Wales Autism Research Centre: April 2012-March 2013

It is 2013 and the Wales Autism Research Centre is thriving. In the last year there have been many highlights on the research front and in our policy and practice work.

On the research front, a major highlight has been the acceptance of our paper on the new DSM-5 criteria for Autism Spectrum Disorder in the Journal of Child Psychology and Psychiatry. The new DSM-5 criteria have raised concern and controversy that some individuals will miss out on a diagnosis. Our research paper will help to reassure people on this issue. This work was led by Dr Sarah Carrington and Rachel Kent and was an international collaboration including colleagues in the Netherlands, Belgium and Newcastle University, as well as the National Autistic Society.

On the policy and practice front, an award from the Economic and Social Research Council and the Welsh Government enabled us to start an exciting new project “Developing a Research-Policy-Practice Hub” in December 2012. The Hub will offer opportunities to network and exchange knowledge between the three communities of research, policy and practice and provide connections to individuals and families affected by autism. In addition to this project, we have also been working closely with the Welsh Government and NHS Clinical Network and colleagues at the National Autistic Society to develop diagnosis training materials.

In addition to many new initiatives, this year has also brought endings. We said goodbye and many thanks to Professor Dylan Jones, the Chair of the Advisory Group. Prof. Jones was pivotal to the creation of the Wales Autism Research Centre, and has given the Centre every possible support. Our Baily Thomas research project also ended this year and we bade farewell to Dr Jane Lidstone who took up a teaching appointment at Durham University at the end of last year. The project was linked to a PhD project from the Welsh Government, awarded to Mirko U ljarević, who came to Wales from Serbia to carry out this research. Not only did these joint studies bring exciting new research findings on repetitive behaviours, sensory features and anxiety in children with autism (see p. 9 of this report), they also helped to connect us to many families who gave their time to make the project a success. We would like to thank every single family who contributed to this study and hope they will stay in contact. This project also brought us the opportunity to develop a network of research and clinical collaboration that extended from NHS clinicians in Gwent and Cardiff to researchers in Newcastle, USA and Australia.

We are continuing to develop and expand in number. In addition to welcoming the team of four on the new Research-policy-practice project (Lynda Morgan, Louise White, Chris Ramsden, Katy Lake), we have also attracted many new students and interns from Cardiff University and beyond. We hope that they have enjoyed their training and experience at the Centre. We also send a warm welcome to Dr Catherine Jones and Dr Kate Langley who arrive this summer. Both carry out research in autism and related neurodevelopmental disorders and have been awarded lectureship appointments in the School of Psychology. Finally, we are delighted to welcome Prof. Edward Wilding, our new Head of School who is the new Chair of WARC Advisory group.

We look forward to many more new beginnings for 2013-2014!

Sue Leekam
Chair in Autism
Director of the Wales Autism Research Centre
Wales Autism Research Centre: April 2012 - March 2013

Wales Autism Research Centre Annual Report 2012-2013

The Wales Autism Research Centre (WARC) was officially launched in the School of Psychology, Cardiff University in Sept 2010. WARC is the UK’s first national research centre for autism, initiated through the unique collaboration of two charities, Autism Cymru and Autistica, working together with the School of Psychology, Cardiff University and the Welsh Government. This collaborative venture was supported by generous donations from six charities, Autism Initiatives, Waterloo Foundation, Baily Thomas Charitable Fund, Freemasons’ Grand Charity, Jane Hodge Foundation and Research Autism. The funding created two new appointments, Chair in Autism, (Prof. Susan Leekam) and postdoctoral researcher (Dr Sarah Carrington). In addition further funds were also gratefully received in 2011 from the Gwendoline and Margaret Davies Charity and the William and Christine Eynon Charity.

Mission

“Advancing scientific understanding of autism to create positive change”

We are achieving this mission in two ways. First by facilitating new scientific research of international standing and second by integrating scientific evidence with policy and practice.

A set of four objectives guide us in this mission. These objectives are;

1. to conduct internationally competitive scientific research projects
2. to facilitate interdisciplinary research and research networks
3. to develop research and training that supports and influences practice and policy
4. to improve public and professional awareness of research

The Annual Report 2012-2013 outlines the achievements of the Centre against these objectives. For each section of the report below, we show the activities as planned in our five year plan and the actual results this year in terms of activities completed from April 2012 to March 2013.
Wales Autism Research Centre Membership 2013-2013

Members of the Centre (foundation funding)

Director: Professor Sue Leekam

Postdoctoral Research Associate: Dr Sarah Carrington

Research Staff employed during April 2012 and March 2013 (external grant funding)

Dr Chris Ramsden
online Project Manager, ESRC Research Policy & Practice Hub

Lynda Morgan
co-offline Project Manager, ESRC Research Policy & Practice Hub

Dr Louise White
co-offline Project Manager, ESRC Research Policy & Practice Hub

Dr Jane Lidstone,
Research Associate,
Bally Thomas Charitable Fund

Katy Lake
Research Administrative Officer, ESRC Research Policy & Practice Hub

Beverley Winn
Parent Consultant and ESRC Research Assistant

PhD Students

Rachel Kent
funded by ESRC CASE Award
(Oct 2009 – Sep 2013)

Mirko Ulijarević
funded by WORD studentship
(Jan 10- Dec 2012)

Rhiannon Fyfield
second supervisor
Prof. Leekam
(Oct 10 – Sep 2014)

Alice Winstanley
second supervisor
Prof. Leekam
(Oct 08 – Sep 2012)
New students joining the team

Beverley Winn – PhD – Beverley started her PhD in Jan 2013. This project is investigating the link between adult symptoms of autism spectrum condition (ASC) and the quality of couple relationships and whether these links have implications for adult mental health and well-being.

Sarah Barratt – MSc (Oct 2012 - Sept 2013) - Sarah’s project is investigating the relationship between imagination and repetitive behaviours in adults with ASD. Previous research has found evidence of an inverse relationship between repetitive behaviour and pretend play in children with ASD. Sarah is studying whether this relationship persists in adulthood.

Student research assistants

Laura Fasoli, Research Assistant, Baily Thomas Project (Dec 2011-June 2012)

Lilya Dankova, Research Assistant, Baily Thomas Project (May 2012-Sep 2012)

Matthew Price, Summer Internship, funded by School of Psychology (Jun 2012-Aug 2012)

Abbie Williams, part-time Research Assistant, funded by Ashgrove School (Sep 2012-Dec 2012)
Staff members joining in 2013

Dr Catherine Jones joins us in May – New Lecturer:

Dr Jones is a newly appointed lecturer within the School of Psychology joining us from the University of Essex. Catherine spent six years working as a post-doctoral researcher on the Special Needs and Autism Project (SNAP). Catherine’s other projects include an investigation of the sensitivity of individuals with autism to emotional stimuli, and the use of eye-tracking technology to explore how people with autism look at faces. Her future work will expand on these studies of face and emotion processing, as well as explore sensory processing difficulties in autism.

Dr Kate Langley, Cardiff University School of Medicine:- New Lecturer

Dr Langley is a newly appointed lecturer within the School of Psychology, with a background in Developmental and Abnormal Psychology Research description. Her interests lie in investigating the aetiology and developmental course of Neurodevelopmental disorders, specifically ADHD, Conduct Disorder and co-occurring disorders such as Autism Spectrum Disorders. Kate is especially interested in how the clinical presentation and course of disorder are influenced by genetic and environmental factors.

Advisory Committee

Prof. Edward Wilding (Head of School of Psychology, Cardiff University)
Mr. Hugh Morgan, OBE (Chief Executive Officer, Autism Cymru)
Dr Simon Wallace (Director of Research, Autistica)
Mrs. Julie Annetts (Adult Social Services Policy) Welsh Government
Prof. Sue Leekam (Chair of Autism Research, Cardiff University)
Prof. Margot Prior (External Advisor) University of Melbourne, Senior international scientist and Chair of Advisory Board for Olga Tennison Research Centre, Australia

Thank you to Professor Dylan Jones for inspiring and supporting the work of the Wales Autism Research Centre. 17th July 2012.
Objective 1: Conducting internationally competitive scientific research projects

The Centre’s mission relies on the production of innovative, high quality research grant awards, publications in top-quality scientific journals and dissemination of results at international conferences and national meetings.

Priority areas for research projects include (a) Identification (b) Diagnosis (c) Developmental processes (d) Intervention. Details of these projects can be found on our website www.walesautismresearchcentre.com/

Planned activities
- New grants applied for and success in funding applications
- Publication in high quality scientific journals
- International conference presentations and invited talks
- Databases and measures developed

Several new grants have started during this year, and our research findings have been published in 10 peer reviewed academic publications in print or in press for between April 2012 & March 2013. Members of the team have presented their work at both national and international conferences this year, including the International Meeting for Autism Research, Toronto.
Grants

**New grants starting April 2012-March 2013**


- Cardiff University PhD Studentship. REACH project: Research Exploring Autism Spectrum Condition Couple relationship satisfaction, Health & wellbeing. PI: Winn, B (PhD student); supervisors: Dr Katherine Shelton & Professor Susan Leekam. £60,000 Jan 2013-Jan-2018.


- Strategic Insight Partnership Grant. Funding to work with Dr Judith Gould in meetings with Cardiff University and the Welsh Government. £2,000. July 2012.


**Ongoing grants**


- SENSE Scotland. Joint attention in deaf-blind children. PI. Dr M. Nunez, Glasgow Caledonian. Collaborators, Dr F Franco, Middlesex University, Prof S. Leekam, Cardiff University. Sept 2011-Sept 2013.


- ESRC. CASE Award Using the Diagnostic Interview for Social and Communication Disorders (DISCO) for research. PI; Prof. Leekam in partnership with NAS. £64,000. Start date: Oct 09 (4 yrs). (PhD student Rachel Kent).
Grants completed

Other grants applied for
- Wellcome Trust/NISCHR. Physiological and psychological mechanisms of restricted and repetitive behaviours in children with ASD. Nov 23 2012 (unsuccessful).
- BBSRC Case Studentship Application: Development and validation of a mobile software application for monitoring infant health and development. Gattis M (first Supervisor) Leekam S.R. (second supervisor), Cardiff University, Lead Department, School of Psychology. Submitted July 2012 (unsuccessful).
The Children’s and Parent’s Behaviour Study

Funded by: The Baily Thomas Charitable Fund and the Wales Office for Research and Development in Health and Social Care

Prof. Leekam, Dr Jane Lidstone and Mirko Uljarević worked with a team of clinicians from Cardiff (Dr Ruth Paradice and Julie Mullis) and Newport (Anne-Marie McKigney and Hilary Kanaris) on a project that researched the link between repetitive, restricted behaviours, anxiety and sensory difficulties in children with autism. This research formed part of a wider research programme of national and international research collaboration on repetitive behaviours and anxiety including Newcastle University (Prof. McConachie, Prof. Le Couteur, Prof. Freeston, Dr Rodgers, and Dr Honey), Bucknell University, USA (Prof. Evans) and Melbourne University, Australia (Prof. Prior).

Sixty families took part in this project. Parents completed questionnaires about their children’s development and about their own stress and well-being. We found that anxiety was common in children. It affected 49% of the children and it was strongly related to one subtype of behaviour; restricted behaviours that include routine and sameness. We found that this relation between anxiety and restricted behaviours was linked to particular types of sensory reactions such as sensory avoidance and lesser extent, sensitivity. The other subtype of repetitive behaviour - repetitive motor movements such as hand-flapping and spinning was not related to anxiety. However these types of behaviour were related to sensation-seeking and sensation-avoiding. These results indicate that repetitive behaviours may serve to regulate the amount of sensory input a child receives.

Anxiety was also common in the parents in this study and nearly a half of parents showed high levels of anxiety. This is a finding we would like to follow up with further research.

We hope that these findings will be helpful for professionals when they plan parent support programs and design interventions for children that aim to target anxiety, sensory responsiveness and repetitive behaviours.

The Wales Autism Research Centre team with clinical project collaborators (back row, from left to right: Dr Jane Lidstone, Prof. Sue Leekam, Mirko Uljarević; front row, left to right: Anne-Marie McKigney, Hilary Kanaris, Julie Mullis, Dr Ruth Paradice).
Publications

Publications in print


Publications in press


Publications submitted and under peer review

Publications in preparation


International conference presentations and invited talks


Some of the team’s presentations at the International Meeting for Autism Research in Toronto, May 2012.
National conference presentations and other external presentations:


Internal academic presentations


- Uljarević, M. Sensory problems, anxiety and repetitive behaviours in children with ASD. School of Psychology seminar, 29th June 2012.

- Kent, R.G. Adapting the DISCO to meet changes in current International diagnostic criteria (DSM-5). School of Psychology seminar, 22nd June 2012.

Databases and measures developed

- Prof. Sue Leekam, Rachel Kent and Dr Sarah Carrington have led a team of international researchers in the development of new diagnostic algorithms for use with the Diagnostic Interview for Social and Communication Disorders (DISCO). The first of these is an algorithm for the draft DSM-5 diagnostic guidelines due to be published in May 2013. The second is a set of abbreviated DISCO interviews for referral and to guide diagnosis in a more clinically feasible time-frame.

- Dr Mirko Uljarević, Dr Louise White and the WARC team developed a Research Awares booklet - A family-friendly leaflet providing information to help parents of children with ASD in choosing an intervention for their child. July 2012.

- The Research Register is now set up and we are adding the details of people who would like to hear about up-coming research projects (for more information, please contact warc@cardiff.ac.uk).

- ASD Database. Dr Dawn Wimpory and Prof Susan Leekam developed a pilot for a national ASD database. The database provided an enhancement of the Community Child Health Database already used in the NHS, to enable ASD diagnosis to be recorded. The ASD database pilot was run in Betsi Caldwald University Health Board as a trial. From Jan-June 2012, it recorded 1000 cases of ASD. The longer term value and potential expansion of the ASD data is currently being evaluated in an independent evaluation by the Welsh Government.
Objective 2. Facilitating interdisciplinary research and research networks

A second priority of the Wales Autism Research Centre is to promote collaborative research involving researchers from different disciplines. Collaborative research allows us to share knowledge and expertise across many different subject areas, and is therefore essential when working with a condition as complex as Autism Spectrum Disorder. During this year, we have established a new research network with members of Brunel University (see below). We have also led an international team of researchers and clinicians investigating the diagnosis of Autism Spectrum Disorder using the Diagnostic Interview for Social and Communication Disorders, and strengthened teams working within the Neuroscience and Mental Health Research Institute in Cardiff University.

Research network meetings

- ‘Looking forward’ meeting, Cardiff University, hosted by the Wales Autism Research Centre. Attended by Dr Simon Wallace & Olivia Curno (Austistica), Hugh Morgan (Autism Cymru), Sarah Shenow (The Waterloo Foundation), Julie Annetts & Alyson Collins (The Welsh Government), Sue Murphy (Autism Initiatives), & Andrew Wells (ESRC). Jan 21st 2013.

- British Autism Study of Infant Siblings Annual Scientific Meeting, London. Attended by Prof. S. Leekam, Dr J. Lidstone, Ms. A. Winstanley, Ms. K. Ellis-Davies. 19th Sept 2012.

- Bristol Autism Research Group. Attended by Prof. S. Leekam, Dr J. Lidstone, Dr S. Carrington, Ms. R. Kent, Dr M. Ulijarević. 18th Sept 2012.

- Skype meeting with members of the International Advisory group supporting the Baily Thomas and Welsh Office for Research and Development Project. Attended by Prof. Sue Leekam, Dr Jane Lidstone, Dr Mirko Ulijarević, Prof. David Evans, Bucknell University (USA), Prof. Margot Prior, Melbourne University (Australia), Dr Jacqui Rodgers, Newcastle University and Prof Helen McConachie, Newcastle University (UK). 26th July 2012.

- Inaugural meeting with international DISCO research team. Presentations given by Prof. S. Leekam, Ms. R. Kent and Dr S. Carrington. Attended by researchers from the UK, Belgium, the Netherlands, Japan, and Canada (by Skype) and Japan 19th June 2012.

- Skype meetings with Prof Leekam and Hong Kong collaborators, Prof Brendan Weekes and Dr Linda Iao. Jan 2013. As part of new research project “Word imageability and N400 in individuals with ASD” Sponsored by Hong Kong University, Dec 2012-Dec 2013.

- Bi-monthly meeting of interdisciplinary researchers working on the Autism Speaks Trailblazer project “Tuning Anxiety Out” 2012-2013.
Invited academic visitors


- Prof. David Evans, Bucknell University, USA. Research visit 23rd to 27th July 2012. Collaboration with Dr Jane Lidstone and Dr Mirko Uljarević as part of the Baily Thomas project. Invited seminar presented for the School of Psychology: Repetitive behaviour in the context of typical development: Genes, brains, and behaviour. 27th July 2012.

- Prof. Teresa McCormack, Queens University, Belfast. Seminar delivered for Developmental Psychology Research Group: Children’s understanding of time and causality. 26th Apr 2012.

Wales Autism Research Centre Lab Group meetings

Fortnightly lab group meetings bring all core and associate members of the Wales Autism Research Centre together to discuss recent developments and on-going work within the team as well as new publications within the field of autism. The team includes people working on a wide range of projects including developmental psychology, diagnosis, intervention studies, and studies exploring the neurobiology and genetics of ASD. This wide range of interests allows for an interesting exchange of ideas and helps ensure that the team’s work develops from a broad research context. The lab group meetings are organised by Dr Mirko Uljarević and Miss Rachel Kent.
New collaborative networks
● Collaboration with Dr Mark Atherton (Brunel University), Sue Osborn (Kingwood Trust) and Hilary Gilfoy exploring noise cancellation and sound sensitivity. Funded by an Autism Speaks Trailblazers Award.

● International team of researchers working with the Diagnostic Instrument for Social and Communication Disorders

Autism Speaks Trailblazer Grant – Tuning anxiety out: noise cancellation project
May 2012- May 2013:
Prof. Leekam, Dr David McGonigle, Rachel Kent and Dr Mirko Uljarević are working with engineer Dr Mark Atherton and his colleagues at Brunel University, with Sue Osborn and her team at Kingwood Trust, and with Hilary Gilfoy, on a project funded by the international charity Autism Speaks. The project evaluates the effectiveness of a state-of-the-art noise cancellation system. Adults with an ASD are asked to rate sounds that they hear through headphones with and without the device. This noise cancellation system selectively attenuates sounds that are found challenging in order to reduce anxiety and discomfort caused by auditory hypersensitivity in ASD. Difficulties in processing sensory stimuli such as sight, touch, taste, smell and particularly hearing are a common but poorly understood aspect of autism, affecting up to 90% of those with a diagnosis of an ASD. Whatever the cause, sensory difficulties can seriously impact quality of life, making simple everyday experiences such as a visit to a supermarket or a normal day at school fraught with difficulty. Typically those most affected are forced to wear ear protectors when outside their home. If successful the project opens the way to a technological intervention that will greatly enhance quality of life for those with autism by addressing what many find a key disabling feature.

Collaborators on all 2012-2013 grants and funding sources
● Dr Dawn Wimpory, Bangor University, (Welsh Government and ESRC)
● Dr David McGonigle, Cardiff University (Waterloo Foundation and Autism Speaks)
● Sue Osborn, Kingwood (Autism Speaks)
● Prof. Margot Prior, University of Melbourne (Baily Thomas Charitable Fund)
● Prof. David Evans, (Baily Thomas Charitable Fund)
● Prof. Helen McConachie, Prof Mark Freeston, Prof. Ann Le Couteur, Dr. Jacqui Rodgers, Newcastle University (Baily Thomas Charitable Fund, NIHR funding)
● Maggie Bowen and Lynn Plimley, Autism Cymru (Waterloo Foundation)
● Dr. Judith Gould and Dr. Lorna Wing, National Autistic Society and Prof. Ann Le Couteur, Newcastle University (ESRC)
● Mr Hugh Morgan, Autism Cymru, Mr Jonathan Morgan, Insight Wales Consultancy (ESRC and the Welsh Government)
● Mrs Hilary Kanaris, Aneurin Bevan NHS (Baily Thomas Charitable Fund)
● Mrs Anne Marie McKigney, Aneurin Bevan NHS (Baily Thomas Charitable Fund)
● Mrs Julie Mullis, Cardiff and Vale NHS (Baily Thomas Charitable Fund)
● Dr Ruth Paradise, Cardiff and Vale NHS (Baily Thomas Charitable Fund)
● Dr Marianne Van den Bree, Prof. Michael Owen, Prof. Anita Thapar, Dr Joanne Doherty, Prof. Stephanie van Goozen, Prof. Derek Jones, Cardiff University (Wellcome Trust)
Objective 3. Developing research and training that supports and influences practice and policy

The Wales Autism Research Centre aims to develop research and training to support and influence practice and government policy. This explicit goal is unique amongst autism research centres and is one that we have advanced significantly during this year primarily through work funded by the ESRC. Our ESRC Knowledge Exchange grant, ending September 2012, enabled us to develop materials to increase research awareness amongst professionals and parents. Building on this work, new ESRC funding was obtained to develop a Research-Policy-Practice Hub. This project began in December 2012 and has brought three new members of staff to the centre. In another project, our team is leading new work in the development of clinical tools that will be used for both child and adult diagnosis, and have conducted some preliminary training for researchers in the use of these tools.

Meetings and exchanges with third sector and educational organisations, practitioners, charities, and the Welsh Government

- Presentation by Dr C. Ramsden, Mrs. L. Morgan and Prof. S. Leekam with Jonathan Morgan and Hugh Morgan. Seminar to Welsh Government hosted by Mark Drakeford (Minister for Health). 12th Mar 2013.

- Meeting with Deepa Korea, Chief Executive Research Autism to discuss WARC’s current and future projects. Attended by Prof. S. Leekam, Dr C. Ramsden, Dr L. White, Dr M. Ulijarević, Mrs L. Morgan and Mrs B. Winn. 5th Mar 2013.


- Meeting with Mrs Sarah Shenow (The Waterloo Foundation). Attended by Prof. S. Leekam and Dr L. White. 20th Feb 2013.

Meetings and exchanges with third sector and educational organisations, practitioners, charities, and the Welsh Government

Meeting with Autism Alliance. Attended by Prof. S. Leekam, Dr C. Ramsden, Dr L. White, Mrs L. Morgan, Ms. K. Lake. 15th Jan 2013.

Meeting with the Autism Support Team, Mynachdy Centre, Cardiff to discuss implementation of the Wales Autism Intervention Survey and research findings on anxiety and coping in parents of children with Autism Spectrum Disorders. 12th Sept 2012. Attended by Dr M. Uljarević. 12th Sept 2012.

Baily Thomas and WORD project– Prof. S. Leekam, Dr J. Lidstone, Dr M. Uljarević, Bi-monthly meetings with clinicians Hilary Kanaris, Anne Marie McKigney, Julie Mullis, Dr Ruth Paradise. 12th Sept 2012.

Meeting with clinicians in Newport to discuss implementation of abbreviated DISCO within clinical practice in Wales. Attended by Prof. S. Leekam, Ms. R. Kent, and Dr S. Carrington. 20th Aug 2012.

Welsh Government members David Clayton (WG Dept leading Social Services legislation) and Alyson Collins (WG Adults Social Services) visited the Wales Autism Research Centre. They were given a tour of Cardiff University Brain Research Imaging Centre and attended poster presentations by the team. 24th July 2012.

Monthly meetings of the ASD All Wales Clinical Network for Adult Diagnosis attended by Prof. S. Leekam. 2012-2013.

Events attended
- NAS Professionals Conference. Attended by Dr Carrington and Miss Kent. 3rd -4th Mar 2013.
- The NAS Cardiff and Vale Support Group Workshop by Chris Alders, Educational Psychologist. Attended by parent consultant, Mrs. B. Winn. 24th May 2012.

Training
- Introduction training session to Ashgrove School Occupational Therapists in the use of the Vineland Adaptive Behaviour Scales delivered by Prof. S. Leekam and Dr. Uljarević. 30th January 2013.
- Administration of the Brief DISCO interview for researchers delivered by Prof. S. Leekam, Dr S. Carrington & Miss R. Kent. November 2012.

Undergraduate Applied student training experience
- Three undergraduate final year project students in progress. 2012-2013.
- Eight-week internship for final-year undergraduate student (Mr. M. Price) following completion of exams. July-August 2012.
- Cardiff University Research Opportunities Programme student (Ms. L. Dankova). May-September 2012.
- Three undergraduate project students successfully completed (2011-2012).
James Tucker  
Supervisor: Dr S. Carrington  
Inhibitory control and autistic traits in a typical population

Catherine Walters  
Supervisor: Prof. S. Leekam  
Anxiety, sensory features and autistic traits

Naomi Warne  
Supervisor: Dr S. Carrington  
Schizotypal and autistic traits in a typical population

Continuing professional development

- Leading and Managing Teams (course delivered by Cardiff University and accredited by the Institute of Leadership and Management) – Dr Lidstone and Dr Carrington passed written and oral assessments in July 2012 and Nov 2012.

- Diagnostic Interview for Social and Communication Disorders (DISCO) training – qualification achieved by Miss Kent.

The Diagnostic Interview for Social and Communication Disorders (DISCO)
The DISCO is a semi-structured clinical interview carried out with a parent or caregiver. The aim of the interview is to assist a clinician when making a diagnosis of ASD and provide recommendations according to an individual’s needs. Clinicians and researchers from around the world have been trained to work with the DISCO and it has been translated into several languages, including Swedish and Japanese. Prof. Sue Leekam, Dr Sarah Carrington, and Rachel Kent are part of an international team of researchers working with the DISCO. The Wales Autism Research Centre has led two new strands of research involving the DISCO. The first is to update the DISCO so that it can be used to assist in the diagnosis of ASD according to the new international classification systems due to be introduced later this year (DSM-5).

The second strand of work with the DISCO is the development of an adaptation of the DISCO that may help to guide practice for simple, more straightforward cases, allowing for referral and more detailed assessment where the diagnosis is less clear. These tools will be implemented in clinical practice throughout Wales and the Cardiff team are engaged in the development of training materials and courses for clinicians. This work has been partially supported by the Welsh Government and the tools under development will be integrated within clinical practice throughout Wales.
Objective 4. Improving public and professional awareness of research.

A priority for the Wales Autism Research Centre is to raise awareness of autism and to ensure that the content and purpose of work is clear and accessible to the public. We feel it is important to promote research awareness to help improve understanding of how research works and why it is needed. To achieve this aim, we held a series of ‘Researcher on the Road’ events as part of our ESRC Knowledge Exchange Grant, which gave us the opportunity to hear first-hand from parents what they thought of research. A clear message from parents was that they wanted more communication of research in non-scientific language. As a direct result of this feedback, we applied for and were awarded a community engagement grant from Cardiff University to further develop the content of our website to include more accessible information about what we are doing. We have also developed a series of materials for professionals, parents, and individuals with autism to make our work more accessible and to raise awareness.

The team have continued to give talks to parent and interest groups in the autism community, including stakeholder and social groups, and the National Autistic Society Professional’s conference. We also continue to host visitors to the centre and this year have met with members of staff from Ashgrove School as well as representatives from charities and the police. We have increased our use of social networking sites, with over 476 likes on our Facebook page and an active twitter account.
Materials and procedures developed to promote the Wales Autism Research Centre to the public, professional groups and media.

For Professional groups:
- A ‘Research Toolkit’: A booklet and set of guidelines about research methods for professionals involved with interventions for ASD. Developed in partnership with Sarah Shenow, Waterloo Foundation and Gina Gomez, National Autistic Society.
- AWARES Talk: An online forum developed in partnership with Autism Cymru to enable researchers and professionals to discuss issues pertaining to ASD.

For Participants and parents
- New family-friendly content for Wales Autism Research Centre web pages developed as a direct result of the ESRC funded ‘Researcher on the Road’ events.
- Research Awares Booklet on interventions: A family-friendly leaflet providing information to help parents of children with ASD in choosing an intervention for their child.
- A Research Awares Bookmark to complement the Interventions booklet. The bookmark has abbreviated information about choosing an intervention.
- The Wales Autism Research Centre Brain Imaging Volunteer DVD: A short film following a participant as they participate in a brain imaging study. A tool developed to introduce the imaging experience to help families decide whether they would like to take part in brain imaging research.
- A model of the ‘headcoil’ from a MRI machine to allow potential participants to familiarise themselves with it in a safe environment.
- Annual Wales Autism Research Centre Newsletter.
- Facebook and Twitter used to increase awareness of the research activities and public engagement by the Wales Autism Research Centre 476 users.

Provide events targeting public and professional awareness of autism scientific research in autism and monitor outcomes
- Meeting with intervention study participants to share findings from completed project: ‘Developing targeted intervention for repetitive behaviours and anxiety in children with Autism Spectrum Disorder’ (Baily Thomas Charitable Fund). Hosted by Prof. S. Leekam and Dr J. Lidstone. 21st Sept 2012.
- Cardiff and the Vale of Glamorgan NAS Branch event, co-hosted by the Wales Autism Research Centre. Keynote speaker Dr Wendy Lawson. 17th September 2012.
- Integrating research and practice in autism spectrum disorders. Presentation by Dr L. White to disseminate the outcome from the ESRC Knowledge Exchange Grant. Cardiff & the Vale NAS Branch Event 17th Sept 2012.
- Children’s and parents’ behaviour study. Presentation by Dr J. Lidstone and Dr M. Ulijarević to disseminate the outcome of work supported by the Baily Thomas Charitable Fund. Cardiff & the Vale NAS Branch Event 17th Sept 2012.
- Linking brain to behaviour in autism spectrum disorder: the neurobiology of sensory symptoms. Presentation by Dr D. McGonigle to disseminate the outcome from work supported by The Waterloo Foundation. Cardiff & the Vale NAS Branch Event 17th Sept 2012.
- Researchers on the Road, Merthyr Tydfil – Tydfil Autism Support Group NAS Bridgend Parent Support group. Organised by Dr White, Dr Carrington, Mrs Winn and Mrs Morgan. Hosted by Dr L. White and Mrs B. Winn. 19th June 2012
Non-academic visitors to the Wales Autism Research Centre

- Ashgrove School Visit – Occupational Therapists and teaching staff visited the Centre. Hosted by Prof. Leekam and Dr Ulijaric. 30th Jan 2013.

- Meeting with members of the Belarussian Orphanage Project to discuss autism research and clinical strategy. Organised by Dr Mirko Ulijaric and co-hosted by Anne Marie McKigney. 18th Oct 2012.

- Ashgrove School visit – Teachers, senior staff and management visited the Centre. Presentations given by the whole team. 2nd Aug 2012.

- Snap Cymru - Angie Contestabile. 6th July 2012.

- Police Constable Kristian Harris, Policing Family Co-ordinator South Wales Police Force. 4th July 2012.

- Go Compare – CEO Mr Lee Griffin and Miss Lynsey Walden (PR). 21st June 2012.

Consultancy and Professional Engagements

Other consultancy and professional engagements (Prof. Leekam)

- PhD internal examining – School of Psychology, Cardiff University. 4th Feb 2013.

- PhD external examining – Goldsmiths College, University of London. 7th Jan 2013.

- PhD internal examining – School of Psychology, Cardiff University. 22nd Nov 2012.

- PhD external examining – Institute of Education, University of London. 2nd Nov 2012.

- Member of Board of Trustees for Autism Cymru Trustees.

- Member of Scientific Board of the British Autism Siblings Study (BASIS) UK network.

- Member of the management board of the Learning Disability and Autism Research Network (LDAN).

- Member of the Award Committee for the BPS Neil O’Connor Award.
- Member of Editorial Board for the journal 'Autism'.

- Grant reviewing for Medical Research Council, British Academy, Canadian Government.


**Other consultancy and professional engagements (Research Associates and Postgraduates)**

- Dr Carrington: Member of the Cardiff University Neuroscience and Mental Health Research Institute public engagement committee.

- Dr Carrington and Dr Lidstone: Member of the School Psychology Board, Cardiff University.

- Miss Kent: Member of the committee “Speaking of Science” for postgraduates at Cardiff University.


Autistica has launched a One in a Hundred report, featuring the findings of their consultation with over 1,000 people with autism and their families. You can download a copy of their report at
