#### ARTICLE IN PRESS

Social Science & Medicine xxx (2014) 1-8



Contents lists available at ScienceDirect

## Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed



# Infancy, autism, and the emergence of a socially disordered body\*

Gregory J.S. Hollin <sup>a, \*</sup>, Alison Pilnick <sup>b</sup>

- <sup>a</sup> Institute for Science and Society, School of Sociology and Social Policy, University of Nottingham, University Park, Nottingham NG7 2RD, UK
- <sup>b</sup> School of Sociology and Social Policy, University of Nottingham, University Park, Nottingham NG7 2RD, UK

#### ARTICLE INFO

Article history: Available online xxx

Keywords: United Kingdom Autism Neuroscience Psychology Infancy

#### ABSTRACT

Twenty academic psychologists and neuroscientists, with an interest in autism and based within the United Kingdom, were interviewed between 2012 and 2013 on a variety of topics related to the condition. Within these qualitative interviews researchers often argued that there had been a 'turn to infancy' since the beginning of the 21st century with focus moving away from the high functioning adolescent and towards the pre-diagnostic infant deemed to be 'at risk' of autism. The archetypal research of this type is the 'infant sibs' study whereby infants with an elder sibling already diagnosed with autism are subjected to a range of tests, the results of which are examined only once it becomes apparent whether that infant has autism. It is claimed in this paper that the turn to infancy has been facilitated by two phenomena; the autism epidemic of the 1990s and the emergence of various methodological techniques, largely although not exclusively based within neuroscience, which seek to examine social disorder in the absence of comprehension or engagement on the part of the participant: these are experiments done to participants rather than with them. Interviewees claimed that these novel methods allowed researchers to see a 'real' autism that lay 'behind' methodology. That claim is disputed here and instead it is argued that these emerging methodologies other various phenomena, reorienting the social abnormality believed typical of autism away from language and meaning and towards the body. The paper concludes by suggesting that an attempt to draw comparisons between the symptoms of autism in infant populations and adults with the condition inevitably leads to a somaticisation of autism.

© 2014 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/3.0/).

#### 1. Introduction

Autism's diagnostic history began in 1943 (Kanner, 1943) and while there have certainly been significant changes in the perceived symptomology of autism since that time, autism has come to be characterised as featuring a triad of core features in "impaired social interaction, impaired verbal and non-verbal communication and the presence of repetitive and restricted patterns of behaviour" (White, 2013: 114). While autism is widely understood as a 'neurodevelopmental' condition (Norbury and Sparks, 2013), there is neither cause nor cure known for it.

As others have noted, autism is "... the condition of fascination of the moment, occupying a number of cultural locations that

 $\label{lem:email} \textit{E-mail addresses:} \ \ \text{gregory.hollin@nottingham.ac.uk} \ \ (G.J.S. \ \ \, Hollin), \ \ \, Alison. \\ pilnick@nottingham.ac.uk \ (A. Pilnick).$ 

reflect a spectrum of wonder and nervousness" (Murray, 2008: 5). Undoubtedly, the social science department has been one cultural location to express a particular wonder with autism. To this end, a number of recent pieces have considered autism in relation to affect (Fitzgerald, 2013; Silverman, 2012), gender (Cheslack-Postava and Jordan-Young, 2012), and socio-historical change (Evans, 2013; Eyal et al., 2010; Nadesan, 2005). With reference to this final topic in particular, Danziger's claim that methodology is not ontologically neutral (Danziger, 1988) has been repeatedly borne out.

Kanner borrowed the term 'autism' from Bleuler, who referred to a mode of thinking evident "... in dreams, pretend play and reveries, and in the fantasies and delusions of the schizophrenic" (Feinstein, 2010: 6). This notion of 'autistic fantasy' was of central importance for psychoanalysis. Autistic fantasy, however, was a phenomena hard to capture within a psychology that had become increasingly dependent upon statistics and randomisation by the middle of twentieth century (Danziger, 2000: 344). Thus, as autism research moved towards experimental psychology in the 1960s the notion of 'autistic fantasy', so amenable to the psychoanalytic case study and yet so elusive within the laboratory, was largely abandoned (Evans, 2013: 4). It appears to be the case, therefore, that changes in

http://dx.doi.org/10.1016/j.socscimed.2014.07.050

0277-9536/© 2014 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY license (http://creativecommons.org/licenses/by/3.0/).

Please cite this article in press as: Hollin, G.J.S., Pilnick, A., Infancy, autism, and the emergence of a socially disordered body, Social Science & Medicine (2014), http://dx.doi.org/10.1016/j.socscimed.2014.07.050

<sup>\*</sup> This research arises from a thesis funded through the ESRC Open Competition (ES/I01196X/1) and was subsequently supported by a Mildred Blaxter Post-Doctoral Fellowship from the Foundation for the Sociology of Health and Illness. We would like to thank the two anonymous peer reviewers for their insightful comments. The advice of Paul Martin and Antonia Hamilton throughout has been invaluable.

<sup>\*</sup> Corresponding author.

2

theory and methodology appear to have instigated significant changes in the constructions of autism, with the previously central phenomena of fantasy and hallucination becoming divorced from the disease construct and replaced with cognitive and behavioural symptoms more amenable to experimental cognitive psychology. It has also been claimed that these changing methods allowed the space for an examination of the modularisation of cognition, meaning that it became possible to think of specific cognitive deficits as causing autism outside of an interpersonal, contextualised environment (Hollin, 2014; Nadesan, 2005: 120).

This article contributes to this growing body of social scientific knowledge concerning autism by considering two recent, related, changes of focus within the psychological investigation of the condition. Firstly, a turn to neuroscience; and, secondly, a turn to infancy which has seen research increasingly focus upon children that have not been, and may never be, diagnosed as autistic. Through an analysis of interviews conducted with neuroscientists and psychologists it is argued here that this turn to infancy has been facilitated by particular neuroscientific techniques which are performed on, rather than with, these children. Moreover, this consideration of the infant is, once more, reconstructing autism with focus shifting away from explicit communicative acts (e.g. language) and towards non-conscious bodily expression.

#### 2. Methods

The analyses within this paper rely upon data obtained through qualitative interview and a critical reading of the published literature. The decision to utilise interviews was believed to be justified in this case because the field of autism research is of note, at least in part, because of the plethora of viewpoints and competing claims surrounding the condition; it was believed to be important that such competing claims were investigated. Thus, the use of a method that facilitated the sampling of a wide range of sites, and potential viewpoints, was deemed to be the most appropriate.

The questions driving the project from which this paper arises concerned the construction of autism within cognitive psychology and social neuroscience, and an interview schedule of around 20 questions were drawn up with those themes in mind. It was decided that pre-determined questions, formalised in interview schedules, would be kept to a small number and that questions and topics that arose during the course of the interviews would, to a significant degree, guide the discussion. The resultant interviews are therefore best described as semi-structured.

The attempt made to keep interview questions/prompts as general as possible was a deliberate strategy for this project, in order to avoid "a piece of interview research [that] is chasing its own tail, offering up its own agendas and categories and getting those same agendas and categories back in a refined or filtered or inverted form" (Potter and Hepburn, 2005: 293). Broadly, these interview questions covered five areas; (i) how the participant came to be interested in their research topic, (ii) the nature of autism, (iii) the nature of the participant's current research, (iv) the impact of social neuroscience, and (v) the role of advocacy groups in research. A great deal of flexibility was included however and topics of discussion were allowed to digress to a quite significant degree, within the time constraints that existed. Interviews that were conducted lasted between 38 and 73 min, with a mean length of 55 min. Approximately one-half of the interviews reached a natural close while the other half were ended at a scheduled time, usually an hour.

#### 2.1. Sampling

The intent of this project was to interview researchers with interests in psychology, neuroscience, and autism and who were based in the United Kingdom. In addition to existing knowledge of the field, potential participants suitable for interviewing were sought through a variety of means; an internet search, discussion with psychologists at the authors' own academic institution, and finally by asking interviewees for further contacts. Potential interviewees were contacted by e-mail with a brief explanation of the project. It was made clear to participants that both individual and institutional identities disclosed within interviews would be removed in the act of transcription, that data would be securely stored, and that the project had passed the School of Sociology and Social Policy at The University of Nottingham's internal ethics procedures. Though first author's first and Masters degree were obtained in psychology, the project presented here was designed as sociological in nature, and so the researcher presented himself to interviewees as a sociologist interested in autism. Nonetheless, the interviewer's background was never withheld from participants and the first author's background and current supervisory relationship with an autism neuroscientist was discussed on occasion. Participants were given the opportunity to ask any outstanding questions and, once satisfied, signed a consent form. If participants had any further questions they were answered informally, again by

Twenty research interviews were undertaken for this project, taking place between August 2012 and February 2013, all of which were conducted in person by the first author. This sample consisted of 13 women and 7 men or, alternatively, 7 Professors, 2 Readers, 1 Senior Lecturer, 1 Associate Professor, 2 Lecturers, and 7 Post-doctoral Researchers of various kinds. Eighteen researchers were interviewed at their place of work, 1 was interviewed at a restaurant, and 1 was interviewed at their home. Twelve researchers declined to take part in the project for a variety of reasons and an additional 12 researchers were contacted but did not respond.

#### 2.2. Analyses

All interviews were recorded verbatim and transcribed in full. The extracts presented here have been anonymised and conclude with a note of both the interviewee's academic position and the interview number (e.g. Professor, interview 9). Some extracts also include dialogue from the interviewer and those sections are preceded by an "I:". The interviewee's response during these interactional extracts is preceded by a two letter acronym based upon their academic position (e.g. PD for Postdoctoral Researcher). Transcripts were interrogated by hand in order to explore reoccurring themes. While the broad themes identified in the sections above were of a priori interest, the specific topics presented here arose within interviews and where not of pre-existing concern. Once specific themes had been established within interview there was a critical reading of published literature in order to provide a socio-historical context to this primary data. As the following section is intended to demonstrate, it is through this contrast with historical readings that the changing narratives within autism research become most readily apparent.

#### 2.3. A turn to infancy

#### 2.3.1. A changing picture

It is the central argument of this paper that, within autism studies, there has been a recent orientation towards infancy and the body and that this shift has produced a significantly altered disease construction of autism. In order to expand upon this point, it is worth considering experiments from both the 1980s and today which are ostensibly concerned with the same phenomenon; an examination of the social disorder believed to be at the core of autism. The first passage for consideration comes from the methods

## Download English Version:

# https://daneshyari.com/en/article/7331646

Download Persian Version:

https://daneshyari.com/article/7331646

<u>Daneshyari.com</u>