



Understanding Chromosome & Gene Disorders

# How to get legal help and advocacy



[rarechromo.org](http://rarechromo.org)

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“ Never give up, you are your child's voice, make your voice heard. ”

## How to get legal help and advocacy

Sometimes we can find ourselves in a situation where we need some legal advice, it might be because we need help getting support for our child with a rare chromosome or gene disorder. Or it might be that we need help for a family matter or other issue. It is often very difficult to know who to turn to, where to go for that help, and what our rights are. This guide has been produced to help parents find that support.

In this guide we have tried to list sources of help into categories, however, some of the listed solicitors/organisations may assist with more than one of those categories. What they can help with will be mentioned in the text where known; but you may have to investigate further by visiting websites or contacting a law centre.

This guide is beneficial to Unique parents living in England and the rest of the UK.



## Legal Acts

The UK government passes legal acts (primary legislation) to protect its citizens, the most common ones you might come up against are mentioned below. The acts can be read online but are long and arduous, so you might need to sift through what you might need to quote in order to get the services you or your child need. Details on all legislation can be found here: <https://www.legislation.gov.uk/>

- ◆ **The Children’s Act of 2004**  
<https://www.legislation.gov.uk/ukpga/2004/31/contents>
- ◆ **Mental Capacity Act of 2005** <https://tinyurl.com/yxxphvjx>
- ◆ **Equality Act 2010**  
<https://www.legislation.gov.uk/ukpga/2010/15/contents>
- ◆ **Children and Families Act 2014**  
<https://www.legislation.gov.uk/ukpga/2014/6/contents>
- ◆ **The Care Act 2014**  
<https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

**British and Irish Legal Information Institute** <https://www.bailii.org/> BAILII, based at the Institute of Advanced Legal Studies, has British and Irish case law & legislation, European Union case law, Law Commission reports, and other law-related British and Irish material.

## Advocacy

*What is advocacy?*

Advocacy is when a person or organisation helps you or your family member express your views, allowing your voice to be heard and standing up for your rights. This could be in relation to receiving support services, health services, or your legal rights.



## Pro Bono

*What is Pro Bono?*

You may hear the term pro bono and wonder what it even means? Pro bono is shortened from the Latin term ‘pro bono publico’, meaning ‘for the public good’. Someone who works ‘pro bono’ is usually a lawyer or a law student who gives up some of their time on a voluntary basis, to help people who need legal assistance, but aren’t able to pay for legal help.

## Legal Aid

*What is legal aid?*

Legal aid can help meet the costs of legal advice, family mediation and representation in a court or tribunal. You'll usually need to show that:

- ◆ your case is eligible for legal aid
- ◆ the problem is serious
- ◆ you cannot afford to pay for legal costs.

Legal aid is assessed on the income of the person applying, so if it's on behalf of a disabled adult on benefits, they may be entitled even if their parents wouldn't meet the means testing criteria.

**UK Government advice on legal aid** <https://www.gov.uk/legal-aid>  
**Find a legal advisor** <https://www.gov.uk/find-a-legal-adviser>

◆ **Access Social Care** <https://www.accesscharity.org.uk/>  
Provides free legal advice and support to people in England to get the care they are entitled to. Access can't yet take referrals from the general public. All referrals are submitted via member organisations (which you can find listed on the website. However, there are some useful factsheets and template letters in the resources section of their website:  
<https://www.accesscharity.org.uk/resources>

◆ **Advice Now** <https://www.advicenow.org.uk/>  
Advice for England and Wales only. Advice now is a service provided by Law for Life <https://www.advicenow.org.uk/lawforlife>  
Foundation for Public Legal Education  
4th Floor, 18 St. Cross Street, London, EC1N 8UN

◆ **Advocate** <https://weareadvocate.org.uk/>  
Advocate DX, 50-52 Chancery Lane, London WC2A 1HL  
020 7092 3960  
Email: [enquiries@weareadvocate.org.uk](mailto:enquiries@weareadvocate.org.uk)  
Advocate helps to find free legal assistance from volunteer barristers. It was established to provide free advice and representation in deserving cases where Legal Aid is not available, or where the applicant is unable to afford legal assistance. Advocate are the pro bono charity of the Bar, supported by the Bar Council.

◆ **Disability Law Service**  
<https://dls.org.uk/>  
The Foundry, 17 Oval Way, London SE11 5RR  
Free Legal Advice 0207 791 9800  
Email: [advice@dls.org.uk](mailto:advice@dls.org.uk)  
Facebook: <https://www.facebook.com/disabilitylawservice>  
DLS runs a national Advice line which is available from: Monday to Friday 10am - 1pm and 2pm - 5pm. DLS is run by disabled people and funded to

provide free advice line sessions in these specific areas of law:

- ◆ Consumer
- ◆ Community Care
- ◆ Disability Discrimination
- ◆ Education
- ◆ Employment
- ◆ Welfare Benefits

◆ **Law Centres Network** <https://www.lawcentres.org.uk/>

020 3637 1330 (office number, not an advice line)

Facebook: <https://www.facebook.com/LawCentres>

The Law Centres Network promotes Law Centres in England, Wales and Northern Ireland. Law Centres are not-for-profit legal practices providing free legal advice and representation to disadvantaged people. The Law Centres Federation does not provide legal advice. Please go to this page to find your nearest law centre: <https://tinyurl.com/3xrd2r8e>

◆ **Irwin Mitchell solicitors** <https://www.irwinmitchell.com/>

For general enquiries: 0370 1500 100

For health-related enquiries: 0800 028 1943

Facebook: <https://www.facebook.com/IrwinMitchellSolicitors>

**Advice on:** Human Rights, Deprivation of Liberty Safeguards, Disability Law, Health & Social Care Law.

**Useful factsheets and template letters**

<https://tinyurl.com/3us24e8p>

Irwin Mitchell have expert social and healthcare lawyers who can help you to challenge decisions and protect your best interests. They can help clients in a range of disputes over medical and social care issues.

◆ **POhWER** <https://www.pohwer.net/>

0300 456 2370

Email: [pohwer@pohwer.net](mailto:pohwer@pohwer.net)

Advocacy help.

◆ **Rook Irwin Sweeney LLP** <https://rookirwinsweeney.co.uk/>

107-111 Fleet Street, London, EC4A 2AB

0207 936 9886 Email: [enquiries@rislaw.co.uk](mailto:enquiries@rislaw.co.uk)

Experienced public law and human rights lawyers, having acted in many of the leading cases of the last decade.

## Carers rights, health and social care

### ◆ **Luke Clements** <http://www.lukeclements.co.uk/>

Luke Clements is the Cerebra Professor of Law and Social Justice at the School of Law, Leeds University. Luke is also a solicitor with Scott-Moncrieff & Associates Ltd.

### ◆ **CASCAIDR** <https://www.cascaidr.org.uk/>

Referral form via the website, alternatively  
Email: [belinda@CASCAIDr.org.uk](mailto:belinda@CASCAIDr.org.uk)  
Twitter: @BelindaSchwehr  
Facebook: <https://www.facebook.com/cascaidr>  
The Centre for Adults' Social Care – Advice, Information and Dispute Resolution. FREE resources and information about adult social care legal problems - and chargeable but inexpensive advice for related matters.



### ◆ **Care to be different**

<https://caretobedifferent.co.uk/>

0161 979 0430

A specialist online information resource all about NHS Continuing Healthcare funding in England.

### ◆ **AVMA (Action Against Medical Accidents)**

<https://www.avma.org.uk/>

Helpline: 0845 123 2352 Monday to Friday 10am to 3.30pm.

The UK charity for patient safety & justice. Before calling the AVMA helpline number, please check out their range of online self-help guides <https://www.avma.org.uk/help-advice/guides/> which may contain the information you are looking for.

## Formal complaints

If you make a formal complaint to Social Services or the NHS or other public service and it isn't dealt with appropriately, you can ask the **Public Services Ombudsman's Office** in your respective country to investigate.

◆ **England** <https://www.lgo.org.uk/>

◆ **Wales** <https://www.ombudsman.wales/>

◆ **Scotland** <https://www.spsso.org.uk/>

◆ **Northern Ireland** <https://tinyurl.com/4vfs9ahy>

### ◆ **Safeguarding Futures** <https://safeguardingfutures.co.uk/>

Melanie or Steve Parsons 07795 578700 or 07904 480164

Email: [info@safeguardingfutures.co.uk](mailto:info@safeguardingfutures.co.uk)

Facebook: <https://www.facebook.com/groups/660675124407882>

Health and social care support. Very knowledgeable about CHC funding.

## Children's law and Education

Education problems in particular are one of the biggest issues facing parents who have a child with a rare chromosome or gene disorder. Getting the right support for our children is so important. The SEND code of practice: 0 to 25 years details guidance on the special educational needs and disability (SEND) system for children and young people aged 0 to 25 <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

◆ **IPSEA** (Independent Provider of Special Education Advice)  
<https://www.ipsea.org.uk/>

01799 582030 (Monday to Friday, 9am-5pm)

Email: [office@ipsea.net](mailto:office@ipsea.net)

Please note: admin office staff are unable to give advice – if you have a query relating to your child's SEND, you will need to book a helpline appointment online. IPSEA have some model letters that you can adapt to your own requirements: <https://www.ipsea.org.uk/model-letters>

◆ **SOS!SEN** <https://sossen.org.uk/>

0208 538 3731

Email: [admin@sossen.org.uk](mailto:admin@sossen.org.uk)

Facebook: <https://www.facebook.com/SOSSpecialEducationalNeeds>

- ◆ getting the right help for your child
- ◆ dealing with the school or local authority
- ◆ interpreting official letters
- ◆ getting a statement for your child
- ◆ finding independent expert professional advice
- ◆ appealing to the Special Educational Needs and Disability Tribunal.

Both IPSEA and SOS!SEN do great courses - essential for anyone getting to grips with EHCP's before you start hiring expensive lawyers. IPSEA provides pro bono help with going to tribunal but you need to persevere to get an appointment for a consultation. However, they have a fantastic list of template letters For many typical situations along the way E.G. the LA refusing to assess, or not specifying how much therapy input will be provided in the EHCP, etc.

◆ **SENDIAS** (SEND Information, Advice and Support)

All local authorities in England will provide a SEND information, advice and support service for parents of children and young people who have special educational needs and/or disabilities. You will find contact details on your county council website.

◆ **Coram Children's Legal Centre**

<https://www.childrenslegalcentre.com/>

Family, Child & Education Legal Advice: 08088 020 008 (Mon-Fri 8am-8pm)

Facebook: <https://www.facebook.com/CCLCUK/>

Free legal advice on English law and policy affecting children and families. Coram Children's Legal Centre provides free legal information, advice and representation to children, their families and carers, as well as international consultancy on child law and children's rights. They offer expertise in all areas of family, child and education law, including:

- ◆ domestic violence
- ◆ child protection
- ◆ immigration/asylum
- ◆ school admissions

Part of the Coram group of charities, the Centre is staffed by lawyers and professionals with expertise in child, family, education and human rights law.

◆ **Cerebra's Pro Bono Programme (UK)** <https://cerebra.org.uk/>

Freephone helpline 0800 328 1159

Email: [info@cerebra.org.uk](mailto:info@cerebra.org.uk)

**Legal rights service** <https://tinyurl.com/h3pr58xf>

Cerebra's Legal Entitlements and Problem-Solving (LEaP) Project and the Legal Rights Service that runs alongside it have come out of a collaboration with the University of Leeds School of Law.

The LEaP Project is open to parents and carers of children aged 16 or under who have a brain condition and who need help to resolve a legal problem regarding access to health, social care or other support services.

It is an innovative problem-solving project that has been developed with the School of Law at the University of Leeds. Cerebra also has some very useful template letters that will help parents living in England, Wales and Scotland to make a complaint: <https://cerebra.org.uk/get-advice-support/legal-and-financial/template-letters/>

◆ **Allen and Co. Solicitor** <https://www.allenandcosolicitor.co.uk/>

01494 870270

Email: [tracey@allenandcosolicitor.co.uk](mailto:tracey@allenandcosolicitor.co.uk)

Allen and Co is a solicitor's practice based in Chalfont St Giles Bucks, specialising in education law. They can help with school admission appeals and exclusions from school, special educational needs and disability matters (SEND) and home to school transport problems. Legal help and advice for children and young people with learning difficulties/ SEND.

◆ **Douglas Silas Solicitors (DSS)**

<https://www.specialeducationalneeds.co.uk/>

0208 349 7700 Email: [info@dsslaw.co.uk](mailto:info@dsslaw.co.uk)

A small, nationally acclaimed and renowned firm of solicitors run by Douglas Silas. They specialise exclusively in advising and representing parents of children and young people with Special Educational Needs (SEN).

◆ **Just For Kids Law** <https://justforkidslaw.org/>

Unit 2, Crystal Wharf, 36 Graham Street, London N1 8GJ  
0203 174 2279

Email: [info@justforkidslaw.org](mailto:info@justforkidslaw.org)

Just for Kids Law is a UK charity that works with and for children and young people providing legal representation and advice, direct advocacy and support, and campaigning to ensure children and young people in the UK have their legal rights and entitlements respected and promoted, and their voices heard and valued. Because of the nature of the work, the firm works closely with young people with learning difficulties, emotional behavioural difficulties and more severe mental health problems. It specialises in representing children with these difficulties and litigating for their level of understanding within the criminal justice system. It has experience of working with young people who have been diagnosed with an autism spectrum disorder (ASD). Just for Kids Law provides advocacy, support and assistance to young people in difficulty; particularly those in trouble with the law, looked after children and those at risk of exclusion from school.



◆ **The Queen Mary Legal Advice Centre** <http://www.lac.qmul.ac.uk/>

020 7882 3931

Email: [lac@qmul.ac.uk](mailto:lac@qmul.ac.uk)

Facebook: <https://www.facebook.com/QMLAC/>

The Queen Mary Legal Advice Centre is a free community law centre which is run by Queen Mary University of London. Trained and supervised law students give free legal advice to members of the public through a range of different clinics and across different areas of the law. Recognising the huge unmet need for legal advice, for families living with Special Educational Needs, the QMLAC launched a specialist clinic in this area. The Centre is based in the heart of east London and uses Student Advisers (supervised by volunteer barristers and solicitors who are specialist in the SEND law) to advise clients on a range of legal issues. The Centre is open during university term time and is free of charge.

◆ **SEN Legal** <https://www.senlegal.co.uk/>

SEN Legal Ltd, Unit 3 - 4 Forbes Business Centre, Kempson Way,  
Bury St Edmunds, IP32 7AR  
01284 723952

Email: [customerservices@senlegal.co.uk](mailto:customerservices@senlegal.co.uk)

Facebook: <https://www.facebook.com/senlegal>

SEN Legal is a national and specialised legal practice. They specialise in education law, in particular Special Educational Needs and Disability for children and young persons aged 0-25. A nationwide practice available to anyone in England and Wales.

◆ **Sinclairs Law** <https://www.sinclairslaw.co.uk/>

◆ Cardiff 029 2038 8398

◆ London 020 8891 4488

◆ Penarth 029 2070 6444

◆ Twickenham 020 8891 4488

Email: [education@sinclairslaw.co.uk](mailto:education@sinclairslaw.co.uk)

Sinclairs Law is a specialist law firm that specialises in education law, representing many clients at Special Educational Needs Tribunals. In addition, they assist families who are having difficulty with children with emotional behavioural difficulties and autism-related conditions and securing social services provision.

◆ **Tayntons LLP Solicitors** <https://www.tayntons.co.uk/>

0800 158 4147

Email: [info@tayntons.co.uk](mailto:info@tayntons.co.uk)

Tayntons LLP Solicitors offer specialist help and guidance to parents who have children with special educational needs. This includes students who are in further education. They will then guide you through the stages, whether at nursery or school level, of requesting a statutory assessment from your local authority and the EHCP process. Tayntons can also help if you have had an assessment request refused or you are not satisfied with the outcome of one. They can guide you through the formal appeals and tribunal process.

◆ **The Children's Legal Practice Ltd**

<https://www.childrenslegalpractice.com/>

01329 823 322

A specialist firm of solicitors focused on education and family law.

◆ **Turner's Solicitors**

<http://educationlawspecialists.co.uk/>

01656 768 500

Provides legal advice to parents of children with special needs. They deal with appeals to the special educational needs tribunal and advise parents on the appropriate evidence that is needed to bring a successful appeal. Turner's Solicitors also assist parents in getting the right community care provision at home, so their family and other children can have a break from the responsibilities of caring.

◆ **Wordswell** <https://www.wordswell.co.uk/>

0333 123 8895

Wordswell are a team of independent speech and language therapists, providing Assessment; Reports, including those for special educational needs statementing; Medico-legal reports; Individual therapy; Therapy groups including social skills; Home visits; School visits; Review; Speech and language therapy programmes; Attendance at SENDIST tribunals or at court as an expert witness.

# Disability rights

## ◆ Equality and Human rights commission

<https://www.equalityhumanrights.com/en>

0808 800 0082

Opening hours: 9am to 8pm Monday to Friday

10am to 2pm Saturday

Closed on Sundays and Bank Holidays.

If you need expert information, advice and support on discrimination and human rights issues and the applicable law, especially if you need more help than advice agencies and other local organisations can provide.



## ◆ The Ann Craft Trust (ACT)

<https://www.anncrafttrust.org/>

The Ann Craft Trust (ACT) was founded by Dr Ann Craft in 1992 under the name of NAPSAC - the National Association for the Protection from Sexual Abuse of Adults and Children with Learning Disabilities. For over 21 years ACT has championed the rights of disabled people and pushed forward the UK's understanding of safeguarding.

## ◆ Disability Rights UK <https://www.disabilityrightsuk.org/>

General enquiries: Office Number: 020 7250 8181 This line open Mon-Fri, between 10am and 12.30pm and 1.30 and 4pm. Please note: This line is not an advice line.

Email: [enquiries@disabilityrightsuk.org](mailto:enquiries@disabilityrightsuk.org)

Disability Rights UK works to create a society where everyone with lived experience of disability or health conditions can participate equally as full citizens.

## ◆ DIDLAW <https://didlaw.com/>

Disability discrimination law & mental health at work.

“ Our Citizen's Advice Bureau (CAB) put me in touch with the local Advocacy agency. My daughter's advocate represented her in meetings with our local authority and the charity who runs several of our local individual homes for disabled people (providing 24-hour-care). As these advocacy services are INDEPENDENT, they would have been able to challenge the position of the local council on my daughter's behalf. I found their service invaluable, especially as our advocate knew when to step up and ask questions on my behalf whenever I got to the point where I couldn't cope anymore. To me, it was also of great importance to have an independent witness at these meetings who would take notes and confirm what had been said/promised/agreed. ”

# Best interests' decisions, Court of Protection, DOLs, Lasting Power of Attorney, Mental Capacity, Wills and Trusts

## Best interests' decisions

If a person has been assessed as lacking capacity, then any action taken, or any decision made for, or on behalf of that person, must be made in his or her 'best interests'. The person who has to make the decision is known as the 'decision-maker', this could be the parent/carer or a medical professional e.g. a doctor or paediatrician.

### ***What are the 'best interests'?***

Health professionals and others must act in the best interests of the person who lacks capacity before taking certain steps that affect their care and treatment. Some of the factors to take into consideration are: supporting their involvement in acts done for them and decisions affecting them

- ◆ considering all the wishes, feelings or instructions they expressed before losing capacity to make the decision, as well as any beliefs and values that are important to them.
- ◆ considering the views of their carers, family, or people who may have an interest in their welfare, or people they have been appointed to act for them.

## Mental Capacity Act Code of Practice

<https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>

The code of practice gives guidance to people who:

- ◆ work with people who can't make decisions for themselves
- ◆ care for people who can't make decisions for themselves

It says what you must do when you act or make decisions on behalf of people who can't act or make those decisions for themselves. The Mental Capacity Act 2005 (MCA) says certain people must think about the code of practice when they act or make decisions on the other person's behalf. This includes:

- ◆ an attorney appointed under a lasting power of attorney
- ◆ a deputy appointed by the Court of Protection
- ◆ an independent mental capacity advocate
- ◆ a person doing research approved in accordance with the MCA
- ◆ a person who acts in a professional capacity for, or in relation to, people who can't make decisions for themselves
- ◆ a person who is paid to act for or in relation to people who can't make decisions for themselves

- ◆ **Mencap** has also produced a guide on the Mental Capacity Act, you can view it here: <https://tinyurl.com/2zd65tsv>

## DOLs (Deprivation of Liberty safeguards)

The Deprivation of Liberty Safeguards (DOLs) is part of the Mental Capacity Act 2005. The aim of DOLs is to ensure that people in care homes and hospitals are cared for in a way that does not restrict their rights to freedom.

## Wills and Trusts

### **THIS IS ONE OF THE MOST IMPORTANT THINGS YOU MUST DO!**

It is absolutely essential that you do not leave money in your will to your disabled children and you warn grandparents and other friends and relatives not to. **If your disabled son or daughter inherits from you or others more than £x, they may not get support with care and housing from their Local Authority. If you die without a will, they will automatically inherit a share of your estate which may affect their entitlement for support. If you want to avoid that, please consult a solicitor to draw up a will leaving their share in trust.**

As each family's circumstances will be different, you will need to discuss with a solicitor which type of trust is appropriate for you. The two trusts available are the **Discretionary trust** and the **Disabled persons trust**.

**Discretionary trusts** are where the trustees can make certain decisions about how to use the trust income, and sometimes the capital. Depending on the trust deed, trustees can decide:

- ◆ what gets paid out (income or capital)
- ◆ which beneficiary to make payments to
- ◆ how often payments are made
- ◆ any conditions to impose on the beneficiaries

Discretionary trusts are sometimes set up to put assets aside for:

- ◆ a future need, like a grandchild who may need more financial help than other beneficiaries at some point in their life
- ◆ beneficiaries who are not capable or responsible enough to deal with money themselves

**Disabled persons trust** also known as a Special Needs Trust or Vulnerable Persons Trust has more favourable tax treatment for inheritance tax, capital gains tax, and income tax purposes than a discretionary trust. For more information:

<https://www.gov.uk/trusts-taxes/types-of-trust> and

<https://www.gov.uk/trusts-taxes/trusts-for-vulnerable-people>

A good/essential starting point it is to do the mencap wills and trusts training Mencap for courses and online advice

<https://www.mencap.org.uk/advice-and-support/wills-and-trusts-service>

## Court of Protection and Deputyship

<https://www.gov.uk/courts-tribunals/court-of-protection>

You can apply to become someone's deputy if they 'lack mental capacity' - meaning that they can't make a decision for themselves at the time it needs to be made. They may still be able to make decisions for themselves at certain times.

As a deputy, you'll be authorised by the Court of Protection to make decisions on their behalf. There are 2 types of deputy:

- ◆ property and financial affairs, e.g. paying bills, organising a pension
- ◆ personal welfare, e.g. making decisions about medical treatment and how someone is looked after.

You can apply to be just one type of deputy or both. If you're appointed, you'll get a court order stating what you can and can't do.

### How to apply

Check you meet the requirements to be a deputy. Send the application forms to the Court of Protection and pay the application fee. You don't need to be a deputy if you're just looking after someone's benefits. Apply to become an appointee instead.

### Checks on your application

The Court of Protection will check:

- ◆ whether the person needs a deputy, or some other kind of help
- ◆ there are no objections to your appointment.

If you're appointed, the Office of the Public Guardian will help you carry out your responsibilities. You may have to complete an annual report. You'll continue to be a deputy until your court order is changed, cancelled or expires.

### Other ways to make decisions for someone

If you want to make a single important decision, you can apply to the Court of Protection for a one-off order.

### Who can apply to be a deputy?

You can apply to be a deputy if you're 18 or over. Deputies are usually close relatives or friends of the person who needs help making decisions. If you want to become a property and affairs deputy, you need to have the skills to make financial decisions for someone else. The court can appoint 2 or more deputies for the same person. The court will tell you how to make decisions if you're not the only deputy. It will be either:

- ◆ together (usually called 'jointly'), which means all the deputies have to agree on the decision
- ◆ separately or together, which means deputies can make decisions on their own, or with other deputies.

### Other types of deputy

Some people are paid to act as deputies, e.g. accountants, solicitors or representatives of the local authority. The Court of Protection can appoint a specialist deputy (called a 'panel deputy') from a list of approved law firms and charities if no one else is available.

## Responsibilities

As a deputy, you're responsible for helping someone make decisions or, making decisions on their behalf. You must consider someone's level of mental capacity every time you make a decision for them. You can't assume it's the same at all times and for all things. You'll get a court order from the Court of Protection which says what you can and can't do.

### When you're making a decision, you must:

- ◆ make sure it's in the other person's best interests
- ◆ consider what they've done in the past
- ◆ apply a high standard of care - this might mean involving other people, e.g. getting information from relatives and professionals e.g. doctors or therapists.
- ◆ do everything you can to help the other person understand the decision, e.g. explain what's going to happen with the help of pictures or sign language.

### You must not:

- ◆ restrain the person, unless it's to stop them from coming to harm
- ◆ stop life-sustaining medical treatment
- ◆ take advantage of the person's situation, e.g. abuse them or profit from a decision you've taken on their behalf
- ◆ make a will for the person, or change their existing will
- ◆ make gifts unless the court order says you can
- ◆ hold any money or property in your own name on the person's behalf (except if they live at home and you receive welfare benefits for them to pay for care, etc.).

## Property and affairs deputies

You must make sure:

- ◆ your own property and money is separate from the other person's
- ◆ you keep records of the finances you manage on their behalf

You may need to manage a Court Funds Office account on the other person's behalf.

**Apply to be a deputy** <https://www.gov.uk/become-deputy/apply-deputy> to download and fill in:

- ◆ an application form (COP1)
- ◆ an assessment of capacity form (COP3)
- ◆ a deputy's declaration (COP4)
- ◆ an information form (COP1A) if you're applying to be a property and affairs deputy
- ◆ an information form (COP1B) if you're applying to be a personal welfare deputy

Send the originals to the Court of Protection with:

- ◆ 2 copies of your application form
- ◆ 1 copy of the other forms
- ◆ a cheque for the application fee.

PO Box 70185, First Avenue House, London WC1A 9JA

The court will aim to send you a stamped copy of your application within a

week of receiving it. This means your application is being considered (it has been 'issued'). You'll be sent a letter explaining what to do next. Within 14 days of the application being issued, you must tell (sometimes called 'serving') the following people :

- ◆ the person you're applying to be a deputy for
- ◆ anyone named in your application as having an interest, e.g. the person's close relatives.

## Lasting Power of Attorney

<https://www.gov.uk/power-of-attorney>

A lasting power of attorney (LPA) is a legal document that lets you (the 'donor') appoint one or more people (known as 'attorneys') to help you make decisions or to make decisions on your behalf. This gives you more control over what happens to you if you have an accident or an illness and cannot make your own decisions (you 'lack mental capacity'). A lasting power of attorney (LPA) is a legal document that lets your child (the 'donor') appoint one or more people (known as 'attorneys') to help them make decisions or to make decisions on their behalf. This gives them more control over what happens to them if, for example, they have an accident or an illness and can't make decisions at the time they need to be made (they 'lack mental capacity'). Your child must be 18 or over and must have mental capacity (the ability to make their own decisions) when they make their LPA. **There is often confusion about where it applies to people with special needs/disabilities. An LPA only applies to higher functioning adults (who understand money for example)** but prefer their parents to look after it for them There are 2 types of LPA:

- ◆ health and welfare
  - ◆ property and financial affairs
- They can choose to make one type or both.

There's a different process in:

**Scotland** (Guardianship) <http://www.publicguardian-scotland.gov.uk/>

This website provides a single information point about financial provisions contained in the Adults with Incapacity (Scotland) Act 2000.

**Northern Ireland:** <https://www.nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney>

## How to make a lasting power of attorney

Choose your attorney (you can have more than one). Fill in the forms to appoint them as an attorney. Register your LPA with the Office of the Public Guardian (this can take up to 12 weeks). It costs about £80 to register an LPA, unless you get a reduction or exemption.

1. Health and welfare lasting power of attorney

Use this LPA to give an attorney the power to make decisions about things like:

- ◆ your child's daily routine, e.g. washing, dressing, eating

- ◆ medical care
- ◆ moving into a care home
- ◆ life-sustaining treatment

It can only be used when your child is unable to make their own decisions.

## 2. Property and financial affairs lasting power of attorney

Use this LPA to give an attorney the power to make decisions about money and property for your child, for example:

- ◆ managing a bank or building society account
- ◆ paying bills
- ◆ collecting benefits or a pension
- ◆ selling the donor's (your child's) home

Both LPA's can only be used after they have been registered with the Office of the Public Guardian, then

- ◆ Property and Financial affairs – can be used by an attorney even when the donor (your child) still has mental capacity, but
- ◆ Health and Welfare – cannot be used by an attorney whilst the donor still has mental capacity.

Contact the Office of the Public Guardian if you need help and to find out more information on fees.

### Office of the Public Guardian

0300 456 0300 Email: [customerservices@publicguardian.gov.uk](mailto:customerservices@publicguardian.gov.uk)

Monday, Tuesday, Thursday, Friday, 9am-5pm Wednesday, 10am-5pm

- ◆ **Ben Hoare Bell LLP** <https://www.benhoarebell.co.uk/>

Ouseburn Point, 40 Shields Road, Newcastle-upon-Tyne NE6 1DR  
0191 275 2626

Ben Hoare Bell deal with all aspects of Community Care law and with Court of Protection welfare proceedings. They have mental health, housing, public law and criminal law departments but do not cover education. They also offer advice and representation in Family Law. The client groups they cover include those with autism, learning disabilities, mental health conditions, acquired brain injury, older people and the carers of all those groups. The health and social care department of the firm comprises female and male solicitors.

- ◆ **Campbell Law Solicitors** <http://www.campbell-law.co.uk/>

3b Opal Court, Opal Drive, Fox Milne, Milton Keynes, MK15 0DF  
01908 803492

Email: [mail@campbell-law.co.uk](mailto:mail@campbell-law.co.uk)

Solicitors' practice offering advice, assistance and representation in the areas of mental health, mental capacity and community care law. As well as the issues listed below the firm also offers support with Lasting powers of attorney and Court of Protection.

◆ **Gorvins Solicitors** <https://www.gorvins.com/>

Dale House, Tiviot Dale, Stockport SK1 1TA  
0161 930 5151

Provides legal advice to parents and families in relation to Will planning (with the use of trusts to protect vulnerable beneficiaries), Powers of Attorney and applications to the Court of Protection.

◆ **Mackintosh Law** <https://www.macklaw.co.uk/>

020 7357 6464

Email: [iconinfo@macklaw.co.uk](mailto:iconinfo@macklaw.co.uk)

Twitter [@macklawlondon](https://twitter.com/macklawlondon)

A specialist law firm providing legal advice and representation to disabled clients in the niche areas of mental capacity and community care.

◆ **Renaissance legal**

<https://www.renaissancelegal.co.uk/our-clients/disabled-and-vulnerable/>

Pacific House, 126 Dyke Road, Brighton, BN1 3TE

01273 610 611

Email: [info@renaissancelegal.co.uk](mailto:info@renaissancelegal.co.uk)

Solicitors for Disabled and Vulnerable Person in Brighton and SE England.

◆ **Whitehead Monckton - Lawyers and Investment Managers**

<https://www.whitehead-monckton.co.uk/for-individuals>

01622 698000

Email: [enquiries@Whitehead-Monckton.co.uk](mailto:enquiries@Whitehead-Monckton.co.uk)

Whitehead Monckton is a law firm with offices in Maidstone and Tenterden, Kent. They offer advice in areas of mental health, mental capacity, wills and trusts and lasting powers of attorney, as well as Court of Protection matters.



◆ **Wrigleys Solicitors**

<https://www.wrigleys.co.uk/injured-disabled-or-vulnerable-people/>

0114 267 5588

Wrigleys acts as deputies, trustees and trust administrators for vulnerable people. Their aim is to develop a comprehensive legal service for people with disabilities. They provide specialist wills and trusts advice to disabled people and their families. They are Court of Protection specialists.

## Family Law

### ◆ **FLIP (Family Law in Partnership)**

<https://www.flip.co.uk/children-with-special-educational-needs-divorce-education/>

Family Law in Partnership, Melbourne House,  
46 Aldwych, London WC2B 4LL  
020 7420 5000

Email: [hello@flip.co.uk](mailto:hello@flip.co.uk)

Facebook: <https://www.facebook.com/familylawinpartnership>

Family law including divorce.

### ◆ **Oratto** <https://oratto.co.uk/>

St John's House, St John's Street, Chichester, West Sussex PO19 1UU  
01243 850603

E-mail: [contact@oratto.co.uk](mailto:contact@oratto.co.uk)

Oratto is a free online resource providing information and guides on a wide range of family law areas. National Helpline and Live Chat are open Monday-Friday 8.30am to 5.30pm. Evening and Weekend telephone appointments are available, email to arrange an appointment.

### ◆ **Coram**

<https://www.childrenslegalcentre.com/get-legal-advice/child-and-family/>

Coram Children's Legal Centre's Child Law Advice Service provides free legal advice and information on child and family issues. For child law advice please visit: <https://childlawadvice.org.uk/>

Family or Child law: 0300 330 5480.

Education law: 0300 330 5485. Monday – Friday between 8am to 6pm

The demand for both lines are high and they are only able to answer a limited number of calls. They can only advise residents of England

### ◆ **Slater Heelis solicitors** <https://www.slaterheelis.co.uk/>

0161 969 3131

Based in the Manchester area, Slater Heelis is a firm of solicitors providing a wide range of specialist legal help to individuals.

## Housing law

Housing law includes a range of landlord and tenant issues, covering various areas of law from criminal damage to breach of contract. For more information: <https://www.hlpa.org.uk/cms/>

## Scotland

### ◆ **Cairn Legal** <http://www.cairnlegal.co.uk>

Regent House, West Regent Street, Glasgow, G2 2RU

0141 221 7948 Email: [info@cairnlegal.co.uk](mailto:info@cairnlegal.co.uk)

Cairn Legal are a small, specialist law firm with expertise in the areas of wills, trusts, guardianship applications, powers of attorney, adult protection, community care, disability discrimination and education law.

◆ **Citizens Advice** <https://www.citizensadvice.org.uk/scotland/>

◆ **Enquire** <https://enquire.org.uk/>

Helpline on 0345 123 2303

Enquire is the Scottish advice service for additional support for learning

◆ **Govan law centre** <https://govanlawcentre.org/>

0800 043 0306 Email: [m@govanlc.com](mailto:m@govanlc.com)

Facebook:

<https://www.facebook.com/Govan-Law-Centre-485591671499123/>

Govan Law Centre is a free legal resource. Through the legal practice of Dailly & Co., Solicitors. They offer expert advice, court and tribunal representation in Scotland. They use the law to challenge poverty, discrimination and disadvantage. They specialise in housing, landlord and tenant, homelessness, welfare rights, money advice, social services, consumer and debt. They also have an education law unit and work with carers and around mental health.

◆ **The Scottish Child Law Centre**

<https://sclc.org.uk/>

91 George Street, Edinburgh, EH2 3ES

0131 667 6333 Email: [advice@sclc.org.uk](mailto:advice@sclc.org.uk)

Free legal advice on children's rights and child law across Scotland. This service is provided via telephone and email, on all aspects of Scots law relating to children and young people, including education; additional support needs. All calls and emails are answered by fully qualified solicitors and their advice is impartial, confidential and child centred.

◆ **TC Young solicitors**

<https://www.tcyoung.co.uk/>

⇒ Glasgow 0141 221 5562

⇒ Edinburgh 0131 220 7660

TC Young solicitors have experience in adult incapacity law and associated areas of law in Scotland. They assist with power of attorney for people who are legally capable and give advice on guardianships for those who are not.



## Wales

◆ **SNAP Cymru**

<https://www.snipcymru.org/>

SNAP Cymru provides information, advice and support for parents, children and young people who have, or may have, special educational needs or disabilities

### ◆ All Wales Forum

<http://www.allwalesforum.org.uk/>

The AWF is unique among Learning Disabilities bodies in Wales in that it is the only organisation that represents nationally, collectively and solely the views of Parents and Carers of people with learning disabilities.

## Northern Ireland

### ◆ Citizens Advice

<https://www.citizensadvice.org.uk/about-us/northern-ireland/>

### ◆ Special Educational Needs Advice Centre (SENAC)

<https://senac.co.uk/>

ADVICE LINE – 028 9079 5779

Advice Coordinator: Rosie Oakes [rosieoakes@senac.co.uk](mailto:rosieoakes@senac.co.uk)

Providing confidential, independent advice and advocacy on behalf of children and young people with disabilities and special educational needs (SEN) attending schools in Northern Ireland up to the age of 19 years. They give advice and support on a range of issues including statutory assessments, statements of special educational needs, obtaining provision in school and appeals.

## USA

In the USA there is a specific set of laws. Americans with Disabilities Act (ADA) which govern all the ways people with disabilities are specifically protected. The government overview can be found here: <https://www.ada.gov/cguide.htm>

The area that parents of children with chromosome disorders will most often deal with is called IDEA (Individuals with Disability Education Act). This requires all public schools to provide an IEP (Individualized Education Plan) for all children with disabilities, to make sure they are able to access their education.

This most often includes things like accommodation for their needs - wheelchair ramps, sensory breaks, extra time on tests, etc. and then services, like speech therapy, occupational therapy, etc. For example: in California there is a non-profit that specifically works to provide legal advice and help for any suspected violations of ADA law. There are similar organisations in other states: <https://www.disabilityrightsca.org/>



## Parent Quotes

*(USA parent quote). “ DRC helped me a lot. First they gave me vocabulary to help make the school pay closer attention - saying “my son is unable to access his services in this online format”, which got MUCH more attention than “he hates it online, please can we change.” But in our school’s case they were still not willing to do more than promise they would “try to hire someone in person the next year”. So DRC advised me on how to file an official IDEA violation complaint with the state. The claim was investigated by the California department of education, and the school was found in partial violation of FAPE (Free and Accessible Public Education) and required to provide extra service hours to make up for the lost time. We then had a special meeting to discuss the new plan, and a DRC lawyer attended the meeting with me to help make sure the law was followed and that I understood what was discussed. At first I was so stressed out about the whole process. Just the idea of making a legal complaint sounded so intimidating. But it really was not that big of an issue, as everyone I dealt with was so helpful. The disability rights advocate emailed and called regularly to talk me through the process. The state education investigators explained what information they needed from me and what they would be doing. Then the decisions came back via email and the lawyer explained it to me and then came to our school meeting to help. And it was all free! A few times I did get emotionally tired of the whole process, and considered giving up. But the disability rights advocate reminded me that I wasn’t doing it just for my son. I was making the case for all the kids who were not being given the services they needed and that organizations will always try to do the least hard and cheapest thing and it’s up to us parents to advocate and fight to make sure our kids get what they are entitled to. That meant a lot to me; I pictured myself paving the way for all the future kids who came behind. It was lots of work but it was worth it in the end! I hope this can encourage other families! ”*

*“ We really struggled with the EHCP process. I received excellent support from IPSEA. They helped me through mediation and 2 tribunals. They also do a really good parents legal course regarding EHCP’s which is so helpful. The National Autistic Trust also do a good support scheme for young people who are also on the spectrum. SENDIAS is also helpful. ”*

“ When our daughter was first offered an EHCP, we had no reason to question the professionals who assessed her on behalf of the Local Authority we fall under. We were grateful for the support given and believed it was collaborative. Our daughters primary need was considered to be Communication and Interaction Needs and she was placed in a mainstream school with a COIN unit. All was well in Reception. In Year 1, we were told that our daughter was not progressing, and she may have Down Syndrome as she benefitted from strategies that the Speech and Language Therapist used for teaching children with Down Syndrome. We were referred by our GP to a Paediatrician who referred us to a Geneticist. We found out our daughter has an 18p deletion when she was 5 years old. At the Annual Review in Year 2, we were told that the school could no longer meet her needs and they recommended a change of placement. This was in April 2019. The LA SEND Team completely ignored us as a family and only answered formal letters at the end of stages as per the SEND Code of Practise. For the formal letters I used templates available from IPSEA. I sought advice from IPSEA and SOS!SEN and I also was able to draw on the experiences of other parents who are members of the Facebook page that Unique has set up and from a local EHCP Experiences Group. The LA SEND Team did not carry out any assessments to ascertain need when it was clear that the provision had to change. As an example, the LA SEND Team had a request to carry out an Occupational Therapy Assessment but failed to carry one out (requested December 2018 and not carried out by Tribunal May 2020). We did carry out our own independent assessments and found that our daughter's primary need is Speech and Language Communication Needs, which was ascertained by an Educational Psychologist, a Speech and Language Therapist, and a Specialist Teacher. Her Occupational Therapy needs were determined to be significant. Additionally, it was found that she has significant issues with visual spatial perception and is under the care of a Behavioural Optometrist, who has provided Vision Therapy. All of these combined, affects how our daughter can access her education, and our choice of school was one that most suited her needs. We preferred an independent specialist provision that helps children whose main need is SLCN. Despite sharing all of this information with the LA SEND Team, their Speech and Language Therapy Team together with an LA SEND Educational Psychologist who never met my child deemed our daughter to have Developmental Language Delay. Once they had this diagnosis the LA SEND Team said that our daughter should remain in a similar banded provision within a unit at a mainstream school. After waiting the statutory period for the LA SEND Team to issue the Final Amended EHCP, it was still not ready, and I demanded the completed document so I could utilise my right of appeal. The completed document was almost exactly the same as the document it was meant to replace that was 3 years old! It was at this stage that I contacted an advocate in order that I did not jeopardise the outcome when going to Tribunal. The advocate was recommended, knowledgeable, understanding and helpful. The advocate was able to ensure things kept moving, understood all of the legal jargon and was familiar with the legal team at the LA. I believe that this made things easier. As the advocate was

....continued...

not emotionally involved, she was able to be objective at each stage. For us, securing the correct placement was paramount. Yes, this was expensive, and yes it can be done without an advocate – but if I had to do it all again, I would not hesitate to have the assistance that I had by utilising an advocate. At the Tribunal, the Tribunal Judge commented on how well we as parents had worked with the school SENCo who supported the move, and how the LA SEND Team had ignored us. The LA SEND Team conceded 1 and a half hours into the Tribunal and all of the recommendations suggested by the independent assessments are now in the Post Tribunal Final Amended EHCP and our daughter has been at her new school for one year. At her latest Annual Review, she had made progress across all of the 4 broad areas of the EHCP – and is making her way to be the best she can be. Having this achievement, due to the dedication and support of the teaching team and integrated therapies, has been worth utilising an advocate. Following the Tribunal I did go through the LA's complaint service and then to the Local Government Ombudsmen who found the LA at fault. The advocate (as well as being recommended by parents on the Facebook EHCP Experiences page), was recommended to me by a parent who has a daughter with the same deletion and our daughters are now at the same school – which is astounding. I made contact with this parent through Unique and would never have thought 3 years later our daughters would be at school together! There are only between 65 and 70 pupils at this school. ”

“ We got our son's diagnosis for 47XYY at the end of year 2. By the middle of year 5, the local authority were still refusing to award Top-Up funding and as a result, the school were left paying for a 1:1 learning support assistant out of their own budget. I contacted a charitable education law organisation called IPSEA, who listened to the whole story and then advised that I apply directly for an EHCP. Upon receiving the application, the local authority immediately wanted to award Top-Up funding if I withdrew the EHCP application, which I declined. When asked why, I explained that they'd indirectly told me that my son's EHCP application would be successful, and because they'd made us wait for so long, I now wanted the legal protection an EHCP would give us. I felt very angry that we'd been left without any funding for the best part of three years in spite of 5 applications, several Educational Psychologist visits and a formal complaint about an Educational Psychologist. I'm also angry that if I hadn't been so capable of tackling the system, he'd still be without support, and I wonder how many children slip through the net because their parents can't advocate for them. Since then, I've also had to apply to tribunal for a secondary school place, which was a very intimidating process with a lengthy application form. ”

# Notes



# Notes



# Inform Network Support



Understanding Chromosome & Gene Disorders

Rare Chromosome Disorder Support Group  
The Stables, Station Road West, Oxted, Surrey RH8 9EE,  
United Kingdom  
Tel: +44(0)1883 723356  
info@rarechromo.org | www.rarechromo.org

Join Unique for family links, information and support.

Unique is a charity without government funding, existing entirely on donations and grants. If you can, please make a donation via our website at [www.rarechromo.org](http://www.rarechromo.org)  
Please help us to help you!

Thank you to all of the Unique parents that contributed to this guide.  
Credits: Cover Photo by Sora Shimazaki from Pexels

Unique guides: There will be some overlap between this guide and other Unique practical guides. So information might be repeated.

Disclaimer: Unique does not recommend a particular solicitor for individual work. All those mentioned in this guide are for information purposes only.

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