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Co-designing methods with autistic students to facilitate discussions of sensory preferences with school staff: exploring the double empathy problem

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Co-designing methods with autistic students to facilitate discussions of sensory preferences with school staff: exploring the double empathy problem

Reviews have called for the greater involvement of autistic young people in developing methods for eliciting their views. Methodologically, co-design is important for developing credible and acceptable approaches; conceptually and practically, co-design offers a means through which to address the double empathy problem for research and practice, which states that autistic people have difficulties understanding the perspectives and communication of non-autistic people, and vice versa. This study reports both methodological and pedagogical observations through critical reflections on a co-design process of a paper-based method for sharing information about sensory preferences with six autistic students aged 12-13 years, 16 educational practitioners, and five autistic adults. The co-design process supported students to share information with each other and build self-awareness. Participants were positive about the potential for sharing information but raised concerns about the extent to which new knowledge would impact on teaching practices. Co-designed methods are needed in tandem with sustained autism awareness to change attitudes and educational practices.

Keywords: autism; education; co-design; participatory

# Introduction

‘Social research no longer needs to justify children’s participation in research, but there is now a need to question how to achieve their participation’ (Ellis, 2017; p.23).

Ellis’ (2017) comment relates to the methodological developments in social research over the past two decades in supporting children’s more active engagement with, and participation in, research. Such engagement is important for respecting children as competent agents and knowers within their own lives (LeFrançois & Coppock, 2014) and, relatedly, in enabling more authentic and meaningful insights into their lived experiences (Lewis, 2002). Such developments have centred around visual, creative and arts-based methods for supporting the engagement of children with and without disabilities in research (Thomson, 2008), including: photographs (Hoy et al., 2008), drawings (Leitch, 2008), symbols (Germain, 2004), cue-cards (Lewis et al., 2008), arts-based projects (Nind et al., 2012), and drama (Whitehurst, 2007).

Nevertheless, the views of autistic children and young people remain substantially underexplored and underrepresented internationally (Cascio, Weiss, & Racine, 2021; Ellis, 2017; Fayette & Bond, 2017). This is mainly due to a pervasive presumption that autistic children are especially ‘hard to reach’ due to the social and communication difficulties that characterise an autism diagnosis (Franklin & Sloper, 2009; p.4). However, rather than blaming children for their own communication difficulties, the onus clearly lies with researchers to develop appropriate methods and participatory approaches for enabling participation and respecting different communication modes and preferences (Ellis, 2017; Nind, 2008; Parsons et al., 2021). In the autism field, the methodological challenge of enabling voices to be heard includes, and extends beyond, the types of visual or creative methods utilised. Important critiques question the nature of knowledge generation in research and the dominance of ‘neurotypical’ and biomedical perspectives therein (where neurotypical refers to people who are not neurodivergent; see Silberman, 2015). Such critiques point to the lack of autistic voices directly leading, shaping and informing research agendas (Milton, 2014), and the prioritisation of some kinds of evidence (formal, ‘scientific’) over others (phenomenological, personal) (Lawlor & Solomon, 2017), echoing arguments of the Disability Rights Movement and concomitant debates and developments in research towards more emancipatory and inclusive methodologies (e.g. Armstrong et al., 2019; Bunning et al., 2017; Johnson & Walmsley, 2003).

Additionally, the ‘double empathy problem’ as proposed by Milton (2012), states that autistic people have different ways of experiencing and understanding the world due to perceptual, sensory, and cognitive differences. These differences are difficult for non-autistic people to understand, and vice versa, which can lead to mutual misunderstanding if not navigated effectively. Crucially, the methodological implications of the double empathy problem are significant, as research needs to develop and apply methods that enable the meaningful and accessible sharing of perspectives which are informed directly by autistic people. In other words, given the range and complexity of communication preferences across the autism spectrum, it is not enough to simply ask someone to explain their views or what life is like for them (Silver, 2019). Instead, autistic people need to be more involved in the creation and evaluation of methods and questions that are applied in research to ensure they are fit for purpose (Parsons et al., 2021). Additionally, adults who know autistic children well (e.g., parents and teachers) are also vital sources of information and facilitators or enablers of participation, and so it is important to recognise their roles in methodological developments too (Ellis, 2017).

## The special challenge of education in England as a site for autism social research

Education practice occupies an important space within discussions about voice and participation since, unlike many other areas of autism research, the contributions of autistic children’s voices to decision-making about service provision and transitions in England are mandated by the Special Educational Needs and Disability (SEND) Code of Practice (Department for Education, 2015). Specifically, the Code of Practice is clear that the views of children with SEND must be sought directly and that proxy views are not appropriate. Educational experiences and outcomes for many autistic children and young people are well-documented as being poor (APPGA & NAS, 2017; Parsons et al., 2011), with strong recognition of the need to understand individual perspectives and experiences to create more inclusive educational environments and improve outcomes (Parsons et al., 2011; Parsons, 2015). However, children’s views are often subverted within formal processes and reviews (Palikara et al., 2018), and strengths and capabilities overlooked (Parsons et al., 2021). Chief amongst the challenges reported by autistic pupils and their families is the failure of teachers to understand autism in general, and the needs of individuals specifically (APPGA & NAS, 2017). Thus, there is a strong convergence of the needs of research and practice in education to find more effective ways to enable autistic children’s voices to be heard.

Fayette and Bond (2017)’s systematic review of the international literature, focusing specifically on qualitative research methods used to elicit the views of autistic young people, drew a similar conclusion:

‘…collaboration between researchers, practitioners and the individuals themselves can help improve the appropriateness of the questions and the methods as a whole… in practice, young people should be actively involved in the development and evaluation of ways in which professionals such as teachers, careers advisors and educational psychologists elicit their views in matters that affect their lives’ (p.363).

However, Fayette and Bond (2017) also concluded that most research studies that have aimed to elicit the views of autistic children and young people have not been carried out with their active involvement or collaboration, but have instead been applied to them. Thus, there is considerable room for the development of methods in co-construction with autistic young people. Moreover, Fayette and Bond (2017; p362) recommend that researchers need to provide ‘detailed documentation’ about their methodologies and the aspects that were successful in order to enable participation in research and strengthen links between research and practice. It is in response to this recommendation that we contribute this paper. When reflecting on research in education, especially within the context of highly situated, participatory research such as this, there is inevitably considerable overlap between research methodology and pedagogical methodology and implications, and thus this paper comments on both.

# Materials and methods

We draw upon the Doctoral research of the first author (Hummerstone, 2018) to illustrate and critically discuss one approach to methodological co-design focusing on understanding sensory differences. The first phase of the research worked with six autistic students aged 11-13 years to explore their experiences of support and communication in mainstream secondary schools in England using a photo-elicitation methodology (Hummerstone & Parsons, 2021). Seven teaching staff were also interviewed to understand what support for, and communication with, autistic students was like from their perspectives. Findings identified four main areas where students’ and teachers’ perspectives differed from each other (for details see Hummerstone, 2018), which were subsequently explored in the second phase by co-designing activity-based research methods for each area with autistic students. The information from these activities was then summarised in a personalised student information sheet. The aim was to facilitate communication and support between the autistic students and staff members by increasing the latter’s knowledge about the students.

The general design philosophy and overall approach related to all four activities is described below before focusing on the development of the method for exploring sensory differences. Students identified several examples of how sensory experiences impacted them, yet staff members showed minimal knowledge about this despite sensory differences being well-recognised in major reports (e.g., APPGA & NAS, 2017). We focus on this area due to its identification as a top ten priority for autism research by autistic individuals (James Lind Alliance, 2016), and given its increasing prominence in reports of (usually negative) educational experiences (Hummerstone & Parsons, 2021; Bogdashina, 2003).

## Design philosophy and choice of participatory approach

A user-centred design approach was applied whereby the ‘users’ of any method or technology (in this case, the students) are seen to have specific knowledge and needs that must be captured to create an effective design. Accordingly, the design process focuses on understanding what those needs are, addressing them in the design, and then gaining feedback (often iteratively) on the design, prototype or product developed (e.g., Parsons and Cobb, 2014). User-centred design also aligns very clearly with the important concept of ‘insider epistemology’ (Tangen, 2008; p.159) which states that is vital to listen to students’ voices because they can provide unique insights about their thoughts and feelings that cannot be observed or hypothesised by others. Druin’s (2002) conceptualisation of informant design, in which children play important roles in design processes through sharing their ideas and perspectives and feeding back on researcher-initiated prototypes, was also useful for clarifying the autistic students’ contributions in this research. Choosing informant design meant the students were included at several stages of the activity designs, while overall control was retained by the first author to answer specific research questions as part of a Doctoral thesis. Design feedback was also sought from five autistic adults – recruited from an autism advocacy group – to help avoid normative assumptions and interpretations of the students’ responses made by a non-autistic researcher, and to more effectively consider possible communication differences that might affect the research (thus navigating the double empathy problem). Informant design therefore not only suited the level of involvement desired for the students, but also included the adults’ contributions while allowing the researcher to ‘recognise the different contributions made by different contributors’ (Brna, 2008, p.61).

## Avoiding the blank page: researcher-led design initiation

Given the importance of visual representation and methods for autistic children (e.g., Ellis, 2017), the initial design needed to be interactive to promote engagement, and flexible enough to accommodate the diversity of individual students’ expertise and experiences (Porayska-Pomsta et al., 2012). Incorporating a visual element also allowed for different communication preferences when completing the activity, as students could provide non-verbal (written) and / or verbal information. Although apps are available for users to represent their sensory experiences, given the constraints and debates on using apps within schools (Selwyn & Aagaard, 2020), and limited opportunities for personalisation, it was important that any methods developed would not be vulnerable to these concerns. Any activities designed also needed to be easy to edit, transport and reproduce for use in the school environment, and therefore these factors had to be considered.

In terms of the design content, it is not optimal to begin a design process with a blank page; some initial ideas are needed to successfully kickstart the generation and review of ideas (e.g., Frauenberger, Good, Alcorn & Pain, 2013; Benton & Johnson, 2014), and this is also true for encouraging detail about sensory experiences (Hart & Whalon, 2008). Concrete sensory examples to use were therefore chosen from the literature review of the thesis, and from the experiences of the autistic adults and students in the first research phase (see Hummerstone, 2018 for details). These considerations resulted in an initial design which was monochrome, paper-based, and modelled on the idea of a mixing desk in a recording studio, resulting in the name ‘Motivation Mixer’. Each ‘channel’ on the mixing desk was envisaged as a different sensory experience, the ‘level’ of which could be adjusted (see Figure 1).

## Informant participatory design process: participants and procedure

Students and autistic adults involved in the first research phase indicated that they were happy to continue their participation into this second phase. The participants comprised six students (five male, one female, although gender neutral pronouns and pseudonyms are used throughout) on the autism spectrum aged 12-13 years attending two different mainstream secondary schools (three in each school): Bob, Genji, Hanzo, Jack, Sage, and Yazi. The five autistic adults had received a diagnosis of either Asperger Syndrome or Autism Spectrum Disorder as adults and were aged 30-70 years: Alex, Ann, Dan, Emily, and Peter (all pseudonyms apart from Dan, who wanted to use his own name). The adult participants received information sheets about the research and were asked to sign consent forms. Parents of the students were also requested to provide informed consent, and the young people provided their assent to take part following the sharing of more accessible, student-friendly project information. The research was reviewed and approved by the University’s Faculty of Social Sciences Research Ethics Committee (Ethics number: 23921).

The researcher met with the adults for a focus group discussion about the Motivation Mixer. The group was asked to consider the ways in which the design could help students to communicate to teachers, for teachers to understand more about the student, and how it could be improved. The discussion was audio-recorded, and the group’s feedback summarised and agreed upon during the session. Students were visited in their schools to discuss the design in groups. Meetings took place within private rooms and were audio recorded. Students were asked to consider whether the design could help them to talk to teaching staff, whether it could help teaching staff to support them, and how the design could be improved. Following the discussion, the researcher summarised the feedback and the students confirmed it was an accurate representation of what they had said.

## Iterative design based on feedback

Overall, the autistic adults were positive and hopeful about the potential of the Motivation Mixer to improve the understanding of students by teachers:

‘The process of looking at [the activities] will definitely help to identify how to help people…because when you’re younger, you have no idea that your experience of the world is different to everyone else’s, so you might not think to mention the fact that actually, certain things are really stressing you out. You might not have realised that, actually, it’s the noticeboard. Or you might say ‘it’s the noticeboard’ but no one would understand why or what’s wrong with the noticeboard and why you aren’t paying attention in class. It’s drawing both the [staff] and the students’ attention to the possibilities’ (Emily)

However, the students and adults all highlighted the need for more specific instructions and examples to make the activity clearer to understand. For example, feedback suggested that the Motivation Mixer labels needed to be changed to add different sensory categories, rename the category labels, add a written prompt sheet, include colour pictures, and remove some of the text. Figure 1 shows the subsequent revised version.

[Figure 1 to be inserted here]

Implementing the designs with students to create individualised information sheets

Students met with the researcher individually over a two-month period to complete the activities, including the Motivation Mixer. All six students added their own annotations when completing the Motivation Mixer activity. For example, Bob talked about the need for background noise to concentrate; fiddling with pens and general stationery helped to channel anxiety in new situations or with new people; and higher levels of excitement led to increased movement, e.g., when playing video games. Sage identified specific noises and smells that induced nausea, pain and tears. Genji identified that ‘not shouting’ was the most important thing teachers could do to help, whereas for Yazi, being allowed to fiddle without being told off was crucial in reducing anxiety.

Once the activities had been completed, detailed discussions took place about the information and graphics that each student wanted to be included in an information sheet that would be shared with teachers, including the specific sensory information, preferred colour combinations, writing styles (e.g., first or third person), favourite things that they wished to be featured in the images, and font choices. Students were offered the option of creating their own information sheets without the researcher present, but all were reticent about the idea of doing ‘extra work’ outside of the meetings.

## Evaluation with educators: participants and procedure

Sixteen educational practitioners (two males, fourteen females) provided feedback on the students’ information sheets. Participants were between 20-60 years old and had a range of SEN experience and job titles, including learning support assistant, speech and language therapist, assistant headteacher, and SEN Co-ordinator. Two staff members knew some of the students and participated via a semi-structured interview at their schools. The remaining educational practitioners provided feedback via email. The two audio-recorded interviews were transcribed and added to the fourteen emailed responses, which were then uploaded to NVivo and coded inductively using thematic analysis.

# Results

## Students’ evaluation

While the students were generally positive about the activities themselves, they were not at all hopeful that completing the activities and sharing information with staff members would help staff to develop their understanding about the students:

‘It’s great you are doing [the activities] with me and the others, but it won’t change what [member of staff] thinks about me. [Member of staff] will always hate me; [they] don’t get me at all.’ (Sage)

Similarly, Yazi gave the following example of a teacher not understanding their need to stim (self-stimulating behaviour linked to sensory needs; see Lilley, 2017, for a discussion) with the fidget putty they had been given:

‘[The teacher gave me a dirty look] … and I was like, ‘well, ok, but I’m still going to fiddle with this…it’s in my rights now because I’ve got a diagnosis’’.

Yazi expressed feeling initially guilty because of fidgeting, before remembering that the use of fidget putty had been included as a coping strategy in a report from Child and Adolescent Mental Health Services (CAMHS). However, Yazi still felt that this member of staff disapproved, despite being explicitly told that fidgeting helps Yazi to concentrate. In exploring the reasons why students felt nothing would change, Bob mentioned that some staff were willing to understand, and some were not. When pressed to explain this further, Bob replied ‘I don’t know…some just care more, maybe’.

## Educators’ evaluation

A clear theme was that the personalised information sheets were useful for increasing understanding of individual students:

‘I like that it's in [their] own words. So often, the conversation about a student involves a myriad of people, but not the child.’ (Siobhan, Peripatetic music teacher)

The two teachers who knew the students indicated that they were familiar with some of the information but there were also some surprises:

‘Things like the sensory stuff – sensitive to hearing, touch – I mean, these are things that I would never ever have known, and that’s not the sort of information that would come through something like that [gestures to Jack’s individual learning plan].’ (Nancy, Assistant Head of Department)

Educational practitioners who did not know the students suggested that the knowledge gained would be valuable:

‘[Genji’s] information about memes and cartoons: This suggests an area of expertise, and thus the ability to acquire knowledge. It also expresses a desire to share.’ (Stella, Secondary school teacher)

There were also examples of how the information sheets could promote wider awareness of the needs of autistic students:

‘[The knowledge from Jack’s information sheet] would make me question the behaviours of other children and the underlying reasons…I could also use some of the strategies suggested by Jack to see if they help other children whom appear to be struggling.’ (Helen, Assistant Headteacher)

Interestingly, one teacher commented how this kind of approach could be extended to include the teacher’s perspective thereby addressing both sides of the double empathy problem:

‘You know something that would be interesting...Two columns – that side is the student [left], this side is how the teacher perceives the student…just saying ‘my impression of you is this’…so the students have access to this too, and they can see ‘oh right ok, this is what they [member of staff] feel when I do X/Y/Z’.’ (Nancy, Assistant Head of Department)

Another key theme related to how educators would use the information to adapt their communication to support the students:

‘When speaking to Bob, have some form of guide or prop that [they] can choose to look at rather than expecting [them] to maintain eye contact (instruction sheet, work, a demonstration item etc).’ (Victoria, Assistant Head of Department)

Three educators suggested that additional information was needed to adequately create communication guidelines from the information provided, e.g.:

‘I believe it would be best if I worked with Jack’s parents/carer to get as much information and…communicate with [Jack] in a way that [they are] used to. Also, gain an understanding from them [parents/carer] of what I should look out for as initial signs of interest/ distraction/ distress/ difficulty (verbal and non-verbal) when I work with Jack.’ (Mira, Lecturer in Higher Education)

Some comments also related to the limitations such as whether teachers felt they had sufficient time, resources and support to implement any changes to practice:

‘The problem is it’s all very well me doing this while I’m teaching [Sage], but what happens if a supply teacher comes in? Or [Sage] annoys one of the cleaners because [Sage is] upset by some of the smells…I know it’s meant to help, but you can’t give all this information to everyone who will come into contact with [Sage] just in case [Sage] gets upset – that’s just not possible.’ (John, Secondary school teacher)

‘If you were teaching several students that had these [information sheets] it would take a long time to read them all and information could be muddled.’ (Carol, Head of Department)

‘I would not have enough time to prepare adequately to address [Genji’s] issues, so I would have to do my best… Even with a TA it would be difficult to adequately plan.’ (Stella, Secondary school teacher)

Finally, one teacher commented how the information could be the students’ responsibility to remind teachers about periodically:

‘I think what [the information sheet] does…it creates a dialogue with the teacher. And then it’s up to [Yazi] to keep having a go at the dialogue, say once a term, as a reminder - because as teachers, we get set in things and focussed on other stuff.’ (Amy, Head of Department)

# Discussion

Methodologically, the co-design of methods for supporting autistic children and young people to share their views is a much needed yet significantly under-researched area (Ellis, 2017; Fayette & Bond, 2018). Participatory approaches to research are lauded (Fletcher-Watson et al., 2019), and needed for reducing marginalisation and improving the authentic generation of knowledge (Milton, 2014), but are rarely straightforward in practice (Parsons & Cobb, 2014; Seale et al., 2014). Therefore, it is important to share experiences and to reflect critically on what has been learned as well as where the limitations and compromises to participation may lie.

Our co-design approach with autistic students is aligned with Druin’s (2002) conceptualisation of informant design, in which children play important roles in design processes through sharing their ideas and perspectives and feeding back on researcher-initiated prototypes. This approach inevitably required a compromise in shared power and decision-making and is recognised by others (e.g., Mearns et al., 2014). However, this compromise was likely necessary for enabling the participation of otherwise marginalised voices in ways that felt supportive and constructive for them. Starting with an empty design space, with young people who may not be used to having or enacting choices (Nind, 2008) may be disabling and disempowering, resulting in disengagement, and so we purposely avoided doing this. Such an approach has also been noted as important for participatory research in education more generally (Parsons & Cobb, 2014; p.351):

‘…in conducting participatory research in education, it is often problematic to commence with a research space that is too wide and open – a blank slate of possibilities may not be helpful. Instead, the people we engage in the research process often require and value some initial ideas and suggestions (from academic researchers) as a starting or discussion point.’

The students appreciated the methodological starting points provided by the researcher, and were engaged with the ideas, but were also clear that they did not want to spend time outside of our sessions together doing the ‘work’ that fuller participation may have entailed (something also experienced by Hall, 2014). This led to the practical negotiation of how their involvement would be managed, which was always within school time and in pre-arranged sessions with the researcher. Due to time constraints this meant a final ‘sign-off’ of their information sheets was missing from the students. This lack of member checking (Guba & Lincoln, 1989) therefore limits the credibility of the information presented in students’ sheets, and the findings based upon them.

It could be that students would have been more motivated to contribute ‘work’ for the project had the initial ideas for the information-sharing methods come from them. Alternatively, it could be that a more open starting point would have been more challenging and off-putting, resulting in a lack of engagement or withdrawal, thereby undermining the entire participatory intent. We cannot know what would have happened had we tried to do things differently, but acknowledge that the decision about where and how to start and sustain a participatory research process has some important implications for research practices, illustrating why the kind of detail about methods as requested by Fayette and Bond (2017) is needed. In addition, it should be noted that the autistic adult participants were highly motivated and could express themselves verbally, and that the student participants were similarly capable and attending mainstream education. Therefore, the success of these methods with non-verbal autistic individuals in different educational settings cannot be generalised.

Despite the compromises around idea-initiation, there were apparent benefits to the students in participating in the design process overall. Including a group element in activities that asked explicit questions about students’ experiences seemed to increase their own levels of self- awareness and awareness of others’ experiences of autism. For example, after completing the Motivation Mixer with Hanzo and Jack, Bob commented how different the responses were between them:

‘It’s interesting…we’re all in different places [on the sensory channel of ‘speed of thoughts’] even though we all have autism.’

As diagnosis and experience of any student is highly individual, this comment reinforces that it is vital to find out what individuals think and feel to understand their experiences of education, and to find ways to listen effectively to what they have to say. Strengthening self-awareness can be effortful for autistic individuals (Müller, Schuler & Yates, 2008), and therefore group-based activities may be useful for enabling autistic students to explore their needs and support communication of these needs with others in school. This highlights that involvement in co-design processes (or participatory research more generally) can have intrinsic value apart from the outcome of any design process or endpoint of the research. Parsons and Cobb (2014; p.437) draw a similar conclusion and propose that researchers should:

‘…consider the learning outcomes that emerge through the processes of engagement and participation along the way, as well as via use of the ‘learning object’ that is eventually produced.’

Such consideration could be one way of recognising participation in a more nuanced way over time. For example, while the students did not initiate ideas or want to do any independent ‘work’ outside the design sessions with the researcher, the time that they did spend participating in the project was considerable and sustained over a few months. Their participation was scaffolded and negotiated with them, and this is not a trivial observation or undertaking.

It was also clear that students’ contributions helped to raise awareness amongst educators about some of the challenges they faced, and this has important implications for teacher training as well as for research methods. When evaluating the information obtained about students through the completion of the co-designed methods, the two teachers who knew the students directly commented, with some surprise, on the sensory information provided, despite knowing the students and being in receipt of their Individual Education Plans. Sensory differences cannot be observed by others, and therefore without the students’ perspectives, the impact of these – both positive and negative – may not be considered by educational practitioners when planning to communicate with and support students. Information about the students’ sensory experiences was therefore seen as something new and useful, and that could change the way these teachers worked with students. Through the students’ contributions of their lived experiences within school contexts from the co-design of materials aimed at eliciting their views, teachers were supported to gain greater insights into those experiences, thereby helping them to gain more ‘interactional expertise’ (Milton, 2014; p.795). Indeed, educators also made positive suggestions for how teaching and learning strategies for students could be personalised based on the shared information. This is not a trivial observation either, since findings from the first phase of this Doctoral research had revealed that teachers tended to consider the needs of the group (whole class) rather than the individual, with the result that students often felt they were not understood (Hummerstone & Parsons, 2021).

However, it was also clear that translating helpful knowledge about the student into classroom practice was potentially problematic. The students did not think that teaching staff would change their behaviour in response to information learned about them; unfortunately, some of the staff comments suggested that the students might be right. Although educators identified detailed and insightful suggestions for how they could individually support these students, their comments suggested that there was a limit to how much responsibility they were willing or able to take. In some cases, resources and time were cited as barriers; in other cases, the tension between the needs of individuals versus the group was mentioned, with one teacher suggesting that it should be the responsibility of the student to remind staff about their own needs and preferences. Extending the methodology to explore both sides of the double empathy problem could potentially challenge some of this thinking, and lead to greater understanding, empathy, and collaboration on both sides of the classroom.

Secondary school staff were also difficult to include in the design process due to their lack of time and availability outside of their core responsibilities, suggesting that the purpose of this activity did not warrant prioritisation of their time. For example, the original research plan for staff feedback was to organise focus groups for those who worked with the students to create some general guidelines about how the information sheet might be used and adapted to inform their communication and support. However, of the seven staff members included in the first phase of the research, only two responded when contacted. As one of the teachers observed, it would have been good to include teachers’ views alongside students to really share both perspectives, suggesting a missed opportunity to address more fully both sides of the double empathy problem.

Able et al. (2015) identified that teachers’ knowledge about autism and their levels of confidence in their ability to work with autistic students are two crucial factors affecting their support for students. This suggests that there are challenges involved when using the personalised information sheets that may not relate to its design or content, but instead relate to the experience and confidence of the educational practitioners using it. Thus, the co-design of methods for enabling students to share their views is just a starting point in a process for addressing the double empathy problem between teachers and student**s**; teacher training may also provide a valuable opportunity to highlight the importance of personalised strategies. While the practice context for the research reported in this paper was in England, the methodological implications have wider relevance since finding ways to more effectively include autistic students through listening to their views is an international concern. This is also a good reminder that listening to students’ voices (and finding ways to do this) is not the same as hearing those voices, which requires a commitment to action to implement changes to practice based on what is heard (e.g., Samways & Seal, 2011). Addressing this issue requires whole-school approaches, prioritised by leadership, that support and enable the respectful sharing of voices between staff and students in ways that are embedded throughout all school activities (Breslin, 2011; Thomas, Walker & Webb, 1998). Part of understanding and sharing this multiplicity of voices is also about understanding autism so that all teachers have key foundational knowledge upon which they can build meaningful relationships with students as well as their own confidence (APPGA & NAS, 2017; Ravet, 2011).

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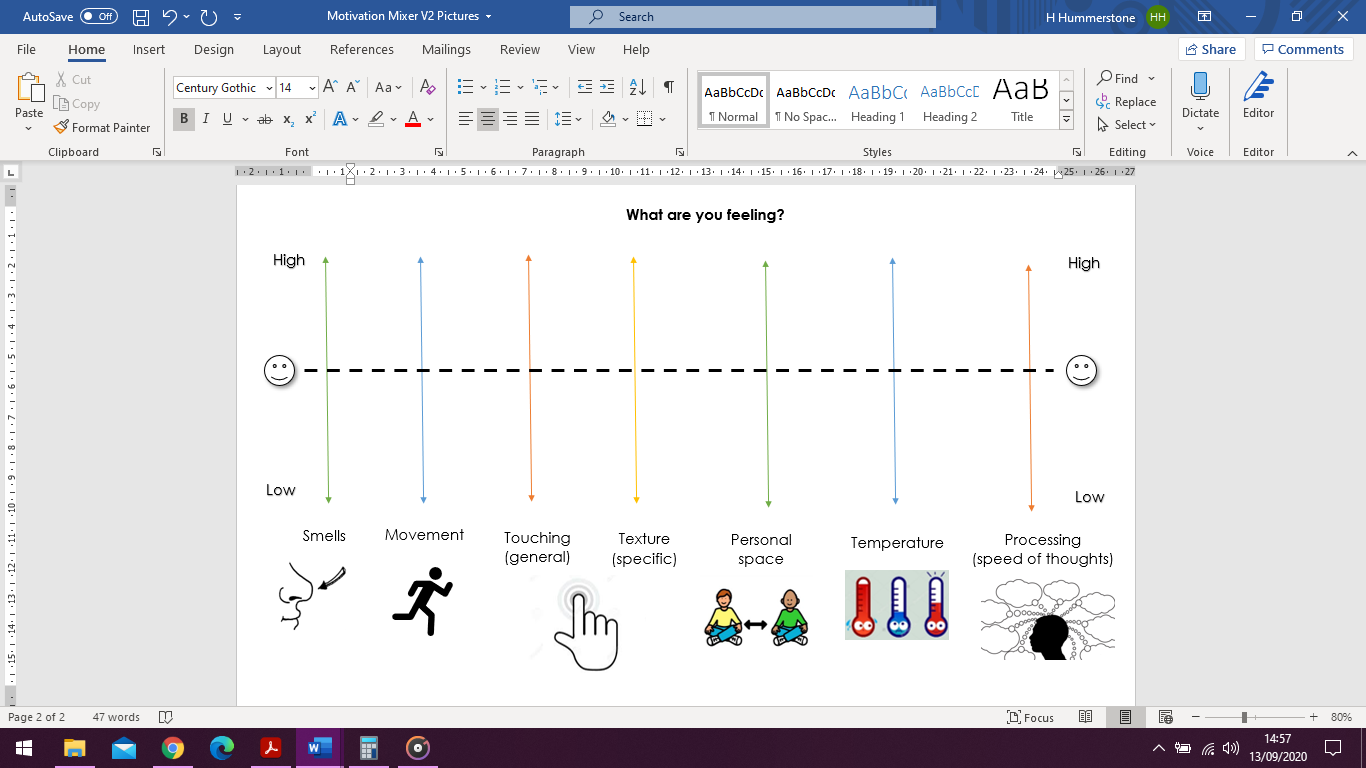
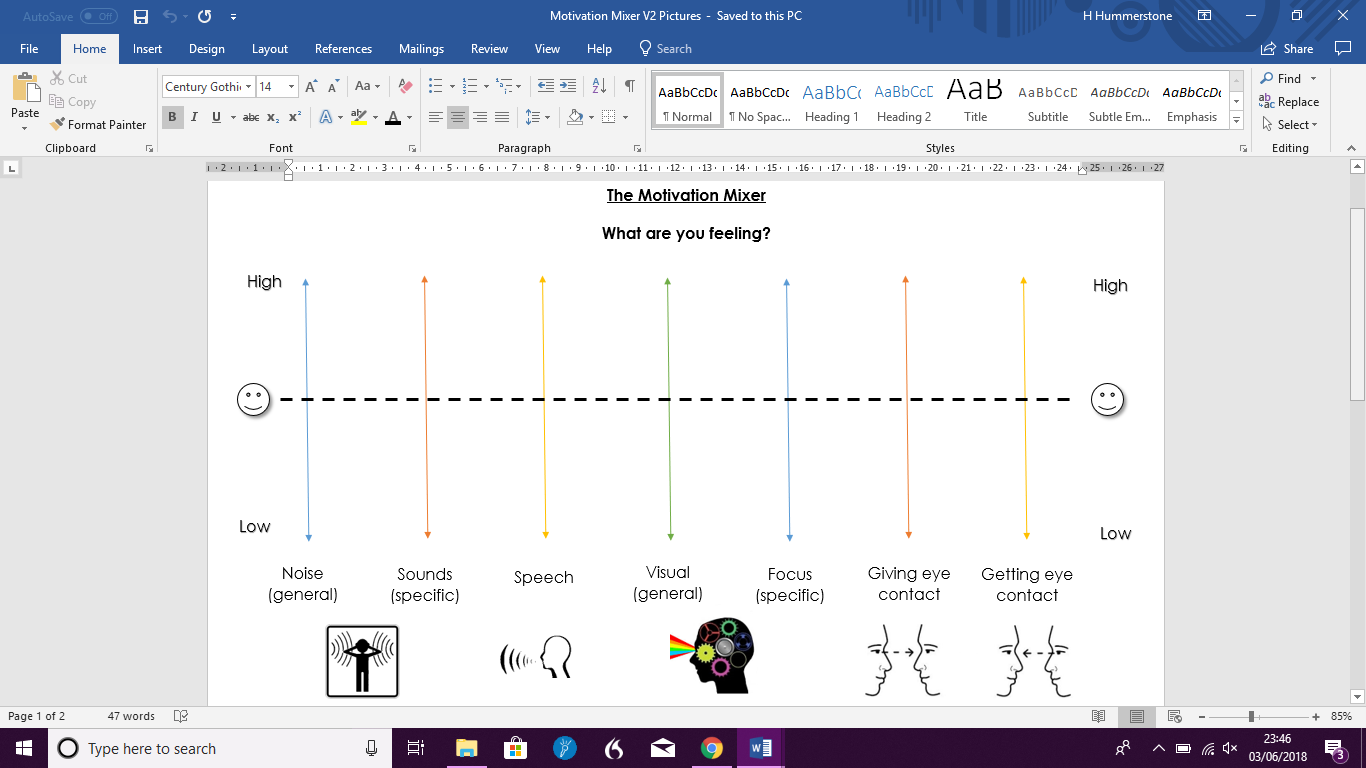
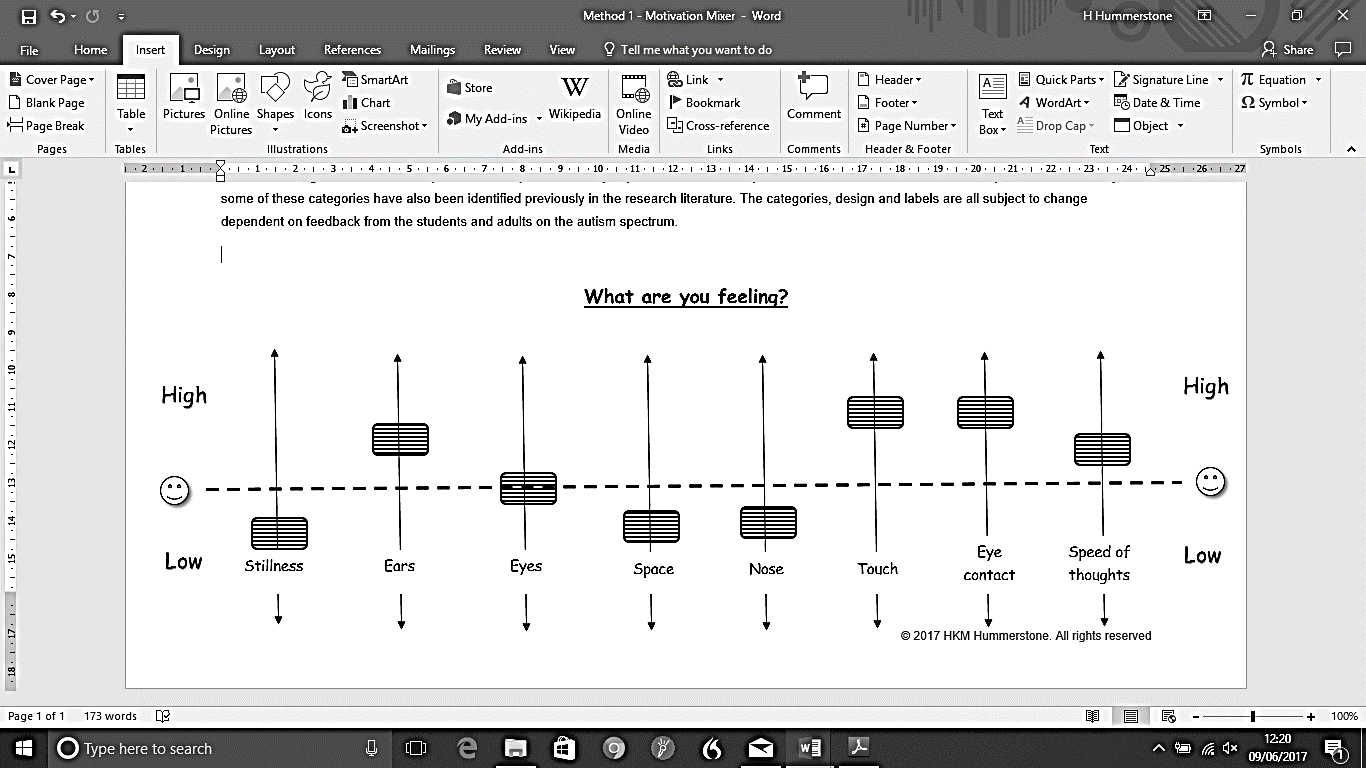
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Figure 1



Original (1 page, grayscale)

Revised (2 pages, colour)

Figure 1. Two versions of the Motivation Mixer: before (original) and after (revised) consultations with autistic students and adults.

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