Benefits Series

Disability Living Allowance
Claiming for children under 3 years of age.

Date: April 2021 | Information updated annually
Please see our website for up-to-date information: www.downs-syndrome.org.uk
If you have concerns, please ring the DSA’s Benefits Adviser: Helen Wild
Monday & Thursday 10am-4pm Tues & Weds 10am-12.30pm | Telephone: 0333 1212 300

What is Disability Living Allowance? .................................................................3
  Introduction to DLA .........................................................................................3
  How much is DLA..........................................................................................4
  When to make a first claim ............................................................................5
  Renewal claims ...............................................................................................5
  Length of award ...............................................................................................6
The mobility component ....................................................................................6
  What needs count for the care component? ..................................................8
  The rules for the lower, middle and highest rates for children under 16 ........7
  Filling in the form – practical tips .................................................................11
  Summary of the claim form ..........................................................................12
Filling in the form for children from birth to 3 ...........................................12
  General questions – birth to 3 .....................................................................13
  Mobility questions – birth to 3 .....................................................................13
  Care Questions – birth to 3 ..........................................................................14
The non-disability conditions .........................................................................10
  The "residence and presence conditions" ....................................................10
  The qualifying periods ..................................................................................11
  The special rules ............................................................................................11
Challenging decisions .......................................................................................20
  Reconsiderations and revisions ...................................................................20
  Supercessions .................................................................................................21
  Appeals ...........................................................................................................22
DLA and other benefits ....................................................................................22
  Carer’s Allowance .........................................................................................23
  Blue Badge scheme ......................................................................................23
  Means-tested benefits ..................................................................................23
DLA contacts .....................................................................................................24
What is Disability Living Allowance?

Introduction to DLA

Disability Living Allowance (DLA) is a benefit for children up to age 16 to help with the extra cost of a long-term disability or illness. It is not means tested, so any savings or capital that you have will not affect the award. An award of DLA may entitle you to extra amounts within means tested benefit you may already be claiming such as Universal credit or Tax credits.

DLA is made up of two parts, the care component and the mobility component.

- The care component is paid to someone who needs extra help with personal care. It can be awarded is from 3 months of age. The extra needs should have been present for 3 months prior to claiming and be expected to last at least another 6 months. There are 3 rates, lowest, middle and highest. The only time the 3 months qualifying period for care does not apply, is if a child has a terminal illness, thankfully this is a rare occurrence. These rules are called ‘Special Rules’.

- The mobility component is paid to someone who needs help with getting around out of doors. There are 2 rates. The earliest time that it can be awarded is 3 years of age for the higher rate and age 5 years for the lower rate.

You can receive the care component, or the mobility component, or both.

Claimants over age 16 will claim Personal Independence Payment (PIP). This replaced DLA for people of working age (16-64).
How much is DLA this year?

April 2021 to 2022

<table>
<thead>
<tr>
<th>Component</th>
<th>Rate</th>
<th>Per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care component</td>
<td>Lowest</td>
<td>£ 23.70</td>
</tr>
<tr>
<td></td>
<td>Middle</td>
<td>£ 60.00</td>
</tr>
<tr>
<td></td>
<td>Highest</td>
<td>£ 89.60</td>
</tr>
<tr>
<td>Mobility component</td>
<td>Lower</td>
<td>£ 23.70</td>
</tr>
<tr>
<td></td>
<td>Higher</td>
<td>£ 62.55</td>
</tr>
</tbody>
</table>

- **What about income and savings?**

You can claim DLA no matter what your income or savings are. It is not means-tested.

- **What if I claim other benefits?**

An award of DLA does not reduce the amount of other benefits you may already receive. It is paid on top of these. If you are claiming Tax Credits or Universal Credit, you may receive extra money because your child is receiving DLA. You may be able to claim Carers Allowance once your child receives DLA (but only with the middle or highest rate award).

- **Which rate of DLA should my child get?**

**CARE COMPONENT**
Because children’s needs vary, the award depends on the amount of extra care or mobility needs, there is no way of telling.

However, as an example, if your child is over the age of one and only receiving the lowest rate of the care component, they may be entitled to an increase in their award. You can always call and chat to our adviser.

**MOBILITY COMPONENT**
Some children may qualify for the higher rate mobility component at age 3 if they have physical problems with walking or their behavioural problems are severe enough to qualify.

Most children with Down’s syndrome should receive the lower rate of the mobility component at age 5 (which is the earliest time this rate can be awarded).
When to make a first claim

If claiming from 3 months of age, you need to show that the care needed is substantially in excess of that usually required by a child of the same age. Some children who have Down's syndrome will qualify for DLA at 3 months, usually because they have an additional medical condition that needs extra care. They may be tube feeding or need regular administration of oxygen.

Provide as much detail as you can. DLA will not consider potential needs or award solely on diagnosis.

If your child is very ill, you may be able to claim earlier under the special rules but thankfully this is rare.

Age 3 years is the earliest time you can claim for the mobility component.

Claim when you feel that your child has more care than most other children of the same age. If you would like to discuss when to claim for your child, please call the DSA benefits adviser.

How to claim

You will need to fill in a DLA claim form. Forms are available online on the government website at GOV.UK. Or ask for a form from the DLA Helpline on 0800 121 4600.

Help with the form

The form may appear complicated but we will help you to complete it.

Our benefits adviser is available on 0333 12 12 300

  Monday & Thursday 10-4 pm.
  Tuesdays and Wednesdays 10-12.30 pm.

If your child is coming up to 3 years of age, use the DSA Guidelines to claiming Disability Living Allowance age 3 – 16. You will need to look at the mobility component as well as the care component.

Renewal claims
Most DLA claims are made for a limited time, often for a period of two to three years. You will need to make a renewal claim to get another award of DLA.

You must fill in the renewal claim form in detail, as if it were the first claim. The DWP can refuse or reduce benefit on renewal claims if they do not get full information.

If your child is already getting DLA, you should be sent claim forms to make a renewal claim about 6 months before your DLA runs out. These forms are similar to the first claim form. If you don’t receive a renewal form, ring the DLA Unit on 0800 121 4600 and ask for one. Explain that you are making a renewal claim.

It is important to send the renewal claims back before the existing award runs out. If you send them back in good time, then the new award should start as soon as the old one finishes. If you send them back a short time before it runs out, there could be a gap in your payments. You will get a back payment once they have dealt with the claim.

If you send back the renewal forms after your child’s DLA ends, backdating won’t be given for the time between the first award ending and when they get your renewal claim.

**Length of award**

For young children, DLA is usually awarded for 2 to 3 years. Although you may feel that the award’s not long enough, it gives you the opportunity to check whether your child may also be eligible for an award of the mobility component. The higher rate mobility can be awarded from age 3 and the lower rate can be awarded from age 5. If someone gets both care and mobility for a fixed period, their awards will end on the same date. Generally longer awards are made after age 5. It is always handy to keep a copy of the last form you filled in. You can then use this as a starting point for the renewal form and add your child’s most recent care/mobility needs to it.

**The mobility component**

Children under 3 years of age cannot get the mobility component so you don’t have to complete this section until your child is coming up to age 3.

**The care component**

There are three rates.

**Lowest rate**

Your child may get the lower rate if: *[they require] in connection with [their] bodily functions attention from another person for a significant portion of the day (whether during a single period or a number of periods).*
Middle rate

Your child may get the middle rate if they meet one of the daytime conditions, OR one of the night-time conditions.

These are, during the day:
‘Frequent attention throughout the day in connection with [their] bodily functions, or continual supervision throughout the day in order to avoid substantial danger to themselves or others,
or during the night
Prolonged or repeated attention in connection with their bodily functions or In order to avoid substantial danger to [themselves] or others, [they require] another person to be awake for a prolonged period or at frequent intervals for the purpose of watching over [them].’

Highest rate

Your child may get the highest rate if they meet one of the daytime conditions AND one of the night-time conditions listed above in the middle rate explanation.

To sum up, your child may be awarded the lower rate if they need about an hour’s extra help during the day. They will be awarded the middle rate if they need a lot of extra help EITHER during the day OR during the night. They will be awarded the highest rate if they need a lot of extra help BOTH during the day AND during the night.

The rate received depends on the amount of help needed with personal care.

All children need help from their parents. A child will receive DLA if they need a lot more attention or supervision than another child of the same age. This may be;

- because the help given takes a lot longer than for most children of their age; or
- because of the degree of attention or supervision which is needed is greater, or more intense, or more constant; or
- because the help given is usually needed by younger children, but not by most children of that age.

Think about why the help your child receives is more than the help needed by other children of their age. We give examples of the kinds of extra help that children with Down’s syndrome might need in our Filling in the form section.
Definitions

Definition of Attention for DLA?
Attention is doing something of a close and personal nature for the person in their presence. It must be “attention in connection with bodily functions”. Bodily functions is defined as movement of the limbs, operation of the senses and cognitive functioning. [Mallinson, Fairey and Cockburn: House of Lords]

Attention often involves physical contact, but it can be by the spoken word – encouragement, reminders, or reassurance. The help needed may count where it is related to the child, both in, or outside of the home, to lead as ‘normal’ life as possible. [Fairey: House of Lords]. Attention does not usually include help with shopping, laundry, or other household tasks.

What counts as supervision or watching over?
Supervision is being there ready to help if needed. It must be needed to prevent danger. The danger need never have happened, but there must be a real, serious risk. Supervision needs to be “continual” – not every single second, but constant.

"Watching over” is supervision at night. You must be awake and getting up to help, or awake and listening out to prevent danger.

Attention and supervision/watching over can clearly overlap. If you are unsure if a particular activity is "attention" or "supervision", just describe what you do in a suitable section of the claim form.

Significant portion of the day:
A "significant portion of the day" is about an hour in total. The help might be given all at once, or at different times during the day. But if you give your child help throughout the day, they could qualify for the middle rate.

Frequent attention throughout the day:
"Frequent" means more than once or twice, and "throughout the day” means exactly what it says, that the help you give your child is spread out at intervals through the whole day. There can be gaps in the day when your child doesn’t need help but the pattern must be over the whole day. It is therefore important to include all the help you give your child, since the Department for Work and Pensions (DWP) look at how often you give that help, as well as what kind of help it is.

Different kinds of help are "added together to meet the "frequent attention" condition."
**Continual supervision**: All children need a lot of supervision to keep them safe. Children with Down's syndrome under 2 may not need extra supervision unless they have another medical condition, such as a heart, lung or bowel problem. To qualify for the 'extra test for children', you would have to show that your child was more at risk if left alone in another room than a child of that age would normally be. For example, a baby with a severe heart defect or breathing problems may need careful watching. There has to be a real danger of harm - parental anxieties are not taken into account. If your baby has a naso-gastric tube or a catheter, you may have to watch for them pulling it out and so this may count.

Over age 2, children with Down’s syndrome may need more supervision than other children of their age because of their learning disability. For example, they may be much slower to learn about common household dangers (hot water, knives, electricity), or they cannot be left alone safely in the same way that another child of the same age could be.

**Prolonged or repeated attention at night**: "Night" had been defined as a time after the whole household had shut down, not starting from your child’s bedtime, but after you and other adults in the household have gone to bed. Recently it has been ruled that 'night’ should be viewed as being between the hours of 11pm and 7am the following morning. This was because some parents have to be awake regularly and beyond their normal bedtime or be up earlier than they would generally in order to attend to their disabled child’s care needs. [CDLA/127/2018:Upper Tribunal Judge Hemingway, and R(A)1/04: Upper Tribunal Judge Agnew].

"Attention": means the same as for the day-time conditions. Remember it includes soothing someone back to sleep. Prolonged attention is taken to be 20 minutes or more. Repeated attention is twice or more. However, it is usual for young children to need attention at night. In order to count, the attention your child needs has to be different, or take longer, or be attention that usually only a younger child would need.

You don’t have to give this help every night. It just has to be "more likely than not" that you will have to get up, whether once for a "prolonged" period, or twice or more. In practice, it appears that the DWP considers that it is not enough if you get up 3 nights out of the 7.

**Watching over**: - similar to the day-time condition of "continual supervision".

"Watching over" includes both getting up and checking on someone, and simply being awake and listening out. It has to be either "prolonged" - 20 minutes or more - or "frequent" - at least 3 times. You need to be awake – just being asleep in the house isn't enough.

The reason for someone needing "watching over" has to be because otherwise they would be at risk in some way. The danger need not ever have actually happened, though you need to explain why you think it might.

Remember, when you are thinking about attention and supervision/watching over for children, it has to be a lot more than that needed by other children of the same age in order to count.

**Help which isn’t counted;**
Parking and petrol costs for extra hospital appointments, having to turn the heating up or if you have taken the decision not to go back to work are not considered.

Another form of help that would not count is any help given that could be made unnecessary by using an available aid or piece of equipment—this could mean things like grabbing sticks or aids to open tins or jars etc. Generally this would apply to older people with dexterity issues. For our members there is still an issue around cognitive impairment and you would still have to supervise the situation.

Some parents find the form difficult to fill in. It will focus on milestones not yet reached instead of the positive achievements. It is important not to underestimate the amount of extra time you give for your child to attain these developmental milestones.

Give full details, even if it is a renewal form.

If you need information or advice about filling in the form, please call the DSA benefits adviser on 0333 12 12 300.

**The non-disability conditions**

These apply to both the care component and the mobility component.

If you think you might be “subject to immigration control”, get advice before you claim DLA. If you are subject to immigration control, claiming DLA may cause you to lose the right to stay in the UK.

**The "residence and presence conditions"**

To make a DLA claim your child:

- Should be habitually resident in the UK, the Channel Islands, the Isle of Man or the Republic of Ireland AND

- Be present in Great Britain (but they can be away temporarily) AND

- Has been present in Great Britain for a total of 104 weeks in the past 156 weeks (2 out of the past 3 years). If you claim when your baby is less than 6 months old, they need only to have been present for 13 weeks. This applies until their first birthday. If you claim for a baby aged 6-36 months, the test is 26 weeks in the past 156 weeks (6 months out of the past 3 years).

The upper Tribunal recently found that it was unlawful to apply a 104 week waiting period for children age 3 to 16 returning to the UK and ruled that this should be 26 weeks as it was before the changes came into effect (in 2013).

This ruling is EK v SSWP CDLA/2019/2018 and also TS v SSWP CDLA/2208/2018.

It is also known as EK and TS
The qualifying periods

Your child has to satisfy one of the disability conditions for at least 3 months to get DLA and likely to satisfy one of the disability conditions for the next 6 months (called the prospective test).

This means that although you can apply for the care component of DLA for your child at birth, the child cannot usually start to get the benefit until the age of 3 months. We advise people to wait until their child is at least 3 months old before claiming.

For the mobility component, the lower age limit is 3 years old (higher rate) and 5 years old (lower rate). The three months before your child’s 3rd or 5th birthday can count as the qualifying period, if your child meets one of the disability conditions during those 3 months, so that your child can start getting the mobility component of DLA from their 3rd or 5th birthday.

The special rules

You may notice that there is information in the DLA claim pack about “special rules”. These are for people who are terminally ill, that is, they are not expected to live beyond the next 6 months. The qualifying periods do not apply for the care component in these cases. The highest rate of the care component is automatically awarded, but there is no automatic award for the mobility component which can be claimed in the usual way from age 3 years.

Practical tips

- **KEEP A COPY OF YOUR COMPLETED FORM.** It helps if you disagree with the decision. It can also serve as a prompt when you complete a renewal claim.

- It will be useful to keep a diary for a while. You could do this before filling in the form, to view the full picture of your child’s needs. It is easy to forget about things when they become part of your daily routine. You may want to include a copy of your diary when you return the form.

- If there isn’t enough room on the form to give all the information you want to, continue on a separate sheet of paper, attach it to the form, and make sure you note on the form what you have done. Write your child’s name, date of birth and reference number (if you have it) at the top of each sheet in case it becomes detached.

- You may want to give the same information in answer to different questions. You can choose to repeat the information, or you can simply put “see page x for details about.....” It does not matter where you write things if the information is on the form and your answers are consistent.
• How many times a day/night? and How long for each time? are problematic to answer. You can put “all the time” or “continually”, for example, if the question is about communication, or development. If your child needs extra supervision, it is obvious that if the need exists, help will have to be more or less all the time.

If your child needs help at mealtimes, or with physiotherapy exercises, or with washing, or at night, it may be possible to give more specific details of how often and how long it takes.

• What if the help your child needs changes from day to day? Try to give an average, and you can also give a range of times. For example, “On average, it takes 15 minutes, but it can sometimes be as short as 5 minutes or up to an hour” or “It takes an hour about 5 times a week”.

• It may be helpful to think about your child in comparison with your other children (if you have them), or with other children of the same age you know.

• It is more important to be clear than to stick to their layout. If you want to explain in detail, and the box isn’t big enough, use extra pages if you run out of space. Remember to put your child’s name and date of birth on any loose sheets you send in case they become detached at DWP (as they will be easy to link together again).

• If your child has no issues in certain areas, just tick the “no” box at the top of the page and leave it blank.

• Remember that the different kinds of help your child needs are “added together”. Nothing is ever too minor to mention. For example, a child might have sticky eyes which need cleaning 2-3 times a day. It may only take 5 minutes each time - but worth adding.

Completing the DLA form

The claim forms for a first claim and for renewal claims are similar. Layouts change from time to time, so although we update every year, your claim form may be in a slightly different order from the info. given here.

The first questions on the form relate to personal details and circumstances, medical condition, medication and therapies.

It also asks for addresses of health care professionals that may be involved.

Statement from someone else who knows the child. This can be signed by anyone who knows your child well. It is possibly better to get a professional (GP, nurse, teacher, etc) to sign, but don’t delay sending back your form for too long by waiting for a particular person’s
signature. A relative or friend can sign. You don’t have to get anyone to sign, but this may delay your claim.

The best thing to remember is to give information about why your child has extra needs.

Remember to concentrate on why the help is different, or takes longer, or if it is help that you would generally be giving to a child younger in age.

If unsure about what to do, ring the Down’s Syndrome Association’s Benefits Adviser.

**General questions – birth to 3**

- About your child’s illness or disability.
  Give information about all your child’s conditions. For example, if they have a hearing impairment, or low muscle tone, or dry skin, list them separately, even if they are conditions common with people who have Down’s syndrome.

  Therapy is treatment, so if your child has speech therapy, physiotherapy, portage etc. list how often you practice the therapy – for example - 3 times a day for 20 minutes each time. List what you do with your child each day. If you are unsure how long these activities take, try keeping a diary of what you and your child do for a couple of days and then you may find these questions are much easier to answer.

- Aids or adaptations.
  These could be things that a child of this age would not normally require such as hearing aids, glasses, contact lenses, support chair to help with sitting up etc. You could also mention if your child has to use a special feeding spout or if they have to be fed via a naso-gastric tube. Remember to list it if it is something that a child of this age would not normally require.

- When the child needs help
  Your child’s needs may vary throughout the day and sometimes they may need more help when they have a chest infection for example. However, this would not mean that overall their care needs varied, they should count as being the same most of the time as the chest infection would be an increase on existing extra care needs.

**Mobility questions – birth to 3**

The earliest time the mobility component can be awarded is from 3 years of age. The higher rate of the mobility component can be awarded 3 years of age, the lower rate can be awarded from 5 years of age. If your child is under the age of 2 ½ years, these questions are not applicable. You can either leave them blank or write ‘not applicable’.
If your child is 2 ½ or older, or if your current award ends at age 3 and you have already been sent a renewal form, go to Mobility questions in the DLA Guidelines age 3-16 which gives details about the mobility component.

**Care Questions – birth to 3**

- **Getting in and out of bed, or settling in bed during the day**

  As babies generally would need lifting in and out of a cot or bed and settling, it may not apply at an early age. It may apply to a toddler who has physical problems settling or is more difficult to soothe because of cognitive issues.

  Remember that the needs should be over and above those normally required by a child of the same age.

- **Toilet needs**

  This question may not apply to very young children as all young children under 3 need help with toileting. However, if you have a child with a catheter or a colostomy bag or any other toileting difficulties, you need to tell them. Be as specific as you can about what extra you do for your child.

  Do they need changing much more frequently than other children, for example, if they are on some kinds of medication such as diuretics? They may also have extra needs if they often get very constipated. Around the age of 2, most children will start potty training and have some awareness of bowel habits. If you have a toddler who has not yet reached this stage, explain about this. Some children will ‘smear’ through natural curiosity and may not understand that this is unhygienic. If this is an issue, let DLA know.

- **Moving around indoors**

  Children who have Down’s syndrome often have a delay in mobility.

  Babies generally will sit up unsupported at around 7-8 months, start to crawl at around 9-10 months and then walking starts any time after this. Most children are walking by the age of 17 months.

  If your child is delayed with their physical development and is not sitting up unsupported, crawling or walking when most other children are, they have extra needs in this area. You may need to help them learn these skills in a much more focused way, perhaps with the help of a physiotherapist, or portage worker. The time you spend doing exercises with them counts for DLA. You can give details of what you do
here, or in the section headed ‘taking medicine and having therapy’. Be as detailed as you can, for example, “The physio visits every 2 weeks, and gives me exercises to do with her, 3 times a day, for 20 minutes each time.”

If your child’s physical development is delayed, you may find you carry them more as they are unable to move and explore their world at an age when other children are independently mobile. This is extra help – it takes more time and is different to the help needed by most children of that age.

If they need a special chair to help them sit e.g. a ‘bumbo’ seat or a chair recommended by a physiotherapist (at an age when they would normally be sitting), then you need to mention this here.

Remember, if you run out of room on the form, use a blank piece of paper, making sure to put your child’s name, date of birth and National Insurance number at the top.

• Washing, bathing and looking after your appearance

It’s unlikely that your baby would have more needs than most other babies. It may however be relevant if they need to be washed / bathed / changed more often because of frequent vomit after feeds or if they fill their nappies much more often than usual.

As children become toddlers, they would be expected to start co-operating in these daily routines. Children who have Down’s syndrome may need extra help with washing and bathing after, say, a year, if they still need to be held and washed more like a newborn.

Sometimes children who have Down’s syndrome have very dry skin and need creams applied after every wash. The time this takes is extra help.

• Dressing and undressing

This would not really apply to babies unless they had a physical problem.

For toddler age, you may have to help more than generally expected with putting arms and legs into clothes – children at 11-12 months will help by holding their arms out. At 2-3, children generally may help themselves quite a lot, so think hard about what help you give your child at this age – is it extra?

Some children who have Down’s syndrome frequently take their clothes off. They may have sensory issues, which make them unhappy with the feel of wearing clothes. Mention this if it is a feature of your child behaviour.

• Eating and drinking

Some children who have a heart defect may need feeding via a nasal gastric tube and if so you should mention this here. Give details of the process too – inserting the tube, checking it is in baby’s tummy etc. This is classed as a technical procedure.
If your baby does not have a feeding tube but requires a substantial amount of help/time to feed, keep a feeding diary for a day or so to give you some idea of how long it is taking you. Most babies finish a bottle of milk in 15-20 minutes. Breastfeeding babies may be more demanding. Remember it’s about how often you feed, as well as how long it takes.

If your baby is taking 40+ minutes to finish feeding because they nod off or because they have problems with their sucking reflex, you need to mention this. Also if your child is not gaining weight adequately or has a supplement added to their milk to increase calorie intake.

For the older child, it may be problems with feeding themselves at an age when most children would be able to do this. Maybe your child eats inappropriate things or puts things into their mouth at an age when normally this behaviour would have stopped. If your young child is unable to tolerate lumpy food or is on pureed food at a time when they would not normally be, then let them know. Most children move onto solids at about 6 months.

It can also be a good idea to state the birth weight and current weight of your child if as it can re-enforce any feeding issues you are writing about.

- Taking medicines and doing therapy

All children under the age of 3 need help with taking medication. This question applies to those children who need to take medication on a regular basis. For example, a child may need to take tablets several times throughout the day due to a heart condition. They may need to have regular tests to monitor their blood or they may need help with an inhaler.

You would also list any therapies that your child has, such as physiotherapy, speech therapy or portage/play therapy. It is the time that you spend doing these therapies with your child. If you are unsure, just keep a notebook and write down the times spent. It makes it much easier when completing the form.

- Vision

If your child wears glasses or contact lenses and they still have trouble seeing clearly or focusing, you should put this. Nystagmus or trouble focusing can still be an issue even if they wear glasses. There can also be the additional problems of young children not co-operating with wearing their glasses, or the stressful situation of trying to put contact lenses into your child’s eyes.

- Hearing

Your child may have to wear a hearing aid. If your child routinely pulls their hearing aid out or you have trouble getting them to wear it or keep it in, mention this also. For a
young child, being able to hear is essential to developing clear speech, so the extra needs for attention and supervision around keeping hearing aids in are very important.

• Speaking

It is important to be aware of the normal range of speech development when completing this section. Most children who have Down’s syndrome experience delay in their speech. Sometimes this can be due to a problem with hearing.

At the earliest stages of speech development, babies will coo and babble. At the age of 9 months, they start to make sounds such as ‘dada’ and ‘mama’ even though they may not understand their meaning. At age 12 months they should be able to imitate sounds.

Most toddlers will have around 20 words in their vocabulary by the age of 18 months and around 50 words by the age of 2 years when they will start to string a couple of words together. After the age of 2, a child’s vocabulary increases and they will be able to talk in sentences of two and three words.

If your child is not talking, tell them. If your child is age 2 and non-verbal, explain and follow it up saying that a child of this age would normally be using simple sentences etc.

• Communication

This is how your baby or young child communicates with you and it also involves a level of comprehension. Parents should be able to understand around half of their child’s speech at age 2 and three quarters of their speech at age 3. Between 18 – 24 months a child would be expected to follow a command of two stages, for example, ‘pick up dolly and put her in the toy box’.

As with speech, most young children who have Down’s syndrome will have delay in this area. If you practice Makaton or your child communicates by pointing, write about this and compare it to the normally expected development at this age.

• Blackouts or seizures

If your child has any type of seizure or fit, complete this section. Obviously for very young children they will not have awareness and will be totally dependent on their parent or care giver. If your child has frequent fits, note down the times over a week or so, it makes it much easier when completing the form.

• Supervision during the day

All young children need a high level of supervision throughout the day in order to keep them safe. Most children under 2 who have Down’s syndrome have no need for extra supervision, but they may have a heart, bowel or lung problem which leads to a more intense, or constant need for supervision.
For children over 2, more supervision may be needed because of a delay in learning about common dangers, such as the cooker or iron, hot water, knives. They may be more unpredictable in what they do, which may lead to a need for extra supervision.

- **Help with development**

  This is an important question for children with global development delay. Children who have Down’s syndrome go through the same stages of development as other children, just more slowly. They also learn in specific ways, for example, they find it easier to learn if activities are broken down into small steps, repeated more often and taught in visual ways rather than listening. You can give details about how your child learns differently, about what you do to help them, and the time it takes to help your child learn about their world and interact with other people.

  It may be useful to point out here how delayed your child is in motor, cognitive, and social development.

- **Help at school or nursery**

  This would not be relevant for a very young baby.

  It may be relevant for a child over the age of 2 if they attend nursery and they need 1-1 help there. Explain about this and why they need the help, for example with understanding simple instructions or help eating their food. Remember that it would have to be help over and above the needs a child would generally have at this age.

- **Help to take part in hobbies and leisure activities.**

  Although not relevant to babies, a younger child over the age of 12 months may need a lot more help than their peers to interact socially, or to be able to take part in an activity. This may be because of communication difficulties (speaking, hearing) or because of needing activities to be broken down into smaller steps, constant explanations of what’s going on, or much more encouragement to take part.

- **Night needs**

  "Night" is defined as between 11pm and 7am the following morning. Write about times when you attend to your child in the morning if it is a time when you would normally still be asleep, or if you have to stay awake longer than you normally would. It is helpful if you keep a diary of the times you wake during the night and what you do when your child wakes, also how it differs from a typically developing child.

  Remember that the needs have to be over and above the needs a baby or child would normally require at this age.

  Babies and very young children have needs at night. Your child may have extra needs if they still need help most nights after the age of about 12 months. Some children are more restless and wakeful at night, sometimes because they are prone to colds and
chest infections, sometimes because they simply don’t sleep very soundly. Other children who take a long time to feed may still need night feeds after the age when most children drop their night feed.

It can be difficult to assess whether night needs are “extra” or not. The age that children stop needing help at night varies a lot. However, the comparison is with “most children”. Most children probably won’t need help on the majority nights from their parents after about 12 months, and not after 2 years of age.

- Extra information

If there is anything that you haven’t had chance to explain, then this is the place to put it.

If you run out of room, use an extra sheet of paper to attach to the form. Remember to put your child’s name, date of birth and reference number if you have it at the top of any extra sheets.

- When the needs started

It can be difficult to think of an actual date when your child’s extra needs started. Sometimes the date could be when you noticed that your child’s development was delayed. Some babies need a lot of extra care from birth, for example if your baby has a heart condition and needs medication or is being tube fed. For these babies you would put their date of birth.

There is a three month qualifying period for DLA and so the earliest it can be awarded from is 3 months of age (unless you are claiming under the special rules).

- Information about yourself, other benefits you get, and your bank account details.

Make sure that you sign and date the form, make a copy and send it signed for so you can track it’s journey.
Challenging decisions

What to do if you are unhappy with a decision

When you receive your decision;

- Your child may be refused completely.
- Your child may be given a rate you are unhappy with.
- Your child may be given a limited award, for example, only for two years.
- The award may start from a date which you feel is not right.

This could happen whether it is your first claim, or a renewal claim. It is possible to get your decision changed.

The DWP can revise a decision. This means that they think the original decision was wrong. The revised decision takes effect from the date of the original decision.

The DWP can supercede a decision. This means they agree that something has changed since the original decision and that it should be changed. The new decision takes effect from the time that it is made. This can only be done if you have an existing DLA award- you cannot ask for a previously rejected claim to be superceded because your needs have since increased. You would have to make a fresh claim.

Both revisions and supercessions are called “reconsiderations” by the DWP, since they involve a DWP decision maker looking at a case again.

Reconsiderations

If you are unhappy with the new decision, you can make a request for a reconsideration. This must be received within one calendar month of the day after the date on the decision letter. For example, if the decision letter is dated 2 April, your request must be received by 2 May. If there is no corresponding date in the following month, your deadline is the last day of that month. For example, if your letter is dated 31 May, your deadline is 30 June.

This deadline can be extended in some circumstances. The most common one is requesting written reasons for the decision. This will extend your deadline for asking for a reconsideration by 14 days. Often the written reasons are not very helpful in giving an insight into why a decision was made.

Remember to ask for a reconsideration within the one month deadline, even if you have asked for written reasons.

If you miss the one month deadline, you can ask for a late revision in very limited circumstances. Don’t delay and get advice in this situation.
How do I get a reconsideration?

The easiest way to apply for a reconsideration is to download form CRMR1 from the gov.uk website, to fill in online, print and send in.


If you intend to send in supporting information after submitting the form, you can tell them and they will give you a date that they need it by. If you send it in later, a decision may be made without considering the new information. It is helpful to send in extra information at this stage.

A different decision maker will look at your case again. The decision maker does not have to consider any point you don’t raise specifically. Think about:

- How your child’s needs are relevant to the DLA rules
- Explaining any information which looks inconsistent.
- Explaining clearly how your child’s needs vary (if they do)
- Setting out information in the form of a diary
- Sending reports from professionals who know your child. Though be careful – often medical or education professionals describe things in a positive way which isn’t always helpful when you are trying to prove a point.

A different DWP decision maker will look at your case again. They may decide to change the decision. This is called a revision. It will take effect from the date of the original decision.

If they do not revise the decision, you can ask for an appeal. You can do this within one month of the date of the reconsideration decision.

If you want to go to appeal, you must ask for a reconsideration (a revision or a supercession) first.

Supercessions

If you want your child’s award of DLA changed, but you are not within one month of a decision, you can ask for a supercession.

You can only get a supercession for certain reasons, for example, your child’s needs have increased, or you think the original decision was wrong because the DWP did not know important facts, or they made a mistake.

You need to write to the DWP, explaining the grounds for the supercession. You will usually have to fill in another form. This gives you the chance to include new information about your child’s needs.

A DWP decision maker will look at the new form and decide whether to supercede.
If the decision is superceded, backdating of any increased benefit will only go back to the date you asked for the supercession.

**Appeals**

If the decision isn’t revised or superceded, you can then ask for an appeal. You can do this within one calendar month of the day after the date of the revision or supercession decision.

Appeals are made to the Social Security and Child Support Tribunals of HM Courts and Tribunals Service. You need to include a copy of the reconsideration decision that you are appealing against.

[https://www.appeal-benefit-decision.service.gov.uk/benefit-type](https://www.appeal-benefit-decision.service.gov.uk/benefit-type)

Going to appeal allows your case to be looked at by an independent body and gives you the chance to discuss your case with someone face to face, (if you decide to attend in person).

If you want to appeal get advice. The process is complicated, and statistics show your chances of success are greater if you get advice.

Contact the DSA Benefits Adviser on 0333 12 12 300.

If you challenge a DWP decision, keep copies of letters, and make a note of the dates of phone calls, a summary of what was said, and the name of the person you spoke to.

**DLA and other benefits**

DLA may affect your other benefits in a positive way. You may get more money once your child gets DLA. If your child is awarded the middle or highest rate of the care component of DLA, you may get Carer’s Allowance.

If you are in receipt of Universal credit, you may get the carer amount added plus an amount for your child getting DLA. The carer amount on UC does not have an earnings limit attached to it and you do not have to have claimed carers allowance. As long as you have regular and substantial caring responsibilities, this is enough for the amount to be added.

It can also positively impact Child tax credit or any income based benefit you may receive. As soon as you have an award of DLA, let the appropriate office know.

Check with:
- your local DWP office (for Income Support, Jobseeker’s Allowance, Universal Credit) or
- your local council (for Housing Benefit and Council Tax Support) or
- the Tax Credit Helpline on 0345 300 3900 for Child Tax Credit and Working Tax Credit
Carer’s Allowance

Blue Badge scheme
DLA and other contacts

Disability Living Allowance Unit
Tel: 0800 121 4600
Disability Benefit Centre 4
Post Handling Site B
Wolverhampton
WV99 1BY

Personal Independence payment
0800 121 4433

Carer's Allowance Unit
Tel: 0800 731 0297
Palatine House
Lancaster Road
Preston
PR1 1HB

MENCAP National Office
Tel: 0808 808 1111
123 Golden Lane
London
EC1Y 0RT

Motability Car Scheme
Tel: 0300 456 4566  Minicom: 0845 675 0009
Motability Operations
City Gate House
22 Southwark Bridge Road
London
SE1 9HB

HMRC Tax Credits Helpline
Tel: 0345 300 3900
Text phone: 0345 300 3909