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The history of Autism is a discourse (Waltz, 2013), a journey through a disputed landscape, whose territories are alternatively staked by Politics, Education, Society and Culture. It is diachronic in nature, as the knowledge of the present is built upon the past, but a diachronic that has progressed differently in different states, at different rates as each impact upon each other. Essentially its origins are lost in myth (Frith, 1992) but its presence has always been felt in one way or another, even before the concept of autism was framed in Western psychiatric narrative.

It is important for the continued understanding of the position that autism occupies as a ‘phenomenon’ in England to restore the emphasis of the narrative to the cultural landscape as this is the day to day experience of people living and working with this contested construct and category of humanity. Although the discourse of autism has been framed by professionals and academics, it is in reality only one side of the triangle, whose base is the people who have been ever increasingly subsumed into the category, whilst on the other side of the professionals are the parents who have applied political pressure and undertaken practical projects to improve the lives of their children. In the middle is everything else, media representation, popular fictions and alas a cloud of misunderstanding. However without autistic people themselves there would be no discourse at all. It is then a landscape of neurological difference emerging through the subjective experience, upon which political and cultural divisions have been drawn.

Early History.

Although Autism as a term was not coined until 1912 or formally delineated until the 1940s its phenotype can be found in England at the beginning of the psychiatric narrative through a new understanding of the writings of John Langdon Down. (Waltz, 2013) It can also be found in literature in the equally astute observations of authors whose fictional characters are based on their perspicacity. Sherlock Holmes springs instantly to mind, but there are examples to be found in Dickens, Hardy and so on, going all the way back to Shakespeare, whose professional clown Robert Armin wrote “foole on foole” both a history of his profession and a narrative of the ’natural‘, amongst which descriptions you can be certain to find the traits of autism as it is now conceived. (Mc Donagh, 2008)

Current understandings of autism emerged mostly after the second world war, with the predominant psychoanalytical school holding sway with the notion of the ‘refrigerator mother’ precipitating her offspring into the form of the unreachable child afflicted with some kind of severe psychosis, to use Bettelheim’s metaphor of the ‘empty fortress’. In cultural terms it has become an othering narrative (Said, 1977) whose effect on the popular perception of the autistic can still be seen today in popular fiction. For example, Stuart Murray instances (Murray S. , 2008) an Observer Sunday supplement article of the mid 1960s dealing with the ’pioneering’ efforts of the Lindens school to ’reach’ autistic children. and prepare them for mainstream schooling.

It is important to remember that Education in England since the 1944 education act was predicated on separation of children into categories one of which was Educationally Subnormal (ESN) further subdivided into moderate and severe. Children in the severe category were deemed as ‘ineducable’ and only capable of training. Most children who would then have been identified as autistic (if at all) would have fallen into one of the ESN categories. This was a state of affairs that was perhaps first challenged in (1962) by a group of London Based parents (including Lorna Wing q.v.) who decided to take matters into their own hands forming the the Autistic Children's Aid Society of North London to establish a school for education of their autistic children. The Sybil Elgar school was opened in 1965 and the Helen Allison school in 1968. As with many societies who had been established in similar fashion by parents of children with a range of impairments there were some with purely local and others with regional or national scope.

 In time the North London group assumed a national focus, and with the realisation that autistic children grew up to be autistic adults, dropped the ‘children’ from the title becoming what we now know as the National Autistic Society (NAS). This was a pattern reflected by other impairment groups who had focussed originally on children.

**Research**

One of the earliest researchers to take an interest in the phenomenon of Autism was Sir Michael Rutter who has been associated with the Institute of Psychiatry Kings College London since 1965, firstly as a consultant psychiatrist at the Maudsley hospital and later as the first chair of child psychiatry. He currently holds the position of professor of Developmental Psychopathology. Although Rutter can best be characterised as ‘old school’ in terms of current developments in the study of autism (particularly in terms of gender qv) he did contribute much to the field of epidemiology and helped to establish autism as a probably genetic condition in reaction to the former psychoanalytical and behaviorist perspectives, thus helping to put the study of autism on a firm scientific footing.

The 1970s saw changes in education, leading to the establishment of special schools and following on the publication of the influential Warnock Report this was crystallised into the 1981 Education act, with the widespread use of ‘special needs’ as a category replacing ‘subnormal’ a broader term encompassing a range of impairments and disabilities including autism, with an emphasis on mainstream schooling with appropriate provision for those needs with the role of the Special Educational Needs Co-ordinator (SENCO) being prominent. The 1970s were also a time for the broadening of the phenotype of autism to include a larger population of autistic people hitherto unrecognised.

Lorna Wing in particular, with her NAS colleague Judy Gould has arguably made one of the greatest contributions to the understanding of Autism through the introduction of the concept of an ‘autistic spectrum’ (Wing & Gould, 1979) to refer to this broader conception of the term ‘autism’ which came about after one of the first widespread epidemiological surveys in Camberwell identifying a larger number of people with the traits of autism than those previously recognised as having the condition. Along with Uta Frith, Wing also helped to introduce the work of Austrian Paediatrician Hans Asperger to the English speaking world. At the time she saw the use of the term ‘Asperger’s (or Asperger) syndrome as less stigmatising to autistic people whose intelligence fell within and beyond the normal range.

Uta Frith, who completed her PhD in Autism in 1968 at University College London, has also been an influential writer and researcher bringing the study of autism as a neuro-cognitive phenomenon into greater prominence. She developed the weak central coherence explanation of autism which in common with Asperger’s paper, which she was the first to translate into English , recognised strengths as well as deficits in autistic cognition. As author of ‘Autism Exploring the Enigma’, she also strayed into cultural territory giving an overview of what Autism might have looked like in historical times. She has supervised a number of researchers who have gone on to prominence including Francesca Happé who has further developed the central coherence theory (Happé, 1999), and Frith also supervised Simon Baron-Cohen. (qv)

The seventies and on into the eighties also saw other developments in the perceptions of disability which would have a subsequent impact on the landscape of Autism.

With growing social awareness and paralleling the civil rights movement of the USA and anti-apartheid movements in South Africa, segregation became to be seen by groups of radicalised disabled people as an experience not unique to race and something accomplished by the educational system, institutionalised care and prejudicial treatment of disabled people in the workforce. Out of this grew the social model of disability which posited that disability arose from societal attitudes and barriers, and impairment was not its cause (Oliver, 1990) (Finkelstein, 1975).

In terms of legislation the 1970s brought in the Chronically Sick and Disabled Persons Act, which began to confer new rights to individuals (autistic people and the parents of autistic children amongst them) and new duties upon local authorities and health providers, and ushered in Social Services departments.

Another force for social change was the growth of an ‘anti psychiatry’ movement which questioned the basis of contemporary psychiatry as more of a means of containment and control than directed towards recovery, drawing on the works of Foucault and Goffman and exemplified by R D Laing as a radical psychiatrist in England. Autism research would thus far seem to be untouched by this movement except so far as to become finally detached from its initial consideration as a psychosis and possible form of childhood schizophrenia through its inclusion in the Diagnostic and Statistical Manual, third edition (DSM-III) of the American Psychiatric Association in 1980 (APA, 1980)

Simon Baron Cohen, based at the Autism Research Centre Cambridge University (founded in 1998), did much to popularise the ‘Theory of Mind’ model which he had developed in 1985 (Baron-Cohen, Frith, & Leslie, 1985). He has subsequently gone on to more controversial research positing the Extreme Male Brain Theory (Baron-Cohen, 2002) which has been challenged by Autistic scholars such as Melanie Yergau and others including the authors of this article. (Yergau, 2013)

Dinah Murray developed the interest theory of Autism (readers may be more familiar with the terms single attention and monotropism) with Mike Lesser (Murray, Lesser, & Lawson, 2005), Although this has not become a mainstream model of autism to the extent of Theory of Mind or Central Coherence it has nevertheless found favour with Autistic scholars as a fairer means of describing the neurological mechanisms of autism than any specific model which posits deficit. Murray argues that Autistic people’s strengths and special interests can play an important role in their education and provide a dividend for the employment of autistic people as adults as instanced by the work of Specialisterne, who have been elsewhere in the UK employing Autistic people in testing software.

Research Autism was established by the NAS in 2004 to evaluate and raise funds for research into interventions in Autism as well as providing authoritative guidance for professionals and the public on the bewildering variety of interventions that exist. It is currently winding down with its functions being re-absorbed into the work of the NAS.

Current centres for research, education, and publishing

Whilst most of the research into autism has been conducted within the medical framework, there has been a significant focus on Education with certain programs attracting an increasing number of autistic students and researchers such as the Autism Centre for Educational Research at the University of Birmingham and the Sheffield Hallam University Autism Centre’s Post Graduate Certificate run in conjunction with the NAS, both of which have included autistic people in providing course materials, teaching and tutoring.

Other prominent research arenas include the Centre for Research into Autism and Education (CRAE) at University College London (UCL), whose former director, Liz Pellicano, has led the way in involving autistic people in setting a research agenda through the shaping autism research series of seminars. Other autistic-led research initiatives worthy of mention include the Participatory Autism Research Collective (PARC) – whose aim is to build a community of those who wish to see more significant involvement of autistic people in autism research – and the team of primarily autistic researchers responsible for recent surveys of support for autistic students at university and in colleges of further education in England.

Besides the Kings College Institute of Psychiatry Kings College have been involved in examining the ethical basis of autism research, hosting an ethics discussion group including autistic activists, ethicists and philosophers as well as autism researchers in an endeavour which led to the conference Autism, Ethics and Society held at UCL in 2010

The Autism Research Group (ARG) at City University, London has also led medical research in attempting to establish the neuro-biological and genetic underpinnings of the cognitive and psychological differences in Autism

The open access academic journal ‘Autonomy’ (the Critical Journal of Interdisciplinary Autism Studies) was first published in 2012 with Larry Arnold as Editor. Autonomy has probably published more contributions by autistic scholars than any other individual academic journal since it was founded. (Arnold, Editorial, 2012)

Advocacy

The 1990s saw the beginnings of a backlash against the framing of autism without input from autistic people and with the growth of access to the internet during this period, this took on an international dimension as the ideas of Sinclair (Sinclair, 2005) and others became available to autistic people in England. Significant in England at the time were the on line facilities offered by Martijn Dekker which allowed groups of autistic people to discuss a variety of topics regarding self-help and advocacy. From those beginnings individuals who had initially met on line started to meet face-to-face to achieve other aims. These movements drew upon the notion of ‘neurodiversity’, a term first coined by Judy Singer in 1998 to refer to the natural variation in neurotype. In parallel to Dekker’s mailing list there were others centred upon other forms of neurodiversity such as dyspraxia. Mary Colley (a dyspraxic adult) was a significant figure in this discourse and instrumental in forming the Developmental Adult Neurodiversity Association (DANDA) in 2003 following dissatisfaction with the parent-led focus of the Dyspraxia Foundation charity, dyspraxia as a condition having strong overlaps with Autism. Many of the early members of this organisation were also Autistic and went on to play significant roles in other autistic and neurodivergent movements including membership of the Disability Rights Commission neurodiversity action group established in 2005

In 1999] the NAS saw its first autistic Council member (Richard Exley) and in 2001 saw its first Autistic Board member (Larry Arnold), whose appointment led to significant changes within the organisation including constitutional amendment to ensure equal rights and greater participation for autistic people within the organisation and significant changes to their public presentation and campaigning.

In 2005 a group of Autistic people were asking why there was no equivalent in Europe of Autreat (a retreat-style conference run by and for autistic people), a question which led to the introduction of a similar event in England known as Autscape. Initially with assistance and advice from Autism Network International (ANI) members Jim Sinclair and Patty Clarke, in its first year it managed to attract an international attendance, from the USA, Israel, and with a strong presence from the Nordic Countries and the Netherlands. Autscape emphasised the importance of autistic people as an international community.

In 2007 a group of politically motivated individuals met together at Autscape which led to the formation of the London Autistic Rights movement, launched at a meeting in City Hall London where the key speakers were Dinah Murray, Larry Arnold, and David Morris, the London Mayors senior disability policy advisor. (Arnold, Provisional Front Page for Autreach, 2007) The group initially had a specific focus on the capital, with access to the Westminster Parliament, however this led to a UK-wide focus and the formation of Autistic UK which is the only national campaigning organisation in the UK run by autistic people.

Autistica was founded in 2004 as Autism Speaks UK by Dame Stephanie “Steve” Shirley. In 2009 it decided to end its links with the US Autism Speaks Its aims are to *promote and fund “medical research to understand the causes of autism, improve diagnosis, and develop new treatments and interventions”.*

In 2008 the founders of US based Autism Speaks, toured to promote the organisation in the UK. This was vigorously opposed by autism rights campaigners who saw the organisation as erasing autistic identity and rights. Of significant import was the Tree House (currently Ambitious about Autism) annual lecture. Tree House had inadvertently invited Bob and Suzanne Wright, the founders of Autism Speaks. In order to balance the expression of opinions, they commissioned Autreach to make a video to be shown at the event. The video called ‘Something About Us’ (Murray & Benstock, 2007) consisted of a collection of autistic people – not all of them verbal – presenting individual segments about the positive aspects of autism, to counter the negative stereotypes and pity invoking narratives of hard line organisations committed to the elimination of autism.

An example of the progress resulting from such dialogues was the National Autism Project established in 2015 with the aim of providing *“authoritative recommendations on those aspects of autism research and practice that have demonstrable effectiveness in benefiting autistic people and their communities.”*. Dinah Murray’s own advisory team of autistic people subsequently became the autistic advisory panel for the whole project, marking a significant breakthrough in terms of the input of autistic people to a national autism initiative.

**Current issues and controversies**

Gender

Autism was once thought of as a predominantly male phenomenon with an oft quoted ratio of four males to one female (and higher in so called ’low functioning‘ individuals). This was defended on the basis that these were the research findings which has led to the Extreme Male Brain Theory of autism (op cit). This has been much criticised from a feminist perspective (Yergau op cit) as stereotyping the so-called traits of maleness.

Behavioural Approaches to Autism

For the most part the UK has adopted an eclectic approach to “intervention” and education, including the NAS’ SPELL (Structure, Positive, Low arousal, Links) TEACH (Teaching, Expanding, Appreciating, Collaborating and Cooperating, Holistic), Social StoriesTM and counselling, in contrast to the predominance of ABA (Applied Behavioral Analysis) in the USA. ABA however has found its strong proponents in the Treehouse School. (op cit). Mentoring has been found to be of value in higher education and employment and an autistic mentoring project (the Cygnet Project) was developed by London South Bank University led by Nicki Martin and Damian Milton.

Pseudo science and Cures

Ever since the psychodynamic approach to autism was challenged by Bernard Rimland (Rimland, 1964) there has been an increasingly biomedical focus on Autism in some quarters prompted much by Rimland’s later work at the Autism Research Institute (USA), whose findings have been met with some scepticism elsewhere. Undoubtedly the most damaging controversy to emerge initially in England was the Measles, Mumps, and Rubella (MMR) vaccine scare which was bolstered by the since retracted and discredited study of Andrew Wakefield. (Flaherty, 2011) Since then there has been an explosion in alternative medicine and the promotion of non-validated and potentially dangerous ’cures‘.

Employment

Historically, it is likely that autistic people found it easier to get work, but in an increasingly demanding environment this is no longer the case. Notwithstanding the potential problem of successful autistic people being underdiagnosed, there is now substantial evidence of high unemployment of autistic people even amongst those who are highly qualified. A great deal of this can be attributable to structural exclusion of autistic people through advertisements and selection processes which generally reflect those traits that autistic people are less likely to have.

There have been numerous attempts, such as the NAS prospects service, to provide employment support for individuals to help integrate them into the workforce and to keep positions in a highly socialised and rapidly changing environment. Likewise there have been approaches concentrating upon the strengths of autistic people in recruiting for example software engineers and testers. Economic cases have also been made out for the costs of excluding autistic skills.

Recommendations for successful employment involve creating less sensorially stressful working environments and job mentoring through the social aspects of employment.

**Legal perspectives on autism**

Discrimination on the grounds of race and gender in England had been outlawed by UK legislation in 1965 and 1975 respectively. However, it was not until the Disability Discrimination Act (DDA) 1995 that discrimination on the grounds of disability was made illegal (in respect of employment and the provision of goods and services). The DDA introduced the concept of “reasonable adjustments” for those with disabilities. The Special Educational Needs and Disability Act of 2001 extended the ban on disability discrimination and introduction of reasonable adjustments to the education sector. In 2010 the Equality Act subsumed all previous UK disability discrimination legislation.

Although it took three decades for the law in England to treat disability on an equal footing to race and gender, this is only the beginning. Despite race discrimination legislation having been in place for many years, the Metropolitan Police Service were described as “institutionally racist” by the Macpherson Report of 1999. Institutional racism is likely to be endemic despite the efforts of anti-racism campaigners and legislation. Even if disability discrimination is not endemic, and there are those who argue that it is, the legal requirement to provide reasonable adjustments is not fully complied with in many areas of society including higher education despite the legislative requirement being in place for more than 15 years.The first diagnostic acknowledgement of autism (in the DSM-III) was only one year before the legislative objective to achieve inclusive education was enacted and the introduction of the process around SEN. Although both covered autism, there was likely to be a delay in achieving both objectives in comparison to well-established disability categories.

The Autism Act 2009 is the first autism-specific law in the world and first law specific to a particular disability in England. This Act makes imposes certain requirements on local authorities in relation to provision for autistic adults and required the Government to produce an adult autism strategy. The first Adult Autism Strategy was produced in 2010 and updated in 2014. Unfortunately, despite the efforts of those pushing for autism legislation, the Act does not cover children and young people which might have helped autism ‘catch up’ with other SEN categories in education. And as with previous legislation (e.g. the Education Act 1981) no additional funding was forthcoming from Government for implementing the Autism Act provisions.

In terms of general welfare provision, the Community Care Act 1990) a modernisation of the pioneering Chronically Sick and Disabled Persons Act 1970 which ushered in modern social service provision which currently includes provision for services for autistic people include direct payments and personal budgets. Its workings are however currently much restrained by the climate of austerity.

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