

Lewis, Kathryn, Hamilton, Lorna G. ORCID logoORCID: https://orcid.org/0000-0003-0526-8252 and Vincent, Jonathan ORCID logoORCID: https://orcid.org/0000-0001-6278-4670 (2023) Exploring the experiences of autistic pupils through creative research methods: Reflections on a participatory approach. Infant and Child Development, 33 (3).

Downloaded from: https://ray.yorksj.ac.uk/id/eprint/8683/

The version presented here may differ from the published version or version of record. If you intend to cite from the work you are advised to consult the publisher's version: https://doi.org/10.1002/icd.2467

Research at York St John (RaY) is an institutional repository. It supports the principles of open access by making the research outputs of the University available in digital form. Copyright of the items stored in RaY reside with the authors and/or other copyright owners. Users may access full text items free of charge, and may download a copy for private study or non-commercial research. For further reuse terms, see licence terms governing individual outputs. Institutional Repositories Policy Statement

RaY

Research at the University of York St John
For more information please contact RaY at ray@yorksj.ac.uk

DOI: 10.1002/icd.2467

METHODOLOGICAL ARTICLE



Wiley

Exploring the experiences of autistic pupils through creative research methods: Reflections on a participatory approach

Lorna G. Hamilton Donathan Vincent 1,2 0 Kathryn Lewis ¹ •

Correspondence

Lorna G. Hamilton, School of Education, Language and Psychology, York St John University, York YO31 7EX, UK. Email: I.hamilton1@yorksj.ac.uk

Funding information

Sir Halley Stewart Trust, Grant/Award

Number: 4026

Abstract

The use of creative qualitative research methods in psychology and other disciplines has increased over recent decades to address power imbalances within research and to centre the voices of participants. These considerations are particularly salient when conducting research with historically marginalized groups, including neurodivergent people. However, research foregrounding the first-person perspectives of neurodivergent children is still limited. In this paper, we discuss the application of creative qualitative research methods when conducting research with neurodivergent children with a range of communication and wider skill profiles. The benefits and challenges of each method are considered, drawing on examples from the first phase of an ongoing longitudinal study. Additional considerations for working ethically and respectfully with neurodivergent children are discussed. Readers are encouraged to consider how best to adapt their research protocols when working with neurodivergent children, in order to minimize research hierarchies, build positive relationships, and produce rich and meaningful data.

KEYWORDS

autism, children, creative methods, neurodiversity, qualitative research

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2023 The Authors. Infant and Child Development published by John Wiley & Sons Ltd.

Inf Child Dev. 2023;e2467. https://doi.org/10.1002/icd.2467

¹School of Education, Language and Psychology, York St John University, York, UK

²Department of Educational Research, Lancaster University, Lancaster, UK

1 | INTRODUCTION

Qualitative methods, which recognize the embodied and affective dimensions of individuals' subjective experiences, have gained traction in psychology since the 1980s (Cromby, 2012; Rennie et al., 2002). In developmental psychology, qualitative approaches are increasingly recognized as a tool to foreground the voices of children and young people, centre their individual experiences within sociocultural contexts, and address power imbalances in the relationship between researcher and researched (Burman, 2017; Demuth & Mey, 2015). These considerations are particularly salient for researchers working with historically minoritized groups, including neurodivergent children and young people. However, while the neurodiversity framework is driving a paradigm shift in the scientific understanding of neurocognitive difference and the way research in this field is conducted (Pellicano & den Houting, 2022), first-person perspectives of neurodivergent children and young people are still largely absent from the literature. In this paper, we consider the benefits and challenges of using creative qualitative methods with neurodivergent children with a range of communication profiles, drawing on the first wave of a longitudinal study of primary-to-secondary school transition (which typically occurs at 11 years old in England).

The neurodiversity paradigm challenges pathologizing, deficit-focused accounts of neurodevelopmental differences, including autism, attention deficit hyperactivity disorder (ADHD), dyslexia, and dyscalculia among others (den Houting, 2019; Dwyer, 2022). From this perspective, these neurodivergencies, which have historically been viewed through a medical lens, are reconceptualized as naturally occurring cognitive variations that can bring both strengths and challenges, becoming disabling through the interaction of the individual with their environment (Chapman, 2021). Pellicano and den Houting (2022) articulate several key challenges for autism science posed by the neurodiversity paradigm. Firstly, a longstanding overfocus on identifying, and seeking to ameliorate, deficits has inhibited the understanding of autistic strengths. Secondly, the medical model prioritizes the individual as the unit of study, thus neglecting the role of sociocultural context in shaping developmental trajectories for autistic people. Thirdly, autism has largely been studied from the outside, with the lived experiences of autistic people and insights of autistic researchers neglected until recently. These challenges are beginning to be addressed through a move to participatory research methods, spearheaded by neurodivergent scholars, which seeks to address the priorities of the communities being studied (den Houting et al., 2021; Fletcher-Watson et al., 2019).

Most psychological research is framed through a lens of objectivity, resting on the (usually unspoken) assumption that research that employs the scientific method is inherently unbiased and value-free. This framework has been problematized, with increasing calls for science to be recognized as a value-laden endeavour underpinned by differing epistemological positions (Levitt et al., 2022). For example, neurodivergent scholars have highlighted how 'objectivity psychology' has perpetuated reductionist and harmful accounts of neurodevelopmental difference, which act to exclude and dehumanize the people it seeks to study (Botha, 2021; Marocchini, 2023). In response, a turn to co-production and participatory methods is beginning to play out in studies with neurodivergent adults (Beresford et al., 2004; Leadbitter et al., 2021). Co-production breaks down traditional boundaries between researcher and participant, by meaningful collaboration throughout the research process from design to dissemination. Participatory action research further challenges power hierarchies in research, by harnessing systematic investigation to promote social change (Langhout & Thomas, 2010). Such approaches can disrupt established power relations in the generation of knowledge, ensuring that resource is directed towards addressing problems of relevance to communities that have historically been the object of investigation (Vaughn & Jacquez, 2020).

Participatory methods are still rarer in studies with neurodivergent children and young people. There are several barriers for researchers in adopting these approaches, including the very wide diversity in communication profiles and preferences in this population, which can mean that traditional 'talking' formats of qualitative data collection, such as interviews or focus groups, may not be fit for purpose or may need to be adapted. However, other disciplines have developed creative, flexible, and child-centred methods that may be instructive for researchers seeking to work with minoritized groups of children in a way that widens access and reduces the 'social distance' between child and researcher.

1.1 | Creative qualitative methods in child research beyond psychology

This turn towards child-oriented and creative methods has been seen in education and disability studies since the 1960s and particularly since the early 2000s (Cuevas-Parra & Tisdall, 2019). At its core is the principle 'nothing about us without us', which repositions disabled children from 'incompetent, unreliable and incomplete... objects to be studied' (Fargas-Malet et al., 2010, p. 175), to 'credible knowers' about their own experiences (Fricker, 2007) who, through more participatory means, have the potential to offer novel insights. Such a democratization of the research process is, in part, a result of international policy, including the Convention on the Rights of the Child (1989) and the Recommendation on the Participation of Children and Young People Under the Age of 18 (Council of Europe, 2012). These frameworks recognize children as social actors with rights to freedom of expression, thought, and free and full participation in cultural life. There is, however, also a connected epistemological dimension. Kellett (2005, 2010), who pioneered children's involvement in research at the Children's Research Centre at the Open University, argues that since children are central to the cultural experience of childhood, they have a unique insider perspective that offers insights often not accessible through adult-led research approaches.

In practice, this involves deploying a more diverse range of qualitative research methods, beyond observations, focus groups or interviews with children, and seeking to directly engage them in building 'understanding from their personal accounts and their own sense-making' (Stafford, 2017, p. 603). A core tenet which underpins the use of child-oriented creative methods is that engaging children in practical tasks of their choosing empowers them to voice their experiences in ways which are meaningful to them and not reliant on verbal competencies (Gallacher & Gallagher, 2008; Lomax, 2012). Such 'creative methods' often encompass visual, performative, and sensory forms of data collection.

The use of visual materials, in approaches such as photovoice, where a child takes photographs to represent meaning about a particular phenomenon and is then interviewed about these, has proven to be useful. Using photographic images in this way can serve as a 'communication bridge' (Collier & Collier, 1986) between researcher and participant, particularly among children for whom verbal communication is more challenging. Kusters et al. (2017, p. 66) argue that using images in this way increases the validity of findings by dealing with the 'monopoly of interpretation', as the child can provide immediate feedback and thus avoid researcher misinterpretation. Other visual methods include video making, collage-making, drawing, mapping, and constructing models using Lego and plasticine, which are then interpreted with the researcher (Ellis, 2017; Lomax, 2012; Wiles et al., 2013). Written data collection has also been deemed effective and can include creative or autobiographical writing (Kuzmičová & Cremin, 2022; Mateos-Blanco et al., 2022; Vincent et al., 2016) as well as essay writing or activity books (Stafford, 2017).

Finally, embodied techniques, which are grounded in Merleau-Ponty's phenomenology of existence and feminist theories of corporeality (Grosz, 1994) have the potential to open up novel and creative data possibilities. Methods include examples such as imaginative play (Lewis et al., 2021), drama or performance (Medina et al., 2021). Increasingly, body-mapping has been shown to be a promising participatory method. This involves tracing around a person's body to create a life-sized outline that then, through a creative and reflective process, is annotated to produce an image representing multiple aspects of their embodied experience (Jager et al., 2016). Guided tours (Camponovo et al., 2021; Stevenson & Adey, 2010) or embodied or walking interviews offer opportunities for better understanding autistic individuals' perceptions and attitudes towards or knowledge and experiences of their lived environment (Marcotte et al., 2022). Recognizing that such methods are more naturalistic than traditional experimental or even qualitative studies in psychology, our aim in this study was to trial and reflect on the possibilities that lie in drawing on different creative and participatory approaches in developmental research. At the heart of this lies the principle of seeing children as 'credible knowers' of their own experiences (Fricker, 2007) and on this basis seeking to democratize the research process such that they have a meaningful voice.

1.2 | Applying creative methods with neurodivergent children in an ongoing longitudinal study

The following sections outline our approach to engaging in a participatory way with neurodivergent child participants, with respect to gaining consent and informed assent, building trust before data collection, and engaging in varied participatory approaches. The approaches discussed here are based on the first two data collection points of a longitudinal study, which aims to understand the individual experiences of neurodivergent pupils transitioning from primary to secondary school in England, and to identify key challenges as well as aspects of the school experience that support wellbeing and belonging in the secondary school environment. The full study involves multiple data collection sessions with pupils using some of the participatory methods as outlined below, as well as supplementary interviews with parents or carers. While the practices are to some degree iterative, we have structured them into a pre-study stage and a data collection stage.

The research team consisted of a PhD student and two lecturers in the areas of psychology and education, all of whom had experience of and interest in participatory and intersectional neurodiversity research.

1.3 | Participants

Our sample included 13 neurodivergent children, all with a diagnosis of, or awaiting assessment for, autism. Included were three girls and ten boys aged 11 years at the first point of data collection; all participants were white British or white European. Table 1 sets out details of needs, interests, and research considerations in relation to each individual child. This information was gathered through a combination of preliminary calls with parents and familiarization sessions with the children before data collection commenced (see 'Procedure—Pre-study stage' below). Collating individual children's profiles in this way allowed us to tailor the subsequent data collection sessions to be maximally accessible and engaging for each child, while avoiding research protocols based on an imagined 'typical autistic child'.

2 | PROCEDURE

2.1 | Pre-study stage

Prior to any methods being developed or data being collected, there were a number of considerations to ensure the study was accessible and inclusive for all participants. These pre-study considerations were essential in providing a strong foundation for the research that followed.

2.1.1 | Gaining consent and assent

Ethical approval for the project was granted by the School of Education, Language and Psychology ethics committee at York St John University. For each participant, written parental/guardian consent was required. However, it was important also to gain the participant's informed assent. This has been argued to be an appropriate alternative to informed consent for younger participants yet to develop the full understanding and maturity required for informed consent (Cocks, 2006). In practice, this involved researchers sending an easy-read outline of the study in advance, with text and pictures, and names and pictures of the research team members, which parents/carers and children could review together. This offered an accessible and effective way to support study understanding (O'Farrelly & Tatlow-Golden, 2022), and helped to reduce any uncertainty and anxiety that child participants may experience in an unfamiliar situation. The same information was reviewed again with children in the first meeting through a short

TABLE 1 Participant information.					
ID	Gender	Additional needs	Specific considerations and preferences	Interests	
P1	Male	Autism, ADHD, tics when stressed	Likes to be active; Visual timetables are useful; Fine in a group	Transformers, Fortnight	
P2	Male	Autism	Use clear language and break questions down; Check understanding/rephrase where needed; Does not need visual timetable but likes to be kept informed; Happy talking once comfortable but can feel anxious; No video diaries; Can struggle with change.	Lego, racing cars, Fortnight, YouTube	
P3	Male	Autism, English as an additional language (EAL)	Very happy chatting; Easily distracted and can quickly lose motivation or interest if bored; Sensitive to sound, light and touch; Enjoys anything technical e.g. clocks and computers.	Electronics, computers	
P4	Male	Autism, ADHD	Can be anxious and quiet, need to build rapport so he feels comfortable, then has plenty to say; Enjoys art activities and can focus well on these; Prefers to understand activities and expectations in advance.	Art/Drawing, Cooking, Swimming	
P5	Male	Autism	Chatty and communicative, enjoys talking to adults; Can focus for a short time then needs movement breaks; Struggles with fine motor skills; Does not enjoy drawing or writing, prefers active activities or just talking.	Music, drumming, toy soldiers	
P6	Female	Autism	Communicative once comfortable; Does not like eye contact; Can become nervous or stressed in unfamiliar situations or when demand is high; Visual schedule would be useful; Does not like writing	Drawing, Harry Potter, mythical creatures	
P7	Male	Autism	Would prefer a drawing-based method; Does not like eye contact and this can make him very anxious; Needs structure, visual schedule would be useful; Fidgets with fingers/hands when feeling distressed; Can struggle identifying and controlling emotions	Drawing, Pop its, computers/ electronics	
P8	Male	Autism, hypermobility	Enjoys drawing and artwork; Happy to talk with adults	Dinosaurs, Netflix, Disney	
P9	Male	Autism, ADHD	Activity alongside interview would be useful e.g., card sort/photovoice; Use clear language and structured questions, likely to give short answers to broad questions; Does not enjoy drawing	Football, being active, science	
P10	Male	Autism, ADHD, Tourette syndrome, selective mutism	Enjoys drawing and creative writing; Can withdraw or stop talking when anxious or stressed; Take time to build rapport	Drawing, Minecraft, Roblox, Stranger Things, YouTube	
P11	Male	Autism	Articulate and communicative 1:1 with adults; Can be anxious in groups or with other children; Benefits from structure and specific questions; May pick at fingers, shrug, or become less verbal when distressed; Games can help to distract when anxious	Ships, Lego, Marvel, mysteries	



TABLE 1 (Continued)

ID	Gender	Additional needs	Specific considerations and preferences	Interests	
P12	Female	Autism, Hemiplegia, Cerebral Palsy	Articulate and communicative once comfortable; Take time to build rapport, initially Use direct questions and clarify when needed; Less likely to talk about school when parents present; Activities to reduce pressure during interview could be useful (e.g., card sort, walking and talking)	Baking	
P13	Female	Autism	Enjoys talking with adults and very communicative; Would prefer not to miss lessons, so meet in break/lunchtimes where possible; Needs reassurance and positive feedback	cative; Would prefer not to miss writing/drawing o meet in break/lunchtimes where	

explanation of the project aims and scope, using accessible language, and with opportunities to ask questions (Jackson-Hollis, 2019).

Participants indicated their assent to participate by circling either a thumbs up or thumbs down image for a list of statements including 'Can I come and visit you at Primary School and again at Secondary School?' and 'Would you like to take part in the activities at school?'. Assent was rechecked at the start of every data collection session and when changing activities, and participants were given explicit opportunities to ask questions in each session. This is important as asking questions may be how some participants process the information, so these questions served as useful indicators for participants' understanding and willingness to participate.

2.1.2 | Preliminary call with parent/carer

Prior to meeting with participants, a member of the research team conducted a short discussion with a parent/carer. Parents/carers provided information about their child's interests and communication preferences, as well as information relating to sources of stress or individual challenges (Table 1). This is recommended for research with children (Irwin & Johnson, 2005; Teachman & Gibson, 2013). Preliminary discussions helped the team develop a better understanding of how participants behaved when relaxed or distressed/withdrawing from the research and helped to inform the choice of creative methods used. An awareness of interests was also useful when meeting with child participants for the first time and building rapport (Rasmussen & Pagsberg, 2019).

2.1.3 | Familiarization meeting with participants

Participants initially met the researchers for a 'get to know you' meeting, during which no data were collected. Such sessions have been found to be effective in affirming reciprocal interest in the research, and building trust in the research space (Bernardi, 2020). During these sessions, the researcher and participant shared details of the things that were important to them, through drawing, writing, creating spider diagrams, or discussion (see Figure 1). These preliminary meetings were beneficial in building trust and developing mutual understanding and respect between researchers and participants. They helped to centre the participant's voice within the research process from the outset and afforded researchers the opportunity to build a participant profile of preferences, likes and dislikes, and communication style. For autistic children who may struggle with new and unfamiliar people or scenarios (Stoner et al., 2007) these initial meetings provided an essential low-pressure environment to develop familiarity.

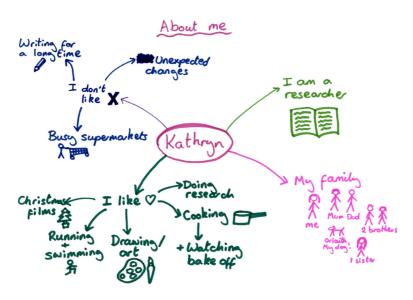


FIGURE 1 Example of an 'about me' exercise completed by the first author (self-referenced) alongside a child participant completing the same exercise.

2.2 | Data collection stage

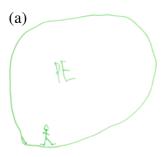
This section outlines the creative methods that were adopted with our child participants. These are broadly structured into visual, embodied, and discursive methods and offer both a description of the procedure and reflections on their perceived value and effectiveness. Individualized research protocols were developed for each child based on the information gathered at the pre-data collection stage; each child participated in a selection of the activities matching their interests and communication profiles.

2.2.1 | Draw, write, tell

For this method, participants were provided with a series of prompts and given time to draw or write their answers before discussing them (Wetton & McWhirter, 1998). This research method is common in research involving children (Kara, 2015), and has been demonstrated to help with event recollection, leading to elicitation of rich and meaningful data (Angell et al., 2015).

Some participants elected just to draw, and others drew images and wrote brief descriptors alongside these. The drawings were not analyzed as separate research outputs but were integrated into interviews and used to direct attention and scaffold discussion. By listening to participants talking about their drawings, we could ensure that meaning was directly attributed rather than inferred (Angell et al., 2015; Kusters et al., 2017). For example, at first glance, image A in Figure 2 appears to show a standard PE lesson. However, for this participant, this image illustrated the daunting size of the field that they were worried about having to run around when moving to secondary school. Secondary school uniform represented an uncomfortable and stifling prospect to the artist of Image B, but for other pupils represented something they enjoyed wearing as it made them feel more mature or smart. The final image C illustrates one participant's experience of hiding their feelings, or masking, whilst at school. This drawing provided an opportunity for the researcher to discuss an emotional topic on the participant's own terms.

Draw-Write-Talk was an accessible way to engage participants who enjoy creative activities. Completing the activity side by side with the researcher reduced the expectation to maintain eye contact for participants who found



WILEY





FIGURE 2 Images produced by child participants.

this overwhelming or anxiety-inducing, and thus children were able to better focus on the discussion. Importantly, this method also allowed sufficient time to consider and reflect on experiences.

However, this method was not suitable or of interest to all participants. In particular, some struggled with fine motor skills, and so activities involving drawing and writing were less accessible. In addition, some participants found the open-ended nature of this task challenging, preferring instead to engage in more directed activities. Whilst participants were asked to describe their experiences to minimize researcher misinterpretation, some participants benefited from additional prompting to answer questions about their drawings, through which researchers may have unwittingly influenced interpretations and discussion.

2.2.2 Photo-elicitation

Photo-elicitation is a visual method where participants either independently take photographs with a camera or device or are provided with images to supplement an interview (Danker et al., 2019; Rose, 2022). For this study, photos were sourced by the research team either from individual school websites or from generic image searches. Participants could choose simply to discuss the images or to use them to create a collage for specific topics (e.g., 'things I like about primary school'). For some participants who completed this exercise, the use of visual stimuli enabled discussions about potentially abstract future school transitions by grounding them within the school environments. The photographs also provided an effective conversation prompt, reducing the pressure for 'on the spot' thinking, and allowing for the discussion of topics to be collaborative and pupil-led.

However, some participants found the unstructured nature of this exercise challenging or overwhelming. In some cases, participants were excited by seeing pictures of recognizable aspects of school and spent much of the interview describing factually what the pictures contained. Whilst this could support rapport building, other methods may have been more effective at eliciting novel insights.

2.2.3 Walk and talk

For the walk and talk exercise, participants were asked to take the researcher around their classroom or school and to show and/or talk about aspects of the environment of particular relevance to them. Children could also be given a camera to take pictures of relevant places (Figure 3).

'Walk and talk' is a useful embodied participatory method which gives agency to the participant in terms of topics discussed, the direction of the conversation, and subverting traditional researcher/participant dynamics. This active research method was offered to participants who benefit from moving around and was especially useful for those with an ADHD profile.



FIGURE 3 Photo taken by participant taking part in a walk and talk session.

However, a limitation of this method was its lack of structure. Participants tended either to show the researcher very little, or to show them every item in the room/building, regardless of personal importance or relevance. One participant, excited by the opportunity to walk freely around the school, took the researcher on a tour of buildings in the school but talked minimally about the environment. Recording these sessions was also challenging as audio equipment worked less well when participants and researchers were moving against background noise and interference. Another challenge related to individual school policies, which sometimes restricted the ability of the participant to move around or to take photos. No pictures featuring other pupils were taken for privacy reasons. Given that many pupil experiences reported within the study revolved around people rather than places, this limited the breadth and depth of conversations resulting from this exercise. A more goal-directed task and/or wearable audio recording equipment may have improved the effectiveness of this method in the school environment.

2.2.4 | Card sort

For this active, discursive method, participants were provided with a set of cards and asked to rate them from one to five stars according to how much they liked them. The cards featured images accompanied by a brief written description, and depicted either school subjects, or wider school experiences (Figure 4; Appendix A). Participants were prompted to give reasons for their ratings after sorting. This method loosely draws on Talking Mats[®] (TM, University of Stirling), which several participants were already familiar with.

The card sort activity proved to be the most widely effective method of data collection, with all participants electing to complete it and one child specifically asking for the session to be extended so that they could complete the second card sort. All explained their decisions following sorting.

A significant strength of this method was the level of interest and engagement it elicited from the participants. Additionally, the cards provided structure to the discussions that followed, allowing participants to have control over the topics discussed within clear boundaries. For participants who found sustained attention more challenging, the task could be easily adapted by sorting small subsets of cards at a time.





FIGURE 4 Card sort exercises completed by participants—school subjects and general school life.

This method had few limitations for the participants in this study, and children reported enjoying completing the card sort. However, in some cases interpretation of items on the cards differed between participants. For example, for some pupils 'learning support' represented a specific intervention offered in lessons, whilst other pupils interpreted this as the support that teachers gave generally in lessons. This challenge was mitigated through discussions and clarifications with participants following the exercise.

2.2.5 | Statement sort

For this exercise participants sorted a series of 20 written statements into 'yes', 'no' or 'not sure' boxes (Figure 5). The statements were adapted from Goodall's (2018) beans and pot exercise, used to investigate the mainstream school experience of autistic young people to be more relevant to the pupils involved in this study and to include some additional transition-based topics (see Appendix B for full set of statements).

In a similar manner to the card sort exercise, this technique was effective in facilitating and structuring participant-led discussion following the exercise.

A key limitation of this method was the reliance on interpretation and understanding of the statements, which varied between participants. The 'not sure' category appears to have been used when the question was hard to understand, rather than because participants were unsure of the answer. Consequently, we found using this method in conjunction with other methods such as interview was useful, as misinterpretations could be addressed and statements clarified. Additionally, the categories offered were somewhat reductive, particularly given the complex and emotional topics covered by the statements. These limitations are illustrated in Figure 5, where the participant made

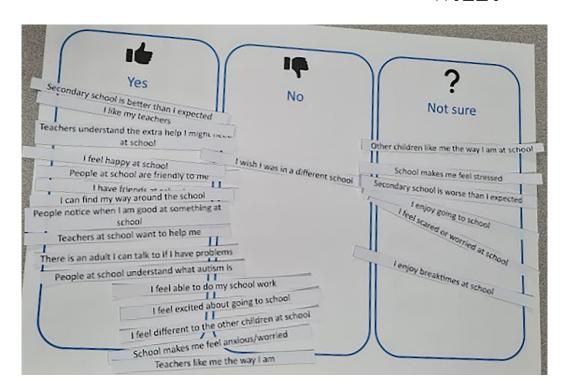


FIGURE 5 Statement sort exercise.

little use of the 'no' category and placed many statements in the 'not sure' category. This participant overcame this limitation somewhat by creating an additional 'between yes and no' category, for statements which they felt were sometimes true.

2.2.6 | Semi-structured interview

Semi-structured interviews utilize a pre-determined interview schedule but allow for flexibility according to participant answers and can elicit rich information and insight (Martin et al., 2019). They can be an effective method for working with children (Greig et al., 2007), as the flexibility of the interview removes the need to stay 'on topic' and allows for the emergence of new topics (Pitt et al., 2021). Semi-structured interviews allow the participant and the researcher to work together to co-create meaning, thus encouraging participatory practice (Kara, 2015), and have been used effectively in studies investigating and amplifying the experiences and voices of autistic children and young people (e.g., Calder et al., 2013; Hamilton et al., 2023; Howard et al., 2019; Malloy et al., 2020). However, the social communication demands of a one-to-one interview may be aversive for some neurodivergent children.

Within the current study, participants were asked a series of questions about their early secondary school experiences in the form of a semi-structured interview alongside or following the other research methods (Appendix C). This approach allowed the researcher to probe specific topics that emerged through previous activities and clarify understanding (Mannay, 2016; Rose, 2022), while avoiding making judgements or assumptions based on preconceptions (Ha & Whittaker, 2016). Adaptations when conducting research with neurodivergent children included rephrasing questions, providing concrete examples, or pausing to check understanding where needed (Zanuttini, 2023).

Situating the interviews towards the end of the data collection sessions allowed the researcher to reflect on topics already discussed, and to limit the interview questions to topics of particular relevance or that had not already been asked. This flexibility was useful, as towards the end of the session participants were sometimes reaching the end of their attentional resources. Being selective about which questions to ask and which to omit facilitated rich insights into a few topics, rather than shorter and less informative answers on a wider range. Participants were more likely to continue to enjoy participating in research long-term, which is highly beneficial for a longitudinal study of this nature.

3 | DISCUSSION

This paper sought to reflect on the potential of participatory and creative methods when conducting research with neurodivergent children. Our ongoing methodological practice and reflections indicate the potential advantages in selecting individualized research methods which respect the neurocognitive needs, interests, and strengths of participants. In particular, we identify the value in generating accessible approaches which are sensitive to the particular child. We argue that maximizing flexibility and accessibility of participation increases the rigour of qualitative research with neurodivergent children, yielding richer data than would be likely in a standardized interview format. Moreover, we highlight the importance of relationships, developing trust and rapport and being responsive to individual needs. Finally, we reflect on the value of thinking reflexively about researcher positionality throughout the process.

Neurodivergent children, as our sample illustrates, are highly heterogeneous in terms of their cognitive profiles, communicative styles, and interests (Masi et al., 2017) and there is thus no 'one-size-fits-all' approach. However, many can experience anxiety surrounding social interactions, require additional processing time or movement breaks, and find unstructured activities difficult (Honeybourne, 2018). Creative methods such as photo-elicitation, card sort, walk and talk, or draw-write-talk had the advantage of reducing the expectation of on-the-spot thinking and allowing for processing time (Beresford et al., 2004). These methods also reduced expectations for eye contact as they can be conducted side by side, rather than face on. For this to be effective, researchers must be cognisant of the individual child and responsive to their behavioural cues, which indicate the extent to which a particular method is working (Cocks, 2006; Kirby, 2020). In our study, these behavioural cues were identified by parents at the outset and included fidgeting, increased restlessness, looking towards the door, reduced communication, or asking questions such as 'how long is left?'. However, for other participants these same cues might simply be means of concentrating or ascertaining information. Such informed reflection in-action (Schön, 1987) requires a level of attentiveness and relates to the need for ongoing assent in the research process (Cree et al., 2002). We suggest, therefore, that creative and participatory methods can facilitate more accessible research environments which account for the strengths and challenges experienced by neurodivergent children and, where utilized with skill, have the potential to generate richer data as a result.

While creative research methods can be effective, they are not a substitute for building positive relationships and good rapport (Scott-Barrett et al., 2018). Building relationships, based on mutual trust and respect, is central to research with neurodivergent children, who have been historically minoritized (Mesa & Hamilton, 2022). Doing so repositions them from 'objects to be studied' (Fargas-Malet et al., 2010, p. 175) to agentic individuals with personalities and interests. In this study, we demonstrated the importance of two-way familiarization between child and researcher through low-pressure 'get-to-know-you' sessions and engaging with parents/carers at the pre-study stage. Following Hoy et al. (2018), one way of developing this relational dimension was by bringing the child's world into the research process itself. Our sample had a wide range of interests including drawing, technology, history, clocks, video games, and creative writing. We directly sought to engage them in these by providing artefacts (pictures of Minecraft or objects such as an antique clock mechanism) and at others more indirectly by simply creating space for participants to discuss them. (Two case studies, describing the individualized strength- and

LEWIS ET AL. WILFY 13 of 22

interest-based approach adopted with two of the participating children are included in Appendices D and E). This approach had the dual result of both demonstrating respect for the child but also building long-term trust and rapport, which can ultimately lead to better quality data (Carroll & Twomey, 2021; O'Reilly, 2009).

A further way to build relationships and show respect was by offering choice and flexibility throughout the research process. Doing so has been linked with increased motivation, effort, and perceived competence (Patall et al., 2008), and allows for renegotiation of traditional school and research-based hierarchies by enhancing participant agency (Bernardi, 2020). In our study children were offered a choice of several research activities (see Appendix E) and could opt to change these at any time. We found it important to offer a diverse range of methods in order to account for individual preferences, but not so many as to be overwhelming. Taking a flexible and adaptable approach as a researcher was therefore necessary, especially in considering which methods to use and how best to implement these with each individual child (Brooks et al., 2020; Macaulay, 2017).

Finally, our ongoing study speaks to the need for researchers working with neurodivergent children to consider their own reflexivity in the research process. Historically children with conditions including autism, dyslexia or ADHD have been pathologized by an overfocus on "deficits" in domains such as theory of mind or weak central coherence (Pellicano & den Houting, 2022). Research within the neurodiversity paradigm does not diminish these neurocognitive differences but seeks to understand them alongside (often related) strengths, such as detail processing or trustworthiness. Research within this framework also moves the object of study to person-in-context, with a focus on changing the environment (or research procedure) rather than the person. At an epistemic level, it repositions neurodivergent individuals—including children—as 'credible knowers' (Fricker, 2007) about their own experiences and encourages neurotypical people—including researchers—to challenge their preconceptions (Guldberg et al., 2019).

As researchers we make explicit the 'double empathy problem' (Milton, 2012) which recognizes that intersubjective interactions are bi-directional and thus perceived misunderstandings, lack of engagement, or emotional overwhelm might stem from the environment created through the research procedure. The responsibility is then on the researcher to put themselves in the participants' shoes, and to identify neurodiversity-affirming approaches to conducting research. Our team includes an autistic researcher who attended school as an autistic pupil; this insider-experience offers unique insight for understanding the needs of the children and creating maximally inclusive approaches. We acknowledge that it is not always possible to include neurodivergent people in devising or conducting research; however, where this is not possible, we recommend drawing on the growing body of literature to enable more respectful and participatory ways of researching with neurodivergent children (Fletcher-Watson et al., 2019).

4 | LIMITATIONS AND FUTURE CONSIDERATIONS

Although this study was effective in engaging participants directly within research and amplifying neurodivergent pupil voice, it was not without limitations. As part of a small-scale longitudinal study, results are not intended to be generalizable to the wider neurodivergent population. Nonetheless, the sample was under-representative of girls and gender non-conforming participants, as well as children from minoritized ethnic backgrounds. This is an ongoing challenge within neurodiversity research, as male and white pupils are more likely to be identified and diagnosed than their peers (Botha & Gillespie-Lynch, 2022). The research team did make significant efforts to recruit a diverse sample, for example, by relaxing recruitment criteria to include children at any stage of the diagnostic pathway. However, the majority of the sample were white boys, as in many previous studies of autism in school contexts. While, the use of participatory approaches should be encouraged to centre neurodivergent voices within research, it is important to recognize that many neurodivergent voices continue to be under-represented.

In addition, while most data collection sessions took place in school, a few early visits took place in participants' homes due to time constraints. Interviews in school are likely to be preferable as the questions related to the school experience, and being in the same environmental context can help with recollection and interpretation of experiences (De Clercq & Petters, 2006). Pupils are likely to be more accustomed to the presence of unfamiliar adults at school, so

this setting was preferable to potential infringement of personal safe spaces at home (Canning & Robinson, 2021). However, many schools do not have a dedicated quiet space for such visits; thus, data collection sessions sometimes took place in an unfamiliar room, or in rooms with high levels of background noise or distraction. Additionally, some children might have benefitted from more sessions of shorter duration; however, this can be difficult to facilitate within busy school timetables. Logistical challenges of conducting research with neurodivergent pupils in schools mirror commonly cited barriers to an inclusive learning environment in busy, mainstream settings (Costley et al., 2021; Mesa & Hamilton, 2022). However, conducting research in a physical environment where neurodivergent children feel comfortable is a paramount concern for research seeking to adopt a neurodiversity-affirming approach.

Obtaining fully informed assent is challenging when working with children, given the pervasive sociocultural context (Bourke & Loveridge, 2014). Sessions took place in school, where participants were used to conforming to instructions and may be primed to seek to please adults (Kirby, 2020; O'Farrelly & Tatlow-Golden, 2022). The challenges of obtaining informed assent were mitigated by maintaining an ongoing awareness of participant behaviour and engagement in the research. However, visual tools such as 'stop', 'move on', or 'break' cards (Goodall, 2018; Richter et al., 2022) or emoji palettes (Howard et al., 2019) may provide an additional layer of agency in how children engage with the research.

Finally, the choice and flexibility in research methods embedded within this study was limited to those already considered by the research team and approved by the ethics committee. Research of this nature could benefit from including an advisory group of neurodivergent children or young people prior to any data collection, who could consider how to optimize interest and accessibility in research methods. This could generate novel ideas not considered by the research team. The timescale and funding constraints for this project meant that this was not possible for the present study.

5 | CONCLUSION

This paper sought to uncover the potential of participatory and creative methods when conducting research with neurodivergent children. We demonstrated through our ongoing methodological practice and reflections that there are many benefits in using more inclusive research approaches. We highlight the importance of the pre-study stage for addressing the 'double empathy problem' (Milton, 2012) by understanding participants' strengths and preferences and building trust before engaging in data collection. Our study also outlines the value of various visual, embodied, and discursive approaches that can serve to generate novel data from neurodivergent children who may have difficulties in social communication, maintaining attention, and future thinking. However, these approaches offer more than simply 'fashionable' or 'innovative' methods for their own sake; creative and participatory methods necessarily reposition neurodivergent children as 'credible knowers' (Fricker, 2007) regarding their own experiences and offer them some degree of control over the research, thus democratizing the process. By building an understanding of the neurocognitive profile, interests, and communication preferences of the child, the researcher facilitates epistemic spaces which allow them to have a meaningful voice, thus enhancing the richness of the data. We therefore encourage other researchers working with neurodivergent child participants to consider the use of creative and participatory methods.

AUTHOR CONTRIBUTIONS

Kathryn Lewis: Conceptualization; methodology; project administration; writing – original draft; writing – review and editing. **Lorna G. Hamilton:** Conceptualization; funding acquisition; methodology; project administration; writing – original draft; writing – review and editing. **Jonathan Vincent:** Conceptualization; funding acquisition; methodology; project administration; writing – original draft; writing – review and editing.

ACKNOWLEDGEMENTS

The authors are grateful to the children and families who are participating in this research. We thank Weronika Robakowska for research assistance, and Professor Matthew Reason for his work on project governance as chair of the project steering group. We are grateful to the Sir Halley Stewart Trust for funding this work.

FUNDING INFORMATION

Sir Halley Stewart Trust, London, WC1N 3XX. Award number: 4026.

CONFLICT OF INTEREST STATEMENT

The authors have no financial or other conflicts of interests to declare.

PEER REVIEW

The peer review history for this article is available at https://www.webofscience.com/api/gateway/wos/peer-review/10.1002/icd.2467.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analysed in this study.

ETHICS STATEMENT

Ethical approval for this project was granted by the School of Education, Language and Psychology Ethics Committee at York St John University. The approval code for the project is RECPSY00048b. Informed consent was obtained from parent/carers of all individuals involved in this study, and informed assent was obtained from all participants.

ORCID

Kathryn Lewis https://orcid.org/0009-0006-9329-8548

Lorna G. Hamilton https://orcid.org/0000-0003-0526-8252

Jonathan Vincent https://orcid.org/0000-0001-6278-4670

REFERENCES

- Angell, C., Alexander, J., & Hunt, J. A. (2015). 'Draw, write and tell': A literature review and methodological development on the 'draw and write' research method. *Journal of Early Childhood Research*, 13(1), 17–28. https://doi.org/10.1177/1476718X14538592
- Beresford, B., Tozer, R., Rabiee, P., & Sloper, P. (2004). Developing an approach to involving children with autistic spectrum disorders in a social care research project. *British Journal of Learning Disabilities*, 32(4), 180–185. https://doi.org/10.1111/j.1468-3156.2004.00318.x
- Bernardi, F. (2020). Autonomy, spontaneity and creativity in research with children. A study of experience and participation, in Central Italy and north West England. *International Journal of Social Research Methodology*, 23(1), 55–74. https://doi.org/10.1080/13645579.2019.1672280
- Botha, M. (2021). Academic, activist, or advocate? Angry, entangled, and emerging: A critical reflection on autism knowledge production. Frontiers in Psychology, 12, 4196. https://doi.org/10.3389/fpsyg.2021.727542
- Botha, M., & Gillespie-Lynch, K. (2022). Come as you are: Examining autistic identity development and the neurodiversity movement through an intersectional lens. *Human Development*, 66, 93–112. https://doi.org/10.1159/000524123
- Bourke, R., & Loveridge, J. (2014). Exploring informed consent and dissent through children's participation in educational research. International Journal of Research and Method in Education, 37(2), 151–165. https://doi.org/10.1080/1743727X.2013.817551
- Brooks, R., Lainio, A., & Lažetić, P. (2020). Using creative methods to research across difference. An introduction to the special issue. *International Journal of Social Research Methodology*, 23(1), 1–6. https://doi.org/10.1080/13645579.2019.1672281
- Burman, E. (2017). Deconstructing developmental psychology (3rd ed.). Routledge.
- Calder, L., Hill, V., & Pellicano, E. (2013). 'Sometimes I want to play by myself': Understanding what friendship means to children with autism in mainstream primary schools. Autism, 17(3), 296–316. https://doi.org/10.1177/1362361312467866
- Camponovo, S., Monnet, N., Moody, Z., & Darbellay, F. (2021). Research with children from a transdisciplinary perspective: Coproduction of knowledge by walking. *Children's Geographies*, 1–14, 163–176. https://doi.org/10.1080/14733285. 2021.2017405
- Canning, N., & Robinson, B. (2021). Blurring boundaries: The invasion of home as a safe space for families and children with SEND during COVID-19 lockdown in England. European Journal of Special Needs Education, 36(1), 65–79. https://doi.org/10.1080/08856257.2021.1872846

- Carroll, C., & Twomey, M. (2021). Voices of children with neurodevelopmental disorders in qualitative research: A scoping review. *Journal of Developmental & Physical Disabilities*, 33, 709–724. https://doi.org/10.1007/s10882-020-09775-5
- Chapman, R. (2021). Neurodiversity and the social ecology of mental functions. Perspectives on Psychological Science, 16(6), 1360–1372. https://doi.org/10.1177/1745691620959833
- Cocks, A. J. (2006). The ethical maze: Finding an inclusive path towards gaining children's agreement to research participation. Childhood, 13(2), 247–266. 10.1177/0907568206062942.
- Collier, J., & Collier, M. (1986). Visual anthropology: Photography as a research method. University of New Mexico Press.
- Convention on the rights of the child. (1989). Treaty no. 27531. United Nations Treaty Series, 1577, pp. 3-178. https://treaties.un.org/doc/Treaties/1990/09/19900902%2003-14%20AM/Ch_IV_11p.pdf
- Costley, D., Emerson, A., Ropar, D., & Sheppard, E. (2021). The anxiety caused by secondary schools for autistic adolescents: In their own words. *Education Sciences*, 11(11), 726. https://doi.org/10.3390/educsci11110726
- Council of Europe. (2012). Recommendation CM/Rec(2012)2 of the Committee of Ministers to member states on the participation of children and young people under the age of 18. wcd.coe.int/ViewDoc.jsp?id=1927229&Site=CM.
- Cree, V., Kay, H., & Tisdall, K. (2002). Research with children: Sharing the dilemmas. Child & Family Social Work, 7(1), 47–56. https://doi.org/10.1046/j.1365-2206.2002.00223.x
- Cromby, J. (2012). Feeling the way: Qualitative clinical research and the affective turn. Qualitative Research in Psychology, 9(1), 88–98. https://doi.org/10.1080/14780887.2012.630831
- Cuevas-Parra, P., & Tisdall, E. K. M. (2019). Child-led research: Questioning knowledge. *Social Sciences*, 8(2), 44. https://doi.org/10.3390/socsci8020044
- Danker, J., Strnadová, I., & Cumming, T. M. (2019). Picture my well-being: Listening to the voices of students with autism spectrum disorder. Research in Developmental Disabilities, 89, 130–140. https://doi.org/10.1016/j.ridd.2019.04.005
- De Clercq, H., & Petters, T. (2006). A partnership between parents and professionals. In J. M. Perez (Ed.), New developments in autism: The future is today (pp. 310–340). Jessica Kingsley Publishers.
- de Jager, A., Tewson, A., Ludlow, B., & Boydell, K. (2016). Embodied ways of storying the self: A systematic review of body-mapping. Forum Qualitative Sozialforschung Forum: Qualitative Sozial Research, 17(2). https://doi.org/10.17169/fqs-17.2.2526
- Demuth, C., & Mey, G. (2015). Qualitative methodology in developmental psychology. In J. Wright (Ed.), International Encyclopedia of the Social and Behavioural Sciences (pp. 668-675). Elsevier. https://doi.org/10.1016/B978-0-08-097086-8.23156-5
- den Houting, J. (2019). Neurodiversity: An insider's perspective. Autism, 23(2), 271–273. https://doi.org/10.1177/ 1362361318820762
- den Houting, J., Higgins, J., Isaacs, K., Mahony, J., & Pellicano, E. (2021). 'I'm not just a Guinea pig': Academic and community perceptions of participatory autism research. Autism, 25(1), 148–163. https://doi.org/10.1177/1362361320951696
- Dwyer, P. (2022). The neurodiversity approach(es): What are they and what do they mean for researchers? *Human Development*, 66(2), 73–92. https://doi.org/10.1159/000523723
- Ellis, J. (2017). Researching the social worlds of autistic children: An exploration of how an understanding of autistic children's social worlds is best achieved. *Children and Society*, 31(1), 23–36. https://doi.org/10.1111/chso.12160
- Fargas-Malet, M., McSherry, D., Larkin, E., & Robinson, C. (2010). Research with children: Methodological issues and innovative techniques. *Journal of Early Childhood Research*, 8(2), 175–192. https://doi.org/10.1177/1476718X09345412
- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, 23(4), 943–953. https://doi.org/10.1177/1362361318786721
- $Fricker,\,M.\,(2007).\,Epistemic\,\,injustice:\,Power\,\,and\,\,the\,\,ethics\,\,of\,\,knowing.\,\,Oxford\,\,University\,\,Press.$
- Gallacher, L. A., & Gallagher, M. (2008). Methodological immaturity in childhood research?: Thinking through 'participatory methods'. Childhood, 15(4), 499–516. https://doi.org/10.1177/0907568208091672
- Goodall, C. (2018). 'I felt closed in and like I couldn't breathe': A qualitative study exploring the mainstream educational experiences of autistic young people. Autism & Developmental Language Impairments, 3, 1–16. https://doi.org/10.1177/2396941518804407
- Greig, A., Taylor, J., & MacKay, T. (2007). Doing research with children. Sage. https://doi.org/10.4135/9781849209045
- Grosz, E. (1994). Lived bodies: Phenomenology and the flesh. In Volatile bodies: Toward a Corporeal Feminism (pp. 86–111). Indiana University Press.
- Guldberg, K., Bradley, R., Wittemeyer, K., Briscombe, J., Phillips, C., & Jones, G. (2019). Good autism practice: Full report. Autism Education Trust.
- Ha, V. S., & Whittaker, A. (2016). 'Closer to my world': Children with autism spectrum disorder tell their stories through photovoice. Global Public Health, 11(5-6), 546-563. https://doi.org/10.1080/17441692.2016.1165721
- Hamilton, L. G., Kelly, L., & Mesa, S. (2023). "I'm able to function better when I know there's a beginning and an end time": Autistic adolescents' experiences of lockdowns during the COVID-19 pandemic. Autism & Developmental Language Impairments, 8, 239694152311595. https://doi.org/10.1177/23969415231159552
- Honeybourne, V. (2018). The neurodiverse classroom. Jessica Kingsley.

LEWIS ET AL.

_WILEY | 17 of 22

- Howard, K. B., Katsos, N., & Gibson, J. L. (2019). The school experiences of bilingual children on the autism spectrum: An interpretative phenomenological analysis. *Research in Developmental Disabilities*, 87, 9–20. https://doi.org/10.1016/j.ridd.2019.01.008
- Hoy, K., Parsons, S., & Kovshoff, H. (2018). Inclusive school practices supporting the primary to secondary transition for autistic children: Pupil, teacher, and parental perspectives. Advances in Autism, 4(4), 184–196. https://doi.org/10.1108/ AIA-05-2018-0016
- Irwin, L. G., & Johnson, J. (2005). Interviewing young children: Explicating our practices and dilemmas. *Qualitative Health Research*, 15(6), 821–831. https://doi.org/10.1177/1049732304273862
- Jackson-Hollis, V. (2019). Qualitative research with primary school-aged children: Ethical and practical considerations of evaluating a safeguarding programme in schools. *Journal of Children's Services*, 14(3), 194–204. https://doi.org/10.1108/ JCS-01-2019-0005
- Kara, H. (2015). Creative research methods in the social sciences: A practical guide. Bristol University Press. https://doi.org/10. 2307/j.ctt1t88xn4
- Kellett, M. (2005). Children as active researchers: a new research paradigm for the 21st century? http://www.ncrm.ac.uk/00000112600/gui/?item=publications/methodsreview/MethodsReviewPaperNCRM-003.pdf
- Kellett, M. (2010). Small shoes, big steps! Empowering children as active researchers. American Journal of Community Psychology, 46, 195–203. https://doi.org/10.1007/s10464-010-9324-y
- Kirby, P. (2020). 'It's never okay to say no to teachers': Children's research consent and dissent in conforming schools contexts. British Educational Research Journal, 46(4), 811–828. https://doi.org/10.1002/berj.3638
- Kusters, A., De Meulder, M., & O'Brien, D. (2017). Innovations in deaf studies: The role of deaf scholars. Oxford University Press.
- Kuzmičová, A., & Cremin, T. (2022). Different fiction genres take children's memories to different places. *Cambridge Journal of Education*, 52(1), 37–53. https://doi.org/10.1080/0305764X.2021.1937523
- Langhout, R. D., & Thomas, E. (2010). Imagining participatory action research in collaboration with children: An introduction. American Journal of Community Psychology, 46, 60–66. https://doi.org/10.1007/s10464-010-9321-1
- Leadbitter, K., Buckle, K. L., Ellis, E., & Dekker, M. (2021). Autistic self-advocacy and the neurodiversity movement: Implications for autism early intervention research and practice. Frontiers in Psychology, 12, 782. https://doi.org/10.3389/fpsyg.2021.635690
- Levitt, H. M., Surace, F. I., Wu, M. B., Chapin, B., Hargrove, J. G., Herbitter, C., Lu, E. C., Maroney, M. R., & Hochman, A. L. (2022). The meaning of scientific objectivity and subjectivity: From the perspective of methodologists. *Psychological Methods*, 27(4), 589-605. https://doi.org/10.1037/met0000363
- Lewis, C., Crampton, A., & Scharber, C. (2021). The sociocultural role of imagination in critical digital literacy. *Pedagogies: An International Journal*, 16(2), 154–172. https://doi.org/10.1080/1554480X.2021.1914056
- Lomax, H. (2012). Contested voices? Methodological tensions in creative visual research with children. *International Journal of Social Research Methodology*, 15(2), 105–117. https://doi.org/10.1080/13645579.2012.649408
- Macaulay, A. C. (2017). Participatory research: What is the history? Has the purpose changed? *Family Practice*, 34(3), 256–258. https://doi.org/10.1093/fampra/cmw117
- Malloy, C., Cuda, J., Kim, S. Y., & Bottema-Beutel, K. (2020). "They can even make waiting in line fun": A quantitative content analysis of autistic children's friendship conceptualizations. *Psychology in the Schools*, *57*(6), 973–989. https://doi.org/10.1002/pits.22362
- Mannay, D. (2016). Visual, narrative and creative research methods: Application, reflection and ethics. Routledge.
- Marcotte, J., Grandisson, M., Milot, É., & Dupéré, S. (2022). The walking interview: A promising method for promoting the participation of autistic people in research projects. *International Journal of Qualitative Methods*, 21, 160940692210900. https://doi.org/10.1177/16094069221090065
- Marocchini, E. (2023). Impairment or difference? The case of theory of mind abilities and pragmatic competence in the autism spectrum. Applied PsychoLinguistics, 44, 365–383. https://doi.org/10.1017/S0142716423000024
- Martin, T., Dixon, R., Verenikina, I., & Costley, D. (2019). Transitioning primary school students with autism Spectrum disorder from a special education setting to a mainstream classroom: Successes and difficulties. *International Journal of Inclusive Education*, 25(5), 640–655. https://doi.org/10.1080/13603116.2019.1568597
- Masi, A., DeMayo, M., Glozier, N., & Guastella, A. J. (2017). An overview of autism spectrum disorder, heterogeneity, and treatment options. *Neuroscience Bulletin*, 33, 183–193. https://doi.org/10.1007/s12264-017-0100-y
- Mateos-Blanco, T., Sánchez-Lissen, E., Gil-Jaurena, I., & Romero-Pérez, C. (2022). Child-led participation: A scoping review of empirical studies. *Social Inclusion*, 10(2), 32–42. https://doi.org/10.17645/si.v10i2.4921
- Medina, C. L., Perry, M., Lee, B. K., & Deliman, A. (2021). Reading with drama: Relations between texts, readers and experiences. *Literacy*, 55(2), 136–144. https://doi.org/10.1111/lit.12246



- Mesa, S., & Hamilton, L.G. (2022). School transitions for autistic young people in mainstream settings: A research report. Available from: https://www.yorksj.ac.uk/media/content-assets/research/institute-for-social-justice/School-transitions-for-autistic-pupils-report.pdf
- Milton, D. (2012). On the ontological status of autism: The double empathy problem. *Disability & Society*, 27(6), 883–887. https://doi.org/10.1080/09687599.2012.710008
- O'Farrelly, C., & Tatlow-Golden, M. (2022). It's up to you if you want to take part. Supporting young children's informed choice about research participation with simple visual booklets. European Early Childhood Education Research Journal, 30(1), 63–80. https://doi.org/10.1080/1350293X.2022.2026434
- O'Reilly, K. (2009). Key concepts in ethnography. Sage. https://doi.org/10.4135/9781446268308
- Patall, E. A., Cooper, H., & Robinson, J. C. (2008). The effects of choice on intrinsic motivation and related outcomes: A meta-analysis of research findings. Psychological Bulletin, 134(2), 270–300. https://doi.org/10.1037/0033-2909.134.2.270
- Pellicano, E., & den Houting, J. (2022). Annual research review: Shifting from 'normal science' to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*, 63(4), 381–396. https://doi.org/10.1111/jcpp.13534
- Pitt, F., Dixon, R., & Vialle, W. (2021). The transition experiences of students with disabilities moving from primary to secondary schools in NSW, Australia. *International Journal of Inclusive Education*, 25(7), 779–794. https://doi.org/10.1080/13603116.2019.1572797
- Rasmussen, P. S., & Pagsberg, A. K. (2019). Customizing methodological approaches in qualitative research on vulnerable children with autism spectrum disorders. *Societies*, 9(4), 75. https://doi.org/10.3390/soc9040075
- Rennie, D. L., Watson, K. D., & Monteiro, A. M. (2002). The rise of qualitative research in psychology. *Canadian Psychology/Psychologie Canadianne*, 43(3), 179–189. https://doi.org/10.1037/h0086914
- Richter, M., Clément, C., & Flavier, E. (2022). Is transition an (adult) problem? Experiences of autistic students during the transition from primary to secondary school. *Journal of Research in Special Educational Needs*, 22(4), 368–379. https://doi.org/10.1111/1471-3802.12574
- Rose, G. (2022). Visual methodologies: An introduction to researching with visual materials. SAGE.
- Schön, D. A. (1987). Educating the reflective practitioner: Toward a new design for teaching and learning in the professions. Jossey-Bass.
- Scott-Barrett, J., Cebula, K., & Florian, L. (2018). Listening to young people with autism: Learning from researcher experiences. *International Journal of Research & Method in Education*, 42(2), 1–22. https://doi.org/10.1080/1743727X.2018. 1462791
- Stafford, L. (2017). 'What about my voice': Emancipating the voices of children with disabilities through participant-centred methods. Children's Geographies, 15(5), 600–613. https://doi.org/10.1080/14733285.2017.1295134
- Stevenson, O., & Adey, C. (2010). Toy tours: Reflections on walking-whilst-talking with young children at home. *Qualitative Research*, 12, 8–10.
- Stoner, J. B., Angell, M. E., House, J. J., & Bock, S. J. (2007). Transitions: Perspectives from parents of young children with autism spectrum disorder (ASD). *Journal of Developmental & Physical Disabilities*, 19, 23–39. https://doi.org/10.1007/s10882-007-9034-z
- Teachman, G., & Gibson, B. E. (2013). Children and youth with disabilities: Innovative methods for single qualitative interviews. Qualitative Health Research, 23(2), 264–274. https://doi.org/10.1177/1049732312468063
- Vaughn, L. M., & Jacquez, F. (2020). Participatory research methods—Choice points in the research process. Journal of Participatory Research Methods, 1(1), 13244. https://doi.org/10.35844/001c.13244
- Vincent, J., Potts, M., Fletcher, D., Hodges, S., Howells, J., Mitchell, A., Mallon, B., & Ledger, T. (2016). 'I think autism is like running on Windows while everyone else is a Mac': using a participatory action research approach with students on the autistic spectrum to rearticulate autism and the lived experience of university. Educational Action Research, 25(2), 300–315. https://doi.org/10.1080/09650792.2016.1153978
- Wetton, N., & McWhirter, J. (1998). Image-based research and curriculum development in health education. In J. Prosser (Ed.), *Image based research*. A source book for qualitative researchers. Falmer Press.
- Wiles, R., Bengry-Howell, A., Crow, G., & Nind, M. (2013). But is it innovation?: The development of novel methodological approaches in qualitative research. Methodological Innovations Online, 8(1), 18–33. https://doi.org/10.4256/mio. 2013.002
- Zanuttini, J. Z. (2023). Capturing the perspectives of students with autism on their educational experiences: A systematic review. *International Journal of Educational Research*, 117, 102115. https://doi.org/10.1016/j.ijer.2022.102115

How to cite this article: Lewis, K., Hamilton, L. G., & Vincent, J. (2023). Exploring the experiences of autistic pupils through creative research methods: Reflections on a participatory approach. *Infant and Child Development*, e2467. https://doi.org/10.1002/icd.2467

APPENDIX A

A.1 | Full list of topics included in card sort exercise—school life.

Note that these were presented on individual cards with accompanying pictures.

School in general [Specific logo and school name changed for each participant]

School food

My teaching assistant/TA

My subject teachers

Making friends

Other pupils

The school uniform

Homework

The library

Breaktimes

Finding my way around school

The SENCOs

Clubs

Travelling to/from school

My form tutor

The learning support classroom [Specific name changed for schools with a designated zone/name]

The sensory room

My head of year [Name/photo changed for each participant]

The headteacher [Name/photo changed for each participant]

My key worker

APPENDIX B

B.1 | Full list of statements provided for the statement sort exercise

I enjoy going to school

Teachers like me the way I am

Teachers understand the extra help I might need at school

There is an adult I can talk to if I have problems

I wish I was in a different school

I feel different to the other children at school

School makes me feel anxious/worried

I feel excited about going to school

I have friends at school

People notice when I am good at something at school

People at school are friendly to me

Teachers at school want to help me

Other children like me the way I am at school				
I feel happy at school				
I feel scared or worried at school				
I feel able to do my schoolwork				
People at school understand what autism is				
I enjoy breaktimes at school				
School makes me feel stressed				
I can find my way around the school				
I like my teachers				
Secondary school is better than I expected				
Secondary school is worse than I expected				

APPENDIX C

C.1 | Semi-structured interview schedule

Theme	Question	Sub-question
General school	Tell me about your school	What's similar to primary school?
		What's different to primary school? (better/worse)
	How does school make you feel?	What do you like about school?
		What do you find challenging about school?
		Is there anything you'd like to change about school?
Subjects/ extracurricular	What are your favourite subjects at school?	
	What's your least favourite subject at school?	How do you find PE lessons? Changing/contact sports
	What do you think about homework?	
	What's your favourite place to go at school	How do you spend your breaktimes and lunchtimes?
		Are you part of any clubs?
	How do you get to/from school?	How do you find this?
Support	What are your teachers like?	What makes a good teacher?
		Do you feel like your teachers understand autism and the ways they can support you at school?
	How much do you think other people at school know about autism?	What would you like them to know?
	If you are having a hard time at school, do you know where to go or who to talk to?	For example, struggling with work, getting around, feeling overwhelmed, lost items, peer relationships
Friendships	Did you know anyone from your old school?	
	Have you made any new friends at school?	What do you do with your friends?

APPENDIX D

D.1 | Case study: Max (name changed to preserve anonymity)

Max (13) is an autistic pupil with ADHD. We have a planned data collection meeting in school, the third meeting Max has had with a member of the research team. The meeting takes place in a small private office and Max is accompanied to the meeting by a teaching assistant. Max initially appears uncertain, and cannot remember me or the details of the project when asked. However, they are happy for me to remind them about the project information, and quickly remember the previous meetings and project details.

From initial meetings with Max, and the initial conversation with Max's parents, I am aware that Max is very comfortable speaking with unfamiliar adults and happy to talk at length on topics of interest, but may become easily distracted or go off-topic. In preparation for our meeting, I have collated a range of activity choices including card sort, photovoice, statement sort and collage/drawing, so that Max has choice throughout the session. Max chooses to first complete the card sort exercise. Rather than giving Max all of the cards to sort at once, I give Max a few cards at a time, and we discuss these once they have been sorted. This adaptation allows for more breaks and reduces the overwhelm of having to discuss lots of topics in one go.

When discussing the card sort, Max frequently responds to questions about card placement with 'I'm not sure'. They continue to respond in this way to probing or clarifying questions. On reflection, I notice that when I pause after this response and allow Max more time to process, they often provide clear and insightful answers. As the interview progresses, I establish that varying the conversation by asking Max a combination of open-ended questions such as 'do you have anything else you want to say about that topic?' and closed questions such as 'do you prefer maths to science?', and giving them the time and space they need to consider answers, is the most effective way to engage them in the research. Max also frequently responds to questions with answers to previous questions, indicating that I am not always allowing them enough time to process questions and to expand on their thoughts. Reflecting on this during the session allowed me to adjust my approach in the second half of the interview.

Max is additionally extremely interested in how the audio recorder works, and frequently interrupts questions to discuss features of the recording device. Rather than removing the device from sight or asking them to focus on the questions, I offer opportunities for Max to use the device throughout the interview, for example, by choosing the settings and introducing each recording session after breaks. This is not always effective, and the conversation continues to return to the device throughout the interview, but we compromise on completing a short task or discussing a few topics before talking more about the technology. Adapting the session to include time to investigate the recording device is effective in keeping Max engaged and interested.

This interaction demonstrates the importance of continual reflection and adaptability during the interview process. It also illustrates the utility of incorporating and building on participant interests. In this interview, it was beneficial to get to know how Max communicated, and to respond to this by allowing for additional time to process questions.

APPENDIX E

E.1 | Case study: Charlie (name changed to preserve anonymity)

Charlie (13) is an autistic pupil with ADHD and selective mutism. They have a planned data collection meeting with me at school. The meeting takes place in a small office adjacent to the main reception, and I am already present when Charlie arrives. Charlie walks in cautiously and stands in the doorway. They look visibly uncomfortable and shrug quickly when I ask if they remember me or the research project.

I introduce myself and offer Charlie three options: They could choose to stay whilst I introduce myself and explain the research project (with no obligation to stay following this), they can return to class, or they can stay in the room and complete an activity they chose such as writing or drawing, without having to engage with me.

15227219. 0. Downloaded from https://onlinelibrary.wiley.com/doi/10.1002/icd.2467 by Test, Wiley Online Library on [17/10/2023]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons Licenses

I partially close the door to reduce noise and onlookers from the busy reception area, leaving it ajar to allow Charlie the option to leave at any time. Charlie takes a seat and picks up the project information leaflet, indicating non-verbal assent for me to begin to talk through the project. Charlie does not offer any response to the consent questions at the end of the introductory information, either verbally or non-verbally by pointing or nodding/shaking their head. I remind Charlie that they can choose to leave the room at any time if they do not wish to have the session today, and that there will be no negative consequences for this. I also offer the option to look at the activities we could complete today in more detail, and Charlie nods their head slightly, so I lay out the drawing pens and paper, card sorting activity, and statement sorting activity. After viewing the options available, they quickly point towards the card sort and drawing activities.

I ask if we can first return to the consent questions, and as we go through these, Charlie points to each statement in turn to indicate their assent. We agree not to voice record our interactions, and to revisit this later if Charlie changes their mind on this.

Charlie quickly completes the card sort exercise relating to school life. As they do this, they make some small comments on the cards, and I offer small prompts in return. By the end of the session, Charlie has a lot to say, and we cover a number of topics, with Charlie displaying real insight into aspects of their school experience. Following the card sort, the school bell rings, and I used this as an opportunity to remind Charlie that they can return to class. They instead chose to complete another activity.

This interaction clearly demonstrates the importance of relationship building, offering choices, and continually reviewing assent as an ongoing process. By working slowly and letting Charlie take the lead on activity choice and communication, I was able to build good rapport and to gain really valuable insights into their school experience. The card sort exercise proved particularly beneficial here in structuring the session and to build rapport independent of speech, for example, with Charlie laughing as they placed homework into the lowest star rating category. This interaction also indicated the importance of flexibility when working with neurodivergent children, both in terms of the topics covered, and the research methods used.