

Better Services for People with an Autistic Spectrum Disorder

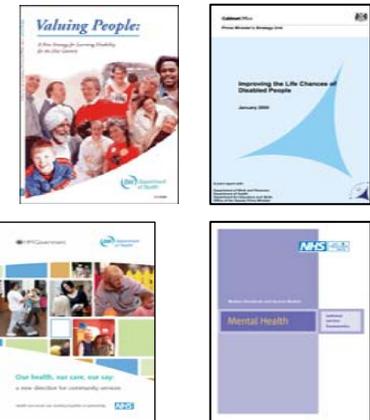
**A note to services saying what Government
policy is and describing good practice**

Easy Read Summary



Introduction

This paper is about some of the Government policies that affect people aged 16 or over with an Autistic Spectrum Disorder (ASD)



It says what the Government expects to happen in services for people with an ASD.

This paper is called “Better Services for People with an Autistic Spectrum Disorder” - we call it *Better Services* for short.



Why did we write Better Services?

Many people with an ASD need help to live their life. Some people who need help get it, but others don't. Sometimes, this is because services do not really understand them; sometimes, it is because services do not listen and sometimes, it is because no-one wants to take responsibility for helping.



This is not what the Government wants. *Better Services* says what services should be doing

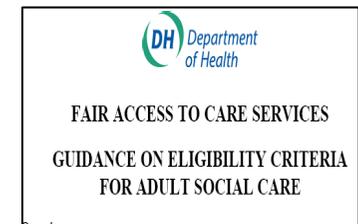
The most important message in *Better Services* is that people who are entitled to get help should get it whether they have an ASD or not. Where people are not getting help because of the reasons above, things should change.



The policies Better Services talks about are:

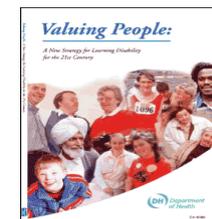
Fair Access to Care

This paper is for local authorities and says how to decide who gets social care.



Valuing People

This says people with learning disabilities ought to have full and active lives. It says what needs to change to make this happen.



National Framework for Mental Health

This says what help people with mental health needs can expect.



Our Health, Our Care, Our Say: A new direction for community services.

This says what the future for services should look like. It says people with complex needs should get the right support close to home.



Improving the Life Chances of Disabled People

This is about disabled people living an independent life and having as many chances as possible to get a good life.



National Service Framework (NSF) on Long Term Neurological Conditions

The NSF on Long Term Neurological Conditions was not written for people with an ASD, but some of the things it says would also help people with an ASD; for example, making services person centred and making sure people who need help don't have to wait a long time for it.



Better Services also talks about young people who have big changes going on in their lives and some of the Government policy that has been written for them.

If you want to say something about what is written here you can contact Judith North by e-mail on judithn@paradigm-uk.org. Judith wrote *Better Services*.

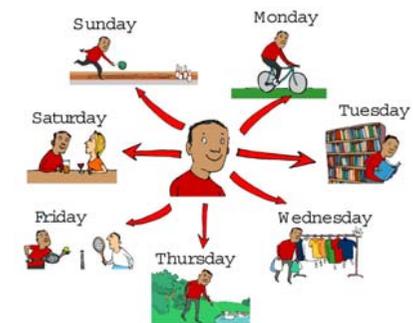
What is an ASD?

People with an ASD can find it harder than others to make sense of things going on around them, like how relationships work. This can make it hard to do things other people take for granted like understanding other people and taking part in groups. Some people with an ASD say they see and experience the world differently to other people.



Some people with an ASD have learning disabilities and some have mental health needs but not everyone does. Some people confuse learning disability, mental health and ASD. They are not the same thing.

Everyone with an ASD is different and is a person first. It is important to know each person, what they can do and what they find difficult. For example, some people with an ASD can get very worried if they have to make choices they don't understand. When this happens, they may try to stick to the same thing and not to make too many changes, but this isn't the same for everyone.



Many of the Government policies make very similar points. The rest of this paper summarises the main points in national policies and says what they mean for people with ASD.

What the Government wants for people with an ASD

- People should get support from the part of the service system that understands their needs best. They should not be sent from one place to another because services disagree about whose job it is to help them.
- In each area there should be written information about who will help people with an ASD. Some places call this “joint working protocols”.
- Services need to be local, so people with an ASD can stay close to friends and family. This is especially important for people who find it hard to make new relationships or adapt to new places.
- People who want to be included in society ought to be included. Services need to think about how they support people to make it happen. If it is to work well for people with an ASD they must be included in things they like and not forced to do the same things most other people like to do – they may not want to.
- People who need help from Social Services should get an assessment from the people who have the best skills in understanding their needs. They should not be passed between departments or sent for extra assessments like IQ tests.



- People ought to be able to get the best service for them and to control the support they get. Direct Payments and Individualised Budgets are two ways to make this more likely.
- Everyone should have a good plan saying what services they will get and how they will be provided.
- People with an ASD who have services should be treated like an expert in knowing the best way to support them. They should be listened to by services.
- If people with an ASD are not entitled to help from Social Services they should be told why not. Information about other ways of getting help should be given to them.
- People with an ASD may need extra help, like advocacy support, to speak up for themselves. Where existing advocacy services exclude people with an ASD then specific advocacy might need to be developed.



What the Government wants for families

- Parents can be experts at knowing the right things for their son or daughter. Staff doing assessments and running services should value this and listen to them.
- Family carers have a right to an assessment. If they are entitled to support, they ought to get it.
- Appropriate respite should be available for families when they need it. Respite needs to be suitable for the person who has to use it. For example, it can be hard to go to some respite services if you find it difficult to be around other people.
- Families should get good information, their views are important in assessments and reviews.



What the Government wants from Service Providers.

- People should not be excluded from services just because they have an ASD. Under the Disability Equality Duty, public sector organisations have a legal obligation to adapt what they do to meet someone's needs.
- Services need to make what they do accessible for people with an ASD. This is not just about writing things down - it is about making sure people are physically able to use services. This might mean thinking about many things that might need to be different for some people, such as lights, sounds, smells, physical design etc. For some people with an ASD, getting this sorted is very important.
- Staff need training to know how to get things right for people with an ASD. Some organisations employ people with an ASD to do this work. Training about being person centred is also important.
- Services need to think about how to keep good staff who the person they are supporting likes and gets on well with. This helps people feel confident.
- Services need to work together to provide good support for people with an ASD. People's lives are too complicated for one service to think it can manage on its own without help from other services, families etc.



- Many people with an ASD want to get out to work. Employment will work well for someone if the person's own interests and skills are matched to a job.
- All services will benefit from listening properly to people with an ASD and their families, although not all do that as well as they should.



What the Government wants from health and specialist services.

- Specialist services should be local wherever possible. People should not have to go a long way away to get the help they need.
- Diagnostic services that give advice and support can be really important to some people with an ASD and their family. Local services should know how to help someone get a diagnosis if they want one.
- Some people with an ASD can be at greater risk of some health conditions than other people. Each person should have a health plan to stop this from happening.
- It is important that people with an ASD and their family know how to get in touch with health services and how they work
- Some people with an ASD will need support to make use of health tests and to find the right doctor (GP practice). Local services, especially community learning disability teams, should help with this.



What the Government wants from commissioning

- Because there can be many people with an ASD in each area, it is important that each area makes good plans and knows who it needs to help and what kind of help they need.
- Plans need to say what help people need, the gaps in services and how they will be filled. It is the job of the Director of Adult Social Services to make sure this happens.
- Some people with an ASD do not like services designed for large groups of people, so some services need to be very individual.
- People who need help with housing or any other kinds of services need different options so they can choose what suits them best. Plans work best when they start with a person first.
- Social services and health services need to write contracts for providers in a way that means people with ASD get the kind of help they need.



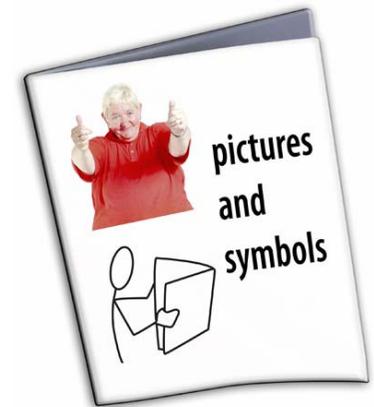
What the Government wants during life changes, changes in services and emergencies

- It is important that people have information about any changes to their services. People need information at the right time for them
- Some areas have one trusted person available to support each person when changes in services are happening. This works well.
- If changes are going to happen, it is important they are planned and work in a way that makes sense to the person.
- If there is an emergency, the important thing is to balance sorting it out quickly and making sure the person is safe, with good planning so someone can cope with change in routine.
- There ought to be information written down about how to do things in a crisis and how decisions will be made.



Summary

This paper is a summary of a bigger document called “Better Services for People with an ASD”. The bigger document has many more points about how the Government wants things to be for people with an ASD.



Glossary – an explanation of some words used in this document

Assessment – is when the Local Authority or Health Service learn about you and what you need help with before deciding if you should get services or treatment.

Commissioning – What the Local Authority or Health Service do when they decide what services they want and pay for them.

Complex Needs – is a label used to refer to people who have many different issues affecting their life (e.g. mobility, communication, daily living skills, challenging behaviour) and means someone might need more help than other people.

Existing Policy – The things Government or organisations write about what they want to see happen about a subject right at this the moment. Policies change and it is important to be up to date with the most recent ones.

Learning Disability - is a label applied to people who find it hard to understand or do new or complex things, cope independently without help and who have found difficulties with this since they were children.

Mental Health – is as important as physical health. Mental health problems range from the worries and grief we all experience to people who feel bleak, suicidal, depressed or have lost touch with reality.

National Policy – Documents or laws the Government has written that say how they want to help people and what they want organisations to do. They apply to the whole country and all the people who live in it.

Respite – A short break from caring for someone or being cared for by someone.

Services – What organisations provide to help people.

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