Abstract

The ‘Talking Together’ community engagement pilot project brought together pairs of autistic and non-autistic strangers to (a) talk about their experiences of loneliness in their local city and (b) think about potential, co-produced responses to the problem.

The project had evolved as a secondary aim, from an initial need to acquire naturalistic conversation data for my Linguistic PhD research investigating a theoretical reframing of autistic language use as ‘different’ not ‘deficient’. The desire to make the data collection a meaningful experience for the participants in its own right was central to the research design and so the ‘Talking Together’ loneliness project was devised as a way to achieve this. However, it was not until the research was underway that the potential for valuable, immediate impact became apparent.

This article reflects on the successes and challenges of the Talking Together pilot as a piece of autistic-led participatory research, and explores how the principles of engaged, participatory research can be applied so as to maximise impact, even where engagement may not be a primary aim. It also explores the ‘participatory’ nature of participatory research where the researcher themselves belongs to the marginalised stakeholder group.

Key words

loneliness; autism; conversations; participatory design; data collection

Key messages

● Engaged research can enrich linguistic data collection on multiple levels, not least in making the experience more meaningful for stakeholder research participants.

● Facilitating strangers to come together to talk about their experiences of loneliness can generate qualitative data on loneliness, whilst at the same time contribute to reducing the impact of loneliness, as an act of radical ‘world-building’.

● Supporting autistic people to access doctoral research opportunities is one way of broadening the body of participatory autism research.
INTRODUCTION

One of the most familiar characteristics of autism — even among those who know little about it — is a difficulty with social communication. In portrayals of autistically-coded characters in film and media, it is something of a popular trope (e.g. Raymond in *Rain Man*, Sheldon Cooper in *The Big Bang Theory*, Christopher in *The Curious Incident of the Dog In the Night-time*...). Within the sciences, since Kanner’s (1943) early observations, there has been a long-held belief that the ‘pragmatic’ (i.e. social / contextually bound) communication of autistic people is impaired (e.g. see: Tager-Flusberg, 1999): something that is usually attributed to a presumed theory-of-mind deficit (e.g. see Baron-Cohen, Leslie and Frith, 1985; Happé, 1993).

However, a growing body of empirical work investigating the ‘Double Empathy Problem’ (Milton 2012; Milton, Heasman and Sheppard, 2018) is beginning to demonstrate that the difficulties in mutual understanding in fact run both ways between autistic and non-autistic people (e.g. see: Brewer et al., 2016; Heasman and Gillespie, 2017; Morrison et al., 2019; Sasson et al., 2017; Sheppard et al., 2015). The primary aim of my PhD research was to bring this difference-not-deficit perspective to an investigation of adult autistic language use, using cognitive linguistic theories to explore the breakdowns in understanding that occur at a pragmatic level between autistic and non-autistic people.

In order to do this, I first needed a body of naturalistic conversation data to analyse. Often, in autism research, conclusions are drawn from data derived from experimental settings. Corpora featuring naturalistic adult autistic conversation are not widely available, and where linguistic research has used naturalistic data as its source material (such as in Loukusa et al., 2007; Ochs and Solomon, 2010; Sirota, 2010; Sterponi and de Kirby, 2016; Sterponi
and Fasulo, 2010), the conversations are usually between autistic children and their caregivers, captured by researchers as ordinary life goes by.

Deciding, then, to create my own dataset from scratch, it felt important to ensure that the data-collecting activity was meaningful in its own right. In this way the research project could become a mutually beneficial endeavor to both me as researcher and the autistic participants who were lending me their time. Coproduction with autistic stakeholders and autistic scholarship that brings autistic voices into the academy are, rightly, increasingly being recognised as providing vital insights to autism research (Chown et al., 2017; Happé and Frith, 2020; Milton and Bracher, 2013; Pellicano et al., 2020). However, it remains the case that ‘the vast majority of research in autism is still undertaken on autistic people, rather than with them, and is often not concerned with improving the day-to-day lives of people with autism’ (Milton and Bracher, 2013: 2). With this in mind I wanted to create a scenario where the conversations I was collecting for my primary linguistic analysis had an intrinsic value for the autistic people taking part in them.

Loneliness is something that I have been personally very familiar with for as long as I can remember (despite being blessed with a coterie of caring friends). This is not at all uncommon for autistic people, such as myself. A pervasive sense of not fitting-in, divergent needs and ways of being in the world that are often misunderstood, and social isolation all contribute to autistic people in the UK being four times as likely to experience loneliness as general population (National Autistic Society, 2018). Recent research findings, such as how non-autistic people tend to form instant, negative, thin-slice judgements about their autistic peers (Sasson et al., 2017) and non-autistic perceptions and biases have a greater role in shaping interaction than actual autistic characteristics (Morrison et al., 2019), paint a bleak
picture of the kind of the additional commonplace, implicit social exclusion that autistic people can face daily.

Around the time that I was beginning to design the empirical part of my PhD research, BBC Radio 4 began broadcasting a series of programmes called *The Anatomy of Loneliness*, presenting the results of the BBC Loneliness Experiment. The experiment took the shape of a large-scale survey, completed by 55,000 people over the age of 16, co-run by researchers from the University of Manchester, Brunel University London and Exeter University and supported by the Wellcome Collection. The questionnaire asked people what they thought loneliness was, when they felt lonely and for how long. Surprisingly, the highest levels of loneliness had been reported in younger respondents (16-24 age group) with 40% feeling lonely, compared with only 27% of older respondents who had completed the study (BBC Radio 4, 2018).

One further, negative autism trope is that autistic people are unaffected by the human need for others: that we are quite happy alone in our own worlds. This, too, relates to a central explanatory theory of autism that gained traction for some time, postulating that the social difficulties observed in autistic people were borne of a pathologically reduced motivation to engage in the social world (Chevallier et al., 2012). This idea no longer holds as much favour as it once did (Jaswal and Akhtar, 2019), particularly because it does not chime with the experiences of autistic self-advocates who have more recently found a public voice and who often report a longing for social connection (see: Causton-Theoharis, Ashby, and Cosier, 2009).

Knowing that I would need non-autistic participants to take part in the necessary conversations, and that these participants would most likely be recruited from the available
pool of University of Brighton Humanities undergraduate students, loneliness suddenly seemed the most obvious focus for these exchanges. Here, two populations who are at increased risk of experiencing loneliness (young people as identified by the BBC Loneliness Experiment, and autistic people) could meet and share their experiences and insights. Connections might be made between members of two social groups that may not ordinarily interact, broadening social horizons, and some valuable qualitative data addressing the lived experience of autistic loneliness might be created. It was out of this requirement for a dataset of naturalistic conversational data, and the strong desire to make whatever conversations that might take place meaningful in their own right, that the ‘Talking Together’ project was born...

THE ‘TALKING TOGETHER’ PROJECT

The Talking Together community engagement project was structured to bring together pairs of autistic and non-autistic strangers to (a) talk about their experiences of loneliness in their local city and (b) think about potential, co-produced responses to the problem. The original wish for the project was that if some clear aims for local actions on loneliness could be identified through these conversations, funding would be sought to develop a second stage where the original participants and further stakeholders could be supported to trial a social enterprise project of their own design, tackling loneliness locally. This potential second stage was beyond the scope of my PhD and securing financial support for an extension of the project proved impossible to obtain at the time despite several attempts. However, I believe gains were made in addressing loneliness on a micro-scale, among the participants of Talking Together, and these are discussed later.
The project’s participants fell into three different groupings. Group A were the core set of eight autistic participants (originally ten, but two had to withdraw on the day due to ill health), recruited through local autism charity, Assert. Assert (https://www.assertbh.org.uk) is a member led organisation, founded in 2002, that supports autistic people traditionally identified as being ‘high functioning’, or having Asperger’s Syndrome, along with their family members, partners or carers. It offers a range of services including a monthly social drop-in, case-work, support in accessing government or local council benefits, educational and life-skills courses to empower autistic clients and autism awareness-raising training for local organisations. The second group of young people, Group B, were recruited through the University of Brighton School of Humanities mailing list and the third group, Group X, represented the friend or family member that the core autistic participant had nominated to come as their first conversation partner.

The core autistic participants (and their chosen, familiar conversation partners) were invited to take part in a piece of doctoral research investigating autistic communication, in the form of a community engagement project around loneliness in the local area. The non-autistic participants (Group B) were invited, in the first instance, to take part in a piece of doctoral research investigating communication between pairs of strangers, in the form of a community engagement project about loneliness. Following their conversations this group were advised that a key aim of the study had been to investigate how different types of people establish and maintain common ground in conversations, and as such their conversation partner “may” have been autistic (I wanted to allow my autistic participants to disclose their own diagnoses on their own terms, should they wish to and to leave some room for ambiguity). It was explained that this information had previously been omitted in
order avoid any potential biases or modifications of their natural speech. Consent to use the conversations was re-confirmed in light of the new information.

Each core participant (A) had three conversations of roughly 10 minutes each, firstly with their chosen, familiar conversation partner (X), secondly with an autistic stranger (another ‘A’) and finally with a non-autistic stranger (B). For each conversation pairing a different set of two prompt questions were provided in order to give the participants somewhere to begin, although it was explained that the questions were just there as a guide and that it was not necessary to answer them directly. Prompts were designed to elicit personal experiences of loneliness, thoughts about loneliness in Brighton and Hove more specifically and to invite ideas around how address those problems within the city.

Increasingly, autistic individuals are receiving their diagnoses later in life, despite autism being present from (at least) birth. As such, it is widely understood that there exists ‘a lost generation of people who were previously excluded from a diagnosis’ often exacerbated by the misdiagnosis of (in particular) women (Lai and Baron-Cohen, 2015: 1013), whose masking behaviours (see: Hull et.al. 2017) — in addition to diagnostic biases — made them harder to detect. And yet achieving a diagnosis of autism in adulthood is not easy. In one study, conducted by the Social Care Institute for Excellence (n=59), only 19% of participants diagnosed as autistic in adulthood found accessing an adult diagnosis ‘easy’; with 81% describing it as ranging from ‘quite difficult’ to ‘not possible’ (Taylor and Marrable, 2011: 18).

In view of this, stipulating that participants must have a formal autism diagnosis seemed unnecessarily limiting. However, in order to add the results of this study to the wider literature surrounding autism research in a meaningful way, participants would be required
to have a formal diagnosis of autism. This was one of several points throughout the data collection design process where it felt like the world of research and the lived world of the researched community were slightly at odds. Eventually it was decided that information pertaining to diagnostic status would be collected based on the self-report of having received a formal diagnosis. All respondents reported a diagnosis of either autism level 1, autism spectrum condition or Asperger’s syndrome: the various terminology reflecting the differing times at which they received their diagnosis. Aside from this, I chose to not impose any further (demographic) stipulations, so as to allow for as much variability as possible within what would be a small case study. Finding a finding a group of ‘typical’ autistic people is nigh impossible, given the characteristic heterogeneity of autism (e.g. see Beardon, 2017; Fletcher-Watson and Happé, 2019, etc…). In some ways then, allowing a degree of chance to play out in terms of who the eventual participants were was part of the purposefulness of the sampling. The eventual eight core participants comprised three white males (two roughly in their 50s, of whom one had additional learning difficulties; and one in his 40s) and five white females (one in her 20s; three in their 30s; and one roughly in her 50s). All were British except the final female participant in her 50s who was French.

LONELINESS, ‘ETHICAL LONELINESS’ AND WORLD-BUILDING

Loneliness is a ‘universal affliction’ (McGraw, 1995: 43) that almost all people will have experienced at some point in their lives. For many, it is a more serious, pervasive and distressing state. Often described as the ‘discrepancy between one’s desired and achieved levels of social relations’ (Perlman and Peplau, 1981:32), loneliness is a risk factor for
various health problems and increased mortality rates (see: Binnie, 2019; Holt-Lunstad, Jeste, Lee and Cacioppo, 2020; Smith, and Layton, 2010; Valtorta, 2016; Wong et al., 2017).

‘Loneliness’, however, can refer to a range of experiences. And as Wong and colleagues (2017) rightly wonder, if we take as a given the oft-cited Perlman and Peplau (1981) definition of loneliness as the gap between the number and kind of social relations that one has, and that one wants, does it entail that ‘loneliness [is] experienced only as a result of deficits in interpersonal relationships?’ (Wong et al., 2017: 1). In a recent opinion piece in JAMA Psychology, Jeste, Lee and Cacioppo (2020: 1) describe loneliness as a ‘hard to detect and lethal behavioural toxin’ contributing to the creeping figures of growing suicide and opiate epidemics. Speculating on its cause, they suggest an ‘underlying thread of social anomie and disconnection’ (Ibid.).

In Wong and colleagues’ (2017) cross-sectional, qualitative study investigating elderly loneliness in Hong Kong, they came to conclude that a significant factor influencing the extent to which the elderly felt lonely was a sense of increased alienation from society as a whole. As they had entered their twilight years, these elders had experienced nationally insufficient care for older people, a growing distance between themselves and the rest of society, and a disintegration of their identity within society (2017: 7). They felt their voices were not heard and their lives were now insignificant. They were experiencing some degree of what might be called ‘ethical loneliness’.

It is this breakdown of a connection with humanity — a connection that ordinarily is upheld by moral, ‘ethical’, principles — that causes the deepest wound of loneliness. To feel ones needs and human rights shrugged off by others erodes ones sense of selfhood and value in the world and it is this that Stauffer (2015) has termed ‘ethical loneliness’. According to
Stauffer, ethical loneliness is ‘a form of social abandonment that can be imposed only by multiple ethical lapses’ (2015: 2), and is experienced when:

...a violated person or [a] member of a persecuted group, has been abandoned by humanity, or by those who have power over one’s life possibilities. It is a condition undergone by persons who have been unjustly treated and dehumanized by human beings and political structures... compounded by the experience of not being heard. (Stauffer, 2015:1)

While Stauffer’s treatise mainly deals with ethical loneliness in the context of political injustice and extreme human rights violations such as torture, this kind of ‘ethical loneliness’ seems particularly relevant when thinking about loneliness and autism. Autistic people are routinely ‘othered’ in macro- and micro-social ways (as was highlighted by the findings of Sasson and colleague’s 2017 study mentioned above, showing that non-autistic people tend to form unconsidered, negative opinions about autistic individuals within the first few seconds of meeting them). Moreover, as are all disabled people, they are statistically more likely than non-autistic people to suffer abuse of some form or another (see e.g. Haruvit-Lamdan et al., 2020; Stalker and McArthur, 2012; Sullivan and Knutson, 2000).

The purpose of this paper is to reflect on the value and challenges of meaningfully engaging autistic participants in the creation of a conversational dataset, not to report on the qualitative loneliness findings that they dataset generated. However, some of the participants’ comments provide useful insight into their experiences of what could be described as ethical loneliness and in the spirit of allowing marginalised voices to be heard, a few short extracts are replicated here.

One bilingual autistic participant in her early 50s (‘A3’), in lamenting her lack of meaningful connections, described her difficulty in making friends:
“...sometimes I have trouble to, erm, to have a conversation or be understood because I don’t, mm, have the same thought process? Which makes it weird sometimes and people are wondering ‘what are you saying?’ or ‘I can’t understand what do you mean’ or, you know, those kind of things and you have to break it down for people.”

“It never lasts, or people — once you leave [a job] — they just forget you. Or they say ‘give me your phone number’ and then they never call so I got used to it and I deleted a lot of phone numbers on my phone. It’s stupid to pretend you have friends when you haven’t got them.”

Another participant (‘A1’), an autistic man with additional learning difficulties, also in his 50s, shared his confusion and sadness about the lack of support available when he needed it:

“...with me having, erm, having, erm, autism, and learning disabilities, I mean I understand a bit more about it today than I did do, but when I wasn’t getting the support I felt very lonely.... You know, cos, er, you know, you know I didn’t have any connection.... I was crying out for that support.”

“...and when you phone it [a helpline] no one ever answers. I mean, I think someone will answer it eventually but from my experience no-one’s ever answered it. I’ve never actually spoken to a person on the other end of the line on this, whatever number it was.... You know, if people are crying out for help because of how they feel and there’s no help then of course they’re going to feel lonely or, you know, get into a state....”

It is exactly this kind abandonment by those in a position to help, that causes ‘a loneliness more profound than simple isolation’ (Stauffer 2015: 5). Not being able to make yourself understood, and not being able to connect in a satisfying way with fellow humans can create a deep pain of isolation. Not having this pain acknowledged can be experienced as soul-crushingly dehumanising.

For Stauffer, being ‘heard’, particularly when wrongs have occurred, is a crucial step towards reconciling the pains of ethical loneliness and re-establishing trust in other humans, or, as she calls it, ‘world-building’:
A survivor will need broad social support that functions as a promise that, though she was once abandoned by humanity, that will not be allowed to happen again. That is an act of world building, which is a cooperative enterprise, not a solitary endeavour.’

(Stauffer 2015: 7)

It is the promise of engagement with others, and the promise that previously ignored voices will now be heard and, importantly, listened to that is most important for rebuilding connection with a world where all people do matter. World-building is a healing, restorative process, involving radical conceptual change about who matters, who is safe, and who belongs in the world following an instance or period of profound disconnection from it.

World-building cannot be done alone: there must be the hand of another reaching out towards ours. ‘My sovereignty depends’, summarises Stauffer (2015: 19). We live under the illusion that we are independent entities but the maintenance of our wellbeing and our very existence is dependent upon an interconnected web of human, (and, arguably, ecological) relations. At the time of writing this article, during a national “lock-down” response to an international pandemic, never has this been more tangible.

TAKING A PARTICIPATORY APPROACH

Participatory research is a methodology, of which a central principle is the disrupting of the ‘traditional power imbalance between researcher and participant’ (Fletcher-Watson et al., 2018: 2). Closely aligned with the critical disability studies movement’s adopted call to arms of ‘nothing about us without us’ (see: Charlton, 1998; Milton and Bracher, 2013), its often emancipatory aims (Bertilsdotter Rosqvist et al., 2019), are to co-produce research that is mutually beneficial for both researcher and participants.
Involving stakeholder voices in the various stages of research design and implementation is important. The alternative — an exclusion of such voices — is ‘both ethically and epistemologically problematic, and constitutes a significant barrier to impact’ (Milton and Bracher, 2013: 61). An example shared by Nicolaïdis et al. (2011), in their paper reporting on the establishment of their community-based participatory research partnership ‘AASPIRE’ (The Academic Autistic Spectrum Partnership in Research and Education), demonstrates this neatly:

For example, the group reviewed a paper about an functional magnetic resonance imaging study whose results were popularized as proving that autistics do not daydream. These reports angered many autistic self-advocates who knew that they daydreamed and felt the research questions were less pressing than other issues affecting their lives. They questioned the validity of the results, noting that the protocols did not take into account literal interpretation of language or challenges related to task switching. They also felt the deficit-based language in the research paper was stigmatizing and the conclusions reinforced dehumanizing stereotypes. (Nicolaïdis et al., 2011:143-144)

For a group of people who already experience a great deal of misconceptions, social exclusion, stigma and lack of understanding (Causton-Theoharis, Ashby and Cosier, 2009; Morrison et al., 2019; National Autistic Society, 2018; Sasson et al., 2017), it seems all the more pressing to ensure that autistic voices are included the production of knowledge relating to their lived experience(s).

A number of simple but considered steps were taken throughout the designing of the Talking Together project, guided by the Participatory Autism Research Starter Pack (Pellicano et al., 2017), to make the research as accessible as possible. Participants were recruited through Assert, a trusted gatekeeper, who also hosted the Talking Together conversations, meaning that the venue and route to get there were familiar. Materials (such
as the information sheets and consent form) were designed so as to maximise white space; plain English was used along with illustrative images; and a photo of me — the as-yet unknown researcher — was also included to help shape expectations.

Drawing on autistic involvement in the design of results dissemination is an important, though often overlooked, feature of truly participatory research (see Nicolaidis, 2019; Pellicano et al., 2017). All too often, research that is pertinent to the lives and wellbeing of autistic people and their families is stashed behind a journal paywall, and even when it is published with open access the dense academic terminology makes it inaccessible to non-experts. For this reason, a follow-up ‘sense-making’ meeting with the original participants was scheduled for nine months after the data collection to provide an opportunity for participants to discuss their experiences of taking part, for me share the initial findings and for us to consider means of accessible dissemination of the findings for a wider autistic public.

PARTICIPATORY ‘ENOUGH’?

A recent editorial (Pellicano et al., 2018) in foremost interdisciplinary autism research journal, Autism, takes as it starting point a change in the focus of the recommendations of the Interagency Autism Coordinating Committee (IACC: an autism research advisory board to the US government) for research to include an emphasis on ‘efforts to improve services across the lifespan’ of autistic people (2018: 1). From here they argue that in order to achieve this, the input of autistic stakeholders with lived experience ‘in the here-and-now’ is essential at all stages of the research: from ‘being a research participant in the orthodox
sense to being actively involved in the design, implementation, interpretation and dissemination of the research itself’ (2018: 1,2).

Yet for relatively small-scale doctoral research, is it realistic to expect (of oneself) such a level of engagement throughout, from multiple autistic voices? How ‘participatory’ does participatory research have to be to ‘count’? This question was deftly explored by Southby (2017) when reflecting on her experience as a PhD candidate undertaking research into the experiences of football fans with learning difficulties. Like Southby, I was the sole creator of priority-setting for my research and of devising the research questions, and there was no stakeholder steering committee reviewing my research design. What is different perhaps, is that I myself belong to the stakeholder group in question: I’m both autistic and a researcher.

In reflecting on the benefit — or otherwise — of leading research as a member of the researched community, it has been difficult to fully separate out my own ‘lived experience’ from what I have learnt from my personal engagement with said ‘community’. The shaping of my research goals has no doubt been influenced by what I have learnt through my membership of what might be termed a loose, online ‘autistic community’ (Bagatell, 2010). Across social media, autistic adults with varying abilities and perspectives from all around the world connect via the #ActuallyAutistic and #AutisticsInAcademia hashtags and here I have borne witness to many debates about issues that while they may not immediately affect me, are deeply important to others. Likewise, I have been steeped in the literature of critical autism studies (see: Woods et al., 2018) and events organised by the Participatory Autism Research Collective (PARC), an autistic-led organisation initially based out of London South Bank University with the purpose of bringing autistic people, scholars, activists and early career researcher together (https://participatoryautismresearch.wordpress.com).
In terms of existing in a dual role as both autist and researcher, overall I would like to think that it added value to the Talking Together project. It’s hard to quantify, but in Talking Together there was a great sense of camaraderie and togetherness that I was able to be part of and help co-create. I was there listening among the participants, rather than listening to them. We shared in our mutual understanding. In ethnographic terms, this study had the opportunity for a deeply emic perspective (i.e. making sense of the participants and their data from an ‘insider’ perspective) rather than an etic one (i.e. drawing conclusions and making assumptions from an ‘outsider’ view). This insider perspective allowed me to take simple steps to make the research as accessible as possible, and to create an ‘autistic-friendly’ space where participants could feel both at ease and welcome.

As well as benefits there were several challenges, although these came exclusively as difficulties engaging with the university culture rather than with the delivery of the Talking Together project itself. For example, as a researcher heavily influenced by critical autism studies and critical disability studies, I felt strongly that paying for participant-contributor’s time and lived experience expertise of being autistic was an essential mark of respect. The National Institute of Health Research’s ‘INVOLVE’ policy, which outlines the fair payment of fees and expenses for members of the public engaging in health research (INVOLVE, 2010) is a national standard hourly and daily rate that has been taken up by British autism research charity Autistica. Further national policies regarding the involvement of service-users or target populations in research generally recognise that as well as meaningful participation, appropriate payment should also be encouraged (see Rickard and Purtell, 2011; and Nicolaidis, 2019 for autism-specific guidelines).
The university’s ethical guidelines, however, stated that financial rewards or inducements must not be offered. The rationale behind this, I believe, is so as to avoid coercion and as such is a valid concern when conducting research that involves the public (and in particular a potentially ‘vulnerable’ public). The issue was further complicated by the fact that this research involved participants of three different types; local autistic members of the general public; students at the university; and an unknown group of familiar conversation partners chosen by the core autistic participants. Would it be ethical, or even reasonable, to pay only some of the participants for their time, even if the remunerating of autistic participants were permitted?

The deliberation over payment was one of several areas that revealed a point of tension between standard, generalised university ethics procedures and research involving so called ‘vulnerable’ autistic participants that perhaps requires a more nuanced, and participatory-informed approach. The resulting compromise for this particular study was to offer all participants reasonable travel expenses to and from the venue where the conversations would take place, with simple refreshments provided. This fulfilled the requirements of the university ethics panel, but left me feeling as if I had not stood up for the rights of my autistic participants. This conflict of interests echoes Southby’s (2017) reflection that ‘participatory research may juxtapose the institutional mechanisms surrounding a research degree and provide practical barriers to research-degree students’ (2017: 128). Bertilsdotter Rosqvist et al. (2019), too, note that ‘academic systems... can be a barrier to the inclusion of autistic voices’ (2019: 1).

It also mirrors another more personal tension in the process of achieving ethical approval. The year that I was submitting my application saw a new piece of university-wide software
introduced as a replacement of the previous MS Word form. I found the software incredibly challenging to access. In part it was ambiguous phrasing of some of the questions, but mostly it was the visual format and layout of the interface (the colours, the endless spidery boxes leading to further, floating, spidery boxes) that I found inordinately taxing. In the end I had to request a deadline extension and the help of an advocate in order to complete it. This, while the content of my application was justifying at length how I was making documents, information and physical spaces accessible to my autistic participants left me feeling that neither this software nor this application process was designed with autistic people in mind. Where that left me, as an autistic researcher trying to navigate the academy, I wasn’t quite sure.

There are manifold barriers — societal, environmental, financial and structural — that make progression into the academy challenging for autistic people; and those who overcome these challenges, such as the viva voce (Chown et al., 2016), and obtain doctoral degrees, still rarely go on to obtain lecturing or research contracts (Barnham and Martin, 2017; Martin 2016). The institution of the academy is, by its nature, constructed around (cognitive) norms (Bertilsdotter Rosqvist et al., 2019) that represent everything that the autist stands outside of, having been defined in opposition to them. Indeed, my own PhD journey has been hampered by unpredictable accessibility issues and lack of institutional understanding around autistic needs and ways of being and working. Paradoxically it may be that more autistic students are needed to progress through to doctoral status before the academic environment can adapt itself to supporting autistic scholars.

Is it sufficient, then, to say that because I (a lone researcher) am a member of the marginalised group I am researching, there has been autistic involvement at every stage of
my research (as advocated by Pellicano et al., 2018, above)? In their starter pack Pellicano et al. (2017) remind readers that, autistic and non-autistic alike, researchers ‘need to listen in order to appreciate the diversity of what it is like to be autistic’ (2017: 2). I fear that in making the claim that my research is participatory, I may myself be indulging in a little of tokenism so rightly criticised by participatory research proponents (such as Fletcher-Watson et al., 2018; Pellicano et al., 2017): in this case tokenistically using the term ‘participatory research’. This project most lacked participatory input is its design and in the devising of the research aims. A more thorough participatory approach might have sought guidance from stakeholder Assert members on priorities for conversation topics, for example, or even on the primary aims of my PhD research. I could have built in an autistic steering committee to provide input on the details of the research design.

However, a doctoral research project is necessarily constrained by time, finances and fledgling ability. And as Southby concluded:

‘While attempts at participatory research may often fall short of their desired goals, being puritanical or dogmatic about what is and is not ‘participatory research’ only serves as a straightjacket for well-meaning researchers and research that may produce valuable results’ (2017:130)

Perhaps for now, at this stage, this project has been — borrowing from Winnicott (1971) — participatory ‘enough’.

OUTCOMES: MAKING A DATASET MULTIPLY VALUABLE

In choosing to meaningfully engage autistic people with the creation of the dataset of naturalistic conversational data, the dataset became multiply valuable, with numerous outcomes achieved. In total, the Talking Together project generated 245 minutes of recorded and transcribed naturalistic conversation data for the primary linguistic analysis. It
also yielded rich, qualitative data relating to experiences of loneliness in Brighton and Hove, available for a secondary thematic analysis (currently in progress). Community engagement around an important issue was realised and in so doing, meaningful interactions between strangers were facilitated, as evidence by the extremely positive immediate feedback from participants. In addition, a new working relationship between the university and a community partner (Assert) was established, with scope for that to be developed.

Where loneliness represents ‘an emotional hunger for intimacy [and] meaning’ (McGraw, 1995: 44), meaningful connection with others is rich nourishment. In Binnie’s (2019) Writing Back project, where she partnered members of the local elderly population with student pen-pals as a means of collecting qualitative data around loneliness, she found that by engaging in the correspondence both demographic groups experienced a positive influence on their mental health. The simple act of connecting with another human being, and feeling heard by another, can be a potent remedy. In Stauffer’s terminology, this becomes an act of world-building: an undoing of the pain of experiencing a disconnect with humanity.

This sentiment was reflected in the follow-up sense-making workshop that took place several months later. Again there were tears, and the general agreement that it had been “a gift” to be able to share the burden of their loneliness with another person. Another participant described how a “weight had been lifted off her shoulders” to be able to admit something she was usually ashamed of (i.e. being lonely) to someone else, present and ready to listen. Many felt that talking to a stranger made the experience both easier and more profound.

Starting a conversation with anyone, taking time to think about why you were lonely and telling someone else that you feel lonely were three of the ten strategies identified within
the BBC Loneliness Experiment to combat loneliness (BBC Radio 4, 2018). Talking Together created an opportunity for these three things — and many more — to occur and in that sense it fulfilled its aim of tackling loneliness without needing to extend itself into a longer-term social enterprise response to local loneliness as had been an original hope. The very act of ‘talking together’ functioned as a re-weaving of some of the rift between self and the human world from which perceived disconnection had created a sense of deep loneliness.

LIMITATIONS

One limitation of this pilot is the lack of objective quantification of impact. It was only once the first stage of the Talking Together project had begun that its potential significance as a piece of impactful engagement really became apparent. Participants were visibly moved by their experiences of taking part — there was raucous laughter, tears and plentiful hugs between people who, fifteen minutes previously, were complete strangers — and many made a point of coming to tell me or my supervisor (who was also present) how much they had enjoyed Talking Together and how useful an activity they thought it was.

Given that the primary aim of the project had been to collect naturalistic conversation data (albeit in a meaningful way), there was nothing built into the design to capture the immediate feedback of the participants in terms of engagement impact. In terms of public engagement activities, ‘impact’ is what occurs ‘when public engagement gives rise to tangible benefits for people (such as enhanced well-being or educational attainment)’ but are ‘typically harder to evidence’ (Public Engagement Evaluation Toolkit, p.12, described in Reed et al., 2018). Talking Together clearly had significant impact and it is a regret that this rich and positive immediate feedback was not somehow recorded.
After the first day of conversations, having witnessed the positive impact the project was having, I sought the approval of the university ethics committee to email out invitations to provide open-ended feedback (by return email), on the experience of participating as a means of trying to capture this. The uptake of this was, as might be expected: low. The enthusiasm of the moment is not something that can really be replicated, and why would participants feel the need to clunkingly regurgitate the heartfelt comments they had already shared with me in person? What I have learnt from this experience is that it would be wise for any participatory research to have built into the design a moment for some form of light-touch, in-the-moment feedback (of which there are many inspiring suggestions in the Public Engagement Evaluation Toolkit: see Reed et al., 2018), regardless of whether or not ‘engagement’ is a primary aim.

**CONCLUSION**

In summary, The Talking Together project demonstrated that the application of engaged, participatory methodologies can enrich the data collection phase of a research project in ways that may not be immediately predictable. In making the conversation task meaningful in its own right the data became multiply valuable both in the sense that it generated numerous additional outputs and that it became a positively impactful exercise for the stakeholder participants.

As to whether research is ‘participatory’ enough if the researcher themselves belongs to the marginalised stakeholder group, it remains difficult to say. Being an engaged member of a researched community allows for intuitive understandings that non-members may have to work harder to achieve, and closer access to a range of perspectives from within that
community. However, wherever possible multiple perspectives should be sought throughout all stages of the research. Additionally, in terms of broadening the scope of participatory autism research, making universities and doctoral level study more accessible to autistic researchers will help to bring more autistic voices into the academy, which will in turn help to shape research aims.

Recalling Stauffer’s ethical loneliness: it is the promise of engagement with others, and the promise that previously ignored voices will now be heard, that is most important for rebuilding trust in a world where all people do matter. For a few days, Talking Together saw people — strangers — come together and share in their experiences of loneliness. People dared to speak, and dared to listen. In so doing, I believe, an act of world-building took place.

ACKNOWLEDGEMENTS

With thanks to Assert Brighton and Hove for their gatekeeping role in the Talking Together project and for the generous use of their premises.

Special thanks to Dr Tim Wharton and Dr Caroline Jagoe for their input and guidance on the research design.

Final thanks to the two anonymous reviewers, the editor and associate editor of this journal as well as the IOE Journal Reviews team for their helpful feedback and critique of the earlier draft.
NOTES ON THE CONTRIBUTOR

Gemma Louise Williams is a final year University of Brighton Doctoral Studentship awardee. Her work investigates the breakdowns in mutual understanding between autistic and non-autistic people, using a synthesis of interdisciplinary tools and theories largely influenced by ‘relevance theory’. A piece of Gemma’s autoethnographic creative writing (‘We’re All Strangers Here’) from her PhD thesis documenting her experience of the Talking Together project, was awarded Honorable Mention in the Society for Humanistic Anthropology 2019 Ethnographic Fiction and Creative Nonfiction Prize.

REFERENCES


Chown, N., Beardon, L., Martin, N. and Ellis, S. (2016) Examining intellectual prowess, not social difference: Removing barriers from the doctoral viva for autistic candidates. *Journal of*
Inclusive Practice in Further and Higher Education, 6 (1): 22- 38. DOI:
10.1080/0309877x.2011.632819

Chown, N., Robinson J, Beardon, L., Downing, J., Hughes, E., Leatherland, J., Fox, K.,
Hickman, L. and MacGregor, D. (2017) Improving research about us, with us: A draft
framework for inclusive autism research, Disability & Society, 32 (5): 720-734. DOI:
10.1080/09687599.2017.1320273

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S.,
research through meaningful participation. Autism. DOI:10.1177/1362361318786721


in the concept of autism and implications for future research. Journal of Child Psychology and

Disorder and Post-Traumatic Stress Disorder: An unexplored co-occurrence of
conditions. Autism: 1362361320912143. DOI: 10.1177/1362361320912143


Morrison, K.E., DeBrabander, K.M., Faso, D.J. and Sasson, N.J. (2019) Variability in first impressions of autistic adults made by neurotypical raters is driven more by characteristics
of the rater than by characteristics of autistic adults. *Autism*, DOI:10.1177/1362361318824104


Southby, K. (2017) Reflecting on (the challenge of) conducting participatory research as a research-degree student. *Research for All*, 1 (1): 128-142. DOI: 10.18546/rfa.01.1.10


