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# The role of reflexivity and ethics in the context of autism

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By Damian E M Milton

Traditionally social research has been dominated by the methodology of the 'hard' sciences in the pursuit of generalisable social 'facts' (Durkheim, 1895), yet in more recent decades, the dominance of the Positivist model of research has diminished (Scott and Usher, 1996, 1999), leading to concerns regarding the 'situatedness' of social researchers as producers of knowledge and as implicated in a relationship of power with their participants. This essay outlines the ethical issues of positionality and reflexivity in research, highlighting how positionality is of the utmost importance with regards to my own research context: the ideology and practices involved in the education of people diagnosed as having an Autism Spectrum Disorder (ASD).

According to Opie (2004) 'positionality' refers to the philosophical position adopted by a researcher, their assumptions regarding the topic under review and the nature of their research endeavour. Therefore, reflecting upon one's own positionality requires a researcher to set out their metaphysical (ontological – nature of reality) and epistemological (nature of knowledge construction) views, as well as their specific views regarding the nature of human agency and how humans relate to their environment. Debates have thus raged for centuries over the ontological and epistemological assumptions of various paradigms that have tried to explain human nature. The Positivist paradigm sees reality as external to the individual consciousness and consequently independent, objectively 'real' and measurable. Interpretive or Hermeneutic theories by contrast stress the socially constructed and subjectively experienced nature of reality (often as expressed through language or 'text'). These ontological debates have also lead to epistemological assumptions regarding the nature of 'valid' knowledge, data collection and interpretation. For Positivists, knowledge is objective and can be empirically 'captured' and quantified. For Interpretive theory, knowledge is experiential, personal and subjective (a constant intersubjective process or negotiation).

For Griffiths (1998) and Greenbank (2003), reflexivity involves making explicit a researcher's social and political value positions in relation to how they may impact on the design and findings of their data and conclusions. Both theorists also argue that the self however, is not truly transparent to itself, and therefore enough description is needed by the researcher to provide their audience with information that can be used to take the researcher's positionality into account, when assessing the research's claims to knowledge. As Greenbank (2003) points out:

"Users of both quantitative and qualitative methods all need to recognise the influence of values on the research process...The inclusion of reflective accounts and the

acknowledgement that educational research cannot be value-free should be included in all forms of research.” (Greenbank, 2003: 798).

Within the field of educational research ‘reflexivity’ has become a popular device for analysing the impact of personal and inter-subjective processes upon a research project. Finlay (2008) argues that acknowledging the ‘situated’ nature of one’s role within the research process provides a way of attaining greater transparency and quality in the product of the research process. Advice from the British Educational Research Association (2009) asks researchers to question themselves regarding the relevance and importance of how a researcher can impact upon a project, due for instance to their age, gender, religion, politics and experiences.

As Positivists, Troyna and Carrington (1989) assume that value-free knowledge is achievable, that is universally applicable. Positivists look to the methodology of the ‘hard’ sciences for inspiration and thus view any influence on research design and findings due to the values and positionality of a researcher, as a bias in need of correction.

Kuhn (1970) famously questioned the dominance of positivism as creating a false picture of reality. For Kuhn (1970) research is theory-led and located within dominant paradigms which are historically and culturally specific. An alternative to positivist social theory was posited by Interpretivism. Tracing its roots back to Max Weber’s (1958) ‘social action theory’ and his notion of ‘verstehen’ (understanding the intentional meanings behind social action and human agency) argues that positivism fails to analyse the complexity of the ‘lifeworld’ of individuals. These ideas were explored in a variety of different directions: Symbolic Interactionism (Mead, 1934), Phenomenology (Husserl, 1960) and Ethnomethodology (Garfinkel, 1967). Generally speaking, Interpretivists wish to preserve a notion of objectivity and thus a loose ‘scientific’ position. Gadamar (1975) takes how meanings of ‘everyday experiences’ are constructed within negotiated social interaction as the locus of his research. For Gadamar (1975) the aim of interpretive research is to make sense of reality through the discourse and frames of reference used by participants. Interpretivist theory states that phenomena are not independent of the context of the meaningful actions of social agents, Interpretivist ontology is therefore in stark contrast to that of Positivists. For Bohman (1991) no interpretation is ever completely definitive and contains the capacity to change, whilst Positivist methodology requires ‘closure’. For Gadamar (1975) knowledge emerges unpredictably from a ‘fusion of horizons’ involving participants, rather than a controlled outcome.

Critical theorists adopt the opposite view from positivists and argue that it is essential to make one’s political and moral values transparent, as they reason that the notion of value-free knowledge about the social world is an illusion. A positivist notion of objectivity requires the researcher to stand outside of their own positionality. The impossibility of such a position is criticised most strikingly as a ‘God’s eye view’ (Haraway, 1989) or as the philosopher Nagel (1989) would say ‘the view from nowhere’. According to the critical theorist Mannheim (1936), the production of knowledge is never ‘neutral’. Scott and Usher (1996) suggest that social research is always of a political nature, whether it is made explicit

or not, as research is constrained by what is termed as 'legitimate' and is thus implicated in power relationships.

Postmodernist views present research as a socially and historically located practice and distrust absolutes and foundational truths in favour of relativism. Thus, according to this view, following Positivist method will not guarantee 'true results' (Lyotard, 1984). Post-Positivist/modernist research can be characterised by an anti-essentialist position on knowledge. Lyotard (1984) sees positivist knowledge as being a culturally located discourse which cannot escape its own 'cultural confusions'. Therefore, in Post-Positivist/modernist research, issues of reflexivity and discourses of power also feature strongly. However, postmodernist praxis can be criticised for its lack of emancipatory effect and for a total refusal to accept that some discourses may be more accurate at describing the noumenal world, leading to the dubious conclusion that one truth may be as good as any other. This may be true of the phenomenal world, yet not the noumenal.

"Bias comes not from having ethical and political positions – this is inevitable – but from not acknowledging them. Not only does such acknowledgement help to unmask any bias that is implicit in those views, but helps to provide a way of responding critically and sensitively to the research" (Griffiths, 1998:133).

According to Scott and Usher (1999) Positivism is losing its dominance in the social sciences, yet not in the 'hard' sciences or in a bureaucratic society reflecting technical, rational principles and policy making. Wider public appreciation of non-Positivist methodology still seems to be hampered by what Weber described as the 'Iron Cage of Bureaucracy' (Weber, 1958).

The critical theorist Habermas (1984) suggested that both the Positivist and Interpretive paradigms neglected the political and ideological situatedness of educational research. Habermas (1984) criticises Interpretive methodology for producing a 'double hermeneutic' as researchers attempt to interpret an 'already interpreted world' as a commentary rather than a criticism. The critical theory of Habermas (1984) by contrast, sets out to:

"...emancipate the disempowered, to redress inequality and promote individual freedoms" (Habermas, 1984:28).

The Neo-Marxist writer Eagleton (1991) suggests that contemporary identities are entrenched within 'false' and 'fragmented' consciousness brought about by relative powerlessness, so research should aim to question the legitimacy of power relations in society and should concentrate on issues of repression, voice, power, participation, representation and inclusion, in the service of equality and democracy.

The intention of critical theory is to be transformative of current social relations seen to be unjust, rather than the 'cold' reporting (and support for) the 'status quo'. Thus, the key questions posed by critical theorists researching education involve: how educational practices perpetuate inequalities, the social construction of 'worthwhile' knowledge and

how power is produced and perpetuated within education. Habermas (1972) suggests that the three main areas of research contain an ideological purpose, for Positivists this is technical (how to solve a perceived problem), for interpretivists it is practical (how best to elucidate the subjectivities of human agents) and for critical theorists it is emancipatory.

Habermas (1972) favours the methodology of ideological critique. This methodology involves the uncovering of vested interests within discursive accounts. For instance, positivist social research with its claims to neutral objectivity is seen by Habermas (1972) as ideologically loaded with laissez-faire values that perpetuate existing power differentials in society. The methodology of ideological critique has also been popular with feminist critical research:

“The drive towards collective, egalitarian and emancipatory qualitative research is seen as necessary if women are to avoid colluding in their own oppression by undertaking positivist, uninvolved, objective research” (Cohen et al., 2000:37).

Roman and Apple (1990) argue for the use of ethnographic techniques combined with ideological critique and evaluating the value of research by its transformative emancipatory power.

Regarding my own philosophical positionality, I have long regarded myself as falling into a ‘broad camp’ of ‘Critical’ theory. On an ontological basis, I would view noumenal materialist reality as existing and shaping the lives of all (ala Marxist thought), yet beyond our immediate comprehension (Kant, 1781). I see the human subjective phenomenological world as one of a constant interactive process and thus favour a generally hermeneutic approach to research, along with ideological criticism. I would argue that the material noumenal environment is in a constant dialectic with human subjectivity and agency, as Marx famously said:

“Men make their own history, but they do not make it just as they please...The tradition of all the dead generations weighs like a nightmare on the brain of the living” (Marx, 1852/1970:15).

The focus of my research is thus empowerment of the Autistic ‘community’ (in regards to Autistic people themselves), a group which is largely powerless and ‘voiceless’ until fairly recently, since the publication of autobiographical ‘first-hand’ accounts by autistic people (Grandin, 1996; Sinclair, 1993; Sainsbury, 2000); the establishment of Autistic charities (e.g. the National Autistic Society - NAS) and the rise of internet forums and groups (e.g. Autism Network International). Within educational research, possibly like no other area, research into the education of Autistic people has been from an ‘outsider’ perspective. For many years research into Autism has been dominated by Psychoanalysis, Behavioural and Cognitive Psychological approaches (Bettleheim, 1967; Lovaas, 1987; Baron-Cohen, 1995; 2008). One of the main ethical issues raised by my research interests, is to be careful not to create a ‘new regime of truth’ (Gore, 1993) and to reflect the subjective ‘voice’ of the participants without unwittingly subverting it. Thus, by using hermeneutic methodologies

(discourse/textual analysis of the narratives of Autistic people), I hope to give 'voice' to a group that traditionally has not had one, which in itself would be an empowering act. Rather than attempting to be 'neutral' however, my own positionality will be laid bare for scrutiny.

By using qualitative methodology, many issues of validity can arise, for example: faulty memory, inadequate vocabulary to express opinions, partial or erroneous knowledge production and the desire to tell the researcher 'what they want to hear'. In this context, interpretations of such data are always tentative and cautious (and based upon 'abductive' reasoning – Opie, 2004).

Opie (2004) also points out, that a researcher's positionality can be affected by their values and belief systems, for example political allegiances', religious faith, class, ethnicity, gender, sexuality, historical and geographical location and so on. In my own case, this is of clear relevance, as I am about to be assessed for ASD myself and my son was diagnosed with ASD some five years ago. As such, I have always seen myself as an 'outsider' looking in on dominant culture (Becker, 1963), yet in this case I am to be producing an 'insider' account of other 'insider' accounts of various stakeholders in the area (as a person on the spectrum, a parent and educational practitioner). Despite a recent general recognition of the validity of 'insider accounts' of Autism (Grayson, 2006), little research has been conducted into the social construction of Autism, and still less concerning Autistic subjectivities regarding educational practices.

Ethical guidelines for research with human participants have been in place for many years with the British Psychological Society (BPS, 2009) and British Educational Research Association (BERA, 2009). These codes of ethics stress the importance of preventing harm to research participants. Cohen et al. (2000) suggest that researchers when reflecting upon ethical issues should ask themselves the question: how would I feel, if I were subjected to these research procedures? If there is any doubt concerning possible harm than this should be considered in great depth.

The issue of informed and voluntary consent is of paramount importance to Burgess (1989), arguing that participants in research should have the legal capacity to give voluntary consent and be situated as to be able to be self-determining in their choices. If one were to take this to an extreme however, one could not research children or groups of vulnerable adults (despite some potentially supporting the use of transformative critical research that may empower their group). Robson (2002) suggests that it is practically impossible to inform participants of every aspect of the research process, which leads on the issues of 'reasonably informed consent' and issues regarding 'advocacy'.

Issues of 'advocacy' are particularly politically loaded within the 'Autistic community' regarding 'who should speak' for them. The 'self-advocacy movement' of Autism Network International and writers such as Sinclair (1993) suggest nothing should be said about Autistic people without passing it by the Autistic community for commentary. As a member of this community, I have a political allegiance to this view regarding those who can speak

for themselves (like me). Having said this, not all Autistic people are able to speak for themselves (like my son) and thus will not be part of any direct intervention within my research project, as 'reasonably informed consent' is practically impossible. The subjective views of those who cannot communicate them are beyond language and thus, as Wittgenstein (1921) might say on this topic 'we must remain silent'! In order to compensate for this vacuum in my research, I aim to expand my literature review into a critical ideological analysis and deconstruction of educational theory and praxis regarding the education of all Autistic people. At this stage however, I am unsettled on how to gain participation from other Autistic people in this regard, to build a possible 'future horizon' (Gadamar, 1975).

It is vitally important not to exploit the group I myself belong to. Greenbank (2003) highlights the potential for conflicting values between the researcher and those being researched. Halliday (2002) argues that researchers should endeavour to be open to the views of research participants and engage in dialogue concerning the research. Autistic people for decades have been subjected to invasive treatments and educational practices that are not in favour amongst many within the Autistic community. Thus, empowerment of the participants in this project is of primary concern. Simons and Usher (2002) take an 'open democratic approach' to research, which entails impartially collating views, inhibiting compulsion, ensuring a participant 'veto' and providing as much clear information to the participants as possible. This negotiation can perhaps never be equal in terms of power between the researcher and the research participants, yet by involving participants as much as possible in the research process, at all stages, and may reduce the power differential whilst accepting the positional influence of myself upon the construction of the project.

Issues of positionality and reflexivity in the area of research into the education of Autistic people have sadly been largely lacking in previous research, as if people with Autism do not have a 'voice'. The thing is, many of them 'do'! Therefore it is the aim of this project to systematically expose the discourses currently being employed in this area, with particular focus on the discourse of Autistic people. It is clear that my positionality is one of entrenchment in Critical Theory, yet being reflective on this intentional 'bias' must not be manipulative of the 'voices' that I am trying to empower, and thus participation of the participants in every aspect of the project will be sought.

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