April 2014 marks five years since my appointment as Chair in Autism. In 2009 our Five Year Plan predicted that “by 2014 the Centre would be starting to advance understanding of the factors affecting the onset and outcome of autism symptoms.” We also envisioned “a developing reputation for PhD and postdoctoral training and for translational work in policy and practice.” I am so delighted at the progress we have made in achieving these goals.

The partnerships formed between scientists, practitioners and policy makers in the last five years have made so many of these achievements possible. For example, our research has led to new published research findings on the effectiveness of DSM-5 criteria for ASD and on ASD symptoms in ADHD. Working with the Welsh Government’s Adult Diagnostic Clinical Network and colleagues at the National Autistic Society, our research on autism diagnosis has been further developed for new training resources and forms of diagnostic interview that we are now embedding into NHS training and clinical practice in Wales.

Our newly published research on sensory and cognitive aspects of autism has clarified the important role of tactile, auditory and visual processing. We have identified how these sensory symptoms are related to both repetitive behaviours and anxiety and the importance of the temporal processing aspect of these difficulties. Our work on sensory symptoms has also led to feasibility projects on interventions, facilitating interdisciplinary collaborations with academic colleagues in Engineering, Optometry and Clinical Genetics and collaborations with clinicians.

Finally, the Autism Research Policy Practice Hub (RPP Hub: http://www.autismrpphub.org/) is a new initiative that brings together our unique focus on partnership working. This open access site is a co-ordinated online platform for the co-production of knowledge across communities, championing the use of research in policy and practice.

As originally planned in 2009 we are developing a growing reputation as a training centre with strong links in the community. Since 2009, the centre has supported nine PhD students, and five postdoctoral researchers. Four interns have joined us over the years and our work on autism is now integrated into student undergraduate programmes and project supervision.

Looking ahead to the next five years, our plan is to strengthen our work on detection and diagnosis and link together research and professional networks. We will also build on our research success in areas of sensory, cognitive and neurobiological aspects of ASD. Finally, an important new direction will be a focus on families, where we aim to develop a new programme of research and support. We look forward to the future!

Sue Leekam
Chair in Autism
Director of Wales Autism Research Centre
Wales Autism Research Centre Annual Report 2013-2014

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. Sue 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 2013-2014 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 2013 to March 2014.
Wales Autism Research Centre Membership 2013-2014

Members of the Centre (foundation funding)

Director: Professor Sue Leekam
Postdoctoral Research Associate: Dr Sarah Carrington

Academic staff associated with the Centre

Dr Catherine Jones
Dr Kate Langley
Dr David McGonigle

Research Staff employed during April 2013 and March 2014 (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 Georgie Powell, Research Associate, Wellcome Trust ISSF
Katy Lake, Research Administrative Officer, ESRC Research Policy & Practice Hub
Beverley Winn, Parent Consultant
PhD Students

Rachel Kent, funded by ESRC CASE Award (Oct 2009 – Apr 2014)

Mirko Ulijarević, funded by WORD studentship (Jan 10- Dec 2013)

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

Beverley Winn, second supervisor Prof. Leekam (Jan 13 – Dec 17)

Associate members

Prof. Dale Hay, Chair in Social Psychology, School of Psychology, Cardiff University

Dr Katherine Shelton, Senior Lecturer, School of Psychology, Cardiff University

Dr Miriam Cooper, Clinical lecturer and PhD student (Wales Clinical Academic Track)

Dr Dawn Wimpory, Lecturer, Bangor University & Consultant Clinical Psychiatrist, Betsi Cadwaladr University Health Board

Dr Linda Iao, Postdoctoral Research Fellow, University of Hong Kong

New PhD students joining the team

Sarah Barrett first joined the team in 2012, while completing her MSc in Social Science Research Methods at Cardiff University. She gained a distinction in her MSc in 2013 and started her PhD in September 2013 under the supervision of Prof Sue Leekam and Dr Catherine Jones. Her PhD is focusing on the nature of imagination in autism, and its relationship with repetitive behaviours. Sarah is funded through the Economic and Social Research Council and Cardiff University School of Psychology.

Sarah Thompson joined the team in September 2013, after completing her MSc Psychology at the University of Essex in 2012. Her PhD is focussing on face processing patterns in autism and will be using eye tracking measures to examine this. Sarah is supervised by Catherine Jones and Sue Leekam. Her PhD is funded by Cardiff University School of Psychology.
School of Psychology Research Internship (SPRInt) Awards

Over the summer of 2013, we had two students working with us on projects funded by the SPRInt scheme.

Kate Fillingham: “I worked with the WARC team for two months, after being awarded funding by the School of Psychology to complete an undergraduate research internship. I have been supervised by Dr Sarah Carrington and Dr Mirko Uljarević and we’ve been working on a project looking at emotional regulation and anxiety. I feel like I have learnt so much from the last 8 weeks. The analysis process provided a much needed refresher of statistics for me, after having a year out from university to complete a placement year. Not only was my statistical knowledge refreshed, but I feel that it was also deepened by having collaborative discussion about the analysis with my supervisors. WARC has been a very welcoming team to come into and I am so appreciative of everyone who has taken the time to talk to me about their research and methods used. Thanks for having me WARC!”

Alessandra Roberts: “After 2 months of working with the WARC team, I feel as though I’ve learnt so much. As an undergraduate, I didn’t have much knowledge about research. I have been supervised by Dr Chris Ramsden, working on a project which has been to develop an online central hub for practitioners, policy workers and researchers in order to create more engagement between areas and translation of knowledge between them too. As part of the development of this, I interviewed a number of practitioners to explore their use of research in practice and ask what they would like from the online “Hub” as well as what is needed for more collaboration with researchers. Having never worked with qualitative methods before this was extremely interesting and I definitely learnt a lot! Everyone at the team has been more than lovely, answering any little question and giving their advice in order to complete the project.”

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 the Advisory Board for Olga Tennison Research Centre, Australia)
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 http://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 we are awaiting decisions on four applications. Our research findings have been published in 13 peer reviewed academic publications in print or in press since April 2013, with a further four currently under review. Members of the team have presented their work at both national and international conferences this year, including the International Meeting for Autism Research, in San Sebastian.
Grants

New grants awarded


On-going grants


Grants completed


Grants applied for (awaiting decision)


- MRC. The AAA Autism Trial: A trial of N-Acetylcysteine and Arbaclofen in Adults with Autism. PI: Murph, D.G.M. (King’s College London); Co-I: McAlonan, G. (King’s College London), Simonoff, E. (King’s College London), Baron-Cohen, S. (University of Cambridge), Leekam, S.R., McGonigle, D., LeCouteur, A. (University of Newcastle), Parr, J. (University of Newcastle), Standfield, A. (University of Edinburgh), Critchley, H. (Brighton and Sussex Medical School), Harrison, D. (Brighton and Sussex Medical School), Brugh, T. (University of Leicester), Gray, R. (University of Oxford), Povey, C. (NAS), Wallace, S. (Autistica), Melville, C. (The University of Glasgow). £3,835,998.


Grants submitted (unsuccessful)


New School of Psychology lecturers joining the Wales Autism Research Centre

This year, we have been joined by two new lecturers, each of whom brings a new perspective to the research of the Wales Autism Research Centre.

Catherine Jones joined the School of Psychology as a lecturer in May 2013. She has a broad range of interest in perception and cognition in ASD. In particular, she is interested in how visual and auditory information is processed.

Catherine says that, “Understanding basic perceptual processing, such as how sensitive individuals with ASD are to sounds, is really important if we want a complete picture of the experience of having autism”. Along with Dave McGonigle she is exploring whether people with ASD are more sensitive to detecting differences in sound and touch and whether this relates to sensory behaviours, a common feature of ASD. She says that, “As psychologists, our motivation for studying perception and cognition in ASD is because it helps us understand the behaviours that individuals on the spectrum show. Characterizing these differences in perception and cognition is an important step in finding ways in which people with ASD can be helped to manage their challenges and difficulties”.

Catherine is also interested in communication, and how people with ASD are able to synchronise their speech with non-verbal forms of communication, such as gestures.

“This type of ‘social co-ordination’ is a subconscious and effortless part of successful social communication for neurotypical individuals. It contributes to social cognitive development and the forming of close relationships. The importance of synchrony to social communication means that there is real value in establishing if synchronous behaviours differ in ASD”.

Catherine will be developing this work in collaboration with Dr Ali Roula from the University of South Wales, with funding from a grant awarded by the Welsh Crucible.

Kate Langley joined WARC and the School of Psychology as a lecturer in August 2013. She is interested in the overlap between ASD and other disorders including ADHD and disruptive behaviour disorders in childhood and adolescence. Kate’s work currently looks at genetic and environmental risk factors for different neurodevelopmental disorders and their overlap.

“Children who have behaviour issues as well as the core symptoms of ASD are likely to have more problems than those with ASD alone and these problems in combination often have a greater impact on the individual and their family than having either problem on their own. The risk factors for the combination of problems might also be different than those for ASD alone. It is therefore important to understand why these disorders occur together and identify those children at risk of developing comorbid disorders”.

In one study, Kate is looking at how the presence of copy number variants (CNVs – submicroscopic duplications and deletions in our DNA) may increase risk for development of ASD and other neurodevelopmental disorders in children with learning problems. This study recently completed the sample collection phase and analysis is underway, so the results will be released soon.

Kate is also interested in how autistic traits influence the presentation of disorder in children with ADHD – until the publication of DSM-5, ASD and ADHD were considered to be mutually exclusive. There is now recognition that this is not the case and that autistic traits are relatively common in children with ADHD and can influence both the presentation and course of ADHD. Kate has been involved in work suggesting that there is overlap in the genetic factors which cause both ADHD and ASD and she is keen to investigate this further.

“I’m really looking forward to the opportunity to work with WARC to understand more about the overlap between ASD and other disorders. Together I believe that we can increase our understanding of these disorders and help improve the lives of individuals with ASD and their families” she says.
Publications

Publications in print


Publications accepted/in-press


Publications submitted and under peer review


Conference presentations and invited talks

International conference presentations

• 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.

Invited Conference Lectures


National conference presentations and other invited presentations


• McGonigle, D. *Confessions of a Neuroscientist with a Methods Problem: Neuroimaging, Touch, and Beyond*. Reading University, 13th Mar, 2014.

• Leekam, S.R. *Joint attention and early communication development*. Northern Region Child and Adolescent Psychiatry academic programme. Newcastle University. 7th Jan, 2014.


Internal Talks

- **Jones, C.** *Timing in clinical populations.* School of Psychology. 28th Mar, 2014.
- **Langley, K.** *Genetic risk factors predicting psychopathology in children with learning disabilities.* School of Psychology. 7th Mar, 2014.

Databases and measures developed

- Training materials for the DISCO Abbreviated. Prof. Sue Leekam, Dr Mirko Ulijarević, 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 in child and adult services 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.
- 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.

Members of the team with Prof. Margot Prior during her visit in June, 2013. Back row (l-r): Dr Louise White, Dr Chris Ramsden, Mrs Lynda Morgan, Dr Mirko Ulijarević, Ms. Katy Lake, Ms. Sarah Barrett; front row (l-r): Prof. Sue Leekam, Prof. Margot Prior, Dr Sarah Carrington, Mrs Beverley Winn.
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 completed a collaborative project with engineers at Brunel University. We have also begun a new interdisciplinary project with colleagues in Optometry and Clinical Genetics (Cardiff University) and the MRC Cognitive and Brain Sciences Unit in Cambridge (see feature). 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 are strengthening links within the Neuroscience and Mental Health Research Institute in Cardiff University.

Research network meetings

- DISCO clinical and research team – meeting with Prof. Sue Leekam, Prof. Ina van Berckelaer-Onnes and Dr Judith Gould. London. 28th June, 2013.
- Autism Speaks Trailblazer project meeting. Attended by Prof. Sue Leekam, Dr David McGonigle, and collaborators from Brunel University and the Kingwood Trust. School of Psychology, Cardiff University. 13th June, 2013.
- Bristol Autism Research Group. Attended by Prof. Sue Leekam, Dr Sarah Carrington, Dr Christopher Ramsden, Dr Louise White, Mrs. Lynda Morgan, Ms. Rachel Kent, Dr Mirko Uljarević. 9th Apr 2013.

Invited academic visitor to WARC

- Dr Emma Gowen, University of Manchester, 26th Mar, 2014.
- Prof. Tokio Uchiyama & Dr Yota Uno, Yokohama Psycho-Developmental Clinic, 28th-29th Jan, 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 Anneli Kylliäinen, University of Tampere, Finland, 21st June 2013.

From left to right: Dr Emma Gowen, Dr Rachael Bedford, Dr Anneli Kylliäinen, Dr Sue Fletcher-Watson.
International visitors to WARC meet members of the Welsh Government

Three international visitors to WARC have held meetings with Julie Annetts and Alyson Collins at the Welsh Government, Department of Health Social Services and Children.

Professor Margot Prior from the School of Psychological Sciences, Melbourne University and Chair of the Advisory Board for the Olga Tennison Autism Research Centre, La Trobe visited WARC in June 2012. Together with her colleague Dr Jackie Roberts, Griffiths University, Queensland (who visits WARC in Sept 2014) she has written guidelines on ASD interventions for the Australian Government entitled ‘Early Intervention for Children with Autism Spectrum Disorders’ Guidelines for Good Practice, 2012’. In Australia, academics and government are working closely together to monitor standards in clinical and educational practice. Prof. Prior explained the Australian model and her work with the Australian Government when she and Prof. Leekam met with Julie Annetts and Alyson Collins from the Welsh Government.

Professor Tokio Uchiyama (right) is the Director of the Yokohama Psycho-Developmental Clinic in Japan. He advises the Japanese Government in a number of areas including ICD-11, the prevention of crime by the people with ASD, and early detection and support for the infant and toddler with neurodevelopmental disorders. Professor Uchiyama and his colleague Dr Yota Uno (left) held a very interesting meeting with Julie Annetts and Alyson Collins to discuss the implications of the new diagnostic criteria for autism, DSM-5 and the likely implications of the impending changes in Europe following the introduction of ICD-11. He was able to learn of differences between Japan and Wales, particular in relation to legislation in Wales and the UK to provide services on the basis of need.

The British Council supported a visit by Dr Sami Basha from Al Ahliyeh College University, Palestine to Cardiff University. Dr Basha is Vice President for Planning and Development Affairs, Director of the Special Education Program and Center, Palestine Ahliya University College. He is currently trying to develop guidelines and policies and provide a proposal for the government. His visit to Wales will help him to contribute to improving the quality of interventions and services offered to autistic children in Palestine. He met with Welsh Government officials and has a special interest in Special Education provision in Wales. During his visit Dr Basha also visited Ashgrove and Hollies Schools and had meetings with WARC staff.

We were also delighted to welcome Monique Post when she came to Wales to meet with parents in Swansea and Cardiff. Monique is a consultant on the Dutch Government’s ‘Looking from Within Autism’ project, and during her visit, she met with Julie Annetts to discuss the Welsh Government’s ASD Strategic Action Plan, with the aim of providing feedback to the Dutch Government’s Board of Experience.
Wales Autism Research Centre: April 2013 – March 2014

Wales Autism Research Centre Lab Group meetings

Our fortnightly lab group meetings are an opportunity for all core and associate members of the Wales Autism Research Centre to discuss recent developments and on-going work within the team as well as new research 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. We also host visitors from collaborators who present their work to the group. The lab group meetings are organised by Miss Rachel Kent.

New research collaborations

- **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 Uljarević, Prof. David Evans (Bucknell University, USA), Dr Sarah Carrington**: data collection using a newly modified adult version of the Childhood Routines Inventory.
- **Dr Mirko Uljarević, 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.

Prof. Tokio Uchiyama with Prof. Sue Leekam during his visit to Cardiff University
Cardiff University Interdisciplinary Collaboration

A new intervention for individuals with neurodevelopmental disorders

Visual attention control in individuals with neurodevelopmental disorders

This project brings together research and clinical expertise in a new collaboration involving Psychology, Optometry, and Clinical Genetics.

In this project we are studying children with neurodevelopmental disorders and their response to a novel training method designed to improve visual attention. The project is developing this training method for the first time for children with neurodevelopmental disorders such as autism and also Rett syndrome.

Prof. Sue Leekam and Dr Georgie Powell are working with researchers from the Optometry (Dr Jon Erichsen and Andrew Millington) and Medical Genetics (Prof Angus Clarke) departments at Cardiff University and the MRC Cognition and Brain Sciences Unit at Cambridge University (Dr Sam Wass).

Early attention abilities play a critical role in social and communication development and so targeting attention at an early age may lead to improvement in these key areas of development. Children watch videos on a computer that uses eye gaze technology. Eye gaze technology is perfectly suited to individuals with ASD and Rett syndrome who may have problems with verbal communication and fine motor skills. By monitoring children’s eye movements we can study their ability to flexibly control where they are looking. We can also assess the kinds of attention skills that individuals will need extra help with.

This is a feasibility study and we will need further project funding in order for a complete trial to be carried out. The research so far completed by Dr Powell is showing that children are responding well to the tasks and this method is suitable to be adopted for a future trial.
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 both 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. New ESRC funding was obtained to develop a Research, Policy, Practice Hub. This 2012-2014 project and has brought three new members of staff to the centre. The WARC team is also carrying out training and evaluation of clinical tools for adult diagnosis.

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://globlearlyautism.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.

Meetings with third sector, practitioner, and educational organisations, and 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.

Left: Prof. Margot Prior with Mrs Beverley Winn at the opening of the Dark and Light exhibition of autism and art; right: Prof. Sue Leekam and Dr Sarah Carrington with Dr Sundari Umapathy and Dr Judith Gould during a training course in the use of the DISCO Abbreviated delivered as part of the All-Wales Diagnosis and Pre-post Diagnosis Service.
WARC research impacts Wales NHS

Wales NHS ASD Adults Diagnostic Network adopts DISCO ‘family’

A three year project funded by the Welsh Government has created the All Wales Clinical Network for the Diagnosis and Counselling of Adults.

This network works to; to (a) facilitate a standardised process of assessment and diagnosis within each NHS Health Board, (b) develop and deliver training for clinicians and (c) enable quality assured improvements and sharing of good practice.

New research:

The use of diagnostic instruments is an important aspect of the assessment process. Members of WARC; Prof Sue Leekam, Dr Sarah Carrington and Rachel Kent have contributed to the network by carrying out original research to develop an abbreviated diagnostic instrument.

The DISCO ‘family’ is the name given to a coordinated set of interviews uniquely designed to be used by the Diagnosis and Pre/post Diagnosis Service.

The full DISCO interview (320 items) was developed by Lorna Wing and Judith Gould (Lorna Wing Centre), to help clinicians to assess an individual’s pattern of behaviours and needs. This interview has been published (Wing et. al., 2002; Leekam et al., 2002) and is already well established in clinical practice.

The new DISCO- Abbreviated Interview (68 items) was designed in 2012 especially to be used as part of this service. In addition a very short ‘signposting’ or screening interview is under development, which once validated would form part of the ‘family’ in the future.

A research publication led by Dr Sarah Carrington identifies essential (abbreviated) items for diagnosis of DSM-5 and has been accepted for publication in Research in Autism Spectrum Disorders. The same results will be reported at the International Meeting for Research in Autism (IMFAR) in May 2014, the world’s largest autism research conference. The IMFAR program committee invited Dr Carrington to give an oral presentation, as the submission received a high rating and was described by the committee as an important topic to be reported.

Prof Leekam and Dr Carrington have also contributed to training. The Training Sub Group of the All-Wales Diagnosis and Pre/post Diagnosis Service for Adults (Dr Sundari, Aneurin Bevan Health Board and Dr Matthews, Hywel Dda Health Board) organised training for the full and abbreviated forms of the DISCO. The training has been led by Dr Judith Gould, Director of the Lorna Wing Centre, National Autistic Society. The WARC team have developed new training materials and manual and contributed to training on the course.

DISCO-Abbreviated training began in July 2013 and three groups have now been trained, in Cardiff, Carmarthen, and Llanfairfechan.
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.

Undergraduate autism teaching

- **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.
Undergraduate autism applied experience

- Final year undergraduate research project students, academic year 2013-2014.

Jess Aldridge

Project title: The ‘mere exposure’ effect: Exploring face preference in individuals with high and low autistic traits.

Supervisor: Dr Catherine Jones

Hannah Bowker

Project title: The relationship between Alexithymia, Social Interaction and Social Anxiety

Supervisor: Dr Sarah Carrington

Carys Williams

Project title: The relationship between repetitive behaviour, executive function and ASD traits in the general population

Supervisor: Dr Sarah Carrington

Sasha Williamson

Project title: Measuring the influence of mild anxiety on executive functioning skills, when paired with ASD traits in a student population

Supervisor: Dr Sarah Carrington

Undergraduate and postgraduate training on research, policy and practice

- 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

Postgraduate Student success

WARC – closing the gap between Research Policy and Practice

The Autism Research Policy Practice Hub (RPP) [http://www.autismrpphub.org/] is an open-access site that champions the use of research in policy and practice in the UK and beyond. The goal of the site is to raise awareness and enhance the translation of knowledge in order to improve outcomes for individuals with ASD. The Hub is shared knowledge translation platform, developed thanks to matched funding from the Economic and Social Research Council and the Welsh Government.

The site has three main components, including Group Discussions, News, and Articles & Resources.

Since the Autism RPP Hub was launched by Gwenda Thomas (Deputy Minister for Social Services) in September 2013, we have held several, free online events.


On 6th Nov, the lead policy officials in the UK from Wales, Northern Ireland, England, and Scotland held their first online discussion on the Autism RPP Hub about developments in legislation, funding and strategies. As a direct outcome of this seminar the four met again in Scotland in early 2014.

(b) Employment Hot Topic: [http://www.autismrpphub.org/groups/practice/753/hot-topic-overcoming-barriers-employment]

In December 2013, we opened a discussion on the Autism RPP Hub on employment issues in autism led by Dr Beatriz López (University of Portsmouth). A key outcome of the event was to share research findings and evidence across the communities and highlight key areas for further attention and research. To date, this discussion topic alone has been viewed over 3,300 times.

(c) Diagnostic interview methods: [http://www.autismrpphub.org/groups/policy/833/diagnostic-methods-online-seminar]

Between October 2013 and February 2014, the RPP hub hosted three online seminars, each of which focused on a different diagnostic assessment, the ADI-R, the 3di and the DISCO. An outcome of these events was to create free access to papers and articles about each of these diagnostic tools on the hub ([http://www.autismrpphub.org/article-resource-categories/diagnostic-interview-tools-awareness-online-conferences]).
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. In addition to the open access online site for Autism Research Policy Practice Hub, we have updated the main Wales Autism Research Centre website and increased our use of social networking sites. We now have over 600 likes on our Facebook page and an active Twitter account. The team have continued to give talks to parent and interest groups in the autism community, including stakeholder and social groups. We also continue to host visitors to the centre, including teachers from local schools and charity representatives. In March 2014 WARC’s visual attention research was presented at the Cardiff University Brain Games event at the National Museum.
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 to be 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. The website has had approximately 3,000 hits in the past 5 months.
- 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.

Parent representative talks to Gwent Magistrates Youth Panel

In February, our Parent Consultant, Beverley Winn was invited to talk to members of the Gwent Magistrates Youth Panel about Autism and Asperger Syndrome. Beverley said:

"The translation of research and policy into practice across different sectors is an important aspect of my role within WARC. I was delighted to present to the Gwent Youth Justice Panel Magistrates in order that they gain understanding of individuals with ASD and to be appropriately sensitive when sentencing."

The title of Beverley’s talk was ‘Autism Spectrum Disorder: Implications for the Youth Justice System’ and it was very well-received. Lady Hayman Joyce JP, Chairman of the Gwent Magistrates Youth Panel wrote to Prof. Leekam to say

“I would like you to know how grateful we are to Beverly for such an invaluable contribution to our job as Justices of the Peace”.

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Events targeting public and professional awareness of autism scientific research in autism

Presentations to the public and professionals

- A joint dissemination event with Research Autism and Institutes of Psychiatry and Education, London “A Future Made Together” and “Autism RPP Hub” will be held on 3rd April 2014 and will attract members of charity, parent, practitioner and policy communities.
- **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.

Press Releases and online features

- A demonstration of the RPP Hub has been given in 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=PLiyKW2t9WyX4BLaRf6-dwu3NwJ9Y-EXS&index=1](https://www.youtube.com/watch?v=BU6JuPo0zfA&list=PLiyKW2t9WyX4BLaRf6-dwu3NwJ9Y-EXS&index=1).

Left: Prof. Sue Leekam and Mrs Lynda Morgan with Carol Povey (Director of the NAS Centre for Autism Research) at the National Autistic Society South West Regional Members Day in Bristol, Apr 2013; centre and right: Dr Catherine Jones, Dr Georgie Powell, and Sarah Thompson hosted a table at the Cardiff University Brain Games event, held at the National Museum Cardiff on the 16th of March, 2014.
Graduating PhD students

Dr Mirko Uljarević completed his medical training in Serbia. He joined the Wales Autism Research Centre in January 2010 to start his PhD, focusing repetitive behaviours, anxiety and sensory problems in children with autism and exploring how these features were related to anxiety in their parents. His PhD was funded by the Wales Office of Research and Development for Health and Social Care, National Institute for Social Care and Health Research. Mirko's wide range of interests allowed him to contribute to several projects within the centre, including a study focusing on tactile sensitivity in ASD (led by Dr David McGonigle), and most recently, the Autism Research Policy Practice Hub. He has developed several successful collaborations with local clinicians and international researchers, including work with Prof. David Evans, Bucknell University (USA) developing questionnaire measures of repetitive behaviours. Mirko successfully defended his thesis in October 2013 and has since been offered a prestigious postdoctoral position in the Olga Tennison Autism Research Centre at La Trobe University in Melbourne. Mirko will be very much missed by all of us at WARC, but we hope that we will continue to work together with him in his new position in Australia.

Dr Miriam Cooper completed her core clinical training in psychiatry in South Wales. She then began her PhD in Child and Adolescent Psychiatry in the Cardiff University Institute of Psychological Medicine and Clinical Neurosciences under the supervision of Prof. Anita Thapar (Section of Child and Adolescent Psychiatry) and Prof. Derek Jones (Cardiff University Brain Research Imaging Centre). Miriam's PhD was part of the Wales Clinical Academic Track (WCAT) scheme, an academic medicine lectureship scheme run by the Wales Deanery and major universities in Wales in association with the Welsh Assembly Government. Her work focused on the clinical and biological significance of autistic traits in adolescents with attention deficit hyperactivity disorder (ADHD), including how both autistic and ADHD traits were related to the structure of the brain's white matter. Miriam successfully defended her thesis in February 2014 and is now completing her specialist training whilst continuing her research with Prof. Thapar. Miriam has been an associated member of WARC since beginning her PhD and has contributed to our activities and lab meetings on a regular basis. We hope to continue this collaboration with her in her postdoctoral position.

Consultancy and Professional Engagements

PhD Examining

- **Prof. Sue Leekam**: External PhD examiner – Matthew Hollocks, Institute of Psychiatry.
- **Prof. Sue Leekam**: External PhD examiner – Adrienne Rombough, Simon Fraser University.
- **Dr Kate Langley**: Internal PhD examiner – Rachel Kent, Cardiff University.
- **Prof. Sue Leekam**: Internal PhD examiner – Jamie Szymanski, Cardiff University.
Esteem indicators

- **Prof. Sue Leekam**: member of the ESRC Centre and Large Grant review panel, July 2013-Jan 2014.
- **Dr Kate Langley**: member of the MRC Fellowship review panel.
- **Dr Catherine Jones**: selected as one of 30 participants for Welsh Crucible 2013 (May-July 2013). The Welsh Crucible is a leadership and development programme for early and mid-career scientists.
- **Prof. Sue Leekam**: member of the Welsh Government ASD Strategic Action Plan Stakeholder Advisory Group.
- **Prof. Sue Leekam**: invited member of the Autistica Advisory Group for ASD-UK.
- **Prof. Sue Leekam**: member of the Scientific Board for the British Autism Infant Siblings Study.
- **Prof. Sue Leekam**: invited to be part of the International Society for Autism Research (INSAR) initiative to host global open-access research tools.