Wales Autism Research Centre: Five Year Priorities 2014-2019

Mission

“Advancing scientific understanding of autism to create positive change”

The mission of the Wales Autism Research Centre is to advance scientific understanding to create positive change and better outcomes for individuals and families affected by autism. Our progress in achieving this mission in the last five years has been driven by a unique collaborative endeavour between scientists, practitioners, policy makers and people living with autism. Our aim for the next five years is to build on the success of our research innovation, impact, and partnerships and to take the work of the centre forward in new directions.

Key developments planned:

- New developments in research on sensory and perceptual responsiveness as part of a research theme on biological and cognitive processes;
- An innovative programme of research on families;
- Research on the development of autism symptoms in children who also have ADHD, typical development and disruptive behaviour problems;
- A coordinated clinical and research network for ASD in Wales in collaboration with the Neuroscience and Mental Health Research Network;
- A family and schools network in collaboration with charities and special schools;
- Development of interventions to aid attention, memory and sensory processing;
- Support for services through professional training, assessment and advice to families and individuals.

Background: The last 5 years:

In our five year plan in 2009, we predicted that “By 2015, the Centre’s mission will have begun to be realised. The integrated and interdisciplinary research conducted by the Centre will be starting to advance understanding of factors that affect the onset and outcome of autism symptoms in childhood and adulthood. It is expected that the Centre will have an excellent international reputation for its research in psychological and biomedical research in autism and related conditions, with a developing reputation as a training centre for PhD and postdoctoral scientists as well as for its translational work in policy and practice. It therefore should provide a model of excellence for research centres in other countries.”

The achievements and research findings of the last 5 years are summarised in the Appendix.
Five year Plan: 2014-2019

Research Themes and Objectives 2014-2019

Research Themes
Three themes have been selected to form the main focus areas for the work of the centre. These themes will consolidate the Wales Autism Research Centre’s growing reputation and expertise in these areas. The themes are:

(i) Behaviour and diagnosis
(ii) Biological and cognitive processes
(iii) Families and relationships.

Within each theme, new basic science research and applied work will bring a change of direction to WARC. A distinctive new priority will be to extend new knowledge into other neurodevelopmental and mental health conditions.

Objectives

The overall objectives and planned activities for the work of the centre are as follows.

Objective 1. To conduct internationally competitive scientific research projects and facilitate collaborative research networks

Planned activities: 2014-2019

- Success in funding applications;
- Publication in high quality journals;
- International conference presentations and invited talks;
- Databases and measures developed;
- WARC seminars;
- Joint activities and meetings with the Neuroscience and Mental Health Research Institute;
- Contributing to the development of research and training networks in Wales, UK and internationally.

Objective 2. To develop research and training for practice and policy and improve professional and public awareness of research

Planned activities 2014-2019

- Evidence and reports to Welsh Assembly Government on diagnostic services;
- Meetings or university exchanges with Welsh Government Members, government staff and practitioners;
- Measurable outcome/impact of research on policy and practice;
- Professional and undergraduate student training;
- Development of materials to promote the Centre and our research to the public, professional groups and media;
- Events targeting public and professional awareness of autism scientific research in autism;

We outline below the research projects and activities that the team would like to see prioritised over the next five years. Three themed areas of research activity have been identified that represent the experience and scientific reputation of the team. Each theme is subdivided into the two main objectives above.

The final themes and measurable objectives in the WARC strategy plan will drive research activity and impact across the next five years. However, this current draft plan is provisional, to be informed by advice from stakeholders and colleagues. We anticipate that the framework for these themes will offer sufficient flexibility for expansion as new appointments are made in WARC. The themes have also been selected to intersect with other programmes of work and to be response to strategic calls by funders. For example, we are currently involved in preparing with Prof Dale Hay (PI), an MRC programme grant on the development of children’s imagination that would intersect with the themes of behaviour and diagnosis and biological and cognitive processes. We have also been invited to join an 8-site EME MRC application for a RCT led by the Institute of Psychiatry that would build capacity in these same themes.

This is a particularly important time to build plans for the future of neurodevelopmental disorders research in Cardiff ASD where expertise is strong and growing. The timing is perfect to align our future work with the new work going forward for CUBRIC-2 and plans for the Neuroscience and Mental Health Research Institute.

**Theme 1: Behaviour and diagnosis**

Theme leaders: Dr Kate Langley, Dr Sarah Carrington

Kate Langley, Sarah Carrington and Sue Leekam carry out research on the behavioural patterns in autism. This work has provided new findings that are informing the area of diagnosis in ASD and other neurodevelopmental conditions. Kate Langley’s research brings a distinctive new direction by examining traits for ASD directly in comparison with those from ADHD and learning difficulties and in the context of genetic findings. Sarah Carrington’s work on detailed and abbreviated diagnostic measurement is having an impact on clinical work on diagnosis and has relevance for neuroimaging of ASD symptoms.

**Objective 1: Scientific research projects and collaborative research networks**

Our aim over the next five years would be to prioritise projects that enhance the detection and understanding of specific, behavioural, genetic and neurobiological problems seen in ASD. We would aim to take forward our current work investigating genetic variants (CNVs)
as predictors of ASD symptomatology. We would also aim to investigate developmental and neurobiological factors in the emergence of ASD traits in ADHD, OCD, schizotypy and learning difficulties and to carry out in-depth analysis of heterogeneous clinical traits to clarify widespread effects of alteration in white matter microstructure.

Alongside these projects we will build a coordinated research and clinical network for ASD in Wales in collaboration with the Neuroscience and Mental Health Research Network. A school and family network in collaboration with charities and other universities will also support this work (see Theme 2 and 3).

**Objective 2. Research and training for practice and policy and improve professional and public awareness of research**

Our goal is to optimise the use of diagnostic tools in research and in clinical practice. Members of WARC have developed diagnostic assessment tools for the DISCO and we will carry out research to examine the effectiveness of not only the DISCO but also different methods of gathering clinical information. We will examine the value of applying a set of brief, essential diagnostic items in research settings, in diagnostic services and schools. We will also find out under which circumstances it is important to assess more complex individual profiles through clinical interview tools.

We will also build on our existing contribution to training and services within the Welsh Government’s All Wales ASD Diagnostic and Pre and Post Diagnostic Counselling Network for Adults. The Welsh Government revision of ASD Action Plan 2014-2019 includes a commitment to data collection and to continuation of the ASD Adult Network and importantly a new Child Diagnosis network. We aim for our new work to extend the previous training models to which we have contributed. We also aim to utilize the ASD module of Child Health Database and to introduce innovative developments for the assessment of ASD symptoms behaviours by teachers in schools.

**Theme 2: Biological and Cognitive Processes**

Theme leaders: Dr Catherine Jones and Dr David McGonigle

Research by Catherine Jones, Dave McGonigle and Sue Leekam, has helped to identify sensory problems as possibly one of the most important symptoms affecting individuals with ASD. Research by Dave McGonigle and Catherine Jones has identified ways that an individual’s atypical sensory and perceptual responses can interfere with ongoing processing of the environment, showing how relatively basic perceptual processing mechanisms impact on cognition and behaviour. Research by Dave McGonigle has shown how atypical sensory responses (hypo- or hyper-sensitivity) have a neurobiological basis affecting adaptation. Our group has also helped to pinpoint the relation between atypical sensory responses, anxiety and repetitive behaviour, and identified first evidence of elevated sensory symptoms in parents. We are also developing new research to establish the process by which restrictedness in behaviour and thinking affects the development of imagination.
Objective 1: Scientific research projects and collaborative research networks

In the next five years Catherine Jones and colleagues at WARC will take research on biological and cognitive processes in a new direction by targeting the role of timing processes in perceptual and sensory processing, and also in social communication and emotion. The research recognises that temporal processing, both perceiving time and the production of time-sensitive responses, are fundamental to human interaction. To be ‘out of synch’ and experience temporal disconnect is likely to have a fundamental impact on cognition and behaviour. The planned work will include projects that focus on how timing difficulties impact the coordination of social communication, how temporal discrimination affects sensory processing and how timing-based memory problems might be helped by developing a new intervention technique.

David McGonigle’s work is based upon the proposal that sensory symptoms offer a non-invasive mechanism to investigate the disorder’s underlying neurobiology. A critical part of this proposal is that ASD is the end result of a number of separate developmental pathologies that target fundamental aspects of synaptic physiology – for example, some affecting membrane receptor subunits, gephyrons, interneuron density, etc. In the next five years research projects in this area will prioritise the use of psychophysical tasks to link behaviours to specific neural mechanisms and aim to identify sensory deficits as causal factors during early development. Future planned work would include: building up a sensory database of sensory deficits in ASD; investigating the involvement of C-Afferents in social touch in ASD; evaluating learning-based theories of ASD from a neuroplasticity perspective; and continuing our work in neuroimaging and neurostimulation focused on both measuring GABA in ASD (MRS) and potentially modulating it (tDCS).

Research by Sue Leekam and her colleagues was among the first to identify difficulties in visual social attention. More recently we have identified the capacity for attentional learning in non-social attention tasks. We are now developing interventions using eye tracking technology to improve attention control. In the next five years we will aim to identify particular visual and cognitive characteristics that are associated with training benefits and uncover the underlying learning and reward mechanisms that create change. An interdisciplinary research network has been set up within current grant-funded work and will be expanded by this new work.

Objective 2. Research and training for practice and policy and improve professional and public awareness of research

Building on our good relations with special and mainstream schools in South Wales, we will create a Schools’ Network, collaborating with specialists in schools to advise and train on cognitive assessment methods, and sensory assessment tools. The goal will be to embed research into practice. This will lead to innovative data collection plans and intervention designs and to the increase of evidence based professional practice approaches. We will also work in similar ways with adult diagnostic and support services and with Autism Cymru to build research-practice networks and initiatives.
**Families and relationships**

Theme leader: Dr Katherine Shelton

A new direction will be brought to existing research at WARC by the work of Dr Katherine Shelton. The projects under this new theme will develop gradually over the five years. The work will adopt a systems perspective as a theoretical framework to consider the complexity of family life, drawing from the field of developmental psychopathology. The main focus will be on the mechanisms that explain the links between child and parent risk factors and parent mental health in the context of ASD.

**Objective 1: Scientific research projects and collaborative research networks**

Some of the new work under this theme will explore how child symptoms interact with parent anxiety, depression and physical health problems. At the level of the family system, the question is how family processes operate among families where a child and/or parents themselves have symptoms of ASD. Child symptoms of ASD and associated behaviour problems may exert an additive effect with poor family functioning adding to children’s anxiety and depression or such risk factors may best be conceptualised as multiplicative. Another question is whether relationship quality with other family members acts to buffer any negative effect of ASD child symptoms on parent mental health.

New research will also highlight how having a parent with ASD can influence outcomes for the child and the interaction between genetic and environmental factors. There might be particular time points when family contribution plays an important role, for example in the transition from adolescence to adulthood, with genetic and environmental factors linked to resilience in the transition. New research is also underway to study relationship satisfaction between adults when at least one in the couple has ASD.

**Objective 2. Research and training for practice and policy and improve professional and public awareness of research**

This is a new research area and the first goal will be to develop research-led approaches to support and advice to families. Working with our established contacts who already work with us at WARC as staff and student members, we would aim to develop a family network to give support on relationship issues in families. This would involve collaborating closely with existing services and local support organisations such as the National Autistic Society and with Autistica’s ASD-UK research database, and Research Autism. We will be informed by Welsh Government’s planned work on parent support as part of the revised ASD strategic action plan to be published at the end of this year.
Appendix

Objectives and planned activities achieved in the last 5 years

Objectives

New research council grants applied for and obtained in last 5 years

- ESRC. CASE Award Using the Diagnostic Interview for Social and Communication Disorders (DISCO) for research. PI: Leekam, S.R. in partnership with NAS, £64,000. Oct 2009-Dec 2013

Success in funding applications (non research council)

- 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. PI: *Leekam*, £2,000. July 2012.
- Autism Speaks Trailblazers Award. *Tuning anxiety out: Exploring the potential of noise cancellation in Autism Spectrum Disorder sound sensitivity*. PI: Dr Mark Atherton, Brunel University; Co-I *Prof. Leekam, Dr McConigle*, Sue Osborn (Kingwood Trust). £100,000. May 2012-June 2013.

**Publication in high quality journals**

*Under review:*
Published or in Press:


**International conference presentations and invited talks**


• Uljarević, M., Carrington S.J., Tucker, J., Evans, D., & Leekam, S. Anxiety, Temperament and Autistic Traits in the General Population. Talk given at the Anxiety pre-meeting, the International Meeting for Autism Research, San Sebastian, May 2013.
• Leekam, S. & Barratt, S. Imagining the worst. Talk given at the Anxiety pre-meeting, the International Meeting for Autism Research, San Sebastian, May 2013.
• Nešić, V., Nešić, M., Kostić, J., Uljarević, M., Ćičević, M. (September 2011). The Neurobiology of Empathy. VII International Conference of Applied Psychology in Nish with the Focus on the Psychology of Communication


• Invited Lectures by **Professor Leekam.** Division of Speech and Hearing Sciences, Hong Kong University, 7-9 March 2011 (Title 1) Specificity and social cognitive impairment in autism (Title 2) Understanding autism as a spectrum: Research using The Diagnostic Interview for Social and Communication Disorders (DISCO).


• Invited Keynote Lecture by **Professor Leekam.** Olga Tennison Research Centre, La Trobe University Australia. Feb 24 2011: Title: Understanding autism as a spectrum: Research using The Diagnostic Interview for Social and Communication Disorders (DISCO).


• **Leekam, S.** Invited Keynote Lecture: Conference of the Danish Association of Special Schools and Treatments Centres for Children with Autism, Skive, Denmark, November 2010


**National conference presentations and other external presentations:**


• **McGonigle, D.** Confessions of a Neuroscientist with a Methods Problem: Neuroimaging, Touch, and Beyond. Reading University, 13th Mar, 2014.
- Leekam, S.R. Specificity and social cognitive impairment in autism. Cambridge University. 22nd Zangwill Talk. Cambridge University, 22nd Feb 2013,
• **Leekam, S.R.** (2012). Invited department seminar at the Institute of Neuroscience, Newcastle University – 8th March, 2012


• **Lidstone, J.** (2011), Private speech and inner speech of children with specific language impairment.


• **Leekam, S.R.** Invited seminar. *Attention in autism*. York University, Nov 2009


• Leekam, S.R. Invited talk: The development of repetitive behaviours UC Davis Mind Institute, Sacramento, April 2009.

Internal academic presentations

• Jones, C. Timing in clinical populations. School of Psychology. 28th Mar, 2014.
• Ujlarević, 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

• Training materials for the DISCO Abbreviated. Prof Sue Leekam, Dr Mirko Ujlarevic, Dr Sarah Carrington, in collaboration with Dr Judith Gould and Mrs Carole Murray. Recording and editing of clinical interviews using the DISCO Abbreviated for training of clinicians throughout Wales.
• Manual for the DISCO Abbreviated. Dr Sarah Carrington.
• Algorithms for the Diagnostic Interview for Social Communication Disorders. Rachel Kent, Dr Sarah Carrington, Prof. Sue Leekam and an international team of researchers and clinicians.
• Development of an Autism Spectrum Disorder database within Betsi Cadwaladr University Health Board. Dr Dawn Wimpory, Bangor University (Co-I: Prof Leekam WARC). Database to develop the use of NHS data (Phase 1 development complete).
• The Wales Autism Research Centre Recruitment Register. Dr. Sarah Carrington, Wales Autism Research Centre. Register for recruitment of potential research participants (Phase 1 development complete).
• Research Awares booklet. Dr Mirko Ujlarević, Dr Louise White and the WARC team. Developed a family-friendly leaflet providing information to help parents of children with ASD in choosing an intervention for their child. July 2012.
• *The adult version of the RBQ-2.* Sarah Barrett and Prof. Sue Leekam.
• *Translation of Wales Autism Research Questionnaires (RBQ-2) into Dutch, French, and Serbian.*

**Objective 2: Facilitating interdisciplinary research and research networks**

The development of Cardiff Autism Research Group seminars and visits to the Centre by international research visitors

**Academic Workshops delivered**

• Early Intervention for young children with ASD. One-day Conference held at Bangor University organized by Professor S Leekam, Dr D. Wimpory and Dr S. Carrington. Speakers- Dr Dawn Wimpory, Dr Catherine Aldred, Prof. Sally Rogers, and Prof. Jonathan Green. 20th June, 2011.
• Restricted and repetitive behaviours. Workshop for child development professionals (ESRC grant-funded). University of Durham. 30 November 2009
• Autism and Neuroscience: Multidisciplinary meeting hosted by Cardiff Neuroscience Centre and funded by Waterloo Foundation. Cardiff University. 22nd January 2010.
• Restricted and Repetitive Behaviours Research Workshop attended by collaborators from throughout the UK. 24th September, 2010,
• Autism, Attention and Eye movements Workshop. 1st July, 2010.

**Invited seminar speakers (Cardiff Autism Research Group)**

• Dr Emma Gowen, University of Manchester, 26th Mar, 2014.
• Dr Rachael Bedford, Institute of Psychiatry, Kings College London, 10-11th Dec, 2013.
• Dr Sue Fletcher Watson, University of Edinburgh, 10th Dec, 2013.
• Dr Maria Nunez, Glasgow Caledonian University, 12th December, 2012.
• Prof. David Evans, Brucknell University, USA, 27th July, 2012.
• Prof. Teresa McCormack, Queens University, Belfast, 26th April, 2012.
• Dr Wendy Keay-Bright, Cardiff School of Art and Design, 28th March 2012.
• Prof. Sir Michael Rutter, Institute of Psychiatry, King’s College, London, 24th Nov, 2011.
• Dr Kristelle Hudry OTARC, La Trobe University, Australia, 6th July, 2011.
• Dr Tony Atkinson, Senior Lecturer, Durham University, 6th June, 2011.
• Dr Liz Pellicano, Senior Lecturer, Institute of Education, University of London, 26th May, 2011.
• Dr Elizabeth Hill, Reader, Goldsmiths, University of London, 3rd February, 2011.
• Prof Vasu Reddy, Portsmouth University 28th October 2010.
• Dr. Josephine Barbaro, La Trobe University, Melbourne, Australia. 8th October 2010.
• Dr. Christine Falter, The University of Oxford, 12th August 2010.
• Dr Maria Nunez, Glasgow Caledonian University, June 2010.
• Prof. Chris Jarrold, Bristol University, 29th April 2010.

**Other academic visitors to the Cardiff Autism Research Group**

• Dr Sami Basha, Director of the Special Education Program and Centre Palestine Ahliya University college, April 2014.
• Prof. Tokio Uchiyama & Dr Yota Uno, Yokohama Psycho-Developmental Clinic, 28th-29th Jan, 2014.
• Monique Post consultant on the Dutch Government’s ‘Looking from Within Autism’ project
• Dr Anneli Kylliainen, University of Tampere, Finland. 21st June, 2013
• Dr Margot Prior, University of Melbourne: External Advisor for WARC, Visit 31 May - 6th June 2013
• Dr Maria Nunez. Glasgow Caledonian University. Research visit Oct-Dec 2012.
• Dr Maria Nunez, Glasgow Caledonian University – 12th December, 2011
• Dr. Christine Ecker, the Institute of Psychiatry;, 24th January, 2011.
• Prof. Vasu Reddy, Portsmouth University: one month sabbatical hosted by the School of Psychology and the Wales Autism Research Centre, Oct-Nov, 2010.
• Prof. Margot Prior, University of Melbourne: External Advisor for WARC, Visit 20-25 Sept 2010

Joint activities with Cardiff Neuroscience Society / Neuroscience and Mental Health Research Institute.

• Prof. Anthony Bailey. The neuroscience of Autism. CNC Seminar. 4th May, 2010
• Autism Research Open Day Conference: Sensory Challenges in Autism. 25th June, 2010, Cardiff University, School of Psychology.
• Neuroscience Café - Understanding Autism: The Science and Experience of Sensory Symptoms. 7th June, 2011.

Contributing to the development of collaborative research and training networks in Wales, UK and internationally.

• Prof. Sue Leekam, Dr Katherine Shelton, Prof. Dale Hay, Dr Sofia Gameiro, Dr Catherine Jones, Dr David McGonigle, Prof. Cheryl Dissanayake (La Trobe University), Prof. Ilse Noens (Catholic University of Leuven), Hugh Morgan (Autism Cymru), Simon Wallace (Autistica), Carole Povey (NAS), Richard Mills (Research Autism). Research collaboration focusing on the Autism Research Parent Partnership.
• Dr Mirko Ułjarević, Prof. David Evans (Bucknell University, USA), Dr Sarah Carrington: data collection using a newly modified adult version of the Childhood Routines Inventory.
• Dr Mirko Ułjarević, Dr Anneli Kylliäinen (Tampere University, Finland), Dr Sarah Carrington: planned research collaboration to investigate motivational approach-avoidance tendencies toward another person’s gaze in children with autism and children with social anxiety, building on Dr Kylliäinen’s previous findings.
• Prof. Sue Leekam, Dr Sarah Carrington, Mrs. Anne Marie McKigney & Dr Alka Ahuja (Aneurin Bevan Health Board): research collaboration to investigate DISCO Abbreviated algorithms in clinical practice.
• Dr Catherine Jones, Dr Ali Roula (University of South Wales): Research collaboration to develop a digital technique for analysing verbal and non-verbal social communication in ASD.
• Dr Catherine Jones, Dr David McGonigle, Dr Alexandros Kontogeorgakopoulos (Cardiff Metropolitan University): Research collaboration to investigate auditory and tactile processing in ASD, and their association with sensory behaviours.
• 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
• Training and research network for the Autism Diagnostic Observation Schedule and Diagnostic Interview for Social and Communication Disorders
• Neuropsychiatry and Mental Health Research Institute: Dr. Carrington and Prof. Leekam –Dr. Van Den Bree, and Prof. Owen (Department of Psychological Medicine and Genetics), and Prof Derek Jones (CUBRIC).
• Wales CRC Network: Learning Disability, Autism and Neurodevelopmental Disorders Network (LDAN) (Prof Leekam on Management Committee)
• Scientific Board of British Autism Siblings Study UK Network (Prof Leekam)
• International research networking: Meetings by Prof Leekam with researchers in Psychology, Linguistics, Psychiatry at La Trobe University and Melbourne University, Australia and researchers Speech and Hearing Sciences, Psychology and Psychiatry at Hong Kong University, Feb 10-March 10 2011.
• Celtic Nations Autism Partnership membership

**Contribution to planning for international conference (2011) organised by Autism Cymru**

Prof. Sally Rogers workshop and presentation at Autism Cymru conference – Invited speaker part funded by WARC ESRC funding 21st & 22nd June, 2011. Prof Leekam chaired the second day of the conference. The Wales Autism Research Centre hosted a stand at the conference for both days. WARC members gave volunteer support throughout the conference.

**Collaborators on 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)
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. Uljarević. 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 Uljarević, 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” Dec 2012-Dec 2013.
- Bi-monthly meeting of interdisciplinary researchers working on the Autism Speaks Trailblazer project “Tuning Anxiety Out” 2012-2013.

Objective 3: Developing research and training that supports and influences practice and policy

Policy and practice related events and presentations

The Autism Research Policy Practice (RPP) Hub has been invited to partner on three international initiatives;
(1) Canada: The Autism RPP hub is a community partner to a global initiative on early identification and intervention: http://globalearlyautism.com/.
(2) Australia: The Autism RPP Hub team have been invited to advise on the development of an ASD Knowledge Hub for the Olga Tennison Autism Research Centre in Australia.
(3) UK/Global: Prof Leekam was invited to be part of the International Society for Autism Research (INSAR) initiative to host global open-access research tools. This invitation was a direct result of the RPP initiative to deliver free resources on diagnostic tools on the hub for the online seminar series.

Evidence and reports to Welsh Assembly Government on diagnostic and intervention services

- Advisory Support 2011-2012: Prof Leekam is on Steering Committee for National ASD Clinical Network (Adults). Subgroup for training. Prof Leekam, Dr Carrington and Ms Kent are providing research evidence on which new abbreviated methods of diagnosis will be based.
- Report: The circumstances and support needs of older people with autism: Proposals for future directions: Proposals submitted by Prof Leekam, Feb 2011, following invitation by Minister in

- Proposals submitted by Prof Leekam, Feb 2011, following invitation by Minister in response to Welsh Assembly Government Report on the circumstances and support needs of older people with autism.
- Report: *Children’s diagnostic services in Wales: Methods of diagnostic practice and clinicians views of service effectiveness*. Dr J. Lidstone: Dr D. Wimpory, Dr. C. Ramsden, Mr. H. Morgan, Ms. J. Manikiza, Ms M. Walters, Ms. M. Rendell. Prof S. Leekam. Submitted Dec 2010
- Advisory support: Following invitation from Minister Mrs Edwina Hart: Prof. Leekam – Meeting with parent group in Sketty, Swansea. Accompanied by Dr Richard Roberts, Head Vaccine Preventable Disease Programme, Public Health Wales and Dr Mike Simmons, Director of Health Protection, Public Health Wales, 27th May, 2010

**Meetings or university exchanges with Welsh Assembly Members, government staff and practitioners**

- Rachel Kent PhD student completed three month ESRC internship with the Welsh Government Oct-Dec 2011
- Hugh Morgan and Jonathan Morgan will spend one day per month at the Wales Autism Research Centre as part of a new ESRC award to develop a “Research-policy-practice hub” 2012-2013
- Open Afternoon for the Deputy Minister for Social Services Gwenda Thomas, and our funders and collaborators. Jan 2011.

**Meetings attended**

- Monthly meetings of the ASD All Wales Clinical Network for Adult Diagnosis attended by Prof. S. Leekam. 2012-2013.
- 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.
- Official launch of the Welsh Assembly Government’s bilingual autism information booklets.
- Prof Leekam: Oral report (older people with ASD) to the WAG meeting on adults (13th Aug 2010)
- Adults with Autism Conference, organised by the Welsh Assembly Government, Autism Cymru, and the Welsh Local Government Association, 10th-11th June, 2010. Attended by Jane Lidstone,
- Launch of Deis Cyfle, The Senydd, Cardiff Bay, 10 May, 2010. Supporting speech from Prof Leekam

**Wales Autism Research Centre talks presented to Welsh Assembly Government audiences**

- **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.
- **Carrington, S.J., Research in the Laboratory: Brain imaging Studies of ASD.** Presentation at ASD leads meeting, Llandrindod Wells 11th March, 2011.
- Open Afternoon for the Deputy Minister, Gwenda Thomas, Deputy Minister, Social Services, our funders and collaborators. Presentations given by Prof. Sue Leekam (WARC), Dr. Dawn Wimpory (Bangor University), Lynn Plimley (Autism Cymru), Dr. Mirko Uljarević (WARC), Nicky Hall (parent), Rachel Kent (WARC), Dr. Jane Lidstone (WARC), Mrs Hilary Kanaris (NHS), Dr. Sarah Carrington (WARC), and Dr. David McGonigle (Cardiff University).
- Launch of the Wales Autism Research Centre and Inaugural Lecture Believing is seeing: A vision for autism. Prof Leekam, 23rd Sept 2010. Introduction by Edwina Hart, Minister of Health and Social Services. Presentations by Lord Dafydd Wigley, Mr. Hugh Morgan, Mrs Hilary Gilfoy (Autistica), Professor Bill Fraser (Autism Cymru).

Meetings and exchanges with third sector and educational organisations, practitioners, charities
- Alliance for Useful Evidence ‘What Works Wales’. A joint seminar held in Cardiff, in partnership with Wales Public Services 2025. Attended by Dr Louise White and Mrs Lynda Morgan 17th May, 2013
- Meeting with Dr Maria Nunez to discuss the SENSE project. Prof. Sue Leekam. London. 25th Aug, 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. Uljarević, 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.
- 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 September 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.
- 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: materials for use by non-academics (e.g. in education services) and student training in practice and policy.

- 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.
- Research Aware Leaflet - A family-friendly leaflet providing information to help parents of children with ASD in choosing an intervention for their child. Developed by Dr Mirko Uljarević, Dr Louise White and the WARC team, July 2012.
- Research Toolkit – A resource for the non-academic professional sector on how to recognise good and poor evidence for interventions (June 2012)

Clinical training delivered

- Carrington, S.J. DISCO algorithms. Training on a clinical DISCO course for experienced NHS clinicians. The Lorna Wing Centre, Bromley. 6th Feb, 2014.

Improved measurable outcome/impact of research on policy and practice

- The Adult ASD strategy has adopted the DISCO in clinical practice. This will include the DSM-5 and abbreviated algorithms developed by the Wales Autism Research Centre and their collaborators.
- 120 researchers and practitioners have joined the on-line forum AWARES-TALK developed as part of our ESRC Knowledge Exchange Grant
- 122 clinicians registered for a talk presented by Prof. Leekam about the Diagnostic Instrument for Social and Communication Disorders
- 18 parent group leaders, representing parent organisations across Wales have attended our Researcher on the Road events.

Undergraduate Applied student training experience

- Four undergraduate project students supervised 2013-2014
- Two summer student placements, Katherine Fillingham and Alessandra Roberts. Funding awarded by the School of Psychology Research Internship scheme, May 2013.
- Three undergraduate project students supervised 2012-2013
• Summer Student Internship, Matthew Price, funded by Cardiff University School of Psychology. June-August 2012.
• Cardiff University Research Opportunities Programme student (Ms. L. Dankova). May-September 2012.
• Three undergraduate project students supervised 2011-2012
• ESRC Internship with WAG. Oct-Dec 2011. PhD student Rachel Kent
• Summer student placement, Donna Harris, funded by Cardiff University Research Opportunities Programme. July-August 2011.
• Cardiff University Professional Placement student – Hollies School and ASD Strategy. Katy Morris. Year end May 2010
• The Autism RPP Hub featured within a university course designed by Dr Mark Brosnan, University of Bath in Feb 2014. Third Year Psychology undergraduates visited the Autism RPP Hub and complete a coursework exercise involving a search for resources and information from the hub.
• Presentation on autism research policy and practice by Prof. Sue Leekam to Educational Psychology Doctoral Training Course, June 2013

Undergraduate autism teaching
• Leekam, S.R. The Development of Autism Spectrum Disorder. Lecture for the final year undergraduate psychology module ‘Developmental Psychopathology and Criminality’.
• Carrington, S.J. ASD and the Brain. Lecture for the final year undergraduate psychology module ‘Developmental Psychopathology and Criminality’.
• Leekam, S.R & Carrington S.J. DSM-5 debate and diagnosing DSM-5 ASD. Workshop for the final year undergraduate psychology module ‘Developmental Psychopathology and Criminality’.
• Jones, C.R.G Social communication difficulties in autism spectrum disorder. Lecture for the second year Developmental Psychology module.
• Jones, C.R.G Differences in perception in autism spectrum disorder. Lecture for the second year Developmental Psychology module.
• Jones, C.R.G Social understanding in the context of developmental disorders. Lecture for the second year Developmental Psychology module.
• Leekam, S.R. Social cognition and developmental disorders: Repetitive behaviours and executive function. Practical course in the second year Developmental Psychology module.
• Carrington, S.J. Social cognition and developmental disorders: Social understanding and repetitive behaviours. Practical course in the second year Developmental Psychology module.

Postgraduate Student success
• Cooper, M. Autistic traits in attention deficit hyperactivity disorder: clinical significance and biological underpinnings. PhD thesis successfully defended, 5th Feb, 2014.
• Barrett, S.L. MSc dissertation. What is the nature of restricted and repetitive behaviours in autism spectrum disorders? Submitted as part of MSc Social Science Research Methods (Psychology), Awarded Distinction, 2013, and received commendation for the highest marks of the master’s year.
• Thompson, S. External training on the Autism Diagnostic Observation Schedule 2. Dec 2013.
• Iao, L-S. Children’s understanding of false representations. Feb, 2011.
Objective 4: Improving public and professional awareness of research.

Develop materials to promote the Centre and our research to the public, professional groups and media.

For Professional groups:

- A ‘Research Toolkit’: Part one. A booklet and set of guidelines about research methods developed in partnership with Sarah Shenow, Waterloo Foundation and Gina Gomez, National Autistic Society, for professionals involved with interventions for ASD.
- Research Aware booklet included in the post diagnostic pack for Aneurin Bevan Health Board (Mrs Anne Marie McKigney and Dr Alka Ahuja).

For participants and parents:

- Our website is http://www.cardiff.ac.uk/psych/home2/warac. The webpages are regularly updated and include a dedicated ‘downloads’ page, where documents such as our Research Aware Leaflet and Annual Reports can be downloaded.
- 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.
- Up to date postings and photos are given weekly on our Facebook page (http://www.facebook.com/#!/pages/Wales-Autism-Research-Centre-WARC/103033943068748) which can be accessed by non-facebook members. Our Facebook page now has 605 fans. We are now also on Twitter and have 434 followers.
- Online forum for researchers and professionals http://awares.org/talk.
- Revision of the recruitment protocol for the Research Recruitment Register (RRR), which is WARC’s database of individuals interested in engaging in research at WARC. The revision has simplified the recruitment process, making the RRR more accessible.
- Annual Wales Autism Research Centre Newsletter.
- 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.
- Research Awareness-raising leaflet developed 2012
- Promotional leaflets have been developed providing a general introduction to the Wales Autism Research Centre
- ‘The Wales Autism Research Centre and Brain Imaging’. A family-friendly booklet developed by Dr Carrington as part of our ESRC knowledge Exchange Grant. The booklet describes what to expect if visiting the brain imaging centre to help out with a study.
- ‘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 scanner to allow potential participants to familiarise themselves with it in a safe environment.
- 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.
Use the latest bibliographic linking tools and search engine facilities to maximise impact of publications

All WARC members’ publications are linked to search tools Researcher ID and Scopus. This ensures that any search for name, topic, keywords, accesses the full title of all scientific publications and their impact (times cited).

Provide events targeting public and professional awareness of autism scientific research in autism

- A joint dissemination event was held by the Wales Autism Research Centre, Research Autism and the Institutes of Psychiatry and Education, London “A Future Made Together” and “Autism RPP Hub on 3rd April 2014.
- Members from the centre participated in the Cardiff University Brain Games event at the National Museum, Cardiff, 16th March, 2014
- Cardiff and the Vale NAS Branch event and dissemination of research findings. Keynote speaker Dr Wendy Lawson. Co-hosted by the Wales Autism Research Centre and Cardiff and the Vale NAS, Cardiff University, 17th September, 2012. 
  5 Researcher on the Road trips to all parts of Wales to engage with the leaders of parent groups (2011-2012)
- Familiarisation procedure for families considering involvement in brain imaging research involving visits to WARC to meet staff
- Cardiff and the Vale NAS Branch event. Keynote speaker Dr John Clements, introductions by Prof. Sue Leekam, Dr Louise White, and Dr Sarah Carrington. Co-hosted by the Wales Autism Research Centre and Cardiff and the Vale NAS, Cardiff University, 21st September, 2011.
- Open Door week 2011 for families to visit the Centre
- Sensory Challenges Conference for families and professionals 2010

Wales Autism Research Centre talks presented to schools, colleges, and parent audiences

Selection only

- Winn, B. Interviewed by Radio Cardiff about her role as the WARC parent consultant and her PhD project. 7th June, 2013.
- Winn, B. interviewed by Radio Cardiff about her role as the WARC parent consultant and her PhD project. 7th June, 2013.
- Barrett, S.L. presented at the Autism Awareness evening as part of Mind Your Head week at Cardiff University. 7th Oct, 2013.
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. 17th Sept 2012.

Children’s and parents’ behaviour study. Presentation by Dr J. Lidstone and Dr M. Uljarević to disseminate the outcome of work supported by the Baily Thomas Charitable Fund. 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 of work supported by The Waterloo Foundation. 17th Sept 2012.

Researchers on the Road, Bangor, Carmarthen, Cardiff, Merthyr Tydfil and Wrexham – 2012. Organised by Dr White, Dr Carrington, Mrs Winn, and Mrs Morgan.

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

Presentation to Carmarthenshire Stakeholder Group, Pontyates. ‘Overview of the Wales Autism Research Centre’. Dr Sarah Carrington and Dr Louise White – 4th Nov, 2011

Cardiff and the Vale NAS Parent Group Conference, hosted by the Wales Autism Research Centre. Introductions given by Prof. Leekam, Dr White, and Dr Carrington – 21st September, 2011.

Dr Carrington and Dr White informal presentation about the Wales Autism Research Centre for the Asperger social group in Pontypridd – 16th June, 2011.

Ashgrove School Fun Day attended by Dr Lidstone and Dr Uljarević – 11th June, 2011

Prof. Leekam speaks at Three Counties Forum Meeting, Carmarthen – 8th June, 2011

Prof. Leekam and Dr Uljarević - Invited talk on Wales Autism Research Centre to Cardiff and the Vale NAS Parent Group, Cardiff, 26th May 2011.


Develop a communications strategy in collaboration with other agencies; e.g. AWARES, Autism Cymru.

The Wales Autism Research Centre Research-Policy-Practice Hub project is focusing on the development of a communication strategy to bring together the research, policy and practice communities. The project involves two policy consultants, Mr. Hugh Morgan and Mr. Jonathan Morgan.
Our current ESRC Follow-on grant involves partnership working with three charities (Autism Cymru, Waterloo Foundation, National Autistic Society)

- Organisation of Wales parent group network will formalise and facilitate communication channels with parents
- Development of AWARES online forum structure will formalise and facilitate communication with professionals

**Press releases**

- **Demonstration of the RPP hub.** A recent video episode of ‘Inside the Lab’ at Olga Tennison Autism Research Centre (OTARC), La Trobe University, Australia. [https://www.youtube.com/watch?v=BU6JuPo0zfA&list=PLiyKW2t9WyX4BLRAf6-dwu3NWj9YS-EXS&index=1](https://www.youtube.com/watch?v=BU6JuPo0zfA&list=PLiyKW2t9WyX4BLRAf6-dwu3NWj9YS-EXS&index=1).
- **Reaching Higher: Wales Autism Research Centre’s new grants.** Included in a discussion article on record university income, by Zoe Slater, in the Cardiff University Magazine, December 2010. [http://viewer.zmags.com/publication/c5e59f6a#/c5e59f6a/1](http://viewer.zmags.com/publication/c5e59f6a#/c5e59f6a/1).
- Research by Dr Kuhn, Dr Kourkoulou and Prof Leekam. See video: [http://www.scivee.tv/node/25133](http://www.scivee.tv/node/25133). 20th October, 2010
- Research by Dr. David McGonigle and the launch of the Wales Autism Research Centre. New autism initiatives outlined in article October, 2010. [http://viewer.zmags.com/publication/c5e59f6a#/c5e59f6a/1](http://viewer.zmags.com/publication/c5e59f6a#/c5e59f6a/1)
- **ITV Wales Tonight News 6/10/10**