

# Campaigning

with The National Autistic Society



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# 1. Introduction to campaigning

## **Why campaign?**

Campaigning is critical if people with autism<sup>1</sup> and their families are to get a better deal from society, and from the services that exist to support them.

People affected by autism themselves or as family members, carers or friends are the greatest campaigning resource at local level. You know what is already available, what is working and what still needs to be done. You are also the people that key decision makers, and particularly elected representatives, are ultimately answerable to.

The National Autistic Society (NAS) works at a national level to champion the rights and interests of people with autism and their families and ensure that policy and legislation reflect their needs. But national policies and laws are interpreted and delivered locally so your contribution is vital to achieve positive changes.

Campaigning can bring about changes on almost anything. You could campaign:

- To improve a service
- To stop a service closing
- For new services to be developed
- For better training for professionals like teachers or police officers
- For something that has arisen as a need only in your area
- For something that has been identified as a priority all over the country – taking part in orchestrated activity, so local people and groups everywhere campaign for the same thing at the same time.

I hope that this toolkit will provide you with the practical information and support you need to campaign. My thanks go to everyone who has contributed to it.

Good luck with your campaigning and please let us know how you get on!  
Email [campaign@nas.org.uk](mailto:campaign@nas.org.uk) or write to Campaign Team, The National Autistic Society, 393 City Road, London, EC1V 1NG.

Clare Corbett  
NAS Campaigns Manager

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<sup>1</sup> The term 'autism' is used throughout this document to refer to all conditions on the autistic spectrum, including Asperger syndrome.

## 2. Building a successful campaign

Some campaigns take place over many years, while others can be thrown together and carried out in a matter of days. The National Autistic Society's campaign building blocks will help you to build an effective and successful campaign.



### **Aims**

**Decide what you want to achieve.**

- Make sure your aims are reasonable, clear and that everyone involved in the campaign agrees with them.
- Write them down so that you can refer back to them at a later stage if you feel you are losing focus.
- Be aspirational! Your campaign will have greater credibility if you can present imaginative solutions to the problems you are outlining.
- Think about what you want in the long run. For example, if a respite centre is to be closed down, think about the overall picture before starting a campaign to keep it open. Is the centre what you really want, or would other options be better, such as individual support to the families involved or better access to direct payments? If you decide on a better option, use the opportunity to campaign for it.

## **Audience**

### **Target the right people.**

There are two types of people you need to influence:

- Decision makers
- People who can influence decision makers, usually the public, via the media.

### **Key people and groups to consider include:**

- Your local council and health agencies
- Your MP
- Your Member of the Scottish Parliament (MSP)
- Your Assembly Member (AM) in Wales
- Interested professionals, such as head teachers, speech and language therapists, and social workers
- The local media. Nearly all decision makers are sensitive to their media image. Refer to page 17 for tips on working with the media.

## **Evidence**

### **Make your case effectively and get your facts right!**

#### **Types of evidence to prepare include:**

- Statistics showing the numbers affected
- Personal testimonials of people who have been affected
- Research from other sources showing how what you are proposing has worked elsewhere
- Information showing the financial implications, including the cost of your solutions, and savings that could be made by the local agencies if they are put in place
- Supporting information from professionals, such as social workers, speech and language therapists or GPs. Make sure you get their consent before using these testimonies.

The National Autistic Society may have information that can support your case. Visit [www.autism.org.uk](http://www.autism.org.uk)

### **Devising your key messages**

Develop a maximum of three or four key messages for your campaign. This will help you maintain focus when you talk to the media or speak at a meeting and ensure that your approach is consistent when different people speak. Your key messages should be short and you must be able to back them up with evidence.

If you are campaigning for short breaks provision for people with autism, your key messages might be:

- Short breaks are desperately needed by people with autism and their families, because of the nature of the condition (provide case studies to demonstrate this).
- There is no effective short break provision locally because the services that do exist cannot cater for people with autism, whose needs are often very specific (be ready to give examples).
- Providing short breaks would cost less than the long term costs incurred when a person or family needs more intensive, long term or emergency intervention that may otherwise be avoided (provide reasonable, researched figures to back this up).

### **Adapt your case and materials for your audience**

- Find out who you need to present the information to and write to them directly.
- State your case in short, clear points. You will be much more likely to engage the person if you do not swamp them with information and detail at the start.
- If you need to give a lot of information, include this in a back-up document, such as a short report.
- Find ways of explaining complex issues, particularly when you are targeting audiences who do not have a detailed knowledge of autism. Give examples to help people understand the condition.
- Make it absolutely clear what you are asking the person to do.
- Get information to people in good time so that they can read it and get back to you for further information if they need to.
- Keep copies of all the information you send, noting when you sent it, who you sent it to, the responses you receive and when and how you follow things up.

## **Partnership working**

**Work together to keep up the pressure.**

However strongly you feel about an issue, campaigning can be hard work! A lot of people must be prepared to take action, such as writing letters and attending meetings and you will need at least one person who is willing and able to commit the time necessary to coordinate activities.

### **Include a wide range of people**

- The more people you can engage to speak ‘with one voice’ in support of your campaign, the greater your credibility with decision makers.
- Working as a group gives you the opportunity to share tasks, pool information, talk things over and get a better overview of what is needed locally. It can also help to dispel the concerns some people may have about being seen as a ‘troublemaker’ or jeopardising services they already receive.
- Involving people with autism is likely to add particular weight to your campaign.

### **Working with other groups**

- If you are campaigning for better local specialist education provision for children with autism, it will be much more powerful if all relevant local groups are asking for the same thing at the same time.
- Consider non autism-specific organisations. For example, if you are campaigning to stop a day service being closed, you may want to work with other local organisations which are involved, such as Mencap or Scope. You do not have to agree on every detail to work well together, but you must agree on the key aims and objectives.
- If you do decide to work with other groups, remember that, although some of the effort can be shared, quite a lot of work is needed to keep a coalition working together, and you will need at least one person to coordinate activities.

*“We got started with more active lobbying because whenever branch members got together we had the same anxious conversations about educational provision in our LEA area. One of our members gathered people’s views and some individual case studies, and together we wrote a report which we gave to the LEA. Since then we have adapted the original report to use in other ways, such as submitting an amended version as evidence to the parliamentary enquiry into special educational needs. With hindsight it would have been even better if we had done a formal questionnaire to provide lots of local statistical evidence to back up the views expressed in the report.”*

NAS Branch member

## **Timing**

### **Campaign at the right time.**

- Policy and decision makers have to make some decisions at particular times, and may not be able to consider changes at other times.
- For example, budget reviews take place at specific points in the year and once the budget is set it is difficult for decision makers to divert funds elsewhere.
- Find out when the key activities you need to influence will take place and work around them. Make sure you get information to your target audiences, your allies and the media with plenty of time for them to act.
- Wherever possible, try to avoid campaigning at 'downtimes', like the summer holidays, when people will be away or busy.

## **Evaluation**

### **Measure your impact.**

During and following a campaign, you should always make an effort to evaluate your success in order to improve your campaigning in the future.

Some questions to consider are:

- Did you ask for the right things? Were you too ambitious, or could you have achieved even more?
- What has the response been from the agency/ies you have been lobbying? Was it positive or dismissive? Why?
- What worked well and what went wrong? Is it possible to say why?
- How many people have taken action on your behalf? Was this enough? What prompted people to get involved? Could you have got more people on board?
- How did the media respond and was this helpful?

If possible, talk to people who work for the agencies you have been lobbying to find out how and why they and their agency responded in the way they did.

## **Campaign case study**

*“As local parents of children with autism we had become increasingly worried about what would happen to our children when they left school. There were no appropriate services or support for adults locally, particularly people with very complex needs, and a lot of young adults were having to move great distances from their families.*

### **First steps**

*As a group we decided to become a branch of the NAS and looked into the possibility of raising funds to develop and run a new service. After research we found this was not feasible and decided that the best route was to lobby the council to provide appropriate services. Our goal was to gain services that enabled adults with autism to live in their local area as part of the community and we took a vote to make sure people agreed with this.*

### **Lobbying local councillors**

*We made contact with the local authority, found out who had responsibility for autism issues and for adults with disabilities and wrote to them to introduce ourselves. We asked for information about local meetings and planning groups, to be added to relevant mailing lists and we attended council meetings to assess the opinions of those involved.*

*Each member of our group wrote to their local councillors and from their responses we were able to identify a number who were supportive of our aims and who agreed to take our points to others in the council. We provided them with strong evidence of why the new services were needed, including an outline of the situation, the number of local people who needed the services, an example from another local authority of the kind of services they wanted, an estimate of the costs, and three people's own stories. We also wrote letters to the local papers outlining the service we wanted and expressing our hope that the council would work with us to achieve it.*

### **Working with our local MP**

*We arranged a meeting with our MP and even invited her to visit one of our homes to meet some of our children. Unfortunately she was not able to do this, but she did agree to write a letter to the Director of Social Services to highlight our concerns. At the same time we asked the Director for a formal meeting. Our NAS Regional Officer attended this meeting with us and gave a presentation about autism.*

### **Taking things forward**

*We identified a council worker in the Social Services Department who felt that our suggestion was the best way forward for the council. He persuaded the Director of Social Services to allow him to look into the issue. We worked with him to develop suggestions which were put before the Social Services Committee for discussion. Just before this meeting, we wrote to the chair of the committee outlining our reasons for wanting the service and our own personal concerns for the future. A local councillor ensured that one of us was invited to speak at the meeting.*

### **Campaign success**

*After many further discussions, it was finally agreed that the council should establish a residential service in the local area for 15-20 adults with autism!*

*Organisations were invited to tender for the contract to develop and run the service and the branch was invited to have a seat on the tender panel. Once the decision had been made and was made public, we put out a press release expressing our delight and our support for the new service.*

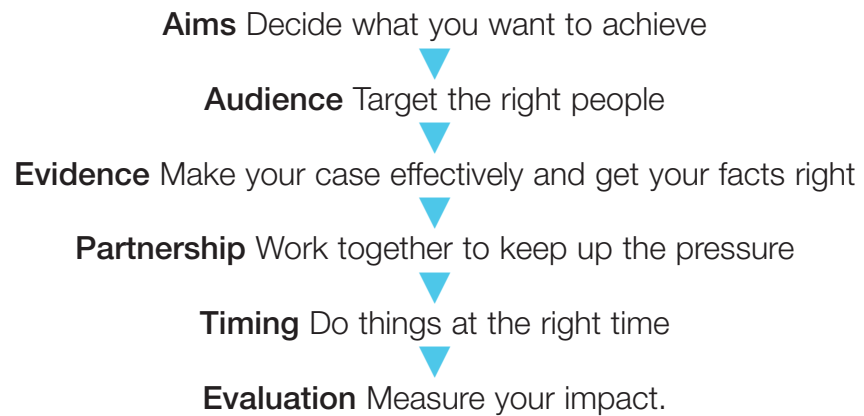
*The new service was developed five years ago. It had taken us about six years of attending meetings, lobbying and pressure to persuade the council to establish it. Sadly the service has not been appropriate for many of our sons and daughters but it does mean that there is for the first time a dedicated service available to adults with autism in the local area. In addition, we now have strong contacts with the local authority, and are regularly approached to take part in planning and development meetings and new projects."*

### **Campaign evaluation**

Members of the branch feel that the key reasons for their success are:

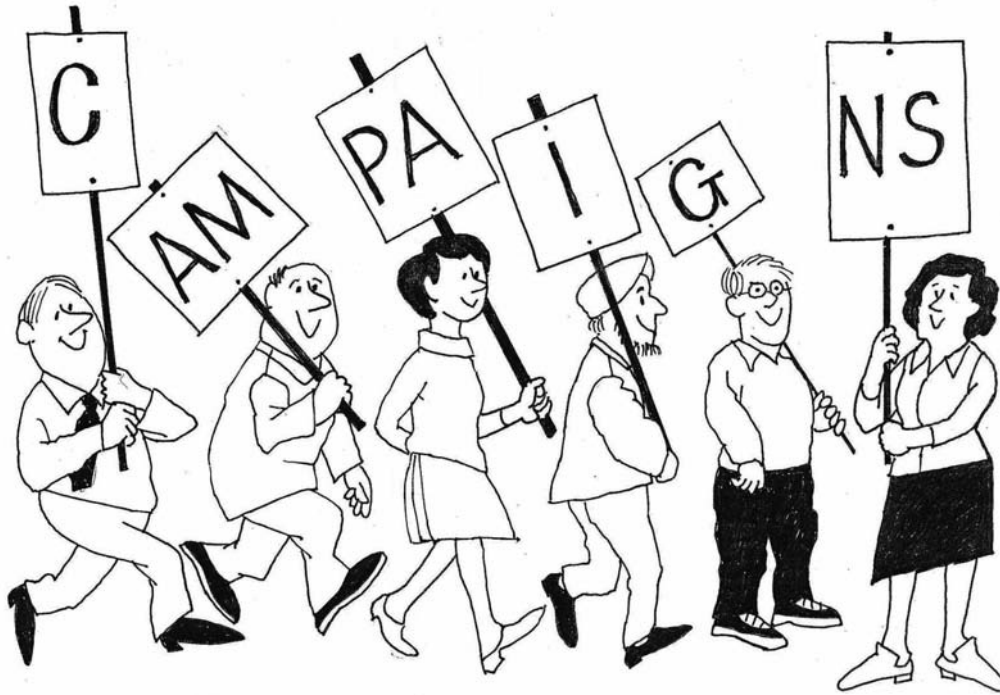
- They worked hard as a group to develop strong contacts, making sure that between them they attended every relevant meeting.
- They used the media very carefully, trying to engage them at times where they had positive comments to make.
- They identified key people to take their campaign forward for them and applied further pressure when it was necessary.
- They worked to gain what was achievable overall, rather than what they wanted on an individual level.

### The National Autistic Society campaign building blocks



Let us know how you get on! Please update the NAS on your campaigning activity by emailing [campaign@nas.org.uk](mailto:campaign@nas.org.uk) or writing to Campaign Team, The National Autistic Society, 393 City Road, London, EC1V 1NG.

### 3. Campaigning methods



#### **Writing letters**

Most campaigns start with some kind of letter writing, even if it's a simple introductory letter, raising the campaign issue and asking for a meeting. At a later stage, you could consider a letter writing campaign where many people write to a decision maker to alert them to the extent of concern and put them under pressure to act.

- Consider the target carefully. Do you want to write to the decision maker, the policy advisor or somebody who can put pressure on them?
- At the start of a campaign you may want to write to the decision maker to alert them to your concerns. If you fail to get a response you may later want to write to someone who can put pressure on them, like your MP/AM/MSP or even the local media. See page 17 on tips from the NAS press team on working with the media.
- Keep your message clear and short, and ask for a reply.
- Encourage as many people as possible to get involved, whether or not they are directly affected by the issue. Tell people who they should write to, what points should go into the letter, and what evidence can back up these points. Try to avoid a template letter, which can be circulated and copied verbatim, but have one available for people if they need it.
- Ask people to note what they have done and to share replies.

## **Meetings with decision or policy makers**

Probably the best way of getting your message across is to meet with the people who are driving policy or who will be responsible for making key decisions. It is a good idea to push for meetings with decision makers at key stages in your campaign, such as when you first wish to raise your concerns or suggestions or shortly before a key vote.

- You will not get an unlimited number of meetings so plan what you want to get out of the meeting and what you want to say.
- Send any detailed information to attendees in advance.
- Make notes of the meeting and write to the people you have met afterwards, thanking them for their time. You can use this opportunity to summarise what you discussed, including any action that you or others have agreed to take.
- If you do agree to take action, or provide any further information, ensure you do this promptly.

## **Public meetings**

Public meetings provide an opportunity for you to demonstrate the level of concern to decision makers and to attract new supporters to your campaign. They can be particularly useful at the beginning of a campaign and around 'pressure points', such as key decision or budget times.

### **Arrangements and preparation**

- Decide on a date and who you want to speak. If it is important to get a particular speaker(s), check the date with them first. You may want to invite a speaker from The National Autistic Society, who can give an overview of the issue.
- Book a venue that is accessible by public transport, has access for people with disabilities, is easy to find and affordable.
- Elect a strong chairperson, who can make sure the meeting stays on track and that everybody is treated with respect.
- Give plenty of notice to everybody, including the media. Free media listings can be used for publicity. See the chapter on page 17 about working with the media for useful tips.

### **At the meeting**

- Welcome people as they come in and give them information about the campaign.
- Circulate a sheet of paper so that people who want to be kept in touch can add their details.

- To comply with data protection legislation, ensure that you keep information confidential and make it clear at the outset why you are asking for their details. For example, state: 'please add your contact details if you would like to join the campaign and receive information about future activities'.
- Your Chair should welcome people to the meeting, explain the purpose, introduce the speakers and allow plenty of time for questions and discussion.
- Make sure that people with autism who attend a public meeting have the opportunity to ask questions if they want. Some people may want to talk to somebody before the meeting to plan the question, and to have support in the meeting so they feel confident they are speaking at an appropriate time.
- Take notes of what is said, including questions that are asked, who asked them, and the answers given.

### **Petitions**

Petitions are a good way to display support and raise awareness of your issue among the general public, providing you can get a large number of signatories. However, be aware that asking people to write individual letters can be more effective.

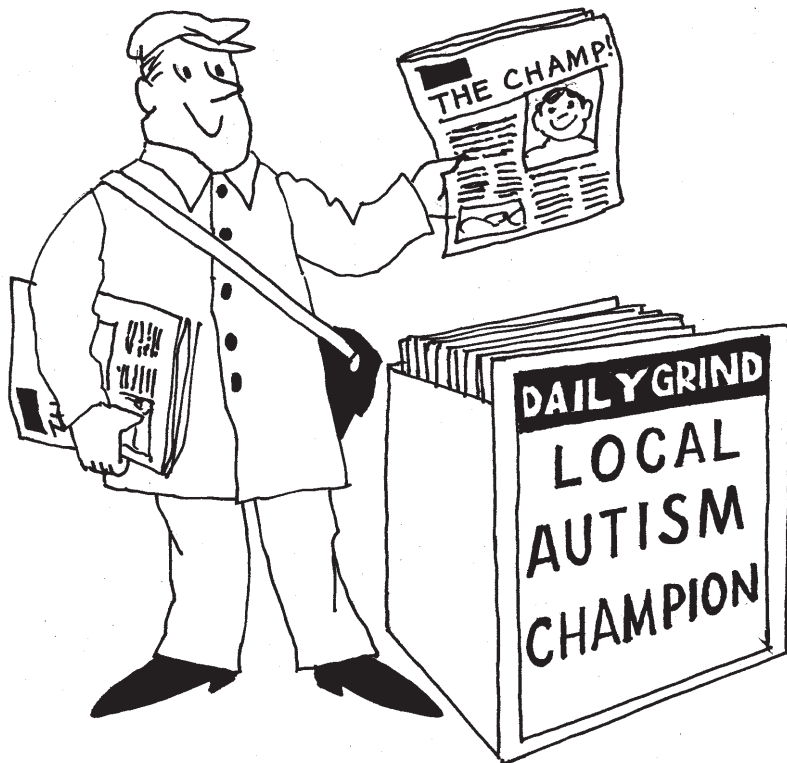
- Make sure your petition statement is short and clear, saying who you want to act and what you want them to do.
- Do not make it threatening or aggressive as this will put people off signing.
- You can petition any decision maker, but it is wise to contact their agency first to find out how you should present it.
- Create a simple fact sheet or leaflet about your campaign for people who are considering signing. If you produce a leaflet you must by law include the name and contact details of your group. If you are a registered charity you must also include your charity number.
- Arrange a time to deliver your petition and alert the local press.
- You may want to speak to your MP, MSP or AM about presenting a petition at Westminster, the Scottish Parliament or at the Welsh Assembly.

## **Publicity stunts**

An imaginative publicity stunt can bring your campaign to the public's attention and is an enjoyable way for campaigners to participate in the campaign.

- Be clear about the message you want to get across.
- Be creative but keep it simple and within the limits of the Law.
- Be visual! Journalists will want to get good pictures and will be much more likely to put the story in if they get them. Think about having something attractive and colourful, like a banner or a visual stunt (for example, people holding a huge key if you are campaigning on housing). If it is used well, music will also attract attention. See the next chapter on working with the media for tips on the best way of engaging your local media.
- Think through the event in advance. What props or materials do you need, who will bring them and how should they transport them? What time should people arrive? What might go wrong and how will you deal with that? Who will talk to people who want to know what is going on?
- Make sure your stunt doesn't last too long. Gather people together at the end and thank them for their involvement.

## 4. Working with the media



Getting your local media involved in your campaign is a great way to raise awareness of your concerns and put pressure on influential parties to take action.

Media activities you can consider include:

- Sending out a press release/s about your campaign and carrying out any interviews that may occur on the back of this
- Writing letters to papers
- Calling local phone-in radio programmes.

For advice and support contact the NAS Press Office.  
Telephone 020 7903 3593 or email [press@nas.org.uk](mailto:press@nas.org.uk)

### **Contacting the media**

- Contact your local media as soon as possible. Journalists work to tight deadlines so make sure you get information to them in good time.
- Be clear about your key messages (as discussed in section 2 – Building a successful campaign – on page 5) and ensure they are stated in all correspondence with the media.
- Ask the NAS Press Office for a list of your local media contacts.

### **How to contact the media**

- It is best to email in the first instance.
- Email your release to the News Desk or a named person if you have details.
- The 'subject' line of your email message should be the title of your release.
- Copy and paste the full release into the body of the email.
- Don't send your release as an attachment as not all journalists can open these.
- If you haven't got an email address, send your release by post.
- Addresses can be obtained by contacting the NAS Press Office on 020 7903 3593 or email: [press@nas.org.uk](mailto:press@nas.org.uk)
- Follow up your email or letter with a phone call to see if they are interested in your story.

## What to do when

WHEN	WHAT
<p>Four-five months before the campaign launch (or as soon as possible!)</p>	<ul style="list-style-type: none"> <li>● Contact the NAS Press Office for tips and advice.</li> <li>● Collate ‘case studies’ or personal stories from people affected by the concerns voiced in your campaign, which can be quoted in a press release.</li> </ul>
<p>One-two months before the campaign launch (or as soon as possible)</p>	<ul style="list-style-type: none"> <li>● Make a list of people who are prepared to talk to the media about their experiences.</li> <li>● Write a press release to announce your campaign launch.</li> <li>● Include relevant dates and information.</li> <li>● Think about suitable photos.</li> <li>● Think about suitable local celebrities or well known faces relevant to your campaign who may be prepared to offer you a comment for your press release.</li> <li>● Send the release to your local media and follow up with a phone call asking them to support the campaign. Talk them through your key messages and concerns.</li> <li>● Put the local press in touch with relevant case studies.</li> <li>● Contact local radio and TV stations to alert them to the campaign and ask them to support it. They will probably ask you to call again a few weeks before the launch.</li> </ul>
<p>Two weeks before the event</p>	<ul style="list-style-type: none"> <li>● Follow up calls to local press, radio and TV stations.</li> <li>● Reiterate your key messages and put them in touch with relevant case studies.</li> </ul>

## Writing your press release

A press release is the most effective means of communication with the media. Press releases must be clearly written and well presented. Use the template press release included in this pack (Appendix 2) as a guide.

### Top tips

- Grab the reader's attention in the first paragraph.
- Write clearly, use plain English wherever possible and avoid jargon.
- Stress the local angle of your story.
- Point out the who?, what?, when?, where? and why? in the first paragraph to catch the journalist's attention.
- Keep your paragraphs short – 40-50 words maximum.
- Add a quote from a spokesperson leading the campaign who can highlight key messages, and a quote from a case study to give a personal perspective and show how real people are affected.
- Add any supporting information, for example information on the NAS and autism, at the end of the press release under the heading 'Notes to Editor'.
- Email your draft release to [press@nas.org.uk](mailto:press@nas.org.uk) and the NAS press team will check it for you.

### Format

- Make sure that the heading 'Press Release' is displayed prominently at the top of your document.
- Give your press release a date and a title that explains the essence of your campaign.
- Use 1.5 spacing so that the editor can make notes and corrections.
- Type your release on one side of A4 paper.
- If you run over one page, at the bottom of each page write '1 of 2', '2 of 2', etc.
- When the press release is finished write 'End.'

## Campaigning with The National Autistic Society

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### **Don't forget to include your contact details!**

- Put your name and telephone number at the end of the release for interviews and photographs.
- Include the NAS Press Office contact details (see page 56) in case journalists want more information on the NAS or autism.

### **Sending out your press release**

Your press release needs to be sent to the right person/place. This will generally be the news editor/news desk but there may be a journalist specifically dealing with local campaigns.

#### **Photographs**

A photograph will gain attention for your campaign and may make the journalist more likely to cover it.

- Photos should be in digital format (ideally a jpeg file).
- Only email your photo to a journalist if they have requested one.
- Do not send a photo with the initial release as it will make the file too large for some journalists to read.
- If you are unable to email your photo ask the journalist if they are able to use a hard copy or suggest they visit you to take one of their own.
- Make sure that everyone in your photo has given written permission for it to be used in press work.

### **Interviews**

If a journalist calls to interview you on your campaign remember:

- To ask them questions to clarify how they plan to cover your campaign such as: What's your angle? When will the article appear? Do you want a photograph? Would you like to follow the campaign through a series of articles?
- You don't have to respond to questions immediately. Journalists have tight deadlines so will want information quickly, but you might feel more comfortable if you have a bit of time to prepare. If this is the case take down their questions and agree a time to ring back.
- To phone again if you have additional information.

### **Local radio and TV**

The most likely slots for your story on local radio and TV are regional news programmes. Target your press release in the same way as for newspaper journalists.

- If you secure an interview, ask how long it will be and prepare accordingly. What are the most important things you want the audience to hear/see in that short time? Limit yourself to two or three main points.
- Radio and television interviews can be live or pre-recorded. They can happen down a phone line, on location, in a studio or remotely from another studio. Pre-recorded interviews will be edited, live interviews cannot be.
- Ask questions when you are first contacted which will help you feel more in control, such as: Is the interview live or pre-recorded? How long will the interview be? What's your angle on the story? Where will the interview take place? Who is the interviewer? When will it be broadcast? Who else have you spoken to and what have they said?

### **Top tips**

- Prepare two, at most three main points including how the audience can support your campaign.
- Be clear about what you can/are prepared to talk about.
- Short answers work better than long rambling ones. Be concise and to the point.
- Try not to get sidetracked by the interviewer and stick to your main points.
- Don't agree to an interview without adequate preparation and call the NAS Press Office for more advice if you need it.

### **Additional guidelines for radio**

- You can have a crib sheet in front of you.
- Speak in vivid language that will create pictures in the mind of the listener.
- Use your voice in a varied way to engage and enthuse the audience.

### **Additional guidelines for television**

- Look at the interviewer not the camera.
- Try to relax and be yourself.
- Remember you have some power in the situation: you would not be there unless you had something to say.
- Dress appropriately for the occasion, something smart but comfortable is probably best.

### **NAS autism facts and figures**

The following information will help if you are asked about the NAS and autism. Use it as a crib sheet when you are doing a newspaper or radio interview.

#### **The National Autistic Society**

The National Autistic Society is the UK's leading charity for people with autism and their families. Founded in 1962, it exists to champion the rights and interests of all people with autism and their families and carers. The NAS provides a wide range of advice and support services to help people with autism and Asperger syndrome live their lives with as much independence as possible.

The NAS relies on the support of its members and donors to continue its important work for people with autism. To become a member, make a donation or to find out more about the work of the NAS, visit the NAS website [www.autism.org.uk](http://www.autism.org.uk) or call the NAS donation line on: 08702 33 40 40 (national rates apply).

#### **What is autism?**

Autism is a lifelong disability which affects a person's social and communication skills. It is a spectrum disorder occurring in varying degrees of severity. Around 535,000 people have autism in the UK today and an estimated 2 million people are affected by it.

#### **What is Asperger syndrome?**

Asperger syndrome is a form of autism used to describe people at the higher functioning end of the autistic spectrum.

*(Continued overleaf)*

### **What is the 'triad of impairments'?**

- Social interaction: difficulty with social relationships, for example appearing aloof and indifferent to other people
- Social communication: difficulty with verbal and non-verbal communication, for example not instinctively knowing the meaning of gestures, facial expressions or tone of voice
- Social imagination: difficulty in the development of play, for example a limited range of imaginative activities, possibly copied and pursued rigidly and repetitively; difficulty understanding what others think and feel.

### **Can people with autism be helped?**

Specialist education and structured support can really make a difference to the life of a person with autism, helping them to maximise their skills and achieve full potential in adulthood.

## 5. Lobbying your Member of Parliament (MP)



### Parliament, constituencies and MPs

- Your MP should help you with matters for which Parliament or central government is responsible.
- However the extent to which MPs will support a campaign depends on the individual and the issue.
- Only your local MP will help you with local campaigning. MPs do not take up issues on behalf of people who are not their constituents and if you contact another MP they will simply direct you to your own.
- MPs cannot usually help in resolving private disputes.
- MPs can't provide legal advice or resolve legal issues.

### Who is my MP?

- Ask at your local reference library or at your local town hall.
- Telephone the House of Commons Information Office on 020 7219 4272.
- Visit [www.locata.co.uk/commons](http://www.locata.co.uk/commons)
- Visit [www.theyworkforyou.com](http://www.theyworkforyou.com)

### **How do I contact my MP?**

- Write to your MP at House of Commons, London SW1A 0AA.
- Telephone 020 7219 3000 and ask for their office.
- Make an appointment to visit the constituency office. Most MPs hold constituency surgeries when they are available for people to raise and discuss issues. For further details contact the constituency or Westminster office or your local library.
- Most MPs can be contacted by email. Email addresses can be found at **[www.parliament.uk](http://www.parliament.uk)**
- Fax your MP for free by completing the form on the website **[www.faxyourmp.com](http://www.faxyourmp.com)**
- You can organise a group lobby of your MP, when a large group travels to Westminster to visit your MP. This may attract media attention, but you must always organise it in advance with your MP's office and with the Serjeant at Arms, who is responsible for ensuring the order and security of the House of Commons.

### **What can my MP do to support my campaign in Parliament?**

- Write to the relevant Government department or make an appointment to see the Minister involved.
- Ask questions in Parliament (Parliamentary Questions or PQs) about Government provision or policies in your area.
- Ask for an adjournment debate in Parliament on the campaign. If your MP feels strongly on a local or national issue, they can ask for a short debate on the subject. A relevant minister will always attend to 'answer' your MP.
- Raise an Early Day Motion. Early Day Motions (EDMs) are House of Commons resolutions, which MPs sign to demonstrate their support for a particular issue. EDMs are not usually debated but they give MPs an opportunity to place their opinion on record and gauge support from fellow MPs.

### **What can my MP do to support my campaign locally?**

- Attend a launch event. This can support your publicity and media work.
- MPs do not direct local services but they can represent your concerns to local institutions, for example, by writing to your Local Authority or Primary Care Trust (PCT) regarding the NAS or your local campaigns.
- Visit a local service or even somebody's home to find out more about living with autism or Asperger syndrome.

- Act on maladministration. If there has been a clear failure in the management of a local service your MP may be able to take your case to the Ombudsman (Parliamentary Commissioner for Administration). The Ombudsman can only be approached via your MP.

*“At the time of the general election we talked to candidates from all the main parties, and kept in contact with them afterwards. This led to a local MP asking a question in Parliament, which revealed some useful statistics and a group of parents being invited to a meeting with another MP who was a Minister at the Department for Education and Skills.”*

NAS Branch member

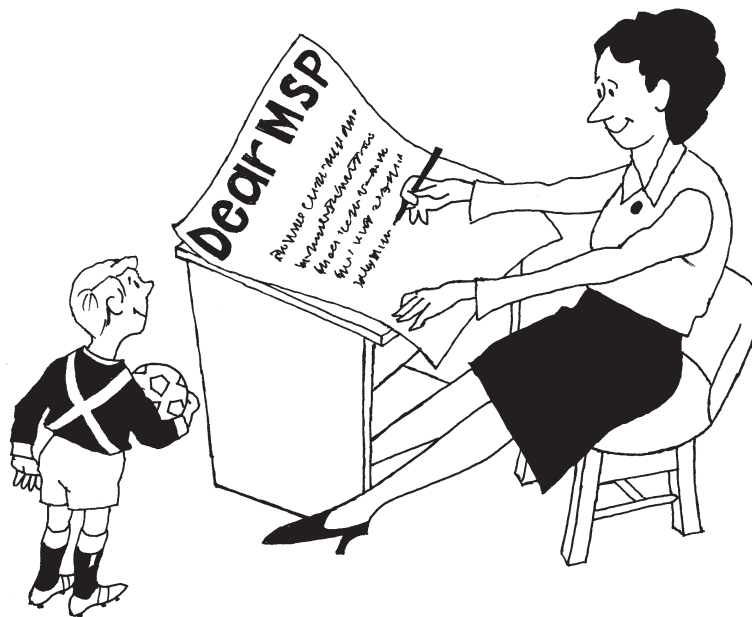
### **Tips on contacting and meeting your MP**

- Write to your MP in the first instance. Keep your letter short and clear – you can follow up with more information later.
- Follow your letter by making an appointment to see your MP at a constituency surgery.
- Before you meet with your MP, research her/his interests. Go to **[www.autism.org.uk/appga](http://www.autism.org.uk/appga)** to find whether your MP has demonstrated an interest in autism by signing up to the All Party Parliamentary Group on Autism manifesto.
- Take a short written summary of your concerns and copies of relevant correspondence you have had with local or other agencies on the issue so they can read this later. If you do not think your MP has much knowledge of autism, it may be helpful to take some information on this as well.
- At the meeting outline your issues clearly, including the goals of your campaign and what you have already done to move towards these.
- Agree and note down any actions, for example, whether you will provide further information, whether they will contact the local authority for you.
- Write to your MP thanking them for their time and support and saying that you would like to meet again in the future. Include a summary of the key points raised, including actions taken. If you have agreed to take any action, do this swiftly and let your MP know you have done it.

### **For further information**

**Contact the House of Commons Information Office 020 7219 4272 or visit [www.explore.parliament.uk](http://www.explore.parliament.uk) or [www.theyworkforyou.com](http://www.theyworkforyou.com)**

## 6. Lobbying the Scottish Parliament and your MSP



### The Scottish Parliament and the Scottish Executive

- People who live in Scotland are represented at Westminster by their MP and by Members of the Scottish Parliament (MSPs), based in Edinburgh.
- The Scottish Parliament has 129 members (MSPs) who are elected by the people of Scotland for a fixed four-year term.
- Each voter has two votes, one to elect a constituency MSP and the other to elect regional MSPs.
- There are 73 constituency MSPs. They represent a specific local area and are elected by the people within that area on a first past the post basis. The remaining 56 seats are filled by regional MSPs. There are eight regions, and each one returns seven MSPs who are elected by proportional representation. Seats are allocated so each party's overall share of seats in the Parliament reflects the share it achieved of the regional vote.
- People who live in Scotland have one constituency MSP and seven regional MSPs.
- Once formed, the Scottish Parliament chooses a First Minister from the MSPs, usually the leader of the biggest party in Parliament. The First Minister appoints a Cabinet which forms the Scottish Executive. The Executive is responsible for setting the legislative and policy agenda for Scotland and implementing it and is accountable to the Scottish Parliament for its decisions and actions.

### **Who is my MSP?**

- Your constituency MSP and your regional MSPs both have a duty to represent you.
- Constituency MSPs may have a more local focus, as they represent a specific, smaller area, and are probably the best person to approach if you want support in a campaign around local agencies.
- However it may still be worth contacting your regional MSPs, particularly if you know that one of them has a strong interest in autism.
- To find out the name of your MSPs contact the information department at the Scottish Parliament. Telephone 0131 348 5000 or 0845 278 1999, email [sp.info@scottish.parliament.uk](mailto:sp.info@scottish.parliament.uk) or visit [www.scottish.parliament.uk/msp/index.htm](http://www.scottish.parliament.uk/msp/index.htm)

### **How should I contact my MSP?**

- It is best to contact your MSP in writing first at the Scottish Parliament, Edinburgh, EH99 1SP.
- You can also arrange to visit your MSPs at one of their constituency surgeries. Details of surgery times and locations are available from your MSP's office in the Scottish Parliament, in the local media, or from your local library.
- You can meet your MSPs in the Scottish Parliament but you must arrange this in advance.

### **What can my MSP do to support my campaign?**

- Raise matters with local agencies. MSPs do not run or direct local services themselves and cannot order agencies to take a particular course of action, but they can contact local agencies to raise issues or concerns on your behalf.
- Increase the profile of your campaign. MSPs are well-known figures and the local media will be interested in stories that involve them.
- Raise matters with the Scottish Executive.
- Ask Parliamentary Questions (PQs).
- Lodge a parliamentary motion, a statement that other MSPs sign up to if they agree with it.

## **Petitions**

- The Scottish Parliament has a strong petitioning system.
- Any individual or organisation can petition the parliament and you do not have to go through your MSP.
- You can raise a petition to ask the parliament to state a view on a particular matter, or to amend or introduce legislation.
- Petitions will only be considered on matters of 'wide public interest' and those which are devolved to the Scottish Parliament.
- They can be presented in writing or via the internet (e-petitions), so you can gather signatures via either of these routes.
- You can have both a written and internet version of the same petition if you choose, but repeat signatures will be removed.
- For further information see  
**[www.scottish.parliament.uk/business/committees/petitions/index.htm](http://www.scottish.parliament.uk/business/committees/petitions/index.htm)**

## **Issues dealt with by the Scottish Parliament and Westminster**

### **The Scottish Parliament has control over the following areas:**

- Health
- Education and training
- Law and home affairs
- Police and fire services
- Local government, including social work
- Housing
- Transport
- Economic development and tourism
- Environment
- Agriculture, fisheries and forestry
- Sport, culture and the arts
- Statistics, public registers and records.

### **The matters reserved for Westminster are:**

- Employment legislation
- Social security
- Equal opportunities and discrimination
- Abortion, human fertilisation, embryology and genetics
- Some aspects of transport (including railways, safety and regulation)
- Data protection
- Constitutional matters
- Tax and the economic and monetary systems.

## 7. Lobbying the National Assembly for Wales and your Assembly Members



### **The National Assembly for Wales and the Welsh Assembly Government**

- If you live in Wales, in addition to your MP, you will elect Assembly Members (AMs) to the National Assembly for Wales.
- The National Assembly for Wales was created in 1999 and has the power to make policy decisions and develop the funding and spending frameworks on various issues in Wales, including health, social care and education.
- The National Assembly for Wales does not have the power to change or create legislation, but it can have involvement in shaping legislation in Westminster to ensure it reflects the needs of the people of Wales.
- It also has the power to interpret law and direct the actions of local authorities in Wales and national agencies, such as Estyn and the Social Care Inspectorate for Wales. For example, if UK law permits local authorities to charge for certain services, the Welsh Assembly Government can give guidance on how they should do this.
- There are some issues which still fall under the control of Westminster. These include law and order, benefits and disability discrimination. If you are campaigning in these areas you should contact your MP.

## Campaigning with The National Autistic Society

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### **Assembly Members (AMs)**

- The National Assembly for Wales is based in Cardiff Bay and is made up of 60 AMs, elected by the people of Wales.
- Each voter has two votes. The first is used to elect their constituency AM on a first past the post basis.
- The second vote is used to elect 20 additional AMs, on a regional basis. These are elected by a proportional representation system, so the number of regional AMs in the Assembly reflects the number of votes their party receives.
- There are 40 constituencies, and 40 constituency AMs. There are five electoral regions, with four regional AMs elected within each.
- People who live in Wales have one constituency AM and four regional AMs.
- AMs elect a First Minister, responsible for the business and decisions of the Assembly. Once elected, the First Minister appoints a Cabinet of Ministers, who each have responsibility for a particular area of policy.
- Committees of AMs reflect each area of cabinet responsibility, standing committees reflect the Assembly's key priorities and four regional committees advise the Assembly on regional issues and the work of public agencies in the regions.

### **Who is my AM?**

You can find out the names and contact details for your AMs by contacting the Welsh Assembly public information line (029 2089 8200) or by visiting [www.wales.gov.uk](http://www.wales.gov.uk)

### **How do I contact my AM?**

- Write to your AM at: National Assembly for Wales, Cardiff Bay, Cardiff CF99 1NA.
- Telephone them at the Assembly via the main switchboard on 029 2082 5111.
- Visit them at a constituency surgery or at the Assembly. For details contact their office at the Assembly.

### **What can my AM do to support my campaign?**

- Raise issues in the National Assembly for Wales.
- Take up your concerns with local agencies and the Welsh Assembly Government.

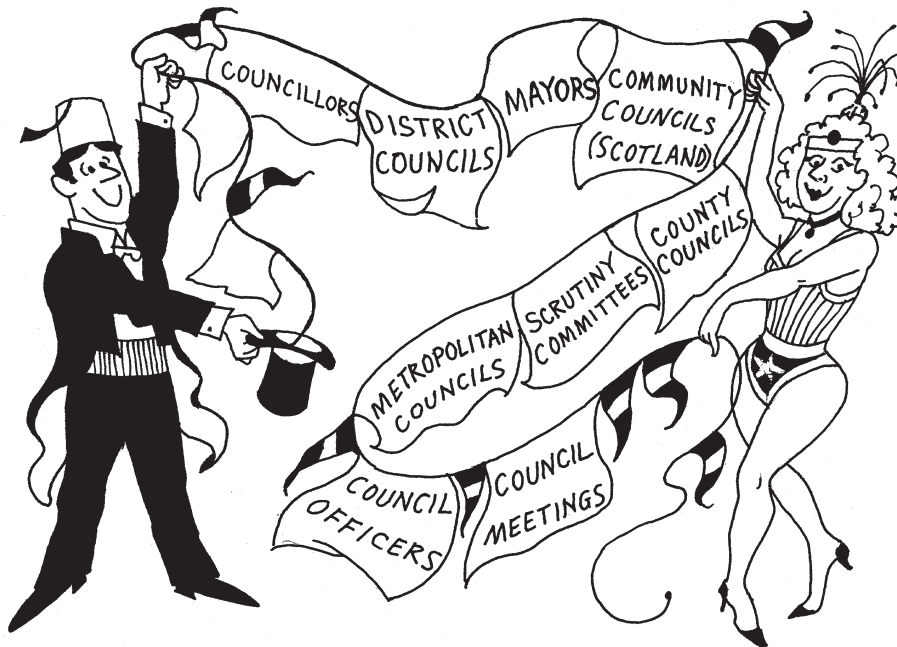
## Campaigning with The National Autistic Society

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- Raise matters with Ministers of the Welsh Assembly Government. If your AM writes to a Minister, the Minister must respond.
- Raise matters with relevant committees at the Assembly.
- Ask Assembly Questions – formal questions of the Welsh Assembly Government. This is often a good way of getting information on a particular issue.

At the time of going to print, a new Government of Wales Bill is going through Parliament in Westminster. If the proposals within the Bill are approved, the Welsh Assembly Government will have greater powers and will be able to change certain legislation through a fast track system in Westminster. For an update contact the Welsh Assembly public information line (029 2089 8200) or visit **[www.wales.gov.uk](http://www.wales.gov.uk)**

## 8. Local councils – how they work and how to lobby them



*“Councillors will all have their own particular interests, and if you can find one who is especially interested in health, education or social services, they might be keen to take up an issue concerning autism which involves their area of interest.”*

NAS Branch Officer

- Local councils or local authorities provide some of the most important services and support for people with autism and their families, including education.
- They are run by democratically-elected councillors who are responsible for making decisions on behalf of the local community about local services, such as schools and social services.
- Councils also employ paid staff (often called Council Officers) including a chief executive, to manage and carry out the day to day work of the authority.
- Councils are increasingly obliged to take service users' and parents' wishes into account, and you may be able to achieve a lot by seeking representation on council boards like planning groups and Learning Disability Partnership Boards.

## How do I find out about my local council and councillors?

- Go to [www.direct.gov.uk](http://www.direct.gov.uk)
- Ask at your local library.
- Visit your council website.
- Attend council meetings that are open to the public and/or read their minutes.

## How can I lobby my council?

### Local councillor/s

- Your councillors have a duty to represent your interests within the council and to make the relevant members or officers aware of concerns or difficulties at council meetings and through other forums.
- They can also bring media attention to your cause and take up individual cases with council officers.
- You can lobby your councillors by letter, at their surgery times or by arranging a specific meeting.
- You can also hold a ‘mass lobby’ of your council, when lots of people turn up together to meet with their councillors. You should arrange this with your council and councillors.

### Council meetings

- Members of the public are entitled to attend certain council meetings, and there are sometimes options to speak at them.

*“When you first start attending meetings, it might seem as if everyone is talking in a foreign language, because of all the jargon they use. But it is the Chair’s job to make sure that everyone understands what is going on, so don’t feel shy about asking what something means, either publicly during the meeting or privately afterwards. You will soon get the hang of it. Remember that at one time you wouldn’t have known what ASD, SEN or IEP\* meant. My husband says he doesn’t understand me now because I can talk in local authority jargon!”*

NAS Branch member

*“It is really important to remember that you are representing other parents when you attend meetings, and not to get personal about bad experiences you or your child may have had. Hard though it can be, if you want the respect of the professionals you have to be as professional as possible yourself, and try not to get emotional or attack the professionals in the room.”*

NAS Branch member

\*ASD = autistic spectrum disorder; SEN = special educational needs; IEP = individual education plan

### **Relevant council officers**

- High ranking paid council staff or officers, such as the Director of Social Services, are key people in the development of policy. Their job is to provide expertise on the issues and advise the council, cabinet and committees on this, as well as to manage the work of their department.
- You can lobby them directly or through your councillors.

### **Members of the opposition parties**

- Councillors from the opposition are extremely good at holding the executive to account and asking penetrating questions of the governing party or parties.
- Members of the opposition parties will be keen to question the actions of those in the ruling party/ies, and to demonstrate how much they can achieve for people in their ward.

### **Scrutiny committees (England and Wales only)**

- Scrutiny committees are groups of backbench councillors from all political parties.
- They meet in public to develop policy and hold the executive to account.
- They can make recommendations to the executive before decisions are made, question executive decisions and actions, and investigate how existing council policy is working.
- Scrutiny committees can include local people who are not councillors, but these people cannot vote at meetings

### **How can I lobby my scrutiny committee?**

- You can lobby your scrutiny committee directly or ask councillors to do so on your behalf.
- Observe meetings and ask questions.
- Lobby members before decisions are made so they can question the Cabinet's actions and make recommendations on policy matters to the Cabinet and full council.
- You can also submit a request for overview or scrutiny of a particular service and offer to give evidence as a witness.

### **Ward and area forums and service user and carer forums**

You can also comment on the services your local council provides via your local ward and area forum and/or your local service user and carer forum. Contact your council to find out more.

### **The Disability Equality Duty**

In 2005 the *Disability Discrimination Act* (DDA) 1995 was amended to ensure that discrimination law covers all activities of the public sector. A new Disability Equality Duty means that public bodies must promote equality of opportunity for disabled people.

The Disability Equality Duty comes into force in 2007 and applies to all public authorities (apart from a small handful which have specific exemptions) including government departments, local authorities, governing bodies of schools and colleges, NHS trusts and boards. Each of these agencies must develop and publish a Disability Equality Scheme showing how they will ensure that disabled people are considered in all areas of their work and identifying how they will promote equality of opportunity. To fulfil the Duty agencies will have to consult with disabled people, which provides an excellent opening for campaigning.

The development of these schemes provides a good opportunity to lobby local agencies on their commitment to disability equality. For more information, contact the Disability Rights Commission on 08457 622 633.

### **How do councils work in England and Wales?**

- Councils in England and Wales fall under the responsibility of the UK Government.
- The Government provides much of their funding and to an extent directs their actions via Acts of Parliament.
- On some issues, councils in Wales receive guidance from the National Assembly for Wales rather than the UK Government.

### **Two types of councils**

- **Unitary or metropolitan authorities.** These account for most councils, including London boroughs, and deal with all local services, from education to rubbish collection.
- **Two-tier councils.** Some local authorities, usually in rural areas, are divided into two levels. The county council provides the major services, such as education and social services. Smaller district councils provide local services like environmental health and highway maintenance. In villages you may also be able to lobby your Parish Council.

### **Councils in England and Wales can be structured in three ways**

- **A leader and cabinet.** Most councils use this structure. The councillors elect a council leader, who appoints individual councillors to a cabinet. Each cabinet member has responsibility for a particular area, such as education or health and social services. You can target them directly and ask your councillor/s to lobby them on your behalf.
- **An elected mayor and cabinet.** In this arrangement the mayor is directly elected by the local people. The mayor chooses a cabinet from the elected councillors and the cabinet works the same way as with a council leader.
- **An elected mayor and a council manager.** In this structure the mayor is elected and the councillors appoint one of the senior council officers as the council manager. The manager works with the mayor to make policy decisions. A council can only have an elected mayor if local people have previously voted for this in a local referendum.

### **Forward plans**

- Councils in England and Wales must set out a 'forward plan', which states decisions to be made over the next four months, when they are expected to be made, who should make them and how these people can be contacted, and how the council is planning to involve local people in the decision-making process.
- This plan must be publicly available and updated every month. It is a good idea to get hold of your council's forward plan, particularly if you are campaigning in a very short timeframe.
- Councils must give five days' notice to the public if they are going to make a decision that is not included in the plan.
- There is also an 'urgency procedure' to make the decision without the five days' notice, but the decision maker has to ask the scrutiny committee for permission to use this procedure.

### **How do councils work in Scotland?**

- Councils in Scotland fall under the responsibility of the Scottish Executive rather than the UK Government.
- Local government in Scotland is currently in a period of change and development. The Scottish Executive, which has responsibility for local government in Scotland, wants councils to move to a more formal leadership structure, although it does not want to prescribe the way they make their decisions. Changes are also planned to the way councillors are elected.
- The new electoral system will be based on proportional representation, and the first elections under it will take place in 2007.

- Each council has reviewed and adapted its decision-making process, and a number of different systems are currently in operation. Most councils retain a committee structure but some have adopted executive and scrutiny processes similar to those in England and Wales. Others have brought together elements of both, or devolved decision-making powers to local committees.
- All councils in Scotland are single-tier and have responsibility for all areas of local government.

### **Community councils**

- Some areas are also subdivided into community councils, which represent the views of local people on issues such as footpaths, playgrounds and local celebrations. Apart from in Eilean Siar (the Western Isles), Orkney and Shetland, these councils have no real administrative power, but act simply as a channel for local people to express their views. They exist only where there are volunteers prepared to run them and most have no budget except for running costs.

### **How do councils work in Northern Ireland?**

- There are 26 district councils in Northern Ireland. They deal with relatively minor local issues, such as leisure centres, parks and refuse collection. Councillors are elected and have a duty to represent their electorate and make decisions on the matters under council control.
- Services such as education, health and social services are provided by different bodies, many of which are planned to come under the control of the Northern Ireland Assembly. While this is suspended, they are accountable to government departments in Westminster, and administered via local boards or agencies within Northern Ireland.
- Social and community care services in Northern Ireland are provided by Health and Social Services (HSS) trusts, which also provide health services, such as primary or hospital care.
- Education and schools fall under the remit of five local Education and Library Boards (ELBs). They are responsible for the strategic planning of educational provision, provide a support service to all schools in their area, including curriculum support, and have responsibility for meeting the needs of children with special educational needs, including the statementing process. Members of ELBs are appointed by the UK Minister who has responsibility for education in Northern Ireland and include elected councillors from each district council within the ELB area and other representatives.

## 9. Lobbying health agencies in the UK



### How do I lobby health agencies?

- NHS agencies are governed by a board of directors. Directors are appointed. They are not elected representatives.
- You can use letter writing campaigns and other campaigning methods to lobby directors and boards of local NHS agencies, or officials who work for them, such as their chief executives.
- Your councillors, MP, MSP or AM can also contact these individuals or agencies on your behalf.
- The boards of most health trusts include individuals who are local people and who represent the interests of the people who use the services that the trust provides. These are key people to lobby.
- Find out who is on the boards of your local trusts, including the service user representatives, and who the senior officials are. Telephone 0845 4647 or visit [www.nhs.uk](http://www.nhs.uk)

## **Which health agencies should I lobby in England?**

### **Strategic Health Authorities**

- There are 28 Strategic Health Authorities (SHAs) in England.
- They are responsible for developing plans for health services in their area, making sure local health services are of a high quality and that national priorities are met.
- They manage the PCTs and NHS trusts within their region.
- If you are unhappy with the service you have received at your local hospital or feel that your hospital trust is not meeting its obligations, you can make a complaint to your Strategic Health Authority by letter or email.

### **Primary Care Trusts (PCTs)**

- Primary care is the service you get when you first seek help for a health problem. Most primary care is provided by your GP, who will refer you for further services if necessary.
- PCTs are free-standing statutory bodies that provide primary and community services and commission secondary (hospital) care on behalf of the local population. They receive 75% of the NHS budget.
- PCTs work with local authorities to provide services and in many cases hold overall responsibility for these relationships. They must make sure there are enough services for people within their area, that services are accessible and that health and social care systems work together to the benefit of patients.
- Most Occupational Therapists (OTs) and Speech and Language Therapists (SaLTs) who work within the NHS are employed by PCTs.
- Contact your PCT and ask for a copy of their Local Delivery Plan, which sets out the the services to be delivered over the next three years and the local priorities and targets that must be met.
- You should lobby your PCT if you are campaigning against service cuts in your area or you are campaigning for alternative services to those that are currently commissioned.

### **NHS Trusts**

- NHS trusts manage hospitals and services provided by them.
- They are responsible for ensuring services are available and for the quality of care offered by hospitals. They also oversee hospital spending, and local hospital strategy.
- Trusts can provide services in the community, through health centres, clinics, or in people's homes.
- Contact your local hospital to get a copy of their patient prospectus and annual patient survey report. If they do not accurately reflect your experiences, write to the head of the trust to highlight the differences.

### **Foundation trusts**

- Foundation trusts are a new type of NHS hospital which are run jointly by managers, staff and members of the public. They have more freedom than other NHS trusts.
- You can influence your foundation trust by identifying and lobbying current board members, observing board members for an inside view of trust strategy or becoming a board member yourself.

### **Care Trusts**

- Care Trusts combine health service and local authority functions.
- They usually provide social care services and may also provide mental health or primary care services.
- They are technically NHS bodies, but they have a large local government element.
- There are currently only a small number of care trusts, but more are expected to be established in the future.

### **Mental Health Trusts**

- Mental Health Trusts provide specialist mental health services for people with severe and ongoing mental health problems.
- The services they provide include adult mental health services, child and adolescent mental health services (CAMHS) and services such as psychotherapy, occupational or art therapy.

### **Learning Disability Trusts**

- There are a very small number of NHS trusts which focus specifically on providing a range of services to support people with learning disabilities.

**The structure of health services is reorganised at intervals so it is important to keep up to date with any changes. For the latest details of health agencies in your local area telephone 0845 4647 or visit [www.nhs.uk](http://www.nhs.uk)**

## **How can I influence my local health services in England?**

### **Patient and Public Involvement (PPI) Forums**

There is an independent PPI Forum for every NHS trust in England. They are made up of ordinary local people and influence how local services are provided.

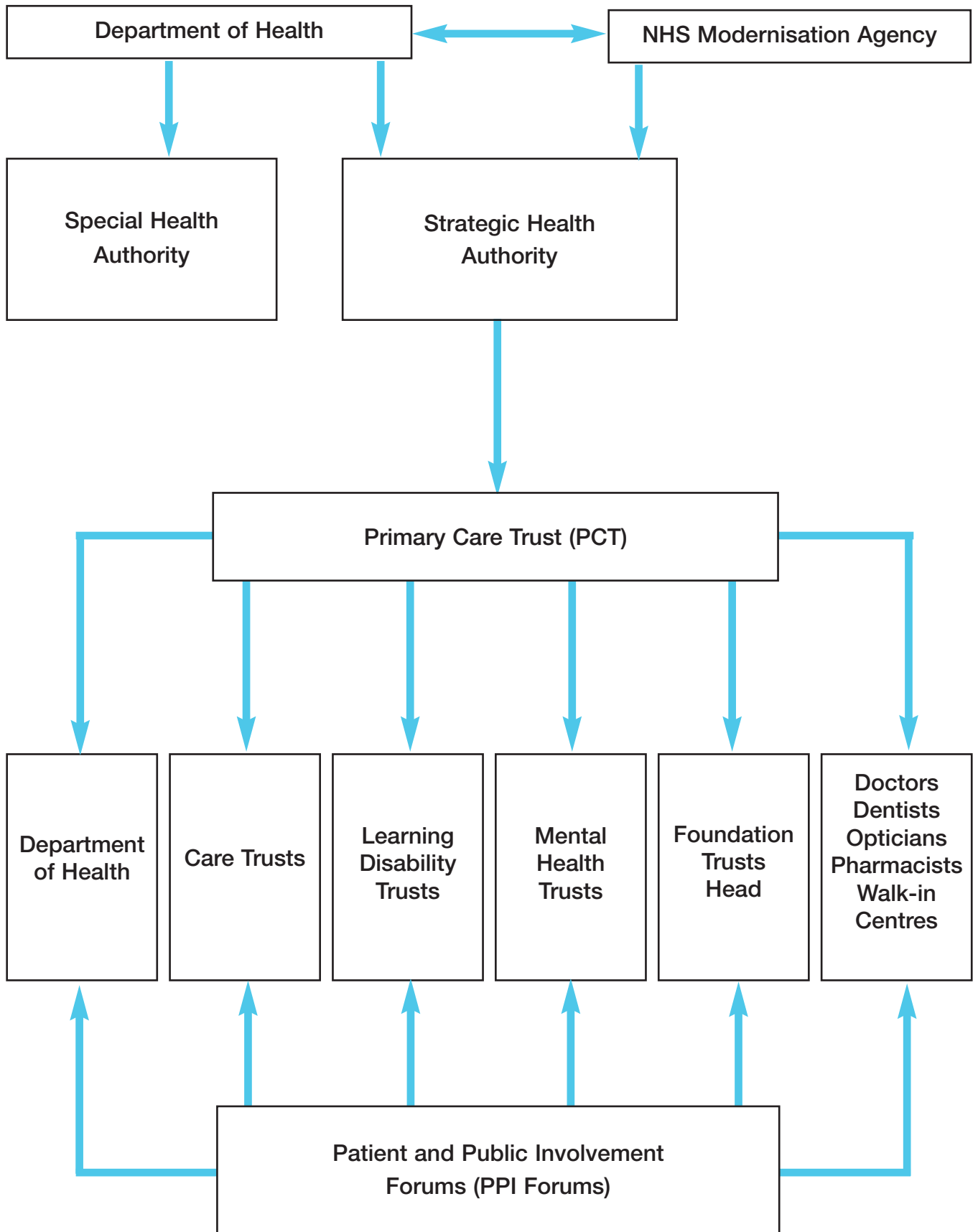
PPI Forums:

- Seek the views of local people about local services.
- Make recommendations and produce reports on the range and delivery of services (the trust they work with must listen to the forum and provide a response).
- Independently monitor the quality of local services through regular visits (reports of these are available to the public).
- Provide information and advice to people about services.
- Monitor the effectiveness of local Patient Advice and Liaison Services (PALS), which offer immediate help and information to service users and carers.

You can get involved with the work of your local PPI Forums by:

- Going to the public meetings the Forum holds to give your views or express any concerns.
- Contacting the Forum to raise particular issues with Forum members.
- Applying to be a member of the Forum. Anybody can apply to be a member of a PPI Forum and members are given training to enable them to take part effectively.
- Telephoning 0845 120 7111, emailing **enquiries@cppih.org** or visiting **www.cppih.org**

## Health services in England



## **Which health agencies should I lobby in Wales?**

The NHS in Wales is managed by the Welsh Assembly Government, which provides policy direction and allocates funding, led by the Minister for Health and Social Services.

### **Local Health Boards**

- 22 Local Health Boards (LHBs) provide health and some social care services in Wales.
- They cover the same areas as the 22 local authorities in Wales and work with councils to improve local services.
- LHBs provide primary care such as GPs and dentists, and commission secondary care from NHS trusts. Decisions are made by a board made up of local doctors and other health professionals, elected members of the local council, voluntary organisations and patient representatives.
- You should lobby your LHB if you are campaigning against service cuts in your area or you are campaigning for alternative services to those that are currently commissioned.

### **NHS Trusts and Hospitals**

The services provided by hospitals and the ambulance service in Wales are managed by 14 NHS Trusts.

- Acute trusts look after hospitals
- Care trusts are set up when the NHS and a local authority decide to work together to provide services such as social care, mental health services and some primary care provision.
- Mental health trusts provide specialist mental health services.

The structure of health services is reorganised at intervals so it is important to keep up to date with any changes. For the latest details of health agencies in your local area telephone 0845 4647 or visit

**[www.wales.nhs.uk](http://www.wales.nhs.uk)**

## How can I influence health services in Wales?

### Community Health Councils

There are 22 Community Health Councils (CHCs) in Wales, one for each of the Local Health Board areas. They:

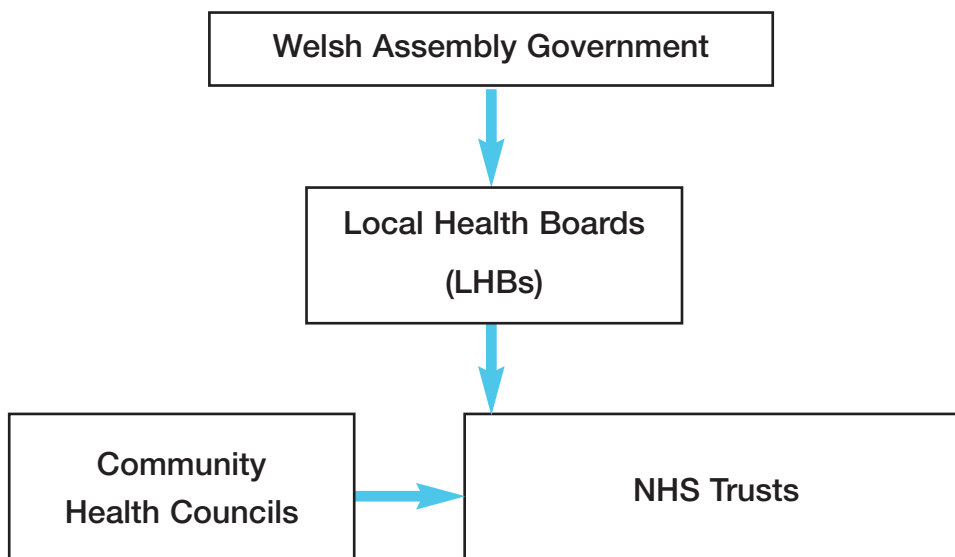
- Provide help and advice to individuals who have problems or complaints about services provided by the NHS
- Ensure that the views and needs of local people influence the way local services are provided
- Monitor the quality of services provided by NHS agencies from the point of view of service users.

### Contacting your local CHC

- Local Health Boards must consult the CHC on any changes to services and the CHC has the right to visit and inspect services provided by a Board.
- Members of each CHC are appointed by the Welsh Assembly, the relevant local council and local voluntary organisations, and are not paid.
- If you want to comment or raise concerns about the services provided by your Local Health Board, you can contact the service directly and you can talk to or lobby your CHC.
- Contact your CHC via their office or attend one of their public meetings. Every CHC must meet in public at least once every three months, but many meet more regularly.

Contact details and dates of upcoming meetings are available from your GP, library or council or at [www.wales.nhs.uk/chc](http://www.wales.nhs.uk/chc)

## Health services in Wales



## **Campaign case study**

*“I have two sons, who have been diagnosed with Asperger syndrome. My eldest son was diagnosed three years ago and has experienced difficulties at home and within mainstream education. At a multi-agency meeting it was decided that he needed a clinical psychology assessment. However, when I tried to get an appointment for him, I received a letter stating that the local trust would not commission aftercare services for children or young people who have a diagnosis of autism or Asperger syndrome. These services include clinical psychology, the learning disability team and community nursing team. They are vital to my children and to the many other children with autism or Asperger syndrome in the area.*

*I decided to start a campaign to regain the services withdrawn or at worst to have written confirmation on how to access services if and when medical need made it necessary.*

*During the campaign I have worked with others to target parents, the local media, our local MP, the Children’s Commissioner for Wales, the local Trust and Local Health Board. We used our branch newsletter to raise awareness of the problem among parents and to ask for help with printing the petition papers. At a stall at our local market and a car boot sale we collected signatures for a petition. Our local MP helped get quick responses to any letters that we sent to the local Trust or the Local Health Board, and the Children’s Commissioner for Wales put pressure on the local trust to commission services. We contacted the Disability Rights Commission for legal information and The National Autistic Society for advice regarding Government policy. The NAS also gave me the encouragement and support that I needed to make a difference. Throughout the campaign we used the media to raise the profile of our concerns and activity.*

*Through the campaign we have persuaded our Local Health Board of the need for aftercare services for children and young people with autism or Asperger syndrome. However, it is one thing having the Local Health Board’s support and another actually gaining back the withdrawn services so the campaign is not over yet!”*

NAS member in Wales

## **Which health agencies should I lobby in Scotland?**

- Health and social care in Scotland is the responsibility of the Scottish Parliament.
- 15 regional NHS Boards decide what health services are needed in their area. Further information is available from [www.scotland.gov.uk/Topics/Health/NHS-Scotland/Boards](http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/Boards)
- Boards are made up of senior medical practitioners and ordinary members of the public and have a duty to encourage the involvement of people who use services in the planning and development of those services.
- There are also eight 'special health boards', which cover a specific service including NHS Quality Improvement Scotland, NHS 24 and the Scottish Ambulance Service. Further information is available from [www.show.scot.nhs.uk/organisations/specialhbs.htm](http://www.show.scot.nhs.uk/organisations/specialhbs.htm)
- Community care, such as support for people with learning disabilities or mental health problems, is the responsibility of Health Boards and they are expected to work in partnership with local authorities in their area to provide these services.

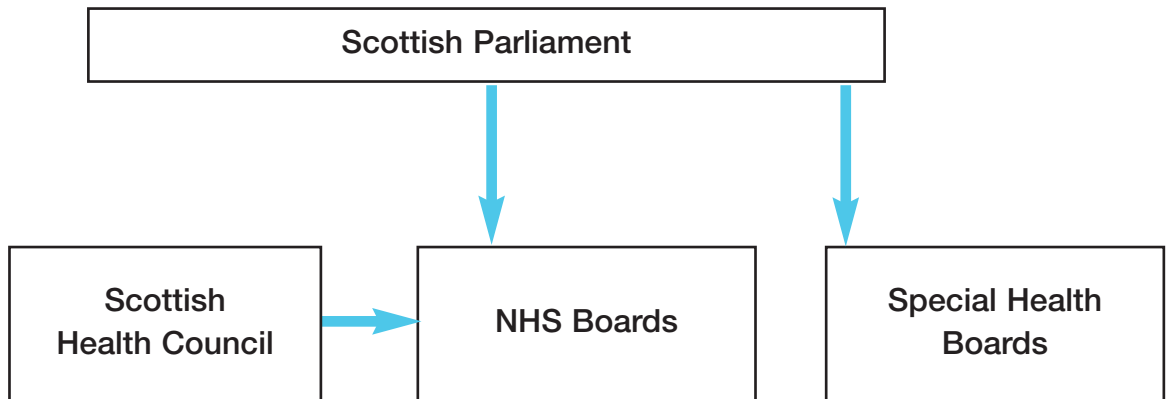
The structure of health services is reorganised at intervals so it is important to keep up to date with any changes. To find details of health agencies in your local area telephone 0845 4 24 24 24 or visit [www.show.scot.nhs.uk](http://www.show.scot.nhs.uk)

## **How can I influence health services in Scotland?**

### **Scottish Health Council**

- The Scottish Health Council aims to improve the way the public can be involved in decisions about health services and scrutinises the work of Health Boards to ensure they are working with and listening to the views of the public.
- The Council has a national office in Glasgow and offices in each Health Board area.
- Members of the community are appointed to serve as voluntary members on a Local Advisory Council for each Health Board.
- For further information, telephone 0141 241 6308 or visit [www.scottishhealthcouncil.org](http://www.scottishhealthcouncil.org)

## Health services in Scotland



## **Which health agencies should I lobby in Northern Ireland?**

In Northern Ireland, health and social services are the responsibility of the Department of Health, Social Services and Public Safety (Northern Ireland), which is answerable to the UK Parliament.

### **Health and Social Services Boards**

There are four regional Health and Social Services (HSS) Boards in Northern Ireland. They develop policy and organise services to meet local needs. Most Boards have a department dedicated to the provision of social services.

### **Local Health and Social Care Groups (LHSCGs)**

- There are 15 Local Health and Social Care Groups (LHSCGs) in Northern Ireland.
- They are committees of Health and Social Services Boards and were introduced in 2002 to give the local community and healthcare staff a bigger say over how health and social services are run.
- LHSCGs plan primary and community care services and will ultimately have more responsibility for commissioning these.
- They are made up of representatives from the HSS Boards and Trusts, the local community, service users and health and social care professionals.

### **Health and Social Services Trusts (HSS Trusts)**

- There are 19 Health and Social Services Trusts which are responsible for the day to day running of health and social care services.
- Some Trusts provide community health and social services, others provide hospital and community health and social services or acute-only hospital services, and one is dedicated to providing the ambulance service for the whole of Northern Ireland.

The structure of health services is reorganised at intervals so it is important to keep up to date with any changes. To find details of health agencies in your local area telephone 0845 4647 or visit [www.n-i.nhs.uk](http://www.n-i.nhs.uk)

## **How should I influence services provided by Health and Social Care services in Northern Ireland?**

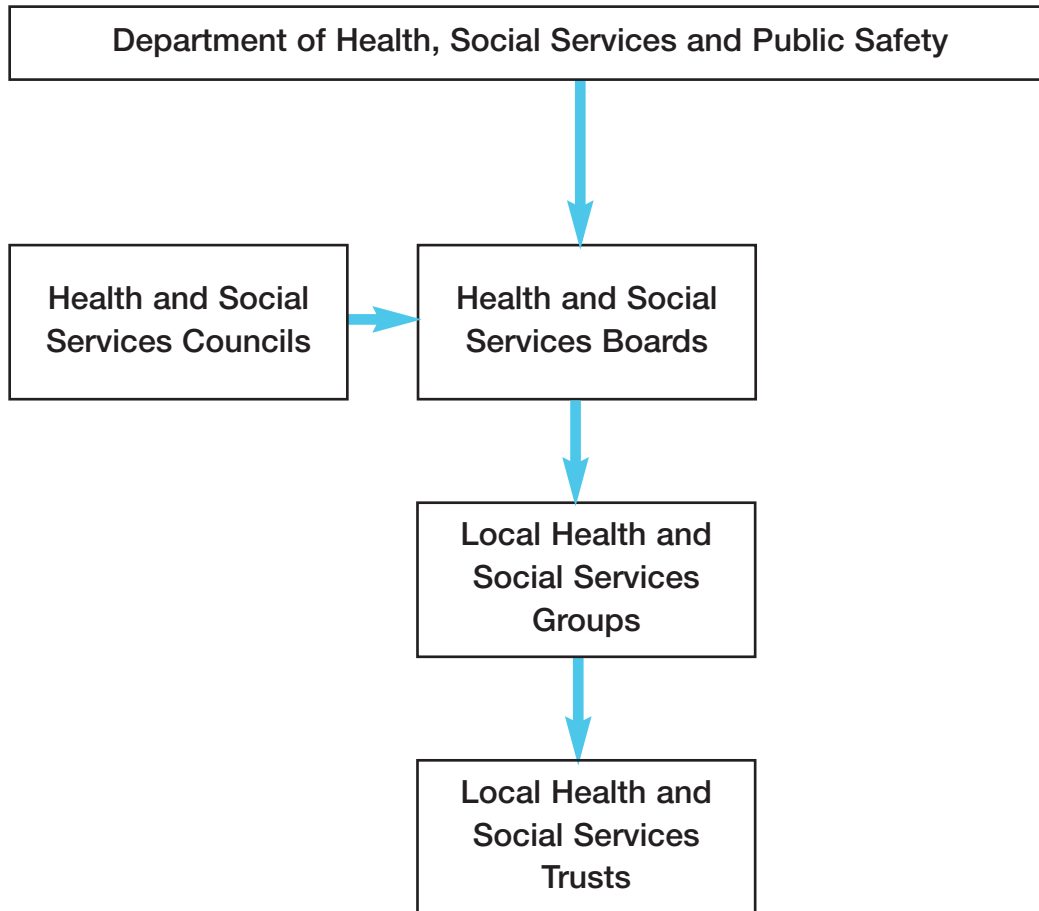
- Unless your concern is about a specific service provided by a HSS Trust or another organisation, you should lobby the body responsible for local planning and the development of services. This is likely to be your HSS Board or a LHSCG.

- HSS Boards have a duty to consult widely with health and social care professionals and with the general public, and to meet in public on a regular basis.
- Your LHSCG's service user and community representatives are key people to lobby.

### **Health and Social Services Councils**

- There are four Health and Social Services Councils in Northern Ireland, one for each of the HSS Boards. They are independent and exist to represent the interests of the public.
- HSS Boards must consult their local HSS Council if they are planning any substantial changes to how services are provided.
- HSS Councils also have the responsibility for visiting and monitoring the quality of local health and social or community care services, identifying gaps in service provision and making recommendations to the HSS Board on how these could be addressed, carrying out surveys to find out the views and comments of local people on the services they receive, raising the concerns and issues of the local community, assisting people who want to make a complaint about the services they are receiving and providing information and advice to local people about health and social services issues.
- Members of HSS Councils are drawn from local authorities, voluntary organisations and other groups and work on a voluntary basis.
- You should lobby your local HSS Council about concerns regarding the health or social services you receive, or about changes and improvements you would like to see.
- You can lobby your HSS council by contacting them directly, attending one of their public meetings, or even applying to become a member of your local HSS Council. Telephone 0845 4647 or visit **[www.n-i.nhs.uk](http://www.n-i.nhs.uk)** for contact details of your HSS council.

## Health services in Northern Ireland



## Further information

### **The National Autistic Society (NAS)**

Campaign Team, The National Autistic Society, 393 City Road, London EC1V 1NG Tel: 020 7903 5799 Email: [campaign@nas.org.uk](mailto:campaign@nas.org.uk)  
**[www.autism.org.uk/campaign](http://www.autism.org.uk/campaign)**

Autism Helpline: 0845 070 4004 Minicom 0845 070 4003  
Email: [autismhelpline@nas.org.uk](mailto:autismhelpline@nas.org.uk)  
Websites: **[www.autism.org.uk](http://www.autism.org.uk)** **[www.info.autism.org.uk](http://www.info.autism.org.uk)**

The Autism Helpline provides impartial and confidential information, advice and support to people with an autistic spectrum disorder, their families and professionals. It is open from Monday to Friday 10am-4pm. Calls from all parts of the UK are charged at local rates.

NAS Press Office: 020 7903 3593  
Email: [press@nas.org.uk](mailto:press@nas.org.uk)

### **Other useful resources**

PACE (2005). *Constructive campaigning for autism services. The PACE parents' handbook*. A practical guide for parent campaigners who want to play a part in building better autism services.

Contact A Family (2005). *Making a difference: how parent groups can use the Children's NSF to influence local services*. Available free at **[www.cafamily.org.uk](http://www.cafamily.org.uk)** or 020 7608 8700.

Contact A Family (2005). *Parent participation: examples in health settings*. Gives practical examples of how parents' experience and expertise has been used to influence the way health services are provided. Available free at **[www.cafamily.org.uk](http://www.cafamily.org.uk)** or 020 7608 8700.

Contact A Family/Council for Disabled Children (2004). *Parent participation: improving services for disabled children: parents' guide*. Useful guide for people who want to work with their local authority. Available free at **[www.cafamily.org.uk/parentparticipationguide.pdf](http://www.cafamily.org.uk/parentparticipationguide.pdf)** or 020 7608 8700.

IPSEA. *Scrutiny review template*. Useful advice on scrutiny reviews. Available free at **[www.ipsea.org.uk/scrutinyreview.htm](http://www.ipsea.org.uk/scrutinyreview.htm)** or 0800 0184016.

The information in *Campaigning with The National Autistic Society* is correct at the time of going to press but is likely to change. For latest updates refer to the contact details in each chapter, visit **[www.autism.org.uk/campaign](http://www.autism.org.uk/campaign)**, email [campaign@nas.org.uk](mailto:campaign@nas.org.uk), telephone 020 7903 5799 or write to Campaign Team, The National Autistic Society, 393 City Road, London, EC1V 1NG.

# Appendix 1

## **Freedom of information**

The UK and Scottish Parliaments have both passed Freedom of Information Acts. These give the public the right to get information from public agencies, like local authorities or health agencies. If you ask a public agency for information they have to tell you whether they have it and provide it for you. There are some exemptions to this, such as when the information is already publicly available, for security reasons or when requests are constantly repeated or 'vexatious'. In some cases the agency providing the information can make a charge for doing so.

Information acquired in this way may well help you develop or support your case when you are campaigning, but remember that much of it may already be available, so you will not necessarily have to resort to legislation to get it.

### **For further information contact:**

#### **England, Wales and Northern Ireland**

The Department for Constitutional Affairs

Tel: 020 7210 8614

Email: [general.queries@dca.gsi.gov.uk](mailto:general.queries@dca.gsi.gov.uk)

[www.dca.gov.uk/foi/](http://www.dca.gov.uk/foi/)

Or the Information Commissioner (Freedom of Information)

[www.informationcommissioner.gov.uk/](http://www.informationcommissioner.gov.uk/)

Information Commissioner: England

Tel: 01625 545 700 Email: [mail@ico.gsi.gov.uk](mailto:mail@ico.gsi.gov.uk)

Information Commissioner: Wales

Tel: 02920 894 929 Email: [wales@ico.gsi.gov.uk](mailto:wales@ico.gsi.gov.uk)

Information Commissioner: Northern Ireland

Tel: 028 9051 1270 Email: [ni@ico.gsi.gov.uk](mailto:ni@ico.gsi.gov.uk)

#### **Scotland**

The Scottish Executive

Tel: 0131 244 5210

Email: [foi@scotland.gsi.gov.uk](mailto:foi@scotland.gsi.gov.uk)

[www.scotland.gov.uk/Topics/Government/FOI](http://www.scotland.gov.uk/Topics/Government/FOI)

The Scottish Information Commissioner

Tel: 01334 464610

Email: [enquiries@itspublicknowledge.info](mailto:enquiries@itspublicknowledge.info)

[www.itspublicknowledge.info/](http://www.itspublicknowledge.info/)

## Appendix 2



### Sample press release

#### NAS Press Office

Tel: 020 7903 3593

Fax: 020 7903 3596

Mobile (24 hours): 07787 124792

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

### Press Release

Date

#### The National Autistic Society XXXXX Branch calls for local respite care services

Today, [date], The National Autistic Society (NAS) XXXXX Branch launches a Respite Care Campaign, calling on Social Services to offer respite care, play and leisure facilities and therapeutic services for families affected by autism in the xxxx area.

The provision of these services would enable families to cope with the daily challenges that living with autism brings. Caring for an individual with autism places significant stress on families. Respite care is an essential part of a family's coping mechanism. Without support such as short break schemes many families, who often don't have access to specialist knowledge of the condition, struggle to cope with the pressures that autism can place on a family.

Susan Waters, Branch Officer, NAS XXXXX Branch, said:

"An estimated xxxx individuals have autism in the xxxxxx area and yet at present there is no appropriate local respite provision for families affected by the disability. Respite care, play and leisure facilities and therapeutic services would provide a much needed support to families who face severe challenges in their daily lives. Currently the play facilities in XXXXX are unable to cope with individuals with autism as facilitators are not trained in the disability. Providing appropriate respite care and facilities would help to prevent families reaching a crisis point due to lack of support. It would alleviate pressures on Social Services in the long term by lessening the possibility of intensive, long term or emergency intervention being needed."

XXXX XXXX, parent of a child with autism, said:

"Our family is currently struggling to cope with the pressures that autism brings. Myself and my wife have two children with autism, Ben, aged five and Anna, aged three. Both children have severe autism and our lives are a constant battle to support the children and meet their many needs. The services in the area are not able to cope with these needs and therefore will not support our children. This means that Ben and Anna do not benefit from play schemes and facilities that would enable them to meet other children and develop, and myself and my wife have no respite, leading to exhaustion and ill health."

If you would like to support the NAS XXXXX Branch Respite Care Campaign please contact xxxxxxxx xxxxxxxxxx on [insert telephone number] or email [insert email]

ENDS

- For interviews, images and further information please contact xxxxxx xxxxxxxx on [insert telephone number for media enquiries] or email [insert email]

### Notes to editors:

- Autism (including Asperger syndrome) is a lifelong developmental disability. It is a spectrum condition occurring in varying degrees of severity. Around 535,000 people have autism in the UK today and over 2 million people are affected by the disability. It is characterised by a triad of impairments: difficulties forming social relationships, problems with verbal and non-verbal communication and the development of strong narrow obsessional interests.
- For further information on The National Autistic Society and autism please contact the NAS Press Office on 020 7903 3593 or email [press@nas.org.uk](mailto:press@nas.org.uk)

The National Autistic Society is the UK's leading charity for people with autistic spectrum disorders and their families. Founded in 1962, it continues to spearhead national and international initiatives and provide a strong voice for all people with autism. The NAS provides a wide range of services to help people with autism and Asperger syndrome live their lives with as much independence as possible.

The NAS relies on the support of its members and donors to continue its vital work for people with autism. To become a member, make a donation or to find out more about the work of the NAS, visit the NAS website [www.autism.org.uk](http://www.autism.org.uk) or call the NAS donation line on 08702 33 40 40 (national rates apply).

For more information about autism and for help in your area, call the NAS Autism Helpline on 0845 070 4004. The Helpline is open from 10am-4pm, Monday to Friday, (local rates apply).

The NAS PARIS (Public Autism Resource and Information Service) website is the largest online autism-specific service directory in the world. Visit [www.info.autism.org.uk](http://www.info.autism.org.uk) to find autism services and support networks in your area.

The National Autistic Society  
393 City Road  
London  
EC1V 1NG  
Switchboard: 020 7833 2299  
Autism Helpline: 0845 070 4004  
Minicom: 0845 070 4003  
Fax: 020 7833 9666  
Email: [nas@nas.org.uk](mailto:nas@nas.org.uk)  
Websites: [www.autism.org.uk](http://www.autism.org.uk)  
[www.info.autism.org.uk](http://www.info.autism.org.uk)

NAS Scotland  
Central Chambers  
109 Hope Street  
Glasgow  
G2 6LL  
Tel: 0141 221 8090  
Fax: 0141 221 8118  
Email: [scotland@nas.org.uk](mailto:scotland@nas.org.uk)

NAS Cymru  
Ground Floor  
6/7 Village Way  
Greenmeadow Springs Business Park  
Tongwynlais  
Cardiff  
CF15 7NE  
Tel: 01792 815 915  
Email: [wales@nas.org.uk](mailto:wales@nas.org.uk)

NAS Northern Ireland  
57A Botanic Avenue  
Belfast  
BT7 2GL  
Tel: 02890 236 235  
Email: [northern.ireland@nas.org.uk](mailto:northern.ireland@nas.org.uk)



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