

Working Group 3 meeting minutes
24 June 2015
University of Strathclyde, Glasgow

REVIEWED BY CHAIR

Members present: **Bill Colley**, Caledonia Learning and Care, **Jayne Kemp**, Social Work Scotland, **Alison Leask**, Autism Argyll, **Jane Neil-MacLachlan**, Independent Advisor, **Maira Park**, Scottish Autism, **Roo Philip**, Tailor Ed, **Jayne Porter**, Autism Network Scotland, **Annette Pyle**, Scottish Government Care, Support and Rights Division, **Lisa Sturgess**, National Autistic Society

Invited guests present: **Donald Macleod**, National Autism Co-Ordination Project, University of Strathclyde, **David Simmons**, Scottish Autism Research Group

Apologies: **Ken Aitken**, Ken Aitken Consultancy, **Aline-Wendy Dunlop**, University of Strathclyde, **Jane Hook**, Parent, **Zoe Robertson**, Social Work Scotland, **Cathy Steedman**, Autism Initiatives, **Charlene Tait**, Scottish Autism

Minutes by: Tracy Wenzl, Autism Network Scotland

- I. **Introductions** - Introductions were made around the table
- II. **Apologies** - JNM gave apologies on behalf of members unable to attend
- III. **Minutes** – the minutes from 15 April 2015 were approved
- IV. **Matters Arising**
 - a. **Report from Governance Group meeting** – JP represented JNM at the meetings and read the report provided. She requested information about the Autism Development Fund projects. AP reported that most of the organisations had been funded up to March 2015 and that not all the final reports have come in yet. They are chasing up the remaining reports. The Scottish Government would undertake to highlight relevant good practice out of the funded projects to showcase at the November Annual Conference. JNM suggested that Working Group 3 develop the framework. AP agreed to discuss this with JMcP.
ACTION ITEM: AP to discuss with JMcP the ADF evaluations.

JP reported that the four working group chairs will be asked to meet with AP and Governance Group Chair Jean MacLellan, to clarify expectations and avoid duplication in work streams.
 - b. **Implications for Group 3** - The group's ability to put on a "good autism practice festival" as part of the Annual Conference will be affected by the availability of ADF evaluation data. AP suggested putting out a call for stands or posters from funded projects, so they can show what they did. Discussion followed around whether an open invitation would allow the selection of good practice. It was agreed that there would need to be some kind of assessment before setting up an event with displays or posters.
- V. **Review of work in progress**
 - a. **Update on Action on Autism Research Series** – TW and JP attended meeting on June 23 where an overview of the themes from each event in the series was presented. The group will meet once more to make final recommendations as a result of the series. AP noted they are mapping current research and will identify gaps, to

influence future funding. Early indications are that gaps are in education and social research. The final report is expected before the next Governance Group meeting in September. There is a possibility that a book or journal may be published from the data they've gathered.

Discussion turned back to ADF projects, and LS asked what kinds of research questions were generated by these projects. JNM noted that CT had been keen to ask what had worked in those projects, along with what didn't work. AP noted that Self Directed Support funded a number of organisations. The projects then got 20 minutes to feed back to a panel. This could be a model. It was asked how many projects received ADF funding, and AP answered that it was about 170 over three years. AP also noted that Tommy Mackay's report on microsegmentation is due at the end of the summer.

JNM noted that part of the group's remit was to assess the ADF projects. AP responded that the group's remit is to review the assessment, not to complete the assessment. She further said that the group should meet when there is activity to feed into, and that the group's role is advisory. DS suggested the group develop a Framework for how to evaluate ADF projects now, so when they arrive, the group will be ready to work. BC noted that developing a framework was a large piece of work and could be tricky.

- b. **Scottish Autism Research Group (SARG) member update** – DS suggested members visit the [SARG website](#). He gave the background of the group, which formed in 1999 at the University of Edinburgh, and was active until 2010. There was a lull for a few years; then the group was re-launched. The group provides networking opportunities to researchers, to discuss research and progress. It acts as a training hub for students and a forum to discuss things of importance. He estimates there are 120 members from across Scotland. The members are researchers, students, and members of the autism and autistic communities. Their February 2015 meeting brought Simon Baron-Cohen in along with a broad range of speakers. This year's theme was "from embryo to employment." Next year's meeting will take place in Glasgow in February (2016.) The focus will be on aging.

He described a new UK-wide initiative to create research databases, funded by Autistica, which would create both subject pools and give people with autism the chance to guide what research is taking place. The one for children is called [ASD-UK](#): "ASD-UK is a UK research family database of children with an autism spectrum disorder (ASD). The aim of ASD-UK is to provide accurate data about children with an ASD to facilitate research and give families the opportunity to take part in research studies." The one for adults is called [ASC-UK](#): "This project is about engaging adults on the autism spectrum and their relatives in research. This project involves the creation of a cohort, or group, of adults on the autism spectrum and their relatives, which we have called the Adult Autism Spectrum Cohort - UK, or ASC-UK."

DS went on to explain that the group hopes to recruit 500 adults with autism, and 500 families to this cohort. SARG is supporting recruiting for this project in Scotland. He has written about this in the latest edition of Scottish Autism's [Share magazine](#).

DS also described another research series, this one funded by the Economic and Social Research Council, which is on [Shaping Autism Practice in the UK](#). The series

kicked off with an invitation-only event in Edinburgh recently. The series aims to look at putting research into practice.

DS thinks that funding research that uses the cohort approach will be more beneficial than current practice of recruiting random pools of people for each new study. He also noted that research needs to be translated so that non-academics can understand and use it.

JP noted that Working Group 3 should be linked in to these kinds of things happening across Scotland. JNM agreed and suggested DS or a representative of SARG attend every meeting. DS noted that he thought SARG would be able to send a representative to each meeting, but the member attending would vary, based on meeting location.

A discussion took place about several other research projects going on; Scottish Autism is looking at research into practice and working on a framework on how to do best do this (Centre for Practice Research.) MP noted that the Autism Toolbox has a "Share Practice" function.

- c. Update on progress towards Scottish edition of Journal of Autism and Developmental Disorders (JADD) – DS noted that KA has said this was likely to be a book instead of a journal
- d. Knowledge Network – JP has created space on the Autism Network Scotland website for this. She has provided examples of blurbs (descriptions) of other virtual networks and the group needs to settle on something for ours. JNM suggested that the group agree the name of the virtual network first – it was agreed that it will be called the "Sharing Practice Network."

ACTION ITEM: JP will draft a blurb based on group feedback and circulate it by email. She will also circulate the Network's Participation Principles for discussion.

The group would like to start out as an open forum (no approval needed) initially, but keep the possibility of closing it/requiring approval later on.

ACTION ITEM: TW to check on technological requirements of open forum, if the forum has capacity to be accessed/registered for by 100+ at once

RP suggested the group time until the event to create material to be used to populate the forum, so there's something on it when it's launched. Some material could be held back and used for regular updates to help foster activity in the early days.

ACTION ITEM: LS to provide TW with contact information for someone who works with the NAS forums, to discuss obstacles, etc

JNM noted that a moderator still needs to be discussed.

- e. JNM wondered if the festival could be done, given the delay in ADF project evaluation. RP suggested looking at other ways of identifying good practice. AP said the Conference would likely include something from the AAR Series, and Mackay's microsegmentation report. JP suggested SARG, the Shirley Project, and the Employment Network's events all be considered for sources of good autism practice. AP added local authorities and the transitions work as more potential sources.

VI. Any other current business

- a. **National Autism Co-ordination Project update** – DM reported that most of the local autism strategies are submitted and many areas are now focused on implementation. The last NACP event for local leads, held at the end of April, focused on out of area placements and complex care. The following week, an event for providers and commissioners was held. This group is also keen to form a collaborative, and further events will be planned. They recently facilitated an event in the Highlands to revitalize their strategy group. North Lanarkshire has produced an employment booklet and a school document. They recently trained 195 teaching staff as autism links. JNM asked about difficulties, and DM responded that there were challenges in a couple areas. A number of places lack strategic buy in.
- b. **Autism Accreditation** - LS noted, in response to prior minutes, that the National Autistic Society does accreditation in schools as well as several other areas, including adult services and prisons, and are developing more. MP noted that Scottish Autism just piloted a programme on training trainers that is accredited.
- c. **Other ongoing programmes of interest** – AL noted that CT is developing an autism framework to sit alongside their public service framework. JP noted that Strathclyde has a new train the trainer programme. MP noted that Scottish Autism is developing Right Click for professionals.

VII. Key messages

- a. SARG is a good resource
- b. ADF – no progress since last meeting
- c. ADF Framework may be taken on, depending on outcome of AP's meeting with JMCP
- d. Knowledge Network moving forward
- e. AAR Series Report due at the end of summer
- f. Micro-segmentation report due at the end of summer

- VIII. Will poll for next meeting date when new work arises.

KEY MESSAGES

Working Group 3 heard an update from a member of the Scottish Autism Research Group. SARG has recently been revitalized, holding an event in February 2015 and planning another for February 2016. They are also involved with Autistica-funded projects to build cohorts of children and adults with autism and their families for participation in autism research.

The Group remains keen to see the outcomes from the Autism Development Fund projects; however, the evaluation of these projects is reliant on final reports and evaluations being completed by the project organisations and for these to be analysed to identify good practice. Timing is tight for this to be completed before the 4th Annual Conference on the Scottish Strategy for Autism, tentatively scheduled for November 2015. The group has offered to support the evaluation by creating a framework, and awaits word from the Scottish Government on whether they should undertake this work.

Post meeting note (AP): Following SG discussions, an evaluation framework will not be developed but funded projects which have had good outcomes will be highlighted and showcased at the annual event.

The Group will be creating an online knowledge network, in the form of a forum hosted on the Autism Network Scotland website. It will be called the "Sharing Practice Network" and development work is continuing. The Group intends to formally launch the network at the November Conference.

The Action on Autism Research Series Report is due to be completed at the end of summer and presented at the next Governance Group meeting.

ACTION ITEMS

ACTION ITEM: AP to discuss with JMcP how ADF will be evaluated and timescales.

ACTION ITEM: JP will draft a blurb based on group feedback and circulate it by email. She will also circulate the Network's Participation Principles for discussion.

ACTION ITEM: TW to check on technological requirements of open forum, if the forum has capacity to be accessed/registered for by 100+ at once

ACTION ITEM: LS to provide TW with contact information for someone who works with the NAS forums, to discuss obstacles, etc