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Interpretative Phenomenological Analysis (IPA) as a tool for participatory research within Critical Autism Studies: A systematic review

**Interpretative Phenomenological Analysis (IPA) as a tool for participatory research within Critical Autism Studies: A systematic review**

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## **Abstract**

### Purpose

Interpretative phenomenological analysis is distinctive in foregrounding participants' interpretations. As such, it is potentially useful for gaining an insight into the lived experience of autistic individuals and aligns well with participatory approaches. This paper provides the first systematic review of IPA studies that have employed a participatory approach and considers their contribution to Critical Autism Studies.

### Method

Four electronic databases were searched to identify peer-reviewed empirical research articles which employed a participatory IPA approach to consult with autistic individuals. Thirteen studies from four countries, published 2008-2018, met the inclusion criteria. These were examined to identify details of the methodology, findings and recommendations in order to consider each in relation to the underpinning philosophies of IPA and participatory research respectively, and their relationship to the stated aims of Critical Autism Studies.

### Results

A range of participatory approaches were employed and their use extended the depth and validity of findings. There was evidence of disruption to power relations in process and outcomes. Making sense of the autism diagnosis was a frequent point of discussion, even when this was not the focus of the study, and across studies, strong commonalities emerged, capturing a multi-dimensionality of 'autistic identities'.

### Conclusion

This review provides evidence of the usefulness of IPA as a research approach to consult with autistic individuals. It lends itself to a range of participatory techniques and there is scope for these to be used with diverse autistic populations, in order to extend the opportunities for autistic individuals to be represented, and represent themselves, within autism research.

## Introduction

Within the field of autism as elsewhere, qualitative research has been the poor cousin of quantitative research, enjoying less funding, respect and attention (Bölte, 2014). This is despite a growing recognition of the need for research that addresses the lived experience of autism and actively engages stakeholders, including autistic individuals (Pellicano, Dinsmore & Charman (2013). There is a newly emerging body of qualitative research which lies at the intersection of three distinct areas:

- i) interpretative phenomenological analysis (IPA), an approach which foregrounds the significance of individual experience (Smith, Flowers & Larkin, 2009);
- ii) participatory research, which aims to be inclusive and relevant to its participants and the communities involved (Bourke, 2009) and – arguably a natural bedfellow to both
- iii) Critical Autism Studies, which, influenced by Critical Disability Studies, critiques the dominant narratives surrounding autism (O'Dell et al., 2016).

Each of these fields is relatively new and evolving. They have in common the explicit intention of subverting the traditional research dynamic, whereby the researcher is viewed as the expert and the research participant employed as a research tool rather than being meaningfully engaged in its aims and processes. The body of work at this intersection is therefore highly novel and

merits closer examination as a distinct oeuvre. This paper undertakes the first systematic review of the published studies located at this intersection, in order to consider how both their methodologies and findings are impacting upon current understandings of autism.

### *The use of IPA with autistic participants*

One thing that can be stated with some assurance is that autistic individuals experience multiple social challenges. Society may seem antagonistic to the autistic individual, offering few opportunities for a synergistic person/society relationship. There is a conspicuous need, therefore, to explore and seek to understand when and how synergy is achieved. Interpretative Phenomenological Analysis (IPA) as an approach is still in its relative infancy, first articulated in the 1990s as a means of offering a qualitative approach that was focused on personal experience and firmly embedded within psychology (Smith, 1996). Phenomenology, developed by Husserl in the early twentieth century, was based on the notion of 'intentionality'; that humans impose meaning on all they experience and that this experience merits examination on its own terms (Smith, Flowers & Larkin, 2009). Early work tended to focus on health psychology, reflecting the interests of its pioneers. The approach is idiographic, concerned with the particular and thus focusing in-depth on a small number of cases, or even a single case. Smith, Flowers & Larkin (2009) argued that nomothetic approaches, which typically deal with large samples and seek to identify generalised trueisms, do so at the expense of the individual experience. In contrast, idiographic approaches, by undertaking a more indepth

exploration of a phenomenon at an individual level, can reveal new insights and identify flaws in existing theory:

Thus in some ways the details of the individual also brings us closer to significant aspects of the general. (p.32)

Therefore a successful IPA study, through a detailed exploration of the specific, may identify universals that are novel and bring new knowledge and understandings to the field. The IPA approach encourages exploration not just of the individual experience, but also how this is contextualised by history, society and dominant cultural forces (Lopez & Willis, 2004). This would seem relevant to the context of autistic individuals, whose impairments are in some senses defined by their social context and their lifeworld. Crucially, the impact of this is largely assessed and measured from the outside, in terms of the ways in which behaviours influence the environment, rather than from the inside, in terms of the ways in which the environment affects the individual. Access to 'insider interpretations' of this phenomenon are currently lacking (Pellicano, Dinsmore & Charman, 2013), and IPA has the potential to expose these, and in doing so, bring forth new understandings. The holistic approach of IPA, focusing on the integrated self (Dickson, Knussen & Flowers, 2008), seems appropriate in exploring the experience of individuals labelled with autism, whereby sense-making may require accommodating (or rejecting) an externally-imposed identity.

Undoubtedly there are limitations inherent in trying to fully understand the inner world of another, since the researcher's conceptions both colour and

complicate the “process of interpretative activity” (Smith, 1996, p. 264). This ‘double hermeneutic’ (Smith and Osborn, 2008) recognises that the participant, in giving their account, offer their own interpretation, which the researcher in turn interprets within their analysis – each bringing their own subjectivities to the endeavour. This can be compared to the ‘double empathy problem’ described by autistic researcher Milton (2012). Within IPA, the double hermeneutic is a more general acknowledgement of the participant’s and researcher’s different experiences of the world, whilst Milton’s example of a double empathy problem serves to remind us that if there is a fundamental difference between the autistic and non-autistic experience, then it is a mutual problem rather than being located entirely with the autistic individual.

### *Participatory research*

Influenced directly by the disability movement, participatory research approaches within disability research have been developed with the overt intention of equalising the balance of power between disabled and non-disabled people (Cook, 2012). They are a response to a body of research that has traditionally objectified disabled participants, leading some disabled stakeholders to view disability research, not as potentially beneficial, but rather as a personal violation and irrelevance (Oliver, 1992). By contrast, participatory approaches have been regarded as carrying the potential to be a transformative experience, both for the individuals involved directly and for disabled communities (Nind, 2011; Danieli & Woodhams, 2005). However, as within the disability movement generally, certain types of individuals have been

viewed as more difficult to engage, and autistic participants have tended to be perceived as such ([Lewis, 2009, Orsini & Davidson, 2013](#)). Autistic researchers have lamented being “...frozen out of the processes of knowledge production.” (Milton & Moon, 2012, p. 794). At the same time, they have argued powerfully that research which makes assumptions about the autistic experience can wrongly presume shared understandings, leading to misinterpretations and flawed research findings (Milton & Bracher, 2013; Nicolaidis et al., 2011). There is a growing body of participatory research studies, undertaken by autistic and non-autistic researchers, demonstrating the potential capabilities of autistic participants, the tendency for this potential to be under-estimated and the value of having their direct input, (Beresford et al., 2004; Harrington et al., 2014; Nicolaidis et al., 2011).

#### *The emergence of Critical Autism Studies*

Critical Disability Studies has [likewise](#) emerged from the disability movement, driven primarily by disabled people and used as a means of critiquing the various ways in which systems and structures act to exclude them from work and society (Shakespeare, 2006). In exploring the experience of disabled people and challenging the existing orthodoxies, Critical Disability Studies has been influenced by, and had overlap with, other marginalised groups such as those concerned with gender, race and class (Goodley, 2013). However, certain types of disabled people have tended to be left out of the debates, most notably those with learning difficulties, who have largely remained caught within a ‘personal tragedy’ narrative (Goodley, 2001).

Autism is described within current diagnostic classifications as a 'disorder' affecting primarily social communication (APA, 2013) and historically has ~~tended to be~~en positioned as a specific learning difficulty. Perhaps for these reasons, autistic voices have been largely absent from discussions within disability studies and "left behind by the progress that much of the rest of the disability community has enjoyed." (Ne'eman, 2010, page unknown). Autism has traditionally been framed using a deficit model, with autistic individuals being subjected to contentious, often invasive interventions in the hope of 'cure' (Silverman, 2008). Autistic narratives often talk of the benefits and originality of thought that an autistic view of the world can bring (Tammet, 2006; Lawson, 2011). Autistic activist Sinclair (1993) characterised autism as a fundamental aspect of the individual and declared that the tragedy is not to be found in autism, but rather, in what autistic children are subjected to as a consequence. However, so far these potential benefits do not seem to have translated to opportunity to any great extent, since outcomes for autistic adults remain relatively poor, regardless of IQ (Van Heijst & Geurts, 2015). Compared to the general population they experience very low employment rates, high dependency on family members (Howlin et al., 2004) and a poor life expectancy (Perkins & Berkman, 2012).

It is from this unsteady landscape that Critical Autism Studies has emerged, seeking to take account of alternative narratives and cultivate research agendas that are inclusive and meaningful for autistic individuals (O'Dell et al., 2016; Woods et al, 2018). The autistic voices joining these debates have

already been influential, both for autistic communities and for non-autistic academics [\(Ne'eman, 2010; Nicolaidis et al., 2011\)](#). 'Insider' accounts have challenged existing stereotypes and articulated the existence of, on the one hand, commonalities between people seemingly at opposite ends of the autism spectrum, and on the other, huge differences between autistic people who are on the face of it very similar [\(LaDawson, Mottron and Gernsbacher, 2008\)](#).

### *Review aims*

IPA is overt in its intention to regard individuals as the expert of their own experience, and as such is well suited to participatory research, which endeavours to create research that is meaningful for participants and for the communities targeted. Its use within the field of autism is increasing and it seems timely to explore this body of work in the context of Critical Autism Studies. Within this systematic review I will [evaluate the contribution of work in this area by seek to](#) addressing the following questions:

1. Why was IPA selected as a research approach and how was it employed?
2. How effective was it as a participatory research approach?
3. What is the contribution of participatory IPA research to current understandings of autism and in particular, to Critical Autism Studies?

### **Procedure for Review of IPA Studies**

This review aimed to identify all original peer-reviewed empirical research articles, published in the English language prior to January 2019, which employed a participatory IPA approach to consult with autistic individuals. The Web of Science database was used for an initial search and results then compared to those from PsychInfo, Proquest Social Science and Scopus databases (see Appendix x for PRISMA flow diagram). Key search terms were 'interpretative phenomenological analysis', 'autis\*', 'Asperger' and 'ASD' using Boolean search terms (AND,OR) and cross-checked with the alternative spelling of '*interpretive* phenomenological analysis. The term 'participatory' was not included as an initial search term. This was to ensure a broad initial search, since the term is not employed consistently within research studies. After duplicates were removed, the combined search indicated a total of eighty-three original articles. Abstracts, and where necessary, full-text documents were then examined to ensure that the target participants were autistic individuals rather than either a mixed sample that included individuals with other types of disability, or parents/carers/professionals. This reduced the records to twenty. These were then searched in two ways.

Firstly, articles were closely read in order to identify whether or not the methodology employed a participatory approach. There is no single accepted definition of the key components of participatory research, but for the purposes of this review, I use Bourke's definition as "a research process which involves those being researched in the decision-making and conduct of the research, including project planning, research design, data collection and analysis, and/or

the distribution and application of research findings” (2009, p. 458). From this definition, those studies to be included needed to go beyond questioning participants using standard approaches. Methodologies needed to evidence that specific effort had been taken to involve autistic people as active stakeholders in different stages of the research process, including but not limited to paying attention to the different conduct that might be appropriate due to autistic differences. Only those studies that specified, for example, some form of participant involvement in research design or credibility checking of findings were considered to be participatory, whilst studies that only adapted their processes to be accessible for autistic participants were excluded. It is acknowledged that some excluded papers may have employed a participatory approach but did not state this within their methodology.

The second stage was to check the reference lists for any relevant articles that may have been overlooked in previous searches and examine these in relation to the inclusion criteria described. Figure 1 provides an overview of the selection process. This provided a total sample of thirteen papers.

[Figure 1 here]

The Critical Appraisal Skills Programme (CASP) checklist for qualitative research (CASP, 2018) was also used as a screening tool to assess each paper for overall rigour. No papers were excluded at this point.

In summary, the papers included met the following criteria:

- Original peer-reviewed English language empirical research article employing an IPA approach and published before January 2019
- Autistic individuals as research participants
- A participatory approach described within the methodology.

### *Summary of Studies*

The studies included in this review were all published between 2008-2018. IPA is relatively new as a specific approach, first developed within the UK. It is therefore not surprising that articles are all relatively recent. Of more interest is the fact that more than half (n=8) of the identified articles have been published post-2015, which indicates a growing interest in its use within the field of autism, specifically in relation to participatory approaches. The articles mainly focus upon the UK context, with one study comparing English and Spanish universities and one based in Belgium. As some articles report on different aspects of the same study, the sample encompasses eight original research studies in total. Participants were mainly adults over the age of eighteen, with three studies focusing exclusively on adolescents and a further two (encompassing four articles) including adolescents within a mixed adolescent/adult sample. Half of the papers (n=7, from three studies) investigated the experience of further or higher education students and with the exception of one study focusing on adults who had experienced acute mental health facilities, none of the studies consulted with autistic participants specified as having additional learning disabilities. For all studies, the primary mode of data collection was one:one verbal interview, recorded and transcribed, which

is the most common methodology employed by IPA. However, these last two points carry particular implications which will be considered later.

### *Data analysis*

The focus of this review was to consider specifically the ways in which participatory methodologies are being used alongside an IPA approach and how these make a contribution to the emerging field of Critical Autism Studies. Orsini & Davidson (2013) identify the important elements of critical autism studies as:

- “ 1. Careful attention to how power relations shape the field of autism
2. Concern to advance new, enabling narratives of autism that challenge the predominant (deficit-focused and degrading) constructions that influence public opinion, policy and popular culture; and
3. Commitment to develop new analytical frameworks using inclusive and non-reductive methodological and theoretical approaches to study the nature *and* culture of autism. The interdisciplinary (particularly social sciences and humanities) research required demands sensitivity to the kaleidoscopic complexity of this highly individualised, relational (dis)order.” (p. 167)

The papers which met this criteria were then examined closely to identify: (1) the specific elements of the participatory IPA methodology, how these were employed and the author’s rationale for their use; (2) themes reported within the findings; (3) main reflections and recommendations offered by the authors on both the findings and the methodology. See table 1 below for a summary of

the data. In interrogating the full-text documents, thematic analysis was employed in order to identify the most common findings (Clarke, Braun & Hayfield, 2015) and in the following section, these are reported within the framework of O'Dell's CAS criteria.

[insert table 1 here]

## **Results**

Firstly, *Attention to power relations* explores how different methodologies were employed and their impact upon the research as whole, the autistic stakeholders and the researchers. Secondly, *Enabling and challenging narratives* considers the original contributions to the field offered by the studies and reflects upon how the participatory IPA approach operated to facilitate this. Finally, *Developing new analytical frameworks* is concerned with the extent to which the researchers employed inclusive methods and theoretical approaches.

### *Attention to power relations*

Two common strategies were employed by all studies included in this review, although their specific methods differed. Firstly and not surprisingly, in all cases researchers endeavoured to make the research process more accessible by offering alternative forms of participation and help to prepare for interviews. Generally this amounted to offering a choice of ways to participate or a choice of venue for interviews, but with greater attention to detail than might usually be expected. For example, Casement, Carpio de los Pinos & Forrester-Jones

(2017) described removing a ticking clock to accommodate the sensory differences of an interviewee. Humphrey & Lewis (2008) accommodated individual preferences by collecting data via drawings for one interviewee, whilst Tierney, Burns & Kilbey (2016) developed sociograms with participants in order to overcome communication barriers.

The examples above give an indication of attempts to render the research process more accessible and meaningful for participants. Of more interest are the techniques used to disrupt the power relations and how these were perceived to influence the research, both by participants and researchers. Most widely used was a form of credibility checking by asking participants to give feedback on researcher interpretations. All but one study (Treweek et al., 2018) employed this technique. Credibility checking is a common technique of validation within qualitative research, but in the context of autism studies, it carries a new significance. Due to the social communication impairments associated with autism, researchers and practitioners alike have been more aware of the barriers to meaningful consultation than of the possibilities (Beresford et al., 2004; Harrington et al., 2014). Credibility checking is one technique that offers the potential for a meaningful dialogue, and crucially, for participants to have a more influential voice, rather than interpretations being entirely in the hands of (mainly non-autistic) researchers. However, credibility checking with participants is not always appropriate to the research topic or participants' needs, not least because of the additional time commitment required from participants (Bourke, 2009). Other techniques were employed by

seven studies in addition to credibility checking, with the exception of Treweek et al., 2018). As described, MacLeod et al. (2013; 2018) entered into a further dialogue with participants in relation to draft publications, allowing participants the opportunity for further reflection and commentary from a temporal distance – an opportunity which only a minority took. Five studies involved autistic stakeholders who were not participants, two of which used the formal Patient and Public Involvement (PPI) process in the planning stages (Casement, Carpio de los Pinos & Forrester-Jones, 2017; Treweek et al., 2018) and one of which involved an autistic stakeholder in reviewing the transcripts (Maloret & Scott, 2018). Jones, Huws & Beck (2013), involved an autistic panel involved throughout.

### *Enabling and challenging narratives*

In the section above I hope I have demonstrated the ways in which this corpus of work has enabled autistic narratives to emerge more clearly. In this section, I will focus on the substance of those narratives and in particular, the ways in which they have challenged dominant interpretations of the autistic experience.

#### *a) Research focus*

A distinctive element of this corpus of studies is their subject matter. In keeping with the IPA philosophy, they have sought to understand the participant experience on its own terms. Within the context of current autism research, this took some into entirely uncharted territory. Although this was in a minority of cases, its significance merits particular consideration here. Four papers offered

explorations that the authors highlighted as being unique at time of publication, in researching the given topic from autistic perspectives, rather than those of family members/clinicians. Punshon, Skirrow & Murphy (2009) considered the impact of diagnosis upon autistic adults, Tierney, Burns & Kilbey (2016) explored the coping strategies of girls, MacLeod et al. (2018) explored the phenomenon of success and Treweek et al. (2018) investigated autistic adults' perspectives on autism stereotypes. Whilst Petalas et al. (2015) and Maloret & Scott (2018) did not state it explicitly, their studies on sibling relationships and acute mental health facilities were also highly novel. The subject matter in each case was an area where current evidence is generally scarce, despite being highlighted within autism research strategies, both in the US and the UK (IACC, 2010; Pellicano, Dinsmore & Charman, 2013). Bringing autistic viewpoints into these live debates is no minor thing, regardless of the relatively small-scale nature of the studies.

It should also be noted that within IPA analysis there is generally an emphasis put on the language used and the meanings, conscious and subconscious, that it may hold for the individual. It could therefore be deemed an inappropriate choice of approach to use with individuals who are, by definition, categorised as experiencing 'impairments' in their social communication. There has not been space within the scope of this review to consider in detail the linguistic elements of the data but in keeping with the presenting of IPA findings, all studies reported data directly from participants in the form of first-person quotes. These data indicated that participants could articulate their views effectively, a finding

that corresponded with the authors' perspectives. Whilst the selection of data can itself be viewed as an activity of subjective interpretation, this direct inclusion of participant voices is also indicative of effort to deliver participant narratives with some transparency, and to allow their own words to represent their ideas.

*b) Findings*

All of the papers under consideration share the common feature of exploring the lived experience of autistic individuals in relation to one aspect of their lives. Three papers focused particularly on experience within an educational setting (Casement, Carpio de los Pinos & Forrester-Jones, 2017); Humphrey & Lewis, 2008); MacLeod et al., 2018), and one on experience within an acute mental health facility (Maloret & Scott, 2018). The other eight papers had broadly the same focus which could be summarised as 'What does it mean to you to be autistic?' Not surprisingly, identifications with autism was a sub-theme common to all eight articles. However, of the five papers with a different focus, three also contained sub-themes pertaining to identifications with autism. A central aim of IPA research is to be led by the participant (Smith, Flowers & Larkin, 2009), so that data may lead the research in a different direction than intended. The fact that participants chose to talk about autism in this way therefore highlights its significance to their lives. In light of this, I will focus here on this as the most common theme across studies, with particular reference to narratives that challenge dominant discourses on autism.

Making sense of the autism diagnosis was a frequent point of discussion, even when this was not the focus of the study, and across studies, strong commonalities emerged. In Punshon, Skirrow & Murphy's study (2015), diagnosis was experienced "not as a single event but as a process that may span months, if not years" (p. 281):

I got the letter saying I had Asperger syndrome, it was a bit like standing up in court and hearing the jury say 'not guilty'. (p.277)

Diagnosis and the label of autism was also described as provoking contradictory responses (eg. Humphrey & Lewis, 2008; Huws & Jones, 2015) and sometimes conferring a label-as-barrier, due to non-autistic people interpreting individuals' actions entirely within the context of their understandings of autism, termed by Jones, Huws & Beck (2013) as "diagnostic over-shadowing" (p. 142).

Petalas et al. (2015) considered sibling relationships from the perspective of the autistic sibling. Their findings were at odds with the admittedly small body of literature focusing on the perspectives of the non-autistic sibling(s) or parent(s). The autistic siblings tended to be more positive, emphasising commonality over difference and prompting the authors to conclude:

"There is a role for normalising children's experiences, and not always assuming an ASD effect." (p. 47)

Participants in the adult studies had often been diagnosed in late adolescence or adulthood. This was sometimes highlighted as a different experience of diagnosis, even a “much sought-after goal” (MacLeod, Lewis & Robertson, 2013, p. 45) but also a challenge in its own right:

It's really difficult when you're between phases, thinking that you might have Asperger syndrome and then getting the official diagnosis because it can take so long and it's so difficult to access...it's not like I could switch off from it... (p.45)

In other cases, participants described conscious efforts to distance themselves from the label:

I haven't read the book on autism which is in the library...it'll probably get us upset or something because I'm reading about something I've got. (Huws & Jones, 2008, p. 104)

Participants in these studies described a range of responses to the autism diagnosis and the experience of living with autism. Authors across studies highlighted the disconnect between this range of responses and the commonly understood ‘facts’ of autism. As illustrated by the quotes above, the sheer intensity of participants’ experiences in navigating their diagnosis was a striking and common theme.

*Developing new analytical frameworks*

The philosophical position taken by IPA overtly acknowledges the participant as expert of their own experience and the researcher as unavoidably situated, leading to a double hermeneutic, whereby “access depends on, and is complicated by, the researcher’s own conceptions (Smith & Osborn, 2008, p. 53). This “dual aspect of interpretation” (Petalas et al., 2015, p. 39) was articulated by the authors as fundamental to their choice of approach, highlighting their conscious efforts to achieve an “empathic interpretation” with their participants (Humphrey & Lewis, 2008, p. 29). Tierney, Burns & Kilbey (2016) describe the use of a reflective log in order to maintain an awareness of their own assumptions throughout the process. In these studies, researchers were conscientiously exploring the territory between participant and researcher interpretations, taking nothing for granted.

In Jones, Huws & Beck’s study (2013), an autistic individual took on a role in analysing the findings, a process that proved so influential that he became third author in the final publication. His input was deemed significant in ensuring that interpretations avoided the “diagnostic overshadowing” (p. 142) described above, whereby autism becomes the default explanation and precludes the possibility of alternative interpretations. Additionally, his perspective as a mature adult who had lived through an autistic adolescence was found valuable to offer interpretations that were situated in experience. In his reflections that aspects of the accounts may be specific to developmental stages, he provided

more positive accounts of the findings' implications as sometimes *temporal*, connected to stage of life, rather than connected to autistic personhood.

The strategy employed by these researchers raises an important question – if IPA is centred on the individual experience, is the perspective of an autistic person who is *not that individual*, and therefore does not have *their* experience, valid? In this context, who is an insider and who is an outsider? In this case, the 'insider' perspective did not undermine participants' sense-making of their experiences, but rather placed them in a different, temporal context. The authors felt that this added significant value to the research, and their argument seems plausible. Maloret & Scott (2018) made a similar observation in relation to the contribution of the autistic stakeholder who conducted a transcript review. Their contributor picked up on issues described around food and not eating, and suggested that these difficulties could be related to sensory processing or desire for sameness in diet. These links had not been articulated by participants but further sense-checking with the study participants confirmed that this alternative explanation was valid, leading the authors to call for greater co-production of both services and research.

Participants across these studies gave accounts of valuing the opportunity to be consulted as active stakeholders. They were only too aware that their opportunities here were unusual. Participants voiced a desire to be included in academic debates and the researchers and authors - perhaps unsurprisingly - assumed a clear position, calling for academics and service providers to

recognise the importance and relevance of this input. Despite this, only one study (Jones, Huws & Beck, 2013) gave authorship to the autistic collaborator (in this case, data analyst). In total, eight of the thirteen thanked participants within their acknowledgements, two of which gave named credit (MacLeod et al., 2013; 2018).

## **Discussion**

This review has aimed to address the following questions in relation to the body of work using participatory IPA approaches to consult with autistic individuals:

1. Why was IPA selected as a research approach and how was it employed?
2. How effective was it as a participatory research approach?
3. What is the contribution of participatory IPA research to current understandings of autism and in particular, to Critical Autism Studies?

These questions will now be considered in turn.

### *Why was IPA selected as a research approach and how was it employed?*

As would be expected in an IPA study, authors cited IPA as a suitable mechanism for gaining insight into the distinctive experience of autistic individuals with specific characteristics, with a focus on identity and how they made sense of the 'autism' label. Research techniques largely followed the conventions of IPA, favouring one: one verbal interviews, although a range of other strategies were in place to encourage active participation. These tended to require additional resource, in

particular time, from both researchers and participants, but seemed to be effective in rendering the process more accessible and in providing spaces for participants' voices to be heard meaningfully.

*How effective was it as a participatory research approach?*

Kitchin (2000) cautions that even research with the best intentions can end up simply reproducing unequal power relationships. This body of research illustrates in some ways the tensions and dilemmas inherent in efforts to shift the nexus of power. Whilst in one case, the contribution of an autistic analyst led to him receiving co-authorship status, in others it did not. It should not be assumed that others would have wanted this, but there are a growing number of autistic people entering academia and in a culture where intellectual credit equates to currency in terms of status and opportunity, the question of how contributions are acknowledged becomes an important one. There need to be opportunities for autistic academics, but not every autistic person wants to be an academic, and autistic academics may not represent those wider communities of autistic individuals. As Kitchin (2000) cautions: "...not all disabled people agree with disabled academics." (p. 39).

Participatory research has the potential to offer a ~~means-voice~~ for ~~the voices to be heard-of~~ those autistic people who do not aspire towards academia but nevertheless, wish to be part of the dialogue.

This leads to another key question of participatory research: 'Whose voice is represented here?' One criticism of small-scale research is that it can not be held to be representative of the community as a whole. The autistic population is notably heterogeneous - and different, sometimes strongly opposing, views can be held by

individuals with the same 'autistic' label. However, this is no different to what can be said of any other autism stakeholder groups. Parent, practitioner and researcher communities are likewise formed not of one common perspective but of many viewpoints, conflicting and ever-changing. The fact that a population contains dissenting voices should never be an argument for silencing or ignoring voices, but an argument for ensuring that the full range of voices is heard.

This leads to the necessary observation that the participant profile of the sample provided here is ~~somewhat~~ narrow. There ~~is~~ can be a tendency for qualitative research methodologies to exhibit an 'elite bias' (Miles & Huberman, 1994), whereby ~~participants in research studies are~~ the most articulate ~~and/or accessible~~ members of a given group are recruited to studies. This accusation could certainly be levelled here, as participants were all verbally articulate and with one exception, possessed no co-morbidities (unlike most of the autistic population; Fombonne, 2003). Whilst this does not compromise the value of these studies, it does indicate a need for participatory IPA researchers to be more diverse and ambitious in their efforts to consult with, and be meaningful to, different autistic communities, following the examples which have been used with success elsewhere (Beresford et al., 2004; Potter, 2015). Goodley (2013) reminds us that “discrimination is an increasingly complicated entanglement of disability, gender, sexuality, nation, ethnicity, age and class.” P. (2013, p. 641). This “complicated entanglement” has been largely overlooked in the field of autism. Two studies here did address important intersections - between autism and gender (Tierney, Burns & Kilbey, 2016) and autism and acute mental health difficulties (Maloret & Scott, 2018). They give an

indication of the role that participatory IPA could have in shining a light into aspects of autism that have been largely obscured.

*What is the contribution of participatory IPA research to current understandings of autism and in particular, to Critical Autism Studies?*

There was evidence of authenticity in relation to the disruption of power relations in these studies. Through the processes that were being reflexively employed to change the conduct of the research, significant findings emerged that would not have been revealed by other methods. The autistic contributions were varied and in numerous ways upheld as valid, adding to current understandings and crucially, providing the insight of lived experience that is lacking in the vast-majority of autism research. Moreover, through the reflections of the authors it is evident that the processes were viewed as important learning experiences for them as researchers, developing their own criticality as non-autistic researchers.

Foucault (1998) contended that power relations are an inevitable part of society, and rather than wanting to be rid of them, we should focus our energies on ensuring our games of power can be played “with as little domination as possible” (p. 298). In this context, a key role for the participatory researcher is to ensure that the rules of power are available to understand and use. Yates (2015) suggests that a Foucauldian critique might usefully cause those in positions of power over disabled people to: “...find their actions problematic in new ways” (p. 103). Perhaps one of the most important aspects of IPA in the context of Critical Autism Studies is in its emphasis on the reflexivity of the researcher. By encouraging the researcher to take a self-critical stance throughout, the power dynamic should necessarily be disrupted

and this can have ~~a number of~~ significant consequences. In the very framing of the questions, the researcher endeavours to 'step back' and consider their role, encouraging a letting go of presumed expertise. Participatory methodologies can take this still further. In my research (MacLeod, 2016), in which I shared initial analysis with participants, I was forced to read each of my analytical comments from the perspective of the participant. In doing so, I identified lapses, where an overly psychological or clinical analysis 'seeped in'. I was challenged to retain the integrity of the analysis but abandon "the professional gaze" (Beauchamp-Pryor, 2011, p.8) and I felt this resulted in real progress in reaching shared understandings. It was also helpful for me personally in moving me away from lazy terminology, commonly employed by professionals but inaccurate in capturing the individuality of experiences described by participants. There is evidence from these studies that the practice of IPA encouraged or enabled researchers to do just that, critiquing their own methods, questioning the validity of their analysis and developing collaborations with autistic participants and partners, with results that often led them in new and surprising directions.

Where a non-autistic researcher is interviewing an autistic research participant about their lived experience in relation to autism, there is much to be gained from deeper exploration of this, potentially very specific, hermeneutic. IPA researcher Shaw (2010) talks of the "challenge-to-competency" (p. 233), and autistic researcher Milton talks of "interactional expertise" (Milton, 2014, p. 795). Both are essentially calling for the same thing – that the researcher use their reflexive position to not just be aware of their positionality, but actively critique it, and in particular, critique the ways in

which it might colour, limit or undermine the exchange. This would seem to be a valuable direction for future work.

One direction in which most studies were led was to the vexing question of ‘the autistic identity’ or perhaps more accurately ‘autistic identities’. I would argue that the explorations found within these studies make a considerable contribution to current understandings of autism. Autism is essentially a shorthand term for a set of characteristics frequently found together, but it can also be an essential gateway to much-needed support. Hacking observed that autism is very much “a moving target” (1999, p. 105) with diagnostic classifications in flux and dominant discourses being challenged by those diagnosed, so that making sense of a diagnosis of autism, with the lifelong implications it carries, is no small thing. In the ongoing arguments about categorisation and criteria for services, the situation of the labelled, or not labelled, individual stuck in the middle can become lost. We saw this in the recent DSM-5 introduction, whereby the category of Asperger syndrome was removed and communities of ‘Aspies’ were “cured overnight” (Goodley, 2001, p.214) or at least, felt that they had lost the diagnosis they had been given, and with it a potentially important aspect of their identity (Volkmar & Reichow, 2013).

Singer (1999), the autistic author credited with coining the term ‘neurodiversity’ and also parent to an autistic child, discussed the pursuit of diagnosis as involving a cost: benefit analysis – a complex weighing-up of the benefits of a clear identity against the potential for further stigma. The first-hand accounts in these studies move beyond the polarised positions of ‘diagnosis good/diagnosis bad’ to capture this multi-dimensionality of experience.

Furthermore, the consistency of accounts across studies suggests that this is a core issue for individuals receiving a diagnosis of autism. They remind us that applying a label that is likely to influence that person for the rest of their life, whether or not they have chosen it themselves, is not a neutral action. Yet in the case of autism, it is too often treated as a one-off event represented by a piece of paper changing hands. Diagnostic policies are slow to change because this aspect of the process – the impact of diagnosis on the individual’s sense of self - is generally not what is being evaluated within research studies. Although each study is, in keeping with the IPA approach, small-scale, these commonalities lend weight to the significance of the separate findings. Smith (2004) has talked of “core constructs” (p. 51) emerging from accumulating studies. Here is the accumulative significance of the IPA approach in evidence, in its ability to gradually build an entirely novel and robust body of evidence from foundations rich in depth, and easily overlooked elsewhere within the research landscape. Returning to notions of power disruption, Hacking (1986) has a conceptual framework that is useful to consider here. He suggests that a framework might be two vectors: “One is a vector of labelling from above, from a community of experts who create a “reality” that some people make their own. Different from this is the vector of autonomous behaviour of the person so labelled, which presses from below, creating a reality every expert must face.” (p. 235)

Viewed in this light, this body of work is far more than a useful addition to the existing literature. It offers a platform for the people carrying the label, creating a new reality, not just for the experts as suggested above, but for all autism stakeholders. This includes autistic individuals reading about autism for the first time. According to

McGeer (2009), “autistic self-narratives have the power to transform what it is to be autistic.” (p. 528) Hacking terms this the “looping effect” (1999, p. 34), whereby autistic accounts, in articulating an experience that is relatable for other autistic people, both validate that experience and record it, creating a new, alternative evidence base of ‘what autism is’.

### **Implications for practice**

These studies provide ample evidence that participatory IPA is an appropriate and useful tool for consulting with autistic individuals. However, for these approaches to be truly meaningful and influential to autistic stakeholders and the ‘loop’ to be completed, more effort needs to be made to ensure that research findings are made accessible for the relevant communities, rather than being confined to academic communities. It is notable that only two articles (Casement, Carpio de los Pinos & Forrester-Jones, 2017; Mattys et al., 2018) declared funding for their studies. Whilst funded studies are often required to plan dissemination activity, unfunded studies often struggle to find the resources needed. Research funders should take note that small-scale qualitative research offers nuanced narratives of autistic lives that cannot be captured by purely quantitative means, and thus need to be supported.

Research communities need to do more to address the research hierarchy, whereby the randomised control trial is viewed as the ‘gold standard’ and other methods seen as inferior. Qualitative research and participatory approaches, in offering in-depth

explanatory analyses, each have critical contributions to make to the “messy worlds” of Social Science and Education research (Thomas, 2016, p. 395).

The studies within this sample were composed of verbally articulate older children and adults. However, some techniques were used which could potentially be employed with younger children and individuals with learning disabilities. The use of these techniques could prove useful in redressing the current imbalance within autism research of this type.

Participants’ efforts to understand the ‘autism’ label in relation to themselves was a theme across studies, even where this was not the research focus. The Equality Act (2010) confers a range of rights and adjustments for disabled people, but these are entirely dependent upon individual disclosure, and disclosure is in turn dependent on the individual having some acceptance, and ideally ownership, of their diagnosis. The nature, quality and indeed existence, or post-diagnostic support should be recognised as a vital component of the diagnostic process.

## **Conclusions**

This is the first review of its kind and captures a body of work that is highly novel, often venturing into areas that have so far been neglected, despite recognition of their importance (Pellicano, Dinsmore and Charman, 2013). Maybe this is because these topics do not lend themselves to the more traditional, normative frameworks that dominate the field (Smith, 1996). This review has considered studies involving a total of one hundred and thirty-eight autistic participants (seventy-two male; forty

female; twenty-six unspecified), so that the research, viewed as a body of work, becomes substantial.

Autism research has persistently seemed to fall behind other areas of disability research in being more wedded to a medicalised view of the condition, and more resistant to the notion of user involvement and co-production. The body of work considered here gives evidence of IPA as an effective participatory approach to be used with autistic individuals, having the potential to create a research environment in which autistic participants are co-producers of autism knowledge and theory, rather than passive recipients (O'Dell et al., 2016). My focus has been on the particular merits of the IPA approach within participatory research. However, qualitative studies in general offer much that is original, not least in their tendency to engage closely with autistic participants and value their lived experience.

Further exploration is needed, both of the specific methodologies employed to consult with autistic participants, and of bodies of small-scale research studies, in order to consolidate the existing evidence and better appreciate what it offers to the field. I do not intend to argue that all research should be participatory, but rather, that all researchers should have an awareness of the potential contribution that autistic people have to make as participants, co-analysts and researchers.

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