

Institution: Goldsmiths, University of London		
Unit of Assessment: 4. Psychology, Psychiatry and Neuroscience		
Title of case study: New government policy improves public awareness of autism diagnosis waiting times		
Period when the underpinning research was undertaken: 2012 to 2014		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Elisabeth Hill	Professor of Psychology	2013 – present
Lorna Goddard	Senior Lecturer	2000 – present
Laura Crane	Research Associate	2015-2017
Period when the claimed impact occurred: August 2013-July 2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact <p>In the response to our research findings, in 2018, for the first time, 378 Mental Health Service Providers (MHSP) across England were required to formally monitor, record and report on autism diagnosis waiting times. The data on 17,970 new referrals was fed back to Local Authorities, the NHS and the UK government, raising awareness of the NHS' ongoing failure to meet National Institute for Health and Care Excellence (NICE) guidelines. Medical practitioners, national health planning services, charities and politicians have benefitted from this information, using it to develop and update their long-term strategy for supporting children and adults affected by an autism diagnosis. The change in data collection was a direct result of our research which showed that children and adults in the UK had a lengthy wait for an autism diagnosis and that this delay negatively impacted on post-diagnostic support.</p>		
2. Underpinning research <p>This case study reflects the work of Goldsmiths' researchers (Crane, Hill and Goddard) who were awarded a British Academy Small Grant (<i>Experiences of receiving and communicating a diagnosis of autism spectrum disorder</i>; 2012-2014) (G1) to explore the current situation regarding autism diagnosis (waiting times and satisfaction) in the United Kingdom (UK). It involved three national surveys (one for parents of children with autism, one for autistic adults, and one for professionals involved in autism diagnosis) and in-depth qualitative research to probe further into perspectives and experiences on autism diagnosis. Three key findings highlighted the importance of securing a timely diagnosis.</p>		
1. Waiting times <p>Our research highlighted lengthy waits to obtain an autism diagnosis in the UK. Parents reported that they tended to wait around 3½ years before receiving an autism diagnosis for their child; a delay that was particularly pronounced for children who received a diagnosis of 'Asperger syndrome' who tended to wait over 4 years, compared to parents of children with a diagnosis of 'autism' who tended to wait 2½ to 3 years). This is probably due to the fact that the signs of autism are more subtle in these verbally and intellectually able children (Crane et al., 2016). Results from our adult sample also suggested lengthy waits to obtain a diagnosis, with an average delay of 2 years.</p>		
2. Satisfaction <p>More than half of the parents who responded to our survey (52%) were dissatisfied with the diagnostic process. This correlated with waiting times (with those experiencing longer delays reporting higher levels of dissatisfaction). Whilst dissatisfaction was slightly less pronounced in our sample of autistic adults (40%), this was linked to the time taken to receive a diagnosis. A</p>		

positive diagnostic experience has been linked to greater levels of acceptance, lower levels of stress, and more effective coping strategies. It is therefore imperative that steps are taken to improve satisfaction with the process of receiving a diagnosis by speeding up the process of diagnosis.

3. Post-diagnostic support

A key finding from our research with parents, adults, and professionals was that the support offered to autistic people and their families post-diagnosis was severely lacking. In particular, professionals identified four key areas in which post-diagnostic improvements were needed: (1) the availability of the support offered by diagnostic services; (2) the availability of long-term support that diagnostic services can direct service users to; (3) streamlining support services (rather than offering a range of disjointed services that do not liaise with each other); and (4) providing specialist provision for under-served groups (e.g., adults without learning disabilities, autistic women).

At the time of publication, the research was the only source of data highlighting the lengthy wait times to autism diagnosis and subsequent dissatisfaction of the service users.

3. References to the research

R1. Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L.A., & Hill, E.L. (2018). 'Autism diagnosis in the United Kingdom: Perspectives of autistic adults, parents and professionals' *Journal of Autism and Developmental Disorders*, 48(11), 3761-3772. doi: 10.1007/s10803-018-3639-1

R2. Crane, L., Chester, J., Goddard, L., Henry, L.A., & Hill, E.L. (2016). 'Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom' *Autism*, 20, 153-162. doi: 10.1177/1362361315573636 [Submitted to REF2]

R3. Jones, L., Goddard, L., Hill, E.L., Henry, L.A., & Crane, L. (2014). 'Experiences of receiving an autism spectrum disorder diagnosis: A survey of adults in the United Kingdom' *Journal of Autism and Developmental Disorders*, 44, 3033-3044. doi: 10.1007/s10803-014-2161-3

R4. Rogers, C., Goddard, L., Hill, E.L., Henry, L.A., & Crane, L. (2016). 'Experiences of diagnosing autism spectrum disorder: a survey of professionals in the United Kingdom' *Autism*, 20, 820-831. doi: 10.1177/1362361315611109

G1. The research was supported by a Small Grant from the British Academy, *Experiences of receiving and communicating a diagnosis of autism spectrum disorder* (£9973, May 2012-April 2014) awarded to Crane, Goddard, Henry, and Hill.

*All outputs available on request

4. Details of the impact

Our research has impacted on health policy and practice in the UK by raising awareness of autism diagnosis waiting times amongst campaign groups, parliamentarians and policy makers, UK health providers and the general public.

The attention that our research has garnered since 2014 benefits charities, who are able to campaign and lobby government efficiently, politicians who have a new understanding of the scale of the problem, health care providers and the NHS who are able to plan services accordingly and children and adults who are waiting for an autism diagnosis whose plight has become a strategic priority.

The NAS launch a campaign to reduce autism diagnosis waiting times in the UK

The NAS are the UK's leading charity for autistic people and their families. Prior to our research, while they were aware of issues surrounding autism diagnosis waiting times, they did not have

reliable data confirming the extent of the problem. We shared this information with them at two knowledge exchange events which we hosted at London South Bank (2012) and Goldsmiths (April 2014). Hill went on to have detailed discussions about our findings with Sarah Lambert, former Head of Policy and Public Affairs. The influence our research had on the NAS campaign strategy is confirmed by Carol Povey, Director of the Centre for Autism, NAS. (S1)

August 2015. Referring exclusively to our research as evidence of an issue around autism diagnosis waiting times that needed to be addressed, the NAS launched the Autism Diagnosis Crisis campaign. It linked directly to our *Diagnosis of Autism* website and highlighted the importance of accessing a timely autism diagnosis since 1 in 100 people are on the autistic spectrum – representing over 750,000 people in the UK alone. Over 12,000 people signed an open letter to the Health Secretary and the Chief Executive of NHS England in support. (S2)

Parliamentarians debate autism diagnosis waiting times

The publicity generated through the NAS campaign about our research on autism diagnosis waiting times was directly cited in two parliamentary debates. As a result, politicians decided to officially record autism diagnosis waiting times for the first time to assess the scale of the problem and establish culpability.

March 2016. Jo Cox MP led a Backbench Business Committee debate highlighting our research findings (of children waiting for 3.5 years and adults waiting 2 years for an autism diagnosis) and called for the Government, local authorities and NHS England to act. (S3)

Sept 2017. The issue of autism diagnosis waiting times was raised in Parliament again in a debate with 30 MPS in attendance. Our research findings were detailed in the briefing papers (House of Commons Library Debate Pack, Number CDP-2017-0158, *Waiting time standard for autism diagnosis*. 12 September 2017) and directly cited by Bambos Charalambous MP, Health Minister, who used it to expose the government's failure to collect adequate data;

"The delay is alarming, and I have had difficulty corroborating it with any Government data. That is because data on the length of time from referral to diagnosis of autism are not collected by NHS trusts or clinical commissioning groups, so there is no way of holding the NHS to account for that failing. [...] I have had numerous tweets and emails, as have colleagues, that support the findings of Dr Laura Crane's study and suggest that the delay in diagnosis is taking years, not months." (S4)

Jackie Doyle-Price MP went on to announce that autism diagnosis waiting times would be officially recorded from April 2018, stating that: *"It is our ambition for people to have a timely autism diagnosis but the cases that hon. Members have raised today to make it clear that the standards that families deserve and have a right to expect have not been met."* (S4)

The NAS describe the significance of this:

"[...] for the first time ever the NHS will start to measure the number of people diagnosed with autism in every area of England. This is a game-changing development. This data can play a vital role in making sure there are enough diagnosis services." (S2)

The NHS, Autistica and the UK Government make reducing autism diagnosis waiting times a priority

The Government established a Working Group at the Department of Health tasked with developing a plan about how data on waiting times could be recorded.

April 2018. The start of formal monitoring of waiting times to diagnosis by Local Authorities across England. (S5)

January 2019. The NHS publish its Long-Term Care Plan and refer directly to our research (R2) in justifying its priority to reduce waiting times for an autism diagnosis. The Report pledges that:

Over the next three years, autism diagnosis will be included alongside work with children and young people's mental health services to test and implement the most effective ways to reduce waiting times for specialist services. This will be a step towards achieving timely diagnostic assessments in line with best practice guidelines. (S6)

May 2019 Autistica, the leading autism research charity in the UK, who campaign and work with policymakers and services, published an action briefing on their Autism Strategy recommendations. They refer to our research (R3, R4) as some of the most important scientific findings of autism diagnosis practice. Accordingly, they highlight that one of their key strategic research priorities is to establish best practices in reducing wait times and delivering an autism diagnosis. (S7)

June 2019. The Government publishes the first draft of results from Local Authorities detailing the current status on 17,970 new referrals for diagnosis. In line with our research findings, a large majority of the 378 NHS MHSPs who were surveyed report waiting times well in excess of NICE guidelines of three months. (S9)

The data is used by policy makers to assess the progress of the Government's Autism strategy *Think Autism* (2014), which seeks to improve the lives of all people with autism.

November 2019. NHS Digital publishes full results of data collected. The information is published as part of the NHS Digital's Autism Statistics, "[...] developed to help achieve better outcomes for children and young people with autism". (S9)

5. Sources to corroborate the impact

S1. Influence of research on NAS campaign strategy: Ms Carol Povey, Director of the Centre for Autism, NAS (June 2020) [Written testimony]

S2. Details of the [National Autistic Society's Autism Diagnosis Crisis](#) campaign and key successes (Retrieved June 2020) [Campaign details]

S3. [Backbench Business Committee debate](#) where Jo Cox MP highlighted our research and the autism diagnosis crisis (March 2016) [Transcript]

S4. [Parliamentary briefing](#), autism diagnosis waiting times (September 2017) [Transcript]

S5. [Executive summary](#) reporting current data local authority responses to diagnostic waiting times (June 2019) [Report]

S6. Pledge to reduce waiting times in [NHS Long Term Plan](#). See Chapter 3.33, pages 52/53 and page 128 for reference to our paper (2019) [Report]

S7. [Autistica's campaign briefing](#) to establish best practice in reducing waiting times and delivering diagnosis of autism (May 2019) [Report]

S8. Government publish results of diagnosis waiting times for 2018. See Section 5 '[Diagnosis](#)' *Autism self-assessment exercise 2018: Executive Summary* (2018) [Report]

S9. NHS Digital publish results of diagnosis waiting times for April 2018-December 2018. See [NHS Digital Autism Statistics](#) website (November 2019) [Website]