Adult Autism Programme Board Minutes of Meeting held on
7 November 2012   2.00pm – 4.00pm
Cathedral Room Richmond House

Present:

Norman Lamb MP	Minister of State for Care & Support – Chair (present for items 8 and 9)
Bruce Calderwood	DH Director, Mental Health, Disability and Equality Division
Anya Ustaszewki	Self-advocate
Debi Evans	Parent Carer Representative
Declan Murphy	Kings College London
Jackie Edwards	Parent Carer Representative
John Skinner	Department of Work and Pensions
John Phillipson	Autism Alliance UK
John Simpson	Self-advocate
Mark Lever	National Autistic Society
Nigel Fulton	Department for Education
Patricia Kearney	Social Care Institute of Excellence
Simon Baron-Cohen	University of Cambridge
Terry Brugha	University of Leicester
Patience Wilson	Deputy Director Learning Disabilities and Autism
Michael Swaffield	DH Autism Policy Lead
Anita Wadhawan	DH Autism Policy Manager & secretariat to the Autism Programme Board
Dr Sheila Shribman	DH National Clinical Director - Children, Young People and Maternity Services (for item 8)
Gyles Glover	Learning Disability Public Health Observatory
Annemarie McNeely	DH Mental Health, Disability and Equality Division

Apologies

Zandrea Stewart	Association for Directors of Adult Social Services
Dawn Fleming	NHS Confederation
Shaun Gallagher	Acting Director General DH
Neil Deuchar	Associate Medical Director East Midlands
Alex Baylis	Care Quality Commission
Paul Williams	Department for Business, Innovation and Skills

1. Welcome, introductions and apologies

1.1 Bruce Calderwood welcomed Board Members to the meeting and noted apologies received.

2. Minutes and matters arising from the meeting held on 7th July 2012 - APB(12)20

2.1 Board members agreed the minutes of the meeting held on 7th July without amendment. On matters arising Bruce asked members to let Michael Swaffield have more examples of good practice in autism services.

Action point 1 – Board Members to let Michael Swaffield have more examples of good practice in autism services.

3. Proposals for the 2013 Review of the Autism Strategy - APB(12)23

3.1 Patience Wilson introduced this item supported by a paper produced by Michael Swaffield outlining a proposed framework and timetable for the review.

3.2 Patience explained that the Autism Strategy had to be reviewed in 2013. The National Audit Office in a report to the Public Accounts Committee in July 2012 concluded that considerable progress had been made in the two years since the Strategy was published. The Review would take place between April and October and it was proposed that it would have three main segments – Cross Government commitments, local implementation and the views of people with autism and their families. It was proposed to have some events around the country to ensure good engagement and involvement of people with Autism, families, care staff, professionals and voluntary organisations.

3.3 Mark Lever from the National Autistic Society (NAS) informed the Board that NAS had flagged up the Review as a main piece of their work for 2013 and they would also carry out research which could also play into the Review. The local authority progress data the NAS collect would also be refreshed in 2013. Board members' were invited to contact Michael outside of the meeting to raise any issues in more detail.

3.4 Some members asked if the membership of the Board could be updated to include organisations such as the Care Quality Commission and the NHS Commissioning Board.

Action point 2 – Michael Swaffield to take forward updating the membership of the Board and Board Members to let Michael Swaffield have any views on the Review of the Strategy.

4. Update on work on developing guidelines for Clinical Commissioning Groups on Diagnostic support and assessment – APB(12)24

4.1 Michael Swaffield updated members on progress, and the proposed scope of the guidelines as set out in his paper. This issues had been a substantive agenda item at the Programme Board meeting in July, following concerns arising from the local authority self- evaluation exercise in 2011. He informed the Board that the plan was to issue guidelines for Clinical Commissioning Groups (CCGs) by March 2013 under the Joint Commissioning Panel for Mental Health and Learning Disabilities. Michael explained that an expert group to help with this had its first meeting on 18 October 2012 and the group would meet again in January 2013.

4.2 Board Members welcomed the approach set out in the paper, and suggested that Michael should share the paper with the Royal Colleges for their views. Members also suggested looking more at support for people and families post diagnosis of Autism and including examples of good practice, services in Bristol, Cambridge and the Sparks Centre in the West Midlands were highlighted. Mark Lever mentioned some work NAS were doing involving the voluntary sector around good practice post diagnosis. John Simpson said that he would be interested to work with NAS on this.

4.3 Bruce Calderwood summed up the discussion by highlighting that it was important that providers of services work together and invest funding wisely to ensure the best value of services post diagnosis are made available to those who need them.

<u>Action Point 3</u> – Michael Swaffield to share the draft guidelines with the Royal Colleges.

5. Report on DSM 5 (the Diagnostic and Statistical Manual of Mental Disorders)

5.1 Professors Terry Brugha and Declan Murphy reported back on the discussion from the meeting held on 24th October 2012 to look at the issue of the revision of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM). Also present at the meeting were the Programme Board Secretariat, representatives from NAS, Autism UK and the family carers and self-advocates from the Programme Board. The focus of the meeting was to consider what effect the revision might have on diagnostic criteria in the UK when DSM5 was published in 2013 in the United States, and also concerns that people might lose their current diagnosis of Asperger Syndrome.

5.2 Some members of the Board expressed concerns that if people didn't get a diagnosis then they would be invisible when it came to planning services. Post diagnostic needs and support were key for many people with autism but a diagnosis was needed to access services.

5.3 Terry Brugha explained that DSM 5 would not have any official status in the UK for at least 7 to 8 years after publication. In the UK, professionals tended to use the WHO’s International Classification of Diseases ICD 10 and that would be revised within the next two to three years.

5.4 Terry Brugha and Declan Murphy suggested that a statement should be issued to the NHS through DH to highlight some key messages to clarify what is happening about DSM 5 and alleviate any misunderstandings. The forthcoming review of the strategy might help enforce these messages too. It was important for clinicians to help people to look at the changes in a more flexible and broader way.

5.5 In summing up, Bruce Calderwood said that he didn't think that it was the role of the Programme Board to say if DSM 5 was right or wrong, and the professional bodies had a role to play here. However when changes were made in the United States this may create certain issues and we would need to be in a position to handle those issues. He would take advice on what clarifications on DSM 5 could be issued and by whom. Some of the issues raised in the discussion could also be included in the refresh of the strategy.

Action Point 4 - Bruce Calderwood to follow up the points raised during the discussion and report back to members.

6. DWP update and Marketing the Access to work Initiative – APB(12)27

6.1 John Skinner from DWP provided Board members with an update from DWP. Following on from the Sayce report there has been a focus on improving marketing so people and employers knew more about the Access to work initiative. This had been ongoing since June 2012 and was intended to last a year. DWP have an expert panel of external people looking at how and what Access to Work supports with funding. The panel are half way through their meetings and will report to the DWP minister in February 2013 with their recommendations.

6.2 Access to Work provides practical advice and support to disabled people and those with a long-term health condition to help them overcome barriers to starting or keeping a job. This can include paying towards special aids and equipment, support workers, communication support at interviews and travel to work. It also provides a support service for people with a mental health condition who need support returning to the workplace or retaining their current employment. Part of the discussion covered whether the initiative is effectively targeting people with autism and their potential employers. John welcomed any comments from the Board on targeting people with autism and potential employers.

6.3 Board members raised a number of questions around practical issues related to the Access to work Initiative. In particular, Debi Evans had some questions related to need and diagnosis. She explained that people on the high end of the autism spectrum are entitled to apply for DLA but that might change in relation to DSM 5. John asked Debi to let him have more information to share with his DWP colleagues. Debi asked what training DWP employed decision makers get about autism before they are able to make decisions.

6.4 Anya Ustaszewki raised some questions about DWP Access to Work support lines that fail to respond to messages left for them which can be upsetting for someone who has autism. Also, the DWP claim forms were not easy to access and could be complex. They were not available in easy read form, no instructions or templates were available and not all people with autism had support workers or family members that could help them complete them. Mark Lever raised some points about the use of sub contracting to providers like Capita and ATOS that could potentially lead to an inconsistent approach to assessment across the country. Mark was not convinced that these providers had sufficient knowledge about people with autism to deliver decisions to DWP on someone's eligibility. Mark asked how DWP would evaluate the assessment process if those carrying them out are doing them differently.

6.5 John said he would report back to members on the questions raised. Bruce suggested having an extended agenda item at the next meeting on what the new DWP benefit looks like and how people with autism are likely to be assessed against their criteria. Patience said she would also welcome some discussion outside the meeting with John about reflecting some of what has been discussed to be taken forward to the Inter-Ministerial disability group looking at employment.

Action Point 5 - John Skinner to respond to the questions raised by members and to report back before the next meeting.

Action Point 6 - The Board's secretariat to add an item on the new benefit system to the agenda at the next meeting.

Action Point 7 – Patience Wilson to discuss the inter-ministerial disability group.

7. Update on work priorities, risk log and the Autism programme plan - APB (12)28

7.1 As time was short Michael Swaffield kept this item brief, he asked members to send him their comments on the updated priorities and risks papers as circulated with the Board papers for the meeting.

Action Point 8 – Board members to let Michael Swaffield have comments on work priorities, risk log and the Autism programme plan.

8. A discussion on Education issues and next steps following the Special Educational Needs Green Paper – APB(12)26

8.1 Nigel Fulton from the Special Educational Needs and Disability Division Department for Education spoke to his paper on developments on the special education needs provision and opened up a discussion on what progress had been made.

8.2 DfE had published a Children and Families Bill at the beginning of September for pre-legislative scrutiny. This was being undertaken by the Education Select Committee who had been taking submissions from people with an interest and hearing from experts in the field and would report towards the end of December. On current expectations, the Bill, reflecting any amendments that the Government wanted to make in light of the Select Committee's report, would be introduced into Parliament early in the new year and receive Royal Assent, again reflecting any changes made through the Parliamentary process, early in 2014. The Bill's provisions would come into effect in September 2014.

8.3 In summary, the Bill proposed to introduce:

- A more streamlined assessment process, which integrates education, health and care services and involves children, young people and their parents;
- A new 0-25 Education, Health and Care Plan, replacing the current system of SEN 'statements' and Learning Difficulty Assessments for post-16s, which reflects the child or young person's aspirations for the future, as well as their current needs;
- A new requirement for local education, health and care services to commission services jointly, to ensure that the needs of young people with SEN and disabilities are met in each area;
- Local authorities to publish a clear and transparent 'local offer' of services for all children and young people with additional needs, so that parents no longer have to fight to understand what is available;
- New statutory protection for young people aged 16-25 in further education and a stronger focus on preparing for adulthood;
- The offer of a personal budget for families and young people with a Plan, extending choice and control over their support;
- Academies, Free Schools, Further Education and Sixth Form colleges to have the same duties as local authority maintained schools to safeguard the education of children and young people with SEN.

8.4 On Autism, DfE had been funding the Autism Education Trust (AET) over the last two years, through a Voluntary and Community Sector grants programme, to develop tiered training at "universal", "enhanced" and "specialist" levels for school staff, teachers and school SEN Co-ordinators. The AET is well on the way to meeting its target of training 5,000 school staff at the universal level by March 2013 and there is strong interest in the higher two levels of training. The Trust has also published national autism standards for educational settings and a competency framework for those working with children and young people with autism. Access www.autismeducationtrust.org.uk/ for details. DfE has announced another grant programme from April 2013 onwards.

8.5 The All Party Parliamentary Group on Autism had published *The right start: reforming the system for children with autism* on 14 June, following its SEN commission. Its first recommendation was that the Government should continue funding for the AET beyond March 2013 so that it could cover all areas of the country.

8.6 In addition, in July DfE published its annual SEN statistical data. This includes data by type of need on children at School Action Plus, the higher of two school-based levels of provision, and with statements. This showed that there were 66,195 children identified with an autistic spectrum disorder by schools and local authorities at January 2012 (21,840 at School Action Plus and 44,355 with statements). The number of children identified with autism has risen every year since DfE started publishing data by type of need in 2004, when there were 31,260 (23,960 with statements and 7,300 on School Action Plus).

8.7 Sheila Shribman informed members that she chaired an external advisory stakeholder group on children's special educational needs, and have recently also set up a group with the health representatives to support some of the work of the DfE pathfinders.

8.8 Mark Lever raised a number of points, including his view that there is an over emphasis on accreditation and qualifications rather than outcomes for individuals who have passed through the system, as funding has been linked to accreditation and qualifications. Mark thought that what needed to happen is for funding to be linked to outcomes for individuals around life skills. There was a need be realistic about what can the further education system deliver to young adults with autism, and what it is that is going to set them up for the rest of their lives.

8.9 As time was short, Bruce Calderwood asked members to let the secretariat have their further questions for Nigel Fulton to respond to after the meeting.

Action Point 9 – **Board members to contact Anita Wadhawan with further questions for Nigel Fulton.**

9. Update on DH Review: Winterbourne View Hospital – APB(12)22

9.1 The Minister had the opportunity to let the Board have his views on the events and the work that had been ongoing over the year on the Review of events at Winterbourne View hospital. He also updated the Board on the publication of the final report and next steps, and thanked those members of the Board who had been involved with the review. The DH Report was subsequently published on 10 December.

10. A report on the main themes to emerge from the Local Authority self-evaluation exercise on progress on implementing the Adult Autism Strategy - APB(12)25

10.1 Gyles Glover spoke to his paper, which set out the main themes to come out of the first self-assessment exercise across Local Authority areas. Gyles summarised the headlines from the report and invited members to ask questions and comment on the report, before it was finalised and published. He reminded members that 136 of the 152 Local authority areas took part in the first self-evaluation exercise. He said that the individual returns were available on the Learning Disability Public Health Observatory's website along with some evaluation of the data submitted. Gyles explained that the aim was for the PHO to repeat the self assessment exercise during 2013, with Local Authorities areas being asked to respond during May/June so that the information can play into the Review of the Autism Strategy.

10.2 Mark Lever suggested that for the second exercise there should be more guidance around how Local Authority areas answer the questions with more clarity about what the red, amber and green RAG ratings mean to ensure consistency.

10.3 In summing up, Bruce Calderwood said it was also important that there should be transparency in this exercise and that it was important to involve the Local Government Association and the Association of Directors of Adult Social Services.

11. Any other Business and date of next meeting

11.1 No other business was raised.

11.2 Programme Board Members agreed that they should be three meeting of the Board in 2013 to allow for overseeing of the Review of the Strategy. The dates were subsequently confirmed and revised as 24 April, 17 July and 22 October.