



**Adult Autism Programme Board
Minutes of Meeting held on 24 April 2013
2.00 pm – 4.00 pm
Board Room, Richmond House, London**

Present:

Norman Lamb MP	Minister of State for Care & Support – Chair
Bruce Calderwood	DH Director, Mental Health, Disability and Equality Division
Anna Christie	Public Health England
Anya Ustaszewski	Self-advocate
Gyles Glover	Public Health England
John Phillipson	Autism Alliance UK
John Simpson	Self-advocate
John Skinner	Department for Work and Pensions
Mark Lever	National Autistic Society
Nigel Fulton	Department for Education
Patricia Kearney	Social Care Institute for Excellence
Sam Cramond	NHS England
Sarah Smith	Ministry of Justice
Terry Brugha	University of Leicester
Zandrea Stewart	Association for Directors of Adult Social Services
Michael Swaffield	DH Autism Policy Lead
Anita Wadhawan	Autism Policy & Secretariat to the Autism Programme Board
Annemarie McNeely	Autism Policy

Apologies :

Alan Rosenbach	Care Quality Commission
Dawn Fleming	NHS Confederation
Debi Evans	Parent Carer Representative
Declan Murphy	Kings College London
Frances Smethurst	Deputy Director Learning Disabilities & Autism – DH
Jackie Edwards	Parent Carer Representative
Jon Rouse	Director General, Social Care, Local Government & Care Partnerships - DH
Nicola Lomas	Department for Work and Pensions
Paul Williams	Department for Business, Innovation and Skills
Simon Baron-Cohen	University of Cambridge

1. Welcome, introductions and apologies

1.1 The Minister welcomed Board Members to the meeting and noted the apologies received.

2. Minutes and matters arising from the meeting held on 7 November 2012 – APB(12)29

2.1 Board members agreed the minutes of the meeting held on 7 November 2012 without amendment.

2.2 On matters arising, Bruce Calderwood asked Michael Swaffield to take the Board through the action points from the last meeting and provide updates.

- **AP1** Michael reminded the Board that DH was keen to receive examples of good practice, particularly during the course of the review.

Action point 1 : examples of good practice to be sent to Michael Swaffield.

- **AP2** The Board now had representatives from NHS England and Public Health England, and would hopefully be joined by representatives from the Care Quality Commission and the Local Government Association at the next meeting.
- **AP3** Draft guidelines for Clinical Commissioning Groups to be discussed at item 7.
- **AP4** The Diagnostic and Statistical Manual of Mental Disorders 5 (DSM5), was expected to be the new diagnostic tool in America. This was subsequently confirmed on 19 May. There had been some concern on how this would impact on diagnosis assessment in the UK, which mainly uses the World Health Organisation ICD10 guidelines. Terry Brugha said that the new American diagnostic tool is more restrictive than the previous version, with Asperger's syndrome being one of four previously separate conditions that have become part of a single condition termed autism spectrum disorder. This issue would be kept under review.
- **AP5 & 6** John Skinner had put together a paper covering how DWP are assisting people with disabilities into employment, and recent benefit changes. To be discussed at item 6.
- **AP7** The Inter-Ministerial Group (IMG) for employment has not met for over a year. As part of the review, DH will identify other cross government ministerial groups to communicate with.

- **AP8** The autism risk and work programme logs are available on the DH website. The logs will be updated regularly and Michael asked members to advise of any changes which needed to be incorporated. The logs would be included as an agenda item at the next meeting. This would allow the Board to see the final work-plan for the review.

Action point 2 : risk and work programme logs to be included as an item agenda at the next APB

Action point 3 : APB members to provide updates for risk and work programme logs to Michael Swaffield as appropriate

- **AP9** The agenda item for DfE was cut short at the previous meeting, an offer was made for any further questions to be passed on – none received.

3. Update on recent Parliamentary meetings APB(13)02

3.1 Michael Swaffield provided the Board with a short information paper summarising three recent Parliamentary meetings on autism - the Public Accounts Committee (PAC) hearing, the All Party Parliamentary Group on Autism (APPGA) on autism and evidence given to a hearing of the Autism and Aging Commission in the House of Lords. In summary :

- The PAC will be issuing a note/report on the hearing, expected in May 2013. This should provide some helpful advice for the review;
- The Minister, Mark Lever and other DH officials attended the APPGA on autism. At that meeting two mothers, with adult children on the autistic spectrum, had shared their experiences about trying to obtain appropriate help and services. There was also discussion about the need for more preventative and advocacy services. The APPGA hoped that the review would help to change things on the ground with more joined up thinking between services;
- The Autism and Aging Commission work would contribute to a report the National Autistic Society (NAS) is due to publish in June. DH will include aging as part of the autism review.

3.2 Mark Lever asked for an update on the strategy commitment for autism training to be embedded in the core curriculum for clinicians. Michael said that there had been some discussion with the Royal Colleges last year, and further discussion would take place with the Royal Colleges and other groups, including Health Education England. Michael advised that some autism training is already in the curriculum, but this needed to be highlighted. There were also a number of DH funded training packages available produced by various groups which needed to be built on. Terry Brugha suggested that the GMC be contacted as they oversee graduate level training.

3.3 The Minister suggested this may be an opportune time to include an

enhanced input on autism and learning disability into the extra year of GP training, currently focussing on mental health and children. He asked officials to speak with the Parliamentary Under Secretary of State Dan Poulter MP, who has Ministerial responsibility for workforce training issues.

Action point 4 : DH to meet with Health Education England, the General Medical Committee, Royal Colleges, and other groups to discuss autism training and update APB.

Action point 5 : officials to take forward whether autism training could be included in GP curriculum.

4. The Review of the Autism Strategy - APB(13)03

4.1 Bruce Calderwood introduced the discussion about the work programme for the Review. He explained that this was an opportunity for Programme Board Members to give a final steer on the make up of the Review. He explained to the Board that the paper also captured the necessary preparatory work underway and what was being planned.

4.2 Bruce said that the focus of the Review would be on progress made, identifying good practice and next steps, and would be carried out by DH, working in partnership with other groups and organisations, including many members of the Autism Programme Board (APB). He also informed members that a project plan with dates for events and details of key contacts for parts of the Review is being compiled and will be circulated to the Board.

4.3 Bruce asked members for their views on the paper and on what will be happening and asked if members wanted to be involved in specific parts of the work of the review. Bruce said that the Board would be the steering group for the review.

4.4 Bruce also outlined the timetable for the review as :

- Phase 1: April : finalising of arrangements with key partners and views from the APB;
- Phase 2: April/May – October : the investigative stage of the review, with emerging findings being reported to the July and October APBs;
- Phase 3: November – January : consideration of initial proposals;
- Phase 4: February – March 2014: Final report.

4.5 The Minister asked about the engagement process and about how the public, families and people with autism can get involved with the review. Bruce said that a number of ways were being considered to do this, including listening events across the country, an on-line survey, and involving the NAS and the Autism Alliance in specific pieces of work on the review. The Minister said that he would be very keen to attend one of the listening events.

4.6 Anya Ustaszewski asked why the Hidden Impairments National Group were going to have focus groups across the north of England, was there a particular reason why the north of England had been targeted for these groups? Michael explained that one of the partners in the Hidden Impairments National Group was the Adsetts Partnership organisations who are mainly based in the North. They, as a group are going to run a number of workshops and will test out the survey there. He reassured Anya that there would be other meetings happening elsewhere as well. Michael said that he was also talking to NAS about this. Michael mentioned other regional groupings around the country, some being led by NAS and some still in place because of funding that had been passed down by Strategic Health Authorities as legacies to continue the work on autism. These groups bring together people from LAs, the NHS and Autism Partnerships. Michael said that he had also been engaging with groups across the country led by service users.

4.7 Mark Lever suggested inviting employers along to some of the listening events. He said that it would be an opportunity to get their experience and perspective of employing people with autism. He mentioned the work the NAS did last year with DWP on the Untapped Talent campaign.

4.8 Members also suggested reaching out to as many audiences as possible using social media networks during the consultation events.

4.9 Zandrea Stewart raised the point about not just reaching out to people accessing services and meeting eligibility criteria but also broadening the exercise to include people's experience of accessing employment and housing who are not receiving statutory services but who are on the autism spectrum and who live in society without support.

4.10 Sarah Smith asked about how the review will pick up issues around the Criminal Justice System (CJS). Michael explained that there are plans to cover this and that he was discussing these with others including NAS and the British Psychological Society. Michael also mentioned the paper that was put to the Board last year on work that was being done on the CJS and autism.

4.11 Sam Cramond raised the point about local authority self-assessments and how they would be publicised to Clinical Commissioning Groups (CCGs) so that CCGs are fully involved. Terry Brugha said that it would be helpful to have some clarity around health commissioning at a local level.

Action point 6 : the secretariat would ensure the points made in the discussion are incorporated in to the final work programme proposal as necessary.

5. The second Local Authority area Self-Assessment Exercise - APB(13)04

5.1 Zandrea Stewart introduced this item. Zandrea explained that linked to the Review, this exercise is being carried out by Public Health England to provide assurance on local progress. It will involve each Local Authority

completing an on-line questionnaire on behalf of them and their partners on progress against key areas of the Strategy. The answers will need to be signed off by the local Autism Partnership Board and further ratified by the Health and Well Being Board. It is proposed to launch the exercise in July and seek returns by mid-September this year. The Board can then consider the high-level information from the returns in the October APB meeting.

5.2 Gyles Glover said that most of the questions had been taken from the same exercise that was done 18 months ago. He said that on this occasion they would be inviting specific examples of good practice to be shared as well as inviting respondents to provide personal experience stories. Gyles also said that the numerical questions being asked would be reduced this time.

5.3 The Minister asked if the returns would have to be signed off by Health and Well-being Boards. Zandrea explained that the coordination responsibility would be from Directors of Adult Services as was done last time, with the aim for them to then go to Autism Partnership Boards for approval. Health and Well-being Being Boards would be asked to discuss the completed answers within 3 months of them being submitted.

5.4 Sam Cramond asked about what publicity was being considered to let people, including CCGs know that this exercise was coming. Sam asked if a short brief could be prepared about the exercise that she could share with colleagues in CCGs and Health and Well-being Boards to let them know about the mechanisms of the exercise and when it would be coming their way.

Action point 7: Zandrea and Michael to prepare a note for Sam Cramond to share with colleagues about the exercise.

5.5 Members requested that the various NICE guidelines published and those in the process of being published should to be referenced in the questions as it would be an opportunity to raise the profile of the guidelines. Terry Brugha flagged up the process (template exercise) that NHS providers have to go through when a NICE guideline is published to identify what is relevant for them to pick up from the guideline.

5.6 Bruce Calderwood agreed that a communication process needed to be drawn up to let people know what will be happening.

Action point 8: The points made in discussion will be incorporated in to the final planning for the exercise as necessary by Michael, Zandrea and Gyles.

6. An update from DWP on policies to get people with autism into work and changes to the benefits system (APB(13)05)

6.1 John Skinner provided a paper to the Board about DWP employment support and the benefit system. John updated the Board on disability employment support and future work in this area.

6.2 DWP are developing a cross-government Disability Employment Strategy (DES). Esther McVeigh the Minister for Disabled People has met with a number of ministerial colleagues across government to discuss various topics. This strategy will be produced in the autumn. The DES will allow DWP an opportunity to consider how successful we had been as a country in assisting and retaining people with disabilities in employment. It will consider what has been done well and not so well. DWP will also look specifically at funding the government contributes to this area to ensure that it is fit for purpose.

6.3 Access to Work, Work Choice and residential training are working with external stakeholders and DWP to improve the service in all three areas. Employer engagement with people with disabilities has improved, but many employers do not have the confidence or support to do this and more work needs to be done in this area. DWP will be holding employer engagement activities over the next few months, which will include a sizeable employer conference, to be attended by the Prime Minister and other Ministers. This work dovetails well as the outcomes of these initiatives will feed into the autism review.

6.4 John went on to say that DWP do not deliver employment tools which are specific to people on the autistic spectrum. He noted the perception among many people on the spectrum was that Access to Work was for individuals with physical disabilities, this is not the case. For example, Access to Work can be used to provide support in the workplace. DWP are looking at how Access to Work can be used in a number of areas. Once the direction has been agreed John will be happy to update the Board.

Action point 9 : John Skinner to share with APB details of Access to Work.

6.5 Mark Lever had spoken with a number of individuals on the autism spectrum who were very anxious about entering into a job because if things did not work out, they would have to battle their way back through the benefit system. It was essential that appropriate workplace support is available. He added he had recently spoken at the Public Sector People Management conference, attended by local government HR directors and asked whether more could be done to drive this issue with large employers such as the civil service. He felt that there was enthusiasm to employ individuals with disabilities but employers needed support to do this.

6.6 Anya Ustaszewski also agreed that it was very important that employers were supported. Anya asked about Work Choice and the Work Programme. In her locality, these initiatives appeared only suitable for individuals who were entering the job market for the first time and developing a first CV. Individuals who had lost their job through redundancy, or deterioration in mental health for example, did not get the appropriate support through these channels. There was also lack of support for self-employed people.

6.7 Anya also said that thought needed to be given to environment and sensory adaptations at job centres, as they were often noisy due to being open plan and had fluorescent lighting. Also, the job centre experience is

heavily centred around phone access, and many people on the autistic spectrum are phone phobic and some have speech issues.

6.8 Terry Brugha challenged the notion that only 14% of people on the autistic spectrum are in employment. The adult psychiatric morbidity survey in 2007 (viewed as a representative example of the adult population in England) clearly indicated that the numbers in employment are much higher. Terry complimented the DWP paper, and would like to see it more widely available so that people on the autistic spectrum realise how many opportunities there are in terms of help and support. John Skinner said if it would be helpful for employers and people on the autistic spectrum to have documents which included autism in its headline, and this could be something that DWP could look at. He also highlighted that while the job centre role is to get people into work DWP also has a responsibility to help individuals retain work.

Action point 10 : John Skinner to discuss with DWP colleagues about helpful headlining of potential DWP assistance/support for individuals on the autistic spectrum in terms of benefits and employment support.

6.9 Bruce Calderwood mentioned that consideration would need to be given to developing employment services which looked at both conditional and behavioural specifics for autistic people, and approaches to help retain employment. This would need to be looked at as part of the review

6.10 Anya Ustaszewski suggested that the two ticks system be more widely promoted. The tendency was to see it included by public organisations but many smaller organisations were unaware of it. John Skinner said the scheme was under review as part of the DES and employment engagement. DWP is consulting with employers, employees and within DWP to see what organisations want from this scheme.

7. Joint Commissioning Panel – A Practical Guide on Autism for CCGs APB(13)06

7.1 Michael Swaffield introduced this item. The guide has previously been shared in outline form. Michael wished the Board to see the current draft and have the opportunity to comment. The guide will be issued by the Joint Commissioning Panel in June/July 2013. An executive summary, references and further examples of services helping in the assessment process would be included. The aim of the guide is to make CCGs aware of autism issues, their statutory responsibilities and to encourage the commissioning of diagnostic pathways. The content is linked to the NICE guidelines, which highlighted that most assessments do not have to be made by specialist autism clinicians.

7.2 There was a role for NHS England and the Royal Colleges in making CCGs and clinicians aware of the guidance. The Department had been a 'helpful encourager' to the process - this will not be a Departmental document. The guide was currently being reviewed by CCG commissioners and service

providers. Michael asked that if the Board had any views or comments on the guide to forward them to him.

Action point 11: Any comments on CCG guide to be sent to Michael Swaffield

7.3 John Simpson had chaired a meeting with experts from the NHS and LAs to discuss the guide. He acknowledged that it had been very difficult to define autism to GPs, as the autistic community found it difficult to agree a definition. Debi Evans had joined this meeting by telephone and asked that more reference be made to pervasive developmental disorders. There were also debates about how people define themselves, in terms of aspergers and autism. The guide had been kept as short as possible in the hope that it would be read and have greater impact. It currently makes reference to NHS Diagnostic Services only, but John was keen that this be widened to reflect that there is no compulsion for the model of diagnostic pathway to be the NHS model. John gave an example of the diagnostic service in the West Midlands, but stressed that this was a work in progress. He stated the need for services to have effective gatekeepers.

7.4 Zandrea Stewart commented that one of points in the current draft of the guide, which may have been misconstrued in the NICE Guidance, was the perception around what the model around the diagnostic pathway service should look like. The guide begins to say what the key principles around a diagnostic pathway are and what they contain. However it will be for local areas to decide what is required to meet the need of their local population. It was important that local areas identify transparent pathways for the local population to gain access to a diagnostic assessment. From an ADASS/LA perspective, both will need to be careful not to set up services that silo individuals on the autistic spectrum away from mainstream services.

7.5 Terry Brugha said that it was important to look at services which have been running for the last 10/15 years for lessons learnt. He would be concerned that as an easy fix, services went to outside organisations so that they could be set up swiftly, without working out how the NHS on the ground is moving along with the process. It was Important that health and social care practitioners are on board – it can be difficult for example convincing psychiatrists and psychologists that this is part of their business.

7.5 Sam Cramond had shared the guide with NHS England colleagues responsible for the process of sharing information with CCGs. She would respond on what NHS England can do to support the guide and in relation to style to ensure it is accessible as possible to GPs.

7.6 Anya Ustaszewski was pleased to see under 'What would a good diagnostic autism service look like' - a reference to preventative interventions. She felt that from talking to people around the country that mental health services had become very much like crisis reaction services, due to lack of resources. She also mentioned that there needed to be an emphasis on environmental appropriateness, as highlighted in the NICE guidance.

8. Any other business

8.1 Nigel Fulton provided the Board with an update on what was happening in DfE.

The Children and Families Bill

8.2 Since the last meeting of the Programme Board the pre-legislative scrutiny had finished. Changes were made to the Bill in light of this and it was introduced into Parliament in February. One change since introduction has been that CCGs and NHS England would be under a duty to arrange the health provision set out in an Education, Health and Care plan – this is not the case with SEN statements, which the plans will replace. The Bill has got through the Commons Committee stage unscathed.

8.3 The “autism lobby” has influenced the Bill through the prominent role organisations like the NAS, the Autism Alliance and Ambitious about Autism play in the SEN world. The APPGA also published a report on what the SEN reforms would mean for children with autism and Edward Timpson, the Minister with responsibility for SEN, responded to a Westminster Hall debate on autism tabled by Robert Buckland, Chair of the APPGA in November last year, and attended an APPGA meeting in February of this year. Also the Department has set up a young persons’ advisory group to advise on the Bill and that included a young person with autism.

Grants and contracts

8.4 DfE had just started another round of its two yearly grant programme to voluntary and community organisations. Under this NAS has been awarded a grant to provide advice to parents on the SEN reforms and promote collaboration amongst professionals. Ambitious about Autism are to work with the Association of Colleges and mainstream colleges on innovative approaches to transition, from school to college for young people with autism; and Autism West Midlands were to help families make informed choices through three specialist care co-ordinators and an on-line platform for families. DfE has also given a contract to the Autism Education Trust to develop its programme of tiered training, national standards and competencies for those working with children with autism to cover more of the country and also early years and FE provision as well as schools.

Quality Outcome Framework (QOF)

8.5 Terry Brugha raised the idea of developing QOF for GP Autism payments. He explained that adding to QOF payments is a challenging process and the commissioning of primary care and primary care contracts are the responsibility of NHS England. Terry said he is working up a briefing paper and DH officials have said they would be to happy arrange a meeting

with colleagues at NHS England who lead on primary care commissioning to discuss the proposal. The Minister noted the points Terry raised.

Action point 12: The secretariat will ensure the points made in the discussion are followed up.

8.6 Anya Ustaszewski requested an item on Tax Credits to be added to the agenda at the next meeting of the Board in July. John Skinner said that he would be happy to send Anya some information around DWP's policy intentions about this.

Action point 13: John Skinner to send the secretariat information on Tax Credits that can be circulated to Anya and the rest of the Programme Board.

9. Date of Next Meeting

9.1 The next APB meeting would be on Wednesday 17 July 2013 in Richmond House from 2.00 - 4.00 pm.

Copies of all the Autism Programme Board papers and minutes of meetings can be found at <https://www.gov.uk/government/policy-advisory-groups/aapb>