

## **Priorities for This is my Life : Renewing Fulfilling and Rewarding Lives, the strategy for adults with autism in England [working title].**

### **Introduction**

1. The aim of this paper is to seek views at the meeting of the Autism Programme Board on 3<sup>rd</sup> February on the possible content of the refresh of the Adult Autism Strategy. We also want to include case studies both of individuals with autism and of good practice, and Programme Board members might wish to suggest examples.

### **The refreshed strategy**

2. A main message to come out of the listening phase of the Review was that the 2010 strategy was still essentially sound but that more action needed to be taken in certain areas. In line with the feedback, we propose to leave the vision of the 2010 strategy as it is, *that all adults with autism are able to live fulfilling and rewarding lives, within a society that accepts and understands them*, but with the addition of reference to “whole life” and “local community” linked to society. This paper identifies 16 priorities for action, under 5 main themes, that emerged from the listening phase and an interactive meeting attended by many members of the Programme Board on 23 January. It also illustrates possible content for the refreshed strategy under each priority at **Annex A**.

3. The paper sets out priorities for action that build on areas that are starting to be addressed. The aim is to put people with autism at the centre of the actions and show how changes in local service planning and delivery will make a difference over the next few years, in a style similar to the recent identification of priorities for “essential change in mental health, following the mental health strategy”.

4. The key actions under the priorities should be forward looking. Some are statements at the moment, against which we are asking the question, what happens next? There will also be other actions that will need to be added.

### **Timescale**

5. The aim is to publish the refresh on 2<sup>nd</sup> April, World Autism Awareness Day. Revised Statutory guidance would follow later in the autumn. Existing parts of the current guidance would need to remain, where there is a need to re-emphasise responsibilities of LAs and the NHS.

## List of Priorities of Action

6. The current proposed 16 priorities are :

### I want to be an equal part of my local community.

1. I want people and organisations in my community to understand and be aware of autism.
2. I want to have my views on the services and support I receive taken into account.
3. I want services and support commissioned that meet my needs, and to be able to get information about this easily.
4. I want to be part of my local community and feel safe from the risk of discrimination and abuse.
5. I want to look after my health and wellbeing like everyone else.
6. If my parents are supporting me, I want to know they can get help if they need it.

### I want to access the right support at the right time during my lifetime.

7. I want to know how I can get a timely diagnosis, with information and support before and after I receive it.
8. I want how my autism affects me as a person at key parts in my life to be understood, so I am supported as I :
  - prepare for transition from school;
  - get older;
  - reach the end of my life.
9. Whoever I am I want my gender, sexual orientation and race to be taken into account in the advice and support I receive.
10. If I have additional needs such as behaviour that is challenging, a learning disability or a mental health problem, I want the appropriate care and support I need, while still having my autism recognised.
11. I want to be helped when my circumstances change and I face a crisis, such as when a relationship breaks down, I am made unemployed or a parent who supports me dies.

I want to know that I can access targeted help and support if I need it.

12. I want staff in health and social care and other settings to understand that I have autism and how this affects me.
13. I want to know there is help and support if I need to do things like claim benefits, apply for housing or make an unfamiliar journey.
14. I want to get the right support and advice if I get into trouble or involved in the criminal justice system in another way, such as a witness to a crime or a victim.

I want to make the most of my skills and abilities.

15. I want support to enhance my skills so I can be as independent as possible.

I want to work to the best of my ability.

16. I want to be helped to get a job and to keep it.

### **Action for Autism Programme Board**

7. Autism Programme Board members to :
  - provide views on the proposed priorities and actions for the refresh of the Adult Autism Strategy, and in particular what should happen next on some of the suggested actions and what other actions should be added;
  - suggest case studies both of individuals with autism and of good practice, for possible inclusion (by 14 February).

Autism Programme Board

Secretariat

January 2014

## Annex A

### Priorities and key actions

#### Note

Likely (this is not an exhaustive list) actions are listed under each priority. Some are subject to further discussions/agreement, including where decisions on funding are awaited.

Leads for further work to tighten/agree the action are indicated.

The refresh will also cover the role of the on-going role of the Autism Programme Board nationally and a proposal that the next review should take place within 5 years.

#### **I want to be an equal part of my local community**

##### **1. I want people and organisations in my community to understand and be aware of autism.**

#### Key actions

- Build on developments like autism friendly theatre/cinema performances, the use of autism identity cards and local awareness work, with a proposed autism inclusive communities initiative based on work on dementia. This would involve some co-ordinated support of ideas and approaches for local areas to become more autism understanding communities. Civic buildings, statutory services, public and private organisations could work towards a specific award to demonstrate their commitment to becoming more autism aware. [DH leading with local areas and organisations building a broad coalition – subject to funding]
- Autism Education Trust's training programme in early years settings, schools and FE colleges. [DfE]

##### **2. I want to have my views on the services and support I receive taken into account.**

#### Key actions

- That the self assessment exercise for LAs and their partners be a regular event so that local people can pass back their views on services and their experiences, to challenge service development and have productive

discussions with local decision makers and the local autism partnership or other equivalent group. [DH, Public Health England and local areas]

- Also to put self assessment progress data together with data collected by the National Autistic Society (NAS) in a user friendly format to form an interactive map on the internet, and update each year. [DH, Public Health England and NAS – subject to funding]
- Under the Children and Families Bill parents and young people will have to be consulted about the local offer which local authorities will have to draw up setting out the services (not just education services) which people can expect to be available in their local areas. The new assessment process under the Bill is meant to be a more participative process and the Bill prescribes that local authorities, when carrying out their SEN duties, must have regard to the views wishes and feelings of the child, parent and young person. [DfE]

### **3. I want services and support commissioned that meet my needs, and to be able to get information about this easily.**

#### Key actions

- Local areas have access to a wide range of local information sources to look at for joint strategic needs assessments and planning services for people with autism. [Outcomes of NAS led local data group] – What should happen next?
- The zero based review of adult social care collections mean that all LAs have to now record information about a person's primary reason for support and whether the person has reported certain other health conditions, such as autism. [DH, with local authorities to action]
- There should also be a recognised and easily accessed source of information about services for people with autism to access – some areas have had success with one-stop shops. [LAs and NHS] – What should happen next?
- A proposed fund to be bid against by local areas to undertake a limited number of projects to demonstrate innovative approaches in delivery, scalability, replicability and value for money, particularly in relation to support for people who do not meet Fair Access to Care Services criteria. [DH – subject to funding]
- The Children and Families Bill prescribes joint commissioning duties on local authorities and their partner commissioning bodies for the education, health and care needs for children and YP with SEN. [DfE]

**4. I want to be part of my local community and feel safe from the risk of discrimination and abuse.**

Key actions

- Linking autism into the work of the Hate Crime Action Plan and other initiatives. [DH, working with the Home Office and Ministry of Justice] – What should happen next?

**5. I want to look after my health and wellbeing like everyone else.**

Key actions

- People with autism need equal access to mainstream health and community provision through appropriate reasonable adjustments. A number of guides have been issued on issues such as accessing GP practices and mental health services. [DH, NHS England, Public Health England. The Autism Alliance UK will issue a further guide as a result of the Review] – What should happen next?

**6. If my parents are supporting me, I want to know they can get help if they need it.**

Key actions

- Highlight support for carers under the Care Bill. [DH, with LGA and Care Bill implementation processes]

**I want to access the right support at the right time during my lifetime.**

**7. I want to know how I can get a timely diagnosis, with information and support before and after I receive it.**

Key actions

- It is important that there is a recognised and understood local pathway to diagnosis and Health and Wellbeing Boards could define their expectations. [LGA]
- Re-enforcement of the main issues from the 3 clinical guidelines on Autism by the National Institute for Health and Care Excellence, and their recent Autism Quality Standard. [NICE]

**8. I want how my autism affects me as a person at key parts in my life to be understood, so I am supported as I :**

- **prepare for transition from school;**
- **get older;**

- **reach the end of my life.**

#### Key actions

- The replacement of the current SEN statements with 0-25 Education, Health and Care plans, drawn up following more joined up assessments of children and young people needs will benefit those with autism who currently predominantly have statements and help improve transitions from school to adult life. [DfE]
- A programme of work is testing out the proposals in the Children and Families Bill, through 20 pathfinders, covering 31 LA areas piloting aspects of the SEN reforms including preparing for adulthood. [DfE] – What should happen next?
- The Autism Education Trust has extended its training programme to cover further education colleges and Ambitious about Autism has been grant-funded for their Finished at School programme to look at the transition of young people with autism from school to further education colleges. [DfE]
- Build on the NAS report on Autism and Aging which built on work by the House of Lords Autism and Aging Commission. A symposium or event with lead clinical people and interested parties to talk through the issues, agreeing priority actions. [DH, NHS England, LGA, ADASS, NAS etc]

### **9. Whoever I am I want my gender, sexual orientation and race to be taken into account in the advice and support I receive.**

#### Key actions

- Proposed work to look at issues experienced by women, lesbian, gay and bi-sexual people and members of the black and ethnic minority community, linked to wider communities work challenging stereotypes. [DH to lead, with NHS England, LGA, ADASS, NAS etc] – What should happen next?

### **10. If I have additional needs such as behaviour that is challenging, a learning disability or a mental health problem, I want the appropriate care and support I need, while still having my autism recognised.**

#### Key actions

People with autistic spectrum conditions may have other, additional needs.

*Transforming care*, the Department of Health's report following its review of events at Winterbourne View hospital and the accompanying Concordat set out a programme of action agreed to by over 50 organisations. A joint Local Government Association

and NHS England improvement programme is providing leadership and support to transform local services, with actions that include :

- working with independent advocacy organisations to improving the quality of independent advocacy and commissioning of advocacy services so that people in hospital get good access to information, advice and advocacy that supports their particular needs. [DH]
- working with partners to produce guidance on best practice in positive behaviour support and physical restraint (DH) and promoting training in and implementation of positive behavioural support across all care settings. [British Psychological Society]
- producing good practice standards to promote reasonable adjustments to meet speech, language and communication needs of people in specialist learning disability or autism hospital and residential settings. [Royal College of Speech and Language Therapists]
- developing practical resources for commissioners of services for people with learning disabilities, including model service specifications to support commissioning specialist services for children, young people and adults with behaviour that challenges. [NHS England and Association of Directors of Adult Social Services]

**11. I want to be helped when my circumstances change and I face a crisis, such as when a relationship breaks down, I am made unemployed or a parent who supports me dies.**

Key actions

- To highlight the importance of planning such help which is of benefit to the person and cost effective for the NHS. [DH – for statutory guidance] – What should happen next?
- The Royal College of GPs soon to start Clinical Priority programme on autism could give a lead to GPs on this issue. [Royal College of GPs]



## **I want to know that I can access targeted help and support if I need it**

### **12. I want staff in health and social care and other settings to understand that I have autism and how this affects me.**

#### **Key actions**

- The original statutory guidance for LAs and the NHS made it clear that awareness training should be available to all staff working in health and social care. [DH – also for statutory guidance]
- The regulations to support the Care Bill will require community care assessors to be suitably trained. [DH]
- A requirement in DH's Mandate with Health Education England for them to work with the Royal Colleges on autism awareness in line with the 2010 strategy and its refresh. [DH, HEE and the Royal Colleges]
- Support for the updating and e-learning training that DH commissioned in 2011. [DH – subject to funding]

### **13. I want to know there is help and support if I need to do things like claim benefits, in getting housing or make an unfamiliar journey.**

#### **Key actions**

- That people with autism know what benefits they are entitled to, that through reasonable adjustments they can make applications for support, and that people assessing them have had autism awareness training. [DWP] – What should happen next?
- That staff allocating housing understand that some accommodation may not be suitable for people with autism and that certain locations may make them more vulnerable to hate crime. [LGA, ADASS and LAs] – What should happen next?
- Establishing a national association for professionals involved in travel training. [Department of Transport] – What should happen next?

### **14. I want to get the right support and advice if I get into trouble or involved in the criminal justice system in another way, such as a witness to a crime or a victim.**

#### **Key actions**

- Issues from the listening exercise included having screening tools for people who come to the attention of the police, courts and prisons, and more training

for those in the CJS. Autism is included in the Liaison and Diversion programme, which is currently being rolled out. If trials are successful, Liaison and Diversion services will be available in every police custody suite and criminal court in England by 2017/18. [Ministry of Justice, Home Office, National Offender Management Service, DH, NHS England] – What should happen next?

- The awaited recommendations of the British Psychological Society's current Autism and the CJS project will be examined by Government Departments. [DH, Ministry of Justice, Home Office, National Offender Management Service, NHS England]
- Provision of special measures to victims and witnesses, including the Witness Intermediary Scheme (WIS) is currently being reviewed, with a view of increasing the uptake and consequently the support to vulnerable and intimidated witnesses when giving evidence to the police and in court. [Ministry of Justice]
- The need to refer people with autism for appropriate health and care support to divert and prevent re-offending. [DH, Ministry of Justice, Home Office, National Offender Management Service, NHS England] – What should happen next?
- Much also can be done by the defendant's own legal representative to alert the CJS to a person's autism, if then acted upon. [Ministry of Justice, Home Office, National Offender Management Service.] – What should happen next?

### **I want to make the most of my skills and abilities**

#### **15. I want support to enhance my skills so I can be as independent as possible.**

##### **Key Actions**

- More personalisation in responding to individuals who meet social care needs criteria and encourage information and support for those who do not, also through the proposed innovation fund. [DH – subject to funding]
- DH has funded a 3 year NAS brokerage/personalisation project to help support up to 2,000 people with autism to get more personalised support and develop a self sustaining model for the future. Look at how new technology can help increase and maintain independence. [DH and NAS]

## **I want to work to the best of my ability**

### **16. I want to be helped to get a job and keep it.**

#### **Key Actions**

- The Government's Disability and Health Employment Strategy is an overarching new development. DWP to look at their existing programmes like Access to Work and how the operation of these can be tailored more to support people with autism. [DWP] – What should happen next?
- Through the Disability Confident campaign DWP also have a focus on employer attitudes, awareness and understanding in employing people with disabilities, including autism. [DWP] – What should happen next?
- Look at how young people with autism at school and university are being prepared for the working environment. [DH, DWP and Business Industry and Skills]
- Under the Children and Families Bill young people on an apprenticeship, traineeship or supported internship, or who are undertaking training with a private training provider, can receive support through an Education and Health plan. [DfE]

#### **We commit that**

All of the above activities will be taken forward in a way that involves and engages people with autism and their families and carers.