**Institution:** Cardiff University

**Unit of Assessment:** Psychology, Psychiatry and Neuroscience (4)

**Title of case study:** Improving professional practice of autism using a coordinated set of diagnostic and awareness-raising tools

**Period when the underpinning research was undertaken:** 2013 - 2019

**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: |
|---|---|---|
| Susan Leekam | Professor | 01/04/2009-31/03/2019 |
| Catherine Jones | Senior Lecturer | 01/05/2013-present |
| Sarah Carrington | Post-doctoral researcher | 26/04/2010-24/07/2014 |
| Sarah Barrett | Post-doctoral researcher | 01/03/2017-14/08/2019 |

**Period when the claimed impact occurred:** 2013 - 2020

**Is this case study continued from a case study submitted in 2014?** No

**1. Summary of the impact** (indicative maximum 100 words)

Early referral for diagnosis of Autism Spectrum Disorder (ASD) maximises better outcomes for children; however, the varied and often subtle manifestations of ASD are difficult to recognise, both in community settings and by specialists. Cardiff researchers adapted a key ASD diagnostic tool (DISCO), generating new measures now used in clinical practice across Wales and by the National Autistic Society across the UK. The Cardiff team also created materials (*The Birthday Party* film; SIGNS posters) for use in community settings to raise awareness of ASD indicators in children. Aligned to the Welsh Government's ASD Strategic Action Plan, these materials were provided to all GPs and schools in Wales. *The Birthday Party* was additionally adopted into training for teachers, health professionals and psychiatrists in seventeen countries worldwide.

**2. Underpinning research** (indicative maximum 500 words)

Autism Spectrum Disorder (ASD) is defined as a lifelong neurodevelopmental disorder characterised by difficulties with social communication and the presence of restricted and repetitive behaviours. Prior to this REF period, in 1997, Leekam worked with Wing and Gould (founders of the National Autistic Society's Lorna Wing Centre for Autism) to test the reliability of a diagnostic interview for ASD which captured both obvious and more subtle manifestations of the autism spectrum: the Diagnostic Interview for Social and Communication Disorders (DISCO). Leekam joined Cardiff in 2009, where she founded the Wales Autism Research Centre (the first UK national autism research centre) in 2010 **[G3.1]** and undertook further diagnostic research work enhancing the utility of DISCO.

In 2013, the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) was updated to formally redefine autism as a spectrum condition for the first time. The Cardiff team was uniquely able to test whether this definition could be incorporated into the DISCO tool. Their research resulted in the following outcomes:

**2.1 The first diagnostic interview to use the DSM-5 classification system (DISCO DSM-5 algorithm)**

The Cardiff team used a set of DISCO interview items to create a new, robust and specific algorithm for DSM-5 diagnosis. A subset of the DISCO's 320 interview items was selected, weighted and combined. The method used detailed clinical consensus and receiver operating characteristic statistical analysis to correctly fit the DISCO items to diagnostic criteria. The broad range of items within the DISCO meant that it was possible to achieve a new algorithm for the DSM-5 criteria with high levels of sensitivity and specificity, while other similar diagnostic instruments could not. This made Cardiff's research the first algorithm for ASD able to capture the range of DSM-5 criteria within a single interview method, able to be used in

diagnostic assessments **[3.1]**. To date, DISCO DSM-5 remains one of only two interview algorithms produced internationally for DSM-5 ASD criteria in children and adolescents **[3.2]**.

**2.2 Shorter and more flexible diagnostic interviews using a sub-set of the original diagnostic interview items (DISCO Abbreviated)**

The full set of DSM-5 diagnostic algorithm items as described in Section 2.1 was designed to be used within the original long (320-item, 2-3 hour) interview. Many clinicians, and in particular the Welsh Government (that was launching a new national adult autism service) called for a shorter interview, streamlining clinical time available to support diagnostic assessments in Wales. At the time, brief diagnostic interview tools lacked sufficient sensitivity and specificity. Therefore, in 2014-15, the Cardiff team designed a novel, shorter DISCO interview, and created an abbreviated DSM-5 interview algorithm, which demonstrated the same high levels of specificity and sensitivity as before **[3.3]**. Known as the DISCO Abbreviated Interview, this allowed clinicians to carry out shorter diagnostic interviews while still being able to extract a robust (abbreviated) set of items aligned to DSM-5 diagnostic criteria to support a diagnosis **[3.4]**.

**2.3 A further, shorter subset of DISCO items that could be used to raise awareness of the condition in community settings (DISCO Signposting Set)**

In 2015, the team developed the Signposting Set of 14 DISCO interview items **[3.5]**, and in 2017-19 adapted these into a questionnaire **[3.6]**, both of which had good psychometric properties for distinguishing individuals with ASD. These brief tools were unique in providing a set of items statistically extracted from both the full DISCO and DISCO Abbreviated interviews (described in Section 2.1. and 2.2,). These 14 items were the most discriminating DISCO items for ASD according to the DSM-5 criteria. Due to their brevity, they are not stand-alone diagnostic tools; instead they provide a much-needed, and valuable tool for families, and for use in community settings, enabling identification of ASD behaviours signalling the need for more detailed clinical assessment.

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

**[3.1]** Kent, R.G., **Carrington, S.J.**, Le Couteur, A., Gould, J., Wing, L., Maljaars, J., Noens, I., Berckaleur-Onnes, I., & **Leekam, S.R.** (2013). Diagnosing Autism Spectrum Disorder: who will get a DSM-5 diagnosis? *Journal of Child Psychology and Psychiatry*, 54(11), 1242-1250. (10.1111/jcpp.1208).

**[3.2]** Evers, K; Maljaars, J; **Carrington, S.J.**; Carter, A.J. Happé, F., Steyaert, J., **Leekam, S.R.**, & Noens, I. (2020). How well are DSM-5 diagnostic criteria for ASD represented in standardized diagnostic instruments? *European Child & Adolescent Psychiatry* (2020) (10.1007/s00787-020-01481-z)

**[3.3] Carrington, S. J.**, Kent, R. G., Maljaars, J., Le Couteur, A., Gould, J., Wing, L., Noens, I., Van Berckelaer-Onnes, I. & **Leekam, S. R.** (2014). DSM-5 Autism Spectrum Disorder: In search of essential behaviours for diagnosis. *Research in Autism Spectrum Disorders*, 8(6), 701-715. (10.1016/j.rasd.2014.03.017)

**[3.4] Carrington, S.J.**, **Barrett, S.L.**, Sivagamasundari, U., Fretwell, C., Noens, I., Maljaars, J., & **Leekam, S.R.** (2019). Describing the profile of diagnostic features in autistic adults using an abbreviated version of the Diagnostic Interview for Social and Communication Disorders (DISCO-Abbreviated). *Journal of Autism and Developmental Disorders*, 49 (12), 1-11. (10.1007/s10803-019-04214-7)

**[3.5] Carrington, S.J.**, **Leekam, S.R.**, Kent, R.G., Maljaars, J., Gould, J., Wing, L., Le Couteur, A. & Van Berckelaer-Onnes, I. (2015). Signposting for diagnosis of Autism Spectrum Disorder using the Diagnostic Interview for Social and Communication Disorders (DISCO). *Research in Autism Spectrum Disorders*, 9, 45-52. (10.1016/j.rasd.2014.10.003)

**[3.6] Jones, C.R.G.**, **Barrett, S.L.**, Bite, I., Higgins, A., Honey, K., **Carrington, S.J.**, Hay, D., & **Leekam, S.R.** (2020). Development of the Signposting Questionnaire for Autism (SQ-A): measurement comparison with the ten item Autism spectrum quotient-child and the strengths

and difficulties questionnaire in the UK and Latvia. *Molecular Autism*, 11. (10.1186/S13229-020-00368-9)

**Selected grant:**

**[G3.1] Leekam, S.R.** (PI), Wales Centre of Autism Research. Autism Speaks (£260,000) 01/04/2009-31/03/2014 and Autism Cymru (£180,000), 01/04/2009-31/12/2014

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

The research outlined in Section 2 provided the catalyst for raising awareness of ASD indicators in routine educational and healthcare settings in England, and also in Wales aligned to the Welsh Government's ASD Strategic Action Plan. The impact of Cardiff's research was as follows:

1) use of more flexible interviews to enhance and speed up clinical diagnosis;

2) increased awareness of ASD indicators in children among a wider range of educational and health professionals (e.g., teachers, speech therapists, GPs, psychologists and adoption agency staff).

**4.1 Enhancing clinical diagnosis**

The National Autistic Society's Lorna Wing Centre, Kent, is one of the UK's leading providers of specialist diagnostic training for ASD, with diagnostic expertise and specialisms unavailable elsewhere in the UK. Since late 2013, the Lorna Wing Centre trained 643 clinical practitioners from across the world in the new DISCO DSM-5 algorithm, enhancing their ability to effectively diagnosis ASD **[3.1]**:

"*The DISCO DSM-5 algorithm… is issued to all our trainees…[who] are clinically qualified professionals such as psychologists, psychiatrists, speech and language therapists and paediatricians with a minimum of three years post qualification… and are from all over the UK and overseas (i.e., Japan, South Africa and Ireland)." "The DISCO DSM-5 algorithm enables clinicians to extract items from the DISCO interview in a systematic and streamlined way making it possible to run the diagnostic criteria for DSM-5 using items from the 2013 research findings* **[3.1]**" **[5.1** - NAS Lorna Wing Centre Business & Finance Manager**]**.

A further change in practice occurred in Wales when Cardiff's DISCO Abbreviated Interview **[3.3]** was adopted as part of the diagnostic pathway of the Welsh Government's ASD Strategic Action Plan. Between 2013-2014, all NHS Wales Health Boards delivered DISCO Abbreviated Interview training to the 45 specialist clinicians responsible for diagnosing adults with ASD in Wales, equipping them with the ability to conduct shorter diagnostic interviews using Cardiff's DISCO diagnostic tool **[5.2**, p49**]**.

For example, the Integrated Autism Service at the Aneurin Bevan University Health Board (ABUHB) provides diagnostic assessment for autistic adults. All members of their multidisciplinary diagnostic team have routinely utilised the DSM-5 algorithm **[3.1]** within the DISCO Abbreviated Interview **[3.3]** since 2015, along with other participating Health Boards in Wales. ABUHB receives approximately 350 referrals per year (2018-20), resulting in approximately 160 diagnoses of ASD **[5.3]**.

Sian Lewis, Service Manager for the Gwent Integrated Autism Service (within ABUHB) stated: *"During the interview the clinicians code the responses and use these codes within the DISCO DSM-5 algorithm. This enables a summary of the individual's profile of signs and symptoms. This information provides a key part of the assessment. The diagnostic decision is based on a consensus clinical judgement guided by the needs of the individual. The profile of DSM-5 DISCO algorithm score provides evidence that supports the diagnostic opinion and the recommendations for future support. Supplementary information is also available from the questionnaires we send out before the appointment – the Adult Signposting Questionnaire and the Repetitive Behaviour Questionnaire for Adults based upon the research of Prof Sue Leekam"* **[5.3]**.

**4.2 Increased awareness of ASD indicators among health and education professionals**

The Cardiff team worked with the Welsh Local Government Association (WLGA) to develop materials designed to raise awareness of ASD, aligned to requirements of the Welsh Government's 2016-20 Refreshed ASD Strategic Action Plan **[5.4]**. DISCO interview items **[3.4]** were mapped to the acronym SIGNS, providing an easier checklist able to be used by any parent or professional even without prior understanding of ASD. SIGNS included reference to: impaired **social** interaction and verbal communication; reduced **imagination**; limited **gestures** and non-verbal communication; a **narrow** range of interests, routines and repetitive behaviours; and unusual **sensory** responses **[5.5]**. The SIGNS system was subsequently adopted as part of the All Wales Neurodevelopment Diagnostic Assessment Pathway for children to aid appropriate referrals **[5.6]**.

The Cardiff team then created *The Birthday Party* (an 18-minute training film involving two boys and a girl, with each showing different examples aligned to the SIGNS indicators) **[5.7]**, and four SIGNS posters (covering a general overview; pre-school children; children and younger adolescents; older adolescents and adults) **[5.5]**.

From June 2017 to September 2020, *The Birthday Party* and SIGNS posters formed part of the WLGA's Learning About Autism Programme, a national scheme to raise awareness of autism in all schools in Wales **[5.8]**. All early years' settings, mainstream primary and secondary schools, and Further Education colleges in Wales had access to the resources in English and Welsh. For the first time, educational professionals were able to use a simple set of materials to help ascertain whether a child should be referred for diagnosis. By September 2018, 3,624 teachers had successfully completed the teacher Learning About Autism scheme, with 4,043 individuals completing the learning support assistant version. Both *The Birthday Party* and SIGNS also formed part of the WLGA's online Clinician's Toolkit (27K page impressions by July 2020), which provided key training resources for clinicians working with people with ASD from June 2017 until September 2020. By November 2018, over 4,700 SIGNS posters were distributed to relevant settings, including all GP surgeries in Wales **[5.8]**.

Sara Harvey and Wendy Thomas, WGLA National Autism Leads for Wales state that *the Birthday Party* and posters are a "*significant part of the resources we provide to professionals on our websites (www.AutistieathCymru.org and www.AutismWales.org). The National Autism Team are currently targeting those working in community and health settings. The Birthday Party offers an excellent and easily accessible way of showing the varied presentation of autism*" **[5.8]**. By April 2020, *The Birthday Party* had been viewed 72K times **[5.8]**.

The Cardiff team also received 149 written requests to use the film in training from clinicians, educators, health and care workers, students and families from 16 countries by July 2020 **[5.9]**. Feedback from these requests attests to the film's value in raising awareness and reducing stigma, for example:

- An evaluation of the impact the film had on 1,641 practitioners from the UK, Italy, Spain, Latvia and Lithuania reported: "*significant improvement in understanding the signs of autism" with most participants considering it "a useful tool for reducing stigma*" **[5.10]**. The (translated) video format *was* "*effective in improving understanding of autism signs, even in skilled professionals*" **[5.10]**.
- Following the use of the film as part of early years teacher training in Vietnam, the trainer commented: *"I particularly like the presentation of the girl and the way she carefully copies social behaviour. As girls are so often missed, I thought this was a real strength… [which] promoted quite a lot of discussion"* **[5.11a]**.
- An occupational therapist in Kenya reported that she has been able "*to refer girls to developmental paediatricians who I suspect to be on the spectrum"* and that the film made her *"more aware of the different presentations of Autism"*, helping her *"to differentiate more easily"* **[5.9]**.
- Finally, the Lithuanian Ministry of Education disseminated *The Birthday Party* throughout the country's educational and pedagogical psychology services,

emphasising that *"the film brings a different attitude and understanding to autism than the one we have often seen in Lithuania"* **[5.11b]**.

*The Birthday Party* now forms part of training within the UK and internationally, with some key examples as follows:

- teacher training in Italy, Australia, Spain, The Netherlands, Latvia, Lithuania and Vietnam **[5.9]**;
- inclusion in the Royal College of General Practitioners' ASD online toolkit **[5.12]**;
- specialist training by The National Autistic Society **[5.9]**;
- training for all Italian nursery and kindergarten teachers through the Istituto Superiore di Sanita (leading technical-scientific body of the Italian Health Service) **[5.9]**;
- the Autism Essentials for Psychiatrists training course e-resource developed by Cheshire and Wirral Partnership NHS Foundation Trust and the Centre for Autism Neurodevelopmental Disorders and Intellectual Disability, attended by 500 psychiatrists, who are not autism specialists **[5.9]**;
- Calon Cymru Fostering training **[5.9]**.

In summary, Cardiff's research resulted in a novel, shorter and more flexible interview tool now being used for clinical diagnosis of ASD by the specialist Lorna Wing Centre and across NHS Wales. Complementary resources (*The Birthday Party* and SIGNS) improved awareness of ASD indicators in schools and communities, via Wales's Learning with Autism Programme and extensive use by educators and autism specialists around the world.

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

**[5.1]** Testimonial from the Lorna Wing Centre, confirming use of DSM-5 algorithm

**[5.2]** *Outcome Evaluation of the Welsh Government Autism Spectrum Disorder Strategic Action Plan 2008-2014*. Published 2016. Section 6.5 (p.49)

**[5.3]** Testimonial from Sian Lewis, Service Manager, Gwent Integrated Autism Service, Aneurin Bevan University Health Board

**[5.4]** Welsh Government Refreshed ASD Strategic Action Plan 2016. Section 2.4 (p.9)

**[5.5]** SIGNS poster

**[5.6]** All Wales Neurodevelopment Diagnostic Assessment Pathway (Guidance document and footnote 9)

**[5.7]** *The Birthday Party* (Welsh Government website)

**[5.8]** Welsh Local Government Association testimonial and 'Over 3,000 primary school teachers successfully complete 'Learning with Autism' scheme' (WGLA press release)

**[5.9]** Spreadsheet summarising requests to use the film for training and feedback

**[5.10]** Impact report evaluating *The Birthday Party* in five European countries

**[5.11] a.** Testimonial from Phillipa Pettitt, Saigon Children's Charity teacher training course in Vietnam **b.** Testimonial from the Lithuanian Autism Association

**[5.12]** *The Birthday Party* (Royal College of GPs website)