MORE THAN PICTURE-MAKING: REFLECTING ON COLLAGE AS A NARRATIVE TOOL FOR OPENING DISCOURSE ON THE INVOLVEMENT OF AUTISTICS IN AUTISM RESEARCH

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Abstract:

This paper is a reflection on a workshop that I contributed to the second Theorising Autism conference run by the Theorising Autism Project. As a researcher, I have a particular interest in narratives, discourse and identities, and the performative nature of these, and this constituted the basis of my workshop. Therefore, I first introduce narrative as a research tool, and situate autistic narratives within this. Second, I reflect on three sites of meaning making popular in narrative studies, and specifically within the confines of the workshop, and I include debate around some of the successes and challenges of this approach. The sites concerned are namely, the production of the narrative, or process; the image produced; and the audiencing, negotiation, acceptance or rejection, of the smaller components comprising the final image. Finally, I consider whether combined narrative genres can facilitate a process, whereby majority and minority communities adapt to a new reality and work towards the integration of autistics in debate about their inclusion in and influence on autism research.
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Introduction

The second Theorising Autism Conference run by the Theorising Autism Project (TAP, 2014) was held this March at the Centre for Research into Autism and Education (CRAE) following a first conference at the University of Birmingham (TAP, 2012). The project was established by autistic and neurodiverse colleagues to explore and engage with the range of views held by autistic and non-autistic individuals on autism and draw these together in meaningful discussion. For this purpose, the aim of the second conference was to build on the previous audience and consider improved opportunities for autistic people in all aspects of the research process.

In research particularly, a preference towards a medical model approach manifests itself as a bias towards the expert holding a more objective positionality (Glasby and Beresford, 2006). In the field of autism, the expert has generally been non-autistic, with practitioners placing blame on autistics for their 'dysfunction', as opposed to viewing society's failure to adapt to different cognitive palettes (Arnold, 2012). Additionally, there is a distinct and worrying lack of involvement of autistic individuals in research on autism at all levels (Milton and Bracher, 2013). This lack of inclusion of autistics and their experiences in the research process has resulted in a failure to focus on the priority issues for disabled/differently abled individuals (Barnes, 2003, Beardon and Worton, 2011, Beardon and Edmonds, 2007, Farmer and Macleod, 2011). Autistics need to be included in and listened to in the single one area with the biggest impact on shaping autism in order to bring this in line with legislation (HMSO, 2010). In order to extend this beyond the agenda set by the government strategy on autism (DoH, 2014), this needs to be addressed as a priority. As such, this is the foundation on which the Theorising Autism conferences aim to build: autistic experiences as described and explained by autistics and explored with those interested in the impact of the wider research context.

Theoretical Framework

It is the author's standpoint that the welcoming of diverse communication preferences can be facilitated using different lenses, such as those offered by a combination of narrative and discourse methodologies. Within the social sciences, the 'narrative turn' is recognised as being particularly helpful in facilitating insights into personal experience (Atkinson, 1997). Indeed, the understanding of narrative, in its variety of genres is dependent on an understanding of social and cultural contexts (Czarniawska, 2004).

A useful tool to unpacking different narratives of autism relates to the use of metaphor (Broderick and Ne’eman, 2008, Moon, 2014a, Murray, 2014), whereby ‘popular autism discourse’ relating to policy exists as a counter-narrative to that of autistics, who are more welcoming of a narrative around neurodiversity (ASAN, 2014). Discourse, however, enables the introduction of context and power to the narration and troubles ownership of power (Foucault, 2000) and terminology (Sinclair, 2012). To address the polarised approaches that frequently occur through discourse, Ward (2012) encourages us to consider the tension between discussions on social causation and the discursive construction of [autism] and social constructionism and the lived experiences of [autistics]. With this in mind, perhaps a more helpful way of looking at autism is in terms
of a less linear approach proposed by Arnold (2012), a ‘palette of colours’, or a ‘landscape’. This paper now addresses the nature and importance of autistic narratives.

**Autism and Narratives**

The last twenty years have seen a rise in autistic narratives, which have included a mix of stories, poems, drawings and essays (Grandin, 1995, Hall, 2012, Hammerschmidt, 2002, Halliday-Willey, 2006, Jackson, 2002, Lawson, 2001, Simone, 2014, Williams, 1999a, b), and which have addressed a wide array of issues. This eclectic mix has also been complimented by an increasing influence of diverse online social media outlets, which have provided a powerful opportunity for personal expression (Gauntlett, 2008).

Engaging with a range of autistic narratives is key to building an understanding of the everyday lived experiences of autistics. It enables researchers to familiarise themselves with ‘ways in which [expressed experiences of autistics] can significantly differ from official definitions’ (Connor, 2013). More importantly, narratives, as a flexible approach, allow autistics to create the language they wish to adopt to describe their experiences of autism (Hacking, 2009) and to set the agenda relevant to their requirements.

The following section reflects on the combination of collage and discourse as narrative tools.

**The Combination of a Visual Narrative, Collage, and Discourse**

Collage as a visual narrative tool has not been exploited in relation to autism, but has a role in both creative and practical settings (Kostera, 2010). Studies such as that by Awan (2007) investigating the interplay between young people, identity and the media have illustrated its potential, whilst also highlighting the impact of available resources. Such studies are important, as they indicate pathways to tackling the double empathy problem proposed by Milton (2012).

Constructing identities has tended to situate autism within negative disability discourses (Bagatell, 2007), and for this reason, my interest is in the use of combined methods as a means to tackling this issue.

**Sites of Meaning Making in Narrative Research**

In the body of narrative research, there are various intertwining sites of meaning making applicable to the understanding of a narrative (Rose, 2001). The following section delves into these areas in relation to the workshop I ran to draw people’s thoughts together on key points storied by the morning speakers.

**Ethics**

In the introduction to the day, it was suggested that for ease, collective work produced would remain with the Theorising Autism Project, but that individual pieces could be taken away if wished. The suggestion was also made that any images photographed be referenced to the conference. Since there were no objections, images shared in this article are done so on this basis.

**Workshop Process**

The process of a narrative focuses on its production. The workshop process aimed to draw on key points raised by Pellicano (2013), Murray (2014) and (Moon, 2014b), and included various storytelling methods in the making of a final collage image. Prior to the event, the workshop format had been checked with a number of individuals (autistic and non-autistic) and feedback had enabled adaptations.

Participants were encouraged to note key points from the above-mentioned talks as a context for the workshop activity. As individuals we naturally recall issues of interest using a range of senses, so this emphasised diverse and adaptable methods of recollection, such as memory, writing or drawing. The in the workshop, key points were selected from individual lists to comprise a group list of 5-6 themes, which were
subsequently examined through a combination of word association and mind mapping activities to inform the
collage activity.

In the collage production, choice of narrative genre was influenced by communication preferences for storying
experiences (Kostera, 2010). Participants explored different narrative styles, selecting letters, words and
images, and in some cases linked this with writing, to produce a collage on 'how we see autism and research'
(Ridout, 2014). Exchange of ideas occurred both verbally and visually (through the arrangement of images)
throughout production, so for those that found one or other of these aspects challenging, there was an
alternative option available.

The process attracted diverse individuals to the conference keen to exchange views on autism with different
people. Combined efforts storied past and present narratives of autism and highlighted issues for resolution.
Whilst the relationship between the narrators was different in the case of each image made, all brought their
own knowledges, identities and assumptions to the activity (Hall, 1996). The identities performed by
individuals in each group were dependent on the story they wanted to tell and the ongoing discourse about
issues raised.

Challenges to the process related difficulties working with new people, and some presentation aspects. These
will be reflected on for the future.

Images Produced

Image as a site of meaning making, is concerned with the visualisation, or the rendering as invisible, of social
differences and focuses on such themes as the genre(s) utilised, the specific focus, contradictions, colour and
impact of genre characteristics (Rose, 2001).

Of the four images produced, I now present two, and examine some of the possible narratives and counter-
narratives. I mean narrative to be where the memory of the lived experience is told in the present context,
and the counter-narrative as the challenge against the ‘dominant master narrative’ (Andrews, 2002). The
interpretations are, as stated, my own, and therefore may differ from those intended.

Image 1

The first image presents a possible narrative of autism and research with an eye in the centre of the image.
This may represent an invite to view the story [around autism and research] already told, or provide a new
story from the narrators’ combined perspectives. It highlights differences between the model approach
towards autism as compared to the counter-narrative(s) of autistics themselves, emphasising issues of invisibility
and associated discourse. These are seen in images pointing to causal roots or ‘suspects, and the tension
between maintaining a focus, or ‘spotlight’, on the problem [exclusion], yet respecting the rights to privacy.
The storyline, or plot, also reflects the representation of a minority community by an icon, something that has
occurred across most minority communities.
The morning presentation by Moon (2014b), stated that autistics frequently feel 'fishbowed', or placed in a container through which they can be observed, and this is storied using an image of a chicken accompanied by text ‘Your [word removed] under microscope’. My eye then moves to the words ‘Say no’ situated near to ‘power’ and ‘total control’ with an image of a classroom (a venue addressing perceived norms), and I feel an implicit request for a power shift.

There is emplotment around ‘quirkiness’ and medical normalcy, and with possibly inter-related tales of clinical practice, DNA, doctors, and ethics. The image touches numerous themes, implicit and explicit, and the audience can make their own interpretations.

Image 2

In contrast to the first image shown, this second is presented with different spatial relations between images. It also uses the image signage ‘planning ahead’, though this time preceded by a message, ‘face the facts’, and followed by the more philosophical context of ‘the Enlightenment’, and a need to challenge traditional methods.
The images to the top right of the collage represent the historical context, ‘mourns loss’, challenged by some autistic autobiographies (Sinc, 2012), a desire to be different ‘I want to be somebody else’, perhaps in relation to barriers faced in some [educational or work] settings ‘suspended for wanting more’.

On the top left, the plot is established as one of isolation, being different, and endeavouring to please. This may be a past or present narrative, but in the conference context may be seen as the dominant story influencing the need for a change in attitude regarding autism and research. This is complimented by themes worked across the lower half of the visual addressing notions of a wish/need to be ‘cured’, watching out for the ‘dangerous’ unknown ‘other’ (dinosaur), a contempt for being the subject of scrutiny, and a gap between research and engaging with communities.

Both images comprise statements to form a narrative reflecting the wider political and social context within which autism sits. The statements were perhaps influenced by the media from which they were selected, and this also enabled the authors to emphasize links with the struggles faced by other minority communities.

Authors had a wide range of life experiences impacting on their choices of themes to story, the constructed images and related links. I have presented some options with possible interpretations for audiences, but would urge a new audience to form their own interpretations based on their engagement with autistic individuals. I now discuss the audiencing of these images.

Audience

The process of ‘audiencing’, however, is more specifically related to the acceptance, renegotiation, or rejection of images. It is intertwined with social contexts, and in the case of this conference, ongoing discourse
throughout the workshop, whether as a speaker, a listener, or both. This aspect, then, pays attention to ‘spectating’ and the social identities performed by individuals (Rose, 2001).

Consideration of our ‘fit’ within the process of audiencing is a part of this process. The experiences of conference participants, diverse and similar, influenced decisions made about selected images. Questions can be raised as to whether these images were negotiated with others, or whether some were considered essential or even rejected. Discussions around these areas help those of us interested in autism research to understand real life issues impacting on our choices.

With this in mind, consideration of the technologies of reproduction and circulation of images, and the situating of narratives within a bigger picture of autism research and inclusion of the autistic voice, are additional elements to explore. If we simply target the ‘converted’, or those who are already concerned about what the autistic community and individuals have to say, the value of this work is limited.

Both narratives target an eclectic audience since individuals working on each group piece were differently motivated in terms of their attendance at the conference. In addition, the later sharing of images, choice of medium for the narrative, and any accompanying text to establish a context are also critical influential factors impacting on the received message(s). The conference organisers aimed to investigate inclusion of the autistic voice in research, and to place it as that of the expert, however, this may have differed from the agenda of each individual narrator within this context. I now reflect on the usefulness of this approach as regards the inclusion of the autistic voice in research.

Discussion

Narrating experiences involves taking risks and being vulnerable. It entails working in a space, which, at times, may be socially awkward, and where we can experience a collision of cultures (Silvestrini, 2014). As an audience it may ask that we move out of our comfort zone and are prepared to listen to and see things that we would generally choose to ignore. Narrative as a concept constantly explores an unresolved space between the narrator and the audience, the tension between real life stories and the ‘what if’ stories that refer to imagined alternatives (Andrews, 2014).

Lessons learnt

The context was one which encouraged diverse individuals wishing to exchange experiences and views on autism and the role of autistics within the research process. Despite a welcoming host organisation, provision of an adequate space and ambient environment requires attention for future events.

Delivery of the workshop itself was highly challenging for me as I was anxious to ‘get things right’ and in so doing possibly did not in some areas. Nevertheless, the conference was about providing a forum for positive criticism and feedback in order to move this agenda forwards, and there were many productive discourses throughout the day.

Opening the doors to inclusion of previously disenfranchised individuals brings with it a plethora of topics to address. Following both conferences, it may now be pertinent to reflect on a different structure to the day to permit more in-depth discussion or provision of feedback on individual talks or workshops.

A major issue raised specifically by autistic/disabled individuals attending the day (and the previous conference in Birmingham) was the cost of transport. Currently the Theorising Autism Project has no funding to assist speakers, and participants in receipt of benefits find it difficult to attend. There are very real material objective differences in terms of access to this conference, which require a solution.

Collage as a visual narrative provides a way of tackling ‘the self-narrating zoo exhibit’ approach to autistic ‘inclusion’ in conferences (Sinclair, 2005) by encouraging an open exchange of information. The purpose of
the workshop was to 'trouble' the existing narrative of autism and examine the construction of autism identities within the discourse context of research. The discourse itself, in its variety of genres, appeared to be a facilitator to removing barriers to engagement and reviewing the structure of current research practice. Audiences to the images produced, and the authors themselves, are best-suited to judge success in achieving this goal.

To date, a huge disservice has been done by researchers who fail to engage with autistics. As social creatures, we assess the narratives of others against our own 'norms', so a lack of engagement with autistic individuals and communities has resulted in misrepresentations, which the autistic community are increasingly challenging (Arnold, 2014, Milton and Bracher, 2013, Sinclair, 2005). The checking and re-checking of intended meanings in narratives is vital to establishing a more balanced research agenda.

Exchange of perspectives is an integral part of sociological research. The activity brought together people identifying as autistic, non-autistic and neurodiverse and crossed a variety of practices, including education, the arts, psychology and research. Inclusion can be a messy business when people have been disenfranchised and ‘fishbowedled’ (Moon, 2014b) for so long. However, the event attracted individuals who felt that the agenda needed to be re-shaped, or that not all perspectives were being voiced and heard.

My belief is that the message conference participants take forward from the workshop, and the conference as a whole, has potential for contributing to the research agenda on autism. This would sit well with messages emerging from recent autistic-led conferences. It places autistic individuals as the experts in their experiences, and as key voices in the shaping of their lives (ARGH, 2014, Arnold, 2014).

Bibliography


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