



**Minutes and Actions Autism Programme Board Meeting
Tuesday 22 October 2013 from 2 - 4 pm
The Boardroom, Richmond House**

Present:

Norman Lamb MP	Minister of State for Care & Support, Chair (until 3.30pm)
Jon Rouse	Co-Chair, DG, Social Care, Local Government & Care Partnerships
Frances Smethurst	DH Deputy Director, Disability, Learning Disability and Autism Policy
John Simpson	Self-advocate
Debi Evans	Parent Carer Representative
Jackie Edwards	Parent Carer Representative
Gyles Glover	Public Health England
Anna Christie	Public Health England
Nigel Fulton	Department for Education
Sam Cramond	NHS England
Dominic Slowie	National Clinical Director for Learning Disability NHS England
Mark Lever	National Autistic Society
Sarah Lambert	National Autistic Society
John Phillipson	Autism Alliance UK
Sarah Smith	Ministry of Justice
Terry Brugha	University of Leicester
Zandrea Stewart	Association for Directors of Adult Social Services
Jacqui Hansbro	Department for Work and Pensions
Suzanne Eusman	Autism Plus
Simon Medcalf	DH Social Care Policy
Alan Rosenbach	Care Quality Commission
Michael Swaffield	DH Autism Policy Lead
Anita Wadhawan	DH Autism Policy & Secretariat to the Autism Programme Board
Leonie Carter	DH Autism Policy Administrator

Apologies:

Councillor Linda Thomas	Chair of the LGA's Community Wellbeing Board
Sally Kenny	DH Communications
Declan Murphy	Kings College London
Simon Baron-Cohen	University of Cambridge
Paul Williams	Department for Business, Innovation and Skills

Patricia Kearney
Karen Turner

Anya Ustaszewski
Dawn Fleming
Antonia Romeo

Social Care Institute for Excellence
DH Director, Mental Health, Disability and Equality
Division
Self-advocate
NHS Confederation
Ministry of Justice

Summary of Action Points from meeting

(This does not include views and comments made at the meeting that are linked to the Review and which will be played into thinking and work underway by the secretariat.

Action Point	Action	Owner	Update on action
1	Board members to let Michael Swaffield have feedback and comments on the current Project Plan for the Review and the Risk log.	Board members	None received but documents have been updated.
2	Mark Lever asked if there could be a commitment from the Department of Transport to review the impact of adults with autism to the changing criteria for awarding Blue Badges. NAS was receiving feedback from adults and members that they are going to be losing their right to a blue badge.	Department of Transport	DWP has replaced Disability Living Allowance (DLA), for people aged 16-64, with a new Personal Independence Payment (PIP). As around a third of all Blue Badges were issued to people who received the higher rate mobility component of the DLA, the DfT decided, following consultation, that all people in the affected age group would be automatically eligible for a Blue Badge if they scored 8 points or more in the 'Moving Around' activity of PIP. A score of 8 points or more is awarded to people who are either unable to walk or who cannot walk further than 50 metres. This means that future eligibility for a Blue Badge will be as similar as possible to the eligibility criteria pre-PIP. However, if an individual does not automatically qualify for a badge by virtue of a PIP award, they are still able to

			<p>apply directly to their local authority to see whether they qualify under any of the other criteria. There are no plans to change the underlying eligibility criteria set out in the regulations of 2000. Eligibility for a blue badge is not restricted to specific disabilities and people with physical, mental or cognitive conditions could receive a badge if they have very considerable difficulty walking. It is for the relevant local authority to decide if an applicant meets the eligibility criteria, on a case-by-case basis.</p>
3	<p>John Simpson asked DfE if the free school meals scheme for 5 to 7 year old will be mandatory.</p>	<p>Nigel Fulton (DfE)</p>	<p>DfE confirmed this is a matter for local decision making, and head teachers and school governors are best placed to make decisions that take into account local circumstances. DfE would expect schools which decide to remove packed lunches to work with parents, setting out their objectives and gaining their support for the change. This provides an opportunity for parents to raise pupils' particular dietary needs and for head teachers to take them into account.</p>
4	<p>Dominic Slowie to report back to a future Board meeting on what is happening within specialised commissioning services on training staff providing services within the criminal justice system.</p>	<p>Dominic Slowie (NHS England)</p>	<p>Dominic is unable to attend the meeting on 3rd February and will now send a written note in due course.</p>
5	<p>John Phillipson and selected members of the Board to compile suggestions of reasonable adjustments that could make a difference to help guide services.</p>	<p>John Phillipson (Autism Alliance UK)</p>	<p>Work on this is on-going.</p>

6	Anne Christie/Gyles Glover to link the data and information from the self-assessment exercise when it is ready to the NAS Push for Action website.	Anna Christie/Gyles Glover/ Mark Lever	Consideration being given to how this idea could be further enhanced as an action for the refreshed autism strategy.
7	Members requested that the Programme Board papers be sent out much earlier in the future.	Secretariat	In a bid to send out the main discussion paper (which was formulated after a meeting of some Board Members on 23 January), papers were delayed. Advice was given as to which papers provided a summary if Board Members preparation time was limited.
8	Debi Evans asked about transparency on funding and how much is the DH funding Autism organisations.	Michael Swaffield	To provide a note towards the end of the 2013/14 financial year.

1. Welcome, introductions and apologies

1.1 Jon Rouse welcomed Dominic Slowie the National Clinical Director for Learning Disability for NHS England and Jacqui Hansbro from the Department of Work and Pensions to their first APB meeting.

1.2 Jon explained that the focus of this APB meeting would be on where things were with the Review and the issues that were coming up. He said the agenda allows inputs from a number of sources:

- From Government Departments;
- From the initial data submitted to the local authority self-assessment exercise;
- Oral reports from NAS, Autism Alliance and Autism Plus covering the focus groups and the on-line survey. John Simpson would also outline the work he has undertaken on the use and take up rates of the £500k of training and awareness packages commissioned by DH in 2011 from the Royal Colleges and other organisations.

1.3 Jon explained that the listening stage of the Review was coming to an end and this would be summarised. A revised strategy would be agreed by the end of March, followed later in the year by revised statutory guidance.

2. Minutes and matters arising from the meeting on 17 July 2013

2.1 The minutes from the last APB were agreed as an accurate record without amendment. Under matters arising, Frances drew members' attention to:

- Action point 3 and the issue of the core curricula and autism awareness, where negotiations are on-going to have autism training included in the Mandate between Health Education England (HEE) and DH. 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 relation to education and training can be addressed;
- Also action point 13, on the action to arrange a meeting with the DWP Minister. This would take place during the next stage of the Review when the work on re-freshing the strategy is underway. Members also raised again that standard letters being sent from DWP should be written in an autism friendly way. The Minister said he would like to broaden out the discussion about how DWP systems work when dealing with various groups who could be disadvantaged because of their condition;
- Frances also informed members that the current Project Plan for the Review and the Risk log were circulated to the Board. If members had comments they should send them to the secretariat. She said that the risk log will be updated regularly and comments should go to Michael Swaffield.

Action Point 1

Board members to let Michael Swaffield have feedback and comments on the current Project Plan for the Review and the Risk log.

3. Questions on updates supplied by DWP, DfE, MoJ and Department of Transport

3.1 Michael Swaffield informed members that following the last meeting it was decided to take the Government Departmental updates at the start of future meetings as they can sometimes get timed out at the end of the meeting, and to invite questions rather than have people read through what they have written.

Department of Transport

3.2 Mark Lever asked if there could be a commitment from the Department of Transport to review the impact of adults with autism to the changing criteria for awarding Blue Badges, including the changing criteria from the Department of Health. He said that NAS are receiving a lot of feedback from adults and members that they are going to be losing their right to a blue badge.

Action Point 2

Mark Lever asked if there could be a commitment from the Department of Transport to review the impact of adults with autism to the changing criteria for awarding Blue Badges. NAS was receiving feedback from adults and members that they are going to be losing their right to a blue badge.

Department for Education

3.3 Mark Lever said that as Education, Health and Care Plans would go up to age 25 it would be helpful if in the consultation on the Code of Practice reference could be made to the Autism Act and the obligations under the Autism Act. He said that there are references to other legislation in the Code, but that parents and adults would welcome reference to the statutory guidance that exists within the Autism Act particularly around transition.

3.4. John Simpson asked if the free school meals now provided to 5 to 7 year olds are mandatory.

Action Point 3

John Simpson asked DfE if the free school meals scheme for 5 to 7 year old will be mandatory.

Department for Work and Pensions

3.5 Mark Lever asked Jacqui Hansbro if DWP had numbers and data of people with Autism receiving Disability Support Allowance, how many people with autism are on the Work Programme and Work Choice and how many disability employment advisors have had training in Autism. Jacqui was doubtful that this information would be available but would discuss further at a forthcoming meeting with NAS.

Ministry of Justice

3.6 Debi Evans raised a point about autism awareness training for prison officers. She suggested that there should be standard autism awareness training and not autism training merged with mental health training as currently is the case. Sarah Smith mentioned the work they were doing on Liaison and Court Diversion. The Minister said this work was very valuable, and he requested that autism training in the criminal justice system should feature in the Review. Alan Rosenbach said that young offender institutions should not be forgotten.

3.7 Terry Brugha reminded the Board that we did not know what proportion of people with autism are in the criminal justice system, or how many have a recognised diagnosis of autism. Terry also mentioned prison in-reach services provided by Mental Health teams who are commissioned by NHS England to provide appropriate services in prisons.

3.8 The Minister asked Dominic Slowie how standard commissioning is framed to maximise the opportunity of training those who are providing services in prison on autism. Dominic said the wish is for all those commissioning services to have awareness of unique needs. He said that there was some work taking place with Health Education England to think about learning packages. On specialised commissioning and commissioning services for people in the criminal justice system, he said he would have to find out what was happening ie what specifically are they doing to make sure the staff working in those services are properly educated around the issues on autism awareness and report back to a future meeting on issues such as the design of the commission, what the contract requires, and how people are held to account.

Action Point 4

Dominic Slowie to report back to a future Board meeting on what is happening within specialised commissioning services on training staff providing services within the criminal justice system.

3.9 John Simpson mentioned a friend of his, Marie Tidball from Oxford University, who is working on a piece of research on criminology and autism. She has a number of case studies of people who are going through the criminal justice system and it might be useful for her to share these, and subsequently met with DH officials.

4. Discussion on the draft national eligibility criteria for adult social care and support available to everyone with autism irrespective of FACs criteria

4.1 Simon Metcalf provided the Board with an update on the work on the minimum eligibility threshold for adult care and support that is currently taking place around the draft national eligibility criteria, its links to the Social Care Bill and how the care and support system will work in the future. A lot of the focus in the new legislation and the way the future care system was imagined was about trying to stop people getting to the point of having eligibility needs by preventing need over time. He said that there are new duties in the Bill that say that local authorities must put in place different types of universal services, which are there for everybody locally regardless of their level of need.

4.2 Simon then went on to explain to the Board the timetable and the various engagement processes and consultations that have been planned to make sure full participation and involvement has taken place before final decisions are made and as far as possible trying to match any regulation changes around current practice.

4.3 Members welcomed Simon's contribution to the meeting saying it was a constructive approach. Jackie Edwards talked about different levels of local authority support that can sometimes feel like too much or too little. Debi Evans said that some attention should be given to the standards and expectations of care the autistic community want from services. Mark Lever suggested that the Board should start to think about how the universal services and market shaping mentioned by Simon could be made more accessible for people with autism. He said that we need to think about how we can we create more autism friendly environments, a bit like

the dementia friendly communities. Training for community assessors was important. The final point Mark made was encouraging the mapping of the micro-services Simon mentioned. All the really good local, small charities providing excellent support to people with autism that nobody gets to hear about or where they are, and because they are funded so tightly promotion and awareness is something that is not on their radar. Mark suggested that all those services be mapped so a portal can be provided to people so they are aware of them, and this should feature in the Review.

4.4 Zandrea Stewart mentioned work being done on reviewing training for community care workers and on community care assessments, similar to the points Simon mentioned on the revision of the assessment process. The local authority self-assessments also show that training and awareness was starting to be developed. She also mentioned the 'local offer' and the interface for younger people services and for people with autism on the spectrum to be reflected in the offer. The Local Government Association were also taking a paper on autism to their Community Wellbeing Board to look specifically at how they can support the implementation of the Autism Strategy and the recommendations of the review.

4.5 John Phillipson mentioned the number of focus groups the Autism Alliance held during the investigate stage of the review taking views from people on the review of the strategy. He said that one of consistent messages that came across from potential service users on the spectrum was about how small changes costing very little or nothing at all could make a big difference to services and the lives of people on the spectrum. John offered to compile with some help from other members of the Board, some suggestions about how services could be more accessible and what reasonable adjustments might local authorities, GP services and DWP offices etc could make.

Action Point 5

John Phillipson and selected members of the Board to compile some suggestions of practical examples of reasonable adjustments that could make a difference to help guide services providers and public services that could be widely distributed.

4.6 Dominic Slowie mentioned some good work done by Salford Council for people with learning disabilities and autism over the last few years which he felt made them pioneers in the quality and vision of work they provided. Their strategy has been to encourage existing services to reasonably adjust what they do most of the time at the cost of nothing to make big differences. The Minister made some comparisons with the current work on-going within integrated care on the pioneer programme, showcasing exemplars of services. He thought the Review could consider how areas that were doing good work could be held up as exemplars, with a mechanism for other areas to apply for the same status.

5. High level report on the results of Local Authority areas self-assessment exercise and views of APB self-advocates and carers

5.1 Gyles Glover provided the Board with an update on the initial high level output report based on the returns submitted by Local Authorities and their partners to the Autism self-assessment exercise. He said that the results showed an improvement but these will be looked at in more detail. The paper circulated was only findings from the questions which had hard answers ie the questions that were rated red, amber green, or 'yes' or 'no' answers given.

5.2 Of 152 local areas:

- 149 responded (subsequently all 152 responded);
- 77% said that they had or had a date to discuss the returns with wider groups locally including people with autism;
- Only 9 reported that autism is not in their Joint Strategic Needs Assessment;
- 20 reported that autism was not in their commissioning plan;
- 110 reported details of reasonable adjustments;
- 29 said that no training had been provided for staff that carry out statutory assessments. This training was important so that people with autism have a fair chance of getting FAC support;
- 71 out of 113 areas reported that a wait for a referral was under 20 weeks;
- 102 had a single point of information and advice on autism but this could be a general adult social care information point;
- 113 reported that the Criminal Justice System is engaging with other partners.

5.3 Gyles welcomed comments from the Board as these would help in finalising the initial report and subsequent more comprehensive reports. He said that the individual returns will be publically available on the Public Health Observatory website in due course and Health and Well Being Boards have been asked to discuss them by early in 2014 to raise the issue of autism locally.

5.4 The Minister thanked Gyles and Anna Christie for doing the work. Members said that the exercise certainly generated local interest. Some issues were raised on the whether the correct wording had been used on the question on transition, which should have been worded autism specific. Mark Lever said that this exercise marked a really significant way forward, two years ago there was no data available in this way and the response rate was very encouraging. He said that one of the next

steps is to work with local areas in more detail to explore with them how they can improve what they are currently doing.

5.5 Zandrea Stewart said all local authorities understood their responsibility to the strategy, but some were more advanced than others. The Local Government Association had a role to play here. The examples of good practice needed to be circulated around Local Authorities, and there was also a need to work with CCG colleagues.

5.6 Jon Rouse said there was a real opportunity to link the data and information collected to the NAS Push for Action website where there are descriptions of the individual local authorities and the services they offer. He said there was a need to be transparent about the information we have so the public can take a view on it locally. Jon also raised the point that he was concerned that 41% of areas said they do not have any sort of multi-agency autism training. He said this was a basic component in any local system that should be there but is not, and that this was worrying.

Action Point 6

Anne Christie and Gyles Glover would link the data and information from the self-assessment exercise when it is ready to the NAS Push for Action website.

6. Future working of the Programme Board

6.1 Jon Rouse spoke briefly about the feedback he had received from several members about the function of the Board. He asked members to consider the following questions:

- 1) have we got the right people around the table?
- 2) are there people and or organisations missing from the membership?
- 3) what should we be focusing more time on in Board meetings?

6.2 Members had the opportunity share their views. Debi Evans said she would like to see work being done to look at the benefits of Autism One Stop Shops and to hear more positive stories about good things that are happening about autism.

6.3 On Autism One Stop Shops John Phillipson mentioned two pilot shops in Scotland, both of which were highly rated for the services they provided and Jackie Edwards mentioned one in Bristol she knew of which was very good too. Mark Lever said it was important that the definition of a One Stop Shop was made clear. He mentioned an autism centre the NAS had just opened just outside Cambridge which has a diagnostic clinic run by Simon Baron-Cohen and a post-diagnostic support and a signposting service for families run by NAS. He said the key thing was to have the multiagency approach to such services all on one site and to be able to evaluate the impact on the service if and when required.

6.4 Jon asked if there were more suggestions on improving how the Board works. Members asked for the papers to be sent out earlier. John Simpson said that the self-advocates and parent carers could, time allowing, be involved in more specific

piece of work they can contribute to. Debi Evans asked for more transparency on DH funding to Autism organisations and what organisations were receiving as funding.

Action Point 7

Members requested that the Programme Board papers be sent out by the secretariat much earlier in the future.

Action Point 8

Debi Evans asked the secretariat to find out how much is DH is funding Autism organisations.

7. Review of DH funded training packages

7.1 John Simpson provided the Board with an update on the work he was currently doing on looking at the impact of the online training materials commissioned and funded by DH from nine organisations, including the Royal Colleges, in 2011. He said the work was making good progress and that he plans to write up his findings and produce a report in line with the results of the listening phase of the review. Jon Rouse thanked John for the work he had done. Alan Rosenbach asked if John's report would contain the number of how many of the professional accessed the training. John said he was trying to get hold of numerical data on this to add to the report. Alan also asked if any of the training material were specifically designed specifically for parents or relatives to access. John said he was not aware if any of them were.

8. Updates from the listening stage of the 2010 Adult Autism Review (by NAS, Autism Alliance UK and Autism Plus) and views for the strategy refresh.

8.1 As time was short Jon Rouse gave a brief update on were things had reached on listening stage of the review. He passed on his thanks to Mark Lever (NAS), John Phillipson (Autism Alliance UK) and Suzanne Eusman (Autism Plus) for all their efforts during the engagement process over the last few months on helping and supporting events, holding discussions and focus group sessions.

8.2 Mark, John and Suzanne were all invited to provide feedback on some of the key issues that came out of focus groups and survey. Key messages where :

- people with autism believed that small amounts of support can and would help them to cope better but that their needs are not currently seen as a financial priority by local authorities.
- Local Authority and NHS structural changes have created issues in some areas around progress with implementation of the strategy;

- Some people felt less well served than they should be, but there are also some people who really feel that things have got better for them and their families.
- Training, particularly for GPs and frontline staff remained a big issue;
- Lack of clarity in some areas on diagnostic pathways;
- Many people with autism wanted to work but needed more tailored support and advice;
- From the on-line survey, only 20% of 395 people said they felt they had had adequate Transition support, 60% of 657 people said they not been involved in key meetings when their support was being planned, and only 4% of 529 people were making use of Access to Work to help them into and to stay in employment.

9. Any Other Business

9.1 No other business was raised.

10. Next Meeting

10.1 This was subsequently changed to Monday 3rd February 2014, Richmond House, London.