

Autism Strategy Review Group Minutes

Thursday 2 May 2019

11.00 am – 3.00 pm

Jurys Inn, Inverness

Approved

Present: Gillian Barclay (Chair), Scottish Government; Kabie Brook, Autism Rights Group Highland (ARGH); Fiona Clarke, Parent representative; Anne Marie Gallagher, Greater Glasgow and Clyde National Health Service (GGC NHS); Sonny Hallett, Autistic Mutual Aid Society Edinburgh (AMASE); Richard Ibbotson, The Richmond Fellowship Scotland; Eileen Keogh (minutes), Autism Network Scotland (ANS); Prof Jean MacLellan, University of Strathclyde, Autism Network Scotland (ANS); Fiona Milne, Renfrewshire Carers Autism Spectrum Disorder Support Group; Dorry McLaughlin, Scottish Autism; Annette Pyle, Scottish Government.

Apologies: Arron Ashton, Scottish Government; Lesley Evans, (ANS); Thom Kirkwood, Apex Associates; Janine Robinson, NHS Education for Scotland (NES); Stephanie Rose, Police Scotland; Marion Rutherford, Queen Margaret University; Catherine Steedman, Autism Initiatives; Lynsey Stewart, (ANS); Charlene Tait, Scottish Autism; John Urquhart, COSLA; Nick Ward, National Autistic Society (NAS).

Welcome and Introductions

Michael Perera, General Manager, Mental Health, Learning Disabilities & Drug & Alcohol Recovery Services, NHS Highland, opened the meeting by welcoming all those who had come along. He described the event as an opportunity for the Highlands to provide information about the work that is being undertaken locally as well as a time to learn about the National Review Group remit and approach. In introducing Gillian Barclay (GB), as the Review Group Chair, he closed by making it explicit that the Highlands are supportive of and signed up to the national autism agenda.

GB began by explaining her wide ranging role in Scottish Government which encompasses Dementia and Learning Disabilities as well as Autism. This breadth of perspective may seem disconnected but there are clear similarities in the need for quality diagnosis and for self-understanding. She noted the overlaps whereby 30% of people with a learning disability are also autistic and spoke about how Scottish Government is committed to greater understanding and acceptance of neuro-diverse conditions.

GB outlined the aims and the role of the Scottish Government in relation to The Scottish Strategy for Autism and the purpose of the day, this being to have a two way conversation with the people of the Highland region who were in attendance and the Review Group. This was an opportunity to hear how Highland are developing services and for the people of Highland to hear what is going on at national level.

GB highlighted the four Strategic Outcomes 2018-2021 and the work that is being carried out to achieve these Outcomes:

Outcome One: A Healthy Life: Scottish Government has created the National Diagnostic Improvement Team (NAIT) at Queen Margaret University. The purpose is to work in partnership with practitioners and clinicians across Scotland to improve neuro-diverse pathways. Charlene Tait is also being seconded from Scottish Autism to lead on improving pre and post diagnostic support.

Outcome Two: Choice and Control: Strategy funding continues to support the understanding of autism in both the health and education workforces. **Outcome Three: Independence:** A national awareness campaign will be launched as more understanding and awareness is needed to ensure autistic people's rights are being upheld. It is acknowledged that this will lead to increase in demand for diagnosis and gaps in support will be need to be addressed.

Outcome Four: Active Citizenship: The Autism Team within Scottish Government continue to work with colleagues to address issues such as housing and employment.

Questions from the audience

In response to a question from the floor regarding delivery of the national awareness campaign, **GB** made it clear that the campaign will not be undertaken directly by Scottish Government but with the assistance of a professional agency which will build up a strategy and process with input from the autistic community and from a wide range of grassroots organisations. There will be some associated funding streams that will be subject to the usual tendering process which will be managed by Inspiring Scotland. Opportunities to apply for available funding will be announced in due course and widely advertised e.g. through Autism Network Scotland.

The Local Picture – Arlene Johnstone (AJ), Head of Service, Learning Disabilities and Autism, NHS Highland

AJ spoke on her role and highlighted the difficulties in delivering a Strategy which currently sits in draft format. She commented that having spoken to different autistic people around what NHS Highland can do to improve their lives, there is much more of an understanding of what now needs to be done.

She identified access to Mental Health Services, Access to Information and Diagnostic Services as top priorities. The immediate priorities include setting up a Transitions Team, increasing employment opportunities, finding ways for people to come together/share support and for day centres to increase learning opportunities for individuals.

NHS Highland has funding for Third Sector organisations to bid for. Bids must come from people/organisations who meet the NHS priorities criteria. Help and guidance can be given to those bidding.

AJ responded to the following questions:-

Q. What is the difference between procurement/tender and bids?

A. Over £50K it must go to tender.

Q. Who are people bidding to?

A. NHS Highland.

Q. How many bids can you put in?

A. You can put any amount of bids in.

Q. In terms of Enhanced Shared Support, is this moving people in to forced social events/activities?

A. No

GB thanked **AJ** for her presentation and made clear that the discussion had raised a few issues that Scottish Government can provide support with.

Decider Skills – Faith Wilson (FW), Autism Diagnostician, NHS Highland

FW delivered her presentation on Decider Skills. Decider is a skills manual and programme that has been adapted specifically for individuals to manage and understand their own emotions and mental health. A visual demonstration was given as an example of one of the ways individuals can see themselves in a positive way, bring out the qualities and skills of that individual.

Question and Answer Session

To conclude the morning session, **GB** invited comments and questions. Some autistic individuals expressed a lack of faith in national politicians based on a belief that little had actually changed. **GB** accepted that this is a valid perspective but that some good things had been achieved as a result of the Strategy although there is much yet to be done.

Others spoke passionately about the need for the local One Stop Shops to continue as it made a huge difference to the quality of individuals' lives. **GB** responded by saying that the Scottish Government Autism Team will continue to work with Highland to support the One Stop Shop.

Others stressed that clinician training was badly needed. **GB** spoke about a parallel with dementia where we should be asking more about the 'why' we are diagnosing as opposed the 'how'. She considers one primary purpose to be self-understanding.

Some participants suggested that autistic individuals should be given training opportunities to better understand neuro-typicals in the way that the latter are offered training to understand autistic individuals.

*** Session ends for lunch ***

Highland One Stop Shop (HOSS) – Gill MacLennan (GMaCL) and Andrew Denovan (AD)

GMaCL and **AD** updated on the work that is taking place across the Highland region. Last month they supported 46 individuals. A fundamental focus for HOSS is also building relationships and partnership working with key organisations such as ARGH, Mental Health Services, Housing and DWP, thus supporting autistic people and families through the difficulties, barriers and challenges that they face daily. **GMaCL** reported that HOSS has also provided training for council staff and are working with them to ensure that there are opportunities for employment for autistic people.

Autism Rights Group Highland (ARGH) – Kabie Brook (KB), Chair

KB outlined the background of ARGH and its key mission to:

- Inform service providers about what autistic people really experience.
- Campaign for better services for autistic people in the Highlands and beyond.
- Challenge stigma and discrimination through education about autistic strengths

This year ARGH celebrates its twelfth year in operation and on average receives 500 enquiries a year.

The Autism Alert Card is one initiative undertaken. The card is a communication aid designed for autistic individuals to use when they find it stressful or difficult to talk. The card has proved a valuable asset for autistic people and it also is endorsed by Police Scotland.

Future and present key priority work for ARGH includes:-

- Campaign for the continuation of HOSS.
- Connect and link with the autistic community globally.
- Continue to carry out the work of the National Autistic Taskforce (NAT).
- Continue to take part and collaborate and celebrate in key events such as Autistic Europe Fringe, Autistic Acceptance Day, 2nd April and Autistic Pride Day, 18th June.

Inverness Airport Sunflower Lanyard Scheme – Dan Mason (DM), Airport Operations Manager

DM spoke on the new initiative first started in January 2018 at Inverness Airport. The Sunflower Lanyard Scheme is a voluntary scheme designed for individuals using the airport and who have hidden disabilities to access and wear a lanyard to highlight to airport staff that extra assistance or understanding may be required.

Shirley Project

Neil MacLeod was unable to attend.

Cantraybridge Enterprise Service – Jenny Liddell (JL), and Ian Larg (IL)

JL gave an overview of the background of Cantraybridge College and what it has to offer to the students of the college. The college is a specialist further education college for young adults with additional support needs including autism. They support 20 residential students who are mostly autistic and have 70 students per week overall.

Areas for learning include: café skills, farming, small animals and bird care, property and estate maintenance, wood skills. The college provides transitions support and support for students to find volunteering opportunities/placements and employment.

IL spoke on other services available including Self Directed Support (SDS) and the Employability and Micro Enterprise Service which provides one to one support for individuals to set up fledgling businesses.

GB thanked **JL** and **IL** for their presentation and opened up questions/comments to the audience on what had been discussed throughout the day.

Question and Answer Session

Some individuals stressed the need for some professionals to improve their respect for autistic people. **GB** responded by saying the Awareness Campaign would focus on the importance of respect.

GB also explained that a minute of the event would be issued and that support would continue to be provided. She had found the event to be informative and productive.

End of meeting.

Minutes approved by SG and Highland