

<b>Institution: Leeds Beckett University</b>		
<b>Unit of Assessment: 27, English Language, Literature and Creative Writing</b>		
<b>Title of case study: Naming Adult Autism</b>		
<b>Period when the underpinning research was undertaken:</b> 2015-present		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Dr James McGrath	Senior Lecturer in English and Creative writing	2015 to present
<b>Period when the claimed impact occurred:</b> 2016 to present		
<b>Is this case study continued from a case study submitted in 2014? N</b>		
<b>1. Summary of the impact</b> (indicative maximum 100 words)		
<p>Based on his experiences of an adult diagnosis of autism via literary and cultural studies research into autism, McGrath's impact has led to changes in (a) professional awareness within the NHS of obstacles faced by autistic adults in accessing their services (GP training films); (b) changes in how health professionals accommodate the needs of autistic patients (conference presentations; Q+A sessions; training events) (c) updating content of certified online courses on autism awareness to represent autistic perspectives (High Speed Training UK); (d) policy changes in diagnostic techniques and communication with service users; (e) public awareness that autistic people may succeed in Arts and Humanities, not just STEM domains as previously stereotyped (BBC radio broadcasts; The Conversation).</p>		
<b>2. Underpinning research</b> (indicative maximum 500 words)		
<p>McGrath's adult autism diagnosis was a positive experience in enabling him to understand his condition and access support. However, as a literature scholar and poet, he felt alienated by pervasive scientific as well as cultural narratives that presuppose autistic people lack empathy and imagination and have little potential in arts and humanities subjects (Baron-Cohen, 2001). The stereotypes that pervade both public and professional understanding of autism leave some autistic adults less likely to receive diagnosis and support, simply because they enjoy the arts, and therefore score 'low' for autism characteristics on some standard diagnostic tools.</p> <p>As a result of his experiences, McGrath undertook a concerted study of how autism is narrated across fiction, poetry, songs, television and film, as well as in leading psychiatric discourse. The resulting interdisciplinary book, <i>Naming Adult Autism</i> (2017) (3.2), is a cultural and medical history of the term, foregrounding the role of <i>narrative</i> in how autism is understood and diagnosed (there are no 'biological' tests available).</p> <p>McGrath evaluates the context of Nazi ideology surrounding Hans Asperger's 1944 study, showing how the Austrian paediatrician's publications foregrounded his patients' most culturally valuable talents: gifts in STEM (Science, Technology, Engineering, Maths). McGrath traces how Asperger shaped subsequent psychiatric expectations that autistic people may succeed in STEM areas but show little understanding of the arts (Baron-Cohen, 2001). He highlights how this dehumanizing assumption about autistic people also shapes (and sensationalises) the condition's portrayal across film, television, popular music (see also 3.1) and fiction. Cautioning against the term 'representation' when critiquing these cultural manifestations of the condition, McGrath shows how psychiatry and culture mutually conflate stereotypes of autistic 'minds wired</p>		

for science' (Baron-Cohen, 2012) with little reference to the real experiences of autistic adults (and still less consideration that autistic people might engage with these texts).

The world's most widely-disseminated autism questionnaire – used as both a diagnostic screening tool and the basis for the UK's ongoing Channel 4/*PLOS-One* national survey of autistic traits – is Baron-Cohen's 'Adult Autism Quotient Test' (2001). *Naming Adult Autism* calls for this to be withdrawn from use by GPs and updated for use in national surveys. McGrath uncovers flaws in the test's methodology and scoring, and hence its reliability. The questionnaire was created to help GPs decide whether to refer adults for autism assessment. Yet it served a simultaneous purpose: to support lucrative theories that mathematicians and scientists show more autistic traits than the general population. Answers suggesting an interest in numeracy are scored to raise the likelihood of autism – but answers indicating enjoyment of the arts are scored *negatively*. This major test and survey excludes creativity and imagination from the profile of what autism 'means'.

McGrath traces the history of autism narratives from Asperger to the present, before contemplating its possible futures. If 'preventing' autism becomes possible via prenatal screening, the ways in which the condition is narrated in culture, as well as science, could influence decisions on abortion. Critical study of autism narratives is thus vital. Using literary critical approaches to both scientific and cultural texts, *Naming Adult Autism* seeks to promote further interdisciplinary studies of the subject. McGrath has sought wider audiences for his published research (3.3) because it is urgent that wider constituencies understand the breadth of the autism continuum, and the damaging nature of narrow stereotypes about the condition.

### 3. References to the research (indicative maximum of six references)

1. McGrath, James (2019ebook; 2020 hard copy) 'Doctor I'm damaged: Medical and Cultural Narratives of Nicky Hopkins and the Rolling Stones' in Russell Reising (ed.) *Beggars Banquet and the Rolling Stones Rock and Roll Revolution: 'They Call My Name Disturbance'*. London: Routledge. (ADD DOI when available) [Listed in REF 2b]
2. McGrath, James (2017 hardback and ebook; 2019 paperback) *Naming Adult Autism: Culture, Science, Identity*. London: Rowman and Littlefield. [Listed in REF2b]
3. McGrath, James (2019) Not all Autistic People are Good at Maths and Science, Despite the Stereotypes. *The Conversation*, 3 April, 2019. <https://theconversation.com/not-all-autistic-people-are-good-at-maths-and-science-despite-the-stereotypes-114128> [Readers: 17,990  
Facebook shares: 11.3k  
Tweets: 205 including Steve Silberman, author of *Neurotribes* (the best-selling autism study to date) and Simon Baron-Cohen.

The **significance** of McGrath's study of autism is that it is the first cultural history of autism from the cultural field; it is therefore also **original**. Its **rigour** is signalled by its appearance from an academic press (which had a process of peer review as part of its publication), and its influence on discourses outside the immediate field of literary and cultural studies (for instance medicine and allied professions – e.g. a positive review in the *BMJ*).

### 4. Details of the impact (indicative maximum 750 words)

- (a) Developing Professional Awareness; (b) Changes in Professional Practice; (c) Updating of Professional training Materials

McGrath has presented his work in a number of different forums. A Leeds Cultural Conversation hosted by the CCA at Leeds Beckett in December 2017

(<https://www.leedsbeckett.ac.uk/events/past-events/2016/faculty-events/lcc-james-mcgrath/>) was one of the early outings for the book, but earlier iterations had been presented to patient and service-user groups and to health professionals. He has also worked with this organisation to improve other elements of their practice, showing how **their use of children's toys in adult autism diagnostic assessments** was highly problematic in diagnosing the condition in adults and modifying their practice, so that adults with autism are less humiliated by diagnosis, and more likely to come forward. He has also participated in training films for LADS (4.1) – an online resource for GPs and other health professionals in the Leeds City region (2018). And in 2017 he was instrumental in influencing **modifications in the content and style the Leeds NHS Trust's Autism Awareness online course** (High Speed Training). As a result of his research he was also asked to join the Service Users Group for LADS to advocate for other adult autistic people.

#### **(d) Policy changes in diagnostic techniques and communication with clients**

In 2017, The Leeds Autism Diagnostic Service (LADS) responded to McGrath's research, bought copies of his book as a training resource, and, though we cannot demonstrate a causal link, subsequently **changed one of their key practices – they abandoned the use of the Baron Cohen Autism Quotient Questionnaire from their diagnostic suite (4.7).**

In February 2016, while the book was still in preparation, McGrath presented to the Leeds and York Partnership NHS Trust, Autism Conference to the title 'What is it like to be autistic?' This presentation, given to an audience of NHS staff, combined personal reflections with academic research. **It was announced at the conference that following McGrath's critical observations of how clients are informed of diagnoses** (with clients being 'copied in' to letters to their GPs), **Leeds Autism Diagnostic Services were amending this policy, making both clients and GPs the nominal recipients of diagnostic confirmations.** This matters because it means that adults with autism are being as adults, and directly addressed by the health professionals concerned.

#### **(e) Public awareness of the artistic and creative potential of people with autism**

McGrath has also set out to work with wider publics than the health professional domain. On 6 December 2017, he participated in an hour-long discussion of his book with Kelly-Anne Watson of Leeds Beckett Student Union. This talk was attended by members of the public as well as students and staff. The following day his Leeds Cultural Conversation – a public lecture, brokered in partnership with Leeds City Council and Palgrave's Campaign for the Humanities was well attended, and has garnered 1,460 views on the YouTube archive of the footage.

**Extracts from this talk were used by LADS in their film suite of training materials (4.4)** – see above. He has also appeared on BBC Radio Leeds to discuss autism in culture (April 2016, and December 2017). And he was an invited panellist at *Autism Writes Back!*, part of the International Literature Showcase (sponsored by Arts Council England, British Council and Writers' Centre Norwich) at the 2018 Norfolk and Norwich Festival. His April 2019 article for *The Conversation* (<https://theconversation.com/not-all-autistic-people-are-good-at-maths-and-science-despite-the-stereotypes-114128>) has been widely read, including by **Professor Simon Baron Cohen – who tweeted that he agreed with McGrath's premise** (<https://twitter.com/sbaroncohen/status/1114060989333483520>)

In October and November 2019, building on this work with LADS, McGrath was also a speaker at two face-to-face training events for Leeds GPs and for other health professionals about the need to refocus some elements of standard practice and the damage done by the cultural stereotype of the STEM-focused autistic male. Assessments from these events suggest that the individuals encountering McGrath's work were overwhelmingly likely to change their perspective and practices as a result. (See

<https://www.andrewsimscentre.nhs.uk/assets/downloads/programme-1568798579.pdf>)

In short, McGrath's work has built public awareness of autism as a range of conditions which defy the maths-geek stereotype, and of the need to look more widely at what the condition means for those who have it. The public awareness matters, but the more important impact is that he has also worked with practitioners in the Leeds City Region to modify their practices to better serve their users, and as a result his work has changed professional practices.

**5. Sources to corroborate the impact** (indicative maximum of 10 references)

1. Leeds and York Partnership NHS Trust (2018). 'It's a wrap: James stars in autism film series'. *Imagine: Leeds and York Mental Health & Learning Disability News*. 2 (Spring), pp.6-7.
2. <https://www.leedsandyorkpft.nhs.uk/get-involved/wp-content/uploads/sites/11/2018/03/Imagine-Newsletter-Spring-2018.pdf> [cover story of the magazine and interview about the book]
3. Fox, K. (2018) 'Me- Autistic? As If...'  
<https://katefoxwriter.wordpress.com/2018/03/12/me-autistic-as-if/> [the official blog of poet, comedian and academic Dr Kate Fox]
4. High Speed Training: Autism Awareness Course (updated 2017)  
<https://www.highspeedtraining.co.uk/safeguarding-people/autism-awareness-training-course.aspx>
5. Stansfield, Alison et al. (2017) 'Are we good and are we safe? Measuring quality and assessing risk in adult autism diagnostic service.' *Advances in Autism*. Volume 3.1, pp. 15-26. DoI. 10.1108/AIA-03-2016-0008. Quotes from McGrath – Box 1.
6. Feedback questionnaires from sample GP training events.
7. Review blog article by Anna Stenning, *British Medical Journal*.  
(<https://blogs.bmj.com/medical-humanities/2020/05/07/on-what-it-feels-like-to-be-a-problem/>).
8. Testimonial Letters describing impact from Alison Stansfield, LADS