



**Adult Autism Programme Board
Minutes of the Meeting held on 17 July 2013
2.00 pm – 4.00 pm
Cathedral Room, Richmond House, London**

Present:

Norman Lamb MP	Minister of State for Care & Support – Chair (from 3pm)
Jon Rouse	DG, Social Care, Local Government & Care Partnerships (to 3 pm)
Frances Smethurst	DH Deputy Director, Disability, Learning Disability and Autism Policy
Bruce Calderwood	DH Director, Mental Health, Disability and Equality Division
Anya Ustaszewski	Self-advocate
John Simpson	Self-advocate
Debi Evans	Family carer
Jackie Edwards	Family carer
Gyles Glover	Public Health Observatory
Nigel Fulton	Department for Education
Sam Cramond	NHS England
Amanda Batten	National Autistic Society
Jackie Doughty	Autism Alliance UK
Sarah Smith	Ministry of Justice
Terry Brugha	University of Leicester
Zandrea Stewart	Association for Directors of Adult Social Services
Councillor Linda Thomas	Chair of the LGA's Community Wellbeing Board
Sally Kenny	DH Communications
Michael Swaffield	DH Autism Policy Lead
Anita Wadhawan	DH Autism Policy & Secretariat to the Autism Programme Board
Annemarie McNeely	DH Autism Policy

Apologies:

Mark Lever
John Philipson

Declan Murphy
Simon Baron-Cohen
Paul Williams
Nicola Lomas
Alan Rosenbach
Patricia Kearney

NAS (Amanda Batten attending in place)
Autism Alliance UK (Jackie Doughty attending in place)
Kings College London
University of Cambridge
Department for Business, Innovation and Skills
Department for Work and Pensions
Care Quality Commission
Social Care Institute for Excellence

Summary of Action Points from meeting

Action Point	Action	Owner	Update
1	Michael to circulate an updated Autism Programme issues risk log ahead of the next meeting. Members to provide feedback.	Michael Swaffield	Issues risk log issued ahead of the October meeting. Will be revised and updated from now on.
2	The Autism Programme issues risk log to be a standing agenda item for future programme boards.	Anita Wadhawan	Noted.
3	DH workforce colleagues to be invited to attend the next Board meeting if the curricula training issue not resolved.	Michael Swaffield	Negotiations are on-going to have autism training included in the Mandate between Health Education England (HEE) and DH. The deadline for this is December/January. The Mandate sets out the importance of HEE working with a range of partners, including the Royal Colleges and professional bodies, and in particular in developing curricula to ensure that any issues and problems related to education and training can be addressed.
4	Sally Kenny to develop a communication plan around the publication of the CCG guide	Sally Kenny	The Guide on diagnosis and related support was endorsed by the Joint Commissioning Panel (led by the Royal Colleges of GPs and psychiatrists) at its meeting on 20

			September. It is currently being finalised and typeset and will be issued in the first half of November. A communications plan will be finalised.
5	Terry Brugha to contact Sam Cramond when his work had progressed sufficiently that comments could be sought from NHS England.	Terry Brugha	Terry has put his work on hold to await advice from NHS England and DH.
6	DH to ask partners organising forthcoming Strategy Review focus groups/events to have representation from individuals with autism and families and carers on the agenda and in attendance.	Michael Swaffield	Actioned.
7	DH to put together an information table outlining the main themes and investigative measures to be used to highlight any potential gaps.	Michael Swaffield	A summary table will be circulated before the meeting.
8	Sally Kenny to follow up the offer from Linda Thomas to help influence the LGA Community and Wellbeing Board.	Sally Kenny	Proposed meeting to take place in November (date to be confirmed). Anita Wadhawan to firm up arrangements by the end of October.
9	Jackie Doughty/ Debi Evans to let Anita Wadhawan have information on Scotland's One Stop Shops.	Jackie Doughty	Debi's link to a one stop shop in Edinburgh is http://www.number6.org.uk Jackie Doughty will provide information on another One Stop Shop as soon as it is available from the website.
10	Zandrea and Gyles to action Board members additional questions and suggested changes raised under 6.2 on the Self-Assessment exercise.	Zandrea Stewart and Gyles Glover	Actioned. The Local Authority area self-assessment was issued on 5 August taking on board the suggestions made by Board members.

11	Secretariat to forward to the APB members details of successful autism housing bids.	Anita Wadhawan	A selection of bids have been collated and will be circulated to the Board before the October meeting.
12	DH would raise with DWP the need of appropriately written correspondence if it is known the person being written to has autism.	Michael Swaffield	DWP would address operational issues in due course and their update for the October meeting will set out their timetable for this.
13	DH to arrange a meeting with a DWP Minister, self advocates and family carers to discuss employment for people with autism, how to encourage employers to make more reasonable adjustments and how to involve people on the spectrum in DWP policy decisions before they are made.	Michael Swaffield	It was thought more appropriate that this meeting would take place once the listening phase had ended and during discussions to refresh the strategy. Also that both Minister of State for employment and disability would want to be part of this meeting.
14	APB members to consider future accountability and governance of the APB, and send ideas to Anita Wadhawan.	Board Members	Jon Rouse will talk further to the Board about this at the meeting in October.

1. Welcome, introductions and apologies

1.1 Jon Rouse, Director General for Social Care, Local Government and Care Partnerships in DH introduced himself. He had been in post for four months and this was his first Autism Programme Board (APB) meeting.

1.2 Jon gave the apologies received and welcomed Frances Smethurst, Linda Thomas and Sally Kenny to their first APB meeting. The Minister would be joining the meeting at 3 pm. Jon drew the APB's attention to the written Ministerial statement released that day concerning the Review of the Autism Strategy. It sought to alert MPs to the review and to welcome views from them and their constituents during the investigative stage.

2. Minutes and matters arising from the meeting held on 24 April 2013

2.1 Minutes from the last APB were agreed without amendment.

2.2 On matters arising, Jon asked Anita Wadhawan to take the APB through the action points of the last meeting and provide updates.

Action Point 1

Both the 7 November 2012 and 24 April 2013 APBs asked for examples of good practice to be sent to Michael Swaffield, but none had been received. It was expected that the Review would generate a lot of good practice examples.

Action Points 2, 3 and 6

DH had advised that the autism risk and work programme logs would be included as an item at this meeting and APB members had been requested to provide updates. No updates had been received. Michael apologised to the APB that the logs were not available for the today's meeting. Some work had been carried out on these, but more was required, including updating the risks around the review of the strategy. Michael sought APB approval for him to continue updating the logs and sending a fuller risk log to the Board in good time ahead of the next meeting. This was agreed. Jon Rouse highlighted the importance of work programme and risk logs as a way of holding people to account. He said that the logs need to be a standing item for all future APBs. He agreed that the logs be circulated in writing on this occasion, giving APB members an opportunity to feedback with a view to a fuller discussion at the next meeting.

Action 1 : Michael to circulate an updated log ahead of the next meeting. APB members to provide feedback.

Action 2 : The risk logs to be a standing item for future programme boards.

Action Points 4 and 5

Michael Swaffield was discussing with DH Workforce colleagues the best way to seek the Royal Colleges to build on coverage of autism in each of their core curriculum. This would involve Health Education England (HEE) and the General Medical Council (GMC). Terry Brugha said that he had spoken with the Dean of the Royal College of Psychiatrists and autism is not on their curriculum as a core topic. Jon was concerned about timescales and asked that a meeting with the relevant organisations should be arranged. Michael said that the timescale for solving these issues would be October, i.e. the end of the investigative stage of the Autism Strategy Review. Jon asked that relevant DH workforce colleagues attend the next meeting to provide an update if sufficient progress had not been made.

Anita and John Simpson are undertaking a piece of work to evaluate the training packages funded by DH in 2010, including those provided by the Royal Colleges. John will be speaking with organisations to discuss progress, achievements and future plans. Findings will be shared with the APB.

Action 3 : DH workforce colleagues to be invited to attend the next APB to provide an update if issue not resolved.

Action Points 7 and 8

The second local authority area autism self-assessment exercise would be discussed at Item 6.

Action Points 9, 10 and 13

Nicola Lomas (DWP) had sent apologies for the meeting. DH and DWP officials, along with Anya Ustaszewski had met to discuss how the issue of employment would be considered during the review of the Autism Strategy. This would include what DWP might do during the Review to refresh existing commitments and what changes to operational practice could DWP put in place for people with autism. See also paragraph 7.3 and actions 11 and 12 from this APB meeting.

Action Point 11

Anita said that there have been on-going discussions with the Joint Commissioning Panel (JCP) for Mental Health and Learning Disabilities on finalising the guide on autism for Clinical Commissioning Groups which was due for publication in the autumn. The JCP is a collaboration co-chaired by the Royal College of General Practitioners and the Royal College of Psychiatrists, which brings together organisations and individuals with an interest in commissioning for mental health and learning disabilities. Jon said the document should also be brought to the attention of Health and Wellbeing Boards and Local Authorities (LAs). A strong communications plan needed to be in place to enable maximum and on-going impact.

Action 4 : Sally Kenny to develop a communication plan around the publication of the CCG guide.

Action Point 12

Terry Brugha had proposed a Quality Outcomes Framework (QOF) for GPs. Terry had taken this work forward and hoped to have a first draft soon. It was felt a discussion with NHS England would be helpful.

Action 5 : Terry Brugha to contact Sam Cramond when his work had progressed sufficiently that comments could be sought from NHS England.

**3. The investigative stage of the Review of the Adult Autism Strategy
APB(13)09**

3.1 Michael Swaffield introduced this paper which summarised recent activity, designed to engage those who are implementing the autism strategy and seek

views from individuals on the autistic spectrum. The National Autistic Society (NAS), Autism Plus and Autism Alliance UK were playing a major role in the review. The investigative stage of the review runs until the end of October. This phase has included regional events for local implementation leads and an online survey to seek views from those on the spectrum and which will be followed up by focus groups. A major indicator for those responsible for implementing the strategy and their partners is the LAs area self-assessment exercise which is covered under item 6.

3.2 Michael explained that NAS is undertaking work around local autism partnership boards. They are paying particular attention to the experiences of those who are board members and are on spectrum, and how boards are engaging with people on the spectrum generally. He said that DH will also be organising around 4 “Deep Dives” where small teams of people made up from DH, and partners visit Local Authorities and their partners to discuss emerging findings/issues.

3.3 Another strand of the review will be to look at recommendations made by the National Audit Office, the Public Accounts Committee and the NAS ‘Push for Action’ research. These and other recommendations are being worked through.

3.4 Michael explained that as well as co-ordination the Review, DH (and officials from other Departments), are promoting the Review and engaging with stakeholders. He gave an example of a recent regional event in the North West organised by the NAS and funded by DH. The event was attended by eighty people responsible for implementing the strategy or who have autism. The event looked at good practice, barriers to implementation (of the strategy) and potential solutions. Michael also drew members attention to a paper produced (for discussion at item 7) by self-advocate and family carer APB members which highlighted their views on current progress with implementation of the autism strategy. The early message received from many people on the autism spectrum is that they are not aware of what LAs and their partners are doing in terms of implementation and do not feel it has a great impact on them. Many also said that they have difficulties in accessing statutory social care services and this is thought to be mainly due to their needs not meeting Fair Access to Care criteria thresholds.

3.5 John Simpson expressed concern that at the North West event there was no speaker representation from people with autism. He felt that little could be gained from events without user representation. Michael said that the focus of this particular event was on organisations implementing the strategy and included people on the autism spectrum. The event had had structured discussions about good practice, local issues and possible solutions and group work was undertaken in the geographical areas which make up the North West region. John understood the reason for the focus of the event but felt that events should have someone on the spectrum there to speak and give inspiration. Jon

Rouse stressed that all future events must include a clear service user voice and presence. Frances explained that many of the events are being organised by external partners/networks and said that they will be advised that any future events should have a self-advocate, service user or family carer voice representation.

3.6 Jackie Edwards said that events might only connect with people who have a self-interest, because it is their job or they are part of an existing network. The on-line survey was one means of getting others involved. Terry Brugha commented that events may provide greater value if they were held in areas where the strategy was being implemented well and he suggested Nottingham as an example. Zandrea Stewart added that there were some good examples of work going on in the West Midlands and a show case event would be held there. This has subsequently been arranged for 18 November.

Action 6 : DH to ask partners organising forthcoming Strategy Review focus groups/events to have representation from individuals with autism and families and carers on the agenda and in attendance.

3.7 Amanda Batten asked that the feedback from the events is shared. Jon Rouse suggested that an information table outlining the main themes and different investigative measures used e.g. event/survey to be prepared as this would highlight any gaps.

Action 7: DH to put together a information table outlining the main themes and investigative measures to be used to highlight any potential gaps.

4. NAS 'Push for Action' campaign and its links into the Review APB(13)11

4.1 Amanda Batten deputising for Mark Lever introduced the paper prepared for the meeting. The paper highlighted the local work and main recommendations that make up the NAS report and campaign. DH and others are considering the NAS recommendations as part of the Review process.

4.2 Amanda picked out some key areas from the paper including the research NAS had done to support the review of the strategy and which included interviewing 14 professionals working in health and social care tasked with the implementation of the strategy locally. The interviews looked at the key barriers and enablers to implementing the strategy at a local level. Participants were selected through NAS's area development teams who identified a range of professionals who were at varying stages in terms of local implementation. There had also been an online survey for adults with autism and parents/carers about experiences and ease of accessing support and data NAS had been collecting in every LA in England since the publication of the strategy had been updated.

4.3 Amanda outlined the findings from the research, which showed that the general direction of travel set out in the autism strategy was the right one to drive up the quality of services for people with autism, but also uncovered where things were not so good, showing that progress still needed to be made. She highlighted good progress in most LA areas who have set Autism Partnership Boards. However it seemed only around half of areas have a working diagnostic pathway. Some 70% of adults with autism who responded to the survey told NAS that they thought they are not getting all the support they needed from social services.

4.4 In addition, Amanda explained that their research showed that there were a number of key barriers and challenges to furthering implementation of the strategy, these included:

- Lack of funding;
- Competing priorities and a lack of understanding of the importance of the strategy among senior managers;
- A lack of guidance and expertise on how to implement some key elements of the strategy;
- Difficulties in engaging with other key stakeholders and agencies, most notably health;
- Lack of easily accessible data on the numbers and needs of people with autism in the local area;
- Lack of trained staff with appropriate expertise;
- Lack of awareness of the needs of older people with autism;
- Poor planning for transition.

4.5 Amanda then went on to provide an update on NAS's 'Push for Action' national/local campaign which started in May. The main focus of the campaign was on local engagement with people on the spectrum and their families, trying to progress the strategy in local areas, engaging with the strategy delivery and trying to hold LAs and their partners to account if this was not happening. There will also be work directed at Health and Well Being Board to raise awareness of the strategy and the self-assessment exercise. Amanda mentioned some additional barriers identified through their research, and will be recommending the following as part of the review of the strategy:

- An innovation pot to help professionals with the development, evaluation and dissemination of new service models;
- The inclusion of autism indicators in the new health and social care outcomes frameworks, to help commissioners when setting priorities and record how well they meet targets. This would also incentivise CCGs to engage in implementation and help to monitor progress;

- The CQC to help monitor the implementation of the NICE guidelines on diagnosing and managing autism in adults, as set out in the NICE guidelines.

4.6 There was discussion around the involvement of carers and self-advocates from the Board speaking at the LGA's Community and Wellbeing Board meeting about autism and the review. Linda Thomas raised some points about LA networks, integration of services and having local champions for autism to keep autism on local agendas. Jon Rouse asked if there was a geographical map showing locally points of contact for people with autism to get support if they needed it. He suggested that NAS share their local area profiles with the local MPs to build up their awareness and support so they may be able to raise the profile of autism in their localities.

Action 8 : Sally Kenny to follow up the offer from Linda Thomas to help influence the LGA Community and Wellbeing Board.

5. Autism Alliance UK Review & actions update APB(13)12

5.1 Jackie Doughty spoke about the priorities and activities the Autism Alliance UK is taking forward as part of the review, including organising a number of focus groups in the North, South and Midlands involving people with autism, their families and carers, and local partners who are helping to implement the strategy.

5.2 Jackie mentioned the work and action plan following the DH Review of Winterbourne View that the Joint Improvement Programme (JIP) is taking forward and spoke about the difference the results of those actions would have on the lives of people with a learning disability and autism, which in turn would help to deliver the implementation of the autism strategy. Chris Bull who is leading the JIP work, as well as the Minister had been invited to speak at the Autism Alliance UK's conference on 9 October which was part of the Review. Jackie said that one of their key members meetings in the autumn will focus on housing, which was an important but less discussed area of the autism strategy. The Alliance was looking at different types of assessment models and at the costs of placements and costs.

5.3 Jackie and Debi mentioned "One Stop Shops" in Scotland which have been set up to support people with autism and suggested that the APB may want to look at this in light of some of the issues about having an open door for people with autism to go to get help and support. Debi mentioned Number 6 a One-Stop Shop a service for adults (16 and over) with High Functioning Autism or Asperger Syndrome who live in the Lothians. The service is provided by Autism Initiatives UK and has three distinctive strands within the service they providing; free social opportunities and (1-1 advice and support on a range of issues); Outreach

(funded packages of 1-1 support); Housing advice. Jon Rouse asked if it was possible to get hold of the evidence base on this so it can be considered.

Action 9 : Jackie Doughty and Debi Evans to let the secretariat have information on Scotland's One Stop Shops.

6. The second Local Authority area Self-Assessment Exercise APB(13)10.

6.1 Michael Swaffield gave the background to this work and progress since the last meeting, when a draft list of possible questions had been considered. He explained that this was the last opportunity for the APB to comment on the questions before the Minister signed them off and the questions were sent to Directors of Adult Social Care for them to oversee the exercise.

6.2 Gyles Glover talked the APB through the process of the assessment and explained how the returns would be rated. Zandrea Stewart said that ADASS would be issuing a briefing note to support the exercise. Gyles explained that the information would be published in a similar way to the previous exercise. A report showing headline information from the returns would be prepared in October and would be available to contribute to the investigative stage of the review and be discussed at the next APB. All returns would be available on line by the end of the year. LA areas will have the opportunity this time round to add people's stories to a particular question to their returns which will allow people with autism to add their voice to the exercise. As well as being signed off by the local Autism Partnership Board, the returns should also be discussed by Health and Well Being Boards by early in 2014. Members of the Board had the opportunity to offer their final comments on the self-assessment questions. These were noted and asked to be reflected in the final version to be issued to LAs.

6.3 Zandrea said that she would also make sure that there is some dovetailing with the on-going work on Winterbourne View and relevant information from the self-assessment exercise will also be fed back to the DH Post Winterbourne team. Gyles mentioned another data collection exercise around Winterbourne View which was about to begin on an inpatient census on inpatient mental and behavioural healthcare. This will cover people who have either a learning disabilities and/ or autism. This information will also help give a picture of people with autism in inpatient settings across England.

Action 10 : Zandrea and Gyles to action Board members additional questions and suggested changes raised under 6.2 on the Self-Assessment exercise.

7. Review updates from the APB Board's self-advocates and carers APB (13)13

7.1 Jackie Edwards introduced this item and said that this paper was an amalgamation of the experiences of the family carers and self-advocates on the APB. The paper was also influenced by contacts with local communities both regionally and nationally. Jackie talked briefly through the sections of the paper, with input from Anya, Debi and John. Issues covered included:

Communication - The autism community was pleased that there is an autism strategy and the extent of the work going on in this area. However, there are issues around communication of what is happening as individuals seemed not to be aware of what was happening at the local and national level;

Training and awareness raising - Many LAs are trying to develop training for staff. Jackie has attended one of these sessions, but was disappointed that it centred in the main around psychological theories and she felt it needed to be wider than that. It was important that organisations hear from people on the spectrum talking about their lives, how they interact and engage in their daily lives, and also concentrate on positives;

Diagnosis – This was much better for children than adults and it was still difficult to get a referral for a diagnosis as an adult in some areas;

Transitions - Jackie liked the alternative term “preparing for adulthood” Information held by schools is often lost when a person leaves school. Individuals also lose many statutory services at eighteen years old and as a result they are often left to drift, can become ill and end up in mental health services where healthcare staff may not understand autism;

Criminal Justice System - People with autism are over represented in the CJS system. The Police need to better understand people with autism when they encounter them;

Prevention services – It seemed that Improving Access to Psychological Therapies (IAPT) services did not know how to work with individuals with autism, there was a lack of inventive therapy and a gap in preventative services generally;

Employment and Benefits – Face to face contact with DWP representatives was proving extremely anxiety provoking for individuals on the spectrum. The view expressed was that DWP need to improve on the tone and content of letters sent to people with autism, due to literal interpretation. Many individuals with autism did not have the appropriate support they needed to navigate their way through the employment and benefits system. Concern was expressed that due to

anxieties and phobias around face to face interviews, and changes to benefits many people were choosing not to apply/reapply for support;

Transport – There was a need to improve the knowledge of public transport staff to enable them to reduce the difficulties experienced by people with autism when using public transport;

Health and Safety/Sensory Pollution – The strategy does not address experiences of individuals within the general environment eg noise from traffic, video screens, advertising etc. Noise can generally be quite disorientating and at times cause sensory overload for people on the spectrum;

Housing – Some local authorities were supportive to the needs of people with autism, some less so. Sensory issues need to be given careful consideration.

7.2 Jon Rouse mentioned the recent Housing Support Grant and asked officials to contact relevant colleagues in the DH to obtain detail of successful autism bids.

Action 11 : Secretariat to forward to the APB members details of successful autism housing bids.

7.3 Self-advocates and family carers expressed the importance of input at the outset of policy formulation across Government Departments and not at the end when it is a 'done deal'. Disappointment was expressed about DWP representation at APB meetings. The Minister suggested that a meeting be set up with a DWP Minister, self-advocates and family carers to discuss issues.

Action 12 : DH would raise with DWP the need for appropriately written correspondence if it is known the person being written to has autism.

Action 13 : DH to arrange a meeting with a DWP Minister, self advocates and family carers to discuss employment for people with autism, how to encourage employers to make more reasonable adjustments and how to involve people on the spectrum in DWP policy decisions before they are made.

8. Initial thoughts on future accountability and governance for the Autism Programme Board and implementing the Adult Autism Strategy APB(13)14

8.1 Jon briefly introduced this item. He reminded members that the APB had been in its current format for three years and felt it was good practice to take stock and have a general review of what worked well or not so well. Jon asked that members consider this, with a view to discussing ideas and suggestions at the next meeting.

Action 14 : APB members to consider future accountability and governance of the APB, and send ideas to the secretariat by 11 October for a paper to be discussed at the next Board meeting.

9. Any other business

9.1 None raised.

10. The next meeting

10.1 The next meeting would take place from 2 - 4 pm on Tuesday 22 October 2013 in Richmond House. The meeting after that would take place from 2 - 4pm on 23 January 2014.