Action on Autism
Research in Scotland
– Improving Impact Seminar Series

Seminar 2
4, 5 February 2014
The Lighthouse, Glasgow

Clinical Research,
Interventions and Impact
Welcome

We are delighted to welcome you to the Second Two-day Seminar in the Action on Autism Research in Scotland Seminar Series which aims to link policy, research and practice: An international perspective on Psychological, Clinical, Social and Educational fields of research into autism will show the quality and level of research evidence needed to inform policy direction. Speakers will lead on the topics shown and their presentations will be complemented by local research and practice presentations: each will be asked to demonstrate such connections and explore how their own research links to policy and practices.

International research studies make an enormous contribution to our wider knowledge base and we would like to understand better where Scottish research sits in this picture, where we may be making, or could make, a unique, distinctive or culturally relevant contribution and how this can link to the Scottish policy direction encapsulated in the Scottish Government’s ten year Autism Strategy.

The series was launched in November by Scotland’s Minister for Public Health, Mr Michael Matheson. Each Seminar will be chaired by Professor Tommy MacKay in his role as Interlocuteur for the Series. The development of the series has been led by Professor Aline-Wendy Dunlop with the support of the Organising Team.

PROFESSOR TOMMY MACKAY

Professor Tommy MacKay is Director of Psychology Consultancy Services, Co-Founder of the National Centre for Autism Studies at the University of Strathclyde and Clinical Director of the National Diagnosis and Assessment Service for Autistic Spectrum Disorders. He has over 40 years’ experience in working with children and young people with ASD and other difficulties. His work has won many national awards as an ‘outstanding and original contribution to psychology’. He has been described by former UK Prime Minister Gordon Brown as ‘an inspiration and a visionary’.

PROFESSOR ALINE WENDY DUNLOP

Professor Aline Wendy Dunlop leads the Action on Autism Research in Scotland Seminar Series Organising Team. She is Professor Emerita at the School of Education at the University of Strathclyde, where she was the first Course Director of the Masters in Autism. Aline-Wendy is a member of the Scottish Government Autism Reference Group, Chair of Autism Network Scotland’s Steering Group and was awarded an MBE “for services to autism in Scotland” in June 2013. She extends a huge thank you to each of our funders: Scottish Government, Research Autism and Scottish Autism.
**Tuesday 4th February 2014**

09.45  
**Clinical Research, Interventions and Impact**  
Opening remarks – Professor Tommy MacKay

10.00 – 11.00  
**Professor Helen Tager-Flusberg, Developmental Science Program Director, Boston University**  
“Investigating early behavioral and neurobiological markers of risk for autism spectrum disorder”

Presentation and discussion.

11.00 – 11.30  
**Break**

11.30 - 12.45  
**Seminar 1 – 3 x Scottish Researchers 10 minutes + 5 min Questions. Chair: Anna Robinson**

1. **Professor Anne O’Hare**  
“Autism Achieve Alliance: A national study of risk factors in individuals diagnosed with ASD”

2. **Dr Iain McClure**  
“Waiting for Autism Diagnosis - A National Study”

3. **Dr Judith Piggott**  
“Why Think SMARTS in Autism?”

12.45 – 13.45  
**Lunch (posters + impact)**

13.45 – 14.45  
**Professor Declan Murphy, Mortimer D Sackler Professor of Translational Neurodevelopment, and Director of the Sackler Institute for Translational Neurodevelopment, Institute of Psychiatry, King’s College London.**  
‘Translational neuroscience’ will help improve outcomes in autism. True – or a delusional belief ?’

Presentation and discussion.

14.45 - 15.15  
**Break**

15.15 – 16.15  
**Impact Seminar**

Round table discussion focusing on the potential impact of what we have heard today by use and classification

16.15 - 16.45  
**Summing up from speakers and chair**

17.00  
**Close**
SPEAKERS – DAY 1

PROFESSOR HELEN TAGER-FLUSBERG
“Investigating early behavioral and neurobiological markers of risk for autism spectrum disorder”

Helen Tager-Flusberg received her Bachelors in Science in Psychology from University College London, and her doctorate from Harvard University. From 1978 through 2001 she was a Professor in the Department of Psychology at the University of Massachusetts –Boston and from 1996 – 2001 she also held the position of Senior Scientist at the Eunice Kennedy Shriver Center/UMass Medical Center. Since 2001 Dr. Tager-Flusberg has been at Boston University initially with primary appointments in the Department of Anatomy and Neurobiology and Pediatrics at the School of Medicine and now as Professor of Psychology at Boston University, where she was the Director of the Developmental Science Program from 2009 to 2012. Dr. Tager-Flusberg is now the Director of the Center for Autism Research Excellence at Boston University. Dr. Tager-Flusberg has conducted research on autism and other neurodevelopmental disorders for over 35 years, investigating developmental changes in language and social cognition in these populations using behavioral and brain imaging methodologies. She has edited several books and written over 180 journal articles and book chapters. Dr. Tager-Flusberg is the Past President of the International Society for Autism Research and is Associate Editor of the Journal of Neurodevelopmental Disorders. She has presented her research at many professional conferences, parent advocacy groups, and training institutes.

PROFESSOR DECLAN MURPHY
“Translational neuroscience will help improve outcomes in autism. True – or a delusional belief?”

Professor Declan Murphy trained at the Institute of Psychiatry (King’s College, London), and at the Laboratory of Neurosciences (NIH, USA). His main research interest is in the biological determinants of brain development and ageing; and how abnormalities in this process lead to neuropsychiatric disorders and abnormal social behaviour. Professor Murphy is currently Director of the Mortimer D Sackler Centre for Neurodevelopmental Translational Research, and Head of the Department of Forensic and Neurodevelopmental Sciences, at the Institute of Psychiatry. He is lead investigator on a number of multicentre imaging and translational neuroscience studies – including an MRC funded UK neuroimaging network for research in autism (MRC UK AIMS program), an EU IMI funded programme on autism (EU-AIMS) and an EU postdoctoral imaging training network (EU TRIP). He is also part of TACTICS – a multicentre study on inhibitory mechanisms.

PROFESSOR ANNE O’HARE
“Autism Achieve Alliance: A national study of risk factors in individuals diagnosed with ASD”

Professor Anne O’Hare is Honorary Professor of Child Life & Health, School of Clinical Sciences, University of Edinburgh and Honorary Professor, Queen Margaret University. She works as a consultant paediatrician in community child health and neurosciences in the Royal Hospital for Sick Children, Edinburgh. Her research interests in neurodisability encompass communication impairments, including autism spectrum disorder, developmental co-ordination disorder and sensory impairment. She is the lead clinician for the communication clinic at the Royal Hospital for Sick Children, Edinburgh, and runs a learning disorders clinic in the neurology department. She has published widely in the field of neurodisability and is presently conducting research in the differential ways that children with autism spectrum disorder and developmental coordination disorder learn movement; how services are delivered for children with autism spectrum disorder; and randomized controlled trials on early intervention for children with autism and drooling in children with motor impairment. She is past President of the European Academy of Childhood Disability and is author of the ‘Brain & Learning’, part of the British Paediatric Neurology Association distance learning programme. She is also an executive member of the MSC course in neurodisability based in Sheffield, UK and an associate editor of DMCN and 4th edition of Aicardi’s Diseases of the Nervous System in Childhood.

DR IAIN MCCLURE
“Waiting for Autism Diagnosis - A National Study”

Iain is Consultant Child & Adolescent Psychiatrist for NHS Lothian and Honorary Clinical Senior Lecturer at the University of Edinburgh and Honorary Senior Research Fellow at Heriot-Watt University. He has a longstanding interest in autism, mainly from the perspective of child and adolescent mental health and, in that context, has focussed his research on autism assessment and how to improve it, in terms of accessibility and efficiency. In 2011, the Scottish Government commissioned Iain to lead a project investigating the current situation regarding ASD assessment in Scotland, which led him to form the Autism ACHIEVE Alliance (AAA) with Professor Anne O’Hare (University of Edinburgh) and Professor Kirsty Forsyth (Queen Margaret University). The AAA has recently completed a two-year investigation and change implementation project, which hopefully will contribute significant publications over the next few years. Iain’s other longstanding interest regarding autism is the evidence base and its dissemination. He chaired the SIGN guideline on ASD in children and young people (2007; SIGN 98) and was also External Advisor to the NICE guidelines on Autism in children and adolescents (2011) and Autism in adults (2012). He was recently appointed Chair of the review of SIGN 98 (2014), Iain wrote the chapter on Practice Guidelines in Autism for the Encyclopedia of Autism Spectrum Disorders (Springer; 2013) and the chapter on Developing and Implementing Practice Guidelines for the 4th Edition of the Handbook of Autism, (Yale) (to be published in 2014).

DR JUDITH I. PIGGOT
“Why Think SMARTS in Autism?”

Consultant Child and Adolescent Psychiatrist specialising in Neuro-developmental Disorders, Hon Senior Lecturer, University of Dundee. Previously Clinical Director of UCLA Centre for Autism Research and Treatment and Director of SMART Social Communication Laboratory, and Senior Lecturer Child and Adolescent Psychiatry University of Cardiff and Consultant Lead, South Wales Tertiary ASD Evaluation Clinic. Post Doctoral Fellowship Stanford University Neuroimaging Genetics and Ph.D. Neuro-imaging in Social Communication Disorders.
PROGRAMME DAY 2

Wednesday 5th February 2014

09.30
Arrivals

09.45 – 10.00
Opening remarks – Professor Tommy MacKay

10.00 – 11.00
Professor Fred R Volkmar, M.D., Irving B. Harris Professor Director - Child Study Center, Yale University School of Medicine Chief of Child Psychiatry Yale New Haven Hospital.
“Understanding the social nature of autism : From clinical research to intervention”
Presentation followed by discussion

11.00 – 11.30
Break

11.30 - 12.30
Seminar 2 – 3 x Scottish Researchers 10 minutes + 5 min Questions. Chair: Professor Aline-Wendy Dunlop

1. Dr Bonnie Auyeung
   “Investigating the potential benefits of oxytocin for individuals with autism: Practical considerations”

2. Dr Helen Minnis
   “Autism and Reactive Attachment Disorder: can they be confused?”

3. Dr Andrew Stanfield
   “Misunderstanding social situations: always autism?”

12.45 – 13.45
Lunch (posters + impact)

13.45 – 14.45
Professor Christopher Gillberg, Chair Mental Health and Wellbeing, University of Glasgow; Head of the Gillberg Neuropsychiatry Centre, Sahlgrenska Academy, Gothenburg University:
“Autism Plus” vs “Pure Autism”
Presentation followed by discussion

14.45 - 15.15
Break

15.15 – 16.00
Q&A with Professor Volkmar – leading into Impact Seminar
Round table discussion focusing on the potential impact of what we have heard today by use and classification

16.00 - 16.30
Chair and Key Speakers – Plenary
Pulling everything together on the Seminar theme of Clinical Research, Interventions and Impact: Summing up from speakers and chair

16.30
Departures
Christopher Gillberg has made a career long contribution to current understanding of neuro-psychiatric and neuro-developmental conditions including autism. Chris is Co-founder and Director of the P.A.R.I.S. (Paris Autism Research in Sib-pairs) consortium. He is a member of various other international autism genetics study groups and consortia and member of the Norwegian Academy of Sciences. He has organised major international symposia/world congresses held in Gothenburg, Glasgow and London on autism (1989, 1996, 2003, 2006, 2011). Professor Gillberg is much published: 249 of his 500 international peer-reviewed published papers deal with ASD. He has written many book-chapters, and 30 books in English and Swedish. An active PhD supervisor, continues his involvement in clinical training and holds an array of prestigious national and international awards including most recently the King’s Medal of Seraphim Order 2009, Nicas Oberg Life Watch Award 2010, Dahlberg Gold Medal 2010, and the Söderberg Medicine Prize 2012. He was selected by the Swedish Psychiatric Association as Sweden’s most productive researcher within the discipline of psychiatry 2013.

PROFESSOR CHRISTOPHER GILLBERG

“Autism Plus” vs “Pure Autism”

Dr. Andrew Stanfield is the co-director of the Patrick Wild Centre for Research into Autism, Fragile X Syndrome and Intellectual Disabilities at the University of Edinburgh. Within the NHS, he is also an honorary consultant in intellectual disability psychiatry and a member of the SE Scotland autism diagnostic service. His research is focused around the biological and psychological mechanisms of autism and related conditions, with a particular focus on the translation of these findings into clinical practice.

DR ANDREW STANFIELD

“Misunderstanding social situations: always autism?”

Bonnie Auyeung is a Chancellor’s Fellow at the University of Edinburgh where her work is focused around two central themes: 1) the biological origins of autism and other neurodevelopmental conditions and 2) relieving the symptoms of these conditions which can cause difficulties in everyday life. Her interest this subject stems from clinical and research experience at the UCLA Neuropsychiatric Institute in her home city of Los Angeles. Before coming to Edinburgh, Bonnie completed a PhD at the University of Cambridge’s Autism Research Centre and has since published extensively on the effects of the prenatal environment on later brain and behavioural development.

DR BONNIE AUYEUNG

“Investigating the potential benefits of oxytocin for individuals with autism: Practical considerations”

Helen Minnis is Senior Lecturer in Child and Adolescent Psychiatry at the University of Glasgow. She spent time working as an Orphanage Doctor in Guatemala in the early 1990s prior to training in Psychiatry, and this stimulated an interest in the effects of early maltreatment on children’s development. Her research focus has been on Reactive Attachment Disorder (RAD): clinical aspects, assessment tools and behavioural genetics. She is now conducting intervention research for maltreated children including a randomised controlled trial of an infant mental health service for young children in foster care and has recently been investigating the clinical overlap between RAD and ASD.

DR HELEN MINNIS

“Autism and Reactive Attachment Disorder: can they be confused?”

Helen Minnis is Senior Lecturer in Child and Adolescent Psychiatry at the University of Glasgow. She spent time working as an Orphanage Doctor in Guatemala in the early 1990s prior to training in Psychiatry, and this stimulated an interest in the effects of early maltreatment on children’s development. Her research focus has been on Reactive Attachment Disorder (RAD): clinical aspects, assessment tools and behavioural genetics. She is now conducting intervention research for maltreated children including a randomised controlled trial of an infant mental health service for young children in foster care and has recently been investigating the clinical overlap between RAD and ASD.

PROFESSOR FRED R VOLKMAR

“Understanding the social nature of autism: From clinical research to intervention”

A graduate of the University of Illinois where he received in undergraduate degree in psychology in 1972 and of Stanford University where he received his M.D. and a master’s degree in psychology in 1976. Dr. Volkmar was the primary author of the American Psychiatric Association’s DSM-IV autism and pervasive developmental disorders section. He is the author of several hundred scientific papers and chapters as well as a number of books including Asperger’s Syndrome (Guilford Press), Health Care for Children on the Autism Spectrum (Woodbine Publishing), the Handbook of Autism (Wiley Publishing), and A Practical Guide to Autism: What Every Parent, Teacher and Family Members Needs to Know (Wiley Publishing) with another three books in varying stages of production. He has served as an Associate Editor of a number of journals and currently serves as Editor of the Journal of Autism and Developmental Disorders. He has served as co-chairperson of the autism/intellectual disabilities committee of the American Academy of child and Adolescent Psychiatry. In addition to having directed the internationally known autism clinic he also served as director of autism research at Yale before becoming chairperson of the Department. Dr. Volkmar has been the principal investigator of three program project grants including a CPEA (Collaborative Program of Excellent in Autism) grant from the National Institute of Child Health and Human Development and a STAART (Studies to Advance Autism Research and Treatment) Autism Center Grant from the National Institute of Mental Health.

SPEAKERS – DAY 2

PROFESSOR FRED R VOLKMAR

“Understanding the social nature of autism: From clinical research to intervention”

A graduate of the University of Illinois where he received in undergraduate degree in psychology in 1972 and of Stanford University where he received his M.D. and a master’s degree in psychology in 1976. Dr. Volkmar was the primary author of the American Psychiatric Association’s DSM-IV autism and pervasive developmental disorders section. He is the author of several hundred scientific papers and chapters as well as a number of books including Asperger’s Syndrome (Guilford Press), Health Care for Children on the Autism Spectrum (Woodbine Publishing), the Handbook of Autism (Wiley Publishing), and A Practical Guide to Autism: What Every Parent, Teacher and Family Members Needs to Know (Wiley Publishing) with another three books in varying stages of production. He has served as an Associate Editor of a number of journals and currently serves as Editor of the Journal of Autism and Developmental Disorders. He has served as co-chairperson of the autism/intellectual disabilities committee of the American Academy of Child and Adolescent Psychiatry. In addition to having directed the internationally known autism clinic he also served as director of autism research at Yale before becoming chairperson of the Department. Dr. Volkmar has been the principal investigator of three program project grants including a CPEA (Collaborative Program of Excellent in Autism) grant from the National Institute of Child Health and Human Development and a STAART (Studies to Advance Autism Research and Treatment) Autism Center Grant from the National Institute of Mental Health.
The AAR Seminar Series: Overview

Aims

As our Action on Autism Research Seminar Series develops this year we look forward to building an evidence base and capitalizing on our discussions in order to meet the aims of our series. At each meeting we will ask participants for feedback about their dissemination process so that we can gauge the outcomes of the series.

1. Invite participation from a number of respected international researchers to learn from their work and to debate priorities for the development of new studies.
2. Contribute to a process of mapping current research through involving Scottish autism researchers in presenting their work at a series of two-day seminars.
3. Make a call for paper or poster proposals to populate the working days with contemporary Scottish research into autism.
4. Enhance the relationship between research, policy and practices through knowledge exchange workshops.
5. Consider the relationship between intervention and impact.
6. Generate new research collaborations and proposals where gaps are identified.
9. Commit to building closer relationship between the academic, health, social services and education communities and autism policy development in Scotland.
10. Disseminate the findings of the series with the support of Scottish Government, Autism Network Scotland and Research Autism through their websites, newsletters, a conference, publications and consequent good practice events.

In Seminar 1 we heard from 6 Scottish based researchers and welcomed the following speakers:

Dr Thomas Insel, Director, National Institute of Mental Health (NIMH), USA “Autism: What do we know? What do we need?”


Michelle Dawson, University of Montreal, “Science, ethics, and autism intervention research: Should there be autism-specific standards?”


In our November discussions we considered whether we know enough to inform laws and policies; the kinds of services and training needed and their effects and inclusion, quality and ethics in autism research.

Two further Seminars will take place as follows –

Social Research, Interventions and Impact - 28th & 29th April 2014
Educational Research, Interventions and Impact - 9th & 10th June 2014

The closing Action on Autism Research in Scotland Conference will take place 6th-8th November 2014 in Glasgow.

Invited speakers for these events include –

Dr Katie Maras, University of Bath; Dr David Simmons, Glasgow University; Professor Tony Attwood, Brisbane, Australia; Dame Stephanie Shirley, The Shirley Foundation; Dr Justin Williams, University of Aberdeen; Professor Tony Charman, King’s College, London; Professor Sue Leekam, University of Cardiff; Professor Tommy MacKay, Psychology Consultancy Services; Dr Gary Mesibov, University of North Carolina; Dr Amy Wetherby, Florida State University; Professor Martin Knapp, London School of Economics.

NOTES OF INTEREST - If you or colleagues are conducting research on autism in the UK and would be interested in presenting research at one of the events, we would like to hear from you. Please email caroline.marley@strath.ac.uk to note interest, indicating your topic, whether you would prefer to present a talk or poster, and which of the seminars would be a best fit for the presentation proposed. We will then send you guidelines on submission of a summary for consideration by the review panel.
SEMINAR SERIES
ORGANISING TEAM

ALAN SOMERVILLE

Alan Somerville is Chief Executive of Scottish Autism, Scotland’s national autism charity and co-funder of this seminar series. He is also a Trustee of the Autism Alliance UK and a member of the Scottish Government’s External Reference Group developing and implementing the Scottish Strategy for Autism.

DR ANDREW STANFIELD

Dr Andrew Stanfield is the co-director of the Patrick Wild Centre for Research into Autism, Fragile X Syndrome and Intellectual Disabilities at the University of Edinburgh. Within the NHS, he is also an honorary consultant in intellectual disability psychiatry and a member of the SE Scotland autism diagnostic service. His research is focused around the biological and psychological mechanisms of autism and related conditions, with a particular focus on the translation of these findings into clinical practice.

ANNA ROBINSON

Anna Robinson is the Course Leader for the PgCert;PgDip;MEd in Autism at the University of Strathclyde. Prior to this she managed The Centre for Education and Training in Autism and the Autism Advisory Service for Scottish Autism. She has been a practising therapist for people with Asperger’s Syndrome for over 17 years. Her research explores emotional processing and the mechanisms of change within group Emotion-Focused Therapy.

DR EVELYN MCGREGOR

Dr Evelyn McGregor is a member of academic staff in the School of Education at the University of Edinburgh, a developmental psychologist, and currently Director of Post-Graduate Studies. Evelyn and colleagues formed the Scottish Autism Research Group (SARG): an interdisciplinary group which has run several funded seminar series for academics, practitioners and the autism community in Scotland. Her interests include intervention to help people with autism learn about belief, narrative skills and interests in autism and job interview skills in autism.

DR EWELINA RYDZEWSKA

Dr Ewelina Rydzewska was appointed a Network Adviser for Autism Network Scotland in May 2012. Ewelina’s main research interest is on the process of transition to adulthood for people with autism spectrum disorder (ASD). Ewelina’s research is concerned with multidimensional reflections on adulthood and on the quality of life for people with disabilities. Ewelina is also interested in the impact of the available service provision on service users’ developmental trajectories and opportunities for social engagement.

DR HELEN MARWICK

Dr Helen Marwick is a Senior Lecturer at the University of Strathclyde. A developmental psychologist, she is currently involved in research on intersubjectivity and conceptual development within autism spectrum disorders. She developed the Joint-Play Intersubjectivity Assessment Method (JPIAM), Helen is a member of international research groups investigating neurodevelopmental disorders and social communication, and has published widely in this area.

DR JACKIE RAVET

Dr Jackie Ravet is currently a senior lecturer in the School of Education at the University of Aberdeen. She is also director of the Autism & Learning programme - a Masters pathway for postgraduate students. Jackie has a background in teaching pupils on the autism spectrum and also held the post of Autism Development Coordinator for Moray Council. She now lectures and researches in autism and inclusive practice.

RICHARD MILLS

Richard Mills is the National Autistic Society’s Director of Research and Research Director of Research Autism, an independent UK research charity specifically concerned with research into interventions in autism and co-funders of the present seminar series. His other appointments include Autism Advisor to the States of Jersey CI and Research Fellow, Bond University, Brisbane, Australia; He is Editor of Autism the International Journal of Research and Practice.
Scottish Government recognises that autism is a national priority. Given the importance of this agenda, the development and creation of a new Scottish strategy for autism was vital to ensure progress across Scotland in delivering quality services to people with autism and their families. Scottish Government Autism Strategy funding was awarded to The Action on Autism Research Seminar Series as an initiative to reach out to the autism research community and to bridge research, policy and practice.

Research Autism describes itself as “the only UK charity exclusively dedicated to research into interventions in autism. We carry out high quality, independent research into new and existing health, education, social and other interventions. Our goal is the improvement of quality of life and outlook for people on the autism spectrum and those around them.”

They have generously supplemented the original Scottish Government grant to the series.

http://researchautism.net/pages/welcome/home

Scottish Autism describes itself as “an organisation dedicated to enriching the lives of people with autism. We are the largest provider of autism-specific services in Scotland and a leading authority and advocate for good autism practice. We exist to help those diagnosed with autism to lead full and enriched lives and become valuable members of the community they live in. We also seek to share our knowledge and expertise with parents, carers and other professionals in order to support the development of skills and strategies needed to provide the best care and support for people with autism”.

They have generously supplemented the original Scottish Government grant to the series.

http://www.scottishautism.org/
The Scottish Strategy for Autism
http://www.autismstrategyscotland.org.uk/

You can follow the Autism Seminars online by joining Autism Network Scotland:
www.autismnetworkscotland.org.uk
@Autism_Network

The Universities of Aberdeen, Edinburgh and Strathclyde collaborated with the seminar series proposal to develop the seminar series.