

*Usdaw*

Campaigning  
For Equality

# Parents and Carers Supporting Families With Disabled Children



An advice leaflet  
for Usdaw Members



Usdaw has designed this leaflet to help parents of disabled children get the extra help and support they're entitled to. Families with disabled children often don't know where to

turn for help and advice, particularly when their child is first diagnosed. Usdaw wants to help point parents and carers of disabled children in the right direction.



This leaflet covers:

- Your rights at work.
- Help from social services.
- Financial help.
- Support at nursery or school.
- Help for you as a parent and/or carer.
- Support organisations.

# Your rights at work

There are times when every parent needs time off work to be with their child, but parents of disabled children may need additional support from their employer to juggle caring with paid work.

Sometimes parents know in advance that they need time off but at other times might need to leave work in an emergency.

Parents have rights at work that can help in these circumstances. These are explained below.

## Time off in an emergency or at short notice

All workers have the right to take time off for dependants from day one of their job. You can take a reasonable amount of unpaid time off work to deal with an unexpected situation or emergency involving someone who depends on you.

What is considered reasonable isn't defined in the law and will vary depending on the circumstances however you are entitled to take enough time to enable you to make 'alternative care arrangements'.

## The right to request flexible working

Parents of disabled children have the right to request hours of work that fit around their caring responsibilities and for their request to be taken seriously by their employer. You must have worked for your employer for at least 26 weeks to make a formal request.

If you haven't worked for your employer for 26 weeks and you need to change your hours of work then you can still talk to your employer about this.

If your employer is looking to change your hours and you cannot accommodate the change, any restrictions placed upon you because of your caring responsibilities must be taken into account and seriously considered by your employer.

Once your child reaches the age of 18, you still have the right to request flexible working.



## Parental Leave

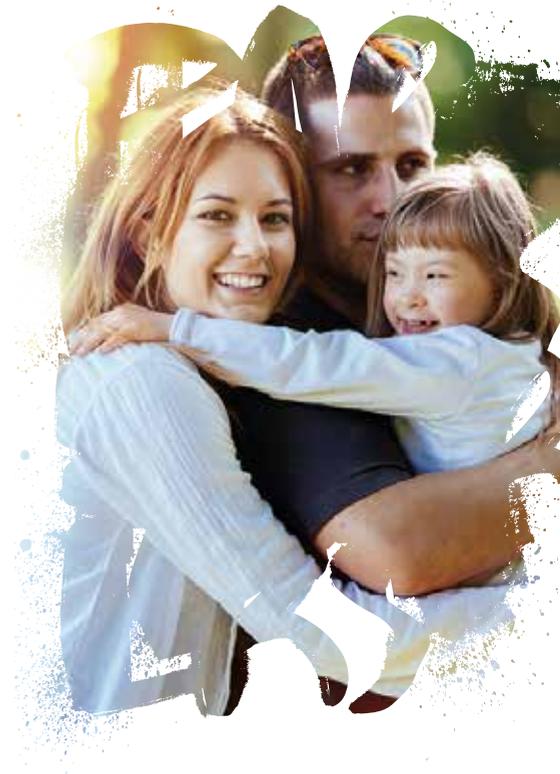
Parents of disabled children who have worked for their employer for one year can take up to 18 weeks unpaid leave before their child's 18th birthday.

In order to take parental leave you must usually (unless you have a workplace agreement that says otherwise) give your employer 21 days notice, in writing of the date you want to start your leave and how much leave you want to take. Usually it must be taken in blocks of a week or more, rather than odd days. However, parents of disabled children may take leave in periods shorter than one week. You cannot take more than four weeks leave per child in any one year.

Your employer can postpone your parental leave once, for up to six months, if the 'functioning of the business would be unduly disrupted by your absence on leave'. However your employer cannot postpone your leave request in the following circumstances:

- If you are the father/partner of the mother and want to take time off for your baby's birth.
- If you are adopting a child and want to take parental leave at the time of the placement.

**For more information about the right to time off for dependants see Usdaw's leaflet 349, *Time Off for Family Emergencies***



## Contractual rights to time off or workplace agreements

Despite what the law says, getting time off work can be difficult because there isn't always a clear cut right to leave and many parents can't afford to take unpaid time off.

That's why wherever possible, Usdaw has negotiated agreements that give parents extra rights over and above the statutory minimums listed above. These 'contractual' rights vary and companies have their own policies and procedures. Many companies have policies to support staff who need time off to care for sick or disabled relatives or children. To find out more, check your staff handbook or speak to your local Usdaw rep or Area Organiser.

# Help from social services

Most families with a disabled child will at some point find it helpful to get support and advice from the local social services department. In Scotland the social services department is called the social work department and in Northern Ireland it is called the health and social services trust.

Social services departments have a legal duty to support families, children and vulnerable adults with the help they need to live a full and independent life.

## A social services assessment

Parents of disabled children have the right to ask for their children's needs to be assessed by social services. This is the first step in sorting out the extra help and support families with disabled children might need.

However, because demand for services is very high, many local authorities have introduced 'eligibility criteria' that are used to decide what services and support a family might be entitled to.

## Asking for an assessment

There are several different ways of getting in touch with social services to ask for an assessment:

A GP, health visitor, community nurse or a paediatrician may make a referral to social services on your behalf or you can ask them to make the referral.

You can get in touch with social services yourself by ringing, emailing or writing to them. Most social services departments have 'children with disabilities' teams. If yours doesn't, contact your local Town Hall and explain you have a disabled child and would like a 'referral' to social services.

## The assessment

Before you first make contact with social services it's worth thinking about the help and support you think you and your child need.

When you first get to talk to someone they will probably ask you to describe your child's disability, details of anyone else that lives in your home, what kind of extra help you or your child need and whether or not you need the help urgently. You might want to make notes or write down any questions you'd like to ask them.

A social worker will then call you back and often arrange to visit you at home to discuss the situation in more detail.



## The services available

This very much depends on your circumstances but the types of services offered include:

- Practical help at home with the physical care needs of your child like washing, dressing or feeding.
- Provision of or support towards the cost of a radio, TV, accessing a library or similar recreational facilities.
- Travel and other assistance.
- Home adaptations and facilities.
- Holidays.
- Meals.
- A person (sometimes called a sitter or attendant) who can come to your house for a few hours every week or month.
- An overnight stay for your child in specialist care to give you a break.
- A place in an ordinary or specialist nursery.
- Other services may be provided including advice and guidance or laundry services.

## How do I pay for social services help?

The type of help available, the eligibility criteria (whether you qualify for help) and how it is funded varies between local authorities. In some places services are free, in others there are fixed charges or families are means-tested (details of household income and savings are taken into account) and asked to pay if they are able to do so.



# Financial help

There are several social security benefits that can be paid to parents that help towards the extra costs of caring for a disabled child.

The rules governing entitlement and the way in which benefits interact with each other are complicated. If you are in any doubt seek expert advice.

## Disability Living Allowance (DLA)

This is a benefit that is paid to parents of disabled children who have care needs or mobility difficulties.

- You can qualify for DLA for a disabled child whether or not you are in paid work.
- It is a non-means tested benefit so the amount of household income or savings you have doesn't matter.
- It is a non-contributory benefit so it doesn't matter whether or not you have paid or are paying National Insurance contributions.
- DLA can be paid on top of other benefits and the amount you receive is disregarded when calculating your entitlement to other benefits.
- You are not a person subject to immigration control.

**For adults of working age, Disability Living Allowance has been replaced by Personal Independence Payment. However, these changes do not apply to children under the age of 16 years old. Disability Living Allowance remains in place for children.**

## How much do I get?

### DLA Mobility Component

DLA mobility component is paid at two weekly rates depending on the extent of your mobility needs.

Children can qualify for the lower rate of the mobility component from age five onwards. This is paid to parents of children who require 'substantially more guidance or supervision when out of doors than children of her/his age in normal physical and mental health' (the wording is that of the regulation).

For example, children with visual impairments or learning difficulties may need adults to physically hold or guide them or watch over them much more attentively than non-disabled children. Similarly a young deaf child may need someone to stay within touching distance, whereas a hearing child would not.

Children can qualify for the higher rate of the mobility component from age three onwards. In order to qualify parents will have to show their child is unable to walk at all or virtually unable to walk before the onset of severe discomfort.

From April 2017, the lower rate is £22 and the higher rate is £58.

You can contact the DLA helpline (run by the Department for Work & Pensions) on 0345 712 3456 (text phone: 0345 722 4433) or seek independent advice from your local Citizens Advice (CA).

To find out where your nearest CA is, visit: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk) or [www.adviceguide.org.uk](http://www.adviceguide.org.uk)

## DLA Care Component

DLA care component is paid at three weekly rates depending on the extent of your child's personal care needs:

- The lower rate £22
- The middle rate £55.65
- The higher rate £83.10

There is no lower age limit for DLA care component. However, a baby still has to meet the qualifying conditions for three months before the allowance becomes payable, unless s/he is terminally ill.

In order to qualify for the care component parents have to show that their child has attention or supervision requirements 'substantially in excess of the normal requirements' of a child of the same age.

As all young children need assistance and supervision it can be difficult for parents of disabled children to explain that they are providing this attention in excess of what all children need.

Examples of the extra care you have to give might be the fact that you not only have to cut up your child's food but you need to feed your child or you have to deal with medication or equipment or you need to be in the same room as your child at all times whereas you might be able to supervise a non-disabled child from a different room.

## How do I claim?

Use claim form DLA 1A Child, available from local benefit offices or by calling:

DLA Helpline: Freephone: 0345 712 3456  
Textphone: 0345 722 4433

Make sure you ask for the form for a child under the age of 16.

You can also seek independent advice from your local Citizens Advice (CA).

To find out where your nearest CA is, visit: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk) or [www.adviceguide.org.uk](http://www.adviceguide.org.uk)



# Tax Credits

There are two types of Tax Credit; Child Tax Credit (CTC) received by most families with income of less than £41,300 and Working Tax Credit (WTC). Tax Credits are administered by Her Majesty's Revenue and Customs (HMRC).

## Working Tax Credit

### Who can claim?

- You are in full-time paid work – what is meant by full-time paid work varies depending on your circumstances so you must either be:
  - Working over 30 hours a week, without children and aged 25 or over.
  - Working at least 16 hours a week and be either a lone parent, a disabled worker or aged over 60.
  - Part of a couple with children whose combined hours of work are at least 24 hours a week. One of you must be working at least 16 hours a week. If only one of you is in paid work then that person must work at least 24 hours.

There are some exceptions to the 24 hour rule. You only have to work 16 hours a week if you are part of a couple with a child and your partner is either:

- incapable of work because of illness or disability; or
- in prison; or
- in hospital; or
- in receipt of Carers Allowance.

- You must be at least 16 years old. There is no upper age limit.
- Working Tax Credit is a means-tested benefit so your household income has to be low enough.
- You are not a person subject to immigration control.

### How much do I get?

The amount you receive varies as it depends upon several factors including your household income and whether or not you or your partner (if you have one) are disabled and the rate of Disability Living Allowance you receive.



# Child Tax Credit

## Who can claim?

- Child Tax Credit is paid to families with children.
- It's a non-contributory benefit so it doesn't matter whether or not you have paid or pay National Insurance contributions.
- You can qualify for Child Tax Credit whether you are in or out of work.
- There is no upper age limit for claiming Child Tax Credit but you (or your partner) must be at least 16 years old. If you are under 16, someone else (eg your parent or the adult with whom you normally live) may be able to claim for you and your child.
- It is a means-tested benefit so your household income has to be low enough.
- You are not a person subject to immigration control.

The Government has introduced a two child limit on Tax Credits. This means that a child element will not be awarded for a child born or after 6 April 2016, if you already have two or more children included in your claim (unless s/he is covered by the exception). You can get a child element for each child born before 6 April 2017, even if you are making a new claim after this date.

You still get the disabled/severely disabled child elements for a third or subsequent child born on or after 6 April 2017.

To get these elements your child must be entitled to Disability Living Allowance.

## Exceptions

The two child limit does not apply in some cases. A child element is payable for a third or subsequent children to whom the limit would apply but who is;

- Born in a multiple birth (other than the first born if you already have two or more children in your award).
- Living with you on a long term basis because s/he is unable live with his/her parents s/he would otherwise be at risk of entering the care system and you are caring for her/him as a family member or friend.
- Being adopted by you from local authority care.
- Likely to have been conceived as a result of rape or in a controlling or coercive relationship and you are not living with the alleged perpetrator.



### How much do I get?

The amount you receive varies as it depends upon your income, but you will receive additional 'elements' for a disabled child or children and the rate of Disability Living Allowance you receive for them.

### How do I claim?

To claim call the Tax Credits helpline on 0345 300 3900 or textphone 0345 300 3909.

### Benefit Cap

Child Tax Credit is included in an overall benefit cap limiting the amount families can claim to a projected £384.62 (£442.31 if you live in Greater London) a week, however there are some exemptions. The exemptions include families where an adult or a child is entitled to Disability Living Allowance and therefore the benefit cap should not apply to households with disabled adults or children.

The cap only applies if you are getting Housing Benefit or Universal Credit.

Universal Credit is a new benefit that combines means-tested support for adults under the qualifying age for Pension Credit and children into one benefit.

It replaces the following means-tested benefits and Tax Credits:

- Income Support
- Income Based Jobseekers Allowance
- Income-Related Employment and Support Allowance
- Housing Benefit
- Child Tax Credit
- Working Tax Credit

It is being introduced gradually across Britain. It is expected that by September 2018 all new claimants across the country will be able to claim Universal Credit. Existing means-tested benefit and tax credit claims are to be transferred to Universal Credit between 2019 and 2022.



# Housing Benefit and help with Council Tax

## Housing Benefit (HB)

### Who can claim?

You can qualify for HB if:

- It is a means-tested benefit so your household income must be low enough.
- You are liable to pay rent.
- The rent you pay is for the home in which you normally live.
- It is a non-contributory benefit so it doesn't matter whether you have paid or pay National Insurance contributions.
- You are not a person subject to immigration control.
- There are no upper or lower age limits but there are special rules for young people aged under 18 years old.
- If you are aged under 35 years old in privately rented accommodation the amount of HB you can get towards your rent might be restricted to the 'single room rent'.

### How much do I get?

The amount of HB you will receive depends on a number of complex factors including your income and savings, your age, the size of your accommodation, how many 'spare bedrooms' you have, and your rent.

### How do I claim?

Contact your local Town Hall/Council Office to ask for a claim form.

## The Bedroom Tax

If you rent your home from a 'social landlord' and you are deemed to have more bedrooms than you need, your rent that is paid by Housing Benefit will reduce by:

- 14% if your home has one bedroom which is considered to be under-occupied – an average reduction of £12 per week (£52 a month).
- 25% if you have two or more bedrooms that are considered under-occupied – an average reduction of £22 per week (£95 a month).

You are allowed (and will receive Housing Benefit for):

- One bedroom per couple or single adult.
- One bedroom for a person who is not a child, ie someone aged 16 or over.



- One bedroom per two children of the same sex until they reach 16.
- One bedroom per two children of the opposite sex who are both under 10.
- A 'child who cannot share a bedroom' – to count as a child who cannot share a bedroom:
  - The child must be under 16 and must be entitled to the middle or highest rate of the care component of Disability Living Allowance; and
  - The local authority must be satisfied that because of her/his disability, the child cannot reasonably share a bedroom with another child.
- A member of a couple who cannot share a bedroom.
- One bedroom for a non-resident carer.



## Council Tax Reduction (CTR)

Council Tax Reduction (sometimes called Council Tax Support) has replaced Council Tax Benefit. Eligibility rules for help with council tax vary as each local authority operates its own scheme. CTR only operates in England, Scotland and Wales. Different schemes operate in Northern Ireland. Contact your Town Hall for help.

### Who can claim?

You can apply for Council Tax Reduction whether you own your home, rent, are unemployed or working.

### What you'll get

You can get up to 100% reduction, depending on:

- Where you live.
- Your circumstances (eg income, number of children).
- Your household income – this includes things like savings, pension, your partner's income.
- If your children live with you.
- If other adults live with you.
- You must not be a full-time student.
- You must be liable to pay Council Tax.
- You are not a person subject to immigration control.

### How do I claim?

Contact your local Town Hall/Council Office to ask for a claim form.

# Carers Allowance (CA)

## Who can claim?

Carers Allowance is paid to people who care for someone who is in receipt of Disability Living Allowance. See below for more information:

- It is a non-means tested benefit so the amount of household income or savings you have doesn't matter.
- It is a non-contributory benefit so it doesn't matter whether or not you have paid or are paying National Insurance contributions.
- You can qualify for Carers Allowance whether you are in or out of work, but you must not earn more than £116 a week.
- You are caring for someone who is getting either the middle or the higher rate of the care component of Disability Living Allowance, either rate of the daily living component of Personal Independence Payment (PIP), or any rate of Attendance Allowance, if over 65.

- You do not have to be the person's relative or live with the person you care for but you do have to be caring for them for at least 35 hours a week.
- There is no upper age limit but you do have to be at least 16 years old to claim.
- You are not a person subject to immigration control.

## How much do I get?

Carers Allowance is paid at £62.70 per week.

## How do I claim?

To claim Carers Allowance you need to get form DS700 or DS700SP (if you're getting a State Pension). You can do this online or over the telephone:

- Online at: [www.gov.uk/carers-allowance](http://www.gov.uk/carers-allowance)
- Calling your local social security office.

## Grants and other sources of financial help

As well as social security benefits there are a number of sources of financial help for families with a disabled child. See the section 'Support Organisations' listed at the end of this leaflet for details of where to go for more information and advice.



# Support at nursery or school

## Special Educational Needs

Children who need extra help to learn are described by education services as having 'special educational needs'. Some children may need additional support with learning even if they don't have a disability or learning difficulty or they may have a learning difficulty or other disability which hasn't yet been diagnosed.

Most children with special educational needs (SEN) go to mainstream schools and the law gives parents the right to say that they prefer this option. Some children will go to a specialist school where they can get the teaching and support that best meets their needs.

Every mainstream school and nursery or playgroup (often referred to as early years settings) has a member of staff called a 'Special Educational Needs Co-ordinator' or 'SENCO'. They are responsible for arranging and co-ordinating the extra support your child needs to get the most out of learning.

Every school also has a SEN policy which sets out the kind of support given to students and pupils. You can ask to see this policy. As a parent you should be consulted and kept fully informed about the help your child needs and is given and how well they are doing.



## Statutory Assessments (known as 'Statements')

Some children may need more help than the school is able to provide. This is where a 'statement of special educational needs' comes in. If your child needs one to one support for example or lots of help from specialist services, such as speech and language therapy, your child may require a 'statement'. This is a legal document issued by your local authority which sets out your child's needs and the extra support that is required to meet them.

Before a statement is issued, the local authority will carry out a full assessment of your child's needs. This is called a statutory assessment. Either you or the school can request a statement. The local authority has six weeks to consider the request and make a decision.

If the local authority refuse to carry out an assessment because they think the school doesn't need the extra resources to meet your child's needs or because they think your child's difficulties aren't severe enough to justify one, then you have the right to appeal to an independent tribunal.

## Help?

Making sure your child gets all the help they need to meet their learning needs is very important but it can be time consuming and confusing.

The support organisation 'Contact a Family' is a national charity that exists to support the families of disabled children, whatever their condition or disability.

They have advice for families on a wide range of subjects, including education. They have, for example, developed a standard letter that you can fill in to ask your local authority to carry out a statutory assessment.

There is also a special educational needs (SEN) Code of Practice which explains in detail how support is provided for children with special educational needs. It can be downloaded from the Department for Education's website. Simply search 'Special Educational Needs Code of Practice'.

### Contact a family

Find out more by visiting [cafamily.org.uk](http://cafamily.org.uk) or ring their national helpline on 0808 808 3555.

## Help for you as a parent and/or carer

Providing regular care for a disabled child as well as trying to look after yourself, other members of your family and holding down a paid job can all take its toll on your own health and well-being.

Carers have a number of rights, including the right to their own assessment, the right to request flexible working and rights under the Equality Act to be protected from being treated less favorably than parents of non-disabled children.

Carers UK, a leading national charity for Carers, publishes detailed advice and guidance for carers. Find out more by visiting [www.carersuk.org](http://www.carersuk.org) or ring their advice line on 0808 808 7777.



# Support organisations

This information was taken from a booklet published by the Department for Education. The original document (Crown Copyright) entitled 'Early Support: Helping every child succeed: Background Information; Useful contacts and organisations' contains many more useful contacts than are listed here.

## British Institute for Learning Disabilities (BILD)

Offers a range of services to support those working with people with learning disabilities and their families. Services include: training for professionals; information services; and one-day events and conferences.

Tel: 0121 415 6960  
email: [enquiries@bild.org.uk](mailto:enquiries@bild.org.uk)  
Web: [www.bild.org.uk](http://www.bild.org.uk)

## Carers UK

A registered charity that provides support to anyone who is a carer. They offer information and advice and produce a range of publications and also campaign for carers' rights. Carers run the organisation.

Tel: 0808 808 7777  
email: [advice@carersuk.org](mailto:advice@carersuk.org)  
Web: [www.carersuk.org](http://www.carersuk.org)

## Challenging Behaviour Foundation

The Challenging Behaviour Foundation provides information and support to parents and carers of individuals with severe learning disabilities who are described as having challenging behaviour. Resources available are information sheets/packs and DVDs, free to unpaid carers. There is also a Family Support Network and a professional email network – for sharing best practice.

Tel: 0300 666 0126  
email: [info@thecbf.org.uk](mailto:info@thecbf.org.uk)  
Web: [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

## Citizens Advice

Citizens Advice helps people resolve their legal, money and other problems by providing free, confidential and impartial information and advice. They have a number of field offices across England.

For information about local offices see their website: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk) or [www.adviceguide.org.uk](http://www.adviceguide.org.uk) or look under C in the Yellow Pages

## Contact a Family

Contact a Family is a UK-wide charity providing support, advice and information for families with disabled children. They run a helpline for family members.

Contact a Family can also help you get in touch with other parents of disabled children living near you.

Tel: 0808 808 3555  
Textphone: 0808 808 3556  
(Free for parents and families  
10am – 4pm, Monday – Friday)  
email: [helpline@cafamily.org.uk](mailto:helpline@cafamily.org.uk)  
Web: [www.cafamily.org.uk](http://www.cafamily.org.uk)



## Family Fund

An independent organisation funded by government administrations of England, Scotland, Northern Ireland and Wales. The fund can give grants and information to families caring for a severely disabled child up to the age of 18.

Tel: 01904 550 055  
email: [info@familyfund.org.uk](mailto:info@familyfund.org.uk)  
Web: [www.familyfund.org.uk](http://www.familyfund.org.uk)

## Family Information Service (FIS)

The Family Information Service can give you information about the full range of childcare and other services for children, family and young people available in your area. You can contact the FIS through your local authority offices or the National Association of Family Information Services (NAFIS). NAFIS is a registered charity that supports, links and promotes Family Information Services (FIS) in Great Britain.

Web: [findyourfis.familyandchildcaretrust.org](http://findyourfis.familyandchildcaretrust.org)

## Gingerbread

Gingerbread is a charity working nationally and locally, for and with single parent families, to improve their lives. They achieve change by championing their voices and needs and providing support services.

Tel: 0808 802 0925 – Freephone helpline (free to landlines and mobiles, except those that have Tesco as a service provider).  
email: [info@gingerbread.org.uk](mailto:info@gingerbread.org.uk)  
Web: [www.gingerbread.org.uk](http://www.gingerbread.org.uk)

## Working Families

Provides information and advice to working parents. It has an established network of parents of disabled children.

Tel: 0300 012 0312  
email: [advice@workingfamilies.org.uk](mailto:advice@workingfamilies.org.uk)  
Web: [www.workingfamilies.org.uk](http://www.workingfamilies.org.uk)

## The Carers Trust

Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems. With our Network Partners, we aim to ensure that information, advice and practical support are available to all carers across the UK.

Web: [www.carers.org](http://www.carers.org)

## Family Action

Provides a wide range of support to children and families living with poverty, ill-health and social isolation in Hull and the East Riding of Yorkshire. Help includes specialist work with children with disabilities and financial support to families.

Tel: 020 7254 6251  
Web: [www.family-action.org.uk](http://www.family-action.org.uk)



# Usdaw Contacts

To find out more about the work of the Divisional Equalities Forums and Usdaw's equality work or about joining Usdaw contact:

## South Wales and Western Division

Cardiff Office  
Tel: 029 2073 1131  
email: cardiff@usdaw.org.uk

## Eastern Division

Waltham Cross Office  
Tel: 01992 709280  
email: walthamx@usdaw.org.uk

## Midlands Division

Redditch Office  
Tel: 01527 406290  
email: redditch@usdaw.org.uk

## North Eastern Division

Leeds Office  
Tel: 0113 232 1320  
email: leeds@usdaw.org.uk

## Scottish Division

Glasgow Office  
Tel: 0141 427 6561  
email: glasgow@usdaw.org.uk

## Southern Division

Morden Office  
Tel: 020 8687 5950  
email: morden@usdaw.org.uk

## North West Division

Warrington Office  
Tel: 01925 578050  
email: warrington@usdaw.org.uk

## Equalities Section

Usdaw  
188 Wilmslow Road  
Manchester M14 6LJ  
Tel: 0161 224 2804  
email: equalitymatters@usdaw.org.uk



Improving workers' lives –  
Winning for members

[www.usdaw.org.uk/equalities](http://www.usdaw.org.uk/equalities)

*Usdaw*

Campaigning  
For Equality