

## Running your own local discussions: Consulting on the statutory guidance on services for adults with autism in England

A guide for organisations and facilitators

November 2014

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#### Target audience:

- Adults with autism, their families, friends and carers;
- Health and social care bodies responsible for the planning, commissioning and provision of services for adults with autism and their families;
- Representative local and national organisations;
- Health and social care professionals, and
- Any other party with an interest in improving the health and social care provided to adults with autism and their families and carers.

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### Introduction

Thank you for your interest in running a local event about the statutory guidance on services for adults with autism in England. It is really important that we hear from as many people with autism as possible as well as family members/carers, and professionals. You can help us to achieve this by running your own event.

This document is intended to help organisations that want to hold their own local discussion. It includes the following information:

- What is the consultation on the statutory guidance?
- What do we want you to do?
- What is involved in running a local discussion?
- The suggested approach
- Guidelines for involving people with autism in events
- How to feedback your results
- What will happen to the results?
- What is the deadline to feed back?

Materials that you could use to help you run events are available as separate documents, and can found on the autism consultation website at:

#### https://www.gov.uk/government/consultations/adult-autism-strategy-guidanceupdate

These are a selection of resources that you can pick and choose from depending on the type of event you are running and who with, as well as what you feel comfortable with – you don't have to use all of them:

- Introductory presentation about the Adult Autism statutory guidance consultation (this can be used and adapted by you to explain the background to the consultation and local event);
- the draft statutory guidance and answer booklet, which can be downloaded from the autism consultation website (this can also be used to explain the background to the consultation and local event). It might be helpful for participants to receive this in advance of the meeting with the date, location and timing added in.

If you need copies of the draft guidance and booklets, including easy read versions, you can request these by sending an email to autism@dh.gsi.gov.uk

• Feedback form for events.

## What is the consultation on the statutory guidance?

In line with duties under the Autism Act 2009, and following the publication on 2nd April 2014 of 'Think Autism' the update to the 2010 Adult Autism Strategy, the Department of Health is holding a 6 week public consultation on new statutory guidance to support the implementation of the updated strategy.

The Department of Health is seeking views on proposed new statutory guidance to local authorities and NHS bodies via a public consultation from people whose lives are affected by autism, whether they are a person with autism themselves, a parent or carer of someone with autism or a professional working with adults with autism.

The cross-Government Adult Autism strategy is an essential step towards realising the Government's long term vision for transforming the lives and outcomes for adults with autism. 'Think Autism' sets out a clear programme of action to support people with autism, primarily through supporting local authorities, the NHS, other public services and their local partners with local implementation work.

The draft statutory guidance is directed at local authorities and NHS bodies. It updates the existing guidance in line with progress made since 2010 and makes changes in line with recent legislation such as the Care Act 2014 and the Children and Families Act 2014. The guidance will apply to England only.

The revised statutory guidance is important because it will set out clear actions that local authorities and NHS bodies should take, before deciding on the final content of the statutory guidance, which will be published in early 2015.

The consultation seeks views on the draft guidance to local authorities and NHS bodies. Specific questions on the draft guidance are raised within 9 sections of the consultation document covering:

- 1. Training of staff who provide services to adults with autism;
- 2. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services;
- 3. Planning in relation to the provision of services to people with autism as they move from being children to adults;
- 4. Local planning and leadership in relation to the provision of services for adults with autism;
- 5. Preventative support and safeguarding in line with the Care Act;
- 6. Reasonable adjustments;
- 7. Supporting people with complex needs, whose behaviour may challenge or who may lack capacity ;
- 8. Employment for adults with autism;
- 9. Working with the criminal justice system;

The Department of Health want to hear from:

- Adults with autism, their families, friends and carers;
- Health and social care bodies responsible for the planning, commissioning and provision of services for adults with autism and their families;
- Representative local and national organisations;
- Health and social care professionals, and
- Any other party with an interest in improving the health and social care provided to adults with autism and their families and carers.

Responses to the consultation will need to be completed by 19 December 2014.

The consultation will result in new statutory guidance that local authorities and NHS bodies have to follow. It is important that we get the guidance right. The Government want to consult as many people as possible to make sure the guidance is right. We need your help to achieve this.

### What do we want you to do?

You can help us in a number of ways:

- Find out what adults with autism think locally
- Find out what parents and carers think locally
- Find out what professionals working with adults who have autism think locally. How do mainstream services respond to the demands made by the 2010 Adult Autism Strategy and the 2014 'Think Autism' update?
- Find out what ideas local people in your area have

We are asking event organisers to feedback the outcomes of their own events via the feedback form provided and to either email an electronic version of this to:

autism@dh.gsi.gov.uk

OR

Post the form to:

Consultation Co-ordinator Adult Autism Statutory Guidance Review Consultation Department of Health 3rd Floor, Area 313A Richmond House 79 Whitehall London, SW1A 2NS

# What is involved in running a local discussion?

How you run your own local discussion is totally up to you:

• You might want to run:

- One to one interviews
- A group discussion (e.g. 3-6 people for around 2.5 hours working with one or more facilitators) this could be a slot within an event that is already planned to happen within the consultation period
- A workshop (10 to 20 people for around 2.5 hours working with two or 3 facilitators ideally 1 facilitator per 4-6 adults)

As far as possible, we would like you to use the suggested approach and pro forma provided. This will help us collate everyone's views quickly and consistently.

#### THE SUGGESTED APPROACH

A suggested agenda and suggested presentation have been provided. However, these are just ideas to help you run your own events. Depending on the number of participants you have attending and their areas of interest; you may wish to consider adapting these.

## Guidelines for involving people with autism in events

If you work closely with people with autism it is likely that you are aware of much of the information below, but just in case you have not run many events with adults with autism we have included some guidelines.

#### Before the events

- 1. Give people plenty of notice to prepare themselves for taking part in the event.
- 2. Once you have told people what is expected of them and/or made an arrangement, try not to change this without good reason.
- 3. Let people know who they should contact with queries or for more information and what to do if that person is unavailable.
- 4. Make sure that any facilitators are familiar with the research questions and materials.
- 5. Print out copies of the materials; if possible use coloured paper instead of white, like pale yellow.
- 6. Arrange a computer with PowerPoint.

#### The location of the events

- 1. The room should be quiet and spacious. It may be helpful to offer the opportunity for an individual with autism to visit the room prior to the group work so that they feel comfortable with the surroundings.
- 2. Things which may distract, such as loud air conditioning, strip lighting, highly patterned blinds and noisy rooms next to the meeting room, should be avoided.
- 3. Name badges or place names on the table in front of each person are a useful aid to identifying and remembering who people are. It may be helpful to have a diagram of where people are sitting, and for them to sit in the same place at each meeting.
- 4. If possible, provide a break out room for people to go to if the meeting gets too much for them.

#### During the discussions

- 1. Use clear and accessible language do not use complicated words, abbreviations, or jargon.
- 2. Make sure that everyone understands what is being discussed. The facilitator should summarise key points from time to time to make sure everyone understands.
- 3. You may like to write complicated points on flipchart to help people focus.
- 4. Make it clear when you want people to contribute. This might mean asking a question and then getting each person to take it in turns to respond.
- 5. If you can, provide access to advocates or support workers who are skilled in the preferred methods of communication of the adults with autism who are attending, e.g. communication aids or symbols.
- 6. Avoid abstract concepts and metaphors use concrete questions and, for people with more complex needs, base discussions on their experience and current circumstances.
- 7. Where possible, try to reinforce what you are saying with visual aids such as symbols and photos.
- 8. Have a clear agenda, making it clear when each agenda is finished and the next is about to begin. It may help to summarise your discussion from time to time or to write up complex points on a flip chart to help people focus.

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### How do you send back your results?

We have provided a feedback form for you to give us the results of your own discussions.

Please email this form to autism@dh.gsi.gov.uk

or send it via post to:

Consultation Co-ordinator Adult Autism Statutory Guidance Review Consultation Department of Health 3rd Floor, Area 313A Richmond House 79 Whitehall London, SW1A 2NS

Individuals can also send in their views using the answer booklet. These can be returned by email and sent to <a href="mailto:autism@dh.gsi.gov.uk">autism@dh.gsi.gov.uk</a> or by post to the address above. What will happen to the results?

#### WHAT WILL HAPPEN TO THE RESULTS?

Everyone's responses will be analysed alongside one another together after the closing date of the consultation.

We will not be attributing individual or organisational views without prior permission to do so.

#### WHAT IS THE DEADLINE?

The consultation on the statutory guidance closes on Friday 19 December 2014. Please send us your responses before that date.

Good luck and enjoy the event!