

Cover Sheet Autism Programme Board Papers

Date of meeting

24 April 2013

Attachment number

APB (13) 03

Title of paper

The Autism Strategy Review Programme

Summary

This paper outlines the proposed work programme for the Review (however some necessary preparatory work is underway). Co-production is a core component of the Review.

Action required / recommendation

This is an opportunity for Programme Board Members to comment on the proposed work programme prior to it being agreed by the Care and Support Minister Norman Lamb MP.

The Autism Strategy Review Programme

Overall Approach

1. The 2010 Adult Autism Strategy for England and its related statutory guidance is being reviewed during 2013/14. The Secretary of State for Health has a duty, under the Autism Act, to formally review progress after 3 years. DH is the lead Government Department for Autism but much of the responsibility for implementing recommendations rest with Local Authorities (LAs) and NHS bodies.
2. The focus of the review will be on progress made and on identifying good practice and next steps, and it will be carried out by DH working in partnership with other groups and organisations. Apart from the Statutory requirement to carry out the Review, there is a large body of expectation from MPs, Peers and the Autism sector that the review will be undertaken as comprehensively as possible. Many LAs and NHS bodies are looking to the Review and the good practice it will identify to help them take forward their local plans.
3. DH will act as the overall co-ordinator of the work and its outcomes, and form a “virtual” review team with core partners including the Association of Directors of Adult Social Services, the Autism Alliance UK and the National Autistic Society (NAS).

The Review

4. The Review will :
 - consider current progress and practices towards adults with autism and their families by LAs and NHS organisations;
 - identify best practice on how services for people with autism should be delivered;
 - develop further advice for front line and mainstream services if necessary.
5. Although DH will report to Ministers on outcomes to emerge from the Review, much of the work will undertaken in partnership with LAs, NHS bodies and Review partners. The :
 - Association of Directors of Adult Social Services, the Autism Alliance UK and NAS are important members of the Autism Programme Board and will take forward a number of work strands. The Alliance has a membership of 14 specialist provider organisations and is the largest networking body for the autism

voluntary sector in the UK. NAS has over 20,000 members and over 100 volunteer run branches across the UK;

- voice of people with autism should also be at the heart of the work and engaged in appropriate ways, recognising the different needs of different individuals, and that services listen to what they have to say.
6. The Review will have 4 phases :
- Identify priority themes;
 - Finalise methodology and conduct review;
 - Analysis of review results and development of next steps;
 - Report and communicate.
7. An outline timetable is attached at **Annex A**.

Phase 1: Identify Priority Themes for Review

8. Priority themes for the Review have been identified by :
- Key themes set out in Autism Strategy;
 - Consultation with key stakeholders such as ADASS, the Autism Alliance UK, NAS, the Autism Programme Board, the National Hidden Impairments Groups, DWP, DfE, LAs and NHS representatives and people with autism;
 - Issues identified in 2012 NAO Memorandum for the Public Accounts Committee;
 - Issues identified from 1st self-assessment exercise published in 2012;
 - Issues identified from NAS data collection.
9. The priority themes currently identified for LAs and the NHS are :
- **autism awareness** – not only the training of key staff groups but general awareness of staff in more mainstream services who may have to make adjustments to services so that people with autism can access them;
 - **social care assessment and support** - provision of community care assessments including for those with high functioning autism, and the operation of personal budgets;
 - **diagnosis** - development of pathways to improve the diagnosis of people with autism (including the extent to which the 2012 NICE adult autism guidelines have been implemented);

- **needs assessment, commissioning and service planning** - development of local commissioning plans and extent to which the needs of adults with autism are being taken into account in local Joint Strategic Needs Assessments;
- **involvement** - the extent and way which the views of adults with autism and carers have been sought both locally and nationally to inform the design and delivery of local services and to inform national policies across Government;
- **the identification of good practice** – in areas like personalised budgets, advocacy services and in making adjustments to main stream services;
- **lifecourse** – the transition between children and young people's plans and services into adults' and support across different stages of life, including older people with autism.

10. The review will also look across other service areas including :

- Criminal justice system;
- Employment, education and training;
- Housing and other benefits;
- Health.

Phase 2: Develop Review Methodology and Conduct Review

11. It is proposed the review methodology will have 8 strands. This methodology has been informed by discussion with key stakeholders and learning from the methodologies employed by Prime Minister's Implementation Unit:

(i) Data review:

DH analysts will undertake with partners to be agreed a review of existing data sources on autism, including:

- Health and social care data;
- SEN data;
- Data from inspectorates/regulators;
- Other data supplied by OGDs e.g. employment, benefits, education and training;
- Data gathered and published by other key stakeholders including voluntary sector organisations and Royal Colleges;
- Data and insight gathered by DH policy team for other purposes e.g. producing Winterbourne View Report.

This will take a broad view of relevant data.

(ii) Listening Events:

There will be two types of listening/engagement events :

- Geographical events for users/carers on Partnership Boards (North, Midlands, London and South West);
- Thematic events (e.g. health and social care, employment, education and training, criminal justice system and transition & lifecourse) involving key professionals, commissioners and providers and relevant policy makers across Government.

Voluntary sector and other groups will organise and facilitate these events, including supporting and enabling people with autism and family/carers to attend (eg by supporting travel arrangements).

(iii) Online Survey:

We know that many adults with autism are not comfortable with attending meetings, which in any event will tend to only target those who are known to local services/LAs.

The DWP led Hidden Impairments National Group will survey people with autism via an internet based questionnaire and follow up with 15 small focus groups across the North of England organised by the Adsetts Partnership organisation.

(iv) Local Authority area Self-Evaluation Exercise:

The Improving Health and Lives Team at Public Health England will carry out a second LA self-evaluation exercise. The results of this will require Health and Wellbeing Board sign off locally and will be examined by people with autism and other stakeholders locally as part of a validation process.

(v) NAS

We have provisionally agreed with NAS that they will lead a specific piece of work following the reporting in May of research they commissioned among professionals about key barriers and enablers for strategy implementation, as well as research into current experiences of people with autism and their families. We are to discuss their draft recommendations and agree which ones would most benefit directly LAs, the NHS and people with autism and therefore be suitable for being taken forward.

The issue of Autism and ageing was not included in the Autism Strategy. With NAS support, a number of Peers in the House of Lords formed the Autism and Aging Commission to look at the challenges facing people with

autism as they move into older age and how these challenges can be met by LAs and the NHS. Their report is expected in June but discussions on likely recommendations that NAS could take forward during the review will take place in advance of publication.

Autism Alliance

We have provisionally agreed with Autism Alliance that as part of the review, they will lead a specific piece of work linked to identifying good practice and commissioner and provider relationships.

(vi) Local Area Reviews/"Deep Dives"

It will be useful if some local areas are studied in more depth to test out what is happening on the ground with LAs and the NHS. With input and advice from key stakeholders, we will identify four local areas representing a range of demographic and other key characteristics and, towards the end of the review period, with small review team (eg 3 people, including 1 non-DH) conduct a series of semi-structured interviews with a standardised feedback form. Questions based on perceived issues and risks identified during the data review and early engagement events. To include :

- Service users (higher and low levels of need);
- Service providers;
- Commissioners;
- Key professionals.

This will provide an opportunity to explore in a place-based way the emerging themes, explore the barriers to progress and examples of good practice and looking behind the numbers. This would Not be about performance management but about understanding an area's activities, both to help local development and for highlighting to other areas around the country.

(vii) Other Government Departments (OGDs) Interviews and Meetings

Discussions with OGDs re progress on other key elements of strategy and with the devolved administrations on issues to emerge from work on their own strategies.

Phase 3: Analysis of Review Results and Development of Next Steps

12. In this phase, there will be an intensive process of writing up the results of the review and the implications for delivery of services. This will involve a range of meetings with key stakeholders including NAS, Autism Alliance and self-advocates/people with autism.

13. A larger LA engagement workshop will be held with ADASS and the LGA to discuss with a wider LA group emerging ideas and views and active engagement in co-producing next steps for LAs and linkages with the NHS.

Phase 4: Report and Communicate

14. During this phase there will be a need to produce and publish a final report and Ministerial Statement aimed at sharing findings on current service delivery with LAs and NHS bodies.

Autism Programme Board Secretariat
April 2013

Annex A

Outline Timetable:

The timetable for the Review is :

- Phase 1: April : finalising of arrangements with key partners and views from the Autism Programme Board on 24 April;
- Phase 2: April – October : the investigative stage of the review, with emerging findings being reported to the July and October Autism Programme Boards;
- Phase 3: November – January : initial proposals consideration;
- Phase 4: February – March 2014 : Final report and publication.