

AUTISTIC SPECTRUM DISORDER (ASD) REFERENCE GROUP

Note of meeting held on 11 February 2010, Hilton Grosvenor Hotel, Edinburgh.

Present :

Ken Aitken- Action Against Autism

Carolyn Brown- Educational Psychologist, Fife Council

Paul Dickinson- Clinical Psychologist, NHS Highland

Professor Aline-Wendy Dunlop- National Centre for Autism Studies

Carol Evans- National Director - Scotland, National Autistic Society

Susan Gilroy- Support for Learning Scottish Government

Ryan Gunn- Adult Care and Support Division Scottish Government

Jane Hook- Parent

Richard Ibbotson- National Director Scotland, Autism Initiatives

Alison Leask- Autism Argyll and Scottish Autism Services Network

Jane Neil-Maclachlan- Autism Co-ordinator, NHS Lothian

Jean MacLellan- Adult Care and Support Division Scottish Government (Chair)

Iain McClure- Consultant Psychiatrist NHS Lothian

Nigel Rooke- Autism Services Coordinator, Glasgow City Council/NHS Greater Glasgow & Clyde

Val Sellars- Director, Scottish Centre for Autism, Yorkhill Hospital

Alan Somerville- Chief Executive Officer, Scottish Society for Autism

Adam Stewart- Policy Officer, COSLA

Charlene Tait- Lecturer, National Centre for Autism Studies

Marion Thompson- Adult Care and Support Division, Scottish Government

Apologies

Stella Macdonald- ASD Co-ordinator, Fife Council

Welcome

Members were welcomed back to a special meeting of the ASD Reference Group and Adam Stewart was welcomed to the group.

Background

The National Autistic Society has launched a campaign for a national strategy on autism backed by legislative powers and there is a proposed Private Member's Bill under consultation for introduction to Parliament. The Scottish Government has undertaken a programme of work to improve services for people on the autism spectrum but it was agreed to reconvene the ASD Reference Group to discuss whether there was a need to do further work on this. A first draft of a position paper was prepared for the meeting detailing some of the work that was done through the Reference Group to address the recommendations of the Public Health Institute of Scotland's ASD Needs Assessment Report (2001). Jean gave an overview of the proposals and action plans on autism laid out by other parts of the UK.

The group split into 4 workshops to discuss the position paper and its recommendations. They were invited to identify what further work could be done. The groups fed back the main points of their discussions in a plenary.

Workshop 1: Assessment & Diagnosis

- There was a concern that although more people were trained there are still waiting lists for diagnosis
- The Directory of those undertaking assessment needs updating
- More work needs done on what follows assessment
- Tools developed need to be used more consistently e.g. Autism Toolbox
- Although there were good examples of new models being started there was concern over the sustainability of projects, e.g. the diagnostic services work funded by the Group
- The redesign of autism services and the move to using the Community Health Care Partnership structure to deliver them has led to the breaking up of regional specialist expertise - need good specialist teams and well trained local teams

Workshop 2: Joined up Working

- Need to address the issue of definitions for those with neither mental health problems nor a learning disability
- Need national leadership to promote working together and sharing budgets
- A framework is required to move forward to address gaps in services
- Need for a central resource to show how legislation, guidelines and statutory obligations fit together
- The dissemination of information on 'what works' is very important

Workshop 3: Training

- Further training tools to build capacity should be drawn from a central location

- Local agencies should be scrutinised to assure quality of training
- Need to do more to ensure that SIGN guidelines are being used effectively - monitoring and audit
- There is no plan as yet to review the SIGN guidelines but we need to review the literature on interventions. This should be done for the UK so will involve discussions with NICE on the timing of the review
- There is a review looking at changing the classifications for diagnosis (DSM-5, ICD-11). This will change practice so we need to be aware of the new criteria when it is agreed.

Workshop 4: Research

- We need to implement interventions we know are working and evidence good practice
- Need more research on the areas which are of concern to parents & carers e.g. sleep problems or anxiety
- Consultants in the health service cannot allocate sufficient time to do relevant research

The Group members agreed that there was a need to formalise the work into a national strategy and that the Group should be formally reconvened. It committed to continuing the work in the long term, beginning with further identification of gaps and solutions. Members agreed to provide these for inclusion into a further paper that would ultimately form a draft strategy that would be subject to public consultation.