Action on Autism Research in Scotland

An advanced international multidisciplinary, multi-agency research seminar series held between November 2013 and November 2014

The Scottish Government

Scottish autism

RESEARCH AUTISM
IMPROVING THE QUALITY OF LIFE
IDENTIFICATION INTERVENTION INCLUSION

Seminar Series Report

Action on Autism Research in Scotland
Final Report

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Every participant: you were asked to justify your place on the programme and your contributions were invaluable.

Our Organising Team who dedicated many hours to the planning, delivery, reflection upon and analysis of the work in the Series.

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The University of Strathclyde holds the data generated by the series as their Intellectual property. The authors hold right of ownership of the contents of this report as their shared intellectual property.

The Scottish Government

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
IMPROVING THE QUALITY OF LIFE

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.ikml

Scottish autism

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/

Executive Summary

Our Aims

There were several drivers to this Seminar Series which can be seen in policy, research and practice terms: the need for the Scottish ASD Reference Group (now Governance Group) to focus on Research Strategy in Scotland and to relate this to international knowledge and current research in Scotland; secondly to mobilise the interest of the Scottish autism research community towards the Scottish ASD Strategy and thirdly to consider the potential of autism research for day-to-day impact and on people's daily lives – families, individuals on the spectrum and the professionals who endeavor to provide support. We expand on our aims in the following report.

Our Approach

An international perspective on Psychological, Clinical, Social and Educational fields of research into autism aimed to show the quality and level of research evidence available to inform policy direction in Scotland. Speakers led on these topics and their presentations were complemented by local research and practice presentations. Each was asked to demonstrate such connections through their own research links to policy and practice. 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.

Sixteen international research presentations and twenty-four contributions from Scottish – based researchers formed the core of the Seminar Series. The single day end point conference saw the return of two of our principal keynote speakers, Professor Fred Volkmar and Professor Christopher Gillberg. Many of the speakers came from a clinical or psychology background, reflected in their research engagement. At each event time was made for discussion in our Impact Sessions.

The Seminar Series has generated a significant set of data about autism research through presentations, poster sessions, video recordings, discussion transcripts and evaluations.

Setting Autism Research in Scotland in Context

We endorse the findings of "A Future Made Together" (Pellicano, Dinsmore & Charman, 2013) presented by Dr Liz Pellicano at our seminar series and discussed in this report. Their three recommendations were that there should be 'investment in new areas of autism research', that there is a 'need for strategic partnerships' and 'an ethic of engagement' (page 39). It is acknowledged that such arrangements and partnership will take time to develop: strategy and ongoing work will be needed by the community of researchers brought together in this series which has served as a catalyst for a range of developments. More immediately we agree that " greater efforts can be made immediately by individual autism researchers and research funders to involve autistic people and the broader autism

community in the design of research, in its conduct and in the translation of its findings to issues of everyday" (page 7, A Future Made Together, 2013).

Main Areas of Research

In the broadest sense of the word, the definition of research includes any gathering of data, information and facts for the advancement of knowledge. The purpose of research can be a complicated issue and varies across different scientific fields and disciplines. At the most basic level, science can be split, loosely, into two types, 'pure research' and 'applied research'. In the AAR Seminar Series we have talked of basic research and applied research.

It is helpful to identify the main areas of research: these have been modeled by Pellicano, Dinsmore & Charman (2013, page 18) as diagnosis; biology; brain and cognition; causes; treatments and interventions; services and societal issues. The balance of research investment in the UK as a whole is weighted significantly to research into biology and causes of autism. Research with immediately practical application to everyday life draws much lower funding levels.

Each of these areas was reflected in our four seminar topics of Psychological Research, Intervention and Impact; Clinical Research, Intervention and Impact; Social Research, Intervention and Impact and Educational Research, Intervention and Impact.

The Question of Impact

The focus throughout the four seminars and final conference has been on answering the following questions through consideration of the instrumental, conceptual and capacity building nature of the basic and applied research represented during the seminar series:

- What do we mean by impact in autism research?
- What claims are currently being made for impact?
- How, methodologically, is this being evidenced?
- Where is impact weak / why?
- How can impact gaps be addressed?
- How can we work across disciplines and interest groups to maximise impact?

Strengths highlighted during the Action on Autism Research in Scotland Seminars

- We have a community of researchers in Scotland
- We know we have the context for research to influence strategy
- There are a variety of different models used to look at autism, but more than anything we are moving from autism to autisms
- Much more money spent on research in US than per capita here
- More money is spent on "biology, brain and cognition" research than anything else
- There are parallels between "A future made together"(2013) and a Scottish Audit (SASN, 2007) on what families and autistic individuals say is needed in services
- There is nan emerging understanding and greater clarity about autism research in Scotland (who is researching, what they are researching, how this is funded)

Gaps that emerged in the Action on Autism Research in Scotland Seminars

In research terms in Scotland, there is a visible gap between research and its application to daily life – "translational gap" (Pellicano)

There is a need to link up to improve research and its quality through partnerships (Murphy)

- We don't know enough about what the "autistic community" thinks is important in research nor are they involved in research to any great extent
- We don't know enough about what practitioners thinks is important in research nor are they involved in research to any great extent
- We don't know enough or fully understand adult autistic experience and changes over the lifetime (Pellicano)
- We don't have basic tools that can be used across studies for profiling strengths, abilities as well as difficulties faced by autistic people (Seminar 1 – Insel, Aitken)
- We don't know how well services work
- We don't know what preventions and interventions are successful
- We don't know how many children, young people and adults are affected by autisms or are autistic
- There is not enough research that supports daily life and where it exists it needs to be more visible and subsequent interventions based on evidence should be supported

Action on Autism Research in Scotland. What does Scotland Need?

There is a visible gap between research and its application to daily life which needs to be bridged:

- There is a need to link up to improve research and its quality through partnerships;
- Policy needs to be based on evidence;
- The ethics of interventions are important;
- That we should be thinking autisms not autism.

We therefore need to:

- We need to develop a full understanding of data that currently exists from Scottish-based autism research - and is under utilised;
- We need to know who is affected by autism in families and all services and who is autistic;
- We need to know the value and success of autism interventions across age groups;
- We need to know what makes an effective autism service at different stages, for various sub groups of autism and across the lifespan;
- While there are strengths in current clinical and psychological research, we need to know much more about the application of such research to interventions and practice: this link is not always made successfully and as a result the impact of research is not evidenced nor visible;
- We need methodologies that enable us to research personalised approaches, what this means, what it looks like in practice and their impact;

- We need to find ways to fund social and educational research which is seen as softer and remains under-funded and possibilities under-explored but potentially have important impact to make;
- We need to know much more about what the overall population thinks and knows about autisms and how to sustain awareness.

Conclusions and Key Recommendations

The Scottish Strategy for Autism creates an opportunity to focus on the strengths, gaps and challenges of researching autism in Scotland and linking this to policy development. The relationship between the Foundation Phase of two year goals could be mapped retrospectively to understand the place research has or could have played in laying the foundation for future synergy: the award for this Seminar Series was part of that work. Currently the Strategy is working with the five year goals of 'The Whole Life Journey' and the ten year goals of moving towards 'Holistic personalised approaches'. Developing proposals for A Scottish Autism Research Plan linked to the strategy means placing a new importance on work that bridges both.

Researchers in Scotland to endeavor to make their work widely known through academic mechanisms such as peer review and Impact factor journals, to reflect on its day-to-day impact, to be supported to address whether it could have a critical part in shaping and influencing national policy and practice, ensuring that public policy decisions and psychological, health, educational and social interventions are based on research of the highest quality;

An independent autism research consultative body, should be set up following publication of this report, to focus on the quality and application of research in Scotland and to be called the 'Independent Autism Research Council Scotland';

The Scottish Autism Strategy should re-focus its work to meet Recommendations 7 and 8 of the Scottish Strategy for Autism (2011).

The Autism Strategy Governance Group should develop and maintain strong links with this independent body, so that research can contribute to:

- Explore how research on autism can be shared and translated into practice (Scottish Government, 2015);
- Further develop opportunities to take forward gaps in autism research (Scottish Government, 2015);
- Inform the direction of the Strategy in its second 5 years;
- Increase the effectiveness and sustainability of public services and policy;
- Enhance quality of life, health and wellbeing.

In conclusion the Action on Autism Research Seminar Series has shed considerable light on the many issues affecting people with autism, their families, carers and the professionals who work with them. A strategic consideration of the data presented will help to develop a Scottish Autism Research Plan in order to effect change.

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1. Introduction

The Minister for Public Health, Michael Matheson launched the Scottish Autism Strategy on 2nd November 2011. Autism is a national priority. Given the importance we attach to this agenda, in collaboration with staff from the University of Glasgow, University of Edinburgh and the University of Aberdeen a series of research seminars was planned to begin to map the state of autism research in Scotland and to consider how the Scottish Autism Strategy can be supported to improve the impact of locally based as well as international research upon the lives of people with autism, their families and the professionals who support them in Scotland. The ASD Reference Group of the time was made up of six sub-groups whose role was to implement the strategy and improve services. One of the sub groups had a research brief.

1.1 The Seminar Series Proposal

Initially the Seminar Series proposal was presented to the Scottish Government Autism Reference Group for their endorsement. The Reference Group considered that this was an important proposal and agreed to fund the seminar programme, making a grant towards the full cost with further support given by Scottish Autism and Research Autism. The generosity of all three funders brought the seminar series to fruition.

Research plays a vital role in providing a rigorous, valid and reliable knowledge base for our understanding of the key features of the condition in providing an evidence base for effective approaches and interventions, and a methodological base for the evaluation of implementation and impact.

The purpose of this seminar series was to explore the state of autism research in Scotland in relation to these three functions. Part of this process was to define 'impact', to consider how evidence supports claims of impact, to identify both research and impact gaps and to work together and across disciplines to consider how to maximise impact.

Autism affects around 1% of people in Scotland today. Much greater clarity is needed about the relationship between research and practice: the contribution that well developed links across research disciplines can make to the daily life of people with autism deserves to be explored in new ways. The research-practice relationship ought to be sufficiently robust to enhance quality of life so that the vision of the Scottish Autism Strategy that "individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives" is achieved.

Four two day seminars were designed to contribute to mapping current research in Scotland through involving Scottish autism researchers in presenting their work at a series of two-day seminars held between November 2013 and June 2014. Invited participation from a number of respected international researchers allowed us to learn from their work, to set the

Scottish contributions in an International context and to debate issues, gaps and concerns towards a better understanding of the relationship between research and practice through impact discussions and follow up good practice events after the series completes, and by generating research recommendations to link with the Scottish Strategy for Autism. A summary conference completed the Series in November 2014.

1.2 Autism in Scotland: Research and the Scottish Autism Strategy

It is now widely accepted that autism is common. In response to this knowledge there has been a new policy and public service interest in enhancing the day-to-day experiences and longer-term outcomes for autistic people and their families and carers. In Scotland what began in 2001 with the Public Health Institute Scotland's Needs Assessment Report into Autism, developed into a long lasting initiative to build on that report's recommendations. From 2001 recommendations were taken forward by a Scottish Executive Autism Reference Group (Later Scottish Government Autism Reference Group): this group re-formed in 2010 . At that time the Scottish Autism Research Group (SARG) in discussing the developing Autism Strategy, said:

The ASD Reference Group has the potential to foster the continuing development of autism research in Scotland. However, if they are to provide a steer in terms of research, it is important that there is transparency with regard to:

(i) appointment of members to this group
(ii) the process of tender/commissioning of research

Further they stated that within the strategy, all stages of research must be considered:

(a) establishing the research that is required/research gaps that exist
(b) conducting research
(c) disseminating research (both that conducted in Scotland and that outwith) and putting research findings into practice.

In 2011 a ten-year Scottish Autism Strategy with 26 new recommendations won Ministerial approval. Working Groups were formed to support implementation, one of which carried a Research brief. Two of these recommendations made specific reference to research:

RECOMMENDATION 7 (page 78)
"It is recommended that the ASD Reference Group commissions research to examine and compare the outcomes in relation to quality of life for those who are supported by autism service providers and individuals who access generic provision and that relevant findings are used to inform revised guidance for commissioners of services for people with ASD".

RECOMMENDATION 12 (page 79)
"It is recommended that an evaluation of existing research is commissioned by the ASD Reference Group as well as consideration given to what further research is necessary with a view to disseminating what is available and the commissioning [of] some pieces that would be of particular practical value to people with ASD and their carers".

It was on the basis of these recommendations and the need to alert autism researchers to the aims of the Autism Strategy, that an approach was made by a consortium of researchers from three Scottish Universities to the Reference Group in 2013 for part-funding to support a proposed series of 4 two-day seminars. The Seminars would explore the status of autism research in Scotland and position current Scottish based research in an international context, in order to work towards an autism research strategy for Scotland. The Series was realised through the generosity of three funders: Scottish Government, Research Autism and Scottish Autism and the in kind support of a staff collaboration across Edinburgh, Aberdeen and Strathclyde Universities.

During the lifetime of the Seminar Series the structure of the Autism Reference Group changed and in the new Strategy Governance Groups, responsibility for research connections was re-distributed between Workgroup 1 – 'Access to Integrated Service Provision' and Workgroup 3 – 'Consistent adoption of good practice in key areas of education, health and social care'. One of the key activities for this group was to take account of 'outputs from the research seminar series and event'. The group also had a publication responsibility.

The 2011 Autism Strategy document had stated "It is essential that the findings from quality research are disseminated and put into practice." To achieve this a team of people with a research knowledge and capacity to critique and evaluate research and its provenance but at the same time be knowledgeable about practice, was formed. As yet, despite a growing understanding of the connect between evidence and practice planning, there is no Strategic Action Plan for Autism Research in Scotland.

"Unlike the United States where the Interagency Autism Coordinating Committee (IACC) was set up through the Children's Health Act (2000), here there is currently no high-level systematic process for identifying and coordinating autism research across organisations to ensure that funds are directed to areas where they are most needed and can make the most impact" (Pellicano, Dinsmore & Charman, 2013, page 13)

As the Autism Strategy now sets out to influence practice rather than fund research, the time is right to form an Independent Autism Research Council in Scotland.

1.3 Autism in Scotland: Mapping Key Dates

To understand the relevance of research and practice developments in Scotland we include significant dates, influential research and publications, influential policy initiatives, events and developments. The following map includes the science of autism, legislative frameworks, policy frameworks, parental self organization, autism self-organisation, service responses, guidance, publications and advocacy, events and strategy.

(Acknowledgements and thanks to the authors of 'A Future Made Together' for their permission to develop their pages 14-17 with a Scottish Focus)

A History of Autism: Key Dates

"A Unique Syndrome"

1943: Leo Kanner, working in Johns Hopkins Hospital in Baltimore, USA, describes a unique syndrome, 'infantile autism' in 11 children with autism.

1943

Asperger Syndrome

1944: Hans Asperger, working in Vienna, describes 'autistic psychopathy' in a series of intellectually able children, which later becomes known as Asperger syndrome.

1944

Early Research

1965: Michael Rutter publishes his first peer-reviewed paper on 'childhood psychosis'.

1965

NAS Formed

1962: The UK parent advocacy group, now known as the National Autistic Society, is founded.

1962

Autistic Perception

1970: London-based researchers, Neil O'Connor and Beate Hermelin, provide the first in-depth study of the psychological features of children with autism.

1970

Scottish Autism Founded

1968: Scottish parent advocacy group – SSA (Scottish Society for Autistic Children) formed - now known as Scottish Autism.

1968

Education

1971: First Autism Primary School Unit in Scotland opened in Edinburgh.

1971

1970: Sula Wolff diagnosing autism in Edinburgh.

Diagnosis in Scotland

Education

1974: Autism education unit opened in Kilmarnock.

1974

"Triad of Impairments"

1979: Lorna Wing and Judith Gould first describe the 'triad of impairments' in their Camberwell (UK) epidemiological study.

1979

"Highly Heritable"

1977: The first twin study by Michael Rutter and Susan Folstein shows that autism is highly heritable.

1977

1977: SSA (Scottish Autism) opens Struan House School, which is later purpose built for children with autism and renamed New Struan School.

New Struan School

DSM-III

DSM-III recognises infantile autism under the umbrella of pervasive developmental disorders.

1980

Balmyre House

1983: Balmyre House opens for young adults with ASD.

1983

Theory of Mind

1985: Simon Baron-Cohen, Alan Leslie and Uta Frith (London, UK) propose that autism is caused by fundamental problems in theory of mind.

1985

Autistic Disorder

1987: The revised DSM-III broadens the definition of autism, which becomes known as 'autistic disorder'.

1987

Grampian Autistic Society Founded

1987: Grampian Autistic Society founded.

Autism Scotland

1988: Autism Scotland is formed becoming the first third sector collaborative group, which runs for five years until 1993.

1988

World Autism Awareness Day

1989: World Autism Awareness Day is celebrated for the first time, before being designated by the United Nations' General Assembly in 2007.

1989

1989: Fife Action on Autism founded.

Fife Action on Autism

1989: Diagnosis - Scottish Centre for Autism running at Yorkhill Hospital.

Diagnosis at Yorkhill

1991

1991: Uta Frith provides the first-ever English translation of Asperger's 1944 paper.

Frith Translation

PHAD Founded

1995: People with High Functioning Autistic Disorder (PHAD) founded in Fife.

1995: NAS opens Glasgow office.

1995

NAS Office

DSM-IV Revision

1994: The diagnostic criteria for autism are broadened once more in the fourth revision to the DSM (DSM-IV).

1994

1993

"Don't Mourn For Us"

1993: Autistic self-advocate Jim Sinclair challenges the notion of 'autism as tragedy' in his widely acclaimed paper titled "Don't Mourn For Us", presented at the Autism Network International.

"The Autism Spectrum"

1996: Lorna Wing coins the term "autism spectrum" to describe the wide variability in symptom presentation.

1996

Charter for Persons with Autism

1996: Charter for Persons with Autism adopted by the European Parliament as a written declaration.

1996

CETA Opens

1996: CETA (Centre for Education and Training in Autism) opens at SSA.

'Autism' Journal Founded

1997: Autism: The International Journal of Research and Practice is founded, in association with the UK's National Autistic Society.

1997

Counselling in Fife

1997: SSA opens AS Counselling Service opens in Fife.

MSc Autism

1998: MSc Autism starts at the University of Strathclyde.

1998

1998: NAS Daldorch House School opens with a 52 weeks a year provision.

Daldorch

1998

"Neurodiversity" coined

1998: Neurodiversity, the notion that people experience the world differently based on their neurological attributes, is coined by Harvey Blume in The New York Times.

1998: The immediately controversial and now retracted Wakefield study is published, which suggests a possible causal link between the MMR vaccination and autism.

False MMR Link

Education Act

2000: Standards in Scotland's Schools etc Act - presumption of mainstream education for all.

SARG

1999: Scottish Autism Research Group (SARG) Founded.

1999

APPGA Formed

2000: The All-Party Parliamentary Group on Autism (APPGA), a cross-party group of MPs and Peers is set up to improve awareness of autism and to lobby the Government for improved services for autistic people and their carers.

2000: Same as You Scotland

England - All Party Parliamentary Group

2000

2000: Inclusion in Autism, is it working? NAS

Inclusion in Autism

Policy

2000

2000: The US Children's Health Act 2000 establishes the Interagency Autism Coordinating Committee (IACC) to coordinate autism research in the US.

Establishment of IACC

Autisme Europe

2000: Autisme Europe Congress, Glasgow - 'Making our Dream a Reality' (Scottish Autism'.

2001

2001: The UK's Medical Research Council undertakes the first comprehensive review of UK research into autism on behalf of the Department of Health.

MRC Review of Autism Research

2001

2001: Public Health Institute of Scotland - Autism Needs Assessment Report.

Autism Needs

PASDA Constituted

2002: PASDA constituted.

2002

2002: Autism in Scotland's Schools - "Crisis or Challenge?" (NAS)

Autism in Schools

2002

Reference Group

2002: Scottish Government Autism Reference Group begins work.

2003

ELAS Constituted

2003: Edinburgh and Lothian Asperger Society constituted.

2003: The charity Research Autism is established, the only UK charity exclusively dedicated to research into interventions in autism.

Research Autism

2004

2004: Launch of the National Centre for Autism Studies (NCAS).

NCAS

2004

Mapping Autism Report

2004: The first review of UK autism research, 'Mapping Autism Research' is published.

2004

2004: Autism National Training Framework - Scotland.

Training Framework

2004

NDAS

2004: Scottish Autism opens National Diagnosis and Assessment Service.

2005

OSS

2005: One Stop Shops for adults with autism opened in Edinburgh and Glasgow.

2006

HMIe Report

2006: HMIe - Education for Pupils with an Autistic Spectrum Disorder Report.

Getting it Right...

2006: Getting it Right for Every Child initiated.

2006

1 in 100

2006: Population-based study estimates the prevalence of autism to be 1 in every 100 children in the UK.

2006: The Autistic Self Advocacy Network (ASAN), a US-based advocacy organisation run by and for autistic adults, is founded by Ari Ne'eman and Scott Michael Robertson.

ASAN Formed

2006

AS Forum

2006: Asperger Forum starts.

2006

SASN

2006: Scottish Autism Services Network starts.

2006: 'Make Schools Make Sense' Report (NAS).

Make Schools...

2007

ARGH Constituted

2007: Autism Rights Group Highland constituted.

2007

2007: SIGN (Scottish Intercollegiate Guidelines Network) produce guidelines on autism.

SIGN Guidelines

2008

2008: The International Meeting for Autism Research (IMFAR) is held in London, the first time outside of North America.

IMFAR, London

Commissioning

2008: Commissioning Services Guidelines

Reference Group

2008: Scottish Autism Reference Group folds.

2008

2008: I EXIST - NAS

I EXIST

2008

2008: The Welsh Assembly Government's Autism Spectrum Disorder (ASD) Strategic Action Plan and the Northern Ireland Assembly ASD Strategic Action are introduced.

Wales and NI Plans

Autism Act

2009: England introduces its first disability-specific law, the Autism Act 2009.

Economic Impact

2009: The first study on the economic consequences of autism for the UK is published, estimated at more than £27 billion per year.

2009

Policy-Practice

2009: Policy into Practice Accreditation Project

2009

2009

2009: Autism Toolbox launched.

Autism Toolbox

2009: The UK autistic led self advocacy organisation, Autism Rights Movement UK (ARM UK), is formed.

ARM UK Formed

2010: UK's Department of Health announces an Adult Autism Strategy, which sets a clear framework for all mainstream services across the public sector to work together for adults with autism.

DoH Strategy

2010

Autism Project

2010: Autism Adult Health and Wellbeing Project

2010

2010: Scottish Autism Reference Group recalled (January 2011, revised remit).

Group Recalled

Guidance

2011: 'An Ordinary Life'.

UK Autism Strategy Plans

2011: The devolved governments in Northern Ireland, Scotland and Wales all publish Autism Strategy plans with the aim of delivering quality services for people with autism and their families.

2011

Autism Strategy

2011: Scottish Autism Strategy launched, November 2011 - £13.4 million over 4 years.

2011

2011: The National Health Service's National Institute for Health and Care Excellence (NICE) announces a suite of guidelines on the identification, diagnosis and management of children, young people and adults with autism.

NICE Guidelines

2012

Microsegmentation

2012: Microsegmentation Project begins.

2012: Scottish Women with Autism Network (SWAN) established.

SWAN

2012

2012: Scottish Strategy for Autism Mapping Report.

Mapping Report

A Future Made Together

2013: A Future Made Together - Shaping Autism Research in the UK.

2013

Education

2013: OU Module in autism and University of Strathclyde PG module offered through strategy funding.

Strathclyde 'Becoming a Trainer' module.

2013: The Keys to Life - Scottish Learning Disabilities Strategy.

Keys to Life

Training

2014: NHS Education for Scotland - Autism Training Framework.

Autism Seminars

2013: Scottish Autism seminar series 2013 - 2015.

2013

2013: Menu of Interventions.

GAP Journal "The Scottish Perspective".

Publications

2014

2014: Scottish National Coordination Project.

Coordination

2013

2013: Scottish Autism Strategy two year goals.

Strategy Goals

Research Seminars

2016: Report of the Autism Research Seminar Series.

Alliance Report

2014: 'ASD: Waiting for Assessment' Autism Achieve Alliance Report.

Autism Ethics

2014: 'Autism and Ethics' conference - ARGH.

2014

2014: Scottish Autism launch Centre for Practice Innovation.

CPI Launched

2014

2016

2016: Autisme Europe Congress in Edinburgh (NAS).

Autisme Europe

2016

2016: Scottish Autism Strategy five year goals.

Strategy Goals

2021

2021: Scottish Autism Strategy ten year goals.

Strategy Goals

1.4 Aims and Outcomes

There were several drivers to this Seminar Series: they can be seen in policy, research and practice terms: the need for the Scottish ASD Reference Group to focus on Research Strategy in Scotland and to relate this to international knowledge and current research in Scotland; to mobilise the interest of the Scottish autism research community towards the Scottish ASD Strategy and thirdly to consider the day-to-day impact and potential of autism research on people's daily lives – families, individuals on the spectrum and the professionals who endeavour to provide support. The AAR Seminar Series therefore aimed to:

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 practice through knowledge exchange workshops;
5. Consider the relationship between intervention and impact;
6. Generate new research collaborations and proposals where gaps are identified;
7. Establish an Action on Autism Research in Scotland Network (through Autism Network Scotland);
8. Make recommendations for a National Research Action Plan for Scotland;
9. Commit to building closer relationship between the academic, health, social services and education communities and autism policy development in Scotland, and
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.

This report focuses on the achievement of these aims.

1.5 Our Approach

An international perspective on Psychological, Clinical, Social and Educational fields of research into autism aimed to show the quality and level of research evidence available to inform policy direction in Scotland. Speakers led on these topics and their presentations were complemented by local research and practice presentations: each was asked to demonstrate such connections through their own research links to policy and practice. International research studies make an enormous contribution to our wider knowledge base and we set out 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.

Four two-day seminar events and a final one-day conference formed the Action on Autism Research in Scotland Seminar Series: the presenters and their presentation titles for each event are included at the end of this summary report. Sixteen international research presentations and twenty-four contributions from Scottish – based researchers formed the core of the Seminar Series. There were also 24 poster presentations. At each event time was made for discussion in our Impact Sessions which drew on participants' knowledge and experience in terms of where they could anticipate impact. The single day end point conference brought together the work of the series and saw the return of two of our principal keynote speakers, Professor Fred Volkmar and Professor Christopher Gillberg.

The Organising Team was led by Professor Aline-Wendy Dunlop and comprised representatives from each collaborating University, the Research Sub Group of the Scottish Autism Strategy Reference Group and from Scottish Autism and Research Autism. Our third funder, Scottish Government, was kept informed of the developing programme of work.

Dr Tommy MacKay and Professor Aline-Wendy Dunlop chaired the meetings with support from all members of the Organising Team. Dr MacKay played the important role of discussant, chair of sessions, reflecting on a day's proceedings with pithy summings-up.

The seminar administration was shouldered by Mrs Caroline Marley, from the Research and Knowledge Exchange Team at University of Strathclyde.

1.6 Approach to Evaluation

The impact sessions at the seminar gave ample room for discussion and a model of self-evaluation was employed, so that during each Seminar Day there were opportunities to feedback on discussions and presentations, and opportunities to shape the future direction of the seminars. This high degree of involvement and a strong focus on providing feedback, disseminating learning and debating the impact of what had been presented, followed an action based approach. We posted an online questionnaire and invited feedback from participants.

1.7 Setting Autism Research in Scotland in Context

International contributions from some of the foremost researchers in autism set the pace for the series. For example,

Dr Tom Insel, Director of the National Institute of Mental Health in USA, and the largest funder of autism research worldwide, opened our session by talking to "Autism: What do we know? What do we need?" and so bringing a wide lens to the challenge of locating Scottish research, policy and practice in what is known and not known about autism.

Dr Liz Pellicano advocated the importance of narrowing the translational gap between research and daily experience by defining research that is more relevant to autistic people and communities, everyday lives and values. It is acknowledged that such arrangements and partnerships take time to develop. Ongoing work will be needed by the community of

researchers brought together in this series which has served as a catalyst for a range of developments, but more immediately we agree that "greater efforts can be made immediately by individual autism researchers and research funders to involve autistic people and the broader autism community in the design of research, in its conduct and in the translation of its findings to issues of everyday" (page 7, A Future Made Together.

Michelle Dawson, University of Montreal, Canada, herself an autistic researcher, took the title "Science, ethics, and autism intervention research: Should there be autism-specific standards?" This was an opportunity to question the quality of research, and to consider that we may need less research, better research and research done for the right reasons.

Dr Ken Aitken brought us home to Scotland through his presentation "The Research, policy and practice context in Scotland": he highlighted the need for communication between research areas and for collaborative funding, the serious limitations in the literature on therapies and the fit between ICD-11 and DSM 5 – emphasising the need to map these onto each other so that research is comparable internationally.

1.8 Areas of Autism Research

It is helpful to identify the main areas of research in autism: these have been modeled by Pellicano, Dinsmore & Charman (2013, page 19) as diagnosis; biology, brain and cognition; causes; treatments and interventions; services and societal issues. Each of these areas was reflected in our programming of the four seminar topics and our final conference.

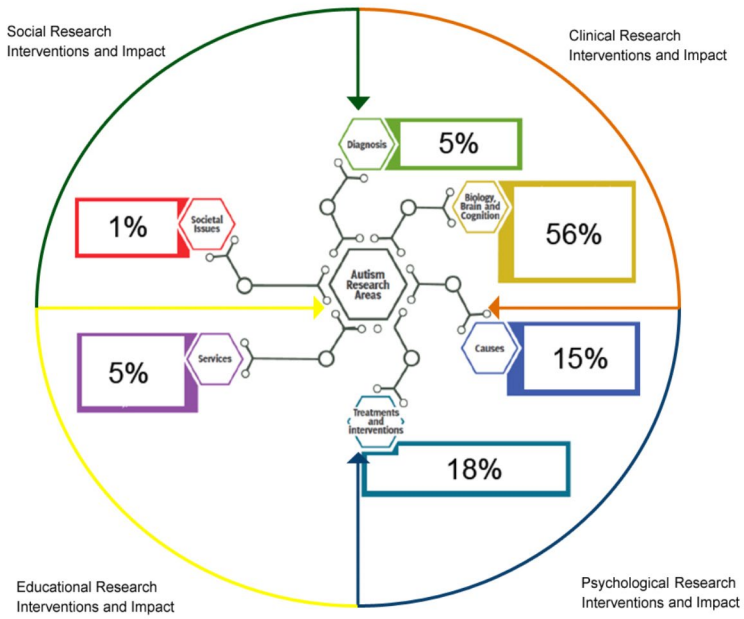


Diagram 1 – Diagram from Pellicano, Dunsmore & Charman (2013) adapted to show connection to AAR Seminar Series Impact and Intervention Themes.

Speakers were invited to present in relation to one of our four seminar themes of clinical, psychological, educational and social research. It was clear that our themes were not discrete and as we planned we found that most research in Scotland is psychological and clinical in nature with social and educational research being less common and more applied in nature. This raises questions about investment in under-researched areas as well as questions about research impact: given the evident disconnect between research and practice all speakers were asked to consider the impact or potential impact of their research.

1.9 The Question of Impact

The process of bringing people with a commitment to autism together in the research seminar series promised to widen knowledge about autism, and to promote sharing and knowledge exchange through developing a dissemination strategy. Impact is variously defined in the literature and by the UK Research Councils. The focus throughout the four seminars and final conference has been on answering these questions in relation to each seminar of the series:

- What do we mean by impact in autism research?
- What claims are currently being made for impact?
- How, methodologically, is this being evidenced?
- Where is impact weak / why?
- How can impact gaps be addressed?
- How can we work across disciplines and interest groups to maximise impact?

In considering research impact it is useful to understand how this concept is being promoted by research councils. The Economic and Social Research Council (ESRC)[1] includes both 'academic impact' and 'economic and societal impact', while the Medical Research Council (MRC) makes the link between research and policy saying that research "also plays a critical part in shaping and influencing national and international policy, ensuring that public policy decisions and health interventions are based on research of the highest quality"[2]

Determining the impact of both basic and applied science research is not a straightforward task. One working definition of impact is "making a demonstrable difference in an academic context" (Woolfson, 2010). This may be further broken down through describing three aspects of impact as defined by the Medical Research Council:

- Instrumental: influencing the development of policy, practice or service provision, shaping legislation, altering behaviour
- Conceptual: contributing to the understanding of policy issues, reframing debates
- Capacity building: through technical and personal skill development.

Impact at local, national and international level will be captured in the shorter term, will be reflected in policy in the medium term and may be sustained through the AAR collaboration

[1] [http://www.esrc.ac.uk/funding-and-guidance/impact-toolkit/what-how-and-why/index.aspx]
[2] [http://www.mrc.ac.uk/research/achievements/policy-engagement/]

in the longer term. The response of the Strategy Governance group to the AAR Series recommendations may address instrumental, conceptual and capacity building issues.

- Increasing the effectiveness and sustainability of public services and policy
- Enhancing quality of life, health and wellbeing.

The research councils also highlight that policy and service development is not a linear process, and decisions are rarely taken on the basis of research evidence alone. This makes it difficult to pin down the role that an individual piece of research has played. The timing of evaluation also presents challenges. Too soon after the research ends may mean that any impact has yet to fully develop. Too late, and the impact may no longer be traceable as people involved have moved on.

To maximise impact the ESRC suggests that there are a number of key factors that are vital for generating impact. These include:

- established networks and relationships with research users
- involving users at all stages of the research, including working with user stakeholder and participatory groups
- well-planned public engagement and knowledge exchange strategies, including the use of product strategies which tailor evidence to the needs of users
- good understanding of policy/ practice contexts eg through use of policy maps
- understand and target barriers to enablers of change
- portfolios of research activity that build up reputations with research users
- excellent infrastructure, leadership and management support
- where appropriate, the involvement of intermediaries and knowledge brokers as translators, amplifiers, network providers.

The ASD Reference Group Research Sub-Group had worked on classifying issues for autism research in Scotland. They found the complexity of the subject meant that they could not present a simple matrix of research requirements. Instead they saw that there would be a need for multiple tables/scales to reference the various projects. Within the Seminar Series we therefore planned impact seminars and discussion sessions to identify how we might do this. In introducing the Impact Sessions participants were asked a series of questions, including:

- What kind of models for social care do we need?
- Looking at practice, do we know enough to know good services from poor services?
- What are good services like?
- We hear a lot about autism specific services, but are these necessarily good things?
- Should we have autism specific standards or standards that apply to everyone?
- What about adults? We hear a lot about children, the research is mainly about children, what about adults and older adults and women?
- We hear about training? What kind of training do people need? Is there such thing as good training?
- What are the effects of services - not outcomes, effects? Do they do harm in some cases? We need to know about the harms interventions can do before we

experiment further.

- Most of the results are achieved under lab conditions: why aren't the lab results repeated in the real world? how do we expand these collaborations between academia and the rest of the world?
- What about the involvement of autistic researchers?
- And what kind of research should we do about the ethical dimensions of participatory aspects of research?
- Should we do less research but improve the quality of it?

Data from all presentations at the Seminar Series has been analysed and themed according to issues raised, and opportunities identified for research to practice links and research to policy links. Gaps in current research in Scotland have been identified. A particular focus has been taken on the two recommendations identified in the Autism Strategy for Scotland, without excluding the wide range of research and issues identified.

1.10 Delivery of the Programme

The format of the AAR Seminar Series was determined by the driving aims of the series which are reflected in the current Scottish policy, research and practice context: the need for the Scottish ASD Reference Group to focus on Research Strategy in Scotland and to relate this to international knowledge and current research in Scotland; to mobilise the interest of the Scottish autism research community towards the Scottish ASD Strategy and thirdly to consider the day-to-day impact and potential of autism research on people's daily lives – families, individuals on the spectrum and the professionals who endeavour to provide support.

The Organising Team included researchers from three of the Scottish Universities involved in the Scottish Universities Insight Institute: Aberdeen, Edinburgh and Strathclyde which was also the Grant Holder. No overheads were applied as the grant focus was judged to be primarily research and its impact. The Universities were joined by the Co-Chairs of the Scottish Autism Strategy's Research Sub Group representing the main funders the Scottish Government Autism Reference Group (one as an Organising Team member and the other by specific invitation) and by representatives of the other funders, Scottish Autism and Research Autism.

The agreed format was to hold two day events to allow time for a spread of presentations from international speakers as well as presentations and poster sessions from Scottish-based researchers. Discussion was an essential part of each seminar and time was allowed for informal networking as well as chaired impact sessions.

The international speakers were invited to present in relation to each seminar theme though it is clear that our themes were not discrete and that most research in Scotland is psychological and clinical in nature with social and educational research being less common and more applied in nature. This raises questions about research impact and all speakers were asked to consider the impact or potential impact of their research.

A Call for Papers was made to researchers based in Scotland and disseminated through University networks. Each abstract submitted was blind peer reviewed by two members of an academic sub group of our Organising Team. All presenters were asked if they would be interested in subsequent publication. Similarly a Call for Posters was made and 20 posters were offered over the series.

The people involved in the Organising Team, the full range of speakers from each of the four seminars and their topics, poster sessions and the end point summary conference "Action on Autism Research in Scotland programme, can each be found in the Annexes listed.

The AAR Seminar Series was advertised on organisations' websites, attendance was free and the main costs incurred were speaker travel, accommodation, catering, design and print, administration and running costs. The Budget breakdown is available in a separate report. There were 136 participants over the four seminars with an average of 60 attendees at each two day event. The final conference invitations were extended to all attendees as well as to the new Autism Governance Group and Implementation Groups – places were available for a maximum of 100 attendees at this event.

No speaker fees were incurred and we warmly thank all involved for giving so generously of their time. Not least a huge thank you is extended to each member of the Organising Team and their employers.

1.11 Participation

Prospective participants were invited to complete a proforma with a statement about why they wished to participate, how they were placed to contribute and their capacity to disseminate the insights from the seminars. All presenters also provided biographical information. We aimed to form a group of participants who would build continuing relationships around research and linking research to practical applications and to policy formation. A strong core of people attended all seminars and most of the others came to three out of five events. This was important in terms of building a community around autism research in Scotland.

Ten broad groups of participants emerged: academic; local authority; health sector; social care; third sector providers; representative autistic people; representative parents; service leads; policy makers; funders. This mix made for interesting and challenging discussions ranging through pure science, applied research, personal experience and practice application in health, social care, education, psychological services, advocacy, practical applications and impact of research. We include a sample set of cameos from Annex 6.

Cameos

Masters Student

As a MSc. student and teacher in a school for children with ASD, I'm hoping to use what I learn at the seminar to both feed into my own masters research and report back to colleagues in my school about the directions autism research is taking in

Scotland. Hopefully, if required, I will be able to communicate some impression of how research and policy are impacting within the special education sector.

Parent /Carer

Involved in the Autism Strategy I have also written a number of discussion papers linked to delivery and improvement of services.

Autistic Person

My intention is to support links to policy & practice nationally with my connection to the ASD reference Group and locally – through ARGH and the Highland Autism Improvement Group (a multidisciplinary, multiagency group chaired by NHS Highland) of which ARGH are members. I also hope to put together a presentation for the final conference which will bring together themes from the seminars presented in the context of what they mean to Autistic people in Scotland.

Educational Psychologist

I plan to attend all 4 two-day sessions. As I work in a Local Authority I am already involved in strategic planning across the authority alongside intervention in schools systems and for individual pupils. I would like to plan to use the research and practice points to illuminate our school practice and authority strategic planning.

Policy Lead

Myself and my team will attend and reflect together on the potential impact on policy development and delivery of policy.

Research Fellow

My contribution to this seminar series will be in critically discussing the current autism research in Scotland, in order to help to identify where further work is needed and how this relates to the Research Strategy in Scotland.

1.12 Approach to Analysis of the Seminar Series Data

The Seminar Series has generated a significant set of data about autism research: we sought permission to video record all presentations and follow up discussion on impact. We audio recorded breakout discussion groups. We employed a transcriber, present at the seminar sessions, to give us a written transcript of discussions. We asked all presenters to provide us with their powerpoint presentations or paper from which they had spoken. We created a record of posters, participant and speaker profiles, dissemination feedback and evaluation.

This wealth of data is rich, important and challenging. The AAR Organising Team developed an approach to analysis. All AAR Seminar material was made available to them and they formed 5 pairs to go through all of the material relating to each of the four seminars and the conference, using a system of thematic analysis (Braun & Clarke, 2006, 2012). From this analysis the team was able to draw out key themes from each AAR event, identify gaps in research knowledge and priorities for policy and practice.

This first layer of analysis was then synthesized into a number of main themes and consequent actions and recommendations. Section 2 presents the themes for each of the seminars and the final conference, explains them and leads to the research gaps and policy priorities identified from the seminar data.

1.13 Abbreviations

AAR – Action on Autism Research

ADHD – Attention Deficit Hyperactivity Disorder

ARGH – Autism Rights Group Highland

AS – Asperger's Syndrome

ASD – Autism Spectrum Disorder

CBT – Cognitive Behavioural Therapy

CJS – Criminal Justice System

DSM-IV/DSM 5 – Fourth/Fifth edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders

ESRC – Economic and Social Research Council

HFA – High-functioning Autism

IACC – Interagency Autism Coordinating Committee

ICD-10 – Tenth revision of the International Statistical Classification of Diseases and Related Health Problems

JADD – Journal of Autism and Developmental Disorders

MRC – Medical Research Council

RAD – Reactive Attachment Disorder

REF – Research Excellence Framework

SARG- Scottish Autism Research Group

SIGN – Scottish Intercollegiate Guidance Network

SIT – Sensory Integration Therapy

SLD – Speech and Language Difficulty

SWAN – Scottish Women's Asperger Network

2 The Seminars & Conference

2.1 Seminar 1 - Psychological research, interventions and impact

2.1.1 Overview and Emerging Themes

The first seminar in the Action on Autism Research in Scotland Seminar Series (AAR) focused on psychological research, interventions and impact. Both broad and specific research was explored across the two days through presentations and discussion forums. These included broader concepts around what is known about Autism Spectrum Disorders (ASD), aspirations and future directions for autism and the science and ethics of autism intervention research. The Scottish presenters covered more specific research areas with ranging psychological and practical application. These included screening methodologies, early affective interventions and validity of research studies.

A key focus throughout AAR was embedding collaboration between the autistic community, researchers, policy makers and practitioners through discussion forums. The main themes are presented below and have been extracted through an analysis of these discussion forums that occurred during Seminar 1.

The main overarching theme to emerge across forum discussions related to *the spectrum of disconnect between research, policy and practice*.

The first subtheme to emerge within this, related to ability versus disability and how much research is aimed at investigating disability or deficits. Participants expressed a concern that researchers tended to focus on deficits and there was a call for a shift away from researching deficits in autism to considering the potential of investigating a skills approach:

i. *A need for researchers to move towards a skill based paradigm*

However, contrary to this Dr Aitken presented what he viewed as a research bias with the majority of research studies presented in peer-reviewed journals reporting findings based upon young males with High Functioning Autism (HFA). This led to the second subtheme related to bias:

ii. A need for recognition of researcher bias, funding bias and publication bias

This second subtheme to emerge from participant discussions related to the imbalance of focus of funding in autism. This echoed findings presented by Dr Pellicano on funding areas of autism research in the UK. Following this, discussion participants argued that there is often researcher bias, with many researchers working in this area as they can then respond to this perceived funding bias, which ultimately leads to a publication bias. Pellicano et al (2013) reported that the majority (56%) of research funding was given to 'biology, brain and cognition', with just 1% being given to societal issues. This discrepancy in bias led to the third subtheme related to participatory research:

iii. A need to be heard

There was a general consensus regarding the concept of representative inclusion demonstrated through its reoccurrence throughout the 2-days, across groups and discussion forums. In his keynote Dr Insel presented our evolving autism knowledge incorporating neurodiversity. Further, the self-advocacy movement was acknowledged recognising the call 'nothing about us without us' from the autistic voice. This call was reflected by participants advocating a need for autistic researchers seen as often bringing interesting insights to research. It was recognised that published research failed to report the largest subset of voices of the autistic population: those with autism plus a learning disability. Further, it was acknowledged that participation studies therefore often relied on those who actively engage in both research activities and practice debates (i.e. people with Asperger Syndrome/HFA or parents). Therefore, adaptations are required to give a voice to those who currently are not heard. Associated to this a fourth subtheme emerged that was also connected to communication:

iv. A need to be communicated with

In accordance with research findings reported by Pellicano et al (2013) participants echoed a translation gap of what the autistic community identify as priorities. It was recognised that there is a disconnect of reporting findings, developments and achievements to the autistic community in meaningful and effective ways. Therefore, it was proposed that there is a need to strengthen an adapted two-way dialogue between researchers, policy makers and practice and autistic community. Further, there was consensus that disconnect exists between expectations of research participants and researchers related to dissemination of research findings. There was agreement that a 2-way dialogue was needed in order to make research challenges transparent to those who have given their time freely, often with very little reward. The fifth subtheme to emerge encapsulated how we might capture this participatory voice:

v. A need for applied social research

There was general consensus amongst discussion participants that disconnect between research and practice exists. In her presentation on the science of ethics in autism research Michelle Dawson strongly advocated that autism research fails to meet many ethical standards. Dawson advocates a need for researchers to raise autism ethics and standards. Although science requiring RCT's was accepted participants also called for applied social research methodology. In order to capture the lived experiences it was agreed that social sciences possess the methods to report the voices of participants.

The final subtheme to emerge across the discussion forums was in response to the question 'what is our definition of policy?' and how this is viewed in a Scottish context.

vi. A need to interconnect policy with research and practice

There was consensus that policy can be viewed as an overarching framework that shapes consistency, good practice, benchmarking and level of quality across Scotland. Participants were in agreement that policy had to be interconnected in order for it to be effective in the lives of the autistic community. One participant expressed that many parents report that

they have never even heard of the Scottish Strategy For Autism. It was acknowledged that research should feed into policy. There was general agreement that many viewed policy as 'not interesting' and therefore efforts should be made to reach out to people by 'making policy more interesting in order to promote active engagement'. There were further calls that policy should measure the impact of policies on the impact of services through collecting the right data. Finally, it was acknowledge that Scotland afforded geographical opportunities to create connections between researchers, practitioners and policy makers.

2.1.2 Research Gaps

- Research occurs in a strategic vacuum where there are no common objectives or even any standardisation of measurement which could provide the basis of meaningful comparison and consolidation.
- Abiding question of how best to define autism
- Clear evidence that these are 'autisms' no longer 'autism'
- To narrow the translational gap – by defining research that is more relevant to autistic people and communities, everyday lives and values
- To create active research partnerships
- A need for practical application of research
- Questioning the quality of research: the need for research that is done for the right reasons

2.1.3 Policy Priorities

- There is no readily identifiable link between research and social policy;
- The importance of arriving at a shared definition of autisms
- A challenge to be clear on definitions of autism - identity, illness, injury or insight?
- To narrow the translational gap - by public dissemination, dialogue and partnership - Universities, Government national & local, Third Sector - research, practice and strategy
- Understanding pure science/applied science and that applied science must bring overlaps between discrete research areas

2.2 Seminar 2 Clinical Research, Interventions and Impact

2.2.i Overview and Emerging Themes

The dominant focus of Seminar 2 was on clinical research and practice in autism and the contribution of neuroscience. Even 70 years after Leo Kanner and Hans Asperger independently identified autism as a clinical, developmental condition, significant challenges remain for both diagnosis and intervention or treatment.

i. Autism is complex and variable

However, in wrestling with those challenges, research and aspects of diagnostic practice have uncovered many indicators that autism is complex and variable, more so than has been thought and thus helped develop our understanding.

In her presentation, "Autism Achieve Alliance: A national study of risk factors in individuals diagnosed with ASD, Professor Anne O'Hare reported on a Scottish study of risk factors for autism using a sample of 80 children with a confirmed diagnosis. Analysis showed very high rates of risk factors, which included speech delay and family members with ASD. An astonishing 98% of the sample showed evidence in their case histories of risk factors - and not only a single factor. The average was 2.6 factors per child. Moreover, 90% had additional support needs.

ii Diagnostic issues persist

Other presenters reported on a similar theme. Professor Chris Gillberg observed that the co-existence of other clinical conditions is so consistent, that autism could be split into 'Autism Plus' and 'Autism Pure'. Moreover, Autism Plus, in which autism co-exists with conditions such as ADHD, OCD, Tourette's, Speech and Language Difficulty (SLD), is by far the more common of the two groupings. Autism Pure, he maintained, would not in itself present much of a difficulty. The real challenges come from the grouping Autism Plus. Professor Declan Murphy concurred and even noted that when he and his team reviewed the cases of those diagnosed with conditions other than autism, they found many missed cases of autism. The condition had not been diagnosed because it was masked by the presenting conditions which included ADHD, anxiety, and depression. Chris Gillberg concluded that the research focus on Autism Pure is a mistake. Autism itself is not a severe disorder, but co-existing with other conditions it is devastating.

This position was largely accepted by the audience in their comments, but led to a number of questions about implications for a National Autism Strategy and for clinical teams such as CAMHS. Chris responded that this is about re-organisation of services and that services should not focus on one condition but need to address the co-occurring conditions.

Dr. Iain McClure reported on the current difficulties with diagnostic processes in Scotland, and on significant delays in diagnosis including the need for a detailed history when a child first entered the system, and better training for those who refer. Given the emerging complexity of making a diagnosis the reported delays are perhaps not so surprising. However, the research team identified strategies for greater efficiency.

Judith Piggot argued in her presentation that diagnostic tools such as the ADOS can create the simplistic impression that autism is about reaching a certain cut-off score. Diagnosing may not be a 'yes or no' process. This echoed Chris Gillberg's stance that "Nature never draws a line without smudging it" (quoting Lorna Wing). However, Judith noted that the process of attempting diagnosis with set criteria could help provide a profile that allows for considering intervention on a sub-group or even individual basis.

iii The resemblance of autism to other conditions

A slightly different sub-theme was on the resemblance of autism to other conditions, and the implications of this for diagnosis. Clinicians need to be careful in distinguishing between conditions in which certain kinds of behaviour overlap. Helen Minnis and Andrew Stanfield both focused on similarities between symptoms of autism and other conditions. Helen Minnis pointed out the similarities in social interaction and social relationships in reactive attachment disorder (RAD) and ASD, particularly the similarity of Inhibited RAD symptoms and ASD signs. She identified subtle differences, and proposed research to develop an observational tool to differentiate ASD and RAD behaviours reliably. Andrew Stanfield highlighted the presentational overlap between ASD and Schizotypy, again identifying similarities in social interaction difficulties. However, he noted that the two conditions could also co-exist, making the need for expertise in diagnosis even more crucial. Neuroscience has a clear role to play, he maintained.

iv Thinking autisms

A recurring theme through the seminar was in the need to think not of *autism* but of *autisms*. Clinical, neuroscientific and genetic research all point clearly in this direction. However, the theme of diagnosis is interwoven with the theme of intervention and one aspect of this, and a longstanding point of agreement is the urgency of early diagnosis to enable early intervention. This was the context of Helen Tager-Flusberg's work on "Investigating early behavioral and neurobiological markers of risk for autism spectrum disorder". In her comprehensive talk Helen spoke of the need to identify early markers of risk. Comparing high risk infant siblings of children with autism with a low risk sample, she reported no signs of autism until year two, and a typical pattern of social interaction at six months. However, using neurobiological comparisons identifies atypical brain asymmetry in response to social stimuli in language regions. She reports heterogeneity in all aspects: the clusters identified echo indicators from genetics. The message is repeated of *autisms* not *autism*. Neuroscience could identify high risk infants for intervention that could minimise the impact of autism.

In a similar vein, Fred Volkmar spoke about the social nature of autism and the early signs of autism in social expressiveness. In relation to early indications of autism and methodology, Volkmar asked whether, if we refine our method, we can refine our differences early?

v Intervention

The second dominant focus of the seminar was intervention. Most presenters connected the research findings on diagnosis to approaches to intervention. The first should inform the second. Judith Piggot argued that diagnostic testing could provide a detailed profile for children and move the skills profile forward. Her programme, SMARTS tries to do this by

aiding social skills. It may also be effective for parents; helping them to help their children develop.

In his exploration of 'Translational neuroscience' Declan Murphy concurred with the view that ASD is complex, with multiple biologies. He noted the huge range and variation in interventions and yet the lack of an evidence base for them. He also pointed out that, given the agreement on the degree of heterogeneity in autism, no intervention could adopt a 'One size fits all' approach. At the same time, reliable evidence of effectiveness is expected. So he argued for a scrutiny of the minority who responded well to an intervention, since each intervention might be suited only to a minority.

Other presentations on intervention included neurochemical approaches. For example, Bonnie Auyeung and Declan Murphy had evidence of improved social behaviour with oxytosin and serotonin respectively.

Introducing the afternoon discussion, the convener noted that the day had highlighted how far we have to go but also how far we have actually already come in autism research, with exciting possibilities. Two themes dominated:

vi Understanding autism towards early intervention

The first, led by Helen Tager-Flusberg, explored how we can understand the autism spectrum better and have early identification - fundamental to intervention.

vii More effective intervention informed by neuroscience

The second theme, led by Declan Murphy concerned how to have more effective intervention based on what we can learn in particular from neuroscience. In subsequent discussion the participants focused on a number of sub-topics which were common to several groups. These included the need to collaborate in developing effective measures in identifying autism and in relation to practitioners running an effective system for diagnosis. One repeated term was 'uncertainty': whether we know what autism really is; whether we are measuring the same thing in diagnosis, and whether intervention should be designed to apply broadly or specifically for autism subgroups. There was concern that clinical anxiety is not fully recognised in autism and so not treated. Linked to this, families want practical advice; they want to know what to do.

viii Translating Research

Specific problems arise too for those living in poverty, or with English as a second language. Overall, there was a strong emphasis on how research might or should inform practice and policy and how to translate research for that purpose. Practitioners would benefit from knowing which researcher groups can have an impact on specific areas.

Overall, the seminar illuminated the consensus that autism is not a single condition but exists in multiple forms. These are challenging to identify and discriminate, so that diagnosis requires considerable specialist knowledge, including awareness of conditions that might present similar signs, or indeed co-exist. These discoveries are significant, but expose how little we still know about autism. Interventions proliferate but may not be based on

evidence and tend to be designed for a one size fits all solution. There is even more work to be done to develop effective intervention that will help those with autism. Co-existent conditions play a large role and the heterogeneity of autism has to be intrinsic to intervention designs. Research on diagnosis and on intervention must develop in tandem for the most effective and meaningful outcomes.

2.2.2 Research Gaps

- Need for a differential observational tool and expertise in diagnosis is crucial
- Neuroscience could identify high risk infants for intervention that could minimise impact of autism
- Scrutiny of minority who respond well to an intervention
- With refined methods can we refine differences early?
- Broader knowledge of Autism Plus and risk factors
- Clearer link between diagnosis and form of intervention
- Stronger evidence base for interventions

2.2.3 Policy Priorities

- Services re-organisation – from specialist to generic
- Better training for those who refer
- Re-organisation of services for more efficient diagnosis
- Investment in early diagnosis using risk factors
- Support for neuroscience to refine understanding of autisms and inform possibilities for interventions
- Explicit role for research in directing policy

2. 3 Seminar 3 Social Research, Interventions and Impact

2.3.i Overview and Emerging Themes

The third seminar in the Action on Autism Seminar Series focused on social research, interventions and impact. A wide variety of research was explored across the two days of presentations, including work on stress, anxiety, sensory processing, emotion-focused therapy, employment, the criminal justice system, transitions to adulthood and practice-based evidence. Professor Gary Mesibov's keynote address on his forty years of autism research was a highlight of this seminar.

The key themes that emerged from the presentations and discussions are summarised below.

i 'Challenge every dogma'

This phrase was used by a speaker to emphasise the importance of questioning notions about autism that become accepted 'truths', just as the concept of the 'refrigerator mother' was questioned and finally discredited in the 1960s.

A widespread dogma challenged by several speakers during Seminar 3 was the idea that a joyful and productive life depends on success in following a traditional life pathway (i.e. job, marriage, career). Considering the challenges that relationships pose for people with autism, and the 'monumental employment problems' they face, it was considered important to resist the idea that '…if someone is 33 years, four months and two days old and isn't married then they're a failure…they've got the wrong goal.' Instead, there were repeated calls in several different workshops to resist traditional pathways and look beyond conformity to existing cultural expectations. It was agreed that a focus on individual needs and experience is necessary to find more realistic, meaningful and achievable life pathways. More focus on happiness and wellbeing, rather than pathology, should be a priority.

> 'The idea that inclusion and a job are right for everybody is taking a somewhat narrow view of it.'
>
> '…we can do a great deal to provide a high level of quality of life in the absence of these traditional outcomes.'

ii Applied Social Research

Whilst it was acknowledged that medical research will always be vital to the ongoing search for causes and treatments, there was a consensus amongst delegates and speakers that there needs to be greater emphasis on applied social research that has the potential to enhance the day to day lives of people with autism. One speaker noted that though research has achieved a lot '…in terms of what affects people's lives, not much has changed…autism research isn't helping people with daily realities.'

> '(Applied social research) is probably the field that opens up the greatest number of real possibilities for helping people with ASC'

A number of points were raised about this. Firstly, it was proposed that we need to look at 'what works' and 'different interventions for different people'. It was also emphasised that

we ought to be looking at qualitative and combined research strategies, as well as the more traditional quantitative research approaches. This will enable us to explore the influence of environmental context on treatment and intervention efficacy, and provide insights into their impact on the subjective experiences of different individuals and groups:

> 'People do not live out their lives in medical paradigms; they live complex, multidimensional lives. Research must cross disciplines to reflect that.'

More applied research will also provide an evidence base for good practice – something that everyone recognised as a significant problem in the field of autism.

Linked to above is the need for a practitioner research model to enable greater evaluation of autism practice. This requires us to address the problem of the current low status of such research by developing a better appreciation of qualitative research approaches and what they can contribute to a wider understanding of autism. For example, ethnographic research methods could provide a more multidimensional understanding of the links between people, environments and behaviour as this approach 'creates a dialogue between clinical interventions and the holistic perspective of the practitioner (and clients).' However, it was noted that this calls for a culture shift in practitioner training and development to explicitly foster enquiry and research skills amongst autism practitioners. A need for guidelines and research standards was also acknowledged.

iii Participation

There was a consensus amongst speakers and delegates that autism research should be more participatory and directly involve people with autism as well as the wider autism community. This was a recurring theme, especially in the impact workshops. Here, delegates on the autism spectrum acknowledged that they would be more willing to contribute to research projects in schools and other services if they could be more involved in the research process itself. It was suggested that a more collaborative approach would result in a process that is of mutual benefit:

> '…I'd be willing (to take part) if it wasn't just for the researcher to give them more information, but to see something that is going to have an impact on the kids.'

Some delegates called for the formation of a network of individuals and groups who declare themselves willing to contribute to autism research. It was also proposed that it is important to forge…

> '…strategic relationships between universities, schools, clinics and other groups who have something to add to research and practice.'

However, it was noted that funding is required for this, plus a better sense of who is responsible for the dissemination of good practice.

iv Who Adapts?

Several speakers in seminar three highlighted the fact that many service environments, and the interventions used within them, are still not adapted to meet the needs of clients with autism. This means that a heavy burden of adaptation falls to individuals with autism, which 'just creates more agitation in the individual' and undermines wellbeing. The problem of

'who adapts?' was therefore an important recurring theme and was repeatedly linked to poor autism awareness and a lack of practitioner training.

Examples specifically explored during the seminar included the lack of environmental adaptations within the criminal justice system (CJS) and employment contexts, as well as the lack of adapted interventions for stress, anxiety, and sensory issues associated with autism. We will briefly consider each of these in turn:

- Lack of Adaptation within the CJS:

People with autism may be over-represented in the CJS as a result of pursuit of fixations, impulsivity, context blindness, weak theory of mind, misunderstanding of social rules, sensory reactivity, etc. 'Mate crime' also occurs where individuals with autisms are duped into illegal activity by peers.

When in the system, there are significant problems for people with autism in responding to questioning and providing evidence linked to poor social communication, poor social understanding and weak episodic memory including:

> '…difficulties with temporal order, the fine details of what happened, the bigger picture of the event, and in organising memory in a semantically meaningful way.'

It was emphasised in seminar three that questioning and evidence-gathering processes within the CJS are currently poorly adapted for individuals with autism. Research suggests that they can be helped significantly by building in extra cues, word associates and more structured questions to aid recall. Going back to the scene of crime may also help, as well as making use of drawing and computers wherever relevant. However, a strong evidence base for these approaches is yet to be established.

A key difficulty is that 'problems do not easily come to light' because of the numbers of undiagnosed offenders and the lack of autism awareness amongst the police and related professionals. The need for training and adapted support mechanisms is therefore urgent, not least because a lack of action means that people with autism 'may never see justice or get parole'. They need more help to navigate the system.

- Lack of Adaptation Within Employment Contexts

It is widely appreciated that individuals with autism can have problems fitting into the culture of work. Equally, research presented in seminar three indicated that employers experience challenges adapting work to employees with autism, finding it difficult to abide by equality, diversity and inclusion legislation and their requirement for 'reasonable adjustments'. They also have problems with disclosure, transitions, coaching and third party support in the workplace.

> 'These things don't tally well with the reality of work organisations. They seem OK and practical in principal, but trying to put them into practice can be difficult.'

We therefore need greater awareness of management control mechanisms in employment contexts and ways of challenging employer views and practice e.g. via more active union / third party involvement.

- Lack of Adaptation to Stress and Anxiety Interventions

One presenter emphasised that '40% of children with ASC would meet the criteria for an anxiety disorder'. Indeed, emotional and mental health problems 'are at very much higher levels within the autism spectrum than the general population'. These problems can arise in relation to a wide range of life experiences, but the transition to adulthood was highlighted as a particularly problematic phase during seminar three. Many people with autism do not have effective coping strategies for dealing with the stress and anxiety that transitions can provoke. The research therefore underscores the need for further action:

> ''…the anxiety side of things is what I'm seeing more and more with young people…You almost feel like you are contributing to the failure because you aren't intervening in the way you could be.'

There was much discussion about the lack of adaptation of therapeutic approaches to the stress and anxiety experienced by clients with autism. Research exploring adapted therapies was therefore welcomed by delegates e.g. emotion-focused therapy using video feedback and adapted forms of cognitive behavioural therapy (CBT), especially those that are highly visual, practical and draw on new technologies such as 'virtual reality'. However, it was also proposed that, rather than focusing research and interventions on stress as it is 'embedded in the person', emphasis should also be placed on the 'stress transaction' i.e. the relationship between the individual and the environment in which stress arises. This enables us to identify how to moderate the stress transaction rather than trying, in some cases, to 'fix what isn't fixable'. There was therefore a clear message to avoid a 'deficit' view that focuses solely on autism as the source of problems, without taking the role of unadapted environments (including untrained staff) into account.

- Lack of Adaptation to Sensory Interventions

Individuals with autism can experience complex combinations of hyper or hypo sensitivities relating to visual, auditory, gustatory, olfactory, tactical, vestibular and proprioceptive modalities. The consensus arising from self-report research seems to suggest that sensory issues increase as autistic trait levels increase, with the greatest number of issues associated with auditory processing. However, predictability and control also affect sensory perception which suggests that the environment can have a significant impact:

> '…a good rule of thumb is if it bothers you, it might bother people with ASD, so give them as much control over their sensory environment as possible.'

The underlying causes of sensory difficulties were explored in seminar three in relation to neural noise theory, though it was emphasised that this research is highly contested. In terms of dealing with sensory issues, Sensory Integration Therapy (SIT) can be a helpful, adapted approach making use of weighted vests, riding boards, coloured filters, etc., to address individual needs. However, it was noted that the evidence base for SIT is weak. Adjusting the environment by removing sensory triggers can also be very effective. However, this relies on conducting an accurate sensory audit and 'educating everyone else about the sensory issues of people with autism.' Thus, again, practitioner training lies at the heart of the matter.

> 'This is of crucial importance because for some people on the spectrum the sensory issues are devastating in terms of impact.'

Overall, the issue of poor service adaptation emerged as a high priority during seminar three. Specifically, we need:

- more adapted therapeutic interventions for stress , anxiety and sensory issues
- adapted support provision within the criminal justice system
- management control mechanisms and better adapted support for employment
- more autism training and environmental adaptations across services

vi Assessment & Diagnosis

It was argued during seminar three that since definitions of autism change over time, there is a need for a clear and common basis for assessment so that comparisons can be made across settings. This would also enable us to develop a pool of useful data for research purposes. The point was made on several occasions that we need to get better at identifying adults, reduce long waiting times for diagnostic assessments and ensure early intervention.

> 'What we need is a common set of basic tools that allow us to profile people's strengths, abilities and difficulties.'

It was proposed that more post-diagnostic counselling for people with autism and their families should also be prioritised.

vii Autism Research Gaps

> 'We're looking for things where the light is clearer, but most of the things we need to find out are the ones in the darkness.'

Delegates expressed their appreciation of the excellent research going on in Scotland and beyond, a small sample of which was presented during seminar three. However, there was wide agreement that there are gaps in the autism research which, as the quote above suggests, currently lie 'in the darkness'. It was therefore proposed that we must cast more light on the research areas summarized below:

- transitions research - especially transitions into adulthood
- research on autism, anxiety, stress and 'stress transactions'
- sensory research with a focus on 'intrinsic neural noise' and the efficacy of sensory integration therapy
- research on autism and the criminal justice system
- research on autism and emotional processing
- research on autism and employment
- research focusing on adults with autism and groups with more severe and complex autism:

  'There is an over-focus on able individuals with autism'

  'The question all of us are being asked is: what about the wider groups…what about those with learning disabilities…what about the adult population?'

In order to address these gaps we need:

- more qualitative/ participatory/ practitioner research

- greater awareness of methodological problems such as replicability issues, treatment fidelity problems, epistemological conflicts, etc.
- guidance on rigorous qualitative methodologies
- better dissemination of research findings to the public

viii Autism Policy Priorities

The following policy priorities emerged from presentations and discussions throughout seminar three. However, they were a particularly strong focus of discussion during the impact workshop at the end of day two:

- Funding for practitioner research and evidence-based practice
- Disseminating research evidence of good practice to the public
- More people with autism involved in policy and service development
- Mechanism and funding to encourage collaboration and partnership e.g. data base of individuals/groups willing to be involved in research.
- More support for transitions to adulthood
- More focus on adult diagnosis and post-diagnostic support, including therapeutic interventions
- Development of a common assessment process
- Development of a national database

2.3.2 Research Gaps

- Transitions
- Anxiety, stress and sensory issues
- Criminal justice system
- Autism and emotional processing
- Autism and employment
- Adults with autism / severe and complex needs

2.3.3 Policy Priorities

- Funding for applied social research
- Better dissemination of research evidence to public
- More people with autism involved in policy /service development
- Funding for research partnerships database
- Support for transitions
- Common assessment process and database
- More adapted therapeutic interventions for stress, anxiety, etc.

2.4 Seminar 4 Educational Research, Interventions and Impact

2.4.1 Overview and Emerging Themes

This final seminar in the series focused on experiences of education, research based interventions and tools that support knowledge translation of research into practical applications. The two days included presentations from a range of disciplines that contribute to education. Applications of science in autism were applied to the social situations implicit in education. Parental, practitioner and researcher perspectives on the challenges and opportunities of education for autism and the importance of such educational opportunity, social relatedness and learning were all considered.

The Seminar opened with an address from the philanthropist Dame Stephanie Shirley who talked to the title 'A Parent's Perspective'. She addressed the implications of autism for families, for individuals and for robust research and the associated advocacy and funding issues. Her comprehensive lecture drove the themes for this seminar.

Professor Tony Attwood's videoed presentation stressed the importance of positive approaches and continuity of education for people on the Spectrum: strengthening the relationship of research to practice to the benefit of people with autism. He stressed many helpful practical approaches that emerge in evidence-based practice, and importantly, that work. Dr Justin Williams, as a Senior Lecturer in Child and Adolescent Psychiatry gave an elegant lecture on Autism and the Science of Social Learning: from Scanner to Stage. His presentation bridged research and practice by modelling the applications of basic science to daily practice and he highlighted what research generated knowledge means for teaching and learning behaviours. Visiting Professor Tommy MacKay took a fresh look at prevalence and cognitive ability: drawing out the implications for education and the autism spectrum in Scotland, saying that we don't know prevalence and distribution of ability in Scotland, in a context where accurate prevalence information is crucial for strategic planning of educational provision. Many strategic planning projects for educational provision for additional support needs have failed or succeeded on the basis of prevalence.

Two groups of presentations were given by Scotland-based researchers. In the first set Dr Catriona Stewart, Dr Barbara Dritschel and Carolyn Brown and Shirley Paterson, Senior Educational Psychologists. Research into the understanding of self and other, the lived experience and anxieties of autistic women and the importance of planned pathways of intervention, education and care rang through these presentations. The juxtaposition of this group of presentations reflected the need for the personal voice, the knowledge voice and the implementation voice to connect. Round table discussions facilitated and continued this engagement.

In the second set of presentations Dr Evelyn McGregor, Dr Jackie Ravet and Jayne Porter and Moira Park each presented on ways of making a difference to the educational experience. Dr McGregor's work looked at narrative related interests and offered rich insight into how this knowledge could be applied to the reading process in primary school. Dr Ravet focused on continuing autism focused interprofessional education and the modification of attitudes,

perceptions and competing discourses and the benefits that accrue for shared working. She highlighted facilitating and inhibiting factors in applying learning to practice

The two days concluded with the big question of "What next in Autism Research?" from the 4 national perspectives of the different parts of the United Kingdom. Presenters in the "What's Next for Autism Research" session, Tommy MacKay for Scotland, Tony Charman for England, Arlene Cassidy for Northern Ireland and Sue Leekam for Wales, illustrated a layered model to build Local, UK-wide, European and International research strategy to address known gaps.

Professor Tony Charman encouraged us to be ambitious and diverse in our research efforts, but particularly emphasised the importance of scientific study of early autism and links between the AAR Seminar Series and 'A Future made Together'. The notion of a bridge was reinforced in Professor Sue Leekam's presentation: this idea is important as we consider how to concentrate on knowledge translation. She emphasised the sharing and using of research in policy and practice, the relationship of basic science research with service research and the need to focus on bridge between the two. Professor MacKay followed through from his earlier presentation by asserting the importance of accurate information on predicted numbers at different levels of learning disability as crucial for planning appropriate training for practitioners and for how both mainstream and special schools are resourced, so tying in with the Microsegmentation Project he is working on. Dr Arlene Cassidy's presentation showed how in Northern Ireland the research investment is differently balanced than in the rest of the UK – it is weighted towards Services and also to Treatments and Interventions. NI research activity is largely generated by agencies close to key stakeholders. In policy terms, the Northern Ireland Autism research to date is driven by early strategic development stage of Autism infrastructure.

This rich mix and the associated impact discussions generated 6 clear themes for educational research and brought policy priorities to the surface.

i Educating for Educational Research, Interventions and Impact

In presentations and discussions there was an emphasis on the nature of the research journey and the essential role research has in implementing strategy. There was an emphasis on robust research design, the sharing of research work, the sharing of data, funders as stakeholders and independent verification of findings. The lack of an evidence-base and understanding of research methods in practice and policy is challenging. In practice terms this may be shifted by more observational research in context, while in policy terms an open dialogue between research and policy that includes discussion of strategy is crucial.

> "Vigorous information sharing amongst researchers and translation of their findings into service provision is needed. Research is humbling and hard work"

Standard educational opportunities are needed for all. Integrative as well as detailed thinking is needed, good research will be inter-disciplinary.

ii Investment matters

There is a need for increased investment in educational and social research. Educational researchers need to be advocates for funding in an underfunded research field. Good practice must be based on evidence. Engagement in research leads to sharing and learning:

> "Research is slow, is expensive, demands involvement, can't be much delegated, progress depends on research"

New findings create new questions, and greater investment must be accompanied by consideration of subject assent, parental permission, legal authority and moral responsibility.

iii Listening to stakeholders' priorities

Impact discussion focused on who the stakeholders are in educational research and interventions. The educational process offers a time of hope for families and learning and development for children and young people. Large scale cohort studies make an important contribution, but we are reminded of the importance of information and the role of Educational Psychologists in bridging research and practice. It is important to respond to Dame Stephanie's message that we need to

> "Understand how parents can bankrupt themselves emotionally, financially, chasing after something, anything, that will help their child"

> "Families are in dire need of results"

It is therefore important to know the home environment – to map the home context, contextual features, cognitive skills, narrative interests and behaviours of children, siblings and peers. Approaches need to be matched to context and to what families are able tell us.

iv Real difference in Services

The huge willingness and commitment to do well in education for children, young people and families means working together on shared engagement. Research and practice links bring a series of incremental advances – this work is both important and urgent

> "Shared voyage of discovery whose purpose is to inform action"

> "Projects that if successful make a real difference, that produce tangible results against the sea of need"

> "Do educators have the tools for their tasks? It's not enough to choose the best intervention for the child: it must be the best for the carer too"

Services need to be able to respond to family systems, to know when and what interventions will make a difference, to build from the strengths of people with autism and to share common platforms for communication. Education needs to embrace mental health

and wellbeing, communication and anxiety alongside learning, and to know that autistic individuals in mainstream may "appear to glide across the surface of life, paddling furiously underneath" (Dr Catriona Stewart)

v Complexity & perplexity

There were many important messages about understanding the effort involved for autistic pupils in mainstream education, not underestimating or passing by an individual's ability and while recognising the complexity of autisms, at the same time challenging a deficit model which becomes an added burden with people who are working hard to keep afloat. Dr Stewart's concept of 'cloaking and masquerading' brings with it the risk of being found out and of experiencing failure.

> "Girls with AS experience intolerance and marginalisation in the mainstream school setting. Unusual and specific sensory and perceptual characteristics often not addressed. The school environment, from the classroom setting to the common social areas, the corridors and stairs and the dining rooms, often cause high levels of stress and anxiety, inhibiting the girls' abilities to function comfortably and leading to somatic symptoms."

Evidence from the literature suggests that boys also experience similar symptoms, but their responses may tend to be overt.

Practitioners and schools were reported to be "feeling much more confident about their involvement in interventions for children" "Autism is becoming the number one across nurseries and schools". It is essential that work continues in educating practitioners about autism, so that it is understood better. This means changes in organisational practice, developing understandings of autism in inclusive contexts; enabling participation for learning and making sense of school for all participants. Evidence suggests that though there are many success stories, every individual's journey through education is different and there continues to be a need for tailored approaches.

> "Schools report they are feeling much more confident about their involvement and progression of youngsters on the spectrum"

> Dame Stephanie referred to "The different aspects of this perplexing disorder which blurs all the social codes"

For these reasons the autism knowledge of education practitioners needs continued investment. The recent work on the digitalising of the Scottish Autism Toolbox is an example of making information available and accessible.

> "There is no magic wand, but the Toolbox provides an excellent Book of Spells"

vi The strategic nature of empathy

Much of what emerged in this Educational Research, Intervention and Impact Seminar promises movement towards needed changes, addressing identified gaps and making

recommendations for policy. Each is informed by a sound understanding of autism and the capacity to translate that understanding into action. Central to effective educational practice is the capacity to communicate:

> "My son likes stories that include emotions and watches my face as I demonstrate sad or excited: the visual aspect is crucial" (McGregor, Fact or Fiction Project)

The social context of learning, the way we learn from each other through imitation, gesture, reading meaning in others, understanding each other's motivation and thinking, drawing on past experience and imagining consequences are central to navigating social contexts. These understandings of autism need to underpin all we do. This is hard work for the autistic person, the rest of us need to adapt to be less ambiguous to the autistic person.

> "Dad I don't want to be in the human race, I just want to watch"
>
> (Justin William's presentation)

2.4.2 Research Gaps

- Understanding of what works and developing an evidence-base built on evaluation of practice
- Evaluation of interventions that consider how this works for both individual and family
- Understanding the mechanisms of intervention before we implement
- Monitoring knowledge change in practice
- Knowledge translation from research to practice
- Understanding of stakeholder concerns

2.4.3 Policy Priorities

- Revisiting stakeholder priorities for knowledge and practical applications of knowledge to create positive change
- Work on the research-practice bridge
- Work on the research – policy bridge
- The need to get together on shared points – to make anything strategic happen
- High tech support for the Scottish Autism Strategy – to measure success
- Developing an open dialogue between Scottish autism researchers, stakeholders and Government Strategy

2.5 Poster Sessions

Overview

A call was made for poster presentations to be offered over the four two-day seminars. There were 20 poster presentations in all – these were displayed throughout the two days and researchers were available to discuss their posters. This opportunity augmented the 24 Scottish research presentations given during the AAR Series.

Posters were themed across 4 domains: clinical (8); psychological (3); Social (4) and educational (1). Interestingly this is reflective of what we know about research funding across the UK (Pellicano, Dinsmore & Charman, 2013), and how different areas of research and therefore studentships are funded. Nevertheless the spread of topics represented was wide and each topic distinctive. It is encouraging that this, mainly student, work was brought to the AAR Seminar Series and indicative of the research environment for autism in Scotland.

The posters illustrated work to develop basic knowledge in the field of autism, work which was more applied in nature showing perceptions held of autism which are informative for a continuing awareness-raising agenda, one project with direct educational application and several which enhance understanding of cognitive processes in autism.

Across the Scottish Universities there are numbers of Masters and Doctoral Students with the aspiration to continue their studies of autism and to influence what happens for all stakeholders into the future.

Their work needs to be made visible and understood for the potential of sustaining the autism research community in Scotland. A number of the poster participants are currently using what they have learned from their studies in day-to-day work with autistic people and autistic services.

A full list of Poster Presentations is included in Annex 4 of this report.

It is important that the work of emerging researchers and their voice is included in the development of a Research Strategy for Scotland.

2.6 Action on Autism Research in Scotland: What Does Scotland Need? Final Conference

2.6.1 Overview and Emerging Themes

The AAR series of four seminars on psychological, clinical, educational and social research was concluded with a final conference held at the University of Strathclyde in November 2014. The interlocutor for the AAR series, Professor Tommy MacKay reflected in his opening talk on recent developments in the politics arena in Scotland by stating that conclusions from recent events surrounding the Scottish independence referendum could also be applied to the field of autism research. Awareness raising and societal involvement should be at the forefront of research developments in this area. He added that the importance of autism research has gained wider recognition in recent years, but this was not always reflected in the quality of evidence or its further policy and practice implication and application.

(…) sheer amount of information being generated, but also the sheer amount of misinformation being generated (…) very poor overall signal to noise ratio and in a lot of these fields [in autism] what we're hearing is actually the noise and we're not finding the signal at all. We have an opportunity to take forward evidence-based practice and generate practice-based evidence. We've got an opportunity to see if all the research in autism that we're doing in Scotland, if we can improve the level of the signal and cut down some of the level of the nuisance noise that we find everywhere, including the highest academic journals and some of the most widely quoted research.'

Professor Tommy MacKay, University of Strathclyde

Professor Aline-Wendy Dunlop reflected in her presentation on the main focus and achievements of the AAR series by adding that its aim was to make recommendations for a national autism research plan in the future as well as mobilise the interest of autism researchers towards the Scottish Autism Strategy (Scottish Government, 2011) by referring to its two recommendations, which are of particular relevance to the research community. These are as follows:

Recommendation 7: It is recommended that the ASD Reference Group commissions research to examine and compare the outcomes in relation to quality of life for those who are supported by autism service providers and individuals who access generic provision and that relevant findings are used to inform revised guidance for commissioners of services for people with ASD.

Recommendation 8: The ASD Reference Group in collaboration with autism service providers will identify the key determinants of service provision that result in improved quality of life for people with ASD, across the spectrum and across the lifespan.

Aline-Wendy Dunlop added that planning stages of the seminars included extensive discussion around the impact of research and quality of work being presented. Four main strands were chosen to organise the talks into psychological, clinical, social and educational research, as these also reflected areas of autism practice. However, the holistic view of autism research across different disciplines was of upmost importance when planning the seminars. This was also one of the reasons why representatives from four different communities of individuals affected by autism, policy-makers, practitioners and researchers were involved in the series. Conference presentations reflected this constituency.

During the AAR conference, six different people from our community of enquiry took their turn to reflect on what had been presented and discussed at the seminars in a "Voices" session. Each offered a glimpse of what the series and process of involvement had meant to them and their communities.

Common themes identified through narrative analysis of these presentations could be briefly expressed by citing the ethos of one of the autism advocacy organisations ARGH whose representative, Kabie Brook also presented at the conference. ARGH's mission is to 'Inform Educate Campaign Challenge'. These four key statements and aims have been used below to describe briefly four main themes identified in the AAR conference evidence.

i Autism Research Priorities – Inform

The report published by the Institute of Education in London 'A future made together: Shaping autism research in the UK' (Pellicano et al., 2013) was often cited during the Action on Autism Research events, including the final conference. The report showed that autism research priorities of people on the spectrum differed slightly from those of practitioners, researchers and family members. For people with autism spectrum disorder (ASD), the biggest priority was to study how public services can best meet the needs of people on the spectrum whilst practitioners, researchers and family members mostly wanted to know what the best ways for improving the life skills of autistic people were. People on the spectrum were also the only group of respondents who considered researching what the future holds for them a priority. They saw autism mostly through the lenses of societal and attitudinal challenges, but did not put great emphasis on the need to 'cure' people of them, which reinstated the dissonance between the existing body of evidence on autism and priorities for autism researchers verbalised by both people on the spectrum and researchers themselves.

Are we providing the building blocks to societal change if the priorities are wrong?

Kabie Brook, ARGH

There was, however, a high degree of consensus amongst different groups of the autism community that what future autism research should inform are the areas of service provision, promotion of life chances of autistic people and knowledge and evidence on how people with ASD think and learn. As Kabie Brook from ARGH reflected in her presentation, these slight differences in priorities challenged one of the myths on autism regarding perceiving views of research and autism communities as typically opposing.

Other research priorities expressed through the AAR presentations were concerned with information on impact of autism on people's lives, the way in which they are treated and how they access services, especially when residing in remote parts of Scotland. Other priorities included changes over the lifetime and research on people who have an accompanying learning disability. It was also stated that more information was needed on educational provision for children with ASD, which can vary significantly in different local authorities across the country. Such research could encompass topics such as exclusion rates, academic results, general wellbeing and attainment in further education and employability. As it was concluded by Aline-Wendy Dunlop, there was a *visible gap between research and its application to daily life* – otherwise called a 'translational gap' Liz Pellicano from the Institute of Education at the University College London.

The importance of accessibility and public engagement in research were also stressed. Researching aspects, which have practical implications, and making use of the expertise of people with autism as researchers, was seen as a priority. Whilst academics value testing theories through research, other groups in the autism community perceive it as a source of innate bias. For this reason, some of the research undertaken by people with ASD (participative research) has a potential to produce more robust results, possibly because it is less biased due to the researchers having a greater interest in finding the truth, rather than verifying their preconceived ideas. It was suggested that valuing and reflecting on participants' experiences of taking part in autism research when reporting findings could be used as stipulation of further research funding.

Aline-Wendy Dunlop added that *the real challenge [was] to determine the impact of two types of research presented at the seminars: basic and applied research*. Presenting evidence of impact as well as defining what it means for autism research and addressing the gaps and maximising impact where such evidence is weak should be a priority. As further noted by Aline-Wendy Dunlop, one of the key elements should be excellence of research, which amongst other things is achieved by 'establishing a network of relationships with research users and involving research users in research at all stages, including working with user stakeholder and participatory groups'.

We need to learn from all forms of research in our journey to improving practice and securing a better quality of life.

Professor Aline-Wendy Dunlop, University of Strathclyde

The whole research community and its interface with practitioners such as ourselves is out of date if indeed such an interface ever existed at all.

Alan Somerville, Scottish Autism

Greater efforts can be made by researcher funders and researchers to involve autistic people and the broader autism community in the design of research, its conduct and translation of its findings into everyday issues. Greater strategic coordination, improved

dialogue and joint agreement on funding priorities should take place between research funders, researchers and the wider autism community.

ii Autism Funding – Campaign

During the conference, Kabie Brook from ARGH cited some of the key findings from the report written by Liz Pellicano and colleagues (2013) where two-thirds of all stakeholders were either dissatisfied or very dissatisfied with the pattern of current autism research funding, as it did not match up to their stated priorities. In addition, despite academics perceiving themselves to be engaged with the broader autism community, other stakeholders, most notably people on the spectrum and their families, often did not share this belief and found research inaccessible and highly jargonistic. They also felt there was not enough awareness and knowledge of the overall state of autism research across the country amongst researchers.

I'm not a researcher myself. I've taken part in some research, but I've often been left feeling quite let down by that researcher and the researchers I've engaged with. I think it can be quite a common feeling. As someone who isn't part of the research community, I've found this series of seminars really intriguing, just as much for the social and community aspects, as for the presentations. It felt surprisingly closed in a way. Lots of people knew each other within the seminars, but when I asked about research happening across the UK, there didn't seem to be much connectivity.

Kabie Brook, ARGH

Kabie emphasised the lack of connectivity between aforementioned research priorities and allocation of research funding. She referred to Liz Pellicano's presentation earlier in the Seminar Series highlighting the discrepancies in amounts spent on different forms of research.

As further reported at the conference, more evidence on economic costs of autism was also needed in order to inform key decisions on practice and policy in this field.

If I as a researcher don't provide good economics evidence, decision makers will go and make decisions anyway and I'd rather they had good evidence in their possession.

Professor Martin Knapp, London School of Economics and Political Science

As reported by Professor Martin Knapp from the London School of Economics and Political Science, given the current economic climate, resources in autism are scarce and it is increasingly difficult to 'meet every [individual support] need, or agree to every request, or accommodate every preference'. Gathering evidence on cost-effectiveness and affordability of new treatments or care arrangements can provide decision makers with information on how to get the best out of available resources.

Research on overall costs of autism, distribution of these costs and patterns of association between them is needed. Evidence of costs involved in providing autism interventions (e.g. psychological therapy) compared to its outcomes and alternative(s) is also regarded as a

priority. These costs can then be compared to savings generated by effective interventions which generate quality of life improvements (Knapp et al, 2009) and how such savings are distributed further. An understanding of how economic incentives might change patterns of behaviour amongst practitioners in existing service provision is also needed.

People with autism can have a wide range of different support needs and use a variety of services, including public and private sectors. Calculating more comprehensive estimates of costs of ASD and comparing these between the US and the UK as well as disaggregating them by age and presence of additional learning disability is needed to present a comprehensive picture of '*good costs and bad costs*'.

If you Google [good costs and bad costs] (…), you won't find any economic theory. It is not an economic theory. It is complete nonsense in that sense, but I think it has intuitive meaning. Some of those costs are good costs. They are the appropriate responses to the needs of individuals. They are the appropriate responses to their preferences. But some of those are bad costs, because those are things that happen to people, because we fail in some other way.

Professor Martin Knapp, London School of Economics and Political Science

Kabie Brook from ARGH in her presentation provided a counterbalance argument against research into autism economics by stating that autism seen in terms of costs and productivity can potentially ignite further societal prejudice and misperceptions of people on the spectrum.

Clearly a balance needs to be struck and research priorities agreed and communicated effectively. There will always be a view that money spent on research may be better spent on services, but one of the strong messages of the Action on Autism Research in Scotland Seminar Series was that without evidence what works is an unknown. We may add 'without practice and innovation there is nothing from which to draw evidence'. Strong linkages and effective communication between research, policy and practice is once again seen to be vital.

iii Myths on Autism – Challenge

"There is a lot of knowledge in a lot of areas but it doesn't coordinate strategically"

Alan Somerville, Scottish Autism

One of the core themes arising from the conference was concerned with challenging autism stigma and discrimination through education about autistic strengths. Some of these myths were concerned with common societal misperceptions of autism features and support needs (e.g. people with autism are often perceived as rude or in need of tailored employment). Other myths were concerned with current state of knowledge and understanding of autism from a research and clinical point of view. Kabie Brook from ARGH reflected on the fact that in research, autism is often seen through the medical model of disability – *the disablism lens*. Therapeutic approaches and interventions are widely researched, but such focus on the

need to provide treatments can in turn bring the risk of pathologising autism and disempowering the autism community. Accessible information on autism is sometimes available through mass media, but such sources are not a reliable source of information. Whilst there is a great amount of research being conducted on autism, researchers seem to mostly work only within the parameters of their different disciplines and multi-disciplinary dialogue on autism research is scarce and does not reflect lived experiences of people on the spectrum.

We don't have a shared destination in life and how we're going to get there is going to be different.

Kabie Brook, ARGH

The concept of Autism Pure vs. Autism Plus introduced by Christopher Gillberg presented 'the autisms' defined as a group of multifactorially determined conditions, that always coexist with other developmental/neurological problems (e.g. ADHD, epilepsy or other medical disorders) in cases where impairment is present in early life (=AUTISM PLUS). It was reported that autism cases not presenting with any comorbidity (=AUTISM PURE) often remained unrecognised, or can be perceived by wider society as exceptionally bright, eccentric or unsociable and aloof. Autism Plus is a concern in health, psychiatry, pediatrics, general medicine, and neurology. Autism Pure is worth thinking about, but potentially more as a matter of enormous theoretical interest rather than as a clinically impairing problem in its own right.

The concept also reinforced the idea that there are no sharp boundaries between ASD and autistic traits or between autistic traits and 'normality'. Whilst autism is a lifelong disorder, impairments may increase or decrease and are often an effect of coexisting problems. It was also discussed that there is no strong evidence that autism prevalence has increased in recent years. Growing strong evidence on small prevalence fluctuations and ASD observed in the elderly was noted instead.

iv Autism Evidence – Educate

The conference contribution made by Scottish Autism reflected further on a proliferation of interventions for people on the autism spectrum. However, the evidence base in support of most of these interventions is currently limited, which makes it increasingly difficult to reflect on fundamental changes to service delivery. Certain empirical processes are used to identify effective practice, which is then disseminated among service-delivery organisations. Whilst there is a certain amount of learning from the publications of professionals, this process is not systematic.

'The service delivery organisations [tend to] inform local authorities and encourage them to award contracts on the basis of this knowledge. Practice development is, therefore, almost entirely bottom-up and almost never top-down.'

Alan Somerville, Scottish Autism

Alan added further that current challenges for evidence-based practice in ASD include lack of:

- focus on practice – information on how to interface with professionals and academics;
- translation of complex psychological concepts into direct practice;
- understanding of why outcomes of the same services vary to such a degree;
- a clearer basis for knowing which individuals should receive which intervention or support.

These challenges in reporting on the effectiveness of autism interventions are exacerbated by lack of common nomenclature in autism research as well as lack of a standardised system for measuring outcomes, which results in relative subjectivity of all measurements used to date. Observational studies and anecdotal evidence could be turned into a more meaningful source of autism evidence if a standardised system for recording such evidence existed in both local and global contexts.

The narcissism of small differences [as Sigmund Freud said]… We have that in autism in spades, because people defend something that they'd invented themselves and it may deviate from someone else's work by the minutest fraction, but they will not adapt or change or adopt a common framework. So this is another process by which we get a proliferation of things and a vast redundancy in interventions.

Alan Somerville, Scottish Autism

There are local authorities in Scotland who treat autism as being learning disability, so if you've got Asperger's syndrome, you don't qualify for any kind of support. It's important generally to have an accepted categorisation, classification, segmentation, call it what you want, that people use across the country and are referring to similar individuals in similar circumstances (…) a generalised acceptance of what a pattern for service provision should look like.

Alan Somerville, Scottish Autism

Research findings that could be potentially useful for the wider autism community often do not get published because they either do not meet the funders' standards or views on what is considered a priority in the field.

So what should the agenda for research supporting the Scottish Strategy for Autism look like? Well, I think the first thing is that it should encompass absolutely everything we need to know. It shouldn't shut out things and we need to widen our perspective. Many people who do think about the narrow, high science, medical line, need to think again, so it's much more skewed towards socioeconomic studies and evidence-based practice than the usual perception of neuroscience and the medical paradigm. And I would like that very much to be accepted on a wider basis.

Alan Somerville, Scottish Autism

2.6.2 Research Gaps

1. More balance is needed in the research process, coordination and funding:

- Dissonance between existing body of evidence and priorities for autism research - the 'translational gap'
- The importance of accessibility and public engagement in research
- Greater strategic coordination, improved dialogue and joint agreement on funding priorities
- More awareness and knowledge of the overall state of autism research is needed amongst researchers across the country

2. Stronger evidence base is needed on:

- access to services, especially in remote parts of Scotland
- autism interventions
- ageing in autism
- research on people with accompanying learning disability
- Impact of autism on people's lives
- Changes over lifetime and life chances
- How people with ASD think and learn
- Economic costs of autism
- Educational provision for children with ASD (e.g. exclusion rates, academic results, general wellbeing and attainment in further education, employability)

3. Participative research including people with autism as partners/co-researchers:

- Reflection on participants' experiences of taking part in autism research could be used as one of the stipulation factors for further research funding
- Information on how to interface with professionals and academics is needed amongst the autism community in order to have a meaningful and active engagement and involvement in the research process.

2.6.3 Policy Priorities

1. A standardised system for measuring and recording evidence on outcomes and effectiveness of interventions

2. Translation of complex psychological concepts into direct practice

3. Educating with evidence:

- Accessible research outputs engaging wider autism community
- Common nomenclature in research, policy and practice
- Reliable and accessible sources of evidence and knowledge on autism

4. Policy and service provision addressing and busting myths on autism:

- autism features and support needs do not always require autism-tailored service base

- autism is seen through disablism lens
- autism pure vs. autism plus
- views of autism communities do not always oppose those of researchers and academics and can and should be incorporated into policy, service commissioning and planning

3. Reflections from the Series Interlocuteur: Dr Tommy Mackay

The whole context of the Action on Autism Research in Scotland Seminars in many ways highlighted the reasons we have for believing that in the international arena Scotland is already leading the way in terms of autism developments that are coordinated at national level. In addition, Scottish researchers are also taking forward projects with potential international impact.

That is reflected in the ambitious aims of the Scottish Strategy for Autism, which provided the context from which these seminars developed. It embraced the vision of 'a national 10 year autism strategy that addresses the entire autism spectrum and the whole lifespan of people living with ASD in Scotland'.

The central way in which that vision is linked to the fundamental place of research in informing policy and practice has already been exemplified by the publication, the month before the seminars began, of the special Scottish issue of the Good Autism Practice Journal. When I was invited to co-edit the Journal issue my main concern was how we could expect, in the short time available between the call for papers and the publication date, to generate sufficient submissions of quality research and practice to fill a whole issue. These fears were soon dispelled, and we published a journal with no less than 15 papers linking Scottish autism policy, research and practice.

When I began working in this field I would have been unable to name a single Scottish University which had an autism research programme. It would now be more challenging to name one without such a programme, with contributions to these seminars by speakers from the Universities of Aberdeen, Dundee, Edinburgh, Glasgow, Heriot Watt, St Andrews, Strathclyde, UHI and Queen Margaret.

It is this aim of linking policy, research and practice, and of pointing to the level of research needed to inform policy direction for autism in Scotland within an international context, that has provided the basis for the Action on Autism Research seminars. The four overlapping themes selected for each two-day seminar – psychological, clinical, social and educational research – cover almost everything that is central to the world of autism research and interventions.

As to psychological research, this has been central to our understanding of the nature of autism itself, as a condition which is defined in behavioural terms, and it is notable that of the Scottish and international speakers who contributed to the four seminars and the final conference, no less than 23 were psychologists, of whom 11 gave keynote addresses However, autism is of biological origin, and in addition to the central role played by clinicians in almost all areas of autism research, ultimately the answers in terms of causation will be clinical answers.

As to social research, the fundamental issue underlying autism is of a social nature. It is the first part of the 'triad', defined in diagnostic terms as 'qualitative abnormalities in reciprocal social interaction'. It relates to social understanding and communication, and to the wider society in which individuals with autism operate. As to the centrality of educational research, education represents the principal and most sustained intervention in autism, dominating almost the first two decades of life. Its centrality was established in the series of studies conducted in the early 1970s by Michael Rutter and Lawrence Bartak, demonstrating the benefits of a structured educational environment for children with autism and paving the way for the development of autism-specific educational strategies and provision.

The seminar series and final conference provided researchers, practitioners, policy-makers and individuals on the spectrum an opportunity to devote themselves to the subject of autism research for nine days through a period of exactly a year, from November 2013 to November 2014. Overall, I took five key messages from the series of five events.

First, the seminars have made a considerable contribution to raising the profile of Scottish autism research in the international sphere. Every event was in itself high profile, and the range of international speakers included names which have become household words in the world of autism across several decades – psychiatrists such as Fred Volkmar and Chris Gillberg, who have helped to transform our understanding of the nature and breadth of the autism spectrum, and psychologists such as Tony Attwood and Gary Mesibov who have helped to transform the lives of vast numbers of people on the spectrum through clinical and educational interventions. Events at this level have a two-way impact: they bring the current international research context to Scotland, but they also bring Scotland to the international context, raising its profile as a hub for research and practice in autism.

Second, the seminars reaffirmed our commitment to the central place of practitioner research. Many of our Scottish researchers who presented their work are people who are first and foremost practitioners, and who have made a direct contribution on the classroom floor, in health services and in a variety of other practical day-to-day settings. There was a clear commitment to the development both of evidence-based practice and of practice-based evidence.

Third, the seminars equally reaffirmed our commitment to the central place of pure science research in autism. Ultimately good practice and good service provision will arise not only from developing practical interventions but from advancing our knowledge of the underlying neurobiological mechanisms in autism, and the ways in which these may interact with a range of genetic factors. Commitment to this field of fundamental scientific research was clear both in the keynotes and in the work of Scottish researchers, and also in the contribution by Dame Stephanie Shirley, whose Foundation has provided crucial funding both for key services and also for pure science research.

Fourth, a very central feature of the series was the importance of coordination and communication among all who are contributing to the field of autism in Scotland. There was a very clear message throughout that research, practice and strategy must operate as part

of a coherent whole, integrating the work of the Universities, the Scottish Government, local authorities, the third sector and all other stakeholders.

Finally, a key feature of the whole series was the importance of follow-through. The emphasis on not only disseminating autism research but in taking its outcomes forward was inherent in the overall title, *Action on Autism Research in Scotland,* and in the sub-title, *Improving Impact Seminar Series.* It was this focus on action and impact that pervaded the organisation of the series and the tone of each day, defining the seminars as something that would not only inspire and inform but also have a marked and lasting impact on taking forward the Scottish Strategy for Autism.

4. Action on Autism Research: What Does Scotland Need?

4.1 Review of progress in relation to anticipated outcomes

The Action on Autism Research in Scotland Seminar Series hosted four international level speakers (one of whom was from Scotland) at each of our 4 seminars: they presented their work, focusing on impact, interventions and policy implications. 24 Scottish individual paper presenters contributed to mapping autism research in Scotland, as did the 20 poster presentations offered over the AAR Series.

On each meeting day impact seminars focused on knowledge exchange to enhance the research-policy-practice-impact cycle and this has led to a clearer understanding of views held on the contribution of intervention to impact. Plenary, discussion and overview sessions have situated Scottish autism research in an international context with an emphasis on gaps, potential and collaborations.

Each seminar presentation was made available online and the opportunity for further discussion and feedback was enhanced through an online network (see Annex 1). Access to this Virtual Network was through membership of the Scottish Autism Network: a guarantee was given to speakers that the filmed material and powerpoint presentations would be available to attendees and others who joined this password protected space and that presentations would not be publicly available without this safeguard. Changes to the Autism Network Website mean this guarantee has not been sustained. We therefore returned to our speakers and while no-one has withdrawn their consent, it is important to plan for the ongoing community of enquiry and to create an alternative virtual research space. A first draft of compilation film has been produced by Michael Dawson, an autistic film-maker, and this will be refined to reflect the seminar outcomes and learning that has taken place.

By situating Scottish autism research internationally the AAR Seminar Organising Team will be better placed to make recommendations towards a National Research Action Plan for Scotland to be debated in two further meetings arranged specifically for analysis of the data generated by the AAR Series and discussion of a Scottish Research Action Plan: under former Strategy arrangements this would have been presented to the Scottish Autism Strategy Research Sub-Group but will now be included as a draft in the Main Report of the Series.

New research and research-policy-practice relationships have been formed during the series and sustained through the regular repeat attendance of participants. These relationships will continue and can be supported through the alternative Action on Autism Research in Scotland Virtual Network, through the re-launched Scottish Autism Research Group and potentially through continuing UK wide cooperation.

One of the points of discussion in our research seminar series has been the importance of creating an inclusive environment where the perspectives of researchers, policy makers, practitioners, parents and the wider community can be shared and knowledge gained, so promoting the research, policy and practice interface. In designing the series we tried to

provide a range of information about research and asked participants to contribute to the success of this process . There is a running question about what benefit research brings to the daily experience of all involved. What is the current and possible impact of autism research and enquiry? How can we ensure the application of the knowledge that research generates will make a difference to daily life for autistic people, their families and carers and those who work with them?

The Autism Strategy Implementation Group 3, charged to look at consistent adoption of good practice guidance in key areas of education, health and social care across all local authority areas, has a focus on "ensuring that research findings are translated into practical applications for improving service provision". The findings of the AAR Seminar Series will contribute to that work.

Publication planning from the series is underway in order to disseminate examples of research-intervention-impact good practice: Springer will consider a proposal for a Monograph of the series, JADD (Journal of Autism and Developmental Disorders) will not devote a complete edition but would be pleased to accept new papers based on presentations made during the series. Conference planning and other ongoing work is expected to be supported through the continuing engagement of the Action on Autism Research in Scotland Group.

4.2 Overview of outcomes

The Action on Autism Research in Scotland Seminar Series has made significant steps towards building research networks in Scotland. The Organising Team has generated a fuller understanding of current research in Scotland, of research gaps and challenges for researchers, and of emerging policy priorities.

The team will bring forward recommendations towards a National Research Plan for Scotland to the Autism Governance Group. The findings of the series will be presented to the Autism Governance Implementation Group 3 as part of the process to ensure the Scottish Government's autism research strategy will address the priorities of people with autism and their families.

The recommendations for a Scottish Autism Research Action Plan defines high quality research, encourages a joined up approach to autism research in Scotland, which in turn promises to

- Stimulate a more evidence-based approach to policy-making in Scotland
- Stimulate a more evidence-based approach to service design and delivery in Scotland
- Have a positive impact on the daily lives of people with autism and their families

A number of immediate outcomes stimulated by the AAR Seminar Series are to be noted:

- Formation of an Action on Autism Research in Scotland Virtual Network (now to be reviewed)
- The Scottish Autism Research Group (SARG) has been re-launched
- Forging of a closer relationship between the academic, health, social services and education communities and autism policy development in Scotland
- Stimulation of the formation of new research collaborations and proposals to address gaps in knowledge
- The research drive towards a clear and quantifiable understanding of the evidence needed to gauge the impact which autism interventions can make on the lives of children with autism and their families is highlighted

In summary the outcomes of the AAR Series tells us that in Scotland we need to develop a full understanding of data that currently exists from Scottish-based autism research, that there is a lack of enquiry into the value and success of autism interventions across age groups, that we know little about what makes an effective autism service at different stages, for various sub groups of autism and across the lifespan.

While there are strengths in current clinical and psychological research, the application of such research to interventions and practice within implementation research is not always made successfully and as a result the impact of research is not visible enough. The funding of social and educational research is seen as softer and remains heavily under-funded and possibilities under-explored but potentially have important impact to make. The 'facts' of autism need to be addressed as new research changes what we know. As is reflected in the research literature, there is a heightened need to address the disconnect between research providers and policy makers.

4.3 Emerging overall themes

Here we draw together the themes identified from the analysis of the seminar series and conference contributions with the key issues, opportunities and concerns that emerged from the Impact discussions. We consider what we know, what we know we don't know, what we need to know and the relationship to policy priorities.

To embed research into policy and policy implementation

One of the greatest policy challenges is to ensure change in practice: the series highlighted the potential for strengthening links between research and the current cycle of practice change and improvement - particularly when an iterative research cycle incorporating an evidence-practice-evidence-research cycle is achieved. We have also worked on making these connections and building a research community in Scotland through an inclusive approach to the series. 32 themes were identified across the 9 days of shared work. The themes group naturally into 6 key issues: these themes are not presented in any order of priority, but rather for the connections between them that give the six key issues.

1. **Autism & Complexity**
2. **The importance of participation**
3. **Interconnecting policy with research and practice**
4. **Being an autism researcher**
5. **Autism Evidence**
6. **Sharing and translating research for impact**

Autism & Complexity

- *Autism is complex and variable*
- *Diagnostic issues persist*
- *The resemblance of autism to other conditions*
- *Thinking autisms*
- *Who Adapts? Finding a balance*
- *Assessment & Diagnosis*
- *Complexity & perplexity*

The importance of participation

- *A need to be heard*
- *A need to be communicated with*
- *Participation*
- *Listening to stakeholders' priorities*
- *The strategic nature of empathy*

Being an autism researcher

- *A need for researchers to move towards a skill based paradigm:*
- *A need for recognition of researcher bias, funding bias and publication bias*
- *Educating for Educational Research, Interventions and Impact*
- *Researchers communicating with other researchers across the country*

Autism Evidence

- *Autism Evidence – Educate*
- *Myths on Autism – Challenge*
- *Autism Research Priorities - inform*
- *Intervention*
- *Understanding autism towards early intervention*
- *A need for applied social research*
- *More effective intervention informed by neuroscience*
- *Real difference in Services*

Sharing and translating research for impact

- *Translating Research*
- *'Challenge every dogma'*
- *Autism Research Gaps*
- *Autism Policy Priorities*

Interconnecting policy with research and practice

- *A need to interconnect policy with research and practice*
- *Investment matters*
- *Autism Funding – Campaign*

4.4 Research Gaps and Policy Priorities

Research Gaps	Policy Priorities
Seminar 1 - Psychological Research, Interventions and Impact	
• Research occurs in a strategic vacuum where there are no common objectives or even any standardisation of measurement which could provide the basis of meaningful comparison and consolidation. • Abiding question of how best to define autism • Clear evidence that there are 'autisms' no longer 'autism' • To narrow the translational gap – by defining research that is more relevant to autistic people and communities, everyday lives and values • To create active research partnerships • A need for practical application of research • Questioning the quality of research: the need for research that is done for the right reasons	• There is no readily identifiable link between research and social policy; • The importance of arriving at a shared definition of autisms • A challenge to be clear on definitions of autism - identity, illness, injury or insight? • To narrow the translational gap - by public dissemination, dialogue and partnership - Universities, Government national & local, Third Sector - research, practice and strategy • Understanding pure science/applied science and that applied science must bring overlaps between discrete research areas
Seminar 2- Clinical Research, Interventions and Impact	
• Need for higher level training in diagnosis • Broader knowledge of Autism Plus and risk factors • Clearer link between diagnosis and form of intervention • Stronger evidence base for interventions	• Re-organisation of services for more efficient diagnosis • Investment in early diagnosis using risk factors • Support for neuroscience to refine understanding of autisms and inform possibilities for interventions • Explicit role for research in directing policy

Research Gaps	Policy Priorities
Seminar 3 – Social Research, Interventions and Impact	
• Need for a differential observational tool & expertise in diagnosis crucial • Neuroscience could identify high risk infants for intervention that could minimise impact of autism • Scrutiny of minority who respond well to an intervention • With refined methods can we define differences early? • Broader knowledge of Autism Plus and risk factors • Clearer link between diagnosis and form of intervention • Stronger evidence base for interventions	• Services re-organisation – from specialist to generic • Better training for those who refer • Re-organisation of services for more efficient diagnosis • Investment in early diagnosis using risk factors • Support for neuroscience to refine understanding of autisms and inform possibilities for interventions • Explicit role for research in directing policy
Seminar 4 - Educational Research, Interventions and Impact	
• Understanding of what works and developing an evidence-base built on evaluation of practice • Evaluation of interventions that consider how this works for both individual and family • Understanding the mechanisms of intervention before we implement • Monitoring knowledge change in practice • Knowledge translation from research to practice • Understanding of stakeholder concerns • High tech support for the Scottish Autism Strategy – to measure success	• Revisiting stakeholder priorities for knowledge and practical applications of knowledge to create positive change • Work on the research-practice bridge • Work on the research – policy bridge • The need to get together on shared points – to make anything strategic happen • Developing an open dialogue between Scottish autism researchers, stakeholders and Government Strategy

Research Gaps	Policy Priorities
Conference - Action on Autism Research in Scotland: What does Scotland Need?	
1. More balance is needed in the research process, coordination and funding: • Dissonance between existing body of evidence and priorities for autism research - the 'translational gap' • The importance of accessibility and public engagement in research • Greater strategic coordination, improved dialogue and joint agreement on funding priorities • More awareness and knowledge of the overall state of autism research is needed amongst researchers across the country 2. Stronger evidence base is needed on: • access to services, especially in remote parts of Scotland • autism interventions • aging in autism • research on people with accompanying learning disability • Impact of autism on people's lives • Changes over lifetime and life chances • How people with ASD think and learn • Economic costs of autism • Educational provision for children with ASD (e.g. exclusion rates, academic results, general wellbeing and attainment in further education, employability) 3. Participative research including people with autism as partners/co-researchers: • Reflection on participants' experiences of taking part in autism research could be used as one of the stipulation factors for further research funding	1. A standardised system for measuring and recording evidence on outcomes and effectiveness of interventions 2. Translation of complex psychological concepts into direct practice 3. Educating with evidence: • Accessible research outputs engaging wider autism community • Common nomenclature in research, policy and practice • Reliable and accessible sources of evidence and knowledge on autism 4. Policy and service provision addressing and busting myths on autism: • autism features and support needs do not always require autism-tailored service base • autism is seen through disablism lens • autism pure vs. autism plus • views of autism communities do not always oppose those of researchers and academics and can and should be incorporated into policy, service commissioning and planning

Research Gaps	Policy Priorities
• Information on how to interface with professionals and academics is needed amongst the autism community in order to have a meaningful and active engagement and involvement in the research process	

4.5 The challenges ahead

Some Key issues from the Action on Autism Research Seminar Series

What have the seminars achieved - messages for autism policy in Scotland?

- Understand what works and what does not
- Policy to reflect heterogeneity and importance of recognising coexisting and comorbid conditions particularly anxiety in diagnosis and treatment
- Importance of personalised approaches
- Joined up approaches
- Recognition of sensory differences
- Hard to reach groups
- Improve GP awareness – restore overview to GP's
- Reduce waiting time for diagnosis
- Raise awareness in nursery staff
- Look at quality of life as an outcome – not reduction of autism
- Recognition some present for first time as adults

Opportunities

- All age concept for autism –
- Changes in legislation and guidance
- Strategy
- SIGN review
- Personalisation-implement in practice
- Training people in evidence supported approaches.
- Better identification and tracking of cases
- Target resources on preventive measures – reducing severity of impact of disorder
- Build on parent involvement
- Reintroduce early oversight of potential cases
- GP recording systems to capture essential data on children (signs not always recorded)

Concerns

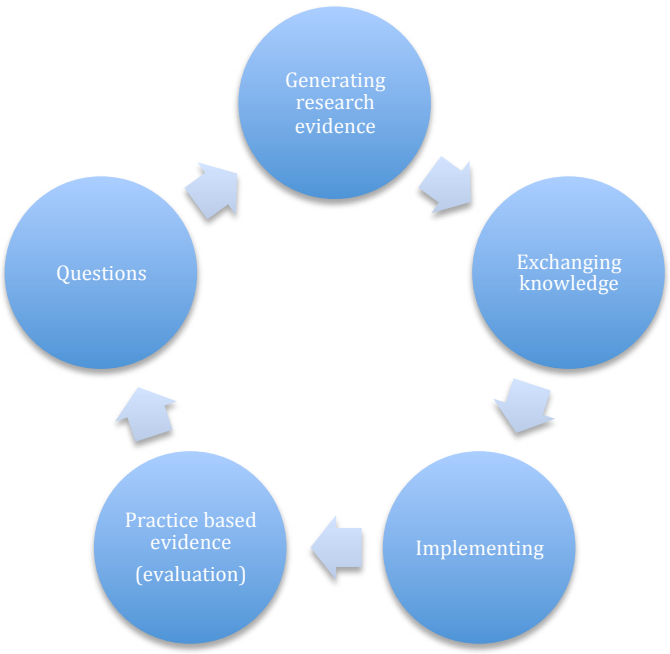
- Resources crisis driven- commissioners take no account of evidence from research
- Promotion of (poorly evidenced) interventions (by providers) and selective information- publication bias
- Information not reaching people
- Pharmacological approaches not effective in ASD unless treatment of definite coexisting disorder
- Evidence for behavioural interventions not robust – weak evidence base in ASD
- Information to hard to reach groups –effects of poverty- minorities
- Effectiveness and limitations of screening
- Groups missing out – older adults - females
- Severe LD miss out
- No protocol for what to do with 'red flag cases'

4.6 Interventions and Impact, Linkages and Discontinuity

- What do we mean by impact in autism research?
- What claims are currently being made for impact?
- How, methodologically, is this being evidenced?
- Where is impact weak / why?
- How can impact gaps be addressed?
- How can we work across disciplines and interest groups to maximise impact?

5 Conclusions and Recommendations

In conclusion the outcomes of the AAR Series tell us that in Scotland we need to clarify what is meant by research: terms which are useful are basic research, applied research and policy research: these can be informed by evaluation research and developed through action research.



5.1 Basic and Applied Research

1. Notwithstanding the essential nature of basic research and its contribution to knowledge, in Scotland we must also invest in applied research, including social and educational research, as a pathway to improvement

5.2 Policy Research and Evaluation Research to ensure a reciprocal relationship between research and practice

2. It is essential to have effective communication between Scottish Autism researchers and Scottish Government to ensure informed policy and practice and have a positive impact on people's lives
3. A Task Force should be established to identify key research priorities based on the knowledge gained from the Action on Autism Research in Scotland Seminar Series, Conference and subsequent analysis, in order to develop a Scottish Research Plan for Autism
4. Such a group should be closely aligned to policy but maintain an independence

5.3 To endorse the recommendations of A Future Made Together

5. 'investment in new areas of autism research',
6. that there is a 'need for strategic partnerships' and
7. 'an ethic of engagement' (page 39).

5.4 To have a positive impact on the daily lives of autistic people and their families and the people that work with them

5.4.i Research Strengths

Pure science generates knowledge about autism that may be generalisable across a specified autism population with common characteristics and the seminar series shed light on investment in basic research which is based on such identified cohorts. Across the UK research into biology, brain and cognition has attracted 56% of funding (Pellicano, Dunsmore & Charman, 2013). 94% of autism research funding is concentrated on Clinical and Pyschological research. Research into services and societal issues take the remaining 6%. Treatment and interventions research benefits from 18% of funding and given numbers of interventions are used in social care and educational settings, however the Scottish Strategy Group 3 in developing the Menu of Interventions (2013) stated "It was rapidly identified that there is a proliferation of "interventions" for people on the autism spectrum. An initial trawl by the group identified several hundred. However, the evidence base in support of most of these interventions is scant." (Neil-Maclachlan & WG3)

The Scotland-based researchers who reported at the seminar series are involved in many important aspects of research into autism: referential cognition; eye-tracking; auditory and language processing; developments in expressive language and symbolic play; autism movement and affective regulation; theory of mind skills teaching; risk factors in individuals diagnosed with autism; autism diagnosis; SMARTS in autism; potential benefits of oxytocin for individuals with autism; misunderstanding social situations; autism and reactive attachment disorder; understanding stress and stress transaction; the social nature of autism; emotion-focused group therapy; exclusion in the workplace; practitioner evidence; transition to adulthood; Homonculi; autism and the science of social learning; prevalence and cognitive ability; the experience of girls with ASC and anxiety; the contribution of educational psychologists; narrative-related interests, behaviours and skills in children, and interprofessional education in autism (Annex 3). The Poster Sessions (Annex 4) were also wide ranging. While not drawing in every case of autism research in Scotland, the seminar series included many pieces of current or recently completed work: despite this activity the funding for such work in Scotland is small. The potential is high given the number of PhD and Masters students so engaged. Many aspects of current work could be developed further and there is scope for innovation in both basic and applied science.

"Different perspectives in health and social care in ASD reflects a history of difference in medical versus social approaches to disability. The traditional medical approach is to focus on the biology and psychology of autism. The traditional social approach is to focus on the environment and particularly the social environment or organisational practices. These historical differences between professions can also be seen in the field of research, reflected in the distinction between medical science and social research."
[http://www.autismrpphub.org/sites/default/files/resources/warc_the_autism_research_toolkit_copyright_cardiff_university_2013.pdf]

In Scottish Autism Strategy terms the greatest need is to generate data on what works in practice in order to make a difference in people's lives. What works for autism or for any

particular autistic individual may be highly dependent on context. There is an identified gap in drawing together the evidence, in knowledge and in practice, about the effectiveness of services, which interventions are helpful and how these may be tailored to present service contexts or how those contexts may be changed and become tailored to autistic people.

5.4.ii Research Gaps

It was therefore proposed that we must cast more light on the research areas summarized in 5.5. below.

In order to address these gaps we need:

- more qualitative/ participatory/ practitioner research
- greater awareness of methodological problems such as replicability issues, treatment fidelity problems, epistemological conflicts, etc.
- guidance on rigorous qualitative methodologies
- better dissemination of research findings to the public

Given the need for evidence, where a research gap exists there is a need to invest to generate reliable information.

Given the need for practice improvement, investment is needed in identified areas of development.

Attention must be given to the level of the research evidence and its impact on practice. Often cited during the Seminar Series, the SIGN Guidelines (2007) reported the poverty of evidence based practice: at the time this paucity of evidence related to non-medical interventions:

- 15 recommendations made on non-med interventions;
- Only 3 had evidence at the highest levels, and all of these were evidence for what you should NOT do;
- Of the 12 positive recommendations, only 3 had any evidence at all; 2 of these were at the lowest level (case reports and expert opinion), and
- The other 9 were 'good practice points' (based on the group's clinical experience), and some of these were expressed as cautions.

In June 2016, the new SIGN Guidelines (Scottish Intercollegiate Guidelines Network, 2016) were published. Four levels of evidence are defined and used. Strong and conditional recommendations on interventions are made and a category or 'recommended best practice' is introduced. Through the work undertaken during and following the Action on Autism Research in Scotland Seminar Series, we have identified a major issue around non-medical 'daily life' educational and social research and practice links: these connect with much lower levels of investment in these research areas. The SIGN 2016 Guidelines identify some of the areas of work that also emerged from the Action on Autism Research in Scotland Seminar Series.

Strong linkages will mean research can inform the need for practice innovation and development. These developments can generate practice data if set up with a research element on a common model so data can be compared; the practice data generates new research evidence, reflection and further tailoring of practice.

5.5 To develop an architecture for autism and autism research in Scotland

The Action on Autism Research Seminar Series has begun the process to develop a comprehensive understanding of data that currently exists from Scottish-based autism research. It has also identified issues and gaps. There is a lack of enquiry into the value and success of autism interventions across age groups, we know little about what makes an effective autism service at different stages, for various sub groups of autism and across the lifespan. While there are strengths in current clinical and psychological research, the application of such research to interventions and practice within implementation research is not always made successfully and as a result the impact of research is not visible enough. The funding of social and educational research is seen as softer and remains under-funded and possibilities under-explored but potentially have important impact to make and are closely linked to daily life: the context for greater understanding of services, educational provision, home contribution to learning and meaning making are some examples of missed opportunities.

The analysis of the Seminar Series has allowed the identification of important research gaps in Scotland and the possibility of linking these with thinking about how to address such gaps and what this means for policy priorities. It has drawn in eminent international researchers, some of them Scottish and in this process has positioned research in Scotland in an international context. This has allowed a view of what is already done well and may be applied across autism and what needs to be more local, tailored and culturally relevant to Scotland at this stage of our policy developments.

The major current concern in Scotland is the impact strategy can have on daily life – this is where research evidence and evidence from practice can crucially combine.

There is a need for a small, skilled, motivated and experienced Strategic Research Group to work with the knowledge generated by the seminar series and reported here. Drawing from the seminar data The following table brings together the analysis of the Seminar data and suggests the direction of travel in terms of identifying research gaps, working on how to address these gaps and linking these to existing and new policy priorities.

Research Gaps	Addressing the Gaps	Policy Priorities
Research into understanding 'autisms'	• Creating a climate for strategic use of research evidence • Work on the research-practice bridge • Work on the research – policy bridge • Work on the autistic community bridge • Creating active research partnerships • Understanding pure science/applied science and that applied science must bring overlaps between discrete research areas • Ensuring linkage between research and social policy • more qualitative/ participatory/ practitioner research • greater awareness of methodological problems such as replicability issues, standardisation, treatment fidelity problems, epistemological conflicts, etc. • guidance on rigorous qualitative methodologies • narrowing the translational gap through better public dissemination of research findings through dialogue and partnership • The inclusion of emerging researchers • Myth busting	• Explicit role for research in directing policy • Developing an open dialogue between Scottish autism researchers, stakeholders and Government Strategy • Funding for practitioner research and evidence-based practice • Understanding the mechanisms of intervention before we implement • Disseminating research evidence of good practice to the public • More people with autism involved in policy and service development • Mechanism and funding to encourage collaboration and partnership e.g. data base of individuals/groups willing to be involved in research. • More support for transitions to adulthood • More focus on adult diagnosis and post-diagnostic support, including therapeutic interventions • A set of common standards for autism services • Development of a common assessment process • Development of a national database
Transitions		
Anxiety, stress and sensory issues		
Criminal justice system		
Autism & emotional processing		
Autism and employment		
Adults with autism / severe and complex needs		
High risk infants		
Clearer link between diagnosis and form of intervention		
Understanding of what works (mechanisms of intervention) and developing an evidence-base built on evaluation of practice		
Stronger evidence base for interventions		
Changes over lifetime and life chances		
Researching what the future holds for individuals with autism as they age		
Access to Services		
Research into standards for specialist autism services		

A Scottish Autism Research Plan has some necessary elements:

- A classification of research activities relevant to the strategy;
- An assessment of the strengths and weaknesses of activity in these areas at present;
- An assessment of socio-economic modelling required even after microsegmentation for rational decision making;
- An assessment of required "infrastructure" – meaning a database, screening methodologies and data gathering from existing service provision;
- A list of high-priority essential and desirable research projects;
- Mechanisms for research data to accumulate and influence;
- Illustrations of the impact of research on daily life, lifelong;
- The management of future funded work;
- Building research community whilst respecting individual strengths;
- Incorporation of the research, policy and practice communities in strong mutually productive connections;
- The development of principles to guide research.

5.6 The future

A clear disconnect has emerged in terms of using autism research in the community to the benefit of the autism community.

The Action on Autism Research in Scotland Organising Group intends to sustain the AAR community established through the research seminars and conference and thereby to foster continuing engagement between researchers and service providers who will jointly consider the recommendations that have emerged from analysis of the Seminar Series.

The existing Organising Group will focus on publication, mapping AAR outcomes to policy, engaging with the wider autism community, fostering publication, creating a safe virtual discussion environment, promoting new research themes and investment in research, making connections with strategy and developing:

1. The National Autism Research Plan
2. An Independent Autism Research Council Scotland.

5.7 We therefore call for….

Researchers in Scotland to endeavor to make their work widely known through academic mechanisms such as peer review and Impact factor journals, to reflect on its day-to-day impact, to be supported to address whether it could have a critical part in shaping and influencing national policy and practice, ensuring that public policy decisions and

psychological, health, educational and social interventions are based on research of the highest quality;

An independent autism research consultative body, to be set up following publication of this report, to focus on the quality and application of research in Scotland and to be called the 'Independent Autism Research Council Scotland';

The Scottish Autism Strategy to work to meet Recommendations 7 and 8:

Recommendation 7: It is recommended that the ASD Reference Group commissions research to examine and compare the outcomes in relation to quality of life for those who are supported by autism service providers and individuals who access generic provision and that relevant findings are used to inform revised guidance for commissioners of services for people with ASD.

Recommendation 8: The ASD Reference Group in collaboration with autism service providers will identify the key determinants of service provision that result in improved quality of life for people with ASD, across the spectrum and across the lifespan.

The Autism Strategy Governance Group to develop and maintain strong links with this independent body, so that research can contribute to

- Explore how research on autism can be shared and translated into practice (Scottish Government, 2015).
- Further develop opportunities to take forward gaps in autism research (Scottish Government, 2015).
- Inform the direction of the Strategy in its second 5 years;
- Increase the effectiveness and sustainability of public services and policy;
- Enhance quality of life, health and wellbeing.

In conclusion the Action on Autism Research Seminar Series has shed considerable light on the many issues affecting people with autism, their families, carers and the professionals who work with them. A strategic consideration of the data presented will help to develop a Scottish Autism Research Plan in order to effect change.

6.1 Glossary of Terms

Advocacy: A process of supporting the wishes, needs and entitlements of a particular person or group of people	**Peer review:** The process by which anonymous experts in a given field evaluate the quality of new research, often to determine its suitability for publication
Applied research: Research that aims to answer real world questions and solve problems	**Philanthropic funding:** Research funded by the private or charity sectors, typically comprised of charitable donations or endowments.
Basic research: Research that aims to increase understanding of fundamental principles, produce knowledge we don't have and does not necessarily provide any immediate implications or applications for day-to-day practice.	**Primary research:** Activities that involve the collection and analysis of new data, or the new analysis of existing data.
Cognition: Any psychological or mental process including but not confined to understanding, awareness, perception, reasoning and judgement.	**Secondary research:** The summary or review of previous primary research. Common examples of secondary research are editorials, literature reviews and commentaries.
Government Funding: Funding which is provided and administered by government, and is therefore primarily comprised of public funds raised through tax revenues.	**Scottish Autism Strategy:** A plan of action with 2, 5 and 10 year goals to bring about the overall aim that individuals with autism have meaningful and satisfying lives.
Intervention: The act of intervening in a difficulty in order to bring about improvement.	**Stakeholder:** Anyone with an interest in autism research, personally or professionally.
Impact: a measure of the effects, actions and influences (in this case of research)	**Thematic Analysis:** A common form of qualitative research analysis which involves sorting, categorizing and taking account of themes in data.
Intellectual disability: A condition characterized by concomitant impairments in general mental abilities and adaptive behavior that first manifest in early development	**Microsegmentation:** segmentating of the autism spectrum, its co-morbid conditions and its associated problems. Micro-segmentation forms a basis for providing a conceptual map of the autism spectrum.
Neurotypical: A label used to describe people with no apparent neurological disorder or atypicality	**Translational research:** Research conducted with the explicit purpose of translating scientific knowledge into clinical practice.
Online academic journal data base: An online database which allows access to summaries of journal articles and other research outputs published for academic journals.	**Services:** Organisations responsible for the provision of activities and the meeting of needs.
Participatory research: The active participation of the people being studied, in the design, implementation and interpretation or research and research findings.	**Wider autism community:** people who are autistic themselves, who care for those with autism, or who work with autistic children, young people or adults.

6.2 References

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6.3 Annexes to the Main Report

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Annex 1: The Action on Autism Research (AAR) in Scotland Organising Team

PROFESSOR TOMMY MACKAY

(Seminar Series Interlocuteur)

PROFESSOR ALINE WENDY DUNLOP

(Lead for the AAR Team)

Organising Team Members

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.

Warm thanks extended to Dr Ken Aitken for his support to the Seminar Series and to Caroline Marley, RAKET, for her excellent administration of the Series.

Annex 2 Aims & Outcomes

The following matched aims and outcomes were developed for the series

AIMS OF SEMINAR SERIES	OUTCOMES OF SEMINAR 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	1. Four international level speakers (one of whom will be from Scotland) will have presented their work, focusing on impact, interventions and policy implications, at each of our 4 seminars
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	2. 24 Scottish individual paper presenters will contribute to mapping autism research in Scotland, as will the poster presentations
3. Make a call for paper or poster proposals to populate the working days with contemporary Scottish research into autism	3. Poster presentations will be available throughout each 2 day seminar
4. Enhance the relationship between research, policy and practice through knowledge exchange workshops	4. Each afternoon impact seminars will focus on knowledge exchange to enhance the research-policy-practice-impact cycle
5. Consider the relationship between intervention and impact	5. By focusing on intervention and impact we will have a clearer understanding of the contribution of intervention to impact
6. Generate new research collaborations and proposals where gaps are identified	6. Plenary, discussion and overviews will have situated Scottish autism research in an international context (gaps, potential, collaboration)
7. Establish an Action on Autism Research in Scotland Network (through Autism Network Scotland)	7. Each seminar presentation will be available online and discussion enhanced through an online network
8. Make recommendations for a National Research Action Plan for Scotland	8. By situating Scottish autism research as in (5) the Scottish Autism Strategy Research Group will be better placed to make recommendations towards a National Research Action Plan for Scotland
9. Commit to building closer relationship between the academic, health, social services and education communities and autism policy development in Scotland	9. New relationships will have been formed and sustained and can be supported through Autism Network Scotland and UK wide cooperation
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	10. A publication is planned from the series; conference planning and other ongoing work is expected to be supported through the Scottish Autism Strategy Reference Group and networking and good practice events

Annex 3: Speakers and Presentation Titles

Programme of Speakers	Presentation Title
Seminar 1 - Psychological Research, Interventions and Impact	
Mr Michael Matheson, Minister for Public Health, Scottish Government	Opening Address to Launch the Series
Professor Aline-Wendy Dunlop, Organising Team Lead	Welcome to the Seminar Series
Professor Tommy MacKay, Chair of the Seminar Series, Director of Psychology Consultancy Services, Visiting Professor at the University of Strathclyde and Clinical Director of the National Diagnosis and Assessment Service for Autistic Spectrum Disorders.	Psychological Research, Interventions and Impact: Opening Remarks
Dr Thomas Insel, Director National Institute for Mental Health, USA	"Autism: What do we know? What do we need?"
Dr Liz Pellicano Institute of Education, London	"A Future Made Together : New directions for autism research in the UK"
Michelle Dawson University of Montreal, Canada	"Science, ethics, and autism intervention research : Should there be autism-specific standards?"
Dr Ken Aitken ASD Reference Group – Research Sub Group:	"The Research, policy and practice context in Scotland"
Dr Karri Gillespie-Smith Heriot Watt University	"Using eye-tracking to study early infant cognition: Implications for clinical practice"
Dr Juan Carlos Gomez University of St Andrews	"Referential cognition and autism : problems and individual differences"
Dr Mary Stewart Heriot Watt University	**"**Auditory and language processing across the autism spectrum"
Dr Helen Marwick Senior Lecturer, University of Strathclyde	"Developments in expressive language and symbolic play of young children with autism through participation in the 'Playboxes' joint-play intervention"
Professor Colwyn Trevarthen, University of Edinburgh and Dr Jonathan Delafield-Butt, University of Strathclyde	"Autism as a disorder of movement and affective regulation"
Dr Sue Fletcher-Watson University of Edinburgh	"Should we be teaching theory of mind skills to children with autism?"
Seminar 2- Clinical Research, Interventions and Impact	
Professor Tommy MacKay	Clinical Research, Interventions and Impact Opening remarks
Professor Helen Tager-Flusberg Developmental Science Program Director, Boston University	"Investigating early behavioral and neurobiological markers of risk for autism spectrum disorder"
Professor Declan Murphy Mortimer D Sackler Professor of Translational Neurodevelopment, and Director of the Sackler Institute for Translational Neurodevelopment,	"Translational neuroscience will help improve outcomes in autism. True – or a delusional belief ?"

Programme of Speakers	Presentation Title
Institute of Psychiatry, King's College London.	
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".
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"
Professor Anne O'Hare Honorary Professor of Child Life & Health, School of Clinical Sciences, University of Edinburgh, Honorary Professor, Queen Margaret University, Consultant paediatrician, Royal Hospital for Sick Children, Edinburgh	"Autism Achieve Alliance: A national study of risk factors in individuals diagnosed with ASD"
Dr Iain McClure Consultant Child & Adolescent Psychiatrist for NHS Lothian, Honorary Clinical Senior Lecturer University of Edinburgh, Honorary Senior Research Fellow at Herriot-Watt University.	"Waiting for Autism Diagnosis - A National Study"
Dr Judith Piggott Consultant Child and Adolescent Psychiatrist specializing in Neuro-developmental Disorders, Hon Senior Lecturer, University of Dundee.	"Why Think SMARTS in Autism?"
Dr Bonnie Auyeung Chancellor's Fellow, University of Edinburgh	"Investigating the potential benefits of oxytocin for individuals with autism: Practical considerations"
Dr Helen Minnis Senior Lecturer in Child and Adolescent Psychiatry, University of Glasgow	"Autism and Reactive Attachment Disorder: can they be confused?"
Dr Andrew Stanfield Co-director of the Patrick Wild Centre for Research into Autism, Fragile X Syndrome and Intellectual Disability. University of Edinburgh, NHS honorary consultant in intellectual disability psychiatry.	"Misunderstanding social situations: always autism?"
Seminar 3 – Social Research, Interventions and Impact	
Professor Tommy MacKay	Social Research, Interventions and Impact: Opening Remarks
Professor Gary Mesibov University of North Carolina	"My Mantras: What I have learned in 40 Years Working with People with Autism Spectrum Disorders and their Families"
Dr Mike McCreadie Clinical Consultant, Studio 3	"Stress and Autism: improving service delivery through better understanding of the stress transaction"
Dr Katie Maras University of Bath	"Implications of autism for the criminal justice system"
Dr David Simmons Lecturer in psychology in the School of Psychology, University of Glasgow	"Understanding the social nature of autism: From clinical research to intervention"
Professor Helen McConachie University of Newcastle	"Understanding and overcoming anxiety in ASD"

Programme of Speakers	Presentation Title
Dr Anna Robinson University of Strathclyde	"Emotion-Focused Group Therapy: can it enhance emotional processing?"
Dr James Richards Heriot-Watt University	"The exclusion of employees with Asperger Syndrome from the Workplace: A critical perspective"
Dr Joe Long Researcher in Residence, Scottish Autism, Honorary Research Fellow University of Aberdeen.	"The Value of Practice-Based Evidence: Practitioner Research at Scottish Autism"
Dr Ewelina Rydewska Network Adviser, Autism Network Scotland University of Strathclyde	"Milestones or Simply Next Steps? Perceptions of Transition to Adulthood for People with Autism Spectrum Disorders"
Dr Ken Aitken	"Evidence based practice meets practice based evidence"
Professor Tommy MacKay	"Homonculi"
Seminar 4 - Educational Research, Interventions and Impact	
Professor Aine-Wendy Dunlop & Professor Tommy MacKay	Educational Research, Interventions and Impact Opening remarks
Dame Stephanie Shirley The Shirley Foundation	
Professor Tony Attwood Clinical psychologist, Adjunct professor at Griffith University, Queensland, Senior consultant Minds and Hearts Clinic, Brisbane.	"Continuity of education for people on the Spectrum: strengthening the relationship of research to practice to the benefit of people with autism."
Dr Justin Williams, Senior Lecturer in Child & Adolescent Psychiatry at the University of Aberdeen, Consultant at Royal Aberdeen Children's Hospital	"Autism and the Science of Social Learning: from Scanner to Stage"
Professor Tommy MacKay	"A fresh look at prevalence and cognitive ability: The implications for education and the autism spectrum in Scotland"
Dr Catriona Stewart Scottish Women with Autism Network (SWAN)	"Experiences of girls with Asperger's syndrome/ASC and anxiety: Where can we be what we are?"
Barbara Dritschel Lecturer in Psychology and Neuroscience at the University of St Andrews.	"Knowing me knowing you: Do individuals with autistic spectrum disorders have a theory of their own mind?"
Carolyn Brown, Depute Principal Psychologist Fife Council Psychological Service. Shirley Paterson, Depute Principal Psychologist South Lanarkshire Council Psychological Service.	"The contribution of educational psychologists to the identification, assessment and diagnosis of autism: a Scottish perspective."
Dr Evelyn McGregor Lecturer in Developmental Psychology, Director of Postgraduate Studies, University of Edinburgh	"Fact or fiction: Narrative-related interests, behaviours and skills in children with autism"
Dr Jackie Ravet Senior Lecturer, School of Education, University of Aberdeen.	"Interprofessional Education in Autism: What Difference Does It Make to Professional Development, Workplace Practice and Individuals on the Autism Spectrum?"
Jayne Porter , Autism Network Scotland Moira Park, Scottish Autism	"From Guidance to Use: taking the Autism Toolbox, a resource for Scottish schools, onto the web."

Programme of Speakers	Presentation Title
Professor Tommy MacKay	"What next in Autism Research in Scotland?"
Professor Tony Charman Chair in Clinical Child Psycholgy at the Institute of Psychiatry, King's College London.	"What next in Autism Research in England?"
Professor Sue Leekam * Director, Wales Autism Research Centre, Cardiff University (Represented by Dr Arlene Cassidy)	"What next in Autism Research in Wales?"
Dr Arlene Cassidy * Chief Executive of Northern Ireland's Autism Charity (Autism NI).	"What next in Autism Research in Northern Ireland?"
Professor Tommy MacKay, Deepa Korea & Dr Maureen Bruce	Summing Up: A response to the AAR Series

Visiting Professor Jean Maclellan, University of Strathclyde and Charlene Tait, Director of Development, Scottish Autism supported the series by chairing in Seminar 3 in addition to the regular chairing of sessions offered by the Organising Team.

Annex 4 Poster Sessions

Perceptions of Facial Expressions of Emotion in Autism Spectrum Disorders: Reading the 'minds eye' using Reverse Correlation. *Kirsty Ainsworth, University of Glasgow.*

Title. *Carrie Ballantyne & Ji Yixuan, University of Edinburgh.*

Explanations of Atypical Salience with ASC. What is the role of Spatial Frequency. *Alistair Clarkson, Scottish Autism.*

Processing? An analysis of the motor difficulties within autism: Do they occur at the planning or execution stage? *Nicole Forsyth, University of Strathclyde.*

Motivation and experiences of learning among university students with high functioning autism. *Juan Gang, University of Edinburgh.*

Depressed Mood and Autistic Traits: Examining the Mediating Role of Social Problem-Solving. *Scott Jackson, St Andrews University.*

The Effect of Autism Spectrum Disorder on Retrieval Induced Forgetting. *Rob Keasley, Swansea University.*

Triadic joint attention with a virtual character in children with and without autism spectrum disorders. *Gillian Little, School of Psychological Sciences & Health, University of Strathclyde.*

Title. *Deborah McCartney, Autism Achieve Alliance*

Adults with Asperger's Syndrome: Views on Diagnosis and Identity. *Evelyn McGregor, University of Edinburgh*

The Homunculi Approach to Social and Emotional Wellbeing. *Tommy Mackay* (University of Strathclyde) *& Anne Greig* (Argyll & Bute Psychological Service).

Introducing a pet dog to families of children with ASD improves quality of life for both children and their parents. *Richard Mills, The National Autistic Society.*

Caution: Yoga Can Cause Confidence*. Lilias Nicholls, National Autistic Society.*

Title*. Maria Núñez. Glasgow Caledonian University, School of Health & Life Sciences*

Categorical speech perception in Autism Spectrum Conditions' and 'Speech pitch perception in autistic traits and its relation to cognitive and language ability. *Alexandra Petrou, Heriot Watt University.*

Audiovisual Integration differences in Autism Spectrum Disorder. *Paula Regener, University of Glasgow.*

An Action Plan to Improve Efficiency and Quality of the Process of ASD Diagnosis in Adults and Children. *Marion Rutherford, Firefly Research.*

Perception of the situation as mediator factor in explanatory model of stress in parents of children with autism: guidelines for intervention. *Encarnación Sarriá Universidad Nacional de Educación a Distancia*

Accessing Autism: The Representation of Autistic Spectrum Disorders in Film and Television. *Leigh Scott, University of Strathclyde.*

Age Related Emotional Recognition of Faces in Adults with Autism. *Ji Yixuan, University of Edinburgh.*

Annex 5 – Conference Programme

Action on Autism Research in Scotland
What does Scotland need?

Friday 7th November 2014
Senate Suite, Collins Building, University of Strathclyde, Richmond Street, Glasgow

A programme of four two day seminars focusing on autism clinical, psychological, social and education research, interventions and impact took place between November 2013 and June 2014. Sixteen international level presentations were supported by 24 Scottish Researcher papers so allowing participants to consider our country based research in the context offered by our international speakers.

Research plays an essential role in providing a rigorous, valid and reliable evidence base for understanding the key features of autism, for exploring effective approaches and interventions, and for evaluating implementation and impact. The purpose of the seminar series was to explore the state of autism research in Scotland in relation to these three functions. Part of this process included defining 'impact', considering how evidence supports claims of impact, identifying both research and impact gaps and working together and across disciplines to consider how to maximise impact.

Evaluation of what has been achieved in relation to the aims of the series, has been informed by professional, researcher, parental and autistic comment, seminar discussions and analysis of the filmed record of proceedings. As a first step in dissemination a one-day conference will allow participants to focus on what we know, what we don't know and how research may be used to inform policy and practices. A continuing networking around research will be facilitated through an online library of all filmed AAR Seminar sessions, learning events and further Scottish Action on Autism Research Conferences.

This conference aims to bring together the thinking from our four seminars to propose a new model for autism research for Scotland.

9.00	**Registration and Coffee**
9.30	**Chair's Opening Remarks** – Professor Tommy MacKay **Address** – Ros Moore, Chief Nursing Officer, Director, Directorate for Chief Nursing Officer, Patients, Public and Health Professionals, Scottish Government
10.00	**What have the seminars achieved?** Professor Aline-Wendy Dunlop, University of Strathclyde & AAR Seminar Series Film (Producer - Michael Dawson)
11.00	**Coffee**
11.20	**Professor Fred Volkmar** Irving B. Harris - Professor Director - Child Study Center, Yale University School of Medicine, Chief of Child Psychiatry Yale New Haven Hospital: "An international perspective on the relationship of Autism Research to practice"
12.30	**Lunch**
13.15	**'Microsegmentation, the economic evidence base and the future of Scottish autism research and practice'** Professor Tommy MacKay, Director of Psychology Consultancy Services, Visiting Professor of Autism Studies, University of Strathclyde and Professor Martin Knapp, London School of Economics
14.15	**Research within an Architecture for Autism Strategy....how practice can influence research and policy** Alan Somerville, Scottish Autism
14.45	**An Autistic perspective on autism research** Kabie Brook, ANS Autism Champion 2014, ARGH (Autism Rights Group Highland)
15.15	**The Impact of Research: Voices - A response from the community to main themes, opportunities, gaps and recommendations for research in Scotland: Chair and Summary – Richard Mills, Research Autism** A Research Voice – Dr Andy Stanfield, University of Edinburgh A Spectrum Voice – Michael Dawson A Policy Voice – Dr John Mitchell, Scottish Government A Funder's Voice – Deepa Korea, Research Autism A Parental Voice – Thom Kirkwood A Practice Voice – Carolyn Brown, Area Depute Principal Psychologist, Fife
16.00	**Afternoon Tea**
16.30	**Reflections on Autism and on what Scotland Needs in Research** Christopher Gillberg, Chair Mental Health and Wellbeing, University of Glasgow; Head of the Gillberg Neuropsychiatry Centre, Sahlgrenska Academy, Gothenburg University
17.30	**Final discussion**
18.00	**Wine Reception & Buffet Supper**
19.30	**Close**

Annex 6: Cameos of participants

PhD Student

As a PhD student the main contribution I can bring to the seminar series is knowledge of current research, methods and technologies in the field of autism research. Aside from this I am extremely interested in government policy in relation to individuals with ASD and would relish the opportunity to be involved in discussions surrounding this area. My PhD work focuses on social interactions in autism spectrum disorders, specifically addressing everyday skills in the perception facial expression of emotion, and interventions surrounding this skill. The opportunity to attend the seminar series would be greatly appreciated and I hope to reciprocate in bringing value to the seminars wherever I can.

Researcher

As a researcher I have been involved in multiple research projects involving autism and have been a co-applicant on two ESRC grants looking at autobiographical memory in children, adolescents and adults. Currently I am supervising a PhD looking at social problem-solving in ASD with the aim of developing an intervention to improve social problem solving in this sample in order to improve their quality of life and reduce vulnerability for depression. Another goal is to look at interventions for improving the ability to retrieve autobiographical memories in order to improve everyday functioning and enhance identity.

PhD Student

I would use the seminars to deepen my understanding of autism and how research currently understands it theoretically and practically. My link to the research community works in two ways, because my own PhD research is interdisciplinary, in the spheres of theology, literary studies and autism studies; I aim to prompt religious and scholarly communities to examine their awareness and celebration of autistic people; and to encourage people with autism to reflect on how they view their own religious or spiritual experiences. To do this I need to be as well informed as possible on current thinking in autism studies, both theoretical and practical. I have a diagnosis of Aspergers Syndrome.

Psychological Services

I have the management lead within Psychological Service for autism, am linked with the diagnostic service and sit on the authority's autism strategy group.

Autism Development Fund Project Team Member

I would be able to contribute my knowledge of autism, particularly in the areas of mental health, psychological research methods and sensory sensitivities. I would particularly value being able to learn from (and network with) the practitioners, researchers and people with autism who would be in attendance. I have completed my PhD in autism and also have practical experience in working as a support worker with young adults with ASD. In my current post, we are developing an intervention for anxiety in adults with ASD which is funded by the Scottish Government Autism Development Fund.

Autism Charity Assistant Director

As the Assistant Director of an autism charity, I will be able to disseminate information back to my teams, service users and parents. I also support a local group run by and for people with Aspergers and I will inform our members of the information gleaned from the seminars. I am a Scottish Autism Strategy Sub-Group Member and my hope is that research initiatives will have a direct bearing on the support strategies in our services.

Practitioner in Developmental Delay

A research colleague asked me to join the seminar group. We are working on a research grant looking at small disruptions in autistic children from a movement perspective. I have a small private practice working with children with developmental delay and have over 40 years experience working with children with autism.

Action Research Coordinator

My role consists in helping to shape, monitor and evaluate multi-agency interventions aimed to improve transition and post-school outcomes for young people with ASD. We are currently looking at ways in which we could evaluate the impact of vocational support and transition planning in post-school outcomes for young people with ASD – including how this may improve their independence, social and cognitive skills.

University Researcher

I hope to take the information from this conference and incorporate it into new clinically relevant research projects as well as learn more about other ways in which I can contribute to Action on Autism Research in Scotland.

Secondary Teacher

Links to policy , research and practice initiatives are central features of my daily working practice and are incorporated into the training programme that has been developed and, although I will clearly enhance my own knowledge and understanding through inclusion in the seminars, I feel that the varied aspects of my work would allow me to be an effective contributor during subsequent discussions.

Principal Teacher

As a Principal Teacher in Autism Outreach Services in my Council's Secondary Schools, I support mainstream inclusion for pupils with a diagnosis of ASD, my work remit also includes supporting teenagers (and their families) who, for a number of reasons, refuse to attend school. I am also involved in supporting the post school transition for pupils with a diagnosis of ASD which has been developed through funding from the Scottish Government's Autism Strategy.

Autism Plan Developer

Employed by a Council to formulate the local autism plan as part of the Scottish Strategy for Autism, my post is for one year and during that time I am trying to discover what is currently offered to those with autism in this area and to use the literature and current research to argue for how current services may be improved/restructured in a way that will be helpful and more accessible to the community.

Educational Psychologist

I plan to attend all 4 two-day sessions. As I work in a Local Authority I am already involved in strategic planning across the authority alongside intervention in schools systems and for individual pupils. I would like to plan to use the research and practice points to illuminate our school practice and authority strategic planning.

Policy Lead

Myself and my team will attend and reflect together on the potential impact on policy development and delivery of policy.

Research Fellow

My contribution to this seminar series will be in critically discussing the current autism research in Scotland, in order to help to identify where further work is needed and how this relates to the Research Strategy in Scotland.

Freelancer

I am a freelancer with experience in social science and health policy areas. I have recently conducted evaluations of transitions services for young people with additional support needs; and am aware of the research around transitions and employment and supported employment. I am involved in turning policy into practice for service providers and disabled people.

Masters Student

As a MSc. student and teacher in a school for children with ASD, I'm hoping to use what I learn at the seminar to both feed into my own masters research and report back to colleagues in my school about the directions autism research is taking in Scotland. Hopefully, if required, I will be able to communicate some impression of how research and policy are impacting within the special education sector.

Parent /Carer

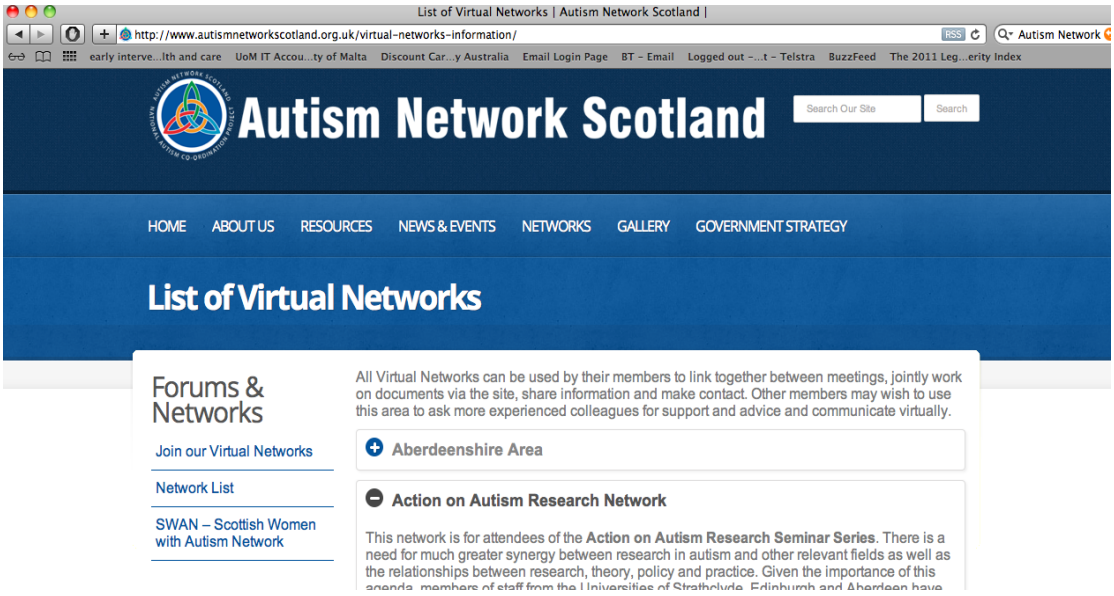
Involved in the Autism Strategy I have also written a number of discussion papers linked to delivery and improvement of services.

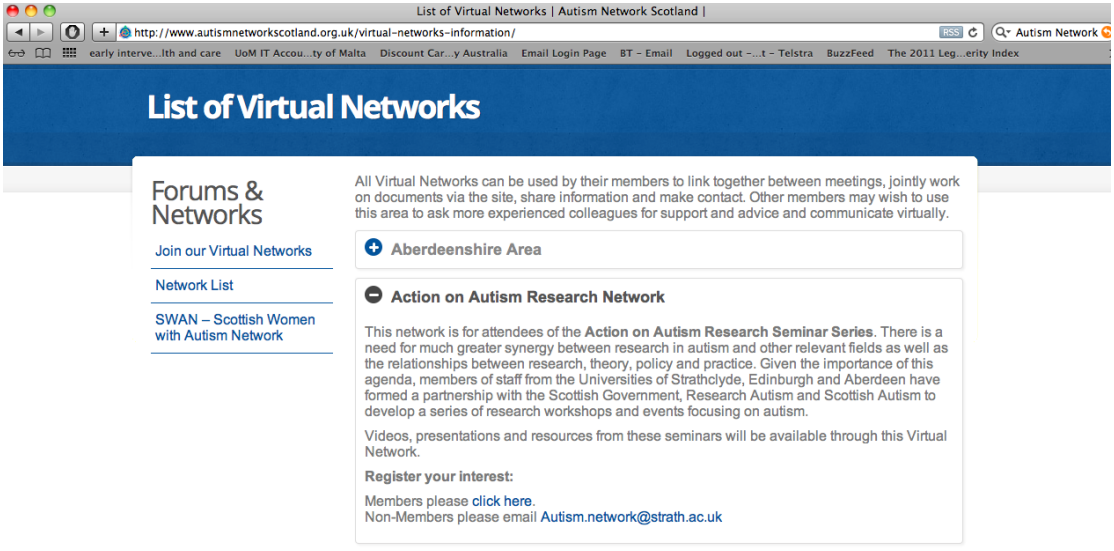
Autistic Presenter

My intention is to support links to policy & practice nationally with my connection to the ASD reference Group and locally – through ARGH and the Highland Autism Improvement Group (a multidisciplinary, multiagency group chaired by NHS Highland) of which ARGH are members. I also hope to put together a presentation for the final conference which will bring together themes from the seminars presented in the context of what they mean to Autistic people in Scotland.

Annex 7: Virtual Networks

- Presentations on Action on Autism Research Virtual Network
  (Password protected access was arranged with Autism Network Scotland-all participants were given information on access)





Annex 8 Attendees

AAR Attendance List - All

FirstName	Surname	Organisation
Kirsty	Ainsworth	University of Glasgow
Ken	Aitken	ASD Reference Group - Research Sub-Group
Debbie	Allan	Autism Strategy Subgroup 6
Claudia	Attucci	Dundee City Council
Richard	Austin	The RS Macdonald Trust
Bonnie	Auyeung	University of Edinburgh
Carrie	Ballantyne	University of Edinburgh
David	Banks	West Lothian Council
Jemma	Boak	Psychological Services
Jim	Boyle	University of Strathclyde
Kabie	Brook	Autism Rights Group Highland
Fiona	Brown	Renfrewshire Learning Disability Service
Carolyn	Brown	ASPEP 2
Maureen	Bruce	Scottish Government
Lorraine	Brunton	
Aisling	Campion	ASPEP 2
Arlene	Cassidy	Autism NI
Katie	Cebula	Moray House School of Education
Tony	Charman	King's College London

FirstName	Surname	Organisation
Alastair	Clarkson	Scottish Autism
Frank	Coletta	Cumbernauld High School
Bill	Colley	Caledonia Learning & Care
Magnus	Cormack	Yarrow View Centre
Pippa	Coutts	Scottish Consortium for Learning Disability
Shona	Crawford	Psychological Service, West Dunbartonshire Council
Michelle	Dawson	University of Montreal
Michael	Dawson	ASD Reference Goup , Sub Group 6
Matthew	Day	Autism Initiatives
Jonathan	Delafield-Butt	University of Strathclyde
John	Dreghorn	Argyll and Bute Hospital
Barbara	Dritschel	University of St Andrews
Aline-Wendy	Dunlop	University of Strathclyde
Ruth	Dunster	University of Glasgow
Maria	Ferrara	University of Strathclyde
Bernard	Fleming	Research Autism
Sue	Fletcher-Watson	University of Edinburgh
Nicole	Forsyth	University of Strathclyde
Andrew	Foster	Kaimes School, Edinburgh
Susan	Fullerton	PLUS (Forth Valley) Ltd
Anne Marie	Gallagher	Adult Autism Team NHS Greater Glasgow and Clyde

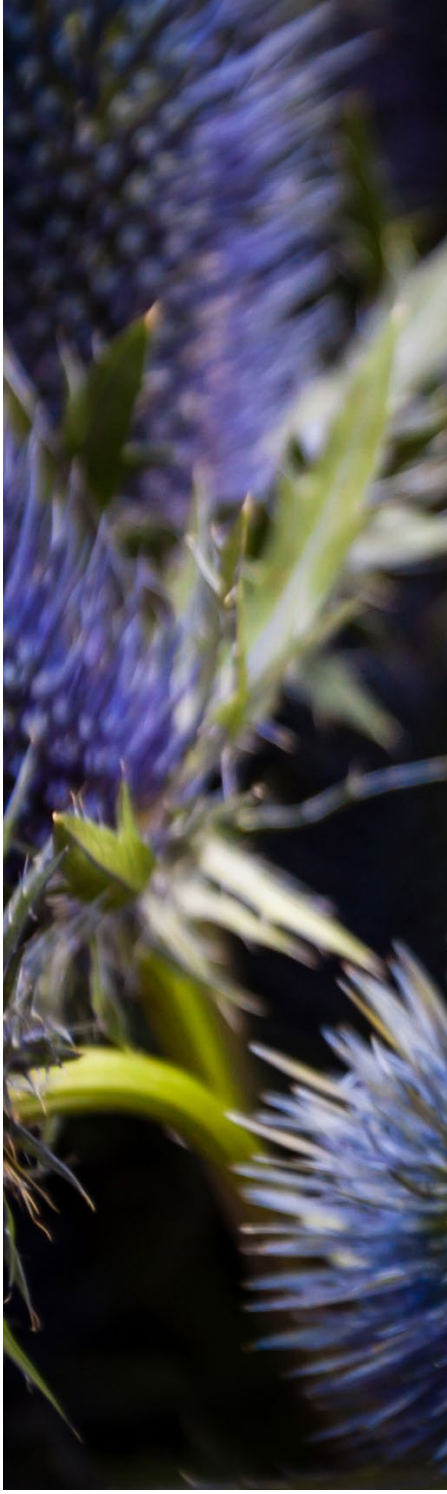
FirstName	Surname	Organisation
Fiona	Gellatly	Southbank Child Centre
Christopher	Gillberg	Gillbergcentrum/Gillberg Neuropsychiatry Centre
Karri	Gillespie-Smith	Heriot Watt University
Juan Carlos	Gómez	University of St Andrews
Douglas	Hamilton	The RS Macdonald Charitable Trust
Emma	Hanley	Autism Network
Sharron	Harper	Dumfries & Galloway Council
Roxanne	Hartley-Davis	
Thomas	Henderson	CRISPESH
Angela	Henderson	Scottish Consortium for Learning Disability
Ian	Hood	LDA Scotland
Richard	Ibbotson	ASD Reference Group, Sub Group 4
Valentina	Iemmi	London School of Economics and Political Science
Tom	Insel	National Institute of Mental Health (NIMH)
Scott	Jackson	St Andrews University
Margaret	Jackson	University of Aberdeen
Lorna	Johnston	City of Edinburgh Council
Rob	Keasley	Swansea University
Janette	Kerr	DEPS St Ninian's PS
Lorraine	Kerr	Daldarch House School
Thom	Kirkwood	Reference Group, Sub Group 6

FirstName	Surname	Organisation
Martin	Knapp	London School of Economics and Political Science
Deepa	Korea	Research Autism
Filippos	Kotsonis-Garedakis	University of Strathclyde
Stephen	Lawrie	University of Edinburgh
Gillian	Little	University of Strathclyde
Peipei	Liu	University of Glasgow
Joseph	Long	Scottish Autism
Erin	Lux	University of Strathclyde
Maura	Lynch	Scottish Consortium for Learning Disability
Tommy	MacKay	Psychology Consultancy Services and University of Strathclyde
Jean	Maclellan	University of Strathclyde
Donald	Macleod	University of Strathclyde
Kirsten	Mann	Castlehill Primary Language & Communication Resource
Katie	Maras	University of Bath
Caroline	Marley	University of Strathclyde
Catriona	Martin	The Richmond Fellowship Scotland
Helen	Marwick	University of Strathclyde
Alison	McCarney	Blackburn Primary School
Deborah	McCartney	Autism Achieve Alliance
Iain	McClure	University of Edinburgh
Helen	McConachie	Institute of Health and Society, Newcastle University

FirstName	Surname	Organisation
Mike	McCreadie	Studio 3
Mary	McCutcheon	Adult Autism Team
Evelyn	McGregor	University of Edinburgh
Andrew	McKechanie	University of Edinburgh
Jess	McPherson	Scottish Government
Craig	Melville	University of Glasgow
Gary	Mesibov	University of North Carolina
Jasmine	Miller	Scottish Autism
Richard	Mills	Research Autism
Helen	Minnis	Academic Unit of Mental Health and Wellbeing
John	Mitchell	Scottish Government
Lynne	Moffat	Autism Network Scotland
Ailsa	Morison	Huntercomb
Declan	Murphy	Institute of Psychiatry
John	Murray	Autism Network Scotland
Lilias	Nicholls	National Autistic Society
Maria	Núñez	Glasgow Caledonian University School of Health & Life Sciences
Anne	O'Hare	NHS
Sharon	Ovenstone	St Ninian's Primary School
Moira	Park	Scottish Autism
Shirley	Paterson	South Lanarkshire Council

FirstName	Surname	Organisation
Fiona	Patrick	The RS Macdonald Trust
Liz	Pellicano	Institute of Education, University of London
Alexandra	Petrou	Heriot Watt University
Roo	Philip	ASD Reference Group, Sub Group 2
Judith	Piggot	NHS Tayside CAMHS
Frank	Pollick	University of Glasgow
Jayne	Porter	Autism Network
Annette	Pyle	Scottish Government
Nicola	Quinn	Visiting Teacher (Spectrum)
Jackie	Ravet	University of Aberdeen
Paula	Regener	University of Glasgow
James	Richards	Heriot-Watt University
Ashley	Robertson	Institute of Health & Wellbeing, University of Glasgow
Janine	Robinson	Educational Projects Manager - Autism NHS Education for Scotland
Anna	Robinson	University of Strathclyde
Marion	Rutherford	Firefly Research
Ewelina	Rydzewska	University of Strathclyde
Encarnación	Sarriá	Universidad Nacional de Educación a Distancia
Leigh	Scott	University of Strathclyde
Kenneth	Shade	Education Services, West Lothian Council
Stephanie	Shirley	The Shirley Foundation

FirstName	Surname	Organisation
David	Simmons	University of Glasgow
Alan	Somerville	Scottish Autism
Andy	Stanfield	University of Edinburgh
Catherine	Steedman	Autism Initiatives Scotland
Catriona	Stewart	SWAN (Scottish Women's Autism Network)
Mary	Stewart	Heriot Watt University
Lisa	Sturgess	The National Autistic Society
Helen	Tager-Flusberg	Boston University
Charlene	Tait	Scottish Autism
Ali	Taylor	Scottish Government
Colwyn	Trevarthen	University of Edinburgh
Fiona	van der Meer	NHS Greater Glasgow & Clyde
Fred	Volkmar	Yale University Child Study Center
Jacqui	Ward	South Ayrshire Council
Elizabeth	Wiesner	USA
Justin	Williams	University of Aberdeen Medical School



Academics from the Universities of Aberdeen, Edinburgh and Strathclyde collaborated to develop the seminar series.

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