduces the A3ReAcH (Autistic, ADHD and AuDHD Research Accessibility in Healthcare) framework, which provides practical guidance for designing and conducting accessible, inclusive and participatory research.

**Method:** Two searches of peer-reviewed studies (2019–2024) were conducted using *Emcare*, *MEDLINE*, *Social Policy and Practice*, *CINAHL*, *the Psychology and Behavioral Sciences Collection*, *Google Scholar*, and *PubMed*. The key themes were identified, and a framework was synthesised that aligns with different stages of the research lifecycle (planning to dissemination).

**Results:** The searches retrieved 86 articles: 54 methodological and 32 original research. Key themes are presented as a 12-item framework. The A3ReAcH framework out-

lines practical strategies such as diversifying research teams, ensuring equitable power-sharing, prioritising participatory methods, and adapting research designs to neurodivergent needs. It also emphasises the importance of accessible recruitment, fair compensation, and inclusive dissemination. Additionally, it highlights the role of intersectionality in shaping neurodivergent experiences and provides recommendations to reduce systemic barriers in research.

**Conclusion:** All healthcare/radiography research should include and respect neurodivergent experiences. The A3ReAcH framework empowers researchers to produce more equitable and actionable research by including neurodivergent voices and dismantling barriers to participation. By integrating these principles, healthcare/radiography researchers can improve the participant experience, enhance data quality, and drive systemic change in healthcare/radiography research, moving towards findings that genuinely represent the diversity of the population.

Throughout this paper, identity-first language is used to respect what is considered as the preference of the autistic community [1–4]. Equally, ADHD is used as an adverb to extend this identity-first linguistic preference to the ADHD community [5]. Further explanation of this can be found in section 4 of the framework.

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## RÉSUMÉ

**Contexte:** Les personnes autistes ou présentant un TDAH ou un TDAH-A sont souvent exclues des recherches en matière de soins de santé et de radiographie en raison de méthodologies inaccessibles et de préjugés systémiques, ce qui perpétue des inégalités bien documentées en matière de santé. Bien que les chercheurs en soient conscients, ils ne disposent pas nécessairement des outils nécessaires pour y remédier efficacement. Cette revue narrative présente le cadre A3ReACh (Autistic, ADHD and AuDHD Research Accessibility in Healthcare), qui fournit des conseils pratiques pour concevoir et mener des recherches accessibles, inclusives et participatives.

**Méthodologie:** Deux recherches sur des études évaluées par des pairs (2019-2024) ont été menées à l'aide d'Emcare, MEDLINE, Social Policy and Practice, CINAHL, la collection Psychology and Behavioral Sciences, Google Scholar et PubMed. Les thèmes clés ont été identifiés et un cadre a été synthétisé afin de s'aligner sur les différentes étapes du cycle de vie de la recherche (de la planification à la diffusion).

**Résultats:** Les recherches ont permis de trouver 86 articles: 54 articles méthodologiques et 32 articles de recherche originale. Les thèmes clés sont présentés sous la forme d'un

cadre en 12 points. Le cadre A3ReACh décrit des stratégies pratiques telles que la diversification des équipes de recherche, la garantie d'un partage équitable du pouvoir, la priorité accordée aux méthodes participatives et l'adaptation des modèles de recherche aux besoins des personnes neurodivergentes. Il souligne également l'importance d'un recrutement accessible, d'une rémunération équitable et d'une diffusion inclusive. En outre, il met en évidence le rôle de l'intersectionnalité dans la formation des expériences neurodivergentes et fournit des recommandations pour réduire les obstacles systémiques en recherche.

**Conclusion:** Toutes les recherches dans le domaine de la santé et de la radiographie devraient inclure et respecter les expériences neurodivergentes. Le cadre A3ReACh permet aux chercheurs de produire des recherches plus équitables et plus exploitables en incluant les voix neurodivergentes et en supprimant les obstacles à leur participation. En intégrant ces principes, les chercheurs dans le domaine de la santé et de la radiographie peuvent améliorer l'expérience des participants, renforcer la qualité des données et favoriser un changement systémique dans la recherche dans ce domaine, afin d'aboutir à des résultats qui reflètent véritablement la diversité de la population.

## Introduction

### *Neuro-inclusivity in healthcare and radiography research*

Neuro-inclusivity represents a critical yet often overlooked dimension in healthcare research, especially within radiography and medical imaging. There are only a few papers led by radiographers/MRTs in this field and the language used or methods employed are not often aligned with best practice or the autistic, ADHD and AuDHD community preferences, which might inadvertently exclude autistic, ADHD and AuDHD people from research projects either as researchers or participants. This lack of accessibility and inclusivity means autistic, ADHD and AuDHD individuals do not have equal access to research participation and representation, and cannot, therefore, influence research agendas or have a voice in healthcare knowledge production [6–11]. This impacts what is known and understood about this population, which may account for the barriers neurodivergent people experience in healthcare services. These include inaccessible environments with overwhelming lighting, noise, and crowding [12–15], healthcare professionals' failure to adapt their communication or assuming an autistic patient lacks competence [13,15–19] and minimal or outdated training on the experience of autism and neurodivergent needs [15,20–23]. Addressing these barriers requires involving neurodivergent people in research. Thus, a paradigm shift in healthcare and radiography research must occur, ensuring it is designed to capture the full diversity of lived experiences, including those of neurodivergent populations.

### *Neurodivergence, autism and ADHD*

Since its conception as a movement framing autism as an aspect of “neurological diversity” [24], the neurodiversity paradigm has continuously evolved, making it, as Chapman [25] describes, a “moving target”. While it applies to any condition that involves neurological divergence from the typical [26], it is most commonly discussed in relation to autism, ADHD, dyslexia, dyspraxia, dysgraphia, and dyscalculia [27].

These each shape an individual's experience of the world in ways that differ from those of neurotypical people. For example, in terms of processing sensory stimuli, proprioception and spatial perception, social and communication preferences, interoception and emotional expression, and monotropism [1,12,28–35]. However, when considering autism and ADHD specifically, there are several overlapping aspects of difference - such as distinct sensory processing profiles - that set them apart from, for example, dyslexia. Furthermore, although the experiences of autism and ADHD may at first seem antithetical, it is estimated that 50–70 % of autistic people are likely also to be ADHD [36,37]. This was reflected in the update of the diagnostic definitions of autism and ADHD in the DSM-V [36] in 2013, where it was recognised that autism (characterised by difficulties with social communication and restrictive behaviours) and ADHD (characterised by difficulty with maintaining concentration, hyperactivity and impulsivity) to occur together. This is becoming commonly referred to as *AuDHD* in academic texts [38,39] and the mainstream press [40]. Given such experiential and diagnostic overlap, it is helpful to group them for research while maintaining awareness of their differences.

Whilst this paper concerns accessible and inclusive practices for autistic, ADHD and AuDHD individuals, the research surrounding ADHD remains strikingly sparse, particularly in research practice and healthcare contexts. Therefore, the primary emphasis remains on autism, reflecting the more established body of evidence. However, as the topics discussed and recommendations provided could present benefits to ADHD people, the framework seeks to address the ADHD gap indirectly by drawing on autism research and inferring a similar experience of marginalisation from belonging in the neurominority whilst the intricacies of the distinct experience may differ.

### *Traditional research paradigms and the shift towards the community*

Historically, autism research has been dominated by neurotypical researchers, often reducing neurodivergent individu-

als to subjects of study rather than active participants [41,42]. This dynamic has led to research priorities that frequently misalign with the lived experiences and needs of neurodivergent people [43]. For example, traditional studies often neglect critical issues such as quality of life, healthcare accessibility, and the broader socio-environmental barriers faced by autistic individuals [41,44–47].

The neurodiversity movement, driven by autistic self-advocacy, has catalysed a shift towards participatory research methods [6,28,48,49]. A result of this is an increase in autistic research led by experts by experience. Thus, the community influences and decides how research is conducted and what it focuses on and ensures that the autistic perspective is central to the aims of the work [1145,50]. While progress has been made, traditional power hierarchies persist, and much of the existing literature still uses language that disregards the preferences of the autistic community [11,41,51]. This underscores the urgent need for a more inclusive and participatory approach to research.

### *Healthcare inequalities*

For autistic individuals, there is a well-established and continuously growing body of evidence highlighting the significant health disparities they experience. These include higher levels of mental health issues [52–54], physical illness [55,56], rates of injury [56] and lower life expectancy [57,58]. While there is a paucity of research on the broader healthcare experiences of ADHD people, there is evidence of a higher likelihood of experiencing issues with mental health (such as addiction and eating disorders) [59–61], physical health (such as sleep issues and accidental injury) [59,60,62] and a lower life expectancy [63].

Addressing these disparities requires improving healthcare practices and ensuring that research methods are accessible and inclusive. Without deliberate efforts to meaningfully engage neurodivergent participants, research risks perpetuating existing biases and failing to capture the diversity of patient experiences necessary to inform effective healthcare interventions [48,64,65].

### *Proposing a framework for accessible and inclusive research*

Research addressing caring for autistic, ADHD and AuDHD individuals in radiography has only begun to develop in the past five years, reflecting a recent and growing area of academic interest [66–72]. If this growth is to continue meaningfully, it is important to ensure that research in this area is conducted using appropriate methods and respectful language. This is essential to prevent the perpetuation of poor or harmful practices and protect study participants from unnecessary exclusion, discrimination or stigmatisation. Furthermore, it is vital that the principles of the neurodiversity movement are actively embedded within research practice.

This paper aims to fill a critical gap by proposing a framework for accessible and inclusive research practices for autistic,

ADHD and AuDHD people – the A3ReAcH (Autistic, ADHD and AuDHD Research Accessibility in Healthcare) Framework. Drawing on lessons and practices from psychology and social sciences, this work introduces these practices to healthcare – specifically radiography – researchers, a field currently lacking guidance. This is not intended to critique colleagues' existing work or potentially discourage future healthcare or, specifically, radiography research, which is limited compared to other disciplines [73,74]. However, by providing approaches for inclusive and accessible research design, this framework seeks to empower healthcare practitioner-researchers to overcome barriers to participation and representation for autistic, ADHD and AuDHD individuals and align their work more closely with the needs and experiences of neurodivergent people.

## **Method**

### *Aim and objectives*

This narrative review aims to summarise different research methods that can make research participation more accessible and inclusive for autistic, ADHD and AuDHD individuals. This focused on identifying key barriers, enablers, and methodological approaches that support accessible and inclusive research practices to synthesise a new model as a framework.

### *Search strategy*

Two individual searches were conducted, spanning different databases, to ensure a comprehensive exploration of the literature.

The initial search that was conducted on the 2<sup>nd</sup> of August 2024 employed *Ovid (Emcare, Ovid MEDLINE(R), and Social Policy and Practice)* and *EBSCO Host (CINAHL and the Psychology and Behavioral Sciences Collection)* so that articles from the social sciences and psychology literature were included. A supplementary second search was undertaken during the following month (14/09/2024) on *Google Scholar* to identify additional papers not captured in the initial database search and *PubMed* to provide further access to biomedical and clinical research.

The search strategies combined the topics of neurodivergent people and inclusive research methods. The search was constructed using the PI(C)O framework [75], as seen in [Table 1](#).

Boolean operators ("AND" and "OR") were used to aid the search. In the case of *Google Scholar*, each search's first 10 pages of results were screened for relevance. Search strings included combinations of the keywords identified by PI(C)O. The search strings that were used are documented in [Appendix A](#).

### *Inclusion and exclusion criteria*

These criteria were

1. Articles that were published and peer-reviewed.
2. Articles in English.
3. Articles published between January 2019 to December 2024.

Table 1

PI(C)O framework of the search strategy.

Population	Neurodivergent People (specifically those that are autistic and/or ADHD).
Intervention	Research methods, research practices, data collection, data analysis, co-production
Comparison	(not applicable)
Outcome	Accessible and inclusive research for neurodivergent (specifically, autistic and/or ADHD people) people

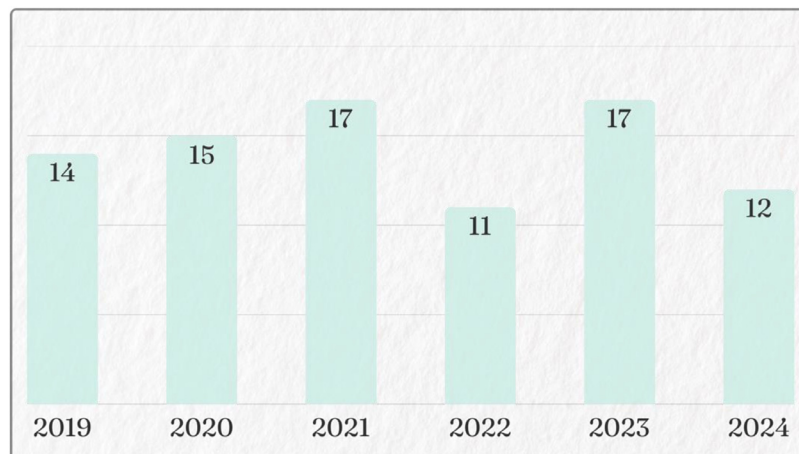


Fig. 1. – Graph showing the number of included articles by year.

- Articles that directly discussed making any stage of the research process inclusive of and accessible for autistic and/or ADHD participation.

Preprints and articles not available as full text were excluded. Additionally, articles solely regarding people with a learning disability were excluded, but articles regarding autistic and/or ADHD people with a learning disability were included.

#### Screening and selection

The first stage of the screening process involved screening titles and abstracts to identify studies that fulfilled the inclusion criteria. The articles were required to report, discuss, or address research that was inclusive of and accessible to autistic and/or ADHD participants. Duplicates were removed from the final list of results.

In the second stage, full-text screening was conducted. The first author, an autistic, ADHD, and dyslexic researcher and diagnostic radiographer, then synthesised these articles using narrative. They remained conscious of the potential for personal experiences to shape the selection and interpretation of the literature. To address this, they engaged in reflexive practices and sought input from diverse research. A reflexivity statement is available in [Appendix B](#).

The narrative synthesis process involved summarising and interpreting the findings from the included studies. This generated common themes and patterns across the literature, forming groupings of similarities in the concept, approach, or method being discussed [76]. These groups were worked into principles and categorised by the stages of the research process in which they apply.

#### Funding

The work for this paper was supported out of a funded PhD studentship awarded by the School of Health & Medical Sciences at City St George's, University of London.

#### Results

86 articles were included; the complete list is in [Appendix C1 and C2](#). The articles discussed research methods, priorities, guidance, and the researcher's experience.

The highest number of articles included in 2019–2024 was from 2021 to 2023 (See [Fig. 1](#)). The research methods reported included various forms of interviews, surveys, focus groups, creative and arts-based communication, and co-creation of instruments or programs.

As shown in [Fig. 2](#), two broad categories of articles were discovered in the searches:

- Methodological:** articles in which the central and primary topic discussed, commented on, or reported accessible or inclusive research practice, methods, or methodology.
- Original research:** articles that reported primary research studies exploring other topics but used accessible and inclusive research practices.

The themes across the methodological articles discussed methods and approaches to inclusive and accessible research, the importance of intersectionality, the community's research priorities, systematic and institutional barriers, insider researchers, and the importance of community partnership. The

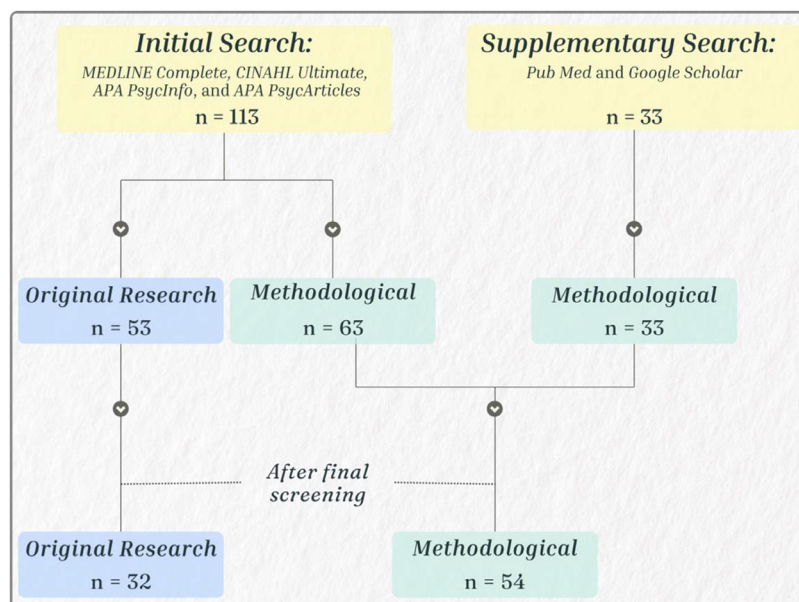


Fig. 2. – Diagram showing the screening and article selection process.

original research papers act as examples and case studies of the themes discussed in the methodology papers in practice.

These themes are discussed below in the framework format. This aims to create a simple but comprehensive research tool that can aid healthcare researchers in conducting research that is accessible and inclusive of the autistic, ADHD and AuDHD populations. For a condensed version of this framework for easy reference, see Fig. 3

### The A3ReAcH (Autistic, ADHD and AuDHD research accessibility in healthcare) framework

#### Planning

##### Facilitating diversity in the research team

In the planning phases of the research, researchers should aim to have a diverse research team. One way to distinguish between lower and higher diversity research teams is to consider which team member brings the neurodivergent perspective. Fig. 4 depicts some simplified structures, where different roles carry various levels of potential or “formal power,” though the hierarchy might change along the research process [77].

For example, in the *Third-Party Expert Paradigm*, the role of the *Expert by Experience* could be purely advisory, and their input result in no real impact on the views or practices of the academic researcher. In contrast, their role might be leading the work and making key decisions. Thus, the academic researcher acts only as a facilitator, providing the administrative and organisational aspects to make it possible. Regardless, the “lay” *Expert by Experience* should have access to the same resources and opportunities as the trained academic researchers [78]. Although these resources might not be present for any party [79]. where they are available, the expenses of presenting at academic conferences and access to further training or

courses should be shared, particularly considering that an *Expert by Experience* might require training for some aspects of the co-researcher role [78,80].

Studies that follow the *Provider Expert Paradigm* could also be called person-centred research. For example, the work by Tesfaye et al. [81] involves the researcher adapting the interview or communication method to the participant’s needs and preferences. However, the insight gained here from the neurodivergent perspective is less about the neurodivergent experience and more about understanding the participant’s preferences.


The *Collector Expert Paradigm* includes a trained researcher who is neurodivergent. This means they can benefit from insider insight that their lived experience brings [82]. For example, including autistic team members can help identify potential barriers within research protocols or aid in the creation of more accessible materials, such as in the case of Lilley et al. [83] Furthermore, as discussed by Grant and Kara [49]. several aspects of the autistic experience are well suited to academic research, such as hyperfocus, attention to detail, creative thinking, and ethical reflexivity. In the case of an all-autistic team, with careful consideration, as demonstrated by Willams et al., [84] a safe space can be built that allows researchers to bring their whole autistic selves, thus reaping the benefits from authentic participation. Additionally, an autistic researcher working with autistic participants may bring other advantages, such as increased trust through a shared understanding and common experiences. However, this does not always equate to better representation and inclusivity [85].

Taking a broader view, the systematic bias found in society has equally dominated autism research, reinforcing hierarchies that privilege neurotypical perspectives over the lived experiences of autistic individuals [6,86]. As Botha [47] argues, the entrenched power structures of academia continue to perpetuate “research-based violence”, where autistic voices are invited

# The A3ReAcH Framework

Principles for Accessible and Inclusive Healthcare Research for Autistic, ADHD and AuDHD Individuals


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## The A3ReAcH Framework:

Principles for Accessible and Inclusive Healthcare Research for Autistic, ADHD and AuDHD Individuals

Principle	Description	
Facilitating Diversity in the Research Team	Include neurodivergent people as experts by experience in research teams to integrate lived experience, enhance authenticity, prioritise the community's needs, and reduce bias. This should include providing equal access to any necessary resources and opportunities.	
Sharing Power and Decision-making	Move beyond the <i>researcher</i> and the <i>subject</i> to create a collaborative co-researcher structure that shares the power, such as neurodivergent co-researchers setting meeting agendas or having final approval on research publications.	
PLANNING	Ensuring Authentic Co-production	Avoid tokenistic involvement and engage meaningfully with neurodivergent people throughout the research process, ensuring their participation creates a tangible impact, e.g., research questions that reflect their priorities.
	Considering Language and Terminology	Demonstrate an understanding of the preferences and perspectives of neurodivergent people by using identity-first language and terminology informed by the social model of disability and the neurodiversity paradigm, i.e., <i>autistic person</i> rather than <i>person with autism</i> .
Accounting for Intersectionality	Acknowledge how intersecting identities like race, gender identity, and socio-economic status influence experiences of discrimination, and adopt strategies to address specific barriers, increase representation and promote equity.	




2

## The A3ReAcH Framework:

Principles for Accessible and Inclusive Healthcare Research for Autistic, ADHD and AuDHD Individuals

RECRUITMENT	Developing Accessible Recruitment Materials	Create recruitment materials that use clear language free of jargon, are available in multiple formats (textual, visual, video), and are co-designed with community input.
	Establishing Transparent Compensation Policies	Recognise participants' contributions by budgeting for fair financial compensation, timely reimbursement, and proper credit (e.g., co-authorship), ensuring transparency and addressing financial inequalities faced by neurodivergent individuals.
DATA COLLECTION	Utilising Participatory Research Methods	Use participatory approaches, such as community-based participatory research (CBPR) or creative and arts-based methods, to actively involve neurodivergent participants in producing relevant and impactful outcomes.
	Using Flexible Multi-modal Participation	Adapt research designs to participants' communication preferences by offering multimodal options (e.g., visual, auditory, creative media) and create protocols for flexible participant-led engagement.
	Tackling the Barriers to Participation	Remove barriers by offering sensory-friendly environments, minimising logistical burdens (e.g., travel or scheduling), and providing clear, accessible procedures to reduce participant anxiety and promote inclusion. This may include visual aids, virtual participation or sensory break areas.



3

## The A3ReAcH Framework:

Principles for Accessible and Inclusive Healthcare Research for Autistic, ADHD and AuDHD Individuals

ANALYSIS	Implementing Feedback Mechanisms	Incorporate participant feedback into data analysis by co-creating interpretations through collaborative discussions and iterative reviews to ensure fair representation and unbiased interpretations of lived experiences.
	DISSEMINATION	Acting and Advocating for the Community



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4

Fig. 3. – The A3ReSeAcH Framework (Reference Version).

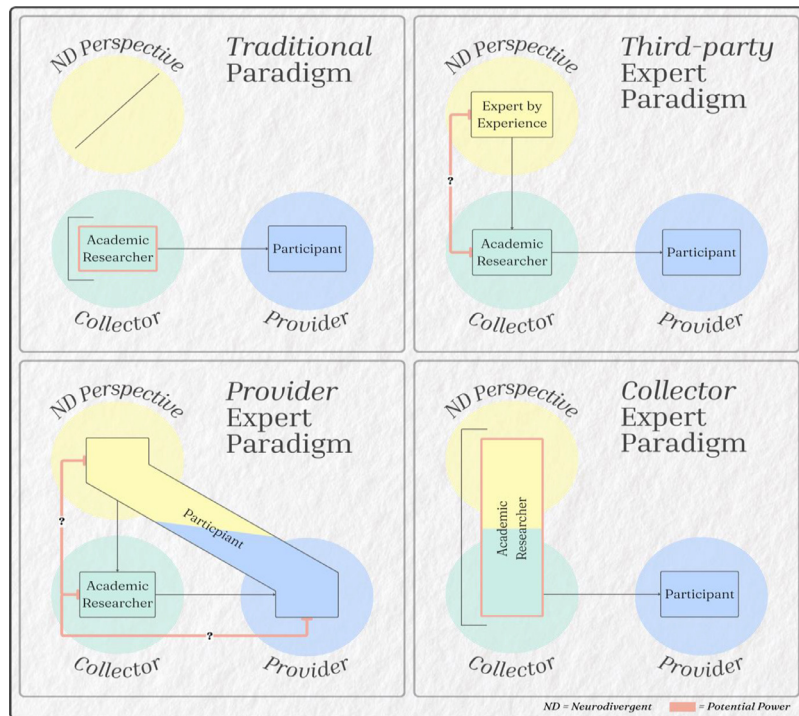


Fig. 4. Diagram showing examples of different research team structures based on which member elevates the neurodivergent perspectives.

into research only superficially, without the opportunity to influence the core of knowledge production. This reflects a more profound, systemic problem: power remains concentrated in the hands of non-autistic researchers, who often dictate the research agenda, funding, methodologies, and interpretation of findings. This is echoed by Raymaker [18], who, as an autistic researcher, reflects on the dual experience of being both empowered and marginalised. A prevailing idea in these articles is that whilst autistic individuals may have roles as insider researchers, their position within the academic system often comes with inherent limitations. Even those within the system must navigate hierarchies where academic norms and expectations still favour non-autistic perspectives.

### Sharing power and decision-making

Power, in a social sense, surrounds everyone and is not something one can possess but can exercise [77]. It should be exercised equally to allow everyone to make the best use of their knowledge, skills and experiences [87]. Collaborators or participants invited to work with a research team to share their lived experiences should be viewed as equal partners with particular expertise at the same level of importance as the researcher's expertise in conducting scientific research [87,88]. Therefore, those providing the neurodivergent perspective should be able to share their views and opinions on the research throughout the process, and these should have equal weighting in a democratic decision-making process [6,80,88]. Their views should not be dismissed or attenuated by a neurotypical bias - whether intentional or not [6,80]. Equally, ensuring transparency and establishing clear roles for public contributors who are neuro-

divergent facilitates team dynamics and provides a culture of trust and professionalism.

As explained by Fletcher-Watson et al. [6], Arnstein's ladder of participation [89] provides a valuable framework for conceptualising this power dynamic (or see Fig. 5 for an alternative), with participation ranging from "no power" (e.g., recipients of therapy) through to "devolved power" (e.g., partnership or citizen control). Many forms of co-production risk are in the middle of the ladder - i.e., tokenistic involvement - where participants may be consulted or informed but lack the power to influence outcomes [10,90]. Current autism research often remains at these stages, with little real power devolved to the autistic community [6,10]. Without a clear structure to distribute power equitably, co-production efforts may fail to deliver authentic engagement.

### Ensuring authentic co-production

Building on the concept of sharing power and team dynamics, authentic co-production is one of the most direct manifestations of inclusive research. Authentic co-production is not symbolic or tokenistic; it requires community members to have a substantive and meaningful impact on the research. In practice, academic researchers and autistic experts by experience collaborate by leveraging their respective knowledge, experiences, and skills to maximise the effectiveness of the research team [50]. For instance, Lilley et al. [83] demonstrated this approach by involving autistic team members as interviewers for autistic participants. Drawing on Pellicano et al., [85] this method likely enhanced the study's outcomes by fostering greater trust among participants, as autistic individuals can feel more at ease with

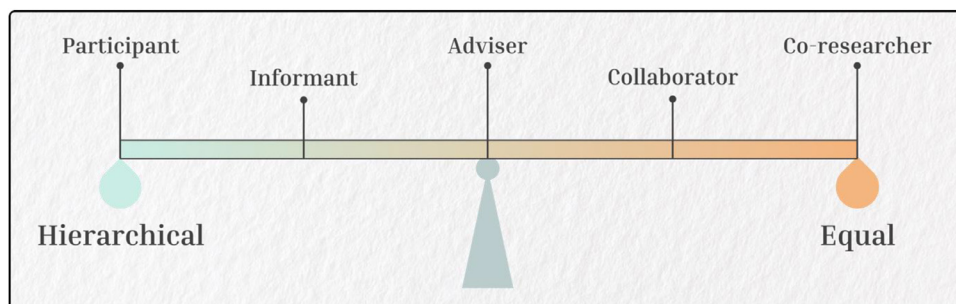


Fig. 5. - Expert by Experience (EbE) Power Scale, adapted from Karnieli-Miller et al. [91] and Smits et al. [92].

autistic researchers who share their common lived experiences and understanding. Meanwhile, other team members focused on complementary tasks such as manuscript drafting, for which their academic training would be most beneficial.

Moreover, Beasant et al. [93] identified that trust could be established simply through a study being labelled as co-produced. When autistic individuals play an active role in a study, thereby endorsing it, their involvement lends significant credibility and reassurance to other autistic participants [93]. This aligns with findings from Grove et al., [44] where autistic women and gender-diverse individuals in Australia identified co-designing research as one of their key priorities. Importantly, Grove et al.'s study was co-produced and led by autistic women and gender-diverse adults in partnership with a non-autistic researcher, ensuring that the research was fully informed by lived experience.

Authentic co-production also facilitates the development of practical tools and approaches, such as programmes [94], design concepts [95], and reporting instruments [96]. Because of its collaborative nature, co-created outputs reflect the community's needs. They are more likely to yield impactful, real-world results, demonstrating the value of participatory approaches in research [79].

However, the co-production approach is not without challenges. It has become a common buzzword that can be misused to describe participants' involvement, which is more symbolic than substantive [6,44,97]. This tokenism can undermine the very goals of participatory research by relegating neurodivergent individuals to marginal positions [6]. Pickard et al., [79] who interviewed 25 researchers at different career stages, found that participation may be framed as collaborative in many cases. Still, the pragmatic realities of institutional constraints, time pressures, funding and lack of resources, and a lack of training in participatory methods can mean that power still rests with researchers rather than the community. The additional work and resources required to carry out participatory research in a system built on traditional practices are underappreciated by institutions and funding bodies [6,79]. Thus, even well-intentioned attempts at inclusivity can perpetuate tokenism. This is consistent with Rosenau and Hotez [90], who argue that lived experience can be an afterthought or seen as a luxury rather than central. Every element of the research process has the potential to present barriers to participation; thus,

including an autistic, ADHD and AuDHD person throughout the research lifecycle to co-produce research practices, from creating funding applications to disseminating findings through mediums and channels that promote inclusivity, provides significant benefit [6,10,78,98,99].

#### *Considering language and terminology*

Understanding and using respectful language is essential when speaking or writing about neurodivergent individuals in research [3,9,100,101]. The terminology chosen should reflect the values of inclusivity, dignity, and recognition of neurodivergent identities, ensuring that language aligns with the lived experiences and preferences of those it describes [1,102]. While there are no absolute rules, as language preferences vary across individuals, discussions or research about neurodivergence require careful consideration, as terminology carries significant implications for how individuals and communities are perceived [3,103].

As seen in Fig. 6, three concepts inform neuro-inclusive language.

*Neurodiversity paradigm.* The neurodiversity Paradigm recognises that neurological diversity is a natural and valuable aspect of human variation. Neurodivergence is not a defect or abnormality but a difference to be understood, respected, and embraced [104]. This perspective rejects deficit-based language that pathologises neurodivergent individuals and instead promotes acceptance of neurodivergence as an integral and positive dimension of diversity [1]. However, the neurodiversity movement and paradigm are not merely arguments for a change of language but a reconceptualisation and recontextualisation of how neurodivergence and neurodivergent people fit into society [105]. The language one uses is a signal of the understanding and use of this concept.

*Social model of disability.* The social model of disability asserts that disability arises not from an individual's neurological or physical differences but from the societal and environmental barriers that exclude or disadvantage them [106]. This model shifts away from "fixing" or "curing" individuals and toward dismantling the structural inequalities and prejudices that create disabling experiences. Language derived from the social model avoids focusing on individual impairments and

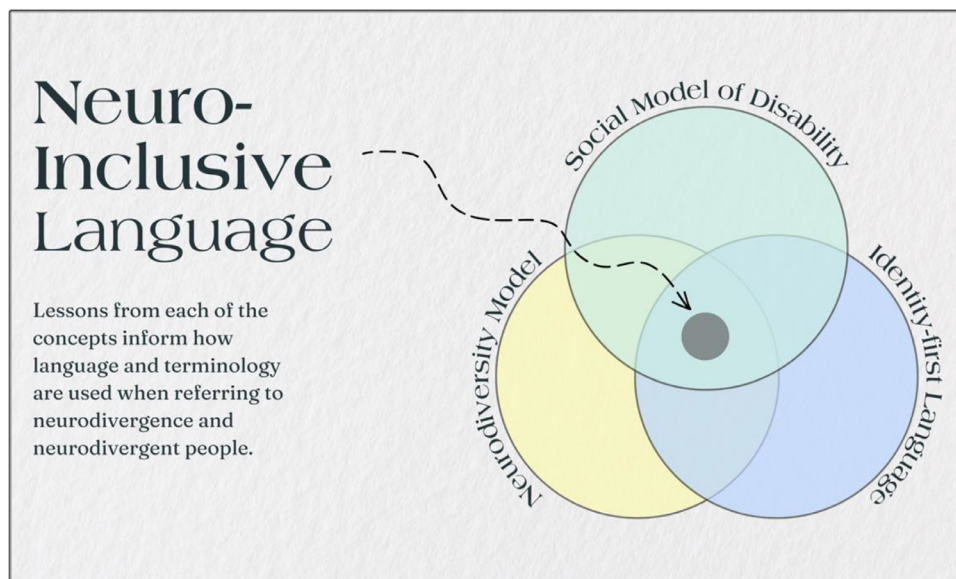


Fig. 6. – Concepts that inform neuro-inclusive language: social model of disability, neurodiversity model and identity-first language.

emphasises societal responsibility to create inclusive environments. For example, rather than describing a person as “suffering from autism,” it would be more appropriate to say, “a neurodivergent person faces barriers or disability due to inaccessible environments or discriminatory attitudes.” [107].

*Identity-first language.* Identity-first language (e.g., “autistic person” rather than “person with autism”) affirms the centrality of neurodivergence to an individual’s sense of self. It recognises that it influences their entire human experience [1,5,108]. Many neurodivergent individuals prefer identity-first language as it reflects pride in their neurodivergent identity and opposes narratives that imply neurodivergence is a medicalised condition to be separated from their personhood [1,4,9,108].

It is essential to consider the language used in any research on neurodivergence, as terminology carries significant implications for how individuals and communities are perceived [3,5,9,86,108,109]. This may be unnatural for researchers in healthcare and radiography/MRT, who instinctively turn to medical and person-first language [1,108]. Although there are no absolutes in the language used, and individual preference should take precedence, using the vocabulary of the neurodiversity model, which is identity-first and informed by the social model of disability, is most likely to be acceptable and less likely to be offensive [1,4,9,108].

#### *Accounting for intersectionality*

Intersectionality, as conceptualised by Crenshaw, describes the interconnected nature of social identities such as race, gender, class, and disability, which interact to create unique experiences of oppression and privilege [110]. Crenshaw introduced the term to highlight how traditional frameworks for addressing inequality often fail to account for the compounded discrimination faced by individuals at the intersection of multiple

marginalised identities, such as black women. Intersectionality is thus a critical framework for understanding and addressing complex social inequalities. In the field of autism research, Malone et al. [111] critique the historical neglect of cultural diversity in autism research, noting that diagnostic criteria and intervention models often reflect Western, individualistic norms. This has led to the exclusion of non-Western perspectives and reinforced systemic inequities.

To address this, researchers should adopt culturally responsive methodologies that respect participants’ linguistic, social, and cultural contexts. For instance, using bilingual materials, co-developing culturally appropriate communication methods with the community, or collaborating with community leaders from underrepresented groups can facilitate trust and engagement [9,78,111]. Cascio et al. [112] propose applying intersectional analysis to identify and mitigate barriers related to race, gender, and socio-economic status, ensuring that research does not perpetuate existing disparities.

Moreover, fostering diversity extends beyond the individual characteristics of participants to include a range of disciplinary expertise in the research team. Malone et al. [111] argue that interdisciplinary teams combining psychology, sociology, and health perspectives can comprehensively address advancing equity and reducing disparities in autism diagnosis and intervention across marginalised communities.

#### *Recruitment*

##### *Developing Accessible Recruitment Materials*

When recruiting participants, providing clear, accessible pre-study information is critical for reducing participant anxiety and ensuring informed consent [9,93]. This should include using straightforward, simple and precise language to explain procedures and expectations and be open about study goals

[9,113,114]. It is essential to foster trust at the first opportunity. Thus, Wylde et al.<sup>115</sup> and Nicolaidis et al. [9] recommend co-designing recruitment strategies with community input to address potential barriers, such as distrust of research institutions or logistical challenges like scheduling. This transparency helps participants feel more comfortable and confident in participating [93]. Furthermore, providing this clear contextual information - avoiding vague or abstract phrasing - can significantly reduce decision-making anxiety [114].

Where research design necessitates partial blinding or limited disclosure, such as Randomised Control Trials (RCTs), accessible recruitment materials can still foster trust and informed decision-making for autistic, ADHD, and AuDHD participants. Recent findings indicate that autistic adults are generally accepting of such approaches when the rationale is communicated transparently and respectfully [93]. Explaining exactly what information can and not be shared and why can help uphold participant autonomy and reduce anxiety while maintaining methodological rigour [113]. Moreover, the objectivity and logical reasoning of an RCT study design may be preferred by some autistic participants [93].

Research materials should be presented in multiple formats to accommodate diverse sensory, cognitive, learning, and communication needs. These formats include textual, video, and verbal explanations and visual formats such as graphs, charts, and diagrams [9,114,115]. Online materials on a project website could consist of hotlinks to define technical terms or provide contextual examples to enhance comprehension [9].

#### *Establishing transparent and fair compensation policies*

The theme of establishing a clear understanding before commencing research extends to the policy of how participation will be compensated. Such policies are crucial for ethical research practices, recognising the value of participants' contributions and fostering trust [6,84,113,116]. There are cases where funding may be stretched or delayed, and there is significant difficulty in paying community partners and experts by experience; however, although these parties may understand this fact [116], healthcare researchers should budget appropriately during grant applications [84,116,117]. This can be critically important with the autistic community, which research indicates is less likely to be in secure employment. Thus, a delay in reimbursed expenses may present significant difficulty [84]. The rate of pay should follow regional or national guidelines for fair payment. An example from UK Research and Innovation is as follows:

*'hourly rate for an activity that is less than 6 hours and requires little or no preparation, for example, taking part in an interview or a focus group or reviewing documents or videos: £25 per hour' [117].*

Fair compensation means the fair representation of the work carried out and the expertise shared by the collaborators. Thus, a co-researcher's place in the team should be represented through co-authorship on resultant publications [6,94,118]. The study by Lam et al. [119] is a prime example of this. The

second-named author of the article was an autistic participant, indicating the level of collaboration that took place during the work and ensuring appropriate credit for this.

#### *Data collection*

##### *Utilising participatory research methods*

The vast majority of the articles advocate prioritising participatory methods when considering data collection methods, highlighting the multiple benefits of this approach [6,9,10,44,47,50,78–80,84,85,90,99,101,113,116,118–135]. Participatory research is a broad conceptual framework that seeks to involve participants actively in the research process. It aims to break down the hierarchical divide between researchers and participants and move beyond the traditional research paradigm [6,10]. Participatory research combines many of the elements already discussed in this framework, including power-sharing, community collaboration, and co-production.

Involving individuals with lived experience enhances research outcomes' relevance, quality, and applicability [6]. For example, participatory approaches in autism research have led to the development of tools that better address community-specific needs, such as improved measures for assessing suicidality [10]. Moreover, co-production fosters trust and mutual understanding, essential for bridging the historical disconnect between researchers and the autistic community [134]. Participatory research methods may also make research more accessible by enabling authentic collaboration without requiring full partnership at every stage [19]. This flexibility makes participatory research a widely applicable concept that informs many practical methods but remains less prescriptive about the degree of power-sharing. Participatory research should aim to include the broader ecosystem, including families, carers and healthcare practitioners, many of which are often left out of the discussion, with dire implications about the feasibility and scalability of any identified solutions [6].

Also discussed are community-based participatory research (CBPR) [6,99,116,132,135], participatory action research (PAR) [119,121] and participatory autism research (PAUR) [121]. These methods are inherently applied and aim to solve real-world problems directly identified by the community [11,99,118,121,126,135]. An example of this is the work by Costley et al. [121] involving autistic adolescents, where participants identified challenges within the school system and designed interventions to address these issues.

##### *Using Flexible Design and Multi-modal Communication*

Autistic individuals may prefer communication methods that deviate from conventional verbal means, such as telephone calls [136,137]. Therefore, researchers should be flexible and adapt their language and communication modes to suit their participants [112,114,138,139].

The *Autism Voices* protocol was created by Courchesne et al. [140] to accommodate a wide range of communication abilities. Participants were assessed before interviews to identify preferred communication modalities, such as spoken language,

writing, pointing, or visual aids. The interview protocol was semi-structured, with the flexibility to adapt the phrasing of questions, skip topics, or follow the participant's lead based on their comfort and communication style—the later study by Tesfaye et al. [81] similarly emphasised the importance of adaptability in which participants could use drawing, thematic ranking activities, or verbal and non-verbal responses to convey their thoughts. These multimodal strategies broadened the scope of participant engagement, recognising that diverse forms of expression - beyond verbal or written communication - could yield valuable insights.

In a more radical application of flexibility, Lam et al. [119] and Reason et al. [141] allowed participants to direct the research through their creative and open-ended expression. Lam et al. [119], using the *Photovoice* method, allowed participants to choose what to photograph, ensuring that the data reflected their priorities and perspectives. Reason et al. [141] worked with multiple artistic media, including painting, performance, and digital art, allowing participants to choose forms of expression that resonated with them.

Many examples support these arts-based methods and indicate their merits. These include using other uses of *Photovoice* and photo elicitation [119,126,142–145] to reach a wide range of demographics, the conceptual depth artistic output can reach, such as exploring new ways of understanding nonverbal communication [146], and demonstrating the adaptability of art-based methods in times of crisis, such as the COVID-19 pandemic [147].

These methods provide a platform for participants to assert their agency, building a sense of ownership and collaboration. Thus, they go beyond accessibility to empowerment [141]. This empowerment is crucial for autistic, ADHD and AuDHD individuals who may have experienced marginalisation or exclusion in other settings [50]. As demonstrated across all these examples, flexible approaches enable researchers to capture a broader spectrum of insights by accommodating diverse forms of expression.

### *Tackling barriers to participation*

Autistic individuals face several systemic barriers to research participation, requiring researchers to adopt more inclusive and accessible practices [80,93,119,148]. Trust is a critical factor, with participants often reluctant to share personal information unless they have established prior relationships with researchers—including the support needed to participate [6,93,148]. Tools like the Research Passport, which improves preparedness and demonstrates an understanding of participants' needs, can help build this trust [148]. However, it should be used cautiously to avoid introducing unrealistic expectations of project resources and available adaptations [148].

Uncertainty and anxiety also hinder participation, particularly in studies like randomised controlled trials (RCTs), which can disrupt routines and introduce stress through unfamiliar procedures or blinding [93]. Providing clear information, accommodating individual preferences, and minimising procedural complexity can help reduce these challenges

[9,93,113,132,149]. Practical constraints - such as the need for travel - pose additional barriers, particularly for those who rely on others for transportation or find public transport overwhelming. As highlighted by Grove et al., [44] decentralised or non-synchronous participation options, like virtual methods, can mitigate these burdens, though care must be taken to avoid digital exclusion [121,133].

Environmental factors, such as harsh lighting or noise, further discourage participation and create unwanted distractions [98,114]. Creating sensory-friendly environments, offering varied forms of communication, and implementing health and safety measures can improve comfort and engagement [98]. Systemic exclusion also remains a significant issue, with traditional methods often excluding nonspeaking autistic individuals or those with intellectual disabilities [49,112,140,141]. Flexible, inclusive methodologies and targeted outreach are essential to addressing this gap [49,115].

### *Data analysis*

#### *Implementing feedback mechanisms*

At this data analysis stage, it is crucial to ensure the researcher acknowledges their reflexivity and addresses their bias and positionality. This is particularly true for a neurotypical researcher working with autistic, ADHD and AuDHD collaborators, where the power reinforces the formal power structure of a traditional research paradigm [6,77]. Furthermore, by using a collaborative and participatory approach involving participants in co-analysing the data, researchers can avoid potential biases and misinterpretations that might arise from an outsider's neurotypical perspective [9,132].

Researchers can foster a co-created approach that centres participants' voices by involving participants in iterative discussions or draft reviews [122,145]. The key differences between the methods in the examples lie in the timing and depth of participant involvement. Strang et al. [150] and Nicolaidis et al. [116] emphasised ongoing collaboration, where participants actively shaped the data analysis. In contrast, Heselton et al. [151,152] incorporated participant input primarily as a post-analysis validation step. Both approaches have merits: the practices of Strang et al. (150) and Nicolaidis et al. [116] are more immersive, offering participants more significant control over the research process. At the same time, Heselton et al.'s [151,152] credibility checking ensures that participant perspectives are included without requiring ongoing involvement throughout the analysis.

The term *credibility checking* used by Heselton et al. in their work [151,152] may not truly represent the process that took place. Whilst there is much validity to ensuring the participants see their experiences in the analysis and thus were not misrepresented by a neurotypical lens (i.e., the double empathy problem [153]), it implies a positivist view that there is only one credible interpretation of the data [154]. In contrast, the credibility checking outlined in the article included participation in reflecting on the analysis and in one case, this resulted in further data being collected. This is a reflexive approach whereby the

researchers and participants analyse, reflect and generate new data, which is more akin to *member reflection* [155] or *collaborative reflection* [154]. This favoured approach is aligned with the co-researcher relationship and participatory practices advocated by many articles in this review [6,130,156–159].

However, the effectiveness of member-checking can be influenced by participants' willingness or ability to engage. While some participants actively contribute to these processes, others may decline or face barriers such as time constraints or difficulties engaging with written materials [144,160]. To maximise accessibility, researchers should offer diverse methods for providing feedback, such as verbal discussions, video summaries, or iterative validation during data collection [138].

Equally, it is worth considering adding methods to gather feedback and open a dialogue about how inclusive and accessible participation or collaboration in the research was. Allowing participants to give feedback on the research process can improve future studies and ensure that participants feel valued [9,113]. This feedback loop can enhance the research experience for all involved [93].

## Dissemination

### *Acting and advocating for the community*

At this final point of dissemination, a strategic, inclusive, and flexible approach is required to ensure that findings are accessible, impactful, and meaningful to diverse audiences. Researchers should prioritise collaboration with community members throughout the dissemination process [10,78,111,116]. Co-production ensures that dissemination efforts are aligned with the priorities and lived experiences of the target audience, fostering trust and increasing the relevance of research outputs [10,132]. Working with genuinely diverse populations might come with challenges, which might be financial for providing all required resources, time delays in going through ethics committees to establish the capacity to consent and organisational, to ensure the right people are at the right place at the right time. While being realistic and honest about budget limitations upfront will be appreciated, researchers should also advocate to research councils about the financial and time constraints and adaptations required to do fully inclusive research that is both respectful and representative of autistic, ADHD and AuDHD communities.

Similarly, radiography/MRT researchers should strive to publish with open access so that the knowledge they produce with the neurodivergent community is available [10,50,161]. Engaging stakeholders in reviewing and shaping dissemination materials, such as co-creating lay summaries or alternative formats, can improve accessibility and strengthen community engagement [113,116]. Moreover, publishing articles in a community-led or community-driven journal, such as *Autism in Adulthood* [162], may have more impact. However, if the work is best suited in a healthcare/radiography/MRT journal, using a journal that welcomes outcomes with alternative media, such as narratives, multimedia, or creative communication, such as the *Journal of Medical Imaging and Radiation Sciences*

[163], may be beneficial in allowing more freedom in the output mode.

Nevertheless, it is essential to acknowledge that traditional academic channels, while valuable, often fail to reach broader audiences and specific intended communities [10,78,161]. Researchers are encouraged to explore creative and varied formats, including blogs, podcasts, talks, blogs, videos, images, theatre, and social media, to expand the reach and resonance of their findings [10,78,101,113]. A creative approach, led by community members, has been shown to engage audiences who may not typically access academic outputs, making the research more widely accessible [78].

Healthcare and radiography/MRT Researchers should remain mindful of their audience's demographic and cultural characteristics, ensuring that dissemination methods are inclusive and avoid perpetuating stigma [101,111,116]. Providing resources directly to relevant organisations, advocacy groups, and stakeholders increases the likelihood that findings will be practical and meaningful and can effectively inform policies, practices, and systems [113,161]. Thus, researchers should consider how findings are shared, with whom they are shared, and how these outputs can empower communities to act [116].

## Limitations

This review aimed to encompass autistic, ADHD and AuDHD perspectives, yet the paucity of studies concerning ADHD people represents a concerning underrepresentation in the field. This gap underscores the urgent need to extend the same principles of inclusive and accessible research practices to ADHD individuals, ensuring their voices and experiences are equally reflected in future studies. By doing so, we can strive for better representation and a more comprehensive understanding of autistic, ADHD and AuDHD experiences.

Additionally, this review specifically focused on autism and ADHD. It did not include articles focusing solely on individuals with learning disabilities despite potential overlaps in challenges and support needs for research participation. The current framework's exclusion of this group indicates a significant gap that necessitates further research and adaptation. To ensure comprehensive inclusivity, future work should focus on integrating cultural adaptations that explicitly address the accessibility and inclusivity of healthcare research practices of individuals with learning disabilities, both independently and when it occurs in the autistic, ADHD and AuDHD populations.

## Conclusion

This review underscores the critical importance of advancing participatory research practices to elevate the voices of autistic, ADHD and AuDHD individuals in all aspects of research in healthcare, especially radiography/MRT. By integrating autistic, ADHD and AuDHD perspectives, sharing decision-making power, using empowering and respectful language preferred by neurodivergent communities, and fostering authentic collaboration, researchers can address systemic barriers

ers and develop methodologies that reflect the lived experiences of the autistic community. The findings demonstrate that participatory approaches are ethical imperatives and catalysts for more robust, culturally responsive, and actionable research outcomes in radiography and healthcare.

To achieve these goals, researchers must embrace flexibility in design, foster intersectionality, and dismantle hierarchical structures that perpetuate tokenistic involvement. Co-production and community collaboration principles throughout the research lifecycle - supported by equitable compensation, accessible recruitment practices, and transparent feedback mechanisms - lay a foundation for meaningful engagement and lasting impact. These strategies further align with the broader goals of social justice, ensuring that research contributes positively to the empowerment of neurodivergent individuals and communities.

Ultimately, this review highlights that participatory research is not merely a methodology but a transformative approach. It challenges traditional healthcare and radiography research paradigms and redefines the relationship between researchers and minoritised communities. By prioritising accessibility, inclusion, collaboration, and shared ownership, the research process becomes a platform for advocacy, empowerment, and meaningful societal change - one that must strive for a comprehensive representation of all neurodivergent voices, including those with ADHD.

## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.jmir.2025.102009](https://doi.org/10.1016/j.jmir.2025.102009).

## References

- [1] Kapp SK, Gillespie-Lynch K, Sherman LE, Hutman T. Deficit, difference, or both? Autism and neurodiversity. *Dev Psychol.* 2013;49(1):59–71.
- [2] Taboas A, Doepke K, Zimmerman C. Preferences for identity-first versus person-first language in a US sample of autism stakeholders. *Autism.* 2023;27(2):565–570.
- [3] Botha M, Hanlon J, Williams GL. Does language matter? Identity-first versus person-first language use in Autism research: a response to Vivanti. *J Autism Dev Disord.* 2023;53(2):870–878.
- [4] Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism.* 2016;20(4):442–462.
- [5] Potts B. Comments on “Classification of children with attention deficit hyperactivity disorder and healthy subjects using Toro’s gyrification index. *J Med Imaging Radiat Sci.* 2023;54(1):215.
- [6] Fletcher-Watson S, Adams J, Brook K, Charman T, Crane L, Cusack J, et al. Making the future together: shaping autism research through meaningful participation. *Autism.* 2019;23(4):943–953.
- [7] Roche L, Adams D, Clark M. Research priorities of the autism community: a systematic review of key stakeholder perspectives. *Autism.* 2021;25(2):336–348.
- [8] Pellicano E, Dinsmore A, Charman T. What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism.* 2014;18(7):756–770.
- [9] Nicolaidis C, Raymaker DM, McDonald KE, Lund EM, Leotti S, Kapp SK, et al. Creating accessible survey instruments for use with autistic adults and people with intellectual disability: lessons learned and recommendations. *Autism Adulthood.* 2020;2(1):61–76.
- [10] Keating CT. Participatory Autism research: how consultation benefits everyone. *Front Psychol [Internet].* 2021;12. Aug 24 [cited 2024 Nov 23] Available from. <https://www.frontiersin.org/journals/psychology/articles/10.3389/fpsyg.2021.713982/full>.
- [11] Den Houting J, Higgins J, Isaacs K, Mahony J, Pellicano E. From ivory tower to inclusion: stakeholders’ experiences of community engagement in Australian autism research. *Front Psychol.* 2022;13:876990.
- [12] Sadatsafavi H, Vanable L, DeGuzman P, Sochor M. Sensory-friendly emergency department visit for patients with Autism spectrum disorder—a scoping review. *Rev J Autism Dev Disord.* 2023;10(4):684–698.
- [13] Doherty M, Neilson S, O’Sullivan J, Carravallah L, Johnson M, Cullen W, et al. Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study. *BMJ Open.* 2022;12(2):e056904.
- [14] Haydon C, Doherty M, Davidson IA. Autism: making reasonable adjustments in healthcare. *Br J Hosp Med.* 2021;82(12):1–11.
- [15] Brice S, Rodgers J, Ingham B, Mason D, Wilson C, Freeston M, et al. The importance and availability of adjustments to improve access for autistic adults who need mental and physical healthcare: findings from UK surveys. *BMJ Open.* 2021;11(3):e043336.
- [16] Nicolaidis C, Raymaker D, McDonald K, Ashkenazy E, Dern S, Boisclair C, et al. Respect the way I need to communicate with you’: healthcare experiences of adults on the autistic spectrum. *J Gen Intern Med.* 2015;26(SUPPL. 1) S184–5.
- [17] Mason D, Ingham B, Birtles H, Michael C, Scarlett C, James IA, et al. How to improve healthcare for autistic people: a qualitative study of the views of autistic people and clinicians. *Autism.* 2021;25(3):774–785.
- [18] Raymaker DM, McDonald KE, Ashkenazy E, Gerrity M, Baggs AM, Kripke C, et al. Barriers to healthcare: instrument development and comparison between autistic adults and adults with and without other disabilities. *Autism.* 2017;21(8):972–984.
- [19] Brasher S, Middour-Oxler B, Chambers R, Calamaro C. Caring for adults with Autism spectrum disorder in the Emergency department: lessons learned from pediatric emergency colleagues. *J Emerg Nurs.* 2021;47(3):384–389.
- [20] Corden K, Brewer R, Cage E. A systematic review of healthcare professionals’ Knowledge, self-efficacy and attitudes towards working with autistic people. *Rev J Autism Dev Disord.* 2022;9(3):386–399.
- [21] Unigwe S, Buckley C, Crane L, Kenny L, Remington A, Pellicano E. GPs’ confidence in caring for their patients on the autism spectrum: an online self-report study. *Br J Gen Pr.* 2017;67(659):e445–e452.
- [22] Mac Cárthaigh S, López B. Factually based autism awareness campaigns may not always be effective in changing attitudes towards autism: evidence from British and South Korean nursing students. *Autism.* 2020;24(5):1177–1190.
- [23] Heidergerken AD, Geffken G, Modi A, Frakey L. A survey of autism knowledge in a health care setting. *J Autism Dev Disord.* 2005;35(3):323–330.
- [24] Botha M, Chapman R, Giwa Onaiwu M, Kapp SK, Stannard Ashley A, Walker N. The neurodiversity concept was developed collectively: An overdue correction on the origins of neurodiversity theory. *Autism.* 2024;28(6):1591–1594. doi:10.1177/1362361324123787.
- [25] Chapman R. *Neurodiversity Studies*. Neurodiversity, disability, wellbeing. Routledge; 2020.
- [26] Stenning A, Bertilsdotter-Rosqvist H. Neurodiversity studies: mapping out possibilities of a new critical paradigm. *Disabil Soc.* 2021;36(9):1532–1537.
- [27] Doyle N. Defining neurodiversity and identifying neurominorities. In: Patton E, Santuzzi AM, eds. *Neurodiversity and Work: Employment, Identity, and Support Networks for Neurominorities [Internet]*. Cham: Springer Nature Switzerland; 2024:13–38. doi:10.1007/978-3-031-55072-0\_2.
- [28] Kapp SK, ed. *Autistic Community and the Neurodiversity Movement: Stories from the Frontline [Internet]*. Singapore: Springer; 2020

- [cited 2024 Dec 18]. Available from <https://link.springer.com/10.1007/978-981-13-8437-0> .
- [29] Kamath MS, Dahm CR, Tucker JR, Huang-Pollock CL, Etter NM, Neely KA. Sensory profiles in adults with and without ADHD. *Res Dev Disabil*. 2020;104:103696.
- [30] Bodalski EA, Flory K, Meinzer MC. A scoping review of factors associated with emotional dysregulation in adults with ADHD. *J Atten Disord*. 2023;27(13):1540–1558.
- [31] Fiene L, Brownlow C. Investigating interoception and body awareness in adults with and without autism spectrum disorder. *Autism Res*. 2015;8(6):709–716.
- [32] Hull L, Petrides KV, Allison C, Smith P, Baron-Cohen S, Lai MC, et al. Putting on my best normal”: social camouflaging in adults with Autism spectrum conditions. *J Autism Dev Disord*. 2017;47(8):2519–2534.
- [33] Brosnan M, Camilleri LJ. Neuro-affirmative support for autism, the Double Empathy Problem and monotropism. *Front Psychiatry [Internet]*. 2025;16. Mar 13 [cited 2025 Mar 30] Available from. <https://www.frontiersin.org/journals/psychiatry/articles/10.3389/fpsy.2025.1538875/full> .
- [34] Sumner E, Hill EL. Oculomotor differences in adults with and without probable developmental coordination disorder. *Front Hum Neurosci [Internet]*. 2024;18. Jul 23 [cited 2025 Mar 30] Available from. <https://www.frontiersin.org/journals/human-neuroscience/articles/10.3389/fnhum.2024.1280585/full> .
- [35] Poulsen R, Williams Z, Dwyer P, Pellicano E, Sowman PF, McAlpine D. How auditory processing influences the autistic profile: a review. *Autism Res*. 2024;17(12):2452–2470.
- [36] *Diagnostic and Statistical Manual of Mental Disorders: DSM-5 [Internet]*. Arlington, VA: American Psychiatric Association; 2013:947.
- [37] Hours C, Recasens C, Baleyte JM. ASD and ADHD comorbidity: what are we talking about? *Front Psychiatry*. 2022;13:837424.
- [38] Craddock E. Raising the voices of AuDHD women and girls: exploring the co-occurring conditions of autism and ADHD. *Disabil Soc*. 2024;39(8):2161–2165.
- [39] Stetson L. Narrative research, reflexivity, and AuDHD lived experiences. In: Bertilsdotter Rosqvist H, Jackson-Perry D, eds. *The Palgrave Handbook of Research Methods and Ethics in Neurodiversity Studies [Internet]*. Cham: Springer Nature Switzerland; 2024:279–290. doi:10.1007/978-3-031-66127-3\_16.
- [40] Boyle S. The sudden rise of AuDHD: what is behind the rocketing rates of this life-changing diagnosis? *Guard [Internet]*. 2024. Apr 4 [cited 2025 Apr 9]; Available from. <https://www.theguardian.com/lifeandstyle/2024/apr/04/audhd-what-is-behind-rocketing-rates-life-changing-diagnosis> .
- [41] Botha M, Cage E. Autism research is in crisis”: A mixed method study of researcher’s constructions of autistic people and autism research. *Front Psychol [Internet]*. 2022;13. [cited 2024 May 14] Available from. <https://www.frontiersin.org/journals/psychology/articles/10.3389/fpsyg.2022.1050897/full> .
- [42] Lovaas OI, Schaeffer B, Simmons JQ. Building social behavior in autistic children by use of electric shock. *J Exp Res Pers*. 1965;1(2):99–109.
- [43] Milton D, Bracher M. Autistics speak but are they heard? *Med Sociol online*. 2013;7(2):61–69.
- [44] Grove R, Clapham H, Moodie T, Gurrin S, Hall G. Nothing about us, without us’: research priorities for autistic girls, women and gender diverse people in Australia. *J Autism Dev Disord [Internet]*. 2024. ((Grove, Clapham, Moodie, Gurrin, Hall) School of Public Health, Faculty of Health, University of Technology Sydney, Ultimo, Australia). Available from. <https://www.springer.com/journal/10803> .
- [45] Haar T, Brownlow C, Hall G, Heyworth M, Lawson W, Poulsen R, et al. We have so much to offer’: community members’ perspectives on autism research. *Autism*. 2024;13623613241248713.
- [46] Cage E, Crompton CJ, Dantas S, Strachan K, Birch R, Robinson M, et al. What are the autism research priorities of autistic adults in Scotland? *Autism*. 2024 13623613231222656.
- [47] Academic BM. Activist, or advocate? Angry, entangled, and emerging: a critical reflection on Autism knowledge production. *Front Psychol [Internet]*. 2021;12. [cited 2024 May 14] Available from. <https://www.frontiersin.org/journals/psychology/articles/10.3389/fpsyg.2021.727542/full> .
- [48] Pellicano E, Den Houting J. Annual research review: shifting from ‘normal science’ to neurodiversity in autism science. *Child Psychol Psychiatry*. 2022;63(4):381–396.
- [49] Grant A, Kara H. Considering the autistic advantage in qualitative research: the strengths of autistic researchers. *Contemp Soc Sci*. 2021;16(5):589–603.
- [50] Bertilsdotter Rosqvist H, Kourti M, Jackson-Perry D, et al. Doing it differently: emancipatory autism studies within a neurodiverse academic space. *Disabil Soc*. 2019;34(7–8):1082–1101.
- [51] Bottini SB, Morton HE, Buchanan KA, Gould K. Moving from disorder to difference: a systematic review of recent language use in Autism research. *Autism Adulthood*. 2023 aut.2023.0030.
- [52] Crane L, Adams F, Harper G, Welch J, Pellicano E. Something needs to change’: mental health experiences of young autistic adults in England. *Autism*. 2019;23(2):477–493.
- [53] Curnow E, Rutherford M, Maciver D, et al. Mental health in autistic adults: a rapid review of prevalence of psychiatric disorders and umbrella review of the effectiveness of interventions within a neurodiversity informed perspective.. *PLoS ONE*. 2023;18(7):e0288275.
- [54] Blanchard A, Chihuri S, DiGuseppi CG, Li G. Risk of self-harm in children and adults with Autism spectrum disorder: a systematic review and meta-analysis. *JAMA Netw Open*. 2021;4(10):e2130272.
- [55] Smith DaWalt L, Hong J, Greenberg JS, Mailick MR. Mortality in individuals with autism spectrum disorder: predictors over a 20-year period. *Autism*. 2019;23(7):1732–1739.
- [56] Catalá-López F, Hutton B, Page MJ, et al. Mortality in persons with autism spectrum disorder or attention-deficit/hyperactivity disorder. *JAMA Pediatr*. 2022;176(4):e216401.
- [57] Hirvikoski T, Mittendorfer-Rutz E, Boman M, Larsson H, Lichtenstein P, Bölte S. Premature mortality in autism spectrum disorder. *Br J Psychiatry*. 2016;208(3):232–238.
- [58] O’Nions E, Lewer D, Petersen I, et al. Estimating life expectancy and years of life lost for autistic people in the UK: a matched cohort study. *Lancet Reg Health – Eur [Internet]*. 2024;36. Jan 1 [cited 2024 May 31] Available from. [https://www.thelancet.com/journals/lanep/article/PIIS2666-7762\(23\)00195-3/fulltext](https://www.thelancet.com/journals/lanep/article/PIIS2666-7762(23)00195-3/fulltext) .
- [59] French B, Nalbant G, Wright H, et al. The impacts associated with having ADHD: an umbrella review. *Front Psychiatry [Internet]*. 2024;15. May 21 [cited 2024 Nov 17] Available from. <https://www.frontiersin.org/journals/psychiatry/articles/10.3389/fpsy.2024.1343314/full> .
- [60] Young S, Asherson P, Lloyd T, et al. Failure of healthcare provision for attention-deficit/hyperactivity disorder in the United Kingdom: a consensus statement. *Front Psychiatry*. 2021;12:649399.
- [61] Magon R, Müller U. ADHD with comorbid substance use disorder: review of treatment. *Adv Psychiatr Treat*. 2012;18(6):436–446.
- [62] Brunkhorst-Kanaan N, Libutzi B, Reif A, Larsson H, McNeill RV, Kitzel-Schneider S. ADHD and accidents over the life span – a systematic review. *Neurosci Biobehav Rev*. 2021;125:582–591.
- [63] O’Nions E, Baou CE, John A, et al. Life expectancy and years of life lost for adults with diagnosed ADHD in the UK: matched cohort study. *Br J Psychiatry*. 2025:1–8.
- [64] Nicolaidis C, Raymaker D, McDonald K, et al. Program Community Health Partnership; 2011:143–150.
- [65] Rios D, Magasi S, Novak C, Harniss M. Conducting accessible research: including people with disabilities in public health, epidemiological, and outcomes studies. *Am J Public Health*. 2016;106(12):2137–2144.
- [66] Stogiannos N, Pavlopoulou G, Papadopoulos C, et al. Strategies to improve the magnetic resonance imaging experience for autistic individuals: a cross-sectional study exploring parents and carers’ experiences. *BMC Health v Res*. 2023;23(1):1375.
- [67] Stogiannos N, Harvey-Lloyd JM, Brammer A, et al. Toward autism-friendly Magnetic resonance imaging: exploring autistic individuals’ Experiences of magnetic resonance imaging scans in

- the United Kingdom, a cross-sectional survey. *Autism Adulthood*. 2023;5(3):248–262.
- [68] Stogiannos N, Carlier S, Harvey-Lloyd JM, et al. A systematic review of person-centred adjustments to facilitate magnetic resonance imaging for autistic patients without the use of sedation or anaesthesia. *Autism*. 2022;26(4):782–797.
- [69] Stogiannos N, Harvey-Lloyd JM, Nugent B, et al. Autism-friendly MRI: improving radiography practice in the UK, a survey of radiographer practitioners. *Radiography*. 2022;28(1):133–141.
- [70] Harvey-Lloyd JM, Clements A, Sims N, Harvey-Lloyd AE. Exploring the experiences of parents of autistic children when attending the diagnostic imaging department for an X-ray examination. *Radiography*. 2024;30(1):28–36.
- [71] Abdelrahman MA, Alhebsi MA, Almulla SI, et al. Exploration of radiographers' knowledge, attitudes, and practices in delivering healthcare to children with autism spectrum disorder. *Radiography*. 2024;30(1):116–122.
- [72] Potts B, White HP. Student radiographers' confidence of adapting practice for autistic patients: a qualitative survey on the role of placement experiences. *Radiography*. 2024;30:34–41.
- [73] Oliveira M, Hogg P, Di Prospero L, Lacey S, El-Farra S, Johansen S. Research activity among diagnostic and therapeutic radiographers: an international survey. *J Med Imaging Radiat Sci*. 2024;55(2):232–243.
- [74] Watts H, Snaith B. Evidence based practice, research and the diagnostic radiographer role. An exploration of engagement, expectations and attitudes at a single centre. *Radiography*. 2023;29(1):124–130.
- [75] Schardt C, Adams MB, Owens T, Keitz S, Fontelo P. Utilization of the PICO framework to improve searching PubMed for clinical questions. *BMC Med Inform Decis Mak*. 2007;7(1):16.
- [76] Green BN, Johnson CD, Adams A. Writing narrative literature reviews for peer-reviewed journals: secrets of the trade. *J Chiropr Med*. 2006;5(3):101–117.
- [77] Ayrton R. *Doing Good Qualitative Research [Internet]*. Power dynamics between researcher and subject. Oxford University Press; 2024 [cited 2024 Aug 29]. p. 0. Available from.
- [78] Aabe NO, Fox F, Rai D, Redwood S. Inside, outside and in-between: the process and impact of co-producing knowledge about autism in a UK Somali community. *Health Expect: Int J Public Particip Health Care Health Policy*. 2019;22(4):752–760.
- [79] Pickard H, Pellicano E, den Houting J, Crane L. Participatory autism research: early career and established researchers' views and experiences. *Autism*. 2022;26(1):75–87.
- [80] den Houting J, Higgins J, Isaacs K, Mahony J, Pellicano E. 'I'm not just a guinea pig': academic and community perceptions of participatory autism research. *Autism*. 2021;25(1):148–163.
- [81] Tesfaye R, Courchesne V, Mirenda P, et al. Autism voices: perspectives of the needs, challenges, and hopes for the future of autistic youth. *Autism*. 2023;27(4):1142–1156.
- [82] Bernard L, Fox S, Kulason K, et al. Not your "typical" research: inclusion ethics in neurodiversity scholarship. *Ind Organ Psychol*. 2023;16(1):50–54.
- [83] Lilley R, Lawson W, Hall G, et al. A way to be me': autobiographical reflections of autistic adults diagnosed in mid-to-late adulthood. *Autism*. 2022;26(6):1395–1408.
- [84] Williams GL, Ellis R, Holloway W, et al. Building our own house' as an insider-only community-partnered participatory research council: co-creating a safe space for autistic knowledge production. *Autism*. 2024;13623613241253014.
- [85] Pellicano E, Lawson W, Hall G, et al. I knew she'd get it, and get me": participants' perspectives of a participatory autism research project. *Autism Adulthood*. 2022;4(2):120–129.
- [86] Karaminis T, Botha M, Longley S, et al. Language matters in British newspapers: a participatory analysis of the Autism UK press corpus. *Autism Adulthood [Internet]*. 2024. [cited 2024 Jun 18]; Available from. <https://www.liebertpub.com/doi/10.1089/aut.2023.0105>.
- [87] Green G, Johns T. Exploring the relationship (and Power Dynamic) between researchers and public partners working together in applied health research teams. *Front Social [Internet]*. 2019. Mar 29 [cited 2024 Sep 2];4. Available from. <https://www.frontiersin.org/journals/sociology/articles/10.3389/fsoc.2019.00020/full>.
- [88] Gillespie-Lynch K, Kapp SK, Brooks PJ, Pickens J, Schwartzman B. Whose expertise is it? Evidence for autistic adults as critical autism experts. *Front Psychol [Internet]*. 2017;8. [cited 2024 May 31] Available from. <http://journal.frontiersin.org/article/10.3389/fpsyg.2017.00438/full>.
- [89] Arnstein SR. A ladder of citizen participation. *J Am Inst Plan*. 1969;35(4):216–224.
- [90] Rosenau KA, Hotez E. Promoting interdisciplinary and participatory autism research. *Pediatrics*. 2022;149:S1–S2.
- [91] Karnieli-Miller O, Strier R, Pessach L. Power relations in qualitative research. *Qual Health Res*. 2009;19(2):279–289.
- [92] Smits DW, van Meeteren K, Klem M, Alsem M, Ketelaar M. Designing a tool to support patient and public involvement in research projects: the involvement matrix. *Res Involv Engag*. 2020;6(1):30.
- [93] Beasant L, Realpe A, Douglas S, Kenny L, Rai D, Mills N. Autistic adults' views on the design and processes within randomised controlled trials: the APriCoT study. *Autism*. 2024;28(6):1540–1550.
- [94] Strang JF, Knauss M, van der Miesen A, et al. A clinical program for transgender and gender-diverse neurodiverse/autistic adolescents developed through community-based participatory design. *J Clin Child Adolesc Psychol*. 2021;50(6):730–745.
- [95] Lattacher SL, Wohofsky L, Scharf P, Krainer D. A customized smart home and interior design concept Co-designed with and for people with Autism spectrum disorder. *Stud Health Technol Inform*. 2021(279):36–37.
- [96] Nicolaidis C, Zhen KY, Lee J, et al. Psychometric testing of a set of patient-reported instruments to assess healthcare interventions for autistic adults. *Autism*. 2021;25(3):786–799.
- [97] Stark E, Ali D, Ayre A, et al. Coproduction with autistic adults: reflections from the authentic research collective. *Autism Adulthood*. 2021;3(2):195–203.
- [98] Le Cunff AL, Glover C, Martis BL, Giampietro V, Dommert E. Methodological adjustments for experimental studies including neurodiverse participants: a checklist for before, during, and after laboratory visits. *MethodsX*. 2024;12:102658.
- [99] Chen J, Yao D, Lin S, et al. Application of the community-based participatory research in autism spectrum disorder: a scoping review. *Rev J Autism Dev Disord [Internet]*. 2024 [cited 2024 Dec 1]; Available from. doi:10.1007/s40489-024-00446-1.
- [100] Natri HM, Abubakare O, Asasumasu K, et al. Anti-ableist language is fully compatible with high-quality autism research: response to Singer et al. (2023). *Autism Res*. 2023;16(4):673–676.
- [101] Dark J. Eight principles of neuro-inclusion; an autistic perspective on innovating inclusive research methods. *Front Psychol [Internet]*. 2024. Feb 27 [cited 2024 Nov 23];15. Available from. <https://www.frontiersin.org/journals/psychology/articles/10.3389/fpsyg.2024.1326536/full>.
- [102] Keating CT, Hickman L, Leung J, et al. Autism-related language preferences of English-speaking individuals across the globe: a mixed methods investigation. *Autism Res*. 2023;16(2):406–428.
- [103] Cage E, Di Monaco J, Newell V. Understanding, attitudes and dehumanisation towards autistic people. *Autism*. 2019;23(6):1373–1383.
- [104] Walker N. *Neuroqueer Heresies: Notes on the Neurodiversity Paradigm, Autistic Empowerment, and Postnormal Possibilities*. Fort Worth: Autonomous Press; 2021:196.
- [105] Cascio MA. Empirical perspectives on neurodiversity and mental health conditions. *AJOB Neurosci*. 2025;16(1):34–36.
- [106] Oliver M. The legal and social context of disability. In: Oliver M, ed. *Social Work with Disabled People [Internet]*. London: Macmillan Education UK; 1983:101–117. doi:10.1007/978-1-349-86058-6\_7.
- [107] Shakespear T. *The Disability Studies Reader*. 5th ed. The social model of disability. Routledge; 2016.
- [108] Potts B, Smith N, Malamateniou C. Respectful language in autism research: In response to Abdelrahman et al. 'exploration of radiographers'

- knowledge, attitudes, and practices in delivering healthcare to children with autism spectrum disorder. *Radiography*. 2024;30(2):702–703.
- [109] Bottema-Beutel K, Kapp SK, Lester JN, Sasson NJ, Hand BN. Avoiding ableist language: suggestions for Autism researchers. *Autism Adulthood*. 2021;3(1):18–29.
- [110] Crenshaw K *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine*. 1989. Feminist Theory and Antiracist Politics. University of Chicago Legal Forum [Internet]; 1989 Available from <https://chicagounbound.uchicago.edu/uclfv1989/iss1/8>.
- [111] Malone KM, Pearson JN, Palazzo KN, Manns LD, Rivera AQ, Mason Martin DL. The scholarly neglect of black autistic adults in autism research. *Autism Adulthood*. 2022;4(4):271–280.
- [112] Cascio MA, Weiss JA, Racine E. Making autism research inclusive by attending to intersectionality: a review of the research ethics literature. *Rev J Autism Dev Disord*. 2021;8(1):22–36.
- [113] Gowen E, Taylor R, Bleazard T, Greenstein A, Baimbridge P, Poole D. Guidelines for conducting research studies with the autism community. *Autism Policy Pr*. 2019;2:29–45 1 A new beginning.
- [114] Stacey R, Cage E. Simultaneously vague and oddly specific”: understanding autistic people’s experiences of decision making and research questionnaires. *Autism Adulthood*. 2023;5(3):263–274.
- [115] Wylde V, Brennan S, Johnson E, Roberts K, Beswick AD, Jameson C. Recommendations for developing accessible patient information leaflets for clinical trials to address English language literacy as a barrier to research participation. *Trials*. 2024;25(1):624.
- [116] Nicolaidis C, Raymaker D, Kapp SK, et al. The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*. 2019;23(8):2007–2019.
- [117] UK Research and Innovation. Guidance on payment for public partners [Internet]. 2024 [cited 2024 Dec 28]. Available from: <https://www.ukri.org/publications/payment-for-public-partners/guidance-on-payment-for-public-partners/>
- [118] Fletcher-Watson S, Brook K, Hallett S, Murray F, Crompton CJ. Inclusive practices for neurodevelopmental research. *Curr Dev Disord Rep*. 2021;8(2):88–97.
- [119] Lam H, Fitzpatrick R, Berkman. Different but connected’: participatory action research using Photovoice to explore well-being in autistic young adults. *Autism*. 2020;24(5):1246–1259.
- [120] Cascio MA, Weiss JA, Racine E. Person-oriented ethics for autism research: creating best practices through engagement with autism and autistic communities. *Autism*. 2020;24(7):1676–1690.
- [121] Costley DM, Emerson A, Ropar D, et al. Trying to solve the ‘worst situation’ together: participatory autism research. *Educ. Action Res*. 2023;31(4):691–708.
- [122] Parsons S, Yuill N, Good J, Brosnan M. Whose agenda? Who knows best? Whose voice? Co-creating a technology research roadmap with autism stakeholders. *Disabil Soc*. 2020;35(2):201–234.
- [123] Filgueira L, Brilhante AVM, de Sa AR, Colares MSF. Development of a participatory research strategy involving autistic people with different levels of support needs. *Cienc Saude Coletiva*. 2023;28(5):1501–1512.
- [124] Agnew-Blais J, Michelini G. Taking stock of the present and looking to the future of ADHD research: A commentary on Sonuga-Barke et al (2023). *J. Child Psychol. Psychiatry*. 2023;64(4):533–536.
- [125] Beaumont J. Commentary on ‘A critical reflection on the development of the Participatory Autism Research Collective (PARC)’. *Tizard Learn. Disabil. Rev.*. 2019;24(2):90–93.
- [126] Courcy I, Koniou I. A scoping review of the use of photo-elicitation and photovoice with autistic and neurodiverse people. Moving towards more inclusive research? *Disabil. Soc.* 2024;39(5):1317–1338.
- [127] Goodall C, MacKenzie A. What about my voice? Autistic young girls’ experiences of mainstream school. *Eur. J Spec Needs Educ*. 2019;34(4):499–513.
- [128] Heselton GA, Rempel GR, Nicholas DB. Realizing the problem wasn’t necessarily me’: the meaning of childhood adversity and resilience in the lives of autistic adults. *Int J Qual Stud Health Well-being [Internet]*. 2022;17(1). Available from. <https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,shib&db=psyh&AN=2022-46718-001&site=ehost-live&scope=site&custid=s1089299>.
- [129] Nimbly E, Maloney E, Duffy F. A call for autism-led research exploring definitions of recovery in autistic individuals with an eating disorder. *Int J Eat Disord*. 2023;56(7):1335–1340.
- [130] Pellicano E. Commentary: broadening the research remit of participatory methods in autism science - a commentary on Happe and Frith (2020). *J Child Psychol Psychiatry Allied Discip*. 2020;61(3):233–235.
- [131] Poulsen R, Dwyer P, Gassner D, Heyworth M, Williams ZJ. The IN-SAR community collaborator request: using community-academic partnerships to enhance outcomes of participatory autism research. *Autism Res*. 2023;16(11):2071–2076.
- [132] Raymaker DM, Kapp SK, McDonald KE, Weiner M, Ashkenazy E, Nicolaidis C. Development of the AASPIRE web accessibility guidelines for autistic web users. *Autism Adulthood*. 2019;1(2):146–157.
- [133] Rudd D, Hwang SK. Participatory research in a pandemic: the impact of COVID-19 on co-designing research with autistic people. *Qual Soc Work: Res Pract*. 2022;21(5):869–879.
- [134] Sonuga-Barke EJS, Chandler S, Lukito S, et al. Participatory translational science of neurodivergence: model for attention-deficit/hyperactivity disorder and autism research. *Br J Psychiatry*. 2024;224(4):127–131.
- [135] Strang JF, Klomp SE, Caplan R, et al. Community-based participatory design for research that impacts the lives of transgender and/or gender-diverse autistic and/or neurodiverse people. *Clin Pract Pediatr Psychol*. 2019;7(4):396–404.
- [136] Howard PL, Sedgewick F. ‘Anything but the phone!’: communication mode preferences in the autism community. *Autism*. 2021;25(8):2265–2278.
- [137] Norris JE, Lei J, Maras K. Adapting communication with autistic service users: co-produced adaptations for medical services, employers, and the third sector. *Neurodiversity*. 2024;2:27546330241266723.
- [138] Trevisan F. Making focus groups accessible and inclusive for people with communication disabilities: a research note. *Qual Res*. 2021;21(4):619–627.
- [139] Szulc JM. Towards more inclusive qualitative research: the practice of interviewing neurominorities. *Labour Ind*. 2023;33(2):179–187.
- [140] Courchesne V, Tesfaye R, Mirenda P, et al. Autism Voices: a novel method to access first-person perspective of autistic youth. *Autism*. 2022;26(5):1123–1136.
- [141] Reason M, Acton K, Foulds D. Working it out together: lessons and insights into inclusive research in an arts context. *Br J Learn Disabil [Internet]*. 2024. ((Reason, Acton) Institute for Social Justice, York St. John University, York, United Kingdom). Available from. [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1468-3156](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1468-3156).
- [142] First JM, Cheak-Zamora NC, Teti M, Maurer-Batjer A, LFirst N. Youth perceptions of stress and coping when transitioning to adulthood with autism: a photovoice study. *Qual Soc Work*. 2019;18(4):601–620.
- [143] Pavlopoulou G, Dimitriou D. In their own words, in their own photos: adolescent females’ siblinghood experiences, needs and perspectives growing up with a preverbal autistic brother or sister. *Res Dev Disabil*. 2020;97:103556.
- [144] Danker J, Strnadová I, Cumming TM. Picture my well-being: listening to the voices of students with autism spectrum disorder. *Res Dev Disabil*. 2019;89:130–140.
- [145] Cage E, Botha M, McDevitt L, et al. Diagnosis as a new beginning not an end: A participatory photovoice study on navigating an autism diagnosis in adulthood. *Autism*. 2024;28(8):2014–2027.
- [146] Van Goidsenhoven L, De Schauwer E. Listening beyond words: swinging together. *Scand J Disabil Res*. 2020;22(1):330–339.
- [147] Cook L, Rothstein P, Emeh L, et al. In the physical to digital transition with friends—A story of performing inclusive research together no matter what life throws at you. *Br J Learn Disabil*. 2021;49(3):271–281.
- [148] Ashworth M, Crane L, Steward R, Bovis M, Pellicano E. Toward empathetic autism research: developing an autism-specific research passport. *Autism Adulthood*. 2021;3(3):280–288 Sep.

- [149] Le Cunff AL, Logan PE, Ford R, et al. Co-Design for participatory neurodiversity research: collaborating with a community advisory board to design a research study. *JPRM [Internet]*. 2023;4(1). [cited 2024 Nov 24] Available from. <https://jprm.scholasticahq.com/article/66184-co-design-for-participatory-neurodiversity-research-collaborating-with-a-community-advisory-board-to-design-a-research-study> .
- [150] Strang JF, Knauss M, van der Miesen A, et al. A clinical program for transgender and gender-diverse neurodiverse/autistic adolescents developed through community-based participatory design. *J Clin Child Adolesc Psychol*. 2021;50(6):730–745.
- [151] Heselton GA, Rempel GR, Nicholas DB. Realizing the problem wasn't necessarily me': the meaning of childhood adversity and resilience in the lives of autistic adults. *Int J Qual Stud Health Well-being*. 2022;17(1):2051237.
- [152] Heselton GA, Rempel GR, Nicholas DB. Integrating community participation with interpretative phenomenological analysis: reflections on engaging the Autism community. *Int J Qual Methods*. 2021;20:160940692110555.
- [153] Milton DEM. On the ontological status of autism: the 'double empathy problem'. *Disabil Soc*. 2012;27(6):883–887.
- [154] Urry K, Chur-Hansen A, Scholz B. From member checking to collaborative reflection: a novel way to use a familiar method for engaging participants in qualitative research. *Qual Res Psychol*. 2024;21(3):357–374.
- [155] Olmos-Vega FM, Stalmeijer RE, Varpio L, Kahlke R. A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Med. Teach.*. 2023;45(3):241–251.
- [156] Keating CT. Participatory Autism research: how consultation benefits everyone. *Front Psychol*. 2021;12:713982.
- [157] Reason M, Acton K, Foulds D. Working it out together: lessons and insights into inclusive research in an arts context. *Br J Learn Disabil [Internet]*. 2024. ((Reason, Acton) Institute for Social Justice, York St. John University, York, United Kingdom). Available from. [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1468-3156](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1468-3156) .
- [158] den Houting J, Higgins J, Isaacs K, Mahony J, Pellicano E. 'I'm not just a guinea pig': academic and community perceptions of participatory autism research. *Autism: Int J Res. Pract*. 2021;25(1):148–163.
- [159] Filgueira LMA, Brillhante AVM, de Sa AR, Colares MSF. Development of a participatory research strategy involving autistic people with different levels of support needs. *Cienc Saude Coletiva*. 2023;28(5):1501–1512.
- [160] MacLeod A. Interpretative phenomenological analysis (IPA) as a tool for participatory research within critical autism studies: a systematic review. *Res Autism Spectr Disord*. 2019;64:49–62.
- [161] Davies J, Romualdez AM, Malyan D, et al. Autistic adults' priorities for future autism employment research: perspectives from the United Kingdom. *Autism Adulthood*. 2024;6(1):72–85.
- [162] Kirby AV, McDonald KE, Cusack J, et al. An expert discussion on knowledge translation in autism in adulthood research. *Autism Adulthood*. 2021;3(1):11–17.
- [163] Bolderston A, Hyde E, Lloyd L, et al. Narratives in the Journal of medical imaging and radiation sciences: publishing stories in an academic journal. *J Med Imaging Radiat Sci*. 2023;54(3):393–397.