

## Impact case study (REF3b)

<b>Institution: University of Leeds</b>
<b>Unit of Assessment: 29: English Language and Literature</b>
<b>Title of case study:</b> Representing Autism: Using cultural narrative to change medical practice, creative and artistic production, and inform and stimulate public debate of the condition
<p><b>1. Summary of the impact</b> (indicative maximum 100 words)</p> <p>Professor Stuart Murray's research on the cultural narratives used to represent autism has influenced and inflected different areas and beneficiaries, from public health providers to arts companies. This case study describes how his research in particular:</p> <ol style="list-style-type: none"> <li>1. Informed and shaped service provision, diagnosis, understanding and awareness of adult autism in Leeds through interaction with the NHS autism diagnosis service;</li> <li>2. Informed and stimulated public discussions of autism nationally;</li> <li>3. Inspired and shaped new approaches by Opera North to the artistic representation of autism.</li> </ol>
<p><b>2. Underpinning research</b> (indicative maximum 500 words)</p> <p>The underpinning research by Murray (Professor of Contemporary Literatures and Film, appointed to Leeds in 2000) was first conducted in <i>Representing Autism</i> [1]. Murray's study was the first monograph in the arts and humanities on the subject and a critical analysis of the ways in which autism has been represented across a range of narrative forms in contemporary society, from medical texts and charity discourse to literature, photography and film. Murray stressed the need to interpret narrative forms as intrinsic to the understanding of the condition. The novelty of the research lay in Murray's introduction of literary/cultural methodologies into discussions of medicine and health practice on autism, as well as of other, public-facing art forms. The book's emphasis on the importance of story and representation to our understandings of disability radically revised dominant medical and sociological models of cognitive disabilities.</p> <p>At its core the book articulated the concept of an 'autistic presence.' Through this original idea, read both in terms of fictional characterisation and social selves, Murray established a case for disabled agency, arguing that people with autism have existed throughout history; and that the person with autism cannot be reduced to metaphor or placed in the margins, as is the case in research paradigms (predominantly medical) for the condition. The book also dealt with public and media responses to autism, identifying how and why the autism spectrum, especially since the mid 1990s, has been subject to fascination. Murray argued that this popular fixation imposes its own, often reductive, set of assumptions and desires on what we believe autism to be, again in narrative or representational terms, requiring, in turn, narrative analysis.</p> <p>In [2], Murray focused predominantly on medical and media (rather than cultural/fictional) narratives. This article showed how notions of 'function' dominate public understanding of 'high' or 'low' autistic subjects, conceived in terms of utility, and produce a normalising effect. Increasingly concerned not only with engaging popular culture materials in his research but also in speaking to non-academic audiences, Murray then produced [3], <i>Autism</i>. Another first, this time the first book to combine medical, cultural and historical approaches to the topic for a general reader, in <i>Autism</i> Murray examined how the condition is seen within public discourse.</p> <p>The aim of Murray's research was twofold: to better understand the ways in which autism is constructed in culture through its circulation in narrative (whether medical diagnosis or popular film); and to commit to the practice of a critical disability advocacy that keeps the person with disability central to the research. Murray's concept of 'autistic presence' has been cited as a major new idea in cultural disability studies, while his analysis of diagnosis has been received as bridging the gap between literary/cultural studies and primary health care. More generally, the research is definitively interdisciplinary as it has been read as original and distinctive in its contributions to psychology, sociological and health sciences, as well as to literary/cultural studies.</p>

Murray's publications led to collaborative research projects examining the subject in different contexts. Supported by a University of Leeds grant, Murray headed an international exploration with the Chinese University of Hong Kong School of Public Health to improve autism services [4]. Further supported by a Wellcome Trust grant, as PI Murray organised three seminars in the series 'Transforming Bodies: New Directions in Medical Humanities and Cultural Disability' to identify how practitioners can help improve healthcare through drawing upon different perspectives and critical narratives [5].

### 3. References to the research

1] *Representing Autism: Culture, Narrative, Fascination* (Liverpool: University of Liverpool Press, 2008), xvi + 236pp. ISBN 978-1-84631-091-1 (hbk), 978-1-84631-092-8 (pbk). This book has been cited 39 times in subsequent work according to Google Scholar, and is accepted as the major text in the literary/cultural discussion of autism representation. [1] and [2] form a double-weighted portfolio in REF2. Available on request.

2] 'Autism Functions/The Function of Autism', *Disability Studies Quarterly*, vol. 30, no. 1, (2010). Special issue on autism and neurodiversity, edited by Emily Thornton Savarese and Ralph James Saverese. Peer-reviewed; oldest and one of the most prestigious journals in the field. Open-access journal. <http://dsq-sds.org/article/view/1048/1229>.

3] *Autism* (New York: Routledge, September 2011). This was selected as the launch text in the new Routledge 'Integrating Science and Culture' series. xiv + 130pp. ISBN 978-0-415-88498-3 (hbk), 978-0-415-88499-0 (pbk). This book was commissioned as a textbook/general readership text by Routledge, designed to have wide appeal, following the success of *Representing Autism*. Available on request.

4] "Do It Yourself" in the parent-professional partnership for the assessment and diagnosis of children with autism spectrum conditions in Hong Kong: A qualitative study,' with co-authors Hilda SW Ho, Huso Yi, Sian Griffiths, Dorothy FY Chan, *Autism* (October 15, 2013). Journal Impact Factor:1.96, Ranking:28/65 in Psychology, Developmental, 5-Year Impact Factor:3.166. Available for download: <http://aut.sagepub.com/content/early/2013/10/14/1362361313508230.full>

5] Wellcome Trust Medical Humanities conference/seminar series -- grant to fund a three-event seminar series, entitled 'Transforming Bodies: New Directions in Medical Humanities and Cultural Disability', 2010, £4054, 093721/Z/10/Z. Murray PI on overall project. [http://www.wellcome.ac.uk/stellent/groups/corporatesite/@msh\\_publishing\\_group/documents/web\\_document/wtvm051669.pdf](http://www.wellcome.ac.uk/stellent/groups/corporatesite/@msh_publishing_group/documents/web_document/wtvm051669.pdf)

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

#### *Service provision for autism in Leeds*

The Leeds City Council's Leeds Adult Autism Strategy (2011 – 2014) established the Leeds Autism Diagnostic Services (LADS) in September 2011 with the aim of improving the wellbeing of people with autism. As well as having diagnostic responsibilities, LADS provides users with information on autistic conditions and signposts to other community services. Murray helped in the very development of the service. He shaped the business case for LADS by allowing them to argue for a 'holistic,' and not simply diagnostic and clinical, response to autism. This secured their funding from the commissioner for the Leeds/York Partnerships NHS Foundation Trust and additional funding for 2 full-time social workers [A].

The interdisciplinary approach and wide understanding of Murray's research broadened LADS' own understanding of autism beyond a biomedical/psychiatric focus. According to the clinical lead for LADS [A], Murray was able to 'challenge us as a team about how and why we were doing this. He came from a totally different view point... [and] led us to developing a more holistic way of

**Impact case study (REF3b)**

working.’ In addition, Murray made a hands-on contribution to LADS, which ranged from changing the language of communications sent to service users and the environment in which assessments take place; through to revising procedures in diagnosing autism. Through LADS, Murray’s approach has had a further beneficial effect on improving the experience of autistic service users. LADS lead states that ‘working with Stuart Murray, developing this holistic approach, means we are getting it right. Feedback has been very positive, especially from service users who said “no one ever understood us before” [A].

Murray’s research has also directly benefitted Leeds/York Partnerships NHS Foundation Trust (LPFT). Following an initial meeting with the Associate Partnerships Director of the Trust, Murray worked with the NHS on delivery of events to emphasise the value of narrative in clinical practice. These included the city-wide LoveArts Festival, organised by the LPFT with the aim of exploring connections between the arts, mental health and wellbeing. Murray organised a theatre performance followed by a panel discussion on the role of theatre in mental health, which was attended by arts and healthcare students as well as health and social care professionals. According to the Deputy Director of Strategy and Partnerships at LPFT, who is also the LoveArts Festival Director, the event ‘raised their awareness and understanding about mental health issues’ [B]. This led to Murray co-delivering with LPFT in June 2013 training accredited by the NHS for the continuing professional development of clinical staff and other healthcare practitioners. The training, ‘Clinical Practice and the Value of Narrative,’ was completed by 16 delegates and served to widen clinical understandings. The Deputy Director of LPFT noted that ‘working with Stuart has helped us by challenging health clinicians to think more broadly’ [B]. On the standard NHS feedback summary, delegates gave ratings of between 4.3 and 4.7 (on a 1-5 disagree/agree scale) for all evaluation questions relating to the event.

*National public discussions*

The research has also been influential in determining the shape and content of public debates about autism. As a result of Murray’s research [1], the producer of BBC Radio 3’s flagship arts programme, *Nightwaves*, invited Murray to take part in June 2008 in an episode dedicated to autism. Murray’s idea of ‘autistic presence’ featured strongly [C]. Further to this, in September 2008, Murray was invited to speak at an international conference organised by the National Autism Society, a UK charity aiming to improve the lives of people with autism. Murray’s session discussing current research into autism and its role in supporting people was attended by professionals, people living with autism and parents.

Murray’s research was also significant for the Institute of Ideas, a UK think tank which organises a festival of debate each year, the *Battle of Ideas*. In October 2009, the Institute selected autism as the subject of one of the sessions. The former Communications Director for the Institute noted that Murray’s research shaped the debate framework and exposed new ideas about autism to the audience, which included people working in autism charities, policy, academic and members of the general public [D].

Murray was also invited as a guest speaker to a British Academy conference when it marked World Autism Day in April 2012, and he was panellist in an ‘Autism and Human Variation’ event in October 2012 held at Leeds Salon, a public debate group. The co-founder of the Salon noted that the debate, founded on Murray’s findings and including NHS clinical staff, was well received and that Murray’s research had undoubtedly extended the reach of the Salon by attracting new panel members and members of the audience, with over 100 people attending, compared to a usual turnout of 40 people [E].

*Opera North*

Murray’s research has led to the commissioning of an opera on the topic of autism by Opera North, a national opera company based in Leeds. According to their Projects Director, Opera North ‘had never thought of representing autism in our work before meeting with Stuart’ [F]. With the opera expected to premier in 2014/15, the immediate impact has been on the conception of, artistic

**Impact case study (REF3b)**

approach of, and understanding of those working in preparing, the opera. Murray's 'research on the social/political aspects of autism and also the artistic representation of autism in a wide variety of forms, in film and theatre and other art forms. . . gave us a framework for what to work towards and what to work against in developing the piece. It really gave us a broader, deeper understanding of the subject' [F].

In particular, Murray's concept of 'autistic presence' has directly influenced creative practices. First, it ensured that the opera was represented from an autistic point of view. Secondly the decision was made to depict the autistic child on stage with a puppet, since, the company decided, they 'didn't want audiences to engage with an actor pretending to be autistic, we wanted them to engage with the experience of autism. It's Stuart's research on other cultural representations that has brought us to that conclusion' [F]. In using Murray's research Opera North in turn feel they are increasing their cultural capital both in national debates about disability and in innovative aesthetics, and further that they are doing something radically new in combining these: 'we are not aware of any other musical theatre work in this territory, so it's really groundbreaking' [F].

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

- A) Testimonial from Associate Medical Director for Learning Disabilities, Leeds/York Partnerships NHS Foundation Trust, and the Clinical Lead for the Leeds Autism Diagnosis Service (LADS), 7 June 2013, available on request.
- B) Testimonial from the Deputy Director of strategy and partnerships at Leeds and York Partnership NHS Foundation Trust and Love Arts Festival Director, 17 June 2013, available on request.
- C) BBC Radio 3's *Nightwaves* programme dedicated to the subject of autism, with Murray as guest interviewee, 26 June 2008, <http://www.bbc.co.uk/programmes/b006tp43/broadcasts/2008/06>.
- D) Transcript of interview Associate Fellow and former Communications Director for the Institute of Ideas, 11 September 2013, available on request.
- E) Transcript of interview with co-founded of Leeds Salon, 23 January 2013, available on request.
- F) Testimonial from Projects Director, Opera North, 16 July 2013, available on request.