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Doing it differently: emancipatory autism studies within a neurodiverse academic space

Bertilsdotter Rosqvist, H., Kourti, M., Jackson Perry, D., Brownlow, C., Allenby, K., Bendelman, D. and O'Dell, L

Abstract

In the current research climate, in which many autistic and autism communities are increasingly calling for a move towards collaborative forms of research, we consider how a loosely formed epistemological community may serve to challenge 'business as usual' in the academy. Mindful of the need to move beyond theory, we use this experience to concretely consider how knowledge about autism and neurotypicality can be meaningfully (co)-produced, and made available both to the research community and also to autistic and autism communities. Here, we use our own co-production of this article to explore how autistic experience may trouble normative meanings of academic knowledge production. We also consider the limits and possibilities of a neurodiverse research collaboration to reflect on ways in which a loose epistemological space may serve to contribute to knowledge about both autism and neurotypicality, adding to debate around collaborative research.

Point of interest

- It is important to include the voices of autistic people (as both researchers and participants) at all stages of research: this leads to higher quality research. Even though this is often mentioned in articles and studies, it is still unusual to see it happening.
- Academic systems (such as the writing of articles, the training of researchers etc.) can be a barrier to the inclusion of autistic voices. We believe encouraging autistic and non-autistic people to work together (as has been done in this article) is a positive step to inclusion more generally.
- We explore the advantages (and the difficulties) of collaborative work.
- We think of this type of collaborative work as a project that can produce new perspectives and contribute to a move towards new ways of thinking about autism that do not rely on existing 'deficit-based' narratives.
- We use the process of writing this article as a 'neurodiverse collective' as a starting point to discuss the benefits and difficulties of emancipatory and participative research more generally.
- We reflect on how our theoretical discussion can be applied concretely at various stages of the research process.

Introduction

Autism research has been expanding dramatically during recent years (Pellicano 2014). It is estimated that 2,400 papers on autism are being published each year (IACC 2013). As well as expanding, autism research is also evolving. A recent editorial in the major international journal *Autism* called for researchers to “acknowledge the need to address the everyday realities of autism” by engaging with autistic people at all steps of the research process, including – but not limited to – establishing directions for research (Pellicano et al. 2018, 1). This ‘partnering’ of researchers with autistic people, together with a recognition of potentially unequal power dynamics between researchers and research participants, is characterised as participatory research (Waltz, 2009; Fletcher-Watson et al., 2018)

However, meaningful inclusion of autistic voices in research tends to be the exception rather than the rule (Chown et al. 2017). This is methodologically and epistemologically problematic (Milton and Bracher 2013). Thus, drawing on an emancipatory as well as participatory framework for autism research can increase the inclusion of autistic voices and contribute to a revision of the non-autistic voices. For example, Waltz (2009) claims that the accuracy of the findings are likely to improve when increasing the involvement of the participants in the process, because their insight will provide important information about their needs, priorities, and challenges, amongst other parameters. Research produced in this way is therefore of “higher quality...(and more) relevant and applicable” (Jivraj et al. 2014, 782). This statement applies to autistic people, researchers as well as participants. For example, autistic researchers suggest that wellbeing for an autistic person would mean adapting lifestyle to an individual’s own personal needs and desires, rather than being forced to mimic behaviours that can be confusing to them (Milton and Bracher 2013), a finding that may come less easily to a non-autistic researcher. The insight of autistic people is of importance if the research community is to have access into autistic ways of thinking (MacLeod et al. 2014) which we,

and others, argue produces better research. As a result, an emancipatory framework can provide crucial contributions to the current understanding of autism.

A recent article by Fletcher-Watson et al. (2018) adds to the literature in this field by summarising the benefits of participatory research, and further identifying challenges and opportunities associated with participatory methodologies. Here, we seek to approach the question of participation from a slightly different perspective. Rather than exploring the interface between research and autistic communities, we look to academic space as a site of emancipation in itself, and consider how the creation of a neurodiverse writing collective may add nuance to existing knowledge creation. We also seek to consider how spaces of this kind may not only challenge existing research paradigms, but also serve to disrupt and deconstruct the (cognitive) norms around which much autism research leans. Consequently, foundations of autism knowledge are questioned, as we, among others (e.g. Milton and Bracher, 2013) argue that the ways in which knowledge about autism is sought have direct effects on the kind of knowledge that is gained.

As a space where social culturalisation and a crafting of academic performances occur (Samek and Donofrio 2013), the academy offers a site in which autistic experiences can challenge the norm and call into question power relations which serve to produce a performance of professional identities. Educational spaces “[train] bodies to behave in socially sanctioned ways” (Cooks and Warren 2011, 211) and interlocking connections of power and privilege discipline bodies into socially acceptable ways of behaving (see Silfver et al. e-pub). If this is true for bodies, is this not also true for minds? How do we ensure that there are spaces within the academy for neurodiverse modes of thinking? Does the academy, with its power and privilege, demand a cognitive normative mode of knowledge production? What could a neurodiverse academic space look like? What could academic knowledge production in such a space look like? In this paper we reflect on our experiences of writing collectively, to explore

how this offers possibilities to rethink knowledge production about autism and neurotypicality. In so doing we occupy knowledge across different positions as a mixed group of neurodivergent and neurotypical scholars. Our discussion contributes to the current debates within autism studies and elsewhere concerning epistemic privilege, knowledge production, and ‘silo mentalities’ (Cilliers and Greyvenstein 2012; Arnold 2016).

This paper is divided into four sections. Firstly, we introduce conceptual, theoretical, and political tools for thinking and writing practice in a neurodiverse academic space. Thereafter we will describe the crafting of our space, including the tensions and dilemmas it brought up, reflecting on previous research on emancipatory approaches within disability studies and outline emancipatory research strategies based on our own experiences. In the concluding reflections we suggest an altered framework for emancipatory autism research in relation to debates around epistemic privilege and authority in autism studies.

Tools for a neurodiverse academic space

In our work, we have drawn on a number of conceptual, theoretical, and political tools to frame our thinking and our writing practice. Normative modes of knowledge production start with a reflection of Foucault's discourse around knowledge/power production, with any system of knowledge production operating within some form of power dynamics (Foucault 1976, 1979). To revise epistemological dynamics of how autistic knowledge is produced within the academy, we must ontologically rewrite the framework which has shaped the situations in which academic knowledge is being produced.

Audre Lorde initially coined the term ‘mythical norm’ to mean ‘white, thin, male, young, heterosexual, Christian, and financially secure’ (Lorde 2017). It is members of this group who Lorde suggests are holders of power and, by extension, the creators of knowledge

that may be seen as holding ‘a credibility excess’ (Fricker 2007, 17), whose words carry more weight than they might have done had they been issued from someone outside this mythical norm. We seek to expand this definition by adding neurotypical (NT) as a further membership card to the mythical norm. In our endeavour to challenge the mythical norm within the context of the ‘neurodiverse (cognitive) other’, following Husserl we should “Go back to the things themselves” (Steinbock 1997). ‘Things’ here refers to the modes of internal expression of encountering our lived-in world. We do not live within a vacuum, therefore, to explore the mythical norm from a neurodiverse perspective is an encountering of how knowledge is produced through the ‘cognitive other’. Our collective writing project, including our reflections on working together, is a key element of going ‘back to the things themselves’.

Queer theory offers ways of breaking down these problems, especially within the space of being within a privileged academic position. Heteronormativity is a mirror to the academic space where access to knowledge is too often inaccessible to the non-academic ‘other’. One example of queer politics would be using what David Halperin (1995, 59) coins “Reverse Discourse”, the act of queering modes of knowledge production to expose the power dynamics which are at play, and this draws similarities to autistic spaces - spaces dominated by autistic people (Sinclair 2010). Autistic communities, while drawing on different social rules depending on the context, challenge spaces dominated by NTs, often by reversing NT normative societal rules and fully accepting what Gadamer has referred to as “cognitive otherness” (as cited in Odenstedt 2005, 43).

This disruption of NT norms is perhaps done unwittingly, but nonetheless the very act of creating an autistic space is liberating. Perhaps in the same way as spaces of sexual otherness, such as Gay and Lesbian spaces, spaces of cognitive otherness offer ways to undo the power relations that exist to make visible the norms of a NT academic space and understand it differently, not as a norm, neutral and unaccounted for, but as one of many kinds of spaces

available to academics and advocates. A neurodiverse academic space inclusive of neurotypical others is equally possible.

This creation of a neurodiverse academic space creates the possibility of what Foucault would call a space of 'Heterotopia' (Foucault 1967, 1986), or, here, a site where normative academic spaces of the cognitive 'normate' (c.f. Garland Thomson 1997) may be rethought and rewritten. To challenge the mythical norm is to explore how these academic spaces can undermine and subvert normative thinking around neurodiversity and neurotypicality. Perhaps aptly so, as the space offers a place where a neurodiverse perception of what could be defined as the cognitive normate and processes of "cognitive othering" (Chaloupka 2015) can fully be explored, picked apart, and developed. Our writing project is a way of creating such an academic space for ourselves to thrive in, and hopefully to be of inspiration to others.

Borrowing insights and concepts from postcolonial theory, in order to 'decolonialise' a colonised (cognitive othered) neurodiverse body we first need to scrutinise what neurodiverse experiences (including what research questions) the (NT) coloniser's gaze enable. What do colonising (NT) constructions of neurodiverse experiences of being included in the research processes in an NT-led project look like? What ideas of the NT as the (veiled) cognitive cultural self (c.f. Garland Thomson 1997) and neurotypical expressions of research and research methods are being performed through that casting of the neurodiverse subject as a cognitive other, including othering neurodiverse expressions of inclusive/participatory research methods?

Crafting a neurodiverse academic space

This paper was initiated as part of various discussions between the team of authors in an effort to capture and combine our shared, but diverse, interests and perspectives. We are a group of academics whose identification spans academic and activist positions in a variety of

ways. As a group we are located within academia, we are located across cultural contexts within Europe and Australia, and there are a number of ways in which we are connected and share history. Some of the authors have been working together for a long time, whereas others have just begun working together. This is the first time we have all written together.

The project arose out of a critical autism studies conference held in London in June 2017 and Autscope (an autistic-led conference organised yearly in the UK) in the same year, as well as other conversations between various group members. The thinking around neurodiverse academic spaces and neurodiverse collaboration has further been developed among most members of the group in the organising or participating in the conference “Intimate lives? Autism, Gender and Sex/uality”, in May 2018 in Birmingham, UK. The contexts for the three conferences are varied. The aim of the conference in London was to map out a critical international agenda for autism studies. Autscope is a pioneering space for autistic-led activism and research discussions on various issues impacting on autistic peoples’ lives. Intimate lives was an academic conference ‘with a difference’, resolutely determined to value lived experience on an equal footing with academic knowledge and to create a space in which the academic/non-academic and autistic/non-autistic dichotomies were disrupted. As a set of authors, we similarly use this paper as a way in which to begin working together and bringing into being a neurodiverse academic space, enabling dialogues and building bridges between ‘silos’. In tracking the norm through the realms of emancipatory research methods, we are also mindful that “normal includes normal business in the academy” (Warner 1993, xxvi), and so the collaborative format of this article, the process, will to some extent be as important as the content.

The project began by a group meeting which was attended by the majority of the authors. During that meeting we shared our thoughts and ideas about the overall themes of the article. The group had initially intended to write an article around the themes of sexuality and

gender. However, after several months attempting this it was decided that we needed first to address the workings of the collaborative process, the loosely formed “epistemological community” (Nelson 1993) that we were forming, and the tensions and opportunities implicit in this formation. It was therefore decided to concentrate on this as the initial theme for our collaboration. We then started on the process of writing the article via email and Skype. The writing process consisted of several ‘rounds’ of writing. Each author was sent the article from the previous author and was asked to make their contributions. The article was then emailed to the next author until all of us had a chance to make our contributions. At times we discussed elements of this paper at group Skype calls. For the first round of article, each author included their personal thoughts on the broad themes of the article. At the end of the first round, the sub-categories of the article were decided, based on everyone’s contributions up until that point. During the second round of the article, the writers added their experiences and thoughts to every section. In the third and final rounds of the article, we refined the narrative. By working together, we elaborated and expanded on each other’s points and highlighted similar concerns and issues from different points of view.

Emancipatory autism studies: learning together

According to Stone and Priestly (1996) in one of the first descriptions of emancipatory approaches within disability research, an emancipatory approach refers to the inclusion of the participants within the research process in a way that they benefit from it and that it expresses their opinions and experiences. An emancipatory framework aims to challenge power structures within the research process (Stone and Priestley 1996) and aims for the equal representation of all ideas and beliefs. It is important to make space in our work for competing discourses as far as it is possible.

In emancipatory research the participants are not passive objects, but actively form the final product (Waltz 2009). Emancipatory research therefore, in contrast to participatory

research, aims not only to record and present the issues of a particular group by involving them in the process, but also to initiate changes that will work for the benefit of the people of the community involved in it (Waltz 2009). Therefore, in order for a research process to be emancipatory, a number of criteria have to be met. The agreement upon this framework from the participants is the first important aspect and engagement with the process for the whole research team from initial conceptualisation to the final product is considered crucial as a shared goal.

Emancipatory research has its roots in investigating marginalised social groups such as ethnic minorities and has been extensively used in feminist research (Stone and Priestly 1996). It also entered the field of disability and mental health research when people with disabilities started to request their rights in the decision-making processes that were related to them (Danieli and Woodhams 2005). Its presence in the field of autism research is, however, relatively new and sporadic (Milton and Bracher 2013; Woods et al. 2018). The nature of the social and communication difficulties of autistic people make researchers sceptical in terms of the ways they might be able to include autistic people in the current research process (Waltz 2009).

“(W)hat happens to the products of the research?” is an essential question to be asked of emancipatory research (Zarb 1992, 128). Ownership is moot if autism research is not accessible by autistic communities. Currently, research findings are often published in academic journals and therefore inaccessible to the majority of the population, including research participants themselves (Pellicano, Crane, and Gaudion 2017). This cannot mitigate the often “troubled relationship” between members of the autism and research communities (Raymaker and Nicolaidis 2013, 175), and delimits research ownership to the latter. Findings should therefore be widely and appropriately disseminated to bring “transformation and the reinforcement and encouragement of further demands for change” (Barton 2005, 321).

However, broad and open-access dissemination alone may not be sufficient to provide an emancipatory effect. As Brewer and Selfe (2014) point out, access alone ('consumptive access'), whereby for example autistic communities would be able to physically access texts, does not equate to 'transformative access', whereby texts are readily understandable by interested parties and can be 'used' by them: "The former involves allowing people to enter a space or access a text. The latter questions and re-thinks the very construct of allowing" (Brewer and Selfe 2014, 153-4). Is it not the latter that we should be aiming for in looking to challenge business as usual within the academy? And how does this sit with generating and adding to theory which can be exclusive and often linguistically inaccessible? There is an inherent tension here: in writing this article, we have found it impossible to discuss complex, abstract, and theoretical concepts in a transformatively accessible way. We have been painfully aware of this tension in writing this article as a group, and we cannot do otherwise than acknowledge the irony of being unable to discuss accessibility in an accessible fashion, and the potentially exclusive consequences of this uncomfortable realisation.

A focus on research methods and the tools we use as researchers is an important aspect of emancipatory research. Creative and visual methods of data generation disrupt traditional methodological frameworks and can be used to promote the inclusion of autistic individuals who are often excluded from research due to being non-verbal or verbally limited. This exclusion demonstrates how the academy privileges certain kinds of knowledge, accessed by particular kinds of research methods.

An arts-based approach can further the emancipatory model through Practice as Research (PaR). This offers ways to destabilise epistemological power structures that can be roadblocks within academic spaces. Following Nelson (2013), this can be described as a process where practice is the main method of enquiry in the research project. PaR takes numerous forms, including dance, theatre and live art.

Disability studies is richly informed through this approach, with much critique given to disability led artists making work regarding the politics that centre around what it means to be 'disabled' in society today. This often-radical work has been documented widely, most importantly through the Live Art Development Agency who in 2012 published an edited collection which brought together through its documentation a vast array of disability led artists (Mitchell & Kedan. 2012). While this work could be argued within the academy to not strictly fulfil the requirements of Practice as Research, this would work to take away from the emancipatory affects that this work can produce. These are powerful works that work to unravel the hegemonies behind how disability as a concept is produced as a discourse that is often riddled with the echoes of Garland Thomson's notion of the 'freakshow. (Garland Thompson, 1996). Consequently, emancipatory research may step outside of the methodological conventions of academic knowledge production to embrace alternative practices as data for legitimate study.

Meanings of space are central in an emancipatory research practice. For example, Hall (2014, 384) terms a "third space for understanding" in which ongoing reciprocal relationships are negotiated. Hall details emerging paradigms for research that aim to work differently to mainstream research practice, offering ways of engaging in what she calls "cross-cultural space". Her research focusses on education practice for Aboriginal people in central Australia, and whilst the topic of her work is different to ours, her thoughts on emerging paradigms are useful in developing our thinking. Hall argues that the history of research in Indigenous communities and the post-colonial legacy is of great importance in making visible research traditions that have "so often damaged, disempowered and silenced" (Hall 2014, 377) and that researchers from a non-Indigenous background acknowledge "the role that their own knowledge paradigms and hegemonies have played in this". Her response to this legacy is to call for research approaches that put "at their heart Indigenous ways of knowing, worldviews,

values, ethics and methodologies” (p.377). To Hall, cross-cultural space is a valuable way of working together to develop research that can challenge oppression and develop knowledge that can genuinely support and enable people. She suggests that paradigms to enable this approach are ethical and values based; positive and holistic in their approach to research; and prioritise benefits for Indigenous people.

A similar approach has begun within disability studies. For example, Seale et al (2015) talk about a shared space for collective understanding. Participatory research with people with learning disabilities has for many years developed and refined ideas about how to work together. Seale et al (2015) draw on the work of Star (2010) who suggests that participatory research is a ‘boundary object’, “boundaries as interfaces facilitating knowledge production” (Seale et al. 2015, 485) and hence it is communication and productive dialogue rather than boundaries that produce division and separation. Seale et al suggest that it is this ‘third space’ that enables them to produce a shared space in which to work collaboratively with people with learning disabilities where ongoing reciprocal relationships are negotiated in research practice.

Implementing emancipatory research strategies within autism studies: some personal reflections

The following section discusses some of our reflections regarding implementing an emancipatory framework in autism studies and the strategies we may have used during framing, doing, and disseminating the research process.

Framing the research

We believe that participatory research should always be the baseline of any autism research project, whoever it is led by. We agree that it is important to value the voice of the ‘other’ as a primary source of knowledge production rather than a secondary source within the

context of power structures around epistemology. However, an emancipatory framework has particular characteristics, although what these are and how they can or should be applied may not be universally agreed upon. Here we discuss some of those characteristics that we consider important.

Firstly, it is important for a researcher – neurodiverse or not - to always be in tune with the different standpoints the participants are taking and try to represent those as accurately as possible. It is also worth debating how possible that is and this should always be placed in the context of continual reflexivity. An important element of this is the researcher's reflexivity on their own positionality and role within a research project. A research project is often conceptualised well in advance of participant recruitment and a researcher therefore needs to consider their personal interest and reasons for involvement in this process as well as the benefits they receive as a result. Furthermore, they need to consider how their position may be similar or different from that of the participants and how this will effect the research process and dissemination of findings.

Autistic and non-autistic researchers have different challenges regarding reflexivity when doing autism research. For autistic researchers, it is important to consider issues of internalised ableism when doing autism research and the effect these may have on their work and interpretations. It is also important to be aware that one's own voice within the context of disability studies can be othered within the academic space, to be aware of the politics in place and to manage ways to be valued as an autistic researcher within the academic space. An example of this is working to have a strong and relevant voice within the academy, when trying to place your own autistic led research and academic voice within a field where the non-autistic led voice often is given more credibility. This problem has far reaching effects, especially when many of the leading journals are producing knowledge within autism research and its related fields but include foremost non-autistic academics on their editorial boards and among their

reviewers. This therefore prioritises particular research to be published. It should however also be acknowledged that the unequal power dynamics which may exist between researchers and participants are not necessarily mitigated by a researcher's autistic identity.

However, non-autistic researchers face a different set of challenges. Involvement in emancipatory research is often met with a certain level of discomfort, as they may feel that it is not their place to engage with this approach. This is also reflected when writing collectively, where individuals may be writing over or through the words and experiences of others. Discussions on how these dilemmas are to be resolved can be lengthy and polarising. An example of this was a debate played out in a series of papers in *Disability & Society* see Branfield, 1998, 1999 and Duckett, 1998. However, the view we take is much more in line with the cross-cultural space as suggested by Hall (2014) or a shared third space in line with the research of Seale et al. (2015), a possible solution is creating a third space, to enable discussion and knowledge production in a shared and enabling space. It is worth exploring further how the concept of a third space would work for autism research and we hope that this article, and the ideas of a neurodiverse academic space, will be one such productive example.

Another solution is to consider whose interests are being represented, rather than the (main) identity/ties of the researcher. A useful framework could be drawn from the field of political science, regarding parliamentary representation specifically, and is that of descriptive and substantive representation (Celis and Childs 2008). Descriptive representation refers to a process where the representative shares an identity with the group they represent (Bratton and Ray 2002) whereas substantive representation refers to a process where the representative represents the interests of the group, rather than (necessarily) sharing their identity (Celis et al. 2008). In the case of autism research, substantive representation may be more important than descriptive representation, even if anyone who represents the 'other's interests runs the risk of losing touch with the issues and voices of the group they aspire to represent. However, linked

to this is the concept of symbolic representation (Meier and Lombardo 2010) and how are autistic people being represented in the researcher (see Childs and Lovenduski 2013).

A second consideration is the level of interest in the topic being researched between researcher and participants/collaborators, and the shared desire to expand both academic and lay knowledge and the pertinence of the study to the community. In a recent example, [name of third author] identified a broad field of research – sexuality – and carried out a survey of 567 autistic adults to solicit their research priorities for future research, and their preferred methods to participate in such research. Sensory experience was the most commonly endorsed research priority, and written questions with time to consider them was the preferred method given by participants.

This in turn is linked to the third aspect, ownership of the work. By ownership we mean, following Cargo and Mercer (2008, 337), “the extent to which non-academic partners carry responsibility for directing core functions of the partnership and its research activities”. At times barriers exist within the academy, which may render the carrying of responsibility by anyone other than the researcher impossible. While epistemic ownership can be negotiated throughout the research process, practical ownership is harder to establish. When the project finishes, whose work is it? This has been particularly salient to those in this group of authors who are working towards a PhD, and who have found that the way in which researchers are trained is actually counter to emancipatory research and co-construction of knowledge. Could a PhD then that uses emancipatory framework be critiqued as not being the student’s own work? PhD work is often cited as a tension and challenge for inclusive work (see for example Woods et al 2018). The competing broader goals within academia therefore present challenges to the upholding of the personal goals of individual researchers and research students. The walls of the academy are often zealously guarded and while at times this is necessary for many ethical and legal reasons, it can also be detrimental when trying to apply an emancipatory framework.

Therefore at times, structural barriers exist within the academy, which may render the carrying of responsibility by any other than the researcher impossible.

Fourthly, considering the ever changing relationship of power dynamics within and outside the academy, a researcher needs to observe inherent power differentials and recognise that certain kinds of knowledge will always be implicitly or explicitly privileged. This may at times be a strength in that some types of knowledge may be more credible than others. For example, adopting the explanation of the double empathy problem (Milton 2012) rather than that of deficit (theory of mind, Happé 1993; Monotropism, Murray et al. 2005 or lack of central coherence Happé et al. 2001), which may be more in line with a critical perspective of autism. However, it is also important to recognise that more hegemonic *and* counter-hegemonic discourses may come with the risk of misrepresenting certain perspectives.

Finally, it is important that we avoid essentialising autistic communities, voices, and views. It is important to recognise that people have different perspectives and approaches, which may all be equally valued and important. This suggests the importance of intersectional approaches for emancipatory autism research: How can concepts relating to patriarchy and other forms of structural oppression be best applied to the situations that autistic people face when navigating structural relationships such as gender and sexual identities, or other differences?

Doing the research

Applying an emancipatory framework during a research process will need to draw on similar principles to those previously discussed. One such characteristic is the diversification of leadership: no single person sets the research goals or processes, and everyone has an opportunity to contribute to the design of the process. This can at times present many practical challenges and may require flexibility on behalf of the organisations, as support to similar projects is crucial when emancipatory and participatory frameworks are implemented. New

styles of academic leadership may therefore be called upon - ones able to incorporate different thinking styles and writing approaches in research processes. Rather than prioritising and defending certain thinking styles, a task for this leadership may be to map out the abilities and tasks as well as individual support needs - regardless of where the individual group member is situated on the neurodiversity continuum - and connect all participants in the research process into a caring network in which the strengths of each individual in the group is used to make up for the challenges experienced by other members of the group.

Another important element of this process is the researcher's own reflexivity and ideological stances in terms of the academic identity itself. Operating in a framework where language is often considered the most important aspect of work, to dive deeper into terminologies and inaccessible rhetoric practices may distance someone from individuals with more lay use of language. Furthermore, the researcher may make decisions about the research project that the participants will have no say in. Although this is worth considering, it is not always unwelcome. The alternative would mean engaging the participants in debates about methods of data collection and analysis, in which they may have no interest in or little to contribute. Considering how the participants' views are represented throughout the project as well as providing those opportunities throughout the project should the participants want to take them would perhaps provide solutions to some of those dilemmas.

Finally, the academic challenge of managing personal philosophies in the de-marginalisation of voice and the requirements of academia and the researcher's ontological stance are important in shaping the way the data is collected, analysed, and discussed. Although often implicit, they are likely to be a significant part of the researcher's approach and often considered broad, theoretical, and abstract. The assumption often is that lay people may not be interested in discussing them, however it would be useful to consider if this is the case in each project separately.

Disseminating the research

For research to be considered emancipatory, it is not sufficient that research process and production be emancipatory, but dissemination of research findings should also fulfill this function. Considering the dissemination of research findings, and the findings themselves produced in an ‘accessible’ format, should be a concern of any researcher who is doing emancipatory research. Methods such as lay summaries, video dissemination, and performance could be useful tools in this process. As Bone (2017, 15) puts it: “Access is not merely letting people have the ability to read our work; access is creating a culture wherein a diversity of learning experiences is permitted to flourish”. It is also important to consider how collaborative approaches would be able to influence the development of policies and research agendas more broadly.

Finally, there is a need for broader recognition of the value for collaborative research practices where autistic people not only participate in research and approve final reports, but actually drive the research agenda. The Participatory Autism Research Collective (PARC) in UK, and the Autism Cooperative Research Centre in Australia are organisations seeking to actively promote the engagement of researchers in the co-production of knowledges. Similar networks in other countries could contribute to a broader ethos in academia and further influence its practices.

Conclusions: Developing a space for emancipatory autism research

Using the words Hall (2014, 388), we hope to tell our own story of the way our collective “we” travelled our research journey and contribute to the emerging ideas about research in a post-colonial academic space. Our writing process has been driven by our need for developing research practices that do not uncritically reproduce cognitive normative academic processes of thinking and working, that aims at de-colonialising rather than continuing colonialising neurodiverse experiences, interrupting cognitive othering including oppression

for neurodiverse people and ‘speaking for’ the ‘other’. This collaboration has been fruitful in ways that have extended beyond the writing of this piece. Since working on this paper, four of the writers worked together in organising a conference where one more presented their research. This has in turn created a ‘snowball effect’ of further projects and collaborations among the team of authors and beyond, slowly building an epistemological ‘intimate’ community of both learning and writing together. Consequently, this re-imagining of spaces of knowledge creation can act as a counter-balance to the existing status quo, disrupting the traditional dynamic without the need for more difficult structural changes (Raymaker and Nicolaidis 2013). In the concluding sections of this paper we would like to propose way forward for emancipatory autism research, based on our experiences of working together across neurodiverse allegiances.

In terms of data collection, it is important that the researcher is flexible in their research approaches in order to enable diverse voices to be captured. It is also important to consider appropriate tools for data generation in order to promote emancipatory research and to broaden participation for those who are often excluded from autism research such as those who are non-verbal and intellectual/learning disabled. Finding the ‘right’ collaborators, as well as the implications of this, can also be a challenge. Often certain groups of people are not interested in being part of emancipatory research, whereas others are particularly interested. Finally, being engaged in different kinds of research will entail different challenges when trying to make it emancipatory and different positions and theoretical frameworks may be of use.

Many areas of research have shown in the past how critical involvement with the field and an insider’s perspective can enrich our understanding. The change of perspective to include insider knowledge has a further advantage, that of turning the spotlight from the ‘neurodiverse deviation from the norm’ and enabling us to study instead the society that produces that norm, and the purposes served by creating ‘cognitive others’ as well as ‘cognitive normate selves’ from a neurodiverse perspective.

There is more than one mainstream norm to consider when being given the task to scrutinise ‘the (cognitive) norm’, so another question to be explored may be the co-workings of intersecting norms. From a neurodiverse perspective, we need to ask ourselves; how can we do this in a way that is inclusive and is as open to as many people as possible? It is not sufficient to ensure access to academic products for those outside the academy. Access requires “creating a culture wherein a diversity of learning experiences is permitted to flourish” (Bone 2017, 15). One in which voices from a range of experience can be heard and valued. Re-thinking, and possible responses to questions of who can speak, and who may be heard, may be a step in the direction of “rhetorical adjacency” (Pryal in Bone 2017, 12), in which academics (and/or non-autistic people) can be positioned beside non-academics, encouraging and supporting their voices while not taking over their agency. We argue that this is a step in the direction of emancipatory research of the type Mike Oliver proposed when he stated that “once people have decided to empower themselves”, research must consider how it can best “facilitate this process” (Oliver 1992, 111).

The epistemic and ethical value of doing otherwise includes respecting neurodiverse people as both holders and producers of knowledge, and opens up discussions about inclusive research methods more generally, both within and beyond the field of autism. Stressing the ‘double empathy problem’ as theorised by Milton (2012), ‘misunderstandings’ between autistic/non-autistic are ‘mutual’. The existence of a mythical norm permits assumptions of deficit, which can act as the ‘starting point’ for much research. The assumptions can serve to “...impede scientific and philosophical progress in our understanding of the phenomena themselves” (Dinishak 2016, 1), where the search to understand phenomenon is ‘pre-empted’ by the assumption of deficit.

The academy is bound within cognitive normative epistemological assumptions and perceptions surrounding autism research. Through collaborative research between both autistic

and non-autistic researchers we can start to change hegemonies of power that operate within the academy, and to a broader extent society. Based on these reflections, we propose a framework for emancipatory autism research in order to contribute to the further development of *framing*, *doing*, and *disseminating* research around autism:

Framing the research

- The context of continual reflexivity: a) the researcher's reflexivity on their own positionality and role within a research project; b) autistic and non-autistic researchers have different challenges regarding reflexivity when doing autism research;
- Similar invested interests in the topic researched and the shared desire to expand the academic and lay knowledge on this particular topic;
- Ownership of the work;
- Challenging epistemic authority/privilege: certain kinds of knowledge will always be implicitly or explicitly privileged. This may at times be strength: some types of knowledge may be more credible than others;
- Intersectionality/difference between and within groups: avoid essentialising autistic communities, voices, and views.

Doing the research

- Diversification of leadership and developing new styles of academic leadership;
- Researcher's own reflexivity and ideological stances in terms of the academic identity itself;
- In terms of data collection, it is important that the researcher is flexible in research approaches in order to enable diverse voices to be captured;
- Being engaged in different kinds of research, such as practice as research.

Disseminating the research

- The findings themselves rendered ‘accessible’, should be a concern of any researcher who is doing emancipatory research;
- Finally, there is a need for broader discipline recognition of the value for collaborative research practices where autistic people not only participate in research and approve final reports, but actually drive the research agenda.

References

Arnold, L. 2016. *The application of video in the education of autistic adults* (Doctoral dissertation, University of Birmingham).

Barton, L. 2005. “Emancipatory research and disabled people: some observations and questions.” *Educational Review* 57(3): 317–327.

Bone, K. M. 2017. “Trapped behind the glass: crip theory and disability identity.” *Disability & Society* 32(9): 1297-1314.

Branfield, F (1998) “What are you doing here?” A response to Robert F Drake. *Disability & Society* 13(1): 143-144

Branfield,F. (1999) The disability movement: a movement of disabled people: a response to Paul S Duckett. *Disability & Society* 14(3): 399-403

Bratton, K. A. and L. P. Ray. 2002. “Descriptive Representation, Policy Outcomes, and Municipal Day-Care Coverage in Norway.” *American Journal of Political Science* 46(2): 428-437.

Brewer, E. and C. L. Selfe. 2014. "Creating a Culture of Access in Composition Studies." *Composition Studies* 422, 151–154.

Duckett, P. (1998) "What are you doing here?" "Non disabled; people and the disability movement: a response to Fran Branfield. *Disability & Society* 13(4): 625-628

Celis, K. and S. Childs. 2008. "Introduction: The descriptive and substantive representation of women: New directions." *Parliamentary Affairs* 61(3): 419-425.

Celis, K., S. Childs, J. Kantola, and M. L. Krook. 2008. "Rethinking women's substantive representation." *Representation* 44(2): 99-110.

Childs, S. and J. Lovenduski. 2013. "Political representation." In *The Oxford handbook of gender and politics*, edited by Georgina Waylen, Karen Celis, Johanna Kantola, and S. Laurel Weldon

Chown, N., J. Robinson, L. Beardon, J. Downing, L. Hughes, J. Leatherland, ... and D. MacGregor. 2017. "Improving research about us, with us: a draft framework for inclusive autism research." *Disability & Society* 32(5): 720-734.

Cilliers, F. and H. Greyvenstein. 2012. "The impact of silo mentality on team identity: An organisational case study." *SA Journal of Industrial Psychology* 38(2): 1-9

Chaloupka, E. 2015. "Imagining Cognitive Disability: Recursive Reading and Viewing Processes in Henry H. Goddard's *The Kallikak Family: A Study in the Heredity of Feeble-mindedness*." *CEA Critic* 77(3): 269-277.

Mitchell, C.J. and L. Kedan. 2012. *Access All Areas: Live Art and Disability*. Live Art Development Agency.

Chappell, Anne Louise (2000) "Emergence of participatory methodology in learning difficulty research: Understanding the context," *British Journal of Learning Disabilities*, 28: 38-48.

Cooks, L. and J.T. Warren. 2011. "SomeBodies(') in School: Introduction." *Text and Performance Quarterly* 31(3): 211-216.

Danieli, A. and C. Woodhams. 2005. "Emancipatory research methodology and disability: A critique." *International Journal of Social Research Methodology* 8(4): 281-296.

Dinishak, J. 2016. "The Deficit View and Its Critics." *Disability Studies Quarterly* 36(4).

Foucault, M. 1986 [1967]. "Of Other Spaces." *Diacritics* 16(1): 22-27.

Foucault, M. 1979 [1976]. *The History of Sexuality Volume 1: An Introduction*. London: Allen Lane.

Garland Thomson, R. 1997. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press.

Garland Thomson, R. 1996. *Freakery: Cultural Spectacles of the Extraordinary Body*. New York University Press.

Goodley, D. and P. Clough. 2004. "Community projects and excluded young people: reflections on a participatory narrative research approach." *International Journal of Inclusive Education* 8(4): 331-351.

Hall, L. 2014. "'With' not 'about' – emerging paradigms for research in a cross-cultural space." *International Journal of Research & Method in Education* 37(4): 376-389.

Halperin, D. M. 1995. *Saint Foucault: towards a gay hagiography*. New York: Oxford University Press.

Happé, F. G. 1993. "Communicative competence and theory of mind in autism: A test of relevance theory." *Cognition* 48(2):101-119.

Happé, F., U. Frith, and J. Briskman. 2001. "Exploring the cognitive phenotype of autism: weak "central coherence" in parents and siblings of children with autism: I. Experimental tests." *The Journal of Child Psychology and Psychiatry and Allied Disciplines* 42(3): 299-307.

Interagency Autism Coordinating Committee. 2013. *IACC/OARC Autism Spectrum Disorder Publications Analysis: The Global Landscape of Autism Research*. Washington, DC: Interagency Autism Coordinating Committee, US Department of Health and Human Services 2012: July.

Jivraj, J., L.-A. Sacrey, A. Newton, Nicholas, D. and L. Zwaigenbaum. 2014. "Assessing the influence of researcher-partner involvement on the process and outcomes of participatory research in autism spectrum disorder and neurodevelopmental disorders: A scoping review." *Autism* 18(7): 782–793.

Liddiard, K. 2011. *(S)exploring Disability Intimacies, Sexualities and Disabilities*. University of Warwick. Thesis (Ph.D.)

MacLeod, A. G., Lewis, A., and C. Robertson. 2014. " 'CHARLIE: PLEASE RESPOND!' Using a participatory methodology with individuals on the autism spectrum." *International Journal of Research & Method in Education* 37(4): 407-420.

Meier, P. and E. Lombardo. 2010. "Towards a new theory on the symbolic representation of women." Paper presented at the American Political Science Association annual meeting, Washington, DC, September, 2–5

Milton, D. and M. Bracher. 2013. "Autistics Speak but Are They Heard?" *Medical Sociology Online* 7(2):61–69.

Milton, D. E. M. 2012. "On the ontological status of autism: the 'double empathy problem'." *Disability & Society* 27(6): 883-887.

Murray, D., Lesser, M., and W. Lawson. 2005. "Attention, monotropism and the diagnostic criteria for autism." *Autism* 9(2): 139-156.

Nelson, R. 2013. *Practice as Research in the arts*. Palgrave Macmillan.

O'Dell, L., H. Bertilsdotter Rosqvist, C. Brownlow, F. Ortega, and M. Orsini. 2016. "Critical autism studies: exploring epistemic dialogues and intersections, challenging dominant understandings of autism." *Disability & Society* 31(2): 166-179.

Odenstedt, A. 2005. "Gadamer on the Limits of Reflection." *Journal of the British Society for Phenomenology* 36(1): 39-54.

Oliver, M. 1992. "Changing the social relations of research production?" *Disability, Handicap & Society* 7(2): 101-114.

Pellicano, L. 2014. "A future made together: new directions in the ethics of autism research." *Journal of Research in Special Educational Needs* 14(3): 200--204.

Pellicano, E., Crane, L. and K. Gaudion. 2017. *Participatory autism research: A starter pack*. London: UCL Institute of Education.

Pellicano, L., W. Mandy, S. Bölte., A. Stahmer, J. Lounds Taylor, and D .S. Mandell. 2018. "A new era for autism research, and for our journal." *Autism* 22(2): 82-83.

Pitkin, H. F. 1967. *The concept of representation*. Berkeley: University of California Press.

Raymaker, D., and C. Nicolaidis. 2013. "Participatory Research With Autistic Communities." In *Worlds of Autism: Across the Spectrum of Neurological Difference*, edited by J. Davidson and M. Orsini, 169–188. Minneapolis: University of Minnesota Press.

Samek, A. A. and T.A. Donofrio. 2013. " 'Academic Drag' and the Performance of the Critical Personae: An Exchange on Sexuality, Politics, and Identity in the Academy." *Women's Studies in Communication* 36(1): 28-55.

Seale, J., M. Nind, E. Tilley, and R. Chapman. 2015. "Negotiating a third space for participatory research with people with learning disabilities: an examination of boundaries and spatial practices." *European Journal of Social Science Research* 28(4): 483-497.

Seidman, S. 1996. "Introduction." In *Queer theory/sociology*, edited by S. Seidman. Cambridge, 1-29. Mass: Blackwell.

Silfver, E., M. Jacobsson, L. Arnell, H. Bertilsdotter-Rosqvist, M. Härgestam, M. Sjöberg, and U. Widding. (e-pub). "Classroom bodies: affect, body language, and discourse when schoolchildren encounter national tests in mathematics." *Gender and Education*

Sinclair, J. 2010. "Cultural Commentary: Being Autistic Together." *Disability Studies Quarterly* 30(1).

Smith, A. J., P. Flowers, and M. Larkin. 2009. *Interpretive Phenomenological Analysis: Theory, Method and Research*. London: Sage Publishing.

Steinbock, A. J. 1997. "Back to the Things Themselves. Introduction." *Human Studies* 20: 127–135.

Stone, E. and M. Priestley. 1996. "Parasites, pawns and partners: disability research and the role of non-disabled researchers." *British Journal of Sociology* 47(4): 699-716.

Waltz, M. 2009. "Participatory and emancipatory autism research: What's the problem?" Presented at Autism 2006 virtual conference.

http://www.awares.org/conferences/print_paper.asp?section=000100010001&conferenceCode=000200020009&id=82

Warner, M. 1993. "Introduction." In *Fear of a queer planet: Queer politics and social theory*, pp vii—xxxi, edited by M. Warner. Minneapolis: University of Minnesota Press.

Woods, R., D. Milton, L. Arnold, and S. Graby. 2018. "Redefining Critical Autism Studies: a more inclusive interpretation." *Disability & Society* 33(6): 974-979.

Zarb, G. 1992. "On the Road to Damascus: First Steps towards Changing the Relations of Disability Research Production." *Disability, Handicap & Society* 7(2): 125–138.