Autism Chair Advisory Group: Extracts from the notes of the eighth meeting held on 6th May, 2014, at 12 noon, in Room 3.10, Tower Building.

Present: Ed Wilding (Chair), Susan Leekam, Julie Annetts, Hugh Morgan, Katherine Shelton, Heather Stevens (observational capacity), Christine Swabey (representing Autism Alliance) and Simon Wallace.

In attendance: Ms Alison Roberts.

Apologies: Apologies were received from Alyson Collins, Francesca Happe and Margaret Prior.

80. Minutes of the last meeting

These were accepted as a correct record.

81. Items from the Head of School of Psychology

Professor Ed Wilding spoke to this item.

NOTED that

81.1 since the establishment of WARC, it has published more than 40 papers, given 200 presentations and had achieved investments of £1.1M with £400K coming from Research Councils. Its success has seen inward investment with three PhD studentships and two lectureships. It was noted that WARC now has a very strong staff base in Cardiff;

81.2 the School is in the process of recruiting new Lecturers/Senior Lecturers and the areas of research could overlap with the research being carried out in WARC;

81.3 plans for developments in neurodevelopmental research are underway and there are a number of encouraging strands connecting WARC to the Neuroscience and Mental Health Research Institute (NMHRI); translational/developmental science; and CUBRIC 2. £44M is being invested in establishing CUBRIC 2 for which the School of Psychology is the catalyst. A five-year fellowship has been set aside for paediatric imaging;

81.4 plans for the continuity of WARC need to be considered. Sue’s role is changing. She is retiring in November but will be continuing in the School on a .2 contract and will be engaged in a range of activities. Consideration needs to be given to identify who to appoint as the new Director of WARC.

81.5 Ed expressed his thanks to Sue for the knowledge and enthusiasm which she has brought to the role.
82. **Items from the Chair in Autism**

Sue Leekam spoke to this item.

**NOTED that**

82.1 Sue thanked the members of the Advisory Group for supporting her and WARC through the 5-years of her appointment as Chair. The Advisory Group’s guidance has enabled her and WARC to achieve its success;

82.2 Sue will be retiring in November this year but will be coming back on a .2 appointment. This will enable her to support, facilitate and mentor ongoing staff and research projects and keep connections with the Welsh Government, charities and other stakeholders;

82.3 a small working group was set up in 2013 that now forms the WARC Planning Group. The group is chaired by Sue and membership includes Dr Katherine Shelton, Dr Catherine Jones, Dr Kate Langley, Dr David McGonigle and Dr Sarah Carrington. Since the establishment of the group, it has met every month to bring together plans for each members’ own research, develop the new 5-year plan for WARC and prepare a large grant proposal submitted Oct 2013;

82.4 Sue presented the new WARC 5-year draft plan from 2014-20019 (document was circulated before meeting). This identifies three key themes for research in the next 5 years, each divided into a basic research and a practice-policy subtheme. The themes are, *Behaviour and diagnosis*, (led by Kate Langley) including ASD traits, behavioural and neurobiological factors – diagnostic tools, NHS training network; *Biological and cognitive processes* (led by Catherine Jones and Dave McGonigle) including sensory and cognitive processing difficulties, cognitive interventions and schools network and *Families and relationships* (led by Katherine Shelton) including parent and child risk and protective factors and health outcomes and a family support network;

82.5 comments on the new 5-year plan have been invited from the Advisory Group. External advisor Prof Margot Prior, encouraged the building of partnerships with other centres and schools and the evaluation of interventions used in schools. Sue welcomed any other suggestions that Advisory Group members wished to make. The plan will also be shared with the ASD community (professionals and families) for their input;

82.6 implementation of the new WARC 5-year plan needs to be done in a strategic way with guidance from the new lead of WARC and from the current or newly formed Advisory Group. The work will need further detailed planning and funding from research grants;

82.7 some successful WARC projects currently underway will be unlikely to continue without additional support. WARC (Sue Leekam and Sarah Carrington) has played an essential part in setting up the All Wales Adult ASD
Diagnostic and Pre and Post Diagnostic Network. This is a unique model of adult diagnosis. More work needs to be done to develop this model through research and training and to extend the model to children’s diagnostic services, but there is no funding for this at the current time. The Autism Research Policy Practice Hub, another initiative supported by the ESRC and Welsh Government, also does not have funds for continuation. The ESRC grant application submitted Oct 2013 that was to support these developments, was not funded. Sarah Carrington’s post ends in July. Therefore specialised operations linked to WARC, for example the WARC website, WARC facebook pages, WARC email address, annual report, blogs and information to the public, will not have any dedicated support going forward without specialist autism-related additional funding;

82.8 on the other hand, there are other major new initiatives, which together with new appointments in the area of autism made by the School, will provide scope for important developments in other directions. The new CUBRIC 2 and the NMHRI and NCMH will provide scope for future collaboration in the areas of diagnosis, neuroimaging and treatment. There is potential for other new collaborations in education. Sue will also be looking for greater involvement across special schools and education to build the applied aspects of the themes in the new 5-year plan;

82.9 Katherine Shelton was welcomed to the meeting. Katherine is involved in family research and supervises Beverley Winn, a part-time PhD student working in this area. The families and relationships theme is a new direction for WARC. Initial work in this area is very promising and it is an important area for research investment. One PhD will be insufficient to take the theme forward but there is scope to expand this research area. It is hoped that future opportunities will enable this theme’s development.

83. Items from the Autistica representative

Simon Wallace spoke to this item.

NOTED that

83.5 Simon thanked Sue and the whole team and stated that it is great to see research at WARC flourishing. WARC is also a great template for policy and practice connecting with research.

84. Items from the Autism Cymru representative

Hugh Morgan spoke to this item.

NOTED that

84.1 in the beginning, when tasked with looking to appoint a Chair in Autism, Autism Cymru had no idea of who could fill such a post but had been extremely fortunate to identify Sue who came to Cardiff from Durham. Sue
has done a brilliant job of setting up WARC and being the figurehead in and around Wales and Cardiff;

84.2 in 2006/7 Autism Cymru took a strategic approach to research into autism in Wales and held three national meetings of researchers from across Wales to identify the extent and focus of autism research in Wales existing at that time. It concluded by highlighting the need for a wales autism research centre and Wales (and the UK’s) first named professorial chair in autism to lead the research centre. Hugh then met with Professor Dylan Jones to seek his agreement in principle for these major developments to be located in the school of psychology. In order to create the funding needed Hugh then sounded out Dame Stephanie Shirley who introduced him to her new charity Autism Speaks (subsequently renamed Autistica) with whom a joint fundraising partnership was established. To kick-off the fundraising process Autism Cymru met with the Minister for Health and Social Services in Welsh Government for an initial commitment and this was followed by wonderful contributions from the Waterloo Foundation, Baily Thomas, Autism Initiatives and others.

85. Items from the Welsh Government representative

Julie Annetts spoke to this item.

NOTED that

85.1 Julie echoed everyone else’s thanks to Sue and is delighted that Sue is not disappearing from Cardiff;

85.2 the Welsh Government is currently finalising the ASD strategy and the document will be available before recess;

85.3 Sue has helped the Welsh Government with its work;

85.4 the Deputy Minister for Health and Social Services wants to set up a task and finish group for children’s diagnosis of ASD which Sue could be part of;

85.5 the Welsh Government was become very reliant on WARC;

87. Any other business

87.1 Ed informed the meeting that Dale Hay is to head a working party whose remit will be to consider recruitment for WARC and talks should take place with Heather Stevens about this and future plans. Sue will be part of this group.

87.2 Ed wants to maintain the Advisory Board for WARC and he and Sue will meet to have discussions about its future. Ed hopes to be able to be in touch with everyone in due course to update them. He would still like to meet the group annually to explore possibilities for working together and providing updates.
87.3 Ed noted that, thanks to Sue and because of all the contributions everyone has made, WARC is in a very strong position.

88. **Date of next meeting**

**AGREED**

88.1 that the next meeting could be linked to the Neurodevelopmental Conference which is to be held in Cardiff. A time and date would be agreed off-line.

NB. Extracts from the minutes are related to WARC business