

## Autism Strategy Review Group Approved Minutes

### CLOSED MEETING

Thursday 27<sup>th</sup> February 2020

10.00 am – 12.00pm

### City of Edinburgh Methodist Church, Edinburgh

**Present:** **Fiona Clarke**, Parent representative; **Lesley Evans (minutes)**, Autism Network Scotland (ANS); **Anne Marie Gallagher**, Greater Glasgow and Clyde National Health Service (GGC NHS); **Thom Kirkwood**, Apex Associates; **Richard Ibbotson**, The Richmond Fellowship Scotland; **Representative**, Autistic Mutual Aid Society Edinburgh (AMASE); **Fiona Milne**, Renfrewshire Carers Autism Spectrum Disorder Support Group; **Annette Pyle (Chair)**, Scottish Government; **Catherine Steedman**, Autism Initiatives; **Charlene Tait**, Scottish Autism; **Nick Ward**, National Autistic Society (NAS).

**Strategy Workstream Partners:** **Pauline Beirne**, Scottish Government; **Dr Sandra Ferguson**, NHS Education for Scotland (NES); **Frances Foreman (previously Ranaldi)**, Education Scotland; **Prof Kirsty Forsyth**, Queen Margaret University (NAIT); **Colin McNab**, Inspiring Scotland.

**Apologies:** **Arron Ashton**, Scottish Government; **Gillian Barclay**, Scottish Government; **Kabie Brook**, Autism Rights Group Highland (ARGH); **Sonny Hallett**, Autistic Mutual Aid Society Edinburgh (AMASE); **Prof Jean MacLellan**, University of Strathclyde, Autism Network Scotland (ANS); **Dr Janine Robinson**, NHS Education for Scotland (NES); **Stephanie Rose**, Police Scotland; **Dr Marion Rutherford**, Queen Margaret University (NAIT); **John Urquhart**, COSLA

Following round table introductions, **Annette Pyle (AP)** apologised for the lack of Review Group Meetings but assured the group that regular meetings with stakeholders were taking place.

There were no actions carried forward from the minutes for either the Open or Closed meeting (02 May 2019).

### Strategy Group Business

#### Scottish Borders Follow Up Meeting

**Louise Scott (LS)** stated the Scottish Borders was doing good work and had buy in from Chief Officers regarding autism and the priorities within the area. At the time of the follow up meeting, the autism officer had just vacated the post. **Fran Foreman (FF)** asked if there was input from education, to which **LS** said not at the meeting but there was buy in from across the local authority.

#### Inverclyde Open Meeting

**Lesley Evans (LE)** distributed the agenda and advised that 14 planned to attend from the Autism Strategy Review Group. **LE** will email the final agenda to the group once received. **Anne Marie Gallagher (AMG)** advised that as she covers this area she is happy to provide input to the day. **LE** agreed to put her in touch with Lynsey Stewart at **ANS** to discuss further. **FF** said she would be interested in knowing what perspective Michael Roach, Head of Service for Education, Inverclyde Council is taking. **Pauline Beirne (PB)** is not available to attend but will look to secure speech and language representation.

## Scottish Government Update

**AP** advised that the Autism and Learning Disabilities Policy, Mental Health Directorate is working with policy colleagues across other directorates.

- The Mental Welfare Commission report<sup>1</sup> published in October 2019 which seeks to drive up standard and practice was welcomed by the Minister. **AP** referenced recommendations 4 & 5 and stated that the Cabinet Secretary issued a statement 26.02.2020 to H&SCPs seeking assurance of measures in place. **AP's** team will use the Social Work Scotland network to touch base with all the H&SCPs to assist with this. An update will be provided following the next Social Work Scotland meeting on 18<sup>th</sup> March 2020.
- The Independent Review of Mental Health Act Scotland report was published in December 2019. Teams are taking the wide ranging recommendations<sup>2</sup> forward. The main Mental Health Review and Forensic Review are ongoing and **AP's** team will continue to work with internal colleagues.
- The Independent Care Review<sup>3</sup> published February 2020 has implications for autism and learning disabilities within it. **AP's** team is connecting with Care Review Policy colleagues.
- Additional Support for Learning<sup>4</sup> – Angela Morgan is reporting to COSLA and Ministers week commencing 24<sup>th</sup> February.
- Fair Start is being reviewed by Employability team.

**Charlene Tait (CT)** stated there are lots of Reviews starting with the PHIS Report with millions spent on them, however, in terms of autistic individuals there has already been lots of research carried out regarding what they need, what the challenges are etc. **CT** asked who pays attention to autism in these specific Reviews, as this group is an Autism Strategy Review Group primarily concerned with autism. **CT** continued by expressing the opinion that money is always available to establish a problem with many Reviews producing the same repeated solutions; we know the problems, so where does the resource come from to implement the Review recommendations and what can the Autism Strategy Review Group do to turn this into an action. When do we stop reviewing and begin to action? **AMG** gave an example of the One Stop Shops being in existence to which **CT** replied they were part of a solution, people need people, not a page on a website. **Catherine Steedman (CS)** agreed, saying solutions were not being realised due to a lack of funding. **CT** reiterated that it was time to start responding to people and asked **SG** how much money is spent on autism and LD in these reviews and who to approach to have this answered. **CT** concluded by reiterating, as members we sit on an Autism Strategy Review Group, with autism as its priority. **Thom Kirkwood (TK)** agreed and suggested mapping the reviews to see how they link to autism as there is a need to be more connected and make better use of these underused resources e.g. microsegmentation report. **LS** responded by saying autism is part of these reviews and they are across Government, however, there is no easy way to get a monetary figure.

A roundtable discussion followed, discussing:

- how stakeholder partners in education, health, social care etc should work more collectively to help people navigate some of the complex, adaptive systems in their local communities, regardless of diagnosis

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<sup>1</sup> [https://www.mwscot.org.uk/sites/default/files/2019-10/ASD\\_ThemeVisitReport-20191030.pdf](https://www.mwscot.org.uk/sites/default/files/2019-10/ASD_ThemeVisitReport-20191030.pdf)

<sup>2</sup> <https://www.irmha.scot/wp-content/uploads/2020/01/IRMHA-Final-report-18-12-19-2.pdf>

<sup>3</sup> <https://www.carereview.scot/>

<sup>4</sup> <https://www.gov.scot/groups/additional-support-for-learning-review/>

### **Scottish Government Update Cont.**

- would an approach like that in England which addresses Human Rights with a joined-up approach to meet needs be the driver required in Scotland?

**FF** brought the discussion to an end, stating that Local Authorities are faced with many reports, however as they are not legally obliged to implement the recommendations it relies on the passion of the people involved. Collaboration makes the difference in meeting the recommendations; however, some Local Authorities are joint services with competing demands. **AMG** felt we had moved on in 10 years and the national campaign to raise awareness will continue to help.

### **National Autism Awareness Campaign**

**AP** thanked **Inspiring Scotland** for organising the Steering Group and advised that **Colin McNab (CMcN)** would say more on the Campaign under agenda item National Strategy Workstream Partner updates. **SG** Marketing colleagues are working closely with **Inspiring Scotland** to create a multi-platform campaign with differing themes, discussing creative ideas gathered from independent research. **AP** is happy for this to be shared with the group once agreed. Following the advice of the **SG** marketing team, the launch of the campaign is planned for early Autumn 2020.

### **Programme for Government (PFG) Commitment**

Funding has been secured for a post diagnostic online resource. A CivTech approach<sup>5</sup> is being adopted at present as this worked well for a similar Dementia resource. **SG** will keep the group updated on progress and will consult and seek views on the resource. **Nick Ward (NW)** asked if the digital resource had already been agreed to which **AP** said it had. **LS** said that alternative options were being considered and there would be an opportunity to link to other resources.

A round table discussion followed regarding the resource's accessibility, relevance and purpose. **LS** said there was a PFG commitment to produce a national resource and discussions were still taking place between **SG** colleagues and practitioners as to the exact working. **AP** advised £250k had been secured for next year with the hope that this would increase the year after. To **NW's** question regarding consultation workshops, **AP** said these would happen.

### **Autism Awareness - Civil Service UK event**

**AP's** department has been approached to assist with speakers at the forthcoming Victoria Quay event around neurological conditions including ADHD, autism, dyslexia to which all Scottish civil servants are invited (expecting 70 attendees). **Fiona Milne (FM)** said it was important to teach school children with **FC** agreeing that inclusion is very important as adaptations will help an entire workforce not just autistic individuals. **FF** said "inclusive practice" is being much more talked about and there was a big emphasis on the work **Education Scotland** does, highlighting the free, online professional learning resource<sup>6</sup> on the **Education Scotland** website. **TK** requested that Lynsey Stewart (**ANS**) ask Michael Roach for an update on how Inverclyde were progressing with regards to communication friendly schools.

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<sup>5</sup> **CivTech** - brings together public sector expertise and private sector creativity to solve real problems, develop new products and deliver better, faster and easier services for everyone. Central to the approach is co-production with the citizen.

<sup>6</sup> <https://professionallearning.education.gov.scot/>

***ACTION: Lynsey Stewart to ask Michael Roach how Inverclyde were progressing with regards to communication friendly schools***

### **National Strategy Workstream Partners Updates**

#### **Autism Network Scotland**

**Jean MacLellan (JMaCL)** to email paper to the group.

#### **Inspiring Scotland**

Paper was distributed prior to the meeting

### **National Awareness Campaign**

**CMcN** advised that APO's were represented in the governance group/steering committee and that 40 autistic adults had provided a notable input to the National Awareness Campaign and that all the fora will be completed by March 2020. The campaign launch is planned for September 2020.

<https://vimeo.com/389507636>

**Richard Ibbotson (IB)** said it would be good to reflect on advisory group involvement and how they steered the thinking. **CMcN** is happy to share this information with the group at a later date.

***ACTION: CMcN to share data on advisory group involvement***

### **Resilience Programme**

This currently runs into July and is aimed at leaders of charities. The next cohort starts week commencing 2<sup>nd</sup> March 2020 with **LS** attending. The Lunch and Learn sessions are also well attended. **CMcN** to send information. **AP** advised the Resilience Programme is funded by **SG** to help charities post funding and many have blossomed through the pro bono support offered by **Inspiring Scotland**. The Programme is now open to local, smaller charities delivering autism services. **CT**, who has attended the course said if **Scottish Autism** can help in any way they would, **PB** would also like to see health embedded. **CMcN** said all help gratefully received and if anyone from the group wished to come along as a speaker, they would be very welcome.

When asked when the programmes would end, **AP** said the Leadership programme was not under review as sustaining the third sector is important. **SG** is committed to the programme for as long as there is an autism budget.

When asked by **FC** if there was autistic representation and to ensure the message reaches the charities, **CMcN** said that the latest fund did involve the community and **AP** advised that SWAN was involved in the leadership group. The representative from AMASE said that time is limited to get involved at a granular level and autistic people not being remunerated.

***ACTION: CMcN to send programme links to LE***

## National Strategy Workstream Partners Updates Cont.

### NHS Education Scotland (NES)

Paper was distributed prior to the meeting

**Sandra Ferguson (SF)** discussed the broad approach **NES** is taking re neurodiversity and how they are building and implementing capacity. There continues to be a challenge with the pipeline of staff to be able to stabilise training. **NES** wants to focus on Post Diagnostic Support, offering autism specific training to Adult Mental Health, Children's Services, Early Interventions, parenting, LD and CAHMS and is keen to spread the scope of the work across multi-professional sectors.

**PB** asked if there was any update for the potential of an allied Speech and Language Therapist to be embedded in the team to which **AP** advised that funding had now been agreed to progress this. **PB** said this was such an important development as allied health best placed to provide nurturing support.

**SF** said that **NES** is looking to have an autism stream rather than an autism strand, **FM** agreed that Health and Education talking together would be great and **FC** stressed the importance of having a speech and language therapist.

**NW** asked what was meant by a neurodiversity approach and did this mean there was no designated pathway? **SF** responded by saying autism training is available, but that **NES** is thinking about what adaptations are there or needed as they are trying to streamline training packages not create additional ones. **NW** asked how **NES** will evaluate and monitor the change, to which **SF** replied that she didn't have a specific answer to that question as practiced impact is difficult to evaluate.

### Education Scotland

**FF** provided a summary of the work undertaken by **Education Scotland** stating that they are working with the 32 local authorities through the Regional Improvements Collaboratives (RICs). This work is also supporting the **SG** Empowerment policy.

Following the first meeting of the ASD round table in 2019 **Education Scotland** contacted the 32 local authorities asking for information on what strategies and approaches were being used to support autistic learners. These reports are now available on the Autism Toolbox<sup>7</sup>.

#### **Education Scotland** Inclusion Wellbeing and Equalities Officers

- Link with local authority inclusion officers and information on the Autism Toolbox has been shared with them
- Support the RICs through the **Education Scotland** Regional Improvement Teams which will provide opportunities to support RIC work streams and to highlight national work e.g. Dyslexia and Autism<sup>89</sup>

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<sup>7</sup> <https://www.gov.scot/publications/evaluation-attainment-scotland-fund-analysis-local-authority-survey-2019/pages/4/>

<sup>8</sup> <http://addressingdyslexia.org/home>

<sup>9</sup> <http://addressingdyslexia.org/free-online-learning-modules>

## National Strategy Workstream Partners Updates Cont.

FF provided a summary of work she is involved in:

- A mapping activity in partnership with **NAIT** and **NES** is underway which includes the LIAM Programme, looking at a local authority level what schools are involved.
- Developing a professional learning offer to support CIRCLE Secondary online module, with an **Education Scotland** Development Officer funded by the strategy. This post will also support the development of the CIRCLE primary and Autism modules, which included building on the toolkit.
- In August 2020 the Autism and Inclusive Practice Module and CIRCLE Primary module are due to be published and supported with a professional learning offer in the RICS.

Schools and local authorities would be supported by a co-ordinated approach e.g. the term neurodiversity is now more commonly used – is there a shared understanding? **FM** asked if anything was being done for National Autism Awareness Day, **FF** said the Toolbox could be highlighted and was open to suggestions. Re the Toolbox, the 32 responses received from local authorities telling **Education Scotland** what they're doing and what resources are available can be found online<sup>1011</sup>. **FF** asked the group how can we take training such as CIRCLE and SCERTS forward collectively?

**CT** stated that neurodiversity is a social construct not a diagnosis and asked if we, as a group are all sharing the same terminology as there is a worry that autistic rights are being diluted by the neurodiversity movement. We need to keep an eye on autistic people's needs across the lifespan. **FC** stated that Neurodiversity is a concept with **AMG** saying that we won't require a diagnosis if we go down the neurodiversity route.

## National Autism Implementation Team (NAIT)

**Kirsty Forsyth (KF)** gave an update on the workstream and distributed a summary paper highlighting the workstreams of all the national partners. **KF** acknowledged the conversation and views in the room and spoke of a co-ordinated and collaborative approach through coalition building of effort, passion and experience.

The areas **NAIT** cover are:

- Diagnosis – Further to the Mental Welfare Commission Report (see footnote <sup>1</sup>) **NAIT** is involved in looking for solutions; currently working with Royal College of Psychiatry to understand how autism can be mainstreamed into mental health provision, Occupational Therapists, Speech & Language
- Schools – partnership with **Education Scotland** on updating Toolbox, working alongside **NES**, Skills Development Scotland, looking at how resources are driven into front line situations for impact; attendee at the roundtable discussion with Deputy First Minister alongside **Scottish Autism, National Autistic Society** and Children in Scotland
- Employment

**KF** re-iterated the importance of having a co-ordinated programme of work as we've not got it right for autistic people yet, as the charities have highlighted.

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<sup>10</sup> <https://education.gov.scot/improvement>

<sup>11</sup> <http://www.autismtoolbox.co.uk/research-and-professional-reading>

## **National Strategy Workstream Partners Updates Cont.**

**NAIT** has a strategic intention to measure impacts:

- Strategic models based on Microsegmentation Report - diagnostic pathways and tools for diagnostic pathways in all health boards
- Set up national events on strategy topics
- Hosting regional events - local based capacities
- Government advisory role with the Health and Sports Ministers as well as diagnostic partners
- Sitting on the Autistic Learners Roundtable and Children and Young People Well-Being Board
- Activity with the Child Task Force
- A school participation questionnaire identifying where and why things go wrong and what needs to change to support inclusion
- Immersion days at Strathclyde University, which if successful may be rolled out across IET's across Scotland
- Autism Guidance Booklets – working with General Teaching Standards Council
- Ongoing dialogue with local authorities and health boards

These are not a set of activities to make improvement, but to build coalitions to embrace complexity.

**AP** stated that some of the work with **NAIT** has been done at pace, due to engagement with MSPs - a recent example of this concerned adult diagnosis. John Mitchell (now retired) met with the Cabinet who spoke of a lack of adult diagnosis across boards and how medication can help some people. John and **AP** were asked to find a solution and approached **NAIT** for support. A workplan was agreed and the MSP is now involved with **NAIT** and the Royal College of Psychiatry looking at how we get psychiatrists to think about diagnosis, and to help inform the national curriculum for Psychiatry.

**KF** concluded by stating there were no competing agendas, but opportunities and that **NAIT** was committed to a collaborative, coalition model, giving an example of collaborating with ARC on the Transitions Bill.

**ACTION: KF to share Royal College of Psychiatry consultation paper by Prem Shah**

### **AOCB**

**PB** stated that **SG** had funded her to look at benchmarking speech and language services across Scotland for children in deprivation which is the first of its kind in the UK. Deputy First Minister has completed the SLT Commission vision statement which will now go to COSLA.

**End of closed meeting**

**Minutes approved by SG**

**Date of Next Meeting: 12<sup>th</sup> March 2020, Inverclyde (Open Meeting)**