

CHAPTER 7

Making systems work for you



We'd be very happy to think that this book so far might provide you with all the help you need. Our experience, however, has been that information on its own is not always enough. Some of us have been quite clear about what is available, yet we've still had to struggle to get it. Sometimes mistakes happen or bad decisions are made. That's when you need to know how to challenge things or complain. In this chapter we will go through the various routes you need to follow to do this.

I thought long and hard before putting in a complaint, but as they had not allocated someone to our case I felt I had no other way to get things moving again. It still felt uncomfortable as I didn't want to alienate the people I needed to help my son.

But before we look at how to resolve individual issues, it is worth pointing out that attitudes towards disability and the rights of disabled adults and children and their carers have improved significantly over the past 30 or 40 years. And the main reason for this has been people coming together to push for change. Later in this chapter we'll explain how the Equality Act should protect your child from disability discrimination. Credit for this belongs to the work of the disability rights movement over the years. The main reason the recent legislation on SEN is so clear about the importance of parents' views is because parent carers have joined together to press for recognition that they are the experts about their children.

Right now, it may feel like it's as much as you can manage to look after your child and stand up for their needs, but many of us have found that coming together with other parents made us feel stronger and less like we were battling away alone. You might choose to become part of the local Parent Carers' Council (PaCC) which is made up of parents like you coming together to have a shared voice about the things that affect us and our children. Brighton & Hove City Council and local health services have been working positively with PaCC and it also links in to a national network of parent carer groups to influence the big picture too. Find out how to join PaCC at www.paccbrighton.org.uk.

HOW THE PUBLIC SERVICES WORK

When things are going wrong some of us have found it helps to have an idea of how the public services work and who is responsible for what. You need to know who is providing a service before you can complain about it. If you feel pretty clear about this, skip to the section on 'Your rights and how to complain'.

National or local?

Ultimately most of the services our children use exist because national government has made laws about them or provides funding to pay for them. A few are provided nationally, for example benefits such as DLA and tax credits. But most are actually run more locally and this includes health services, despite being part of the 'National' Health Service. The three public services mainly affecting parents and their children are education, social care and health. Social care is provided by the local authority – Brighton and Hove City Council. Education is mainly provided by the local authority too but schools and colleges are quite independent. Health services are more complicated, as we will explain. As parents we need services to work together but this does not always happen. The Children's Act 2004 instructed all children's services to work together. The Children and Families Act 2014 has created a legal obligation for local authorities and health to jointly commission services to meet the needs of children and young people with SEN and disabilities. And we now have a local Health and Wellbeing Board to bring health and the council together (see below). This should help.

A word about 'commissioning' as this term is used a lot these days: it means choosing what services should be provided, deciding who should provide them and handing out the funds to pay for them. For example, local authorities commission services and can choose whether to provide them directly or pay someone else to do so – a voluntary organisation perhaps. Joint commissioning means planning together and, if necessary, pooling resources to pay for services.

Health

As we said, the picture of who runs health services is not simple. NHS England gives out funding to local Clinical Commissioning Groups (CCGs). The CCG is a group of GPs

and others. They decide how to use these funds locally to provide community health services, mental health and learning disability services, planned hospital care and emergency care. Mostly they do this by commissioning services from health trusts who run the actual services that we use (see below for the local trusts). A few things are funded directly by NHS England including primary health care services (i.e. GPs, dentists and pharmacists) and specialist services that are not needed by enough people to be commissioned locally. The local authority is responsible for public health and promoting better health in the city.

Brighton and Sussex University Hospitals NHS Trust provides hospital services at all the hospitals in Brighton and Hove and Haywards Heath, including the Royal Alexandra Children's Hospital. Sussex Community NHS Trust provides community health services, such as district nursing, health visiting and community equipment as well as Chailey Heritage clinical services. Their children's health services in Brighton and Hove work in a partnership with the council's Children's Services; for example Seaside View brings together health services for disabled children and the Children's Disability Social Work Team. The Sussex Partnership NHS Trust runs mental health and adult learning disability services across Sussex including the Child and Adolescent Mental Health Service (CAMHS) but in Brighton there are Community CAMHS services, which are part of the local authority Children's Services, and clinical CAMHS, which is part of the Sussex Partnership NHS Trust. The two have a shared referral process so you may need to check which bit of CAMHS you are actually getting your service from.

Another important player locally is the Health and Wellbeing Board (HWB) which brings together the CCG and the council to work together on the health and wellbeing needs of the community. The idea of the HWB is to encourage joint

commissioning and integrating services across health and care. But it is also meant to make things more representative and accountable as local elected councillors and patient reps sit on the board.

Education and social care

Social care services for both children and adults are provided by the local authority (Brighton & Hove City Council). The council can do this by providing a service themselves through their own teams of staff or by commissioning it from another organisation. For example, the local authority (LA) is responsible for deciding which families can get short breaks but the actual breaks could be provided directly by council staff, for example at the council's Drove Road residential facility, or from another organisation such as Barnardo's Family Link.

Whoever actually delivers the service to you will not have final responsibility for making policy or setting budgets. It's the elected councillors, working through their committees, who divide up the 'cake' between the various council departments and who decide upon matters of policy. Council officers are accountable to these elected councillors or 'members'.

The LA is also responsible for many education services including the ones that affect our children most such as the SEN team that deals with EHCPs, school admissions, learning support services, etc. They also distribute funding to most local state schools and make decisions about things like how many places to commission in special schools and units. But academies and free schools are separate from the LA and get funded directly from central government. And even schools that are overseen by the LA have quite a lot of independence in how they operate. In some cases you may find that it is the head and the school governors who have the most say in a decision affecting your child. But all publicly funded services ultimately

have to act within the law, and the SEND Code of Practice applies to academies, free schools and FE colleges as well as schools that are run by the local authority.

YOUR RIGHTS AND HOW TO COMPLAIN

In an ideal world, one in which there was unlimited cash and where everything went without a hitch, none of this would matter too much to the people who use the services. In the real world, cash is always short and hitches do sometimes occur. Making a complaint can feel uncomfortable. It is worth checking if disagreement resolution or mediation is an option in your situation. The Children and Families Act 2014 gave LAs a duty to make disagreement resolution available to parents and young people with special educational needs (SEN) which can be used for disputes with the LA about SEN, with schools and colleges about SEN provision, and with LAs and CCGs about the health and social care sections of an EHCP. It also gave LAs a duty to arrange for independent mediation about EHCPs, including over the health and care parts of the plan.

But if you need to go down the route of making a formal complaint, bear in mind that there are often time limits for making complaints or claims of discrimination, so it always makes sense to get more information and advice promptly if you may decide to go ahead with a complaint. You have the right to see records relating to yourself and your child held by education and social services and health trusts, although you may be charged for the cost of making a copy for you.

Information about how to challenge a benefits decision by the DWP (i.e. being turned down for DLA) is in the chapter on 'Money Matters'.

Education

The law and your rights

The most important laws relating to SEN changed in 2014 when the Children and Families Act became law. Alongside the Act there are regulations and the SEND Code of Practice which set out guidance on how to identify and assess special educational needs. All LAs, schools, FE colleges and early education providers must take note of the Code. You can read or download a copy from the Department for Education (DfE). Parents have rights, which must be explained to them, at all stages when decisions are being made about their children's education. For example, these include the right to be told when their child has been identified as having special educational needs and to see written reports about their child. The chapter on education tells you more about you and your child's rights. See also the section below on the Equality Act and disability discrimination, which explains how the law on equalities applies to schools.

Complaining

The first thing to understand is that in some circumstances you have a right to appeal, and in others you only have the right to complain. We explained in the 'Education' chapter about the rights of appeal in relation to EHC assessments and EHC Plans. These appeals go to the SEND First Tier Tribunal. You can choose to try independent mediation on any part of the plan you are unhappy with, but you can only go to appeal about the education parts. If you are still unhappy with the health and social care provision in an EHCP you need to use the complaints route. You can also appeal at a local level about admissions and exclusions.

If you have a complaint, it's always best to try to sort out problems at a local level with the teacher or professional involved. Your child's class teacher or school head will

probably be the first point of contact. All schools have to have a special educational needs policy and an access policy which includes a procedure for dealing with complaints, and they should provide you with a copy of this. If you need to go further, you should approach the school governors. If that doesn't work you can write to the Director of Children's Services at Kings House in Hove. You can also make a complaint through the city council's Standards and Complaints team. If your child is at an academy or free school you should follow the same process up to the school governors (also known as the academy trust). If this does not resolve things you have to take your complaint to the Education Funding Agency.

If your complaint is not about the school but about the LA and is about an SEN issue, get in touch with the casework officer responsible for your child's Statement or EHCP in the SEN section of the council. If that doesn't resolve things, you can use the disagreement resolution process. You can also contact the Director of Children's Services and/or the Lead Member for Children's Services who will be one of the elected councillors. You can use the council's complaints procedure via the Standards and Complaints team. Finally, if you are still unhappy with their responses, you can try contacting your Member of Parliament (MP) or the Local Government Ombudsman.

There are specialist national organisations, such as IPSEA, that publish useful information sheets about 'taking matters further'. They can also advise you on the various ways of trying to resolve disagreements or registering a complaint. Visit www.ipsea.org.uk

Social care

The law and your rights

It is useful to bear in mind that sometimes the law says that the council must do something (for example to assess a child if they may be in need) and sometimes it gives them the power to do something and they can choose how they do it. Social services' main legal framework for the help it gives to children with special needs is the Children Act 1989 (CA) which works together with the Chronically Sick and Disabled Persons Act 1970 (CSDPA). The CSDPA 1970 establishes the duty to provide most of the services which disabled children will need. The Children Act 1989 establishes the duty to assess children and also requires the provision of certain specific services, particularly residential and foster care short breaks. Assessments made under CA 1989 should also determine whether a child is eligible for support under CSDPA 1970. In addition, the Children and Young Person's Act 2008 clarified the duty for local authorities to provide short breaks for families with disabled children.

Complaining

As with schools, it is usually best to start by talking to the person closest to the problem and then their manager. If you have a complaint that can't be sorted out face to face, by letter or phone call with the person concerned, you can go through the council's own complaints procedure. Contact the city council Standards and Complaints team and they can guide you through the process, or pick up a Complaints, Comments and Compliments form from any council office. There is a two stage process. Stage one is quick and involves a local manager investigating, but if you are not satisfied you can go to stage two where an independent person investigates. As with education, if you can't resolve the problem at this level, your elected council member, your MP and the Local Government Ombudsman can also be approached, the latter only after you

have complained to your local councillor. There is a caseworker based at Brighton Housing Trust who can offer legal advice on community care issues.

The social worker said she can't complain herself, and she said it was so difficult to get parents to complain for something that is their right, and it's the only way that things will get done.

Health

The law and your rights

Unlike education and social care, our right to health care tends to be general rather than specific and individual. So in social care or education, if your child meets certain legal eligibility criteria, they will be entitled to specific things. In health, there is a universal right to health services from the NHS and children, including disabled children, are covered by this. The NHS Constitution sets out broad rights and commitments such as confidentiality, patients' involvement in their treatment, access to records, waiting times for non-urgent treatment, etc. NHS bodies must assess the health requirements of the people in the area they serve, and commission the services that they consider necessary to meet those needs. And under the Children and Families Act they have to jointly commission services to meet the health needs of children with SEN and disabilities. This means children have a right to have their health needs assessed and for services to meet those needs but not a specific right to particular health services or treatments. This means that if you are unhappy with a health decision you will need to use the NHS complaints process, even if it is about something in the health section of an EHC Plan.

Complaining

As with education and social services, it's almost always best to start with the person most directly involved. Quite often complaints turn out to be due to misunderstandings and can be

cleared up quickly by a conversation or letter. But, if this doesn't work and you need to go to someone else within the service, a complaint can sometimes put things right not only for you, but also for others coming after you.

We had quite a problem because the hospital was very, very busy ... we went to visit her and she was fitting and nobody was with her, and it was really horrific, and so we had to do something about that and so we discharged her right away. But we went and talked to the sister and she was brilliant, and she said 'please complain'.

The best place to start for advice about health complaints is Healthwatch. They are a local watchdog service that offer advice and information about health and health related services. They can tell you where to go next. They can link you up with the PALS (Patient Advice and Liaison Service) for the right health trust who may be able to resolve concerns locally and informally through liaison with the relevant NHS staff, without making a formal complaint. Or they can refer you to the Independent Complaints and Advocacy Service (ICAS) who can help you to make a formal complaint.

If you decide to complain formally the NHS has a two stage process. Stage one is 'local resolution' and is about trying to sort out your complaint with the local bit of the health service responsible for the service or issue in your complaint. Stage two involves complaining to the Health Service Ombudsman. At stage one you will need to address your complaint to the Chief Executive of the organisation involved with delivering the care. Each Trust will have information outlining their complaints procedures and ICAS will help you find this.

If you are not happy with the outcome of your local complaint you can go to stage two - the Health Service Ombudsman. The Ombudsman is independent of the NHS and the service is free

and confidential. Again Healthwatch can give information about taking complaints to the Ombudsman and ICAS can give impartial advice.

It won't be any good going to local councillors about things which are only to do with health, as these issues are not their concern, but you can try your MP.

Compensation

If you believe your child has been the victim of a medical accident and could be entitled to financial compensation, you might want to consider taking legal action against the person or establishment concerned. Of course, a good financial settlement would make a huge difference to a child's long term future, as well as to the peace of mind of parents and siblings. However, it is as well to be aware of the possible drawbacks. You could speak to Healthwatch first to look at other ways of resolving the issue.

Lawsuits can be very expensive, and unless you win you will not get your costs paid. Legal Aid is unlikely to be available. The process can take a very long time, sometimes years. You will need plenty of stamina and, above all, good legal advice. If you do decide to carry on with legal action, you can get free preliminary advice from the charity Action for Victims of Medical Accidents (AVMA). They can tell you whether your case is worth pursuing and can also suggest a good solicitor.

THE EQUALITY ACT

The Equality Act 2010 replaced the Disability Discrimination Act 1995. Like the Disability Discrimination Act, the new law recognises that many disabled people get treated worse in lots of ways just because they are disabled. It can also apply to you if you are discriminated against indirectly i.e. because of your child's disability. A 'service' in this Act has a wide meaning - it

could be anything from health, social services and schools to shops, leisure facilities or hotels and restaurants. And since 2006 all public bodies (schools, councils, health services etc.) have also been covered by the Disability Equality Duty which says they have to positively promote equality for disabled people in what they do.

The DDA and now the Equality Act have begun to make a difference to the way disabled children and adults are treated, and to improve their opportunities to take part in activities that many non-disabled people take for granted. Often just reminding people that they have to think about whether what they are doing contravenes the Equality Act will help bring about a change.

If you want to challenge a service about disability discrimination you may want to get specialist advice from local or national disability organisations or the Citizens Advice Bureau. The Equality and Human Rights Commission is the national body responsible for upholding rights under the Equality Act. For individual queries, there's an advice line called the Equality Advisory Support Service (see 'Useful Contacts'). It might also be worth contacting the Disability Law Service.

The Equality Act applies to all services but our experience is that parents are most likely to use it in relation to schools. The EHRC have produced online guidance for schools and for further and higher education providers about how they should apply the Equality Act. It is worth looking at this on the EHRC website if you are thinking of bringing up a disability discrimination question with your child's school or college.

The Equality Act defines 'disability' and it is worth remembering that this is not exactly the same as the definition of SEN, so not all children with special needs will be covered,

but most will. The Act states that schools have a duty not to discriminate by treating a disabled pupil less favourably than other pupils because of their disability or something arising from their disability. This applies unless they can show that this treatment was a proportionate means of achieving a legitimate aim, such as preserving the health and safety of other pupils. The Act also makes it a duty to make reasonable adjustments so that a disabled pupil is not put at a substantial disadvantage compared to other pupils. This includes taking reasonable steps to provide aids and equipment. Putting these two duties together means a school would have to have a lot to prove to justify any discrimination. This applies to everything the school provides as an educational service, and also admissions and exclusions.

These duties don't include physical alterations to buildings, although schools and LAs do have a duty to plan progressively to improve access. And all schools should now have a Disability Equality Scheme which states how they are working to ensure disability equality within the school. You can ask to see this.

If you want to make a claim of discrimination you need to check where to go as this is different if the issue is admissions, exclusions, other school services or an LA service. Bear in mind they will expect you to have first used your right to complain directly to the school and governing body or LA. It is also worth noting that the type of remedies available under the Equality Act are often not very strong, e.g. an apology, staff training or perhaps extra tuition. On the other hand, politely but firmly raising the issue with the headteacher or governors and referring to why you feel they may be in breach of the Equality Act may achieve the change you want without an actual claim ever being needed.

The Equality Act also covers further and higher education and it provides some protection from discrimination by employers

including where someone is discriminated against in the application and interview process. We cannot cover all of this here but the Equality and Human Rights Commission has much more detailed information on their website. For initial advice locally you can try the Fed Centre for Independent Living.

Details of all the organisations and services mentioned in this chapter are, as usual, in the contact details. With all of these issues, Amaze can help too.