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Toward Epistemic Justice: Using a Multimodal Interpretative Phenomenological Analysis Methodological Approach in Research With Autistic Children

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Abstract

In this paper we critically examine the systemic marginalisation of autistic children's contributions in research and make the case for how a multimodal application of Interpretative Phenomenological Analysis (IPA) can contribute towards more inclusive and equitable knowledge production. Drawing on an empirical study into the subjective everyday experiences of ten autistic children aged nine to eleven years in mainstream primary schools in England, our research foregrounds the need for methodological innovation to accommodate diverse communicative modalities, particularly among intermittently- and non-speaking participants. By integrating creative adaptations - including photo-elicitation, asynchronous text-based interviewing, and participant-led multimodal engagement – we provide worked examples of how IPA's flexibility can facilitate more authentic, participant-driven meaning-making processes while maintaining methodological rigour. In doing so, we explore how multimodal IPA can provide a framework for challenging historically dominant neuronormative research practices in an attempt to address both testimonial and hermeneutic forms of epistemic injustice. The paper concludes by exploring the broader ethical and practical implications of our study, arguing for the adoption of approaches to research and professional practice that anticipate and accommodate autistic modes of communication in a shift toward greater inclusivity and epistemic equity.

Keywords

autism, education, inclusive research, IPA, epistemic injustice, school experience, SEND, neurodiversity

Introduction

In accordance with national inclusive education policy, 75% of autistic children in England are educated in mainstream schools (Department for Education, 2024). However, research findings and Government data show they face significant challenges, including educational underachievement (Keen et al., 2016; Kim et al., 2018; Mayes & Calhoun, 2007), higher exclusion rates (Department for Education, 2023; Hatton, 2018), and social isolation (Hebron et al., 2015; Maïano et al., 2016). Compared to non-autistic peers, autistic children report having fewer friends (Bauminger et al., 2003; Dean et al., 2017; Humphrey & Symes, 2011) and experience greater levels of loneliness and social dissatisfaction (Kasari & Sterling, 2014; Locke et al., 2010).

Social isolation has also been linked with increased vulnerability to victimisation and bullying, and reports suggest that autistic children are four times more likely to be bullied than non-autistic children (Sterzing et al., 2012). Autistic children with more obvious behavioural differences are

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especially likely to be targeted by bullies (Hebron & Humphrey, 2014), as are those in mainstream rather than special schools (Rowley et al., 2012; Zablotsky et al., 2013). Frequent bullying is associated with increased anxiety, self-injury, and low self-esteem (Ashburner et al., 2019; Cappadocia et al., 2012) which may be compounded by an increased vulnerability of autistic children and young people to mental health difficulties more generally (Lai et al., 2019). There is also a growing awareness of the increasing numbers of autistic children who find school so stressful that they are unable to attend regularly or at all, with possible links to burnout and exhaustion due to a poorness of fit between the typical school environment and their needs (Connolly et al., 2023; Dalrymple, 2022; Totsika et al., 2020).

A great deal is known about the particular difficulties school-aged autistic children face but how they experience and make sense of these challenges has historically received less attention. Much research relies on standardised tests or data from ostensibly non-autistic parents and staff (e.g., Azad et al., 2018; Danker et al., 2019; Hodges et al., 2020; McKinlay et al., 2022). While offering valuable insights into stakeholder perceptions, prioritising informant accounts over autistic voices has arguably contributed to their marginalisation in research, making them a largely "muted group" (Holmes, 2024, p. 62).

Set within this context, this paper explores the marginalisation of autistic perspectives in research and argues for multimodal Interpretative Phenomenological Analysis as a more inclusive approach. Using a recent study into the everyday experiences of ten autistic children in mainstream primary schools in England, we present worked examples and describe creative and technological adaptations which supported participants' diverse communicative modalities. We conclude with implications for research and professional practice.

Epistemic Injustice in Autism Research

Epistemic injustice refers to harms inflicted on our capacities as knowers, creators, and interpreters of information. According to Fricker (2007), this kind of injustice arises from the imbalances in power between social groups, and takes two forms: (a) testimonial injustice, where minority experiences are discredited or dismissed on the basis of prejudice and stigma, and (b) hermeneutic injustice, where the necessary tools to interpret the experiences of minoritised people are lacking or missing. It has been argued that both kinds of injustice contribute to the oppression and stigmatisation of minoritised communities as a result of the denigration and silencing of their testimonies (Dotson, 2011).

While primarily studied within the contexts of ethnicity and gender (e.g., McKinnon, 2016; Medina, 2013), there is a growing awareness of epistemic injustice in autism research. Milton and Bracher (2013) contend that historically, autistic people have been excluded from the production of knowledge of autism, leading to an undue emphasis on perceived autistic deficits. Carel and Chapman (2021) suggest that this combination of marginalisation and pathologisation has contributed to the construction of a narrative which situates autism as fundamentally incompatible with accepted definitions of a good life - such definitions being based on norms largely agreed by and for non-autistic people. As observed by autistic writer Donna Williams:

> Right from the start, from the time someone came up with the word 'autism', the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced (Williams, 1996, p. 14)

With specific consideration to children, evidence of these outsider pathologised interpretations of autism can be found throughout the autism literature. From the earliest recorded descriptions, autistic children been described in terms of innate deficiency:

> …these children have come into the world with innate inability to form the usual, biologically provided affective contact with people, just as other children come into the world with innate physical or intellectual handicaps (Kanner, 1943, p. 250)

This characterisation has continued over time. From notions of 'feeble-mindedness' and 'retardation' in the 1920s (Waltz, 2023), theories of 'psychological disturbance' in the 1940s (Asperger, 1943/1991; Kanner, 1943), and interpretations of autism as brain damage in the 1960s (Rimland, 1964). In more recent decades, and in line with technological and scientific advancements, there has been a shift in focus to identifying genetic biomarkers of autism (Anwar et al., 2018; Loth et al., 2017), an area of research couched in the language of risk and economic burden.

It is our assertion that the conceptualisation of autistic children as fundamentally impaired is related to the relative scarcity of autistic child voices in the research literature. The historical tendency to view autistic children as unreliable narrators is arguably related to the idea that the views of non-autistic caregivers and professionals offer a more valid account of the autistic experience than the views of autistic children themselves (Pellicano & den Houting, 2022). However, the idea that autistic communication and interaction is defective and in need of modification has been challenged by autistic people for many years (e.g., Baggs, 2007; Sinclair, 1993/2012). This challenge has been theorised as the 'double empathy problem' (Milton, 2012). This theory posits that instead of autistic interaction being wrong and non-autistic interaction being right, they are both simply different. Each communication style is valid but the distinct differences between them can lead to mutual misunderstanding during interaction between autistic and non-autistic people. Milton goes on to explain this as "a 'double problem' because both people experience it, and so it is not a singular problem located in any one person" (Milton, 2012, p. 884). However, due to the power imbalances between autistic (neurominority) and non-autistic people (neuromajority), any difficulties or misunderstandings are generally attributed to the autistic person.

Such conceptualisations of the differences between autistic and non-autistic communication are closely tied to the medical model of disability. Put simply, the medical model of disability is one that makes a distinction between *normal* and *abnormal* development. It locates disability within the individual, and deviations from accepted physical and psychological norms tend to be viewed as "defect[s] in or…failure[s] of a bodily system that is inherently abnormal and pathological" (Goodley, 2016, p. 7). Given the dominance of such medicalised understandings of autism, autistic people report feeling under considerable pressure to adjust their behaviour to more closely match the conventions and expectations of non-autistic people (Hull et al., 2017; Humphrey & Lewis, 2008; Miller et al., 2021), with negative consequences in terms of mental health and wellbeing (Cassidy et al., 2020; Raymaker et al., 2020). In turn, non-autistic people are not usually required to make any adjustments in how they communicate with autistic people because how they behave is considered the accepted norm. Since most autism research has been conducted by non-autistic researchers (Milton, 2014; Roche et al., 2021), the dominance of the medical model and the resulting double empathy gap may go some way towards explaining the preference for informant reports in the literature.

How Interpretative Phenomenological Analysis can Help Tackle Epistemic Injustice in Research with Autistic Children

Fortunately, there is a growing awareness of the need for autism research which actively includes autistic people and aligns with their priorities (Pellicano et al., 2014). In their championing of greater participatory research practices with autistic people, Fletcher-Watson et al. (2019) argue that meaningful research begins with recognising the power imbalance between researcher and participant. Interpretative Phenomenological Analysis (IPA; Smith et al., 2009; 2022) is well placed to support researchers in developing this kind of heightened self-awareness through the double hermeneutic process which frames interpretation as a co-constructive process between researcher and participant (Pietkiewicz & Smith, 2014).

Essential to this co-constructive process are the interwoven and evolving concepts of positionality and reflexivity. Positionality refers to the researcher's chosen stance within a study, shaped by demographics and lived experiences (Holmes, 2020; Savin-Baden & Major, 2013)., and reflexivity is the continuous process of examining how positionality influences research (Hibbert et al., 2010). While positionality and reflexivity are frequently cited as essential to high quality and ethical qualitative research (Braun & Clarke, 2013; Holmes, 2020), it has been observed that engagement with these processes can be superficial and performative (Macfarlane, 2022). We would argue that given IPA's essential focus on the mutuality of the sense-making process via the double-hermeneutic - making sense of our participants' experiences and making meaningful attempts to inhabit their perspectives - demands that we must first establish our own positions, prejudices and fore-understandings. By engaging in such practices, it is our assertion that IPA provides opportunities for greater exploration of the potential epistemological harms caused by the double empathy gap and unconscious biases.

Reflection

In light of this, we would like to make our own position in relation to this research clear. In addition to our research roles, all authors have a personal relationship to the subject matter. The first author is a parent to autistic children, the second author is a clinical psychologist with extensive experience of working therapeutically with autistic children, and the third author is an expert in childhood stigma. However, since none of the authors identify as autistic, self-awareness of the double empathy problem was crucial in the execution of the study at the centre of this paper. To support this reflexive process, the study was assisted by three autistic adult mentors. Their insight into autistic experience, communication and culture played a key role in the design and implementation of this study.

We are not the first authors to highlight the benefits of using IPA in research with autistic people. MacLeod (2019) and Howard et al. (2019) conducted reviews which identified a total of 16 IPA studies about the lived experiences of autistic people and both found it to be a suitable methodology for participatory research with autistic participants. MacLeod notes that "the IPA approach encourages exploration not just of the individual experience, but also how this is contextualised by history, society and dominant cultural forces" (MacLeod, 2019, p. 50). However, she also points out that while IPA has much to recommend in terms of a more equitable research methodology,

> there can be a tendency for qualitative research methodologies to exhibit an 'elite bias' (Miles & Huberman, 1994), whereby the most articulate members of a given group are recruited to studies. (MacLeod, 2019, p. 59)

While we and others have attested to the inclusivity of IPA's underlying philosophy, MacLeod's observation provides us with an opportunity for critical reflection. After all, IPA places a great deal of emphasis on speech. In-depth interviews are the central form of data collection and are described as an exchange in which "for the most part, the participant talks and the interviewer listens" (Smith et al., 2022, p. 54).

Furthermore, linguistic and paralinguistic features play an important role in the analytical process:

> understandings of things that matter to the participant…are often highlighted by descriptions, assumptions, sound bites, acronyms, idiosyncratic figures of speech and emotional responses… (Smith et al., 2022: p. 83)

As highlighted by MacLeod (2019), the extent to which this description of language use matches the reality for many autistic people is underexplored. It is estimated that around a third of autistic people are non-speaking (Rose et al., 2016) and speaking autistic people report finding speech either challenging or impossible when they are tired, stressed or sensorially or emotionally dysregulated (Donaldson et al., 2021; Sequenzia & Grace, 2015), with many preferring written over spoken communication, especially when interacting with unfamiliar people (Howard & Sedgewick, 2021). Moreover, speech represents only one aspect of the diverse range of communicative modalities employed by autistic people, thus to equate productive speech with a person's entire linguistic capacity risks reinforcing ableist assumptions (Bottema-Beutel et al., 2025). Therefore, there remains an urgent imperative to conduct qualitative research which challenges neuronormative ideas of communication. As highlighted by Lebenhagen (2020):

> autistic voice should embrace any self-identified mode of expression, including speaking and nonspeaking patterns of sound, gesture, movement, and silence. (Lebenhagen, 2020, p. 2)

This prompts consideration of linguistic and communicative diversity in our samples, and the potential for hermeneutic injustice stemming from the misinterpretation of or lack of support for authentic autistic expression. Smith et al. (2009) note that IPA studies typically involve small, homogeneous samples to examine convergence and divergence in detail. Given that we have been unable to identify an IPA study that has included non- or intermittently-speaking autistic children alongside those who might communicate in what could be seen as more expected ways, does this mean that researchers have interpreted this homogeneity as applying to communicative ability as well?

If so, we would argue that this is a misunderstanding of IPA. The non-prescriptive nature of IPA and its focus on the subjective allows scope for flexibility and adaptation. In particular, IPA's compatibility with multimodal approaches means that it provides not only scope to include participants with a range of communication styles, but it also provides scaffolding for accessing aspects of human experience that could be difficult for any participant to discuss, regardless of their neurotype. Smith et al. (2022) define 'multimodal' in relation to a range of non-verbal data collection techniques which can enhance or scaffold participant reflection and self-expression. There are a number of examples of IPA studies which have adopted multimodal approaches to data collection including the use of photo-elicitation (Morrey et al., 2022), autobiographical poetry (Spiers & Smith, 2016), and image-making (Boden et al., 2019; Craythorne et al., 2023). Perhaps most relevant to our focus on autistic children, however, is that Smith et al. (2022) emphasise clearly that IPA has the flexibility to include participants however they communicate and express themselves through the use of creative, innovative, flexible and participatory approaches which are led by the needs of participants.

Introducing Our Study

To illustrate our use of multimodal IPA to create a more equitable research process, we will now discuss a recent study. As the publication of its empirical findings of this study are forthcoming, we focus its methodology and our personal reflections, along with illustrative examples of the approach in practice.

As previously discussed, relatively few studies have engaged directly with the question of what it means to be an autistic child in a school environment largely designed by and for non-autistic people. While there has been a welcome increase in published qualitative research on the subjective school experiences of autistic children in recent years (see, Atkinson et al., 2024, Horgan et al., 2023; Williams et al., 2019 for reviews), few have focused on the experiences of younger autistic children who do not meet the criteria for specialist support – a group which constitutes the majority of autistic children in mainstream primary state education in England (Department for Education, 2024). Therefore, this population became our focus and the following primary research question guided our study: how do autistic children describe and make sense of their everyday experiences of mainstream primary school?

Study Method and Recruitment

We recruited 10 participants (5 male, 5 female) aged between nine and eleven years who all attended mainstream primary schools in England, United Kingdom, during the time the study took place, and had a clinical diagnosis of autism confirmed by their parent-carer. A detailed rationale regarding the inclusion criteria for this study is presented in Table 1 below.

Following approval provided by the University of Reading Research Ethics Committee, the first author circulated a study advertisement via email and social media among parent-carer and primary school networks. Interested parent-carers arranged an initial meeting, received study documents, and provided consent. A follow-up meeting with the parent-carers then explored the child's understanding of the study, access needs and communication preferences. This meeting also provided an opportunity for the first author to learn more about the child's interests and hobbies – information that would be

Table 1. Inclusion Criteria.

Criteria	Rationale
Aged 9 – 11 years old	We selected children in the last 2 years of primary school to maximise the length of primary school experience.
Equal gender split	There is some evidence to suggest that gender differences may impact on the school experience of autistic children (Dean et al., 2017; Mandy et al., 2012). In order to provide as much scope for any such differences to be identified in the data, the decision was taken to recruit equal numbers of boys and girls.
Clinical diagnosis of autism as confirmed by parent-carer	Children with a confirmed diagnosis of autism from a suitably qualified NHS or independent health professional/clinician were selected in order to establish a level of diagnostic consistency in the group.
Child is aware of their diagnosis	The autism-specific focus of this study was transparent throughout so it was necessary that participants were aware of their neurodivergence and were comfortable with discussing it should it come up in the course of the investigation.
Not in receipt of an Education Health and Care Plan[1], or in the process of being assessed for one	Identified[2] autistic children who do not meet the criteria for an Education, Health and Care Plan and do not attend schools with autism units or have access to specialist resources represent the majority of autistic children in the English education system but are underrepresented in the qualitative research to date. According to the latest Government statistics, such children represent around 1% of the mainstream primary school population – approximately 46,000 children in the 2023/4 school year.
Currently enrolled in a mainstream primary school without specialist autism resources	

helpful in creating a welcoming and comfortable conversational environment.

The first author then arranged familiarisation meetings with each child, with the aim of introducing herself to them, building rapport, and exploring which creative medium the child might be interested in using during the study. The primary invitation was to take photographs but other options were explored such as writing and drawing, and participants were invited to suggest ideas as well.

Due to the study taking place in the immediate period after the Coronavirus pandemic, all meetings were conducted online via the participant's choice of videoconferencing software. The use of online technology meant that participants had access to a range of ways of communicating with the first author (video on or off during interviews, voice interviews only, or text only interviews in which participants would use chat functions). This meant participants could avoid any aspects of social communication (e.g., eye contact) or speaking that may be uncomfortable or stressful for them (Scott-Barrett et al., 2018).

The participants' ages necessitated formal, written consent from parent-carers but ensuring ongoing participant assent from the children was crucial (Loyd, 2013), with opportunities to decline participation reiterated at every meeting. The first author tried to ensure she was sensitive to both spoken and non-spoken forms of expressions of consent, and participants were also able withdraw consent in concrete ways using the technology employed for conducting the interviews. While none of the participants ultimately chose to end any of the meetings, the first author practised terminating the online meeting with the participants so that they knew the process for doing so, and were assured that they would not be causing any offence, or experience any negative repercussions should they chose to terminate the discussions at any point.

In addition to the advantages listed above, it was clear that being able to participate in the study from the comfort and familiarity of their own homes was instrumental in helping the participants feel more at ease during the data collection process. At various points during the interviews, participants introduced the first author to family members, pets and cherished possessions which enabled her to develop a greater sense of their personalities and understand more about what mattered most to them. Participants were also able to achieve sensory comfort by wearing whichever clothes they preferred and choosing rooms and seating or lying positions which suited them best. It would have been very difficult, if not impossible, to recreate a similar level of comfort in a typical university research setting and it is our assertion that the benefits of conducting the interviews remotely are reflected in the richness of the data collected.

Interviews followed a topic guide which was developed in collaboration with a group of six autistic young adults who participated in a focus group study designed for this purpose (Billington et al., 2024). Given the participants' ages and the potential sensitivity of the topic, each interview began with broad open questions about school experiences. Participant-created photographs and materials then guided discussions, with questions shaped by IPA's iterative focus on meaning-making. However, the topic guide below was helpful for asking questions that may have not been answered by the children spontaneously in the course of our discussions.

Topic guide questions:

- What do you enjoy most about school?
- Which parts of school do you find tricky or difficult?

- Who are the people you like to spend time with at school?
- Who do you not enjoy spending time with?
- What is your teacher like?
- How does your teacher help you?

The interviews took place between one and four weeks after the initial meeting with each child, providing time for the child to plan and create any additional materials they wanted to use as part of the interview discussion.

Multimodal Interpretative Phenomenological Analysis in Practice: Worked Examples

Attempting to overcome the double empathy problem was a central concern throughout this study. Semi-structured interviews are the primary method of data collection in IPA, and this approach was taken in the present study. However, as highlighted earlier, we were aware that some autistic children might find the demands of an in-depth spoken interview inaccessible, challenging or stressful (Harrington et al., 2014; Preece & Jordan, 2010). Therefore, without wanting to make assumptions about our participants' abilities and preferences, we welcomed the choice of non-speaking forms of communication to provide a means for participants to share their experiences in a way that felt most comfortable to them. Not only was this option intended to support any participants for whom spoken communication may have been difficult, tiring or not preferred, it was designed to create alternative opportunities for all participants to express what was meaningful to them in their school lives.

Participants were invited to use a range of creative alternative communication approaches, including photo-elicitation, the process by which photographs are introduced into research interviews to gain insights into participants' experiences and perspectives that might not be readily accessible through spoken discussion alone (Bates et al., 2017; Croghan et al., 2008). Eight of the ten participants engaged in the study in ways that could be described as typical: children took photographs of aspects of their school lives and the images were then discussed during a spoken online interview with the first author. All interviews were transcribed verbatim as were any supplementary written contributions from the participants. The first author then carefully reviewed each participant's transcript in order to identify the most potentially salient aspects of their contributions. At this stage of the process, the aim was to ensure that the first author had understood the participants' contributions as the participants had intended prior to the start of the in-depth analytical process. To this end, once she had identified these key aspects in each of the transcripts, participants were invited for a final checking interview where these observations were discussed in more detail to support a greater level of mutual understanding.

However, two of the participants - Chloe and Emily (pseudonyms), both aged 10 at the time of interview - adopted alternative approaches. Both participants described finding speaking difficult and expressed a preference to participate in the study in non-speaking ways. We will now focus on these two participants to illustrate the flexibility and scope of multimodal IPA and how it might be employed with the aim of creating more equitable autism research. Please note that these worked examples refer almost exclusively to methodological considerations. As referred to earlier in this paper, the empirical findings of this study will be discussed in detail in a forthcoming publication.

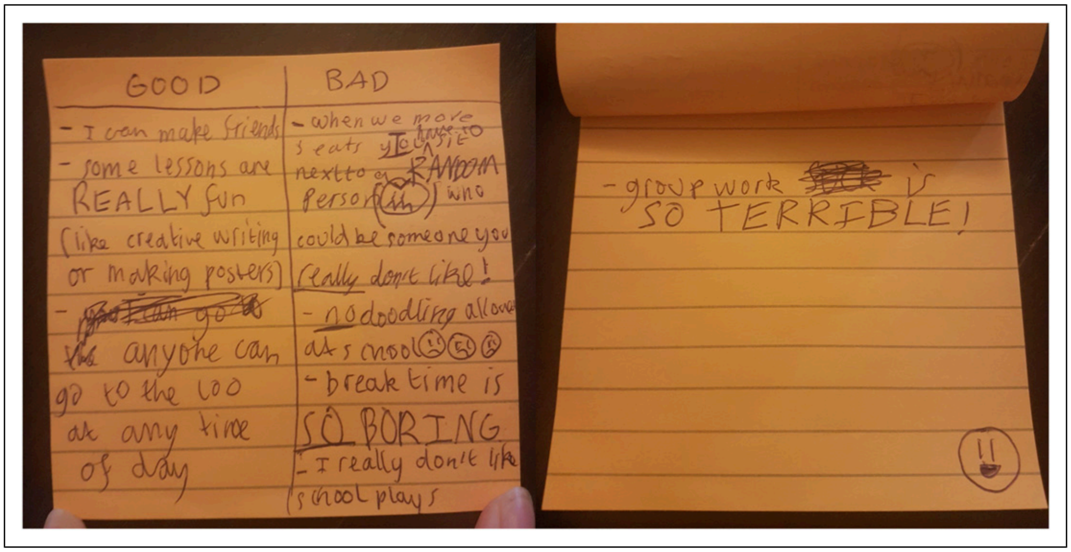
Data Collection Experience with Chloe

During the first author's meeting initial meeting with Chloe's mother, she explained that Chloe often struggled with spoken communication and may prefer to make her contributions in writing. She also shared that Chloe was "not necessarily compliant and has her own boundaries." This was an exciting proposition, and we were keen to explore with Chloe how she would like to participate in the study. In the first meeting with Chloe, she was very clear that she wanted to take part in the study, but she did not want to have to speak and she did not want to take photographs. The primary reason for this was that she did not want to be asked questions by her teachers and peers about why she was taking the photographs. For a child who finds spoken communication difficult, this was entirely understandable and gave us important insight into what it might be like to be an intermittently-speaking person in an environment largely predicated on spoken communication.

Therefore, instead of taking photographs, Chloe asked if she could use handwritten notes to record her thoughts on her school experience. When receiving the notes a few days later, we observed that Chloe had chosen to categorise her school experiences into 'good' and 'bad' which in itself was an interesting interpretation (Figure 1). While there were no plans to formally analyse her notes – all the participants' creative contributions were only intended to scaffold our conversations - we were immediately drawn to her expressive writing style. She had used capitals and underlining for emphasis along with repeated sad-face doodles for aspects of school life that were particularly disliked. Despite there being only two small notes, she had managed to express a great deal of feeling and personality in them.

Chloe's interview followed a few days after receiving the notes and, as already agreed, she chose to keep her camera and microphone switched off and respond to questions using the chat feature only. The interview began with references to Chloe's notes. The first author went through each item in her lists in turn, as exemplified by the excerpt from the transcript below:

> Interviewer: [reading from note] 'breaktime is so boring'…can you describe your breaktimes to me? What are the kind of things you do in breaktime?



GOOD
- I can make friends
- some lessons are REALLY fun (like creative writing or making posters)
- ~~I can go~~ anyone can go to the loo at any time of day

BAD
- when we move seats I have to sit next to a RANDOM person (ugh) who could be someone you really don't like!
- no doodling allowed at school
- break time is SO BORING
- I really don't like school plays

- group work is SO TERRIBLE!

Figure 1. Chloe's Handwritten Notes. Text Reproduction Provided in Appendix A.

Chloe: nothing

Interviewer: So, during breaktimes do you prefer to be alone or do you prefer to be with your friends?

Chloe: ??? my friends are always playing things like tag and i dont like that sort of playing

Interviewer: So, when they're playing tag, what are you doing?

Chloe: nothing

Interviewer: Are you OK with doing nothing or would you rather be doing something else?

Chloe: i'd rather not go outside

Interviewer: Is there anything at all that you can do in the playground that you enjoy?

Chloe: no

The extract demonstrates that with only a few words, Chloe expressed a great deal about her experiences of break time at school. Her note simply says that 'breaktime is SO BORING' but from our exchange above, it is possible to see that rather than merely a lack of interesting play opportunities, there were potentially more complex social forces involved. Chloe shared that she found the activities of her friends unappealing and in the absence of a common interest, she found herself alone. She was definitive in her expression of this sense of being alone and on the fringes of the usual business of the playground. The contrast between Chloe's experiences and those of children and school staff who might commonly associate break time with fun and freedom was striking. It connected with wider themes in the study related to how the usual practices and expectations within schools often did not align with the preferences of the autistic participants who, in the absence of meaningful alternatives, were left alone with nothing to do except wait to be allowed back into the school building at the end of the break.

In terms of the whole interview, keeping the focus on the notes and removing the pressure to speak meant that Chloe could remain in a conversational environment that prioritised her communicative autonomy. As the interview continued, Chloe's contributions became more detailed and it is possible that her comfort levels may have contributed to her feeling able to offer deeper insights into the topics raised in her notes. For example, when discussing the point, 'I can make friends', she continued to expand on the central role of shared interests in her friendships:

> The people I don't like in school are often ones who don't have the same likes as me. The people I get on best with also like the same things as me, such as cats, dragons, craft/art, books, Minecraft. We can talk about the things that we like. I wish there was someone in school who really likes mushrooms and/or cacti because I find them interesting (Chloe)

It was noted how central the presence of mutual hobbies and interests were to the formation and development of Chloe's friendships by her reflection that the people she does not like 'are often ones who don't have the same likes as me'. This could be seen as a limitation for Chloe in her comment 'I wish there was someone in school who really likes mushrooms and/or cacti'. This suggested that her interests were distinct from those of her peers, something that she also hinted at in her discussion about the playground. There was also a sense of yearning in the quote above that suggested a level of dissatisfaction in her social life. Since Chloe found talking difficult, her mentioning 'we can talk about things that we like', may link with the idea that interactions with peers could be less effortful if there was a shared interest on which the conversation can focus.

Data Collection Experience with Emily

Like Chloe, Emily also preferred to communicate via text. While she did initially meet with the first author via video software, the bulk of our exchanges were undertaken via email. She initially tried to participate in a spoken interview, but it was clear that she found this challenging, as demonstrated in this exchange:

> Interviewer: What are the things about school that you enjoy the most?
>
> Emily: [unclear - very quiet voice]
>
> Interviewer: Pardon?
>
> Emily: [unclear - very quiet voice]
>
> Interviewer: I'm sorry, I didn't catch that.
>
> Emily's mother: Use your really big girl voice....
>
> Emily: Gymnastics
>
> Emily's mum: That's it good work

Like Chloe, Emily wanted to participate in the study but found talking very difficult. She was excited about the opportunity to photograph her school life but felt more comfortable exploring her experiences in text rather than speech. However, she found the pressure of typing in real time during an interview challenging so it was agreed that her interview would continue asynchronously via email. She also, in a most welcome surprise, created a 7-page self-written book (reproduced in appendix B) about being autistic entitled 'The secret life of autism' (Figure 2).

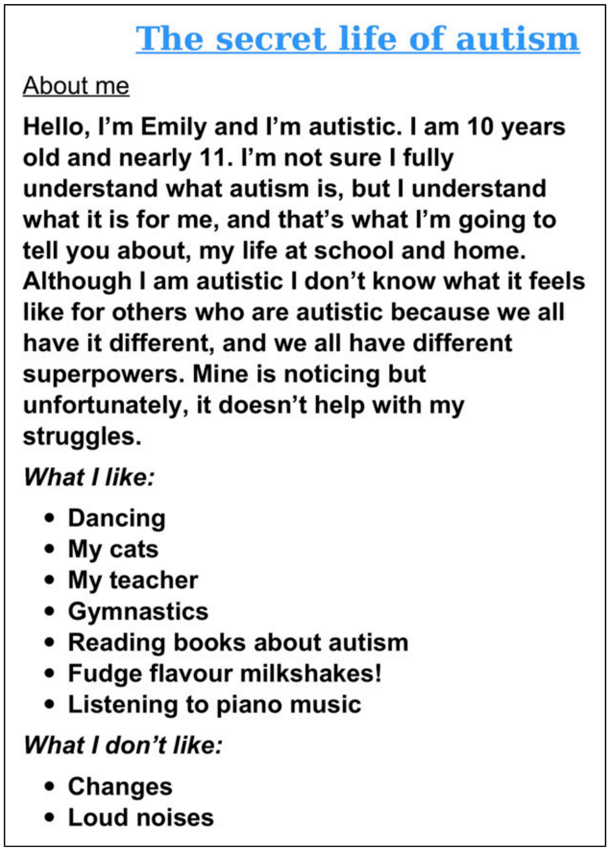
The combination of her book and her photographs gave the first author an abundance of material to draw on in their written exchanges. Many of Emily's contributions centred around the challenges which arose from being a predominantly non-speaking child in an environment which places primacy on talking. In particular, she explained the fatigue this caused her and the impact that had on her mood (Figure 3).

When discussing aspects of school that were less effortful, the issue of communication was also central (Figure 4).

Emily's emphasis on animals understanding her is especially interesting when placed in the context of her difficulties with spoken language. In her interview, she expressed that she often feels misunderstood and commented on not always being given the time and space she needs to communicate. She explained that communicating with animals was preferable to communicating with people since animals placed no pressure on her to communicate in a prescribed way. Her sensitivity to noise was also alluded to when she said that one of the helpful things about the schools' therapy dog is that 'he doesn't bark'. For Emily, the comfort she experienced around Buddy and her cats is expressed in her comment 'They help me calm'. This is all the more salient when contrasted with the tension she tends to feel in school generally. It was suggested that, for Emily, school was a very stressful experience in which most aspects of her day were fraught with tension. This is most plainly expressed when the first author asked her via email how she copes with this tension:

> Interviewer: How do you relax at school if you are feeling sad or overwhelmed?
>
> Emily: I don't relax at school

Emily's response here portrayed a sense of being in an enduring state of bodily and psychological unease. Much of this appeared to be connected to how difficult spoken



The secret life of autism

About me

Hello, I'm Emily and I'm autistic. I am 10 years old and nearly 11. I'm not sure I fully understand what autism is, but I understand what it is for me, and that's what I'm going to tell you about, my life at school and home. Although I am autistic I don't know what it feels like for others who are autistic because we all have it different, and we all have different superpowers. Mine is noticing but unfortunately, it doesn't help with my struggles.

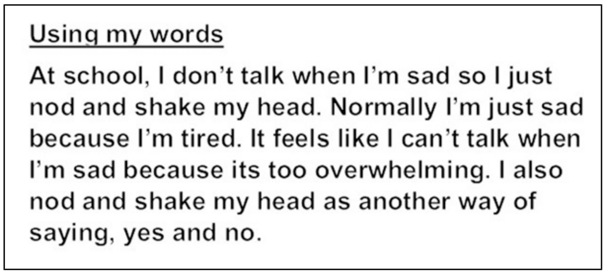
What I like:

- **Dancing**
- **My cats**
- **My teacher**
- **Gymnastics**
- **Reading books about autism**
- **Fudge flavour milkshakes!**
- **Listening to piano music**

What I don't like:

- **Changes**
- **Loud noises**

Figure 2. Front Page of Emily's Book.

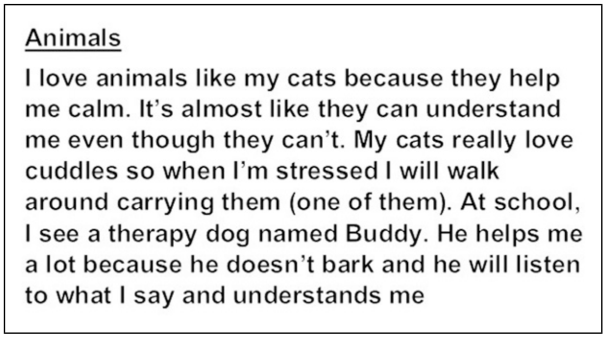


Using my words

At school, I don't talk when I'm sad so I just nod and shake my head. Normally I'm just sad because I'm tired. It feels like I can't talk when I'm sad because its too overwhelming. I also nod and shake my head as another way of saying, yes and no.

Figure 3. Extract From Emily's Book About Feeling Overwhelmed.

communication could be for her. It was possible that, because of the primacy given to oral communication in school, Emily felt she had to remain alert to any communication demands. She may have developed a hypervigilance around communication hence her inability to relax while she was in her school environment. In contrast, Emily's relationships with her chosen animals offer her an experience of connection without the pressure of having to talk. Additionally, Emily explained she cannot talk when she is overwhelmed. It did not appear to be a choice for her. It seemed that the effort involved in being in school was so great that it sometimes left her unable to speak.



Animals

I love animals like my cats because they help me calm. It's almost like they can understand me even though they can't. My cats really love cuddles so when I'm stressed I will walk around carrying them (one of them). At school, I see a therapy dog named Buddy. He helps me a lot because he doesn't bark and he will listen to what I say and understands me

Figure 4. Extract From Emily's Book About the Important Role Animals Play in her Life.

Discussion

As highlighted previously, there has been a welcome increase in recent years in the publication of qualitative investigations into the lived experiences of autistic people. Within the context of education, such research has provided important insights into the everyday challenges experienced by autistic children including sensory discomfort (Birkett et al., 2022), difficulties in accessing academic support (Hummerstone & Parsons, 2021) and the pressure to suppress one's differences (Mesa & Hamilton, 2022). However, within the specific context of IPA, explorations of subjective autistic experiences have largely been confined to older adolescents and adults (see previously mentioned reviews by MacLeod (2019) and Howard et al. (2019) for summaries), with younger autistic children featuring rarely. While the existing literature contributes in important ways to our understanding of autistic people's educational experiences, the tendency in the extant

Table 2. Personal Lessons Learned From This Study.

Study design	It is essential that autistic expertise is embedded within the study from the beginning. This is especially important if the research is being led by non-autistic people. Ensuring that all aspects of the study are underpinned by a detailed understanding of autistic culture and communication will contribute significantly to the overall quality of the study and reduce the potential for epistemic harm.
Participant selection	Prioritise inclusive communication practices when identifying potential participants. Ensure your remit includes those who communicate in non-speaking ways. When speaking autistic people participate in your study, do not assume that speaking will be effortless. Recognise that it may take considerable effort and be energy-depleting. Gather specific information about communication preferences and adjust your interactions with participants accordingly. Assume responsibility for ensuring that participants feel able to take part in the study rather than placing responsibility on them to communicate in particular ways in order to be acceptable.
Gathering consent	Ensure that trust-building is a central part to the consent process. In addition to the usual ethical protections concerning research with human participants, autistic participants and their caregivers need to know that they will be accepted for being themselves while taking part in the study. Parents and carers of autistic children especially need to know that their children are in safe hands and there will be understanding, acceptance and non-judgement of their authentic ways of being throughout the research process. Opportunities for the child to withdraw assent need to be provided regularly and rehearsed if necessary.
Data collection	It is important to build familiarity and predictability so ensure that there are a number of opportunities for participants and caregivers to meet researchers prior to the main data collection exercise taking place. This can be done via introductory documents (e.g., one-page profiles with photographs of the research team), short videos, and face to face or online meetings. Prioritise sensory comfort. For this reason, collecting data when the participant is in a familiar place may help. Otherwise, gather information about which environmental adjustments might help (e.g., low lighting, soft furnishings, the absence of ticking clocks, avoiding strong smells etc (see Doherty et al. (2023) for detailed guidance)
Analysis	For non-autistic researchers, overcoming the double empathy problem is key to a trustworthy analysis. This is where access to autistic expertise is crucial during all stages of the project but particularly during the analysis. In the care of the present study, to ensure mutual understanding, the first author met with participants after the initial analysis but before developing Personal Experiential Themes. Participants received their initial themes in advance to reflect on them before discussion. This meeting ensured ongoing analytical decisions were based on interpretations that the participant deemed meaningful and authentic.
Reporting	How autism research is framed, described and disseminated is central to the theme of epistemic justice in this paper. The avoidance of ableist language and the promotion of affirming conceptualisations of autism which honour each participant's fundamental humanity are essential to reporting research findings in an equitable and ethical way.

IPA literature to focus on older participants could be interpreted as another aspect of the previously mentioned ‘elite bias’.

With the knowledge that the school experiences of younger autistic children – especially those who employ communicative modalities other than speech - are largely absent from the IPA literature, we believe that our study makes a novel and creative contribution to what we know about autistic children’s primary school experiences. By focusing on an underrepresented population and stepping away from the idea that all ten participants needed to engage in the study in similar ways in order for the data to be valid, we were free to accept the invitations they extended to us. We did not consider Chloe’s rejection of the idea to take photographs as a setback and we did not ask Emily to write a book but were delighted when she did. When these two participants told us that they did not want to speak with us, we regarded their written contributions as of equal value to the data collected via the spoken interviews conducted with other participants. It is arguable that had we not made these decisions, Chloe and Emily may have been excluded from the study on account of their inability to conform to normative expectations.

Furthermore, it is probable that the high level of autonomy afforded to the participants enabled the first author to develop a level of trust and familiarity with the participants which we feel is reflected in the richness of the data collected across the sample. It is arguable that our participants’ autonomy was connected in important ways to the use of online platforms for interviews. As this study was conducted in the aftermath of the school closures during the Coronavirus pandemic, we initially viewed remote interviews as a necessary but potentially inferior alternative to face-to-face meetings. However, we soon became aware of the enormous benefits of this approach to data collection with our participants. In addition to the communicative advantages previously described, it was clear that being able to participate in the study from the comfort and familiarity of their own homes was instrumental in helping our participants feel more at ease during the data collection process.

Participants were also able to achieve sensory comfort by wearing clothes they preferred and choosing rooms and seating or lying positions which suited them best. It is estimated that between 65%–80% of autistic children process sensory information differently to non-autistic children (Baranek et al., 2006; Tavassoli et al., 2016). While some of these experiences can be enjoyable, others have been found to be distressing and can have a significant impact on wellbeing (Acker et al., 2018). In particular, oversensitivity to sensory information (e.g., light, sound, temperature etc.) has been associated with increased levels of anxiety (Carpenter et al., 2019; Green & Ben-Sasson, 2010). Therefore, it is possible that the levels of sensory comfort experienced by our participants in their home settings would have been very difficult, if not impossible to recreate in a typical research setting and this could have contributed to the quality of the data we collected.

In addition to the research advantages outlined above, the methodological approach used our study also has potentially important implications for educational and clinical practice given the widespread primacy given to spoken communication in such services. A recent study into barriers to healthcare for autistic adults found that 30% of respondents avoided face to face verbal communication, and 40% remarked that it was easier for them to communicate in writing (Doherty et al., 2022). Such findings have implications not only for primary care but also for mental health services in the UK in which talking therapies are a common first line of response for those experiencing anxiety and/or depression symptoms (Clark, 2011). These implications are even more significant in light of the elevated incidence of anxiety and depression in the autistic population (Hollocks et al., 2019).

Time was the most crucial aspect of this study. We needed sufficient space to build relationships with participants and caregivers, support their need for information processing and self-expression, and engage in deep reflective practice, especially during analysis. Meaningful collaboration with our autistic mentors also required time. Rushing any part of the process would have risked the project’s integrity and potentially undermined the trust we had built our participants and mentors.

To summarise, Table 2 briefly details the key lessons we learned from this study. It is important to note, however, that a detailed description of participatory autism research practices is beyond the scope of this paper. Furthermore, there is an existing literature which focuses specifically on such matters which we would urge researchers to consult before embarking on a study involving autistic participants (e.g., Beck et al., 2025; Botha & Cage, 2022; Bottema-Beutel et al., 2020; Fletcher-Watson et al., 2019, 2024; Pellicano et al., 2022).

Limitations

While this study included intermittently-speaking participants, all participants could communicate with the team in mutually understandable ways. Autistic children who speak no or few words and/or have a co-occurring intellectual disability are a vastly underrepresented population in the research literature and there is an urgent need for research into methodological approaches which support assistive or alternative communication.

Despite the advantages outlined above, the technological requirements of this study could also be seen as a limitation. It would not have been possible to take part in our study without a reliable internet-enabled device and we are aware that this will have potentially been a barrier to participation for some children and their families.

Conclusion

In this paper, we have established how traditional research practices may have contributed towards the marginalisation and pathologisation of autistic people, particularly children. In an attempt to counter historic epistemic injustice, we have explored ways in which multimodal IPA could be employed to include young autistic children with a range of communication preferences in research about their everyday lives. In particular, by providing worked examples from our own research on autistic children's experiences of mainstream primary school, we have attempted to argue the case for how IPA's epistemological underpinnings and methodological flexibility can provide a framework for conducting more equitable and inclusive autism research. Furthermore, by including participants who are underrepresented and potentially excluded from much of the published qualitative autism literature, we have argued for approaches which could potentially address the tendency in qualitative research to only include autistic participants who communicate in normatively typical ways.

In conclusion, there is a need for greater acceptance and legitimisation of the various ways in which autistic children communicate, and how much effort it might take for an autistic child to communicate in ways that are deemed acceptable to others. As observed by Wood (2020), "…to be autistic is to be […] perceived as saying the wrong things, in the wrong way, and at the wrong time" (Wood, 2020, p. 4). It is our assertion that developing an appreciation for the dignity of autistic forms of communication and facilitating alternative forms of communication plays a central role in challenging epistemic injustice in autism research.

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Supplemental Material

Supplemental material for this article is available online.

Notes

1. Education Health and Care Plan – a statutory form of support provided to children and young people in schools in England who are perceived as having special educational needs which exceed the resources typically available to all children in a school.
2. Due to barriers to accurate and timely identification (Crane et al., 2016, 2018) these data are likely an underestimation of the autistic children in the English school system as they are below reported prevalence rates of autism in the general population (Maenner et al., 2023; NHS Digital, 2024).

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