

Your services,  
your say

How to improve support for  
people with autism where you live



## Acknowledgements

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# Your services, your say

How to improve support for people with autism where you live

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# Introduction

**Lots of people with autism don't get the support they need.**

**This guide explains how you can change this by helping to plan support and services for people with autism and their families in your area.**

Local authorities and health services have a legal duty to involve people with autism and their families in planning support and services. This means that local authorities and health services must ask people with autism and their families what support they need and use this information to decide what services they provide.

There are three important ways in which you and your family can get involved in planning local support and services.

- 1 Your local authority or health service might invite you to answer written questions about the services they provide.
- 2 You might go to a meeting to talk about a single subject (eg a particular type of service).
- 3 You might join a group that meets regularly to plan services.

If you decide to join a group that meets regularly, it's a good idea to ask other people to support you in your work with the group. For example, you could join a local organisation for people with autism and their families, such as a branch of The National Autistic Society (NAS).

The NAS can put you in touch with your nearest branch or other local organisations for people with autism and their families. We can also give you advice and help on how to get involved in planning services.

You can contact us in the following ways.

**Write to:**  
**The Campaigns Team**  
**The National Autistic Society**  
**393 City Road**  
**London**  
**EC1V 1NG**

**Email: [campaign@nas.org.uk](mailto:campaign@nas.org.uk)**  
**Phone: 020 7923 5799**



*You can help to shape local services for people affected by autism by meeting with professionals from your local authority*

We hope that you find this guide useful and that it will inspire you to get involved in planning services where you live. Most people who do so find it a really rewarding experience. You will be able to make sure that when services are being planned, professionals know what you, and other people affected by autism, think is needed. You can help to make autism a priority for the people who take decisions in your area.

*"I would recommend that everybody becomes involved in planning local support services, as this is the only way to make progress."  
Adult with Asperger syndrome*

*"I have found involvement very satisfying and I believe that it is very important that parents have a voice when services are being planned."  
Parent*

# 1 You have a right to be heard

## Why should decision-makers listen?

**This section explains why the professionals who make decisions about support and services should involve people affected by autism, like you, in planning those services.**

Firstly, they should listen to you because **you know what it is like to have autism, or to care for somebody with autism**. You know what help you need to do the things you want to do.

Secondly, they should listen to you because **the Government has said that they should**; for example, in the Disability Discrimination Act 2005.

Simply put, you are the expert. You have experience of autism and you know which support and services are the most helpful, and where improvements could be made. Because of this, public authorities are increasingly recognising the value of involving people affected by autism in planning services.

*"Collaboration is vital... we've set up four pilot network groups to support schools in implementing new policy guidelines... parents and professionals are all working together..."*  
*Parent*

*"Having strong parental representation on our forums ensures that developments arise out of identified needs and are driven forward by both the authority and the families we serve."*  
*Local Authority Official*

The invaluable contribution that people with autism and their parents and carers have to make in policy-making and in the planning of services has been recognised in legislation and guidance in England, Scotland, Wales and Northern Ireland – most notably in the Disability Discrimination Act 2005.

The Disability Discrimination Act 2005 contains a new duty – the Disability Equality Duty (DED) – which requires public bodies to actively explore ways to ensure that disabled people are treated equally. This means including disabled people and disability equality in all decisions and activities from the outset. Guidance published in 2006 to accompany the Disability Discrimination Act makes it clear that the definition of disability can cover people with all forms of autism spectrum disorder, including Asperger syndrome.<sup>1</sup>

Certain public bodies, including all local authorities, schools and health services, are also subject to another specific duty – they must show that they have involved disabled people in the development of their Disability Equality Scheme. This includes involving disabled people in the development of an action plan

<sup>1</sup> Department for Work and Pensions. (2006). *Disability Discrimination Act: Guidance on matters to be taken into account in determining questions relating to the definition of disability*, page 39. London: DWP

The Disability Discrimination Act (DDA) defines a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities. So in determining whether a person is disabled for the purposes of the Act, the effect that an impairment has on that person's ability to carry out normal day-to-day activities will be considered rather than the specific nature of the impairment.

# 1 You have a right to be heard

and demonstrating that the public body has undertaken the actions set out in that plan.

More information about the DED, including guidance for public authorities and a toolkit to help disabled people hold a public authority to account, is available at [www.dotheduty.org](http://www.dotheduty.org)

The Government has also used other autism-specific guidance to highlight the need for people with autism and their families to be involved in planning services. For example, in England, the Department of Health clarification note, *Better services for people with an Autistic Spectrum Disorder* emphasises: “the importance of involving people [with an autism spectrum disorder (ASD)] and their families in planning. This works best when planning processes are adapted to help people get and stay involved.”<sup>2</sup>

The Government’s advice for service commissioners also says:

*“To enable people with [an ASD] to be actively involved in the commissioning process, consideration should be given to the choice of ways in which people can take part in decision-making; for example, meetings, email, questionnaires, internet conferences etc. Commissioners are reminded that the Disability Discrimination Act places a duty on public authorities to involve people in decision-making.”<sup>3</sup>*

An Adult Autism Strategy for England is being developed by the Department of Health, with publication expected in 2010. It is likely that this

strategy will also emphasise the need to involve people with autism and their families in planning services.

In Wales, the ASD Strategic Action Plan says that all local authorities have to set up groups to involve people with autism and their families in the development of services.

In Scotland, government guidance to local authorities and health boards states that they should work in partnership to “ensure the involvement of people with ASD in planning services”<sup>4</sup>.

In June 2009, Northern Ireland launched its ASD Strategic Action Plan. Under the plan a Regional ASD Network Group is being established, which will include people with autism and their parents and carers. The group will examine services in order to improve outcomes for people affected by autism. You can read the ASD Strategic Action Plan on the Department of Health, Social Services and Public Safety website at [www.dhsspni.gov.uk](http://www.dhsspni.gov.uk)

## Key points

- Public authorities should listen to you because you have experience of autism and you know which support and services are the most helpful.
- The Disability Equality Duty (DED) requires public bodies to actively explore ways to ensure that disabled people are treated equally.
- The Government has issued guidance for service commissioners about how they should involve people with autism in planning services.

## Why should you get involved?

**This section explains some of the best reasons to get involved in planning services and support, as well as some of the things you might find difficult.**

You will not always see quick results by participating in the consultation and planning process, but without your input, professionals cannot benefit from the advice of people like you, who really know about autism.

*“I was once told by a professional that the council felt it had to do something about autism services because at every meeting, someone was there watching them.”*

*Parent*

Good things about being involved include:

- professionals understanding more about autism
- autism becoming a priority for the people who plan services
- new services being created for people with autism and their families
- getting to meet other people who also have autism or another disability.

Things that can be difficult about being involved include:

- not being listened to properly

- some professionals at the meetings not being properly prepared or committed to making services better for people with autism
- not understanding what you are being asked to do or why
- being asked to do too much or not getting the support you need to be involved.

Despite these difficulties, people who get involved in planning often tell us that they find the experience satisfying and that by taking part they can:

- help to make sure that the needs of people affected by autism are not forgotten
- present not just their own views, but also the views of a support group or a larger group of people
- feel a great sense of pride and achievement when a new service or improvement comes about
- feel valued both by professionals and by those who fund services
- meet other disability groups on a local forum
- feel a personal sense of achievement because they are contributing to the community and making a difference
- act as a voice for autism: thanks to their participation, professionals begin to understand the range of needs of those on the spectrum and their families.

<sup>2</sup> Department of Health. (2006). *Better services for people with an Autistic Spectrum Disorder*. London: DH

<sup>3</sup> Department of Health. (2009). *Services for adults with autistic spectrum conditions (ASC): Good practice advice for primary care trust and local authority commissioners*. London: DH

<sup>4</sup> The Scottish Government. (2008). *Commissioning Services for People on the Autism Spectrum: Policy and Practice Guidance*. Edinburgh: Scottish Government

# 1 You have a right to be heard

In the long term, your involvement can have a real impact on service provision in your area.

*"I am a specialist advocate working for a local advocacy project. I was representing several young people with autism who had lost respite places that they had found enjoyable and fulfilling both socially and recreationally. Along with their parents, we mounted a successful campaign to secure respite provision by bringing together a group of managers and commissioners from all services."*

*Parent*

By getting involved in planning, you will also gain a greater understanding of how the local services planning system works, which in turn will allow you to influence your local authority more effectively, even outside of the group or forum. Most professionals do value constructive input from parents and people with autism, so if your involvement is successful you may well be asked to contribute to other relevant areas of your local authority or health agency's work.

You may also develop skills which you can apply in other areas of your life; for example, you might be able to transfer the meeting skills you develop into your own workplace. You will also meet other like-minded people or people who are in a similar situation to you.

*"You get face to face with senior officers who can do something about the problems you identify. You also get to know other parents and groups and become aware that they share many if not most of the same concerns."*

*Parent and development worker*

## Possible difficulties or challenges

Although the participation of people with autism and their families is vital in order to improve services, there may be things that you find difficult or challenging about getting involved.

Volunteering to participate in consultations, focus groups or committee work demands commitment. Participants have told us that they have sometimes find the following things daunting or challenging.

- Complicated agendas and long meetings.
- A lack of clarity over exactly where the committee or group fits in to the decision-making process (ie who it reports to and who can act on its recommendations).



*The Government says that local authorities should ask the opinions of the people who use their services in order to make the services better.*

- Unfamiliar jargon.
- Occasionally feeling isolated and intimidated, especially when you are new to a group or committee.
- Being frustrated that some issues are discussed more than once and things can take a long time to happen.
- Places on groups may be limited and sometimes it can seem that it is always the same few people who are consulted.
- Professionals at meetings may not be able to provide all the answers as they are not necessarily the people responsible for providing funding. It's important to remember that they, too, can become frustrated by this.
- Sometimes the professionals at meetings are not as well prepared as they could be and, whilst many professionals are passionate about supporting people with autism and their families, some may not be as committed to listening to the voice of those with experience.
- Sometimes people with autism and their families have been asked their opinion only at the end of the process, when it is much harder to achieve change than if they had been involved from the start.
- There is a time and cost commitment to participation, including time away from family and difficulty claiming expenses.
- Issues raised by people with autism and their families may sometimes be seen as only linked to their own personal circumstances. Conversely, sometimes participants are asked to represent the views of other people when they have not been given time to find out those views.

- Some people with autism need to receive information in a particular format, such as Easy Read, or may have a sensory sensitivity which makes it hard for them to access meeting venues. Public authorities should make reasonable adjustments to accommodate these needs, but where they fail to do this, it may become very difficult for the person with autism to get involved.

If you experience any of these difficulties, you are not alone. This guide contains tips from people with experience of participating in the planning process, which will help you to overcome the more challenging aspects of getting involved. It may also be worth talking through anything that you are finding particularly challenging with someone else on the group or committee that you feel comfortable with, or a mentor if you have one. If you are attending as a representative of a local support group, make sure you get help from other members and attend meetings together if one of you is not confident enough to attend alone.

*"We have formed a group called 'Asperger Voices' made up of a group of articulate, passionate adults with Asperger syndrome who attend meetings with me (and others) to put across their own points of view about lack of service provision. This is a very powerful tool when it's put alongside parents' concerns."*

*Parent and chair of Asperger syndrome support group*

Although you may sometimes find participation challenging, once you have accepted a place on a group or committee which meets regularly, you have a responsibility to attend all the meetings, unless you are ill or something else happens that makes it impossible for you to attend. Places on such groups are often limited, so it's really important that you make

the best possible use of your opportunity to represent the interests of people with autism. You should find out as much as you can about the group before you join, so that you can decide whether you will be able to make the commitment needed. It can also be a good idea to join the group as part of a team of people affected by autism, so that you can take it in turns to attend if you can't get to all the meetings yourself.

Ultimately, people with autism and their families who get involved do recognise that their participation is extremely important.

"I believe if we have the opportunity we should try and take it. Our voice is sometimes the only knowledgeable and understanding voice that there is, but also I think it helps me to see things from the other side as well."

Parent



*By helping to improve local services, you will feel a sense of achievement for yourself and others affected by autism.*

## Key points

- > Without your input, professionals will not benefit from the advice of people like you, who really know about autism.
- > You may find participation challenging, but you will feel a personal sense of achievement because you are contributing to the community and making a difference.

## Who makes decisions about support and services where you live?

### If you live in England, Wales or Scotland:

Your local authority (sometimes called the 'council') runs local schools and also provides extra help to pupils with additional support needs.

Your local authority also provides extra help for people with disabilities and their families (sometimes called 'social care services' or, in Scotland, 'social work services').

You can find out how to contact your local authority at your library or online at [www.direct.gov.uk](http://www.direct.gov.uk)

Health services, such as GPs, in your local area are run by the local Primary Care Trust (PCT) if you live in England, the Local Health Board (LHB) if you live in Wales, or the Community Health Partnership (CHP) if you live in Scotland.

You can find out how to contact your health services:

- > at your GP surgery
- > by calling NHS Direct on 0845 4647
- > online at [www.nhs.uk](http://www.nhs.uk) (England); [www.show.scot.nhs.uk](http://www.show.scot.nhs.uk) (Scotland); [www.wales.nhs.uk](http://www.wales.nhs.uk) (Wales).

In England, every Primary Care Trust should also have a guide to health services called *Your guide* which explains how you can get involved in planning health services.

### If you live in Northern Ireland:

Schools are currently run by Education and Library Boards but this will change in 2010 under the Review of Public Administration. The five Education and Library Boards will be replaced by one body called the Education and Skills Authority.

You can find out how to contact your Education and Library Board or the Education and Skills Authority at your library or child's school, online at [www.direct.gov.uk](http://www.direct.gov.uk) or [www.deni.gov.uk](http://www.deni.gov.uk), or by calling the Department of Education on 028 9127 9279.

Social care services and health services are provided by Health and Social Care Trusts.

You can find out how to contact your health and social care services at your GP surgery or online at [www.hscni.net](http://www.hscni.net)

### If you live in Jersey, Guernsey and the Isle of Man:

Jersey, Guernsey and the Isle of Man have their own governments and make their own laws.

Appendix A (at the back of this guide) explains more about how you can get involved in planning services and support for people with autism and their families in Jersey, Guernsey and the Isle of Man.

# 2

## How to get involved in planning services

### Join a group that meets regularly

**There are lots of different groups which meet regularly to plan the services and support provided by local authorities and health services.**

**This section tells you more about these groups and explains which groups talk about the things that are most important to you.**

Our Autism Services Directory also lists contact details for local authorities across the UK and for some types of statutory groups and partnerships. Visit [www.autismdirectory.org.uk](http://www.autismdirectory.org.uk) or call our Autism Helpline on 0845 070 4004 for more details.

If you would like further advice you can contact our campaigns team by calling 020 7923 5799 or emailing [campaign@nas.org.uk](mailto:campaign@nas.org.uk)

There are so many different consultation groups that the options can seem overwhelming at first, but before you choose, remember that different local authorities consult in different ways, so not all the groups listed in this section may be running in your local area.

Most of the following groups are for adults with autism and parents and carers of both adults and children with autism, but it is also important that children and young people themselves have a voice. Many areas provide this opportunity on an ad-hoc basis, so you should contact your local authority to find out how they are involving children and young people with autism in their work.

## 2 How to get involved in planning services

Join this group:	if you live in:	and you are a:	and you want to talk about:	See page:
1 Local Involvement Network (LINK)	England	Adult with autism Parent/carer of an adult Parent/carer of a child	Health services or adult social care services	14
2 Community Health Councils (CHC)	Wales	Adult with autism Parent/carer of an adult Parent/carer of a child	Health services	15
3 Public Partnership Forums	Scotland	Adult with autism Parent/carer of an adult Parent/carer of a child	Health services	16
4 Local Advisory Councils	Scotland	Adult with autism Parent/carer of an adult Parent/carer of a child	Health services	16
5 Learning Disability Partnership Boards	England	Adult with autism Parent/carer of an adult	All learning disability services for adults <i>(N.B. this may include services for adults with autism who have an IQ of above 70)</i>	16
6 Mental Health Partnership Boards	England	Adult with autism Parent/carer of an adult	All services for adults with a mental health condition	17
7 Health, Social Care and Well-being Partnerships	Wales	Adult with autism Parent/carer of an adult	Health services or social care services	17
8 Children and Young People's Partnerships	Wales	Child with autism Parent/carer of a child	All services for children	18
9 Aiming High for Disabled Children: Parent forums	England	Parent/carer of a child	All services for children with SEN	18
10 Parent Partnership Services	England and Wales	Parent/carer of a child	All services for children with SEN	18
11 Becoming a school governor or parent council member	UK-wide	Adult with autism Parent/carer of an adult Parent/carer of a child	Education	18
12 Service User Representation Groups	UK-wide	Adult with autism Parent/carer of an adult Parent/carer of a child	Any service you use	20
13 Local Strategic Partnerships	England	Adult with autism Parent/carer of an adult Parent/carer of a child	All services in your local area	21
14 Community Planning Partnerships	Scotland	Adult with autism Parent/carer of an adult Parent/carer of a child	All services in your local area	21

### 1. Local Involvement Networks

Every local authority in **England** that provides social care services should have a Local Involvement Network (LINK). LINKs make sure that local people can have their say in how health and adult social care services are run. Anyone who lives or works in the local authority area can join the LINK.

LINKs can:

- › visit places where services and care are provided to see how they are being run
- › get information from local authorities and health services
- › make recommendations to local authorities and health services (both of which have to respond to these recommendations)
- › refer matters to the local Overview and Scrutiny Committee and get a response.

Even if you don't have time to join groups or sit on committees, LINKs should provide other ways for you to have your say; for example, by using the internet or attending one-off focus groups or events. You don't have to be a member of the LINK to go to public meetings, and you can be a member without attending every meeting. For example, you could ask only to receive information about written consultations.

To find out more about your LINK, visit [www.nhscentreforinvolvement.nhs.uk/links](http://www.nhscentreforinvolvement.nhs.uk/links), call the LINKs team at the NHS Centre for Involvement on 024 7615 0705 or email [info@links.nhs.uk](mailto:info@links.nhs.uk)

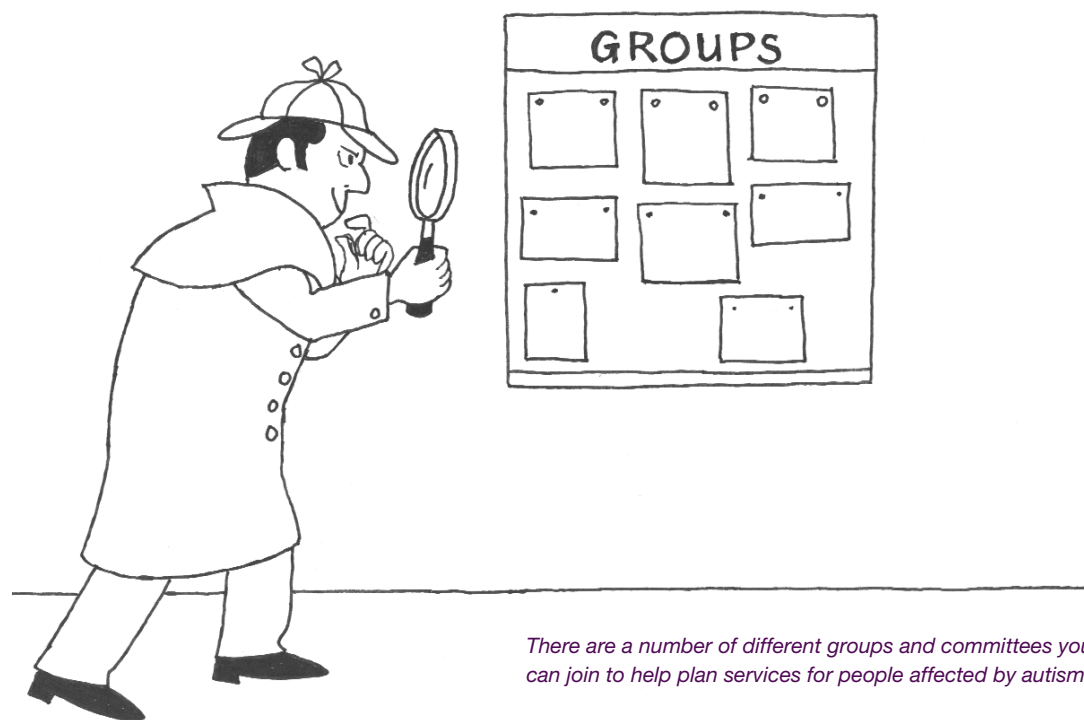
The Community Voices website ([www.communityvoicesonline.org](http://www.communityvoicesonline.org)) also has information about LINKs and includes a search facility to find contact details for the LINK in your authority.

#### Local Hero: Carol-Ann

Carol-Ann Jackson volunteered to join her Local Involvement Network (LINK). She is the chairperson of Supporting Asperger Families in Essex (SAFE), a local support group for people with Asperger syndrome and their families, and the LINK asked her to present a document she had written about the lack of suitable provision for adults with Asperger syndrome in her area to a group of professionals.

As a result of the presentation, her local health services are now discussing the possibility of developing a new service for adults with Asperger syndrome. The Local Involvement Network has also set up a working group to look at support for adults with Asperger syndrome.

## 2 How to get involved in planning services



*There are a number of different groups and committees you can join to help plan services for people affected by autism.*

### 2. Community Health Councils

In **Wales**, Community Health Councils (CHCs) have been set up so that people can have their say about how health services are run.

CHCs can:

- › get information from Local Health Boards and NHS Trusts (the people who make decisions about health services)
- › be asked what they think about proposed changes to health services
- › visit some places where health services are provided to see how they are being run

- › go to meetings with the Local Health Board and NHS Trust (the people who make decisions about health services)
- › help patients who want to complain about health services provided by the NHS.

Generally, members of CHCs do four days of work every month. You cannot simply join your CHC: you need to be nominated to become a member either by the Welsh Assembly Government, your local authority or voluntary organisations. Contact your CHC directly to find out more about this. Even if you are not nominated to be a member, you may still be able to get involved in the work of your CHC in another way. You can find contact details for CHCs online at [www.wales.nhs.uk/chc](http://www.wales.nhs.uk/chc) or by calling 0845 644 7814.

### 3. Public Partnership Forums

In **Scotland**, every Community Health Partnership (the people who make decisions about health services) has set up a Public Partnership Forum (PPF).

PPFs help to tell local people about health services in their area. They also find out what people think about health services and how they can be improved. So, being a member of the PPF means that you will be helping to make decisions about health services where you live.

Anyone who uses health services, cares for someone who uses health services or who might use health services in the future can join their PPF.

Find out how to contact your local PPF by calling Voluntary Health Scotland on 0131 557 6845 or by searching at [www.vhscotland.org.uk](http://www.vhscotland.org.uk).

### 4. Local Advisory Councils

In **Scotland**, the Scottish Health Council wants local people to be involved in making decisions about health services. To make sure this happens, the Scottish Health Council has set up Local Advisory Councils to check that the bodies which make decisions about health services in your area are working with and listening to local people.

Members of the Local Advisory Councils are volunteers. They spend two or three days a month gathering information to monitor what their local NHS Board (a group of people who make decisions about health services) is doing to involve patients and the public before decisions are taken.

For more information about the work of the Scottish Health Council and how to get involved in your Local Advisory Council, visit [www.scottishhealthcouncil.org](http://www.scottishhealthcouncil.org)

### 5. Learning Disability Partnership Boards

Every local authority in **England** that provides social care services should have a Learning Disability Partnership Board (LDPB).

LDPBs aim to improve the lives of adults with learning disabilities and their families and carers. They have written plans which say how they are going to do this.

LDPBs work with the people who take decisions about services to make sure that every adult with a learning disability can get the right service locally.

There should be at least two adults with a learning disability and two carers on every LDPB. The members of the LDPB should have support to take part in the meetings if they need it. Other members of

#### Local Hero: Neil

Neil is an adult with autism. He found out about his LDPB through a local self-advocacy group. Two years after joining the group, he became its co-chairperson.

During his time on the LDPB, Neil worked to set up the Friendly Group. This is a group of people with learning disabilities who meet to discuss different issues. Their views on these issues are then fed back to the LDPB, allowing more people to have their say in its work.

Neil was also involved in recruiting a User Involvement Worker to support the Friendly Group, the other representatives on the LDPB and the co-chairperson.

## 2 How to get involved in planning services

the LDPB come from social services, health services, housing, education and other organisations, like independent service providers or voluntary groups.

You can find out how to contact your local LDPB at <http://valuingpeople.gov.uk/dynamic/valuingpeople211.jsp> or through your local authority's learning disability team.

The Government has said that “adults with Asperger syndrome or higher-functioning autism are not precluded from using learning disability services, where appropriate”<sup>5</sup>. So some learning disabilities teams will support people with autism even if they don't have a learning disability. You may still be able to be part of the LDPB if you, or the person you care for, don't have a learning disability.

Many LDPBs have set up smaller sub-groups to work on specific issues or cover particular geographical areas within the local authority region. These groups are sometimes more informal, and easier to get a place on, so if you don't want to or are not able to join the main LDPB straight away, you could ask if there are any relevant sub-groups that you could sit on

### 6. Mental Health Partnership Boards

Although autism is not a mental health condition, some people with autism also experience mental health problems. Therefore it is vital that there are mental health services that are suitable for people with autism.

In some areas of **England**, Mental Health Partnership Boards have been set up so that adults with mental health conditions and their families can work with

people from health services, social care services, and other services, like housing and employment, to improve mental health provision.

To find out if there is a Mental Health Partnership Board in your area, contact your local authority or mental health service.

### 7. Health, Social Care and Well-being Partnerships

Health, Social Care and Well-being Partnerships have been set up in every local authority in **Wales**. These Partnerships include adults who use health and social care services, and their carers. They work with people from health services, social care services, and other services like housing and employment, to write a plan for what services will be needed to keep people healthy and to support people who are ill or disabled.

Together with Children and Young People's Partnerships (see next page), Health, Social Care and Well-being Partnerships help to make sure that the actions in the Welsh Assembly Government's ASD Action Plan are carried out. The ASD Action Plan says what local authorities and health services should do to support people with autism and their families.

To find out more about your local Health, Social Care and Well-being Partnership, contact your local authority.

### 8. Children and Young People's Partnerships

Every local authority area in **Wales** should have a Children and Young People's Partnership, which is responsible for planning and delivering services for children and young people.

Each Partnership includes children and young people who use health, education and social care services and their parents and carers, who work together with the people who provide these services.

Along with the local Health and Well-being Partnership, the Children and Young People's Partnership helps to make sure that the actions in the Welsh Assembly Government's ASD Action Plan are carried out. The ASD Action Plan says what local authorities and health services should do to support people with autism and their families.

To find out how you can get involved in your Children and Young People's Partnership, contact your local authority.

### 9. Aiming High for Disabled Children: Parent Forums

As part of the *Aiming High for Disabled Children* programme – a government programme to make services for disabled children better – every local authority area in **England** is receiving money to help parents and carers of disabled children get involved in planning services. One group in each local authority will get the money. The group may be the Parent Partnership Service (see next column), or another parent group.

An organisation called *Together for Disabled Children* is responsible for how the money is spent. They have appointed teams to support the delivery of the programme in each region.

Visit [www.togetherfdc.org](http://www.togetherfdc.org), email [mail@togetherfdc.co.uk](mailto:mail@togetherfdc.co.uk) or call 0121 683 2068 to find out who your Local Programme Advisor is. They will be able to tell you which group in your local authority has got the money and how you can get involved.

### 10. Parent Partnership Services

All local authorities that provide education services in **England and Wales** should have a Parent Partnership Service (PPS). The PPS gives information and advice to parents of children with Special Educational Needs (SEN). The PPS should also make sure “that parents' views are heard and understood, and inform and influence the development of local SEN policy and practice”<sup>6</sup>.

You can find details of your local PPS on the website of the National Parent Partnership Network ([www.parentpartnership.org.uk](http://www.parentpartnership.org.uk)) or by calling 020 7843 6334. You can also ask your child's school for details.

### 11. Becoming a school governor or member of a parent council

School governors (or members of the parent council in Scotland) help to make sure that schools are well run. If you think that your child's school isn't doing enough to meet the needs of children with autism,

<sup>5</sup> Department of Health. (2001). *Valuing people: a new strategy for learning disability for the 21st century: implementation*. London: DH

<sup>6</sup> Department for Education and Skills (2001), *Special Educational Needs Code of Practice*, page 28. London: DfES

### Local Hero: Maggie

“Parent Partnership Services are statutory services – this means that each local authority is legally required to provide the service in order to inform and support parents of children with SEN in their area. However, it must also be independent (or at least at ‘arms-length’), confidential and free. In my local authority, the PPS is provided by a local charity called Supportive Parents and everyone who works for them is also a parent of a child with SEN.

“When my oldest son was struggling at school, I used my PPS helpline for information about the SEN process and to talk through my worries. It helped a lot, but eventually we had to take my son out of school. When my youngest son was diagnosed with ASD before his third birthday, I felt I needed to become more expert in how the system worked. I did a parent training course offered by Supportive Parents and started to volunteer as an independent parental supporter, helping other

parents to work in partnership with their child’s school. At the same time, I was also acting as branch officer for the NAS and the skills I developed in this role meant that I was eventually able to find paid employment with the PPS – an exciting opportunity for career progression.

“My PPS also runs an SEN parent forum. We meet with the local authority three times a year to discuss general issues and concerns – and of course the local NAS branch has always been very active as part of this group. In my role with the PPS, I now act as programme lead for phase one of the *Together for Disabled Children* parent participation programme. This has been a really exciting opportunity for the PPS, the local authority and the NAS to work together with other parent groups and professionals to achieve our dream of effective parental involvement in the statutory planning and commissioning of services for disabled children.”

you can help to change this by becoming a school governor or parent council member. This is especially important because more funding and decision-making powers are being given to individual schools.

Normally, a governor or parent council member will do the job for four years, but as volunteers they can resign at any time. Your main responsibility would be to attend meetings of the school’s governing body, which are usually once a term. Anyone who is over the age of 18, has an interest in education and can spare six hours a month can become a school governor or parent council member.

In **England, Wales and Northern Ireland**, parent governors are elected by other parents of children at the school. When a vacancy for a parent governor becomes available, the school must tell all parents of children at the school. Any parent can apply to be a governor and vote in the election. If you apply to be a governor you will usually need to write a small piece about yourself and why you’d be a good choice as a parent governor or member, but it’s unlikely that you’d have to stand up and speak in public. To find out more about becoming a parent governor, contact your child’s school.

In **Scotland** every parent is automatically a member of a school’s Parent Forum. Out of the Parent Forum a Parent Council is likely to have been elected, and often parents are able to volunteer. Each Parent Council operates according to its own rules but you can check with the school or local authority to find out how to become involved.

In **England and Wales**, community governors are appointed by the local authority. Anyone can apply to be a community governor and parents with children at the school can usually be considered too. If you want to be a community governor you should apply to your local authority. You can also write to local schools directly to tell them that you would like to be a governor.

There is usually a member of the governing body with responsibility for special educational needs (SEN). The

role of the SEN governor is to ensure that the governing body and school staff keep in mind the needs of pupils with SEN in all areas of their work. Parents of children with autism often take on this role because of their experience in this area, and it can be a really good opportunity to take a lead in improving the support that the school offers to pupils with SEN. The Department for Children, Schools and Families has produced a guide for SEN governors, called *‘Making a Difference’* which is useful reading for anyone taking on this role<sup>7</sup>.

## 12. Service User Representation Groups

If you already use a service (for example, if you go to a day service) you can tell the people who run the service what you think about it and how you would like it to be improved.

### Service user representation in Surrey

“At our day service, there is a service users’ committee which meets every three weeks. One service user chairs the group and another writes up the minutes each time. The committee is an opportunity for service users to comment on everything, from the activities on offer and the way that staff are working with them, to the food that is served at the centre.

“This year the group were asked to plan a summer activities week and, as a result, a trip to Portsmouth was organised, as well as other visits to the cinema, the seaside and a train trip.

“The group is also responsible for putting together rules about how people should behave at the centre. These rules are included in induction packs for all service users and staff.

“Some of the most able committee members also serve as advocates with the local community. They have given talks and are currently making a film introducing the service to the general public.”

*NAS Horizons day service programme coordinator*

<sup>7</sup> DfES. (2003). *Making a Difference: a Guide for Special Educational Needs (SEN) governors*. London: DfES. Available by calling 0845 602 2260 or emailing dcsf@prolog.uk.com

Lots of services will have meetings where you can have your say, or questionnaires that you can use to say what you think about the services. You could ask your key worker or the manager of your service about this.

### 13. Local Strategic Partnerships (LSPs)

Local Strategic Partnerships (LSPs) bring together people in **England** who represent public services, local businesses, community groups and residents to better plan existing services and set out a future vision for their area.

In most areas, community networks have been set up to help community and voluntary groups get involved in LSPs. If you are not already involved in your LSP, the first step is to contact your local community network. To find out how to do this, call The Urban Forum on 020 7253 4816 or email [info@urbanforum.org.uk](mailto:info@urbanforum.org.uk). Alternatively, you can contact the LSP lead in your local authority.

### 14. Community Planning Partnerships

In **Scotland**, Community Planning Partnerships (CPPs) serve the same purpose as Local Strategic Partnerships in England. Your local authority should be able to provide more details of how you can get involved.

#### Key points

- > There are lots of different groups and committees that you can join to help plan local services, but they may vary from region to region.
- > You should find out what the group or committee discusses before you join, to make sure it is the right group for you.

## Have your say on one issue

**You might not want to join a group that meets regularly, but you may still want to have your say about one thing that is really important to you.**

**Local authorities and health services sometimes ask people what they think about existing services or proposals for new services. This section explains how they might do this and how you can have your say.**

anyone can have their say in these consultations by responding in writing. Figure 1 (page 23) is a template consultation response that you can use to help you write your opinion on a consultation topic.

When the consultation is over, you should be told what the results of the consultation are and how the results have been taken into account in making a final decision. The results of the consultation are usually published in a report. You should not expect to receive feedback on your individual consultation response.

Public authorities may also arrange focus groups to allow people that may be affected by their proposals to say what they think about them in a group meeting.

To find out more about consultations in your area, contact your local authority or health service.

#### Surveys

Sometimes local authorities and health services send a survey to local people to find out what they think about a particular issue. Generally, the people doing the survey will decide who to send the survey to, so you can only take part if you are sent one. But if you do get a survey it is a good chance to have your say.

#### Consultation

Consultation is when the Government and local authorities involve members of the public in their work. Consultation helps the Government to make better decisions because they can find out what the people who would be affected by their decisions think.

Public authorities, such as health services, often consult by publishing proposals on their websites and asking the public to say what they think about them. Usually

#### NHS patient surveys

NHS Trusts are the people who make decisions about health services in England. Each NHS Trust in England has to find out what patients think about the health services they have used.

To help them do this, the Care Quality Commission organises surveys of patients. You can find out more about the surveys at [www.nhssurveys.org](http://www.nhssurveys.org)

The Care Quality Commission uses the results of each survey to tell the public how well health services in their area are performing. You can find out how your local services are doing at [www.cqc.org.uk](http://www.cqc.org.uk)

Figure 1: template consultation response

<b>Title of consultation:</b>
<b>A response by</b> [your name/name of your organisation]
<b>Date:</b>
<b>About us</b>  [If you are responding on behalf of an organisation, use this space to explain: <ul style="list-style-type: none"><li>&gt; when your organisation was set up</li><li>&gt; why your organisation was set up</li><li>&gt; how many members are in your organisation</li><li>&gt; what your organisation does</li></ul> If you are responding as an individual you do not need to include this section, but it is still a good idea to explain why you are responding. For example, you could say that you are a person with autism or the parent/carer of somebody with autism.]
<b>What is an autism spectrum disorder?</b>  [Use this space to explain what autism is, as not all officials have a good understanding of the condition. If you need help writing an explanation of what autism is, there is a definition on page 55. It is also a good idea to explain why the consultation is relevant for people with autism. For example, if you were responding to a consultation on local transport schemes, you could explain that the sensory difficulties that many people with autism experience can make it hard to use noisy, overcrowded public transport and how late-running transport can be distressing for people with autism.]
<b>Issues to raise</b>  [Write a separate heading for each issue and try to sum up your concern in the first sentence before going into more detail. Put the issue that is most important to you first and try to include real-life examples to illustrate your points. Some local groups have carried out a survey of their members on a particular issue to provide additional evidence to support their comments.  Sometimes consultations include specific questions. You can use these as your headings, but if you want to make a relevant point that does not fall within the scope of the questions, you can still do so.]
<b>Contact details</b>  [Include your name and email or postal address.]
<b>Do you want your response to be kept confidential?</b>  [The consulting department may publish your views as part of the results of the consultation. If you do not want them to do this, state clearly that you would like your response to be kept confidential.]



Even if you don't want to join a group that meets regularly, you can still have your say on particular issues at meetings or through consultations.

### Overview and Scrutiny Committees

In **England and Wales**, Overview and Scrutiny Committees are groups of backbench local councillors from all political parties. They meet to develop policy and hold the local authority executive to account. They also have the power to scrutinise the actions of key public service providers, such as the NHS.

Overview and Scrutiny Committees can include local people who are not councillors, but these people cannot vote at meetings. However, just by being part of the committee you can have a real impact in raising awareness of autism.

Meetings of Overview and Scrutiny Committees are held in public, so anyone can attend to observe and ask questions. Local people can also ask for scrutiny of a particular issue or service and offer to give evidence as a witness. You can also ask your councillor to raise an issue on your behalf through a 'councillor call to action'. This means that if a councillor asks an Overview and Scrutiny Committee to look at a

#### Local hero: Russell

An NAS branch officer called Russell has been a member of his local authority's Adult Services and Health Scrutiny Panel for a year. There is also an adult with autism on the panel. Through his membership Russell has been able to arrange a council seminar on autism and has highlighted the lack of provision for those adults with high-functioning autism and Asperger syndrome who don't meet the criteria for learning disability or mental health services. The local authority is now looking at how this gap in services can be closed.

matter which affects people in the area they represent, the committee must discuss the matter at a meeting.

In **Scotland**, each local authority has in place its own form of scrutiny arrangements, so check with the local council what their scrutiny arrangements are.

### Kirklees Metropolitan Council

In 2005, Kirklees Metropolitan Council's Overview and Scrutiny Committee examined support for people with Attention Deficit Hyperactivity Disorder (ADHD) in the local area. The scrutiny was in response to a request by a member of the public who had been diagnosed with ADHD as an adult.

The final report made a number of recommendations about diagnosis of ADHD, support for adults, education, the criminal justice system, housing and public awareness of ADHD. Following the report, there has been a significant investment in the council's services for adults with ADHD.

For more information, visit [www.kirklees.gov.uk/you-kmc/kmc-howcouncilworks/scrutiny/reports/PDFFiles/ADHD.pdf](http://www.kirklees.gov.uk/you-kmc/kmc-howcouncilworks/scrutiny/reports/PDFFiles/ADHD.pdf)

### Patient Advice and Liaison Services (PALS)

You can give feedback about your local health services to the Patient Advice and Liaison Services (PALS). There is a PALS team for every NHS hospital, primary care trust and mental health trust in **England**.

PALS act on behalf of their service users when handling patient and family concerns. They liaise with staff, managers and other relevant organisations to solve individual problems and to help bring about changes to the way that services are delivered. They also monitor trends and gaps in services, so if you feel that services for people with autism are lacking in your area, you may be able to raise this with your PALS so they can look into it and share your concerns with the appropriate people.

You can find contact details for your PALS at your local clinic, GP surgery, health centre or hospital. Alternatively you can call NHS Direct on 0845 46 47 or visit the NHS website ([www.nhs.uk](http://www.nhs.uk)).

### Key points

- If you don't want to join a group that meets regularly, there are still ways to give your opinion about a particular topic.
- Public authorities often hold consultations about changes to services, to which anyone can give their opinion.
- You can get an issue raised through your council's Overview and Scrutiny Committee.

## Join a local forum or autism-specific group

**Some local authorities have set up local forums and groups specifically to discuss issues related to autism. This section provides some examples of autism-specific groups, as well as information about how to campaign for one to be set up in your area.**

### Local forums

As well as statutory bodies, such as Local Involvement Networks and Learning Disability Partnership Boards, there are also forums in many local authorities that allow people who are affected by a particular issue or condition to make their voice heard. These may be organised by the local authority or may be run by separate organisations which act as advocacy groups for local people. NAS branches are an example of the latter type of group, although their level of engagement with the local authority may vary from area to area.

Local forums tend to have different names and different ways of working, depending on where they are based, but names may include carer's forums, SEN forums, disability forums, older people's forums or youth forums. Your local council should be able to provide you with more information about these types of group.

"I sit on a Reading Group [which] looks at council documents to improve the way they are written... I contribute expertise on disability access, especially alternative formats."

*Adult with autism*

Often, change is achieved by several groups working together to be a stronger voice. Sometimes they will work together as part of one larger organisation, so if you are already part of a local support group, you could see if there are other organisations that you can work alongside or become part of in order to share the workload and strengthen your voice.

There are a number of independent groups that can help people with autism and their families to have a say in how local services are run; for example, NAS branches. You can find details of your nearest NAS branch and other local support groups on our Autism Services Directory at [www.autismdirectory.org.uk](http://www.autismdirectory.org.uk) or by calling the NAS Autism Helpline on 0845 070 4004.

### Autism-specific groups

The Welsh Assembly Government's ASD Strategic Action Plan requires all local authorities in **Wales** to set up a multi-agency ASD coordinating group, including people affected by autism, to lead planning and development and act as a driving force for change in their area. To find out more about your local coordinating group and how you can get involved,

### Gloucestershire ASD Partnership Board

In Gloucestershire an ASD Partnership Board has been established, consisting of local authority and primary care trust staff, people on the spectrum and their parents and carers. Representatives from education and employment services also sit on the board and it is envisaged that its membership will extend to include other services, such as housing, in the future.

The board aims to tackle a number of issues affecting people with autism and their families, including a lack of knowledge about what services are available locally, limited awareness of and training in autism for professionals and the fact that people with autism are passed from one service to another, receiving no proper support from any team. An Autism Resource Centre has also been set up to begin to address these issues and to implement measures identified by the Partnership Board.

### Autism Services Development Groups (ASDGs)

In most local authorities in the North West of England, ASDGs have been set up which are attended by multi-agency professionals, people with an ASD and parents and carers. ASDGs aim to improve local services and make them easier to access for all people with an ASD and their families.

Parent and carer representatives are generally drawn from support groups so that they are able to discuss issues and concerns facing a large number of parents. Although ongoing work is needed to involve people with autism in the groups more successfully, ASDG chairpersons are generally very positive about parental involvement in their group, with some saying that parents kept the group focused and motivated and are seen as partners<sup>8</sup>.

contact the NAS Cymru regional team on 02920 629 310 or email [wales@nas.org.uk](mailto:wales@nas.org.uk)

In **Northern Ireland**, under the new ASD Strategic Action Plan, a Regional ASD Network Group has been established. This group is to include statutory bodies, representatives from the voluntary and community sector, people with autism and their parents and carers. The group will examine the commissioning, delivery and redesign of services in order to improve the way

they support people with autism and their families and carers. For more information, contact the NAS Northern Ireland office on 0289 0236 235 or email [campaignni@nas.org.uk](mailto:campaignni@nas.org.uk)

At the time of writing, no formal requirement to set up an autism-specific group exists for local authorities or health agencies in England or Scotland. Even so, some local authorities and health agencies in these nations have set up specific groups to look at the

needs of people with autism in their area. **In England**, the Department of Health's Adult Autism Strategy, due for publication in 2010, is likely to set out a framework for how local agencies should involve people affected by autism in planning services.

Autism-specific groups can take various forms depending on the local area. For example, a specialist multi-agency autism group may have been established or there might be an autism sub-group of your Learning Disability Partnership Board.

Generally, these groups will include representatives from health and social services as well as service users themselves. Other relevant services, such as employment, education and housing, people working in the voluntary and community sector or private service providers, may also be represented. It is good practice for an official to attend who has the power to make decisions (ie someone with commissioning responsibilities).

Many autism-specific, multi-agency groups have come into being thanks to campaigning by parents, carers and people with autism. For example, one of the ASDGs in North West England (see page 27) was established after parents and carers said that there was a need to look at the issues affecting local people with an ASD.

So if your local authority does not have an autism-specific group, and there are not alternative forums which allow you to meaningfully participate in the development of services for people with autism and their families, you may want to request that one be established.

Your request will carry more weight if you can team up to campaign with other local people who are affected by autism. The National Autistic Society can put you in touch with your local NAS branch or other

groups in your area who you may be able to work in partnership with. We can also give you advice about campaigning. You can find out more in our Campaigns Toolkit, which is available online at [www.autism.org.uk/toolkit](http://www.autism.org.uk/toolkit) or by calling 020 7923 5799 or emailing [campaign@nas.org.uk](mailto:campaign@nas.org.uk)

### Key points

- › In Wales and Northern Ireland, public authorities have to set up forums for consulting people affected by autism. English and Scottish local authorities do not have to do this, but many do so anyway.
- › Sometimes, independent bodies such as NAS branches act as a forum for telling local authorities the views of people affected by autism.
- › Many autism-specific groups have come into being thanks to campaigning by parents, carers and people with autism.

<sup>8</sup> Hughes, C. (2005). *Implementation of the North West Autism Task Group Report*

# 3

## Make your involvement count

### Getting started

**Before you decide whether or not you want to join a group which meets regularly to plan services and support, you should find out some information about how the group operates.**

Each group is different, so it is important to be sure that the group you choose is the right one for you before you make a commitment. Some questions to ask include:

- > what topics does the group discuss?
- > what decisions and actions can the group take?
- > what will I have to do as a member of the group?
- > who else is on the group?
- > how often does the group meet?
- > how long do meetings last?
- > how much reading will I have to do to prepare for meetings?
- > how long am I expected to be a member of the group for?
- > will my travel expenses be paid?

Remember to find out if you should just talk about your own experiences or whether you are expected to find out what other people with autism think too.

You should also tell the person running the group about any support you might need to take part. For example, you might want to get documents in Easy Read format, or you might want a mentor, parent/carer or personal assistant to come to the meetings with you. **Find out whether the group can provide this support before you agree to join.**

The professionals you work with as a member of the group have a responsibility to make sure that your participation is meaningful and will have a real impact on decision-making. The NAS has produced a set of free resources to help professionals to involve people affected by autism in their work. If the professionals you are working with don't know about these resources, you could suggest that they order a copy on 020 7923 5799 or email [campaign@nas.org.uk](mailto:campaign@nas.org.uk) – or you could order a copy to give them yourself.

The charity 'Contact a Family' also has a useful guide for professionals about the key principles of participation<sup>9</sup>, while the South West Regional Partnership has produced regional standards for the participation of children and young people with additional special needs and their parents in the planning and review of services. This can be viewed online at [www.sw-special.co.uk/documents/parents](http://www.sw-special.co.uk/documents/parents)

These publications set out the key principles that a group, forum or committee should follow to effectively involve people with autism and their families and carers. However, not all groups will be run to this standard. As being part of a decision-

9 CDC & Contact A Family. (2004). *Parent Participation – improving services for disabled children: professional's guide*. London: Contact A Family

## 3 Make your involvement count



*It's important to choose carefully before you decide to join a group or committee to help plan local services.*

making group can take up a lot of your time, it is important to find out as much as you can before you join so that your involvement is worth your while.

*"Talk to anyone who already attends your local group and get copies of the previous notes to see if it's the opportunity you thought it was... Ask for published information about the aims and criteria - anything that will tell you more about what it's all about... go and observe the first meeting."*

*Parent*

To find out exactly what a group does, you should ask to see a document called its 'terms of reference'. The terms of reference for a group will state:

- > what the purpose of the group is
- > who is on the group
- > how often the group meets

- > who does the administration for the group (eg writing minutes and sending out agendas)
- > which topics or issues the group covers
- > what sort of decisions or action the group can take.

Before committing yourself to a group it will also be useful to find out:

- > how many meetings you will be expected to attend
- > how long representatives are generally expected to be part of the group
- > whether you are being invited to attend as an individual or as a representative of other people with autism
- > how long meetings generally last
- > how much reading you will have to do to prepare for meetings
- > whether there are any other expectations of you as a group member (eg whether you have to sit on sub-committees of the group)
- > what the induction process is and whether any training is offered to support your participation
- > whether your travel expenses will be paid, and those of a support worker or carer if you need someone to come with you
- > whether the group's organisers can meet any other access needs you have (eg having documents produced in Easy Read format).

You can learn more about the group by talking to existing members, or by asking to read the minutes of previous meetings.

### Your role

If you are involved in a focus group or committee, or you are responding to a questionnaire, it is most likely that you just need to respond as an individual, but on certain issues local authorities may also need to consult on a wider basis. In this situation you may be expected to represent the views of a range of people on the autism spectrum. For example, you may be asked for your opinion as someone who represents a local parent support group, an NAS branch or an Asperger syndrome support group.

If you are asked to represent a local support group on a committee, you should consult with other members of

the support group and present their views to the committee at the next meeting.

This may not be as easy as giving your own personal view, but by representing the views of a whole group of people with autism, you may be able to raise the profile of that group with local professionals and decision-makers. Being a representative of a larger group also means that other members of that group can help you to be involved in the committee; for example, it will be easier to find someone to cover for you if you can't attend a meeting. You could even ask the person running the committee to come and speak to the group you are representing and encourage more members to engage with the committee's work.

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### Working in partnership in Hertfordshire

In Hertfordshire, the local NAS branch is working with the Carers in Hertfordshire support group to carry out an investigation into local services for people with Asperger syndrome and high-functioning autism and their families.

The aim of the project is to "produce a shared vision for the delivery of future services for Asperger syndrome and high-functioning autism in Hertfordshire, containing all voices connected with it". The steering group for the project brings together parents and carers, service managers and other professionals.

The project uses the Imagine process, whereby everyone who is touched by autism is encouraged to tell their story, whether they are service managers, commissioners, county councillors, teachers, nursery nurses, GPs, clinicians, social workers or, most importantly, people with autism and their carers. Participants are encouraged not to focus on past problems but to look forward and talk about what the solutions might be.

Working in partnership with Carers in Hertfordshire and local professionals has been the key to building momentum for the project. By adopting a positive approach to each issue, rather than focusing on what might have gone wrong in the past, the project has been able to engage all stakeholders.

The project is now developing an action plan to present to commissioners and councillors.

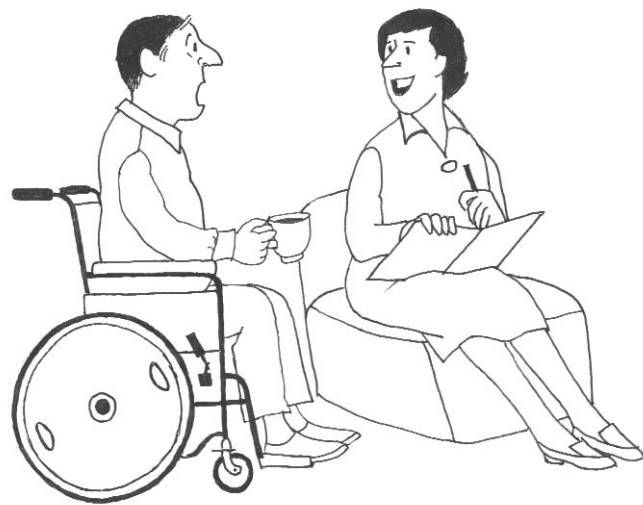
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## 3 Make your involvement count

In order to participate constructively, you will sometimes need to put aside your own feelings and personal experiences in order to work together with professionals. This can be very difficult to do, but by doing so you will forge a much more constructive relationship with professionals, and may even meet someone who can help you with problems concerning your own needs at another time.

"Many of us have had bad personal experiences dealing with professionals, but it is important not to attend meetings and see the professionals there as "the enemy". We achieve more by having a constructive relationship. Many professionals have a poor view of parents because they only meet parents who are angry about bad or inadequate provision... Attending meetings that aren't about our own child are an opportunity to show that we are not always difficult and are prepared to listen to the professionals' point of view. Hopefully this should make them more inclined to listen to us too."

Parent



You may have to represent the views of other service users as well as your own, so it's important to find out what other people think.

Sometimes, parents or people with autism might have different personal views about a particular issue. Whilst it might sometimes be useful to let the authorities see that there is more than one point of view within the autism community, often it can be unhelpful and can give the authority a reason not to do anything at all.

Therefore, it's a good idea to speak to other representatives of the autism community prior to the meeting with professionals and, where possible, try to come to an agreement amongst yourselves about the issue to be discussed. At the very least you should agree to put across opposing views calmly, without arguing over the issue at the local authority meeting.

### Key points

- You should find out as much information as possible about a group before you decide to join it.
- Ask to see the group's 'terms of reference', which will tell you what the group discusses, who is on the group, and how often it meets.
- Find out what your role would be as a member of the group. You may be expected to represent the views of other people affected by autism as well as your own.

## Going to meetings: how to prepare and what to expect

**We have already talked about the different types of group or committee that you can get involved in by attending one-off or regular meetings. Although each group is different, there are some general rules which apply to nearly all of them.**

**If you decide you would like to attend a formal meeting, or a series of meetings, this section will help you to know what to expect.**

### Before the meeting

Each group or committee will hold its meetings in a slightly different way, so it may be helpful to meet with the chairperson before the meeting to find out what to expect. This would also be a chance to tell him or her about any adjustments you might need. For example, you might want a mentor to help you, especially if you are not used to attending meetings.

Some people with autism may find certain meeting venues inaccessible. If the venue is brightly-lit or noisy, it may result in sensory overload. You should tell the chairperson if there are adjustments that he or she can make to the physical environment to make it more accessible, such as using lamps instead of overhead lights.

"There is usually a lack of understanding of the needs of the people with autism they are seeking to assist... If they knew that we're going to find echoing spaces and background noise very difficult this would help us a little more. Has the venue been 'test-driven' for background noise or lighting hazards?"

Adult with autism

Ask for clear directions and a map to the place where the meeting is being held in order to avoid confusion. Check the time and place of the meeting before setting off. Make sure that you take notepaper, a laptop or another preferred method of personal note-taking with you.

If you can't go to the meeting, you must tell the chairperson or secretary as soon as possible. You can do this by phone, email or in writing. Make sure you have the chairperson's contact details in case you need them.

If the timing of meetings makes it difficult for you to attend, you could ask the chairperson if the time of the meeting can be rearranged. The chairperson should make sure that the meeting takes place at a time when as many people as possible can attend.

After you have been to one or two meetings of a group it may be helpful for you to meet with the chairperson again. You could talk about how you are finding the meetings so far, and if there is anything more that the chairperson can do to support you.

## 3 Make your involvement count

### Paperwork

For most meetings there will be an agenda, and possibly other documents, that you should read beforehand.

Normally you will receive any paperwork that you need to read before the meeting happens. It really helps if you have an email address, as local authorities sometimes prefer to send out paperwork electronically. If you are happy to receive the paperwork by email, make sure that the person responsible for sending it has your correct email address. If you would prefer to receive the paperwork by post, make sure that the person responsible has your postal address.

Usually, the paperwork for meetings includes:

- > the agenda
- > additional papers to be discussed
- > the minutes of the previous meeting.

### The Agenda

An agenda is a list of the topics that will be discussed during the meeting. When you join the group or committee it is a good idea to ask how you can get a topic onto the agenda. Then you can make sure that any topics you want the group to discuss are sent to the correct person in time to be put on the agenda.

If you are a member of a support group for people with autism and their families, such as an NAS branch, it would be a good idea to ask other members of the support group what topics they think you should put on the agenda. You could send an email to members, or write something in the support group's newsletter to let the support group know what happens at the meetings.

Most agendas list a topic called 'Any Other Business' or 'AOB'. This is a chance for the people at the meeting to talk about something that isn't on the agenda. However, you should only do this if what you want to talk about is relevant to the work of the group and there is a good reason why you can't wait to put it on the agenda for the next meeting.

When you are reading the agenda, it is a good idea to make a note of any points you want to raise about each topic. This will help you to remember what you want to say when you are in the meeting.

### Additional papers to be discussed

Additional papers give you background information about the topics on the agenda. The information will help you to form opinions and make decisions if you need to.

### The minutes

The minutes are a record of what happened at the previous meeting. There will be an assigned note-taker or clerk at each meeting who is responsible for writing down what is said and producing the minutes after the meeting.

Don't be afraid to challenge inaccurate minutes. If you think that they aren't an accurate record of what was discussed, you can ask for mistakes to be corrected at the next meeting. Usually one of the first points on the agenda will be to approve the minutes of the previous meeting. This is your chance to say if there is anything in the minutes that you think is incorrect.

You should always give yourself enough time to read all the paperwork before the meeting. You may want to



*Make sure you read the meeting agenda beforehand so you know what is going to be discussed.*

talk to the chairperson or another member of the committee about the paperwork. If you have a mentor, you may want to discuss the paperwork with them too.

If you want to, you can send questions about topics on the agenda to the chairperson before the meeting so that he or she is aware of the issues you want to raise. This is especially important if you can't go to a meeting, but still want to have your say on an agenda topic.

Make sure that you keep your paperwork in a safe place once you have read it – and don't forget to take the paperwork to the meeting with you.

## 3 Make your involvement count

### In the meeting

There are lots of different types of meetings. Formal meetings often have written rules, but in less formal meetings the rules are not so clear. For many people with autism, this can make informal meetings more challenging, especially if it feels like everyone else knows what they are expected to do.

You may find there is a lot of eye contact during meetings. If you're unsure of where to look in a meeting, it may be helpful to look at what the chairperson is doing. You could also look at your paperwork if you don't know where else to direct your eyes.

Don't let uncertainty put you off going to meetings. It can be helpful to discuss any concerns you have with the chairperson before the meeting so that he or she knows what you may find difficult and the areas where you need help. For example, it might be useful for the group to have flash cards of the rules.

#### Local hero: Charlotte

Charlotte is an adult with autism who is part of The National Autistic Society's consultative group. The group meets three or four times a year to give its views on Government policy issues affecting people with autism.

Charlotte attends the meetings with a support worker. She was nervous about coming to the meeting because she hadn't been to the venue before. So on the day of the meeting they got to the venue early and had a look around before the meeting started. This helped Charlotte to feel more relaxed and she liked the room because there was lots of space.

In the meeting, concepts like social services and the government were explained in very simple language so that everyone could understand. Members of the group used picture symbols to make a poster showing their aspirations for the future.

Charlotte says she likes going to the group's meetings because she enjoys talking about things and meeting new people.

*"I like the card system that is used at Valuing People meetings. Everybody attending has to hold up one of a set of cards which indicates if they want to ask a question, make a comment or ask the speaker to slow down or stop."*

*Parent*

If you have a mentor at the meeting, make sure you are seated in a place where you can easily communicate with him or her.

At your first meeting, ask the chairperson if all the people around the table will introduce themselves and say what their role is. Don't be afraid to ask for further explanation if you don't understand what someone's job title means. Be prepared to introduce yourself as well.

### Keeping to the agenda

As you work through the meeting agenda you should only talk about things related to the agenda topic being discussed. It may be helpful to tick off each topic on your agenda as you go through them. If you are unsure which agenda topic is being discussed, you should ask the chairperson, or your mentor if you have one.

### Knowing when to speak

The chairperson decides who can speak and when. In some committee meetings you are expected to 'speak through the chairperson'. This means that if you want to say something you must tell the chairperson beforehand. Very often, people do this by 'catching the eye of the chairperson'. This means that they get the chairperson's attention by looking at him or her in the eye.

Catching the chairperson's eye may be difficult for some people with autism, so it might be better for everyone at the meeting to use another method, such as putting up their hand. Very often, people at a meeting will raise their hand and look at the chairperson at the same time to see whether he or she has noticed them. Find out before the meeting what you should do if you want to speak. If necessary, pre-arrange a sign with the chairperson so that he or she will know when you want to say something.

It is the job of the chairperson to make sure that everyone has a chance to speak if they want to. There may be unwritten rules about how long each person is allowed to speak. If you find yourself speaking for longer than other people in the meeting, be aware that other people may want you to stop so that somebody else can speak.

It is also the job of the chairperson to make sure that the meeting finishes on time. If anyone talks too much, the chairperson cannot do this. So if the chairperson asks you to finish making your point, you must do so quickly.

You may find it helpful to agree a signal with the chairperson before the meeting that they can use to indicate when you have spoken for too long on one topic. Alternatively, the chairperson could establish rules that make it clear whose turn it is to speak. For example, members of the group could hold an object when it is their turn to speak, so that others know not to interrupt, or they could pass round a hand-held microphone, so that only one person at a time can speak. At large council meetings, there is often a microphone for each person anyway, which has to be turned on before they can speak. Other people should not interrupt that person when his or her microphone is on.

If you do not have anything that you want to say about a particular topic, you do not have to speak. Sometimes attending a meeting can be worthwhile even if you don't speak, so don't be afraid just to listen for your first few meetings until you feel confident enough to contribute.

### Understanding language

*"If whatever they said was broken down into a plain English, easy format then I'd be able to understand what was going on."*

*Adult with autism*

In meetings, people tend to assume that others understand what they are saying. People may use acronyms (when initials are used instead of words) or jargon (words that are technical or unusual), all

## 3 Make your involvement count

of which can be hard to understand. It is important to ask what something means if you don't know. You don't have to do this during the meeting if you don't want to. Just ask the chairperson, or someone you feel comfortable with, during a break or at the end of the meeting.

Don't be intimidated by terminology or jargon that you don't understand. Often it is easy to learn, so don't let jargon put you off making your views heard.

*"I think it is important that as parents we are not afraid to voice our opinions, whether we feel we are talking in the right language or not. After all, we are the ones who are experiencing and living with a child with the condition, and have the emotional involvement... We have life experience, and know what services and help we need more than anyone else."*

*Parent*

### Decision-making

Decisions at meetings are made in three ways.

- 1 If everyone agrees, a decision is made on that basis.
- 2 If not everyone agrees, the issue is discussed and the people who don't agree may eventually decide to accept the view of the majority.
- 3 If not everyone agrees and some people don't accept the view of the majority, the chairperson may decide to have a vote. This can be done by people putting their hand up, or by the chairperson asking each person individually what their decision is. The majority decision will then win the vote.

When a decision is made, you must accept it and move on to the next item on the agenda. However, if you are not sure what has been decided, don't be afraid to ask the chairperson to explain it again. If you feel that you have not been given a chance to share your views, or that a topic has been added to the agenda too late for you to be able to prepare your argument, you should ask the chairperson, before a vote is taken, whether the issue can be revisited at the next meeting.

### Dealing with disagreements

In some meetings you may find that people disagree with you. They may even become upset or angry. This type of behaviour is not unusual in meetings.

If you have strong views on a particular issue, you should express them firmly but politely. Don't raise your voice when you talk and always give other people the chance to share their views, even if you disagree with them. The chairperson should make sure that issues are discussed in a polite and appropriate way.

*"Even people who let you down are trying their best. Everyone wants to feel good about what they do, so putting positives in with negatives when talking about services."*

*Parent*

### At the end of the meeting

When you have finished discussing all the meeting's agenda topics, ask the chairperson to summarise the main conclusions and points for action. You may find that people stay to chat after the meeting has finished, as some people find it a useful time to talk with professionals and other people affected by autism. Don't feel you have to wait for everyone before you can leave: there will often be other people who leave straight after the meeting, especially if they have another appointment to get to.

### What if I don't want to attend meetings?

Some people with autism will be very happy to attend meetings, especially if certain adjustments are made, but for others this form of involvement may not be appropriate. If you don't feel that meetings are the best way for you to become involved, it may be possible for a local authority or group of professionals to involve you in other ways; for example, through emails, online forums or postal surveys.

*"We find it better to communicate by email... but then there were complaints [from other members of the group] that there were too many emails, so that's going to be addressed by having a proper email forum."*

*Adult with autism*

The National Autistic Society's resources about involving people with autism (see page 30) include suggestions for how local authorities can listen to your views without you having to attend a meeting. In England, the Department of Health's advice note, *Services for adults with Autism Spectrum Conditions (ASC)*<sup>10</sup>, also includes suggested ways for local authorities to involve people with autism.

### Key points

- > Before the meeting, you should read the agenda and any other paperwork so you know what will be discussed and can plan any points you wish to raise.
- > You should talk to the chairperson before the meeting if you need any extra support in order to attend and make contributions.
- > Different meetings have different rules which may not be easy to understand. It would be a good idea to discuss these with the chairperson or somebody else from the group before your first meeting.

<sup>10</sup> Department of Health. (2009). *Services for adults with Autism Spectrum Conditions (ASC)*. London: DH

# Making your point at a meeting

**You do not have to say something about every point on the meeting agenda, or even at every meeting you go to, but when you do want to say something, it is sometimes useful to have evidence to support your argument.**

The most important reason for you to be at the meeting is to be able to share your personal experiences with professionals. These experiences are real and can count as evidence in themselves.

However, if you are a member of a local support group (whether you are formally representing them at the meeting or not) it would be a good idea to get additional evidence by talking to other members of the support group before your meeting. This way, you can find out about their experiences and views on the topics you will be discussing.

To help you gather evidence, you could even encourage your support group to conduct a survey of its members. If you do this, you should submit the findings of the survey to the person responsible for organising the paperwork for your meeting. They can then make sure that the other people attending the meeting get to read the survey results before the meeting takes place.

*"Personally speaking, I try to keep up to date with autism issues locally and nationally... having sound knowledge allows me to be an active participant."*

*Parent*

There are a number of government documents which set out what local authorities and health services should be doing to support people with autism and their families. These can be useful in holding professionals to account if they are not providing the services and support that they should be. Some of these documents are highlighted in Appendix B, starting on page 49.

There may also be research carried out by voluntary organisations which can support your point, or examples of good practice in other areas of the country that could be replicated in your region. Much of this information is published on the NAS website ([www.autism.org.uk](http://www.autism.org.uk)). If you are not sure what document you are looking for, you can use the NAS Autism Data service ([www.autism.org.uk/autismdata](http://www.autism.org.uk/autismdata)) to do a literature search based on the topic you wish to discuss. If you don't have internet access, you can call the NAS Information Centre on 0845 070 4004 and ask them to do a literature search for you.

There are also websites and online forums which you can use to get information and advice from other campaigners. A list of these is available at [www.autism.org.uk/localcampaigning](http://www.autism.org.uk/localcampaigning)

### Key points

- > Your experience of living with autism is the most important thing you can bring to a meeting, but you may have even more influence if you can provide evidence to support your opinion.
- > If you are already a member of a local support or social group for people affected by autism, it would be a good idea to ask the opinions of the other group members and present these at your meeting.
- > The NAS website and Information Centre may be able to provide you with information to support what you say in the meeting.



*If you want to raise a topic in the meeting, you need to submit it as an agenda item beforehand.*

# Developing your skills

**To make your participation as effective as possible, you may find it useful to get some training to develop skills such as public speaking, communication and meeting new people. If you would like to get some training, you should ask the chairperson of the group or committee you belong to whether they can provide this or pay for some or all of your training costs.**

There are many rules of behaviour that apply specifically to being in meetings. These are easier for some people to follow than others, and may be particularly difficult for people with autism. The organiser of your meeting should ensure that adjustments are made, if you need them, to help you understand the rules – but you may also find it helpful to do some social skills training. You can find more information about social skills resources and training on the NAS website ([www.autism.org.uk](http://www.autism.org.uk)).



Taking a course to improve your speaking skills will help you to communicate more effectively in meetings.

There are also some specific training programmes available to help you get involved in local government. A good example is *Partners in Policymaking*, a leadership training course for disabled adults and parents of disabled children. The course lasts for two days a month, over eight months, and the assignments between each training session will give you the opportunity to practice various skills. These include: finding information, making contact with policymakers and people who work in services, presenting your views and learning how decisions get made and how to influence them. Graduates stay in touch after the course, providing a strong support network.

For more information on *Partners in Policymaking*, visit [www.partnersinpolicymaking.co.uk](http://www.partnersinpolicymaking.co.uk) or call 0151 287 7977.

The *Together for Disabled Children* project has produced a list of trainers who are experts in training parents in participation, negotiation and assertiveness. This list is available online at [www.togetherfdc.org](http://www.togetherfdc.org)

"I never thought that I'd be good enough for any of this. I am a patient representative for my local mental health team, but so far I have always felt I'm the 'token person with Asperger syndrome'. I look forward to learning more about how I can represent myself and others who also have Asperger syndrome."

Adult with autism

If the chairperson cannot help you with training, you could still take a course in your own time to help you improve your confidence. Your local Community & Voluntary Service (CVS) may run suitable courses and some may be free of charge.

The DirectGov Careers Advice Service also has a central database of courses across the UK. You can contact this service by calling 0800 100 900 or by visiting the website (<http://careersadvice.direct.gov.uk>).

### Key points

- > Training in public speaking, communication skills and meeting new people may help you to be more effective in making your voice heard.
- > The group or committee you join may be able to arrange training for you, but if not, there are other courses you can take by yourself.

# 4 Conclusion and appendices

**The views of people with autism and parents and carers should always be heard whenever local authorities are planning new services. You have personal experience and expertise, which means you can work with local decision-makers to shape services that are appropriate to real needs. You can also maintain a pressure that prevents important issues from dropping off the local authority agenda.**

**People with autism, their families and professionals all benefit from your involvement.**

It isn't always easy to have a real say in the way your local services are run. Getting involved in the planning process requires commitment and a willingness to discuss other people's ideas as well as your own. There are also other challenges to deal with, especially if you aren't familiar with the way meetings and consultations work.

But remember that local services should be there to support your needs - and if they currently don't, that situation won't change unless you and the other people who use those services make your opinions known. You'll be surprised at the difference you can make.

"By sitting on the steering group for the county's adult learning disability register, I helped to ensure that the criteria did not exclude people with Asperger syndrome and were as ASD-friendly as possible."

*Parent*

"[The good thing about being involved is] that the government is taking an interest in autism and it gets us all together... it's good to get autism on a higher profile."

*Adult with autism*

"A parent representative on our Transition Group raised the issue of ID cards for young autistic people... The result was the introduction of voluntary ID cards for all children and young people on our Disabled Children's Register. This scheme arose from the ground up - it wasn't imposed by the authority but requested by parents as a result of an identified need."

*Local Authority Official*

If you have any questions or would like any more information about what you have read in this guide, contact The National Autistic Society Campaigns Team.

**Write to:**  
**The Campaigns Team**  
**The National Autistic Society**  
**393 City Road**  
**London**  
**EC1V 1NG**

**Email: [campaign@nas.org.uk](mailto:campaign@nas.org.uk)**

**Tel: 020 7923 5799**



# Appendix A: The Crown Dependencies (Jersey, Guernsey and the Isle of Man)

Jersey, Guernsey and the Isle of Man each have independent health, education and social care services, run by their governments, and make their own laws in these and most other areas.

Each government has a department with responsibility for health and social care and a department with responsibility for education.

In Jersey there is an 'Autistic Spectrum Partnership Board', which is the responsibility of the 'Joint Secretariat for People with Special Needs and their families' which is in turn responsible for the development and delivery of services for children and adults with an autism spectrum disorder, and their families. Membership of the Board includes people with autism and their parents and carers. The Jersey branch of The National Autistic Society is represented on the Board, which is driven by *Autism Jersey*, a partner organisation.

Use the following contact details to find out how you can get involved in planning services and support in the Crown Dependencies.

### Jersey

#### Health & Social Services Department

Maison Le Pape,  
The Parade, St Helier  
Jersey  
JE2 3PU  
Tel: 01534 442000  
Email: [health@gov.je](mailto:health@gov.je)

#### Department for Education, Sport and Culture

PO Box 142  
Highlands Campus  
Jersey  
JE4 8QJ  
Tel: 01534 445504  
Email: [esc@gov.je](mailto:esc@gov.je)

#### Autism Jersey

AJ's, 4 Edward Place,  
The Parade,  
St Helier,  
Jersey,  
JE2 7NT  
Tel: 01534 871888  
Email: [admin@autismjersey.org](mailto:admin@autismjersey.org)

### Guernsey

#### Health and Social Services Department

Le Vauquiedor  
St Martin's  
Guernsey GY4 6UU  
Tel: 01481 725 241

#### Education Department

PO Box 32  
Grange Road  
St Peter Port  
Guernsey GY1 3AU  
Tel: 01481 710 821  
Email: [office@education.gov.gg](mailto:office@education.gov.gg)

### Isle of Man

#### Department of Health and Social Security

Social Services  
Hillary House  
Prospect Hill  
Douglas IM1 1EQ  
Tel: 01624 686179  
Email: [customer.services@ceo.dhss.gov.im](mailto:customer.services@ceo.dhss.gov.im)

#### Department of Education

St. George's Court,  
Upper Church Street,  
Douglas IM1 2SG  
Tel: 01624 685820  
Email: [admin@doe.gov.im](mailto:admin@doe.gov.im)

#### Health Services

Crookall House  
Demesne Road  
Douglas IM1 3QA  
Tel: 01624 642608  
Email: [customer.services@ceo.dhss.gov.im](mailto:customer.services@ceo.dhss.gov.im)

# Appendix B: Useful documents

### In England

All the following publications are available to download from the URLs provided but some will also be available in printed format from the relevant Government department.

The National Autistic Society's Information Centre can also help you to obtain copies of useful documents. Call 0845 070 4004 or email [nas@nas.org.uk](mailto:nas@nas.org.uk)

#### **Better Services for People with an Autistic Spectrum Disorder**<sup>11</sup>

This document, produced by the Department of Health, clarifies the nature and intent of existing government policy relating to adults with autism spectrum disorders. It is written to encourage health and social care professionals to develop local agendas for action.

#### **Services for adults with autistic spectrum conditions (ASCs)**<sup>12</sup>

This good practice advice note, produced by the Department of Health, is aimed at commissioners in Primary Care Trusts and local authorities who have responsibility for commissioning services for adults with autism spectrum disorders. It aims to bring existing information and good practice to the attention of commissioners.

This advice note also provides an update on the policies outlined in *Better Services for People with an Autistic Spectrum Disorder*. At the time of writing, further commissioning guidance is being developed along with a national Adult Autism Strategy, due for publication in December 2010, which will outline what local authorities and health agencies should be doing to support adults with autism spectrum disorders.

#### **Supporting people with autism through adulthood**<sup>13</sup>

This report by the National Audit Office examines service provision for adults with autism in England and makes a number of recommendations about improving our knowledge of the number of adults on the spectrum, increasing provision for high-functioning ASD, and offering more training and awareness for service providers. The report suggests that implementing these recommendations would not only improve outcomes for adults with autism, but would also result in public expenditure savings in the longer term.

#### **Aiming High for Disabled Children**<sup>14</sup>

*Aiming High for Disabled Children* was a joint review carried out in 2007 by HM Treasury and the Department for Education and Skills (now the Department for Children, Schools and Families) aimed at improving services for disabled children in England.

Following the review, a package of extra resources to allow local authorities to improve services for disabled

children and their families was announced. This was backed by system reforms which mean that local authorities are now assessed on the services that they provide for disabled children.

The review included a programme of grants and support to help groups develop parent participation activities in each local authority area across England (see page 18).

#### **The Children's National Service Framework (NSF)**<sup>15</sup>

The NSF sets standards for health and social services for children, young people and pregnant women. It aims to ensure fair, high-quality and integrated health and social care from pregnancy and birth right through to adulthood.

The NSF includes a standard for disabled children and sets out what care services a child with autism should expect to receive at each stage of their development, from initial diagnosis through to their transition to adulthood.

#### **Valuing People**<sup>16</sup>

*Valuing People* is the Government's plan for improving the lives of people with learning disabilities and their families and carers. It includes a section on services for people with autism and a learning disability.

The guidance in *Valuing People* says that "adults with Asperger syndrome or higher-functioning autism are not precluded from using learning disability services, where appropriate, and may require an assessment of their social functioning and communications skills in order to establish their level of need."<sup>17</sup>

#### **Code of Practice on Consultation**<sup>18</sup>

This document sets out a code of practice that all UK government departments must follow when doing public consultations. Local authorities and other public bodies are also encouraged to follow this code, although they are not bound to do so. The code does not apply to devolved administrations, although they can adopt it if they wish.

There are six main points to the code.

1. Consult widely throughout the policy development process, allowing a minimum of 12 weeks for at least one written consultation.
2. Be clear about what your proposals are, who may be affected, what questions are being asked and the timescale for responses.
3. Ensure that your consultation is clear, concise and widely accessible.
4. Give feedback regarding the responses received and how the consultation process influenced the policy.
5. Monitor your department's effectiveness at consultation, including through the use of a designated consultation co-ordinator.
6. Ensure your consultation follows better regulation best practice, including carrying out a Regulatory Impact Assessment if appropriate.

#### **National Autism Plan for Children (NAPC)**<sup>19</sup>

These guidelines address the identification, assessment and diagnosis of pre-school and primary

11 [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_065242](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_065242)

12 [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_097418](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_097418)

13 [www.nao.org.uk/publications/0809/autism.aspx](http://www.nao.org.uk/publications/0809/autism.aspx)

14 [www.everychildmatters.gov.uk/ahdc](http://www.everychildmatters.gov.uk/ahdc)

15 [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4089118](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4089118)

16 <http://valuingpeople.gov.uk>

17 Department of Health. (2001). *Valuing people: a new strategy for learning disability for the 21st century: implementation*. London: DH

18 [www.berr.gov.uk/files/file44364.pdf](http://www.berr.gov.uk/files/file44364.pdf)

19 [www.autism.org.uk/napc](http://www.autism.org.uk/napc)



effective services and world class care. It also places an emphasis on user involvement, stating that “we can only achieve a wholesale transformation of our services if those who use services and deliver them at the sharp end are put in the driving seat of redesign.”

### In Scotland

Hard copies of all Scottish Government publications can be ordered through Blackwell’s Bookshop.

Address: 53 South Bridge, Edinburgh EH1 1YS

Tel: 0131 622 8258

Fax: 0131 557 8149

Email: [business.Edinburgh@blackwell.co.uk](mailto:business.Edinburgh@blackwell.co.uk)

#### **Commissioning Services for People on the Autism Spectrum**<sup>30</sup>

This guidance is for commissioning health and social care services for people with autism spectrum disorders in Scotland. It states that local authorities and health agencies should work in partnership to deliver appropriate services for people with autism.

The guidance also stresses the importance of local record-keeping, assessment and diagnosis, as well as training in autism for staff, and states that every local partnership should appoint an ASD Coordinator. Commissioners should also “ensure the involvement of people with ASD in planning services.”

#### **The Same As You?**<sup>31</sup>

In 2000, the Scottish Government carried out a review of services for people with learning disabilities. The

final report produced 29 recommendations about how local authorities and health agencies should make provision for adults with learning disabilities. For the purposes of the review, the term ‘learning disability’ included autism spectrum disorders.

#### **Autistic Spectrum Disorders Needs Assessment Report**<sup>32</sup>

In 2001, the Scottish Executive commissioned the Public Health Institute of Scotland – now NHS Health Scotland – to carry out an Autism Spectrum Disorders Needs Assessment. The report recognised that services for people with ASD needed to be improved and it made a number of recommendations for providing quicker access to assessment and diagnosis and improving post-diagnostic services.

#### **Improving the Wellbeing of people with learning disability and/or autistic spectrum disorder**<sup>33</sup>

This guidance tells Community Health Partnerships how best to plan and deliver services for people with autism. This includes involving people with autism and their families and carers in planning services through Public Partnership Forums.

The guidance also states that NHS Boards should establish wider Learning Disability/ASD Partnerships which bring together public health services, GPs, public health practitioners, child health and learning disability representatives, acute services, local authorities, the voluntary sector, plus service users and their families and carers. These partnerships should be responsible for strategic planning across the NHS Board, identifying priorities and providing advice on the allocation of resources for learning disability and ASD services.

#### **Supporting Children’s Learning – Statutory Guidance relating to the Education (Additional Support for Learning) (Scotland) Act 2004**<sup>34</sup>

The Education (Additional Support for Learning) (Scotland) Act 2004 introduced a new framework for providing for children and young people who require additional help with their learning. The Act aims to ensure that all children and young people are provided with the necessary support to help them achieve their full potential. It also promotes collaborative working among all those supporting children and young people.

This statutory guidance explains what education authorities and other agencies must do to support children’s and young people’s learning

#### **Education for pupils with autism spectrum disorder**<sup>35</sup>

This report by HM Inspectorate of Education (HMIE) looked at educational provision for children with autism across Scotland. It identifies good practice and makes recommendations for improvement, notably in the areas of teacher training, individualised educational programmes and strategic planning of provision for pupils with additional support needs.

### In Northern Ireland

#### **ASD Strategic Action Plan**

The Department of Health Social Services and Public Safety published its ASD Strategic Action Plan in 2009. The Action Plan outlines the development of

ASD services in Northern Ireland until 2011. For further information, contact the NAS Northern Ireland office on 0289 0236 235, email [campaignni@nas.org.uk](mailto:campaignni@nas.org.uk) or visit the Department of Health, Social Services and Public Safety website at [www.dhsspni.gov.uk](http://www.dhsspni.gov.uk)

#### **Report of the Task group on Autism**

The task group report, dating from 2002, outlines the challenges faced by education services and highlights a number of areas where action needs to be taken.<sup>36</sup>

#### **Special Educational needs: a guide for parents**<sup>37</sup>

This is a guide designed for parents to help them understand:

- what special educational needs are
- what schools, Boards and others can do to help
- what their rights are
- how they can play a full part in their child’s education.

#### **Evaluating provision for Autistic Spectrum Disorders in Schools**<sup>38</sup>

This 2005 document was compiled in response to the report published by the Task Group on Autism, which highlighted the pressing need for teachers to have increased support to assist them in working with children and young people on the autism spectrum.

30 [www.scotland.gov.uk/Publications/2008/03/27085247/0](http://www.scotland.gov.uk/Publications/2008/03/27085247/0)

31 [www.scotland.gov.uk/Topics/Health/care/adult-care-and-support/learning-disability/Resources/sameasyou](http://www.scotland.gov.uk/Topics/Health/care/adult-care-and-support/learning-disability/Resources/sameasyou)

32 [www.scotland.gov.uk/Publications/2006/02/28094616/0](http://www.scotland.gov.uk/Publications/2006/02/28094616/0)

33 [www.sehd.scot.nhs.uk/chp/CHPadvicefinalLDAS201205.pdf](http://www.sehd.scot.nhs.uk/chp/CHPadvicefinalLDAS201205.pdf)

34 [www.scotland.gov.uk/Publications/2005/08/15105817/58187](http://www.scotland.gov.uk/Publications/2005/08/15105817/58187)

35 [www.hmie.gov.uk/documents/publication/epasd.pdf](http://www.hmie.gov.uk/documents/publication/epasd.pdf)

36 [http://www.deni.gov.uk/index/7-special\\_educational\\_needs\\_pg/special\\_educational\\_needs\\_-\\_reports\\_and\\_publications-newpage-2/special\\_educational\\_needs\\_-\\_reports\\_and\\_publications-newpage-4.htm](http://www.deni.gov.uk/index/7-special_educational_needs_pg/special_educational_needs_-_reports_and_publications-newpage-2/special_educational_needs_-_reports_and_publications-newpage-4.htm)

37 [http://www.deni.gov.uk/index/7-special\\_educational\\_needs\\_pg/7-special\\_needs-a\\_guide\\_for\\_parents\\_pg/7-special\\_educational\\_needs\\_-\\_a\\_guide\\_for\\_parents-content\\_s\\_pg.htm](http://www.deni.gov.uk/index/7-special_educational_needs_pg/7-special_needs-a_guide_for_parents_pg/7-special_educational_needs_-_a_guide_for_parents-content_s_pg.htm)

38 [http://www.deni.gov.uk/index/7-special\\_educational\\_needs\\_pg/special\\_educational\\_needs-newpage-2.htm](http://www.deni.gov.uk/index/7-special_educational_needs_pg/special_educational_needs-newpage-2.htm)

# Appendix C: What is autism?

When responding to consultations or meeting with officials, you may need to give an explanation of what autism is. If so, the following definition will be useful. The National Autistic Society has produced a leaflet called *What is Autism?* which you can order from our Information Centre on 0845 070 4004 or [nas@nas.org.uk](mailto:nas@nas.org.uk)

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share three main areas of difficulty, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support. The three main areas of difficulty (sometimes known as the 'triad of impairments') are:

### > **difficulty with social interaction**

This includes recognising and understanding other people's feelings and managing their own. Not understanding how to interact with other people can make it hard to form friendships.

### > **difficulty with social communication**

This includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice.

### > **difficulty with social imagination**

This includes the ability to understand and predict other people's intentions and behaviour and to imagine situations outside of their own routine. This can be accompanied by a narrow repetitive range of activities.

People with autism may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language. People with Asperger syndrome do not usually have learning disabilities but may have specific learning difficulties, including dyslexia.

It is thought that autism affects 1 person in every 100 – that's over half a million people in the UK. If you include their families, autism touches the lives of over two million people in this country every day. The average local authority of 250,000 people is likely to have around 2,500 people with autism within its borders.



Lots of people with autism don't get the support they need. If you have autism or you are the parent or carer of a person with autism, you can help to change this.

Your local authority and health service have a legal duty to involve people with autism and their families when planning local support and services. This guide explains the many ways in which you can have your say – you'll be surprised at the difference you can make.

## **The National Autistic Society is the UK's leading charity for people affected by autism.**

Over 500,000 people in the UK have autism. Together with their families they make up over two million people whose lives are touched by autism every single day.

Despite this, autism is still relatively unknown and misunderstood. Which means that many of these two million people get nothing like the level of help, support and understanding they need.

***Together, we are going to change this.***



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