

# **A Better Future:**

**A consultation on a future strategy for adults with  
autistic spectrum conditions**

*The Government Response*

**DH INFORMATION READER BOX**

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# Executive summary

This document is a post-consultation report for the consultation paper 'A Better Future: A Consultation on a future strategy for adults with autistic spectrum conditions', which ran from 29 April 2009 until 15<sup>th</sup> September 2009. The consultation covered five key themes

- social inclusion;
- health;
- choice and control;
- awareness raising and training; and
- access to training and employment.

The Department of Health have published two consultation reports, an overarching piece and an in-depth analysis report. This document sets out the Government response to the consultation submissions by responding to the key headlines identified in 'Overarching report of findings from the Adult Autism Strategy consultation activities' (Opinion Leader for DH, 2010).

This document highlights the next steps for the Department of Health, and a list of respondents is included in **Annex A**, together with a list of consultation events.

This response has been issued after publication of the strategy owing to the breadth of analysis within the consultation reports; it relied closely upon the development of an autism strategy, now published.

## Background

In April 2008, the then minister for care services, Ivan Lewis, announced a programme of work to bring forward a strategy to address the needs of adults with autistic spectrum conditions. The aim was to identify the barriers to independent living experienced by people with autism and their families, and address appropriate actions to enable them to live as full and included citizens. As part of this programme, DH set up an external reference group, chaired by Mark Lever, Chief Executive of the National Autistic Society, and appointed an external advisor.

The formal consultation for the autism strategy was launched by the Minister for Care Services, Phil Hope on 29 April 2009 and ran until 15 September 2009. The consultation paper “A Better Future” did not make proposals or recommendations for action but rather gave an opportunity for adults with autism, their families and the people who work with and support them, to set out their views on what actions, in which areas, could deliver the greatest change for adults with autism.

The aim was to consult openly and widely in co-production with adults with autism and all those involved with working and supporting them. Throughout the consultation, there were over a thousand responses (**Annex A**); an overview of responses can be found at:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_110923](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110923)

A detailed analysis of responses can be found at:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_111278](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_111278)

In addition, all responses to the consultation have been published by Dialogue by Design as part of the process:

<http://adulthoodstrategy.dialoguebydesign.net/>

These three documents have provided the Department with detailed analysis of the consultation.

## Overall Approach

*The Government's approach for transforming public sector services for adults with autism is a practical one. It is shaped by existing policy, in particular:*

- tackling social exclusion
- the personalisation agenda
- the increased emphasis on local solutions to local needs, and
- above all the emphasis on fair chances and opportunities for all.

These policies form the backdrop to the consultation and the work to develop the adult autism strategy and give much of its underlying direction.

More specifically, our strategy recognises the breadth of existing policy and programmes that *should* deliver the support that adults with autism need and focuses on how to make these existing policies work better for adults with autism.

In working to develop the strategy, we have focused on the needs of adults across the whole autistic spectrum including high-functioning autism and Asperger syndrome.

“Fulfilling and rewarding lives - The strategy for adults with autism in England” sets out in more detail improving access to diagnosis, assessment, information, advice and support for people with autism.

The document *Overarching report of findings from the Adult Autism Strategy consultation activities* (Opinion Leader for DH, 2010) summarised all consultation submissions into a number of key headlines, the following pages set out the Government response to these key headlines.

# Key Headlines

**Raising public awareness and acceptance of ASC. Raising the level of understanding and acceptance amongst the general public would improve many aspects of life for adults with autism. This includes understanding of the condition and how to adapt behaviour to meet the needs of adults with ASC.**

## **The Government's response**

We agree that this is important. Our vision is that all adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. A better understanding and awareness of autistic spectrum conditions, and the challenges which people with autism face, is an important step in enabling that.

The goal of increasing awareness of autism is simple: if frontline staff know more about autism, they will be better able to recognise the condition and respond effectively when working with adults with autism. This is essential to making existing policies work for adults with autism.

The Autism Act 2009 has already helped raise awareness of autism, generating widespread media and public discussion. And we believe that third sector organisations such as the National Autistic Society (NAS), Autistic Rights Movement UK (ARMUK) and many other groups will be influential in promoting a cultural shift so that the complexities and challenges of autism are better understood not only by public services but also more widely within society. The government will continue to work with third sector groups to encourage better awareness.

We want to work with staff and stakeholders to identify priorities and develop the right kind of training for different groups/professions.

**Improving key professionals' level of training. Key professionals who work directly with adults with ASC lack awareness of what ASC is and how to work with adults with ASC.**

- **Training levels should be improved amongst frontline health, social care, criminal justice, housing, transport, education and benefits and employment professionals.**
- **Training levels could be tiered so that all practitioners have a basic understanding but they have local experts who provide advice and information as well as a point for referral.**

### **The Government's response**

We agree the importance of training to deliver greater understanding of autism and how to work with people with autism.

Professional training is a key area for development. The Department of Health is committed to working with professional bodies to take action to address training for front-line health and care professionals, for example, GPs and care managers/assessors, on the needs of people with autism. We want to make this an integral part of training programmes across all public services.

Training should include awareness of autism, particularly the spectrum nature of the condition, so as to ensure better identification, as well as service adaptation. Key to ensuring that adults with autism are not socially excluded will be better information, training for staff, and understanding of the reasonable adjustments which may need to be made to all services.

The Royal College of General Practitioners launched an e-Learning programme, on 7 July 2009 for GPs. Autism is also included in the GP curriculum statements on Mental Health and Children and Young People.

Other frontline practitioners who frequently work with potentially vulnerable people (e.g. course tutors, HR departments, prison officers, social workers) should also have the relevant training and awareness to enable them to respond appropriately to the needs of adults with an autism and their families.

It is important that training leads to behavioural change and does not become simply a box-ticking exercise. We believe it is more important to focus on quality of training than quantity.

**Improving access to local services. Adults with ASC in many areas are not receiving the help and support they need. If adults with ASC have an IQ higher than 70 and do not have clinical mental health problems they are generally not eligible to receive support from either learning disabilities or mental health services: frequently, there are no other services to support them.**

### **The Government's response**

Currently, adults with autism find many core public services difficult to access. This is not only due to lack of awareness amongst staff, but also artificial barriers between services and the way the services are delivered, which can be threatening or overwhelming for people with autism.

The Disability Discrimination Act requires public services to make reasonable adjustments for disabled adults including to adults with autism.

It is important to address how we can make personalisation of social care work for adults with autism – giving them greater choice and control over the services and support they receive. While recognising that adults with autism may need more support than others to make choices, due to the nature of the condition, we see personalisation as the key to helping adults with autism live independent lives and become more included within society.

As well as improving mainstream services, we recognise there can be a need locally for specialist services, particularly for those adults with complex needs.

We want to ensure that access to such services is more consistent, and that local areas develop and commission the right kinds of support for the adults with autism in their area

**Improving local leadership. An identified individual or a team must take responsibility for responding to the needs of adults with autism to help them to live their lives to the full, make the most useful contribution to society and avoid crises.**

### **The Government's response**

DH has already provided guidance that Directors of Adult Social Services (DASS) should ensure there is a joint commissioner/senior manager who has in his/her portfolio a clear commissioning responsibility for adults with autism<sup>1</sup>. Implementing that guidance at the local level will – along with the requirement to include adults with autism within the Joint Strategic Needs Assessment (JSNA) process – help ensure the needs of adults with autism are not overlooked.

The key to successful reform of services for adults with autism is to make sure their needs are taken into account in local service planning and commissioning. Estimates of numbers of adults with autism will be included in the next core dataset for JSNAs. This can then inform the relevant single agency or joint strategic commissioning mechanisms.

Local areas will need to develop their own joint commissioning plans for adults with autism. We want local partners to work together to find the most effective ways to support the goal of identifying need and matching services to meet those needs and deliver improved outcomes locally. That may include specialist services and autism partnership boards.

Local leadership and effective local planning and commissioning of services is important in enabling adults with autism to play a fuller part in their communities. It will be important, therefore, to build capacity and capability at local levels to enable local partners to develop relevant services. Key to that will be learning from what works and involving adults with autism in developing those services where appropriate.

The consultation highlighted a number of models adopted in different areas of the country which provide dedicated services for adults with autism, though no particular model has become common practice across the NHS and social care. Rather services have been developed to reflect local needs and priorities. The Department of Health will work with services and people with autism to identify good practice and promote effective service models.

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<sup>1</sup> *Services for adults with autistic spectrum conditions (ASC): good practice advice for primary care trust and local authority commissioners (April 2009)*

**Personalising services.** Autism presents a unique set of challenges for each individual. Designing support or care around the individual is therefore essential to provide support that truly meets the individual's needs. This requires full appreciation of the individual's circumstances, skills and abilities as well as flexibility in the way that services are delivered.

### **The Government's response**

We agree. The personalisation agenda for adult social care and person-centred planning should ensure that mainstream services are tailored to fit the needs of people with autism.

The Department of Health has commissioned the Social Care Institute for Excellence (SCIE) to look at how personalisation works for adults with autism and bring forward guidance on good practice.

**Taking account of sensory issues. Many adults with ASC are highly sensitive to stimuli such as noise, light and touch. Adaptations to a range of settings where appropriate including housing, employment situations and healthcare would improve accessibility.**

### **The Government's response**

We are encouraging commissioners to think about meeting the needs of individuals and the reasonable adjustments which may need to be made to improve accessibility. The autism strategy will remind public bodies of their duties under the Disability Discrimination Act to make reasonable adjustments for people with autism.

Commissioners will need to be innovative, provide services in a smarter way, and spend money more effectively. They will need to consider what may need to be done in terms of physical premises (e.g. quiet areas, subdued lighting).

Flexibility should also be considered in the delivery of mainstream services to ensure that services can be tailored to fit the needs of autism, for example, adapting office space to ensure it is low stimulus.

**Improving the diagnosis pathway. Adults with ASC often receive a late diagnosis or are misdiagnosed. This prevents them from receiving appropriate care and support. There is also a lack of post-diagnosis support. As such there is a need to improve the diagnosis pathway and standardise diagnosis tools to improve rates of recognition and diagnosis.**

### **The Government's response**

We agree the importance of improving access to diagnosis.

Raising practitioner awareness is the first step in generating awareness of autism. It is critically important that GPs, and teams across mental health and learning disabilities, are aware of the behaviours and communication patterns associated with autism to ensure a quick referral and avoid misdiagnosis.

Other frontline practitioners who frequently work with potentially vulnerable people (e.g. course tutors, HR departments, prison officers, social workers) should also be trained to spot potential cases and know and have somewhere to refer the person to.

We agree that there is also a need to provide better access to specialists who can diagnose autism effectively or widen the skills of others (e.g. nurses) to enable them to diagnose autism. Currently, there are not enough specialists to cater for demand, resulting in out of area referrals or private diagnoses at great expense.

It is important that steps are taken to standardise diagnosis in some way to ensure that diagnoses are transferable. It is also important that diagnosis leads on to appropriate post-diagnosis support.

**Ensuring adults with ASC can access the healthcare they need. Adults with ASC can struggle to access the healthcare they need. This can be due to a wide range of issues such as practitioners not identifying the condition, other conditions being overlooked because of ASC 'masking' other conditions. This may be across a range of healthcare settings including Accident and Emergency, outpatient clinics, primary care and mental health services etc. These services must adapt services to ensure adults with ASC have parity of access.**

**The Government's response**

We agree that people with autism should be able to access good quality healthcare and improved health.

The autism strategy will ensure that adults with autism get parity of access to all services. Key to ensuring this is better information, training for staff, understanding of the reasonable adjustments which may need to be made to all services, and building personalised services around the needs of individuals.

# Additional issues

## Data collection

**Within the Social Inclusion chapter there were more responses mentioning the importance of data collection than anything else, the perception being that basic information about the prevalence of autism is fundamental to planning and decisions about resource allocation.**

### **The Government's response**

We know that data collection on adults with autism has been poor and that better data is needed to inform future policy and particularly local service development.

The autism strategy will seek ways to improve the data available to public services without adding to bureaucratic burdens facing public-sector organisations at all levels.

Joint Strategic Needs Assessments (JSNAs) are a key mechanism for commissioners to understand the needs of local people and information included in JSNAs about people with autism is critical to ensuring better services are planned and commissioned locally.

This year we will publish good practice guidance, which will set out what a good JSNA looks like, to help assessors identify the needs of people, like those with autism, who may be at risk of falling through the net.

In advance of that, work is already underway on a project bringing together exemplars from across the country sharing good practice focusing on specific client groups in JSNAs. This work will help improve the information local services can access to inform commissioning decisions.

## Exclusion and discrimination

**Many people felt that adults with autism are subject to widespread discrimination. This is system-wide, e.g. being excluded from services for disabled people, but also arises because of ignorance on the part of others. This results in adults with autism being socially excluded and economically disadvantaged. Women in particular mention feeling discriminated against when trying to get a diagnosis and when revealing their autism to other people because of erroneous stereotyping.**

### **The Government's response**

A key element in developing the autism strategy has been to address how far our current services support people with autism to live independently, or whether processes and practices exclude them. The strategy aims to ensure that programmes are aimed at improving care and transforming public services so that mainstream public services become more inclusive of people with autism, ensuring that they get the right kind of support, including the opportunity to gain employment or receive benefits.

Key to ensuring that adults with autism are not socially excluded will be better information, training for staff, understanding of the reasonable adjustments which may need to be made to all services, and building personalised services around the needs of individuals and challenging the types of stereotyping identified in the consultation.

## Funding and resource issues

Many participants believe that there is a lack of funding and resource available to cater for the needs of adults with autism. This is both on an individual level, e.g. funding support for residential care which could be taken away, and on a wider scale e.g. resources for services would have to be diverted from another client group to cater for adults with autism. This raises real dilemmas for practitioners who may wish to help adults with autism but cannot resource the changes necessary to meet their needs.

### **The Government's response**

The strategy for adults with autism neither promises nor depends on new investment. This is vital in the current economic context, where every public sector organisation is facing budget restrictions and is required to do more with less.

Nor does the strategy seek to increase the burdens on front line staff delivering public services, on businesses nor upon local planners. Instead, it focuses upon public services. Its approach is not to introduce new policies but identify how to make existing ones work better, building on the economic modelling set out in the National Audit Office inquiry into services for adults with autism<sup>2</sup>.

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<sup>2</sup> *Supporting people with autism through adulthood – A report by the Comptroller and Auditor General (June 2009)*

## Equality and Inclusion

The consultation process was grounded within an equality and human rights approach, and a consultation Equality Impact Assessment was published alongside the consultation document. The consultation specifically asked respondents for their opinion on the impact of age, ethnicity, religion or belief, sexual orientation, gender or disability on access and outcomes for adults with autism. A consultation event was held specifically for BME autism groups in association with National Voices.

The detailed analysis report (Dialogue by Design for DH, 2010) highlights the responses relating to equality and diversity from the consultation, these responses influenced the final strategy and informed the final Equality Impact Assessment and action plan which can be found at:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113369](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369)

## Next Steps

The strategy will be supported by a delivery plan to be published by end March 2010.

The Department of Health will consult on the content of guidance for health and social care bodies to support the strategy's delivery over the summer and will publish that guidance before end December 2010.

The autism strategy will be reviewed in three years.

# Annex A - List of Respondents

The strategy has been developed using the core principles of inclusivity and co-production, with extensive public consultation and the involvement of an External Reference Group on autism.

The public consultation gathered 1,133 responses. The majority were from individuals however there were around one hundred from organisations including;

- Autism London
- Learning and Skills Council
- Mencap
- National Autistic Society
- Royal College of General Practitioners
- Royal College of Psychiatrists
- Skills for Care
- Princess Royal Trust for Carers

We held 9 regional events, which involved 264 service users, carers, families , stakeholders:

- Birmingham
- Ipswich
- Leicester
- London
- Manchester
- Newcastle
- Plymouth
- Reading
- Sheffield

We requested information to inform commissioning and strategic barriers with a total of 25 responses including:

- ADASS
- Princess Royal Trust
- Standing Commission on Carers