

Institution: University of Leicester

Unit of Assessment: UoA4

Title of case study: Identifying higher prevalence of autism in adults: improving services and changing attitudes

1. Summary of the impact

Autism or autistic spectrum disorder (ASD) is a lifelong neurodevelopmental condition that affects around 700,000 people in the UK. Until recently knowledge of autism prevalence was mainly restricted to children, but in 2007 the Adult Psychiatric Morbidity Survey (APMS) included for the first time a measure of ASD. Professor Traolach (Terry) Brugha and his group developed an innovative methodology to measure the prevalence of autism in adults – previously not thought possible - and found it to be just over 1% of the population studied. The evidence collated by the Social and Epidemiological Psychiatry group has led to a range of actions across central and local government as well as the charitable sector, and since 2010, has transformed diagnostic and support services. It has also improved professional training, changed attitudes across society and reduced the isolation and exclusion that adults with autism often face.

2. Underpinning research

Background

Leicester researchers have performed the clinical assessment for the APMS since 1993. This is the primary data source for monitoring trends in England's mental health. Around a decade ago, researchers and advocacy groups such as the National Autistic Society (NAS) successfully campaigned for the UK government to develop a national strategy for adults with ASD. This followed evidence that a growing numbers of adults, including people entering higher education, were or could be autistic. Brugha successfully lobbied the Department of Health (DoH) to include autism as an additional condition in surveys of adult mental health.

New research methodology

In 2007 Brugha led a multidisciplinary team in a two-phase epidemiological survey (7,641 screening and 618 diagnostic interviews) to estimate the prevalence of autism in adults living in households throughout England (1). There was no previous comparable research. Leicester was responsible for the clinical assessment work, the National Centre for Social Research carried out the initial questionnaire phase of the survey, and University of Cambridge's Autism Research Centre shared clinical data on patients with autism and unaffected adults to help develop a short questionnaire suitable for identifying adults who might have autism.

Establishing the prevalence of autism in adults

The prevalence of ASDs in the adults surveyed was found to be one in 100, with 1.8% of males having an ASD compared with 0.2% of females. The research revealed that not a single one of these people knew they had the condition. The most surprising finding was that the prevalence of autism was consistent across adults of all ages (up to their 80s). This means that any non-genetic causes of autism have remained constant over the last 70 to 80 years. These findings had two important implications: that services are needed to care for autistic people in all age groups and not just in children and young people; and that there was no evidence of an 'autism epidemic' or marked increase in people with the condition, as was widely - and wildly - reported in the popular media in the UK and abroad at the time. The findings were deemed significant enough to be published in the world's leading mental-health scientific journal, Archives of General Psychiatry, in 2011 (2).

Building on the evidence

Following the 2007 study, the DoH funded a bigger project to look more closely at the numbers of adults with autism in a more representative sample, which included people in residential care settings and those with a more severe learning disability. The research was again led by the Leicester group, in collaboration with the Universities of Cambridge and Glasgow. Combining its findings with the original APMS, it found that the actual prevalence of autism is approximately 1.1% of the English population (3,4). Adults with a more severe learning disability were shown to have a greater likelihood of having autism.

Impact case study (REF3b)

Further research

The group carried out further studies into the prevalence of ASD. In a study that confirmed the validity of the methodology, more detailed clinical evaluations were carried out, including interviewing relatives and carers, in order to obtain information on behaviour in early childhood (5). Analyses were also published showing that people living in the community with autism are at increased risk of having epilepsy, confirming previous findings obtained in patients known to health services (6).

Key staff

Leicester: Terry Brugha, Professor of Psychiatry (1987 to present); Dr John Bankart, Lecturer in Med Stats (2005 to 2013); Freya Tyrer, senior research staff epidemiologist (2004 to present); Howard Meltzer, Professor of Health and Disability (2006 to January 2013); and Jane Smith, senior research associate (1996 to 2013)

Other: Sally McManus (National Centre for Social Research); Professor Simon Baron-Cohen; Dr Fiona Scott (both Cambridge); and Professor Sally-Ann Cooper (Glasgow).

3. References to the research

1 **Brugha T**, McManus S, **Meltzer H**, **Smith J**, Scott FJ, Purdon S, et al. Autism Spectrum Disorders in adults living in households throughout England - report from the Adult Psychiatric Morbidity Survey 2007. Leeds: NHS Information Centre; 2009 Oct 22.

2 **Brugha TS**, McManus S, **Bankart J**, Scott F, Purdon S, **Smith J**, et al. Epidemiology of autism spectrum disorders in adults in the community in England. Arch Gen Psychiatry 2011 May; 68: 459-65.

3 **Brugha T**, Cooper SA, McManus S, Purdon S, Scott FJ, Spiers NA, et al. Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey. Leeds: The NHS Information Centre; 2012 Jan 31.

4 **Brugha T**, Cooper SA, McManus S, Purdon S, Scott FJ, Spiers NA, et al. Estimating the Prevalence of Autism Spectrum Conditions in Adults: Data quality and methodology document. Leeds: The NHS Information Centre; 2012 Jan 31.

5 **Brugha TS**, McManus S, **Smith J**, Scott FJ, **Meltzer H**, Purdon S, et al. Validating two survey methods for identifying cases of autism spectrum disorder among adults in the community. Psychol Med 2012 Mar 29; 42: 647-56.

6 Rai D, Kerr MP, McManus S, Jordanova V, Lewis G, **Brugha TS**. Epilepsy and psychiatric comorbidity: a nationally representative population-based study. Epilepsia 2012 Jun; 53: 1095-103.

Funded projects (total value in excess of £1 million):

National Centre for Social Research. Phase 2 APMS 2006. £361,839.00

Department of Health/NiHR. Phase 3 APMS 2008 DISCO – Clinical Evaluation of Diagnosis of Autistic Disorder in the Adult Psychiatric Morbidity Survey. £45,863.00

NHS Information Centre. Prevalence of autistic spectrum conditions in adults. £600,000

4. Details of the impact

Background

Autism is a disorder of brain development that affects how a person communicates with and relates to other people and how they make sense of the world around them. First described in the 1940s, it is recognised, even at a very young age, in children who have persistent problems in understanding and communication. Sufferers often show fixed repetitive behaviours and may experience social isolation and learning difficulties (Source: NAS). There is no known 'cure'; however, preventative support from specialist teams can enable sufferers to live relatively independently as integrated members of society, with concomitant raised self-esteem.

At the time of the research, services for adults with ASD were sporadic, or sometimes non-existent. Most struggled to find a clinic that could assess them accurately; when diagnosed, they were often left floundering without help. Detailed health and social planning was impossible without information on the prevalence of autism in adults.

Key actions and recommendations for central government

The group's crucial new population data gathered in the 2007 APMS study advanced the government's knowledge and understanding of autism in adults. In March 2010 the government published its strategy for adults with autism in England, *Fulfilling and rewarding lives* (A). The strategy sets out the key actions and recommendations for central government as well as for local authorities and the NHS, focusing on five key areas: increasing awareness and understanding of autism; developing a clear and consistent pathway for diagnosis; improving access to the services and support people need to live independently; employment; and enabling local partners to develop relevant services to meet identified needs and priorities.

In June 2012, the group's research was cited throughout the National Institute for Health and Care Excellence (NICE) guidance: *Autism: recognition, referral, diagnosis and management of adults on the autism spectrum*. The guidance evaluates the diagnostic and treatment evidence base needed to address the population prevalence and age profile, and the group's findings on rates are reflected in terms of the magnitude of the problem and the need for specialist diagnostic, training and support services (B).

An official at the DoH says: "The central work on national prevalence rates provides an accepted overall estimation, which should be the starting point from which local areas can work to develop services and support." (C)

The chief executive of NHS Health and Social Care Information Centre (HSCIC) says of the more inclusive 2011 study: "These estimates...offer a new insight into the prevalence of autism among people with learning disabilities. This information will be of particular importance for those who plan and provide services to support those with learning disabilities or with autism." (D)

Local authority service planning

In April 2011, the Department of Health provided all local authorities in England with the means to assess their progress. These assessments were collated and published by Public Health England's Learning Disabilities Observatory. The report shows that of the 142 local authorities who participated, at least two-thirds either had a plan in progress or had achieved their goal in ten quality outcomes and service ambitions relating to the key areas above. (E)

The prevalence rates established by the group are used in an information database called PANSI (Projecting Adults Needs and Service Information) run by the Institute of Public Care. This is used by local authority planners and commissioners of social care in England to estimate the needs of the local population of adults with ASD and the types of support they commission from providers.

Leicestershire County Council has used the prevalence rates in discussions with three Clinical Commissioning Groups (CCGs) across the region to design new initiatives and services for adults with autism, including the appointment of two Team Seniors to support Social Care Assessment and the Autism Information Hub. In 2012 the Council appointed a GP, on the recommendation of Brugha, who over the last 12 months has delivered autism awareness across Leicestershire in the form of a Top Tips booklet, training sessions, a conference and one-to-one discussions with other GPs to equip them with the knowledge and skills to manage adults with autism within Primary Care and make appropriate referrals for diagnosis (F).

Public awareness and information

All the materials that the NAS, the leading charity in the UK for people with autism and their families, have developed for public information and awareness use the group's prevalence rate. This is part of the core messaging in all NAS campaigns and communications and reaches up to 50,000 people through the helpline, newsletters, policy reports, information leaflets and training (G).

Impact case study (REF3b)

The press attention that the group's findings achieved served to quell public fears of an 'autism epidemic' that had begun in the US and spread to the UK and beyond. By providing a strong counter-argument to an autism-MMR link, Brugha was able to provide some peace of mind to anxious parents as well as prevent precious research funding from being diverted to investigating unlikely environmental causes – mobile phones, processed foods, new medicines and vaccinations – of what is now strongly believed to be an inherited disorder (H).

Other impacts

Based on their findings, the group provided advice and assistance with training to psychiatrists in the diagnosis of ASD in adulthood through the Irish College of Psychiatrists and the Royal College of Psychiatrists Education and Training Centre (I). Brugha has given invited presentations on his research and on autism in the community at influential US institutions: National Institute of Mental Health, Maryland; Centre for Disease Control, Atlanta; and Johns Hopkins Medical School, Baltimore.

In 2012 autism was added to the reporting process of The Lancet's Global Burden of Disease Special Reports following Brugha's advice to data analysts on how to interpret the limited available data on the epidemiology of autism in adulthood around the world. The published findings in December clearly show that rates have been fairly constant between 1990 and 2010 (J).

Brugha is a member of the government's Autism Programme Board, chaired by Minister for Care and Support Norman Lamb, which is preparing a review of progress on the strategy which the Secretary of State for Health Jeremy Hunt is required to present to Parliament for debate in 2014.

5. Sources to corroborate the impact

- A. HM Government. *Fulfilling and rewarding lives: The strategy for adults with autism* (2010) <https://www.gov.uk/government/news/fulfilling-and-rewarding-lives-the-strategy-for-adults-with-autism-in-england>
- B. Nice guidance: Autism: recognition, referral, diagnosis and management of adults on the autism spectrum <http://www.nice.org.uk/nicemedia/live/13774/59684/59684.pdf>
- C. Letter from official responsible for Ministerial Correspondence and Public Enquiries, DoH
- D. Quote from press release issued by HSCIC on 31 January 2012: New study estimates autism prevalence among adults with learning disability <http://www.hscic.gov.uk/article/1733>
- E. Figures derived from Autism Self Assessment 2011: Issues from local authorities (Hazel Roberts, Susannah Baines, Gyles Glover and Chris Hatton). Published by Learning Disabilities Observatory, October 2012 http://www.improvinghealthandlives.org.uk/uploads/doc/vid_17474_1hal%202012-%2010%20Autism%20self%20assessment%202010-11.pdf
- F. Letter from Head of Service, Adult Mental Health, Leicestershire County Council.
- G. Letter from Head of Policy, National Autistic Society.
- H. Quoted in press article 'Autism just as common in adults, so MMR jab is off the hook' by Sarah Bosley (Guardian, 22 Sep 2009) <http://www.theguardian.com/society/2009/sep/22/autism-rate-mmr-vaccine?INTCMP=SRCH>
- I. Diagnostic Interview Guide for the Assessment of Adults with Autism Spectrum Disorder (ASD), Royal College of Psychiatrists, February 2011 https://www.rcpsych.ac.uk/PDF/Asperger_interview_USE_THIS_ONE.pdf
- J. Murray, Christopher J. et al. UK health performance: findings of the Global Burden of Disease Study 2010. The Lancet 23 March 2013, [Volume 381, Issue 9871](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)60355-4/fulltext#article_upsell), pages 997 - 1020. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(13\)60355-4/fulltext#article_upsell](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)60355-4/fulltext#article_upsell)