



GUIDELINES TO CLAIMING

DISABILITY LIVING ALLOWANCE

Ages 8 - 16

April 2007

This information is updated every year.

information

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Change of name

Please note: The Department of Social Security is now called the Department for Work and Pensions (DWP). Benefits Agency offices and Jobcentres are being re-structured and re-named. They will be referred to as DWP offices in this leaflet.

HOW TO USE THESE GUIDELINES

We know that some parents find the Disability Living Allowance claim form difficult to fill in and also that some children and young people are wrongly refused. These guidelines are to help you fill in the form, and to find out if your child is getting the right level of benefit.

First, there is a general outline of how the benefit works, and how to claim it. Then there is a section on the claim form. Then we give details about the rules for the mobility component, and suggestions on answering the mobility questions on the form. This is followed by the rules for the care component, and suggestions about filling in the care questions on the form. Finally, we give information about other aspects of DLA.

The sections about the rules may look complicated. But it is much easier to fill in the form if you understand the reason behind the questions.

You may not need to read the whole leaflet. Select the sections that are helpful for you.

Don't be put off

Filling in the claim form for DLA may be upsetting. It will make you look at negative aspects for your child - what she or he can't do, instead of the positive things. Some of the terms used may seem harsh. It is important, however, not to underestimate your child's needs when you are filling in the form. You need to give full details, even if it is a renewal claim.

If you need more information or advice about claiming DLA, please contact:

Christina Katic or Helen Wild, Welfare Benefits Advisers
Down's Syndrome Association
Langdon Down Centre
2A Langdon Park
Middlesex TW11 9PS

Tel: 0845 230 0372 Mon-Fri 10am – 4pm

We produce these guidelines for children and adults at different ages and they are updated every year.

INTRODUCING DISABILITY LIVING ALLOWANCE

Disability Living Allowance (DLA) is a benefit for people under the age of 65 who have a long term illness or disability. It is designed to help meet the extra costs of having a long term illness or disability.

Our Association believes that most people with Down's syndrome are entitled to some level of DLA.

Do your income or savings matter?

Disability Living Allowance is not means-tested so it does not matter how much your (or your child's) income or savings are.

Will getting DLA reduce other benefits you get?

Getting DLA does not reduce the amount of other benefits you may get. It is paid on top of these. If you are claiming means-tested benefits, like Income Support or Child Tax Credit, you may receive extra money because your child is receiving DLA.

How does Disability Living Allowance work?

Disability Living Allowance is made up of two parts, the mobility component and the care component.

The mobility component is paid to someone who needs help with getting around out of doors.

- There are two rates of the mobility component.
- You can claim the higher rate at 3 years old, and the lower rate at 5.

See "The mobility component – the rules", pages 9-14.

The care component is paid to someone who needs help with personal care.

- There are three rates of the care component.
- You usually claim this part of DLA from 3 months

See "The care component – the rules", pages 20-25.

There are also '**non disability conditions**' and these are explained on page 34.

Will my child get DLA as a right because they have Down's syndrome?

No. The level of benefit you get depends on your child's actual needs. It is not given for the diagnosis and you will have to provide as much detail as you can in your claim.

Making a renewal claim for a child aged 8 to 16

Most children get DLA for a limited period. This means you have to make a renewal claim when it runs out. Lots of awards finish on a child's 8th, or 12th, birthdays.

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 very similar to the first claim form. If you don't receive forms, ring the DLA Unit on 0845 7123456 and ask for a pack. Explain that you are making a renewal claim.

When do I have to send the form back?

Send the renewal claim forms back before your child's DLA 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 this money once they have dealt with the claim. If you send back the renewal forms after your child's DLA ends, you will **NOT** get backdating for the time between the first award ending and when they get your renewal claim.

If you are making a renewal claim for a child aged 8-16, you will usually have to answer the questions on both the care and the mobility components.

Remember, even with renewal claims, you **MUST** fill in the form with full details about your child. **DON'T** think that because your child has been getting DLA, you don't have to give full information.

It is always a good idea to keep a copy of your completed DLA form. If your child's care needs haven't changed, you can copy what you put on the last form.

How to get DLA changed during an award

If you want to get your child's DLA changed in the middle of an award, you need to ask for a revision or a supercession. See pages 35-36.

THE CLAIM FORM

There are no longer two parts to the claim form. The claim form for a first claim, and for renewal claims are not exactly the same, but are very similar. The first part of the claim form is for personal information, whether you are filling the form in on somebody's behalf and special rules. The middle sections are for your care and mobility needs and the back of the claim pack is for information about nights you may have spent in hospital or residential care, benefits and bank account details. The final page is the declaration page.

Statements from other people

At the back of the form, you are asked to get another person to sign. Anyone who knows the child can sign either of the statements, but it is probably a good idea to get a professional (GP, health visitor, teacher, physiotherapist, etc) to sign. Whoever signs does not have to read the form if you don't want them to.

About the child

You will all tick the box "has a learning disability". Sometimes people wonder if they should tick the box "has a mental health problem". "Mental health problems" usually mean illnesses such as depression, schizophrenia and so on, so it's probably not really for children with Down's syndrome. Other boxes may be relevant for some children, particularly problems with hearing, or communication. You might tick the box "has a long term illness" if your child also has an illness like diabetes, leukaemia, or epilepsy. Some children with very challenging behaviour may be described as having "a severe learning disability and severe behavioural problems." (This is about getting the higher rate of the mobility component, see page 12 for more information.)

General points to bear in mind

- You may not have enough room on the form to give all the information you want to. Carry on on a separate sheet of paper, attach it to the form, and make sure you note on the form what you have done.
- 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, as long as the information is on the form somewhere, and you don't say different things in different places.

- *How many times a week or a day/night?* and *How long for each time?* are sometimes the hardest questions to answer. Don't be confused because for some questions, we advise that answering "all the time" or "continually" is OK, and for others, we advise you to try and be more precise. It does make some sense. For questions about communication, or development, or 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. However, 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." Don't underestimate.
- It can be useful to keep a diary for a while. This can make you aware of the full pattern of your child's needs. It's easy to forget about things because they're so much a part of your daily routine. You may want to include a copy of your diary when you return the form.
- 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 much more important to be clear than to stick to their layout. If you want to explain in detail, rather than using their boxes, do it.
- If your child doesn't have problems in a particular area, 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". So nothing is ever too minor to mention.

THE MOBILITY COMPONENT – THE RULES

The mobility component is for "help with getting around".

There are two rates of the mobility component: (April 2007-April 2008)

- **the lower rate (£17.10 per week)**
- **the higher rate (£45.00 per week)**

You have to be aged between 3 and 65 to apply for the mobility component. You can apply for the higher rate when your child reaches the age of 3. You can apply for the lower rate when your child reaches the age of 5.

The higher rate

From the age of 3 years, your child may qualify for the higher rate if:

- They are unable to walk
- They are virtually unable to walk
- The exertion required to walk would constitute a danger to their life or would be likely to lead to a serious deterioration in their health
- They have no legs or feet
- They are both deaf and blind
- They are entitled to the higher rate care component and are "severely mentally impaired with extremely disruptive and dangerous behavioural problems".

The rules for getting the higher rate are strict. Unfortunately, getting the higher rate is not about "what seems fair". It is about whether your child fits into the qualifying conditions. A child may have serious problems with walking, but not fit the rules well enough to get it.

A child with Down's syndrome is most likely to get the higher rate because they are unable to walk, or virtually unable to walk, or exertion would be a risk to their health, or because they have serious behaviour problems. You may feel that your child meets more than one of these conditions.

Unable to walk

A child will get the higher rate of the mobility component if at the age of 3 or over they cannot walk at all.

Virtually unable to walk

To get higher rate mobility under this condition, you need to show that although your child **can** walk, their walking out of doors is so limited that they are “virtually unable to walk”. Someone is “virtually unable to walk” if:

“his ability to walk out of doors is so limited, as regards the distance over which or the speed at which or the length of time for which or the manner in which he can make progress on foot without severe discomfort, that he is virtually unable to walk.”

So getting it depends on:

- How far your child can walk
- How fast your child can walk
- How long it takes to cover a certain distance – as well as speed of walking, this includes pauses, rests, interruptions, refusals, time taken to coax the child to go on, etc.
- The way in which they walk, for example, with poor balance or co-ordination, etc.
- Any walking which is only done with “severe discomfort” doesn’t count.

Measuring walking ability starts from the position of someone who can’t put one foot in front of the other. So if your child can’t walk at all, they get it. If your child can take steps, it is then a question of looking at all the factors, distance, speed, time taken, and manner of walking.

Distance

If your child regularly walks more than 50-100 yards, it is unlikely (though not completely impossible) that they will qualify as “virtually unable to walk”. The decision maker must also consider the other factors, such as how slowly they walk, how often walking is interrupted for rests, how long the rests or pauses take, poor balance and co-ordination, etc.

Speed

Normal walking speed is about 6 km or 3-4 miles an hour. Roughly it takes around a minute to walk 90-100 metres. So if your child can walk this far, but it takes longer, it is very important to say so.

Time

This involves looking at stops and pauses. Your child might need to rest, or you might have to spend time coaxing them to carry on. How long this takes is very important.

Manner of walking

Your child may have poor balance and co-ordination, or very low muscle tone that gives them a different gait. This might mean that they have problems with curbs, steps or uneven ground. They may fall a lot.

Behaviour problems with walking

Some children with Down's syndrome don't walk very far because of behavioural problems rather than any physical problem. They constantly "refuse" to walk. They may be physically capable of walking a long way, but in practice, rarely walk very far before they want to stop.

"Virtually unable to walk" seems to be only about physical problems with walking. However, behaviour problems can **sometimes** be taken into account.

- The behaviour must come directly from a physical cause, that is, having Down's syndrome.
- This means that your child must not be "consciously" refusing to walk. A child who walks to places they like, but refuses on other occasions, would not qualify. A child who regularly, for no apparent reason, refuses to walk regardless of where they are or where they're going, may qualify.
- On an average day, your child's refusals to walk must limit their walking seriously enough in terms of distance, speed, time taken, etc.
- If your child stops, and then can be coaxed to go further, it is the distance walked overall that will count. But if you have to spend ages persuading them to go further, this should also be taken into account.

Sometimes children both refuse to walk, and constantly try to run off. This is a difficult situation. Getting from A to B isn't taken into account. Only the ability to walk, that is, to put one foot in front of the other, counts. So a child who runs off can clearly walk. However, their running off may be very limited as to distance or time, for example, they make short darts away, taking only a few steps. If they also regularly refuse to walk any great distance, they may qualify for the higher rate.

Remember, problems with keeping your child safe **don't** count towards being "virtually unable to walk". They are taken into account for the lower rate.

Severe discomfort

Any walking which can only be done with "severe discomfort" does not count. "Severe discomfort" isn't severe pain. It can include breathless or tiredness as well as aches and pains. "Severe discomfort" has been described as a level of

discomfort that it's not reasonable to expect someone to go through on a daily basis. Your child may stop walking because they're tired. Or you may stop your child walking because you know that if they walk for longer, they are going to be very tired and uncomfortable later. As long as the tiredness comes on soon (that evening, or the next day), only the distance they can walk without risking severe discomfort later counts.

Exertion

Someone could qualify under this condition if they had a health problem which was made worse by walking, for example, a serious heart or lung problem. Some children with Down's syndrome do have such medical problems. You would need information from a doctor.

Severe mental impairment

To qualify under this condition, remember that your child needs to be receiving the **highest rate** care component of DLA. Their behavioural problems also need to be serious, needing someone to be alert and ready to intervene physically at all times (indoors and outdoors) to prevent danger to the child, or other people. It is not just behaviour while walking outside that counts.

To get higher rate mobility through "severe mental impairment", you have to show that your child meets a number of rules. They have to satisfy all of them in order to get it.

- Your child has to be receiving the **highest rate** of the care component.
- Your child has to be accepted as suffering from "a state of arrested development or incomplete physical development of the brain which results in severe impairment of intelligence and social functioning".

Children with Down's syndrome do "suffer from arrested or incomplete development of the brain." Evidence about this can be obtained from the Welfare benefits advisers at the DSA on 0845 230 0372. Recently, "severe impairment of intelligence" has been defined as having an IQ of 55 or less. However, this is very unhelpful. Many psychologists do not use IQ tests and you may not have an IQ score for your child. Instead, you can give information about the level reached by your child in reading, writing and numbers. Does your child have a special needs statement? Information about how independent your child is in daily routines (eating, washing, dressing, going to the toilet, etc) will be useful. Information about their speech will also be useful. This will help the decision maker assess their "social functioning".

- Your child has to "exhibit disruptive behaviour" which is "extreme".

Disruptive behaviour can range from aggression such as hitting, kicking, slapping, spitting, etc, to having tantrums, constantly running away, constantly taking clothes off, talking to imaginary friends, throwing things, stripping bed clothes off, wanting constant attention, sitting down and refusing to move, wanting to play too boisterously, turning on bath taps, emptying cupboards, putting things down the toilet, or simply behaving in any way that is inappropriate and risks upsetting or disturbing other people. There is no suggestion that your child is being deliberately malicious. You will need to describe what your child does in as much detail as possible, giving details of incidents.

- Your child's behaviour must "regularly require another person to intervene and physically restrain them to prevent them causing physical injury to themselves, or another, or damage to property."

Why does your child need to be restrained physically? Will they not stop when told to? Have they hurt themselves, or someone else, or damaged property in the past? You must show them that this happens regularly, on a daily basis. Sometimes it is obvious from the nature of the behaviour. For example, a child who constantly runs away in the street clearly needs to be stopped for their own safety, but you do need to spell out the fact that it has to be **physical** restraint.

- Your child's behaviour is "so unpredictable that they need another person to be present and watching over them all the time they are awake".

This rule is quite strict. If your child can be left in another room in the house, for example, watching a video, by themselves, for more than minutes at a time, then they probably won't satisfy this condition. It's quite possible that, given the realities of family life, you may leave your child alone in another room more than you feel happy about. But if so, do give details of anything that has happened while your child has been on their own.

The rules for "severe mental impairment" are quite complicated. If you want more information or advice, contact Christina Katic or Helen Wild, the Welfare benefits advisers at the DSA.

The lower rate

Someone qualifies for the lower rate if they cannot go to a place they don't know without someone with them to help and guide them. However, no young child can go to unfamiliar places on their own in any case, whether they have a disability or not, so there is an extra test for children.

Extra test for children

There is an extra test for children under 16 for the lower rate. From the age of 5, your child may qualify if they need a lot more guidance or supervision out of doors than other children of their age. Or they need guidance or supervision that other children of their age wouldn't need at all.

Guidance is having someone tell you where to go, or help you get to where you're going. Supervision is having someone there to keep you safe.

So you need to explain in what ways your child needs **EXTRA** guidance or supervision out of doors, over and above what another child of the same age would need. This could be because they are not safety-conscious, or because they need constant reminding where to go, or encouragement to keep walking. These are only examples. There could be other reasons.

In the experience of families who contact the Association, all children with Down's syndrome get the lower rate of the mobility component, and some get the higher rate.

THE MOBILITY COMPONENT - FILLING IN THE FORM

In this section, we go through the mobility questions on the form.

Walking outdoors

This question is about the higher rate of the mobility component. The higher rate can be awarded from age 3.

Does the child have difficulties walking?

The test for walking ability is walking out of doors on the flat. Having a problem because you happen to live on a hill isn't taken into account. But having to deal with normal obstacles, such as curbs, or uneven ground, does count. Walking is simply putting one foot in front of the other and making progress. Not being able to find your way to a particular place doesn't count. Not being able to keep yourself safe doesn't count.

Your child may only be able to walk a short distance or very slowly. This may be because of:

- Low muscle tone
- Loose ligaments
- Other medical conditions, such as a heart or chest problem
- Behavioural problems

Tell us about the difficulties they have with walking and about any equipment they use to help them.

This is where you can explain your child's limitations in walking. Read the information on "Virtually unable to walk", "Exertion" and "Severely mentally impaired" Which condition do you think your child qualifies under? It could be more than one.

Virtually unable to walk

You need to give detailed information about

- Why your child has problems with walking. This can be physical:
 - low muscle tone
 - loose ligaments (weak ankles, or knees)
 - poor balance and co-ordination
 - sensory impairments, such as poor vision or hearing

These can all lead to a child not being able to walk far. Does your child get tired or breathless very quickly, or trip and fall a lot? Do they walk with a different gait or in a different way to other children? Do they have trouble because of other conditions (a heart problem, or problems with seeing or hearing?)

- Why do they stop – are they tired? Breathless? Uncomfortable? Just won't go further? Do they say they are tired or their legs ache? Do they get flushed or go pale? Give details if your child stops because they are in discomfort of any kind.
- What happens then – can they be coaxed to walk further? Do you use a wheelchair ?
- How many interruptions to walking (pauses, refusals) are there during this distance? How long do they last?
- Your child's problems with walking may be mainly behavioural. You need to be open about the fact that physically they can walk, but give details about how limited their walking is because of their behaviour. Does it happen every day? Does it happen in every situation? If your child both runs away and refuses to walk, give very detailed information. Don't just say "runs off". Spell out how far they run, for example: "she will run for about 10 steps..." Remember – a child at this age would normally be able to walk for a considerable time and distance unaided, without exhibiting behavioural problems.

Exertion

Some children are limited in their walking abilities because they have a heart and or lung condition and walking actually makes their condition worse. You will know if this applies to your child as you will have been advised by your child's cardiologist about exercise and exertion limitations. If this applies to your child, say so here. You will need evidence from the consultant. The majority of children with a heart condition will be able to walk without damaging their health.

Severely mentally impaired

You need to give details about:

- Your child's level of social and intellectual functioning. Do they still need help getting dressed and undressed, going to the toilet, at mealtimes, at an age when other children don't? What's their speech like? What level have they reached at school? How's their reading, writing, numbers?
- Your child's behaviour – examples of disruptive behaviour. Remember, it's not just behaviour related to walking, it's behaviour all the time, at home, outside, at school.
- Why and how often you have to restrain your child physically

- Whether they can be left alone at all.

If you think that your child may qualify under this rule, you need to get further information from other people, for example, a letter from someone who knows how your child behaves, for example a teacher or social worker or a health professional. If you would like back up information about “arrested or incomplete development of the brain” (see page 12) to send with your form, please contact the Welfare benefit advisers at the DSA on 0845 230 0372.

How many days a week does the child have these difficulties?

This question is designed to find out if your child’s difficulties occur for the majority of the time. Remember that it is the help the child needs that counts so even though they may only go out 3 times a week, you have to ask yourself – would these problems occur even on the other 4 days if we went out? If the answer is yes, then put 7 days.

How far can the child walk before they have to stop because of severe discomfort?

You have to measure your child’s walking distance fairly accurately. It is very difficult to guess distances. You may not be sure about how far your child can walk measured in metres or yards. It can be a good idea to measure the length of your normal step, and then count how many steps it takes to cover the distance you need to know. Then multiply up to get a good, accurate estimate. Or have a look at your local swimming pool. Most pools are 25 or 30 metres (ask which!) This can give you a guide. Giving a good idea of the distance your child can walk is one of the hardest things on the form. Don’t give a wild guess! Anything you write on the form will be taken seriously and it is very hard to convince them you made a mistake afterwards. If your child’s walking is very limited, you could give the number of steps they take.

Remember, this is walking *without severe discomfort*. Do not count any distance that your child only manages to walk when they are very tired, or breathless, or otherwise uncomfortable.

Your child may not be able to walk far, but may not be stopping because of “discomfort”. Just give how far they walk.

How long does it take them to walk this far?

Normal walking speed is around 6 km or 3-4 miles per hour. Roughly it takes around a minute to walk 90-100 metres. If you’re not sure how long it takes your child to walk a certain distance, don’t guess. Time them. You can get so used to your daily routine that you don’t realise how long it’s taking your child to walk that far.

Remember, even if your child can walk a reasonable distance, if it takes a very long time, either because they walk so slowly, or because of lots of interruptions, your child may qualify.

Usually, if the higher rate of mobility is being considered, you or people who know your child will be asked for more information.

If the child needs someone with them when they are outdoors

This question is about the lower rate of the mobility component. The lower rate can be awarded from age 5.

Does the child need to have someone with them when they are outdoors in places they do not know well?

Children with Down's syndrome aged 8-16 will need someone with them.

Tell us why the child needs someone with them when they are outdoors in places they do not know well.

Look at the information on the lower rate. Remember, you have to show that your child needs more guidance or supervision than other children of their age.

Having a learning disability means your child could get lost or confused more easily than other children of their age. They may not be able to read signs, or follow directions. Your child's speech may be limited or unclear. They may rely on Makaton signs for communication. Children of 8–16 years of age would normally have a good vocabulary and clear speech. They would be able to ask for help if they were lost and give their name and address.

Also, many children with Down's syndrome are particularly vulnerable as they are not aware of 'stranger danger'. They may be a lot more trusting than a child would otherwise be at their age.

Some children with Down's syndrome may not be fully aware of the danger of traffic and the consequences of running into a busy road. They might need a lot more physical supervision, for example, holding hands, or being reminded of danger. Generally speaking, children at 8, and certainly at 16, would have a good degree of road sense and potential danger.

Some children may have hearing problems as well as having Down's syndrome and so have difficulty understanding other people.

These are examples of why your child may need extra guidance or supervision. There could be other reasons.

Do not assume that the decision maker knows about Down's syndrome or about the development of children without a disability. You must explain **why** your child needs the extra guidance or supervision and **why** this differs from a child the same age without learning difficulties.

Remember to keep a copy of your completed form.

THE CARE COMPONENT – THE RULES

The care component is for help with personal care.

There are three rates of the care component: (April 2007- April 2008)

- **the lower rate (£17.10 per week)**
- **the middle rate (£43.15 per week)**
- **the highest rate (£64.50 per week)**

Which rate someone receives depends on the amount of help they need.

When can you claim the care component?

You can claim this part of DLA from birth up to 65 years. But someone can usually only start to get the care component from the age of 3 months, because of the qualifying period (see "The non-disability conditions", page 34).

What is “personal care”?

Someone might get the care component if they need “attention” and/or “supervision”.

Attention

Attention is doing something of a close and personal nature for the disabled person in their presence. It must be “attention in connection with bodily functions” which include: breathing, hearing, seeing, eating, drinking, walking, sitting, sleeping, getting in and out of bed or a chair, going to the toilet, speaking, getting dressed and undressed. Often attention involves physical contact, but it can be by the spoken word – encouragement, reminders or reassurance. Attention doesn’t usually include help with shopping, laundry, or other household tasks.

Supervision

Supervision (or watching over) is being there ready to help if needed. It must be needed to prevent danger. The danger need not ever have actually happened but there must be a real, serious risk. Supervision needs to be “continual” – not every single second, but pretty constant.

If you're not sure if help is "attention" or "supervision"

Attention and supervision can clearly overlap. If you are not sure if a particular activity is "attention" or "supervision", don't worry. Just describe what you do in a suitable section of the claim form.

What kinds of help don't count

You may well need more money because of things like extra hospital appointments, or having to turn the heating up, or not being able to go back to work, but none of these help you get DLA.

The extra test for children

There is an extra test for children under 16. All children need help from their parents. A child will only get DLA if they need a lot more attention or supervision than another child of the same age. Or if they need the kind of help that usually only a younger child would need.

"Attention" or "supervision" for a child may be "extra" because

- it takes longer (for example, at mealtimes); or
- it is different in some way (some kind of help not needed by most other children, for example, physiotherapy, speech therapy, etc); or
- it is the kind of help usually needed only by younger children.

You have to think about why the help your child needs is more than the help needed by other children of their age.

For more information about the kinds of extra help children with Down's syndrome may need, see **"The care component - Filling in the form"**, pages 26-33.

The different rates of the care component

It is when help is needed, how often and how long for, which decides which rate your child will get.

- Your child will get the lower rate if they need extra help for about an hour during the day.
- Your child will get the middle rate if they need enough extra help during the day, or during the night.

- Your child will get the highest rate if they need enough extra help during the day, and during the night.

The rules for the lower rate

Your child may get the lower rate if:

- they need "part time day care", that is, attention in connection with their "bodily functions" for a 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 might qualify for the middle rate.

The rules for the middle rate

Your child may get the middle rate if they need enough extra help **either** during the day, **or** during the night.

The day time conditions

- your child needs frequent attention throughout the day in connection with their "bodily functions"

and/or

- your child needs continual supervision throughout the day in order to avoid substantial danger to themselves or others.

Your child only needs to meet **one** of the daytime conditions to get the middle rate, though many children with Down's syndrome aged 8-16 may meet both.

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. This is why it is so important to include all the help you give your child, since the 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". For example, time spent on speech therapy exercises **AND** extra help with cutting up food at mealtimes **AND** the help your child still needs getting dressed when most children their age could manage alone, etc, are added together to meet the "frequent attention" condition.

Continual supervision

Lots of children aged 8-16 with Down's syndrome will need more supervision than other children of their age because of their learning disability. For example, they may not be aware of common household dangers, or they cannot be left alone in the house in the same way that another child of the same age could be, or they still don't listen to spoken commands but need to be physically stopped or removed from danger. They may not be able to tell the time, and plan their activities, in a way that other children of their age could.

The night time conditions

- your child needs prolonged or repeated attention in connection with their "bodily functions" at night

and/or

- your child needs another person to be awake for a prolonged period, or at frequent intervals, to watch over them in order to avoid substantial danger to them or others.

Your child only needs to meet **one** of the night time conditions to get the middle rate.

Prolonged or repeated attention at night

"Night" is after the whole household has shut down. It does not start from your child's bedtime, but after you and other adults in the household have gone to bed.

"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. So if your child wakes once in the night, and you have to get up, to attend to them, or to help them with a drink or toileting needs or settling back to sleep, and it takes about 20 minutes, then your child meets this condition. Or if you have to get up twice or more (even if only for a very short time each time), then your child meets this condition.

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 say you get up 3 nights out of the 7 or 1 week out of 4. For example, a lot of teenage girls with Down's syndrome who have started their period would probably need more help while it lasts than a girl normally would. However, because this help isn't needed for the majority of the month, it would not be enough, on its own, to qualify for extra night attention.

"Watching over"

This is 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 have 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, for example, a child who has a tendency to wander, and who might fall downstairs or even get out of the house. (The danger need not ever have actually happened, though you need to explain why you think it might.)

Obviously, "attention" and "watching over" during the night could well overlap. If you feel that in your case they do, it is probably best simply to describe what you do, paying particular attention to how often, and how long for, and not try to separate "attention" from "watching over".

Remember, to get the middle rate, your child has to meet one of the daytime conditions **or** one of the night time conditions.

The rules for the highest rate

Your child will get the highest rate if they need extra help during the day **and** during the night.

In other words, your child qualifies for the highest rate if they satisfy one of the day time conditions **and** one of the night time conditions. The conditions are exactly the same as for the middle rate.

For example, your child could need frequent attention throughout the day, and need "watching over" at night.

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

For example, if you have to get up at night, but only in the same kind of way that you would for any child of that age, then that is not “extra” attention or supervision.

THE CARE COMPONENT - FILLING IN THE FORM

Remember, focus on:

- any help that takes longer with your child
- any help that other children don't need
- any help that usually only younger children need

Someone keeping an eye on the child

This question is about “supervision” during the day and “watching over” at night.

During the day

Children with Down's syndrome aged 8-16 will almost always need “continual supervision throughout the day in order to avoid substantial danger to themselves or others” at a level of supervision which is greater than most other children of the same age.

Your child may need more supervision than other children because

- they are slower to learn about common dangers in the home, such as electric sockets, hot water, the cooker, etc.
- they don't respond to verbal commands, but have to be physically stopped from doing something dangerous
- they can't be left on their own, but need help to keep busy
- activities which most children of their age could do independently still need to be supervised

You need to explain in what ways your child needs a higher level of supervision. It is a good idea to compare your child with other children of the same age, for example, if you can remember how your older children behaved at that age, or if you know other children and can compare them with your own child.

Most children at around age 10 can play independently or with friends outside, or can go independently to the local park or swimming pool. They are also able to keep their parents informed of their whereabouts and to ask for help if needed.

How many days a week, etc

Most people are probably going to put “7 days a week” and “all the time” in this section.

During the night

All children need adults to be in the same house during the night. The night time need for “watching over” is about an adult being awake during the night. Helping your child with a drink, or to go to the toilet, is dealt with later on the form. Here you are being asked about the need to wake up, or to be awake, to make sure that your child is safe. You may need to wake up and go to check your child, or to wake and listen out for them. This may be because they have sleep apnoea, or they get up and wander at night.

How many nights a week, etc

It is important to give details of how many nights a week, how many times a night, and how long, you are awake for.

About the child’s development

These questions ask you about your child’s developmental delay.

Does the child have a delay in their development of physical or sensory skills?

Your child may walk unsteadily with a lot of falls. They may have poor balance and co-ordination, so they can’t cope with steps or curbs or uneven ground. They may get tired more quickly than other children because of their poor muscle tone. They may have difficulty with fine motor skills, for example, grasping a pencil, or picking up small objects. They may be seeing a physiotherapist and have to do exercises every day. They may have problems because of poor vision or poor hearing.

Give details about your child’s difficulties. If they see a physiotherapist, you can give full details (how often they see the therapist, how many times a day they do exercises) either here, or on the ‘Help with Therapy’ page.

Does the child have a delay in their development of learning skills?

Yes, your child has a learning disability. Give examples of what this means. For instance, do you have to repeat things more? Do you have to break down activities into smaller steps? Do you have to show your child how to do things, as well as telling them? Maybe they still can’t do things that other children of their age can. Like making a drink, or getting appropriately dressed by themselves. Can they read or write or count yet? Are they in mainstream or special school? What key stage have they reached?

Again, if information here overlaps with other questions (for example, Washing and bathing, or Getting dressed and undressed), you can choose where to put

the details. But make sure that if you give full details somewhere else, you put a note to refer to that page.

Does the child have a delay in their development of social skills?

Your child may be slower in learning to speak, and this might affect their social skills. Information about this may overlap with pages on Communicating with other people. Make sure you refer clearly to information you've given on other pages.

Does someone need to help the child develop through play?

Your child may need help to keep themselves amused and occupied. Do they have a short attention span? What happens if they are left to themselves? Do you have to set up activities for them? Do they like games, toys or activities that, usually, only younger children enjoy? Do they like things to follow a regular routine and need encouragement to take on new activities?

Roughly how many times a day does the child need help?

Roughly how long does it take each time?

You may want to put "all the time" for all these sections, unless there are specific examples (such as physiotherapy exercises) where you can give more detailed times. Be clear if you are talking about ongoing continual help, as well as more specific examples. For example, "She needs help all the time with social skills because she is only using single words and only understands very simple sentences. We also do speech therapy exercises times a day for 20 minutes each time....see page xx"

It is much more important to give full information than to stick to their boxes.

Waking, getting up and going to bed

Your child will probably only need extra help getting in and out of bed if they have a physical disability.

Some children may need a great deal of attention to settle to sleep at night. Normally a child would be able to go to bed at this age once they were told to and no settling would be required.

Settling a child to sleep usually counts as attention during the day. "Night" is when the whole household has closed down for the night, not your child's bedtime. However, some children take so long to settle that you may feel you would go to bed earlier yourself, if your child didn't need this attention. If this is the case, say so.

How many days a week/How many times a day/Roughly how long....

It should be possible to give specific answers to these questions.

Washing and bathing

Your child may need extra help with washing and bathing. You may be unable to leave your child unattended in the bath or you may need to make sure that they use the appropriate washing products. It may take longer than for most other children, perhaps because they dislike certain activities and have to be persuaded. They may need lots of prompting and reminding. They may have very dry skin so you need to spend extra time applying creams after a bath.

How many days a week/How many times a day/Roughly how long...

It should be possible to give specific answers to these questions.

Getting dressed and undressed

Your child may need extra help with getting dressed and undressed. As with washing and bathing, this may be because they still need help from you at an age when most children are doing it for themselves. They may be slower because of poor muscle tone, or because their fine motor skills aren't as good. They may need more help deciding on the right clothes for the weather. Can they manage buttons or laces? They may have favourite clothes and be reluctant to wear others.

How many days/How many times a day/Roughly how long....

It should be possible to give specific answers to these questions.

Help with toilet needs

Your child may need extra help with toilet needs. They may need some help, for example, cleaning themselves, for a lot longer than other children, or they may continue to need supervision, checking that they are OK, at an age when most other children don't.

How many days or nights/How many times a day or night/Roughly how long...

It should be possible to give specific answers to these questions. It is especially important to give full details about your child's night needs.

Communicating with other people

**Does the child need help understanding other people?
Does the child need help being understood by other people?
Is the child unwilling to communicate with other people?**

Some children in this age range with Down's syndrome need extra help understanding and being understood. Some may be unwilling to communicate as well. Give details about your child's understanding and speech. How many words do they use? Do they use phrases or sentences or just single words? Do you speak differently to them – slowly, or more simply? Do you use Makaton signs? You may know the delay in their speech development from a speech and language report. If you do, say so. Is their speech clear? Can they follow instructions? Can they talk to and be understood by people who don't know them well? Does your child have any kind of hearing impairment?

Describe the sort of help they need. This could be the use of Makaton signs, teaching your child new signs, having to say things very simply, or having to repeat things. Do you talk to your child as if they were much younger?

Does your child get speech therapy? Has the speech therapist given you exercises to do with your child? (You may want to describe this in detail on page 16 – Help with therapy but mention it here as well). If they've been assessed as needing therapy but aren't getting it, say so.

How many times a day/Roughly how long does it take each time?

Putting "all the time" or "every time someone speaks to her" is fine, unless you can be more specific, for example, the time you spend practising speech therapy exercises.

Eating and drinking

Your child may need extra help with eating and drinking. Younger children in this age group may still need their food cut up for them. Older children may need more supervision at mealtimes. Some children may eat very slowly so mealtimes take a lot longer than usual. Some children may be resistant to eating different food, and may need lots of prompting and encouragement to try new foods.

How many days or nights/How many times a day or night/Roughly how long...

It should be possible to give specific answers to these questions. Again, it is important to give full details if you get up with your child at night because they need something to eat or drink.

Help with medication

Your child may be on medication, usually for medical conditions other than simply having Down's syndrome.

How many days or nights/How many times a day or night/Roughly how long...

It should be possible to give specific answers to these questions.

Help with therapy

Your child may be seeing:

- a speech therapist
- a physiotherapist
- a clinical or educational psychologist

You may have chosen to give details about your child's therapy in other places on the form.

Speech therapy – you may have chosen to give details on pages headed 'Communicating with other people'.

Physiotherapy – you may have chosen to give details on pages headed 'About the child's development' or 'Movement and co-ordination and Moving about indoors'.

Psychologist – you may have chosen to give details on pages headed 'About the child's development' or 'The child's mental health'.

If so, refer to that here. If you explained why your child needs therapy in other places on the form, but want to give details about the therapy itself here, make sure you put a note to refer to other parts of the form.

It's very important you give information about the exercises you do with your child on a daily basis, not just how often your child visits the professional workers.

If possible, give details of how many days/nights a week, how many times a day or night, and how long for. Don't add all everything together for different therapies. List them separately so the decision maker can see how time-consuming they really are.

Help with medical equipment

Your child with Down's syndrome probably won't need to use medical equipment. They may need to wear special boots. Or they may have needs because of some other condition. This may be a good place to give details if your child needs glasses or hearing aids and you have difficulty getting them to wear them.

Blackouts, fits, seizures or something like this

Your child with Down's syndrome probably won't experience problems like this. However, some children may have diabetes or epilepsy as well.

The child's mental health

This question can be confusing, because "mental health" often refers to illnesses such as schizophrenia or depression. Children with Down's syndrome are not likely to have such an illness, but this is a good place to give information if your child gets very anxious, or panicky, or frustrated or shows difficult behaviour.

Movement and co-ordination

You will probably already have given details on pages 'About the child's development' or 'Walking outdoors' if your child has problems with movement. If so, refer to those pages here or repeat the information.

Moving about indoors

Again, you will probably already have given details at the page 'About the child's development'. If so, refer to those pages here or repeat the information.

When the child is in bed at night

You have already answered questions about your child's needs at night. This is a good place to bring this information together.

List the different reasons you get up in the night for your child. Remember to include the times you wake up to check on, or to listen out for your child.

Obviously, the number of times you get up and how long it takes may vary. You may be able to say "twice a night for 10 minutes 5 days a week." If it's more variable, try to give a picture of an average night, or the range over a week.

Remember, if your child wakes up in the night, the time you spend settling them back to sleep also counts.

Help the child needs when they go out during the day or in the evening

These questions can seem confusing. They're on the form because the help your child needs with social or leisure activities – any help they need to live "a normal life" - counts for DLA.

For young children, you may already have given details on other places on the form, for example, pages headed 'Communicating with other people'. For older children, there may be more examples. Can your child only go to Guides if you go with them? Do you have to stay with them at birthday parties? Do they need help to participate in school clubs or sports?

Anything else about the way the child is affected by their illnesses or disabilities

You can use this space to summarise the information you've put on the form. Or you may feel that in your child's case it would be very helpful to do a diary of a typical day. It may also be very useful to include information about your child's school here. Are they in mainstream or a special needs school? Do they have a statement of special educational needs?

Remember to keep a copy of your completed form.

OTHER USEFUL INFORMATION ABOUT DLA

The non-disability conditions

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

1. The "residence conditions"

To get DLA, your child has to be

- ordinarily resident in Great Britain **AND**
- present in Great Britain (but they can be away temporarily for up to 26 weeks) **AND**
- your child has to have been present in Great Britain for a total of 26 weeks in the past 12 months (babies less than 6 months old need only to have been present for 13 weeks out of the past 26 weeks).

2. The qualifying periods

Your child has to have already satisfied one of the disability conditions for at least 3 months to get DLA. Your child also has to be likely to satisfy one of the disability conditions for the next 6 months.

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.

For the mobility component, the lower age limit is 3 years old (higher rate) and 5 years old (lower rate). But 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 expected to die within the next 6 months. The qualifying periods don't apply in these cases.

REVISIONS, SUPERCESSIONS AND APPEALS

What to do if you are unhappy with a decision

When you apply for DLA for your child, you may not be happy with the DWP decision.

- Your child may be refused completely
- Your child may be given a rate you are not happy 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.

If you want to get your child's benefit changed, you can ask for a revision, a supercession or an appeal. Or sometimes you may need to make a new claim.

If I ask them to look at my child's benefit again, can I lose out?

Yes, in theory. Often when you ask for a revision or a supercession, the DWP say you could lose the benefit you already have. This is possible, but in practice, we have not known it to happen for children with Down's syndrome.

It can be difficult to know what to do, especially if you are refused benefit completely. Get advice. Contact Christina Katic or Helen Wild, the DSA Welfare benefits advisers on 0845 230 0372.

Revisions

You can ask for a revision of the decision if you are unhappy with it for any reason, if you apply within **one month** of the decision. You can ask for a revision by phone, though it is usually sensible to follow up your request in writing. Sometimes revisions are called "reviews" or "re-considerations".

When you ask for a revision, your child's case will be looked at again, from the beginning, by a different person.

The decision maker does not have to consider any point you don't raise specifically. It is obviously sensible to include as much information as possible in your letter, repeating all the information you put on the claim form in your letter, as well as extra details. It can be helpful to set it out in the form of a diary, going through the day and night. Point out why you feel your child needs more attention or supervision.

It is also useful to send supporting letters from health or education professionals who know your child.

If the decision maker thinks that they still do not have enough information, they may send you another form to fill in. It is very similar to the original claim form. Or they may request more information on certain points. You will be given **one month** to respond. If you don't contact them, your child's DLA may be suspended. **It is important to get in touch with them within the time limit, even if you don't yet have the information they need.**

Supercessions

If it is more than **one month** after you have received a decision on DLA, and you are not happy with your child's benefit, you need to ask for a supercession. However, you can only get a supercession for certain reasons, such as your child's needs have increased, or you think the original decision was wrong. If you would like to know more about the grounds for a supercession, please contact Christina Katic or Helen Wild, the Welfare benefits advisers at the Down's Syndrome Association.

You will almost certainly have to fill in another form. They may also request more information on certain points after they get your form. You will be given **one month** to respond to this additional request. If you don't contact them, your child's DLA may be suspended. **It is important to get in touch with them within the time limit, even if you don't yet have the information they need.**

Backdating

Both revisions and supercessions can take some time, 2-3 months or even longer, but if the decision is favourable to you, DLA should be backdated, at least to the date you asked for the revision or supercession, and possibly longer.

Appeals

If you are not happy with a DLA decision, you have the right to appeal to a tribunal. Going to a hearing gives you the chance to put your case to someone face to face.

You can ask for an appeal within **one month** of the decision you are unhappy with. However, it is usually better to ask for a revision first, as appeals take a long time (6-12 months). Then, if you are not happy with the revision, you can ask for an appeal within one month of that decision. You can also ask for an appeal if you are not happy with the outcome of a supercession.

If you want to go to appeal, **GET ADVICE – YOU MAY LOSE OUT IF YOU DON'T.** The process is complicated, and statistics show your chances of success are greater if you get advice from a welfare benefits agency.

Your local Citizen's Advice Bureau, or the Welfare Rights Unit or Advice Shop run by your local council, or your local MENCAP office, may be able to supply someone to help you. Or contact Christina Katic or Helen Wild, the Welfare benefits advisers at the Down's Syndrome Association.

LENGTH OF AWARD

DLA is usually awarded for a fixed period. If someone gets both care and mobility for a fixed period, their awards will end on the same date. DLA can also be awarded for an "indefinite" period. This means it will continue unless the person's needs change.

Lots of children only get 2-3 year awards because the DWP thinks that the child's needs will change as they get older. Parents sometimes feel that they have to fill in claim forms too often. As a child gets older, they do get longer awards. Sometimes an indefinite award is made. But lots of children still only get shorter awards.

RENEWAL CLAIMS

Most children are awarded DLA for a limited period, say, for 2 years, or up to their 8th or 12th or 16th birthday. Forms should be sent to you automatically to make a renewal claim about 6 months before the end of the award. If you do not get forms, ring the DLA Unit and ask for some. **If you do not claim before the end of the award, benefit will not be backdated.**

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

APPOINTEES

While your child is young, the DWP will simply assume that you (as the parent or carer) will manage their benefits for them.

When they turn 16, you have to fill in a form and become an official "appointee". The DWP will then continue to deal with you on your child's behalf. As an appointee, you have the same responsibilities and duties as your child would have, if they were acting for themselves.

Becoming an appointee is usually just a formality.

WHICH RATE OF DLA SHOULD MY CHILD GET?

It's impossible to say. Children's needs vary so widely. However, we feel that if a child with Down's syndrome aged 8-16

- only gets the lower rate care, or
 - doesn't get the lower rate mobility (after they're 5)
- then they are probably missing out. Get advice.

DLA AND OTHER BENEFITS

Carer's Allowance

If your child gets the middle or higher rate of the care component, someone looking after them may be able to get another benefit, Carer's Allowance (formerly Invalid Care Allowance). CA is £48.65 per week (April 2007-April 2008).

You may get Carer's Allowance if:

- You are over 16
- you look after someone who is getting the middle or higher rate of the care component of DLA, for 35 hours or more a week
- you don't work and earn more than £87 a week (certain expenses are deducted from your earnings) or receive state retirement pension
- you are not a student

If you are on Income Support or income-based Jobseeker's Allowance, you don't get the full amount of CA, but you will get some extra money included in your benefit (the carer's premium). However, CA is taken into account as income for other benefits. If you are receiving other benefits, check your situation before claiming CA.

Apply for CA when you claim DLA. Then, even if your DLA claim takes a while to sort out, you can get CA backdated. They will simply not make a decision on your CA claim until the DLA claim is decided.

Means-tested benefits

If you are getting means tested benefits, such as Income Support, income-based Jobseekers' Allowance, Housing Benefit, Council Tax Benefit, Child Tax Credit or Working Tax Credit, you may get some extra money when your child starts to get DLA. Check with your local DWP office (for Income Support and Jobseeker's Allowance) or your local council (for Housing Benefit and Council Tax Benefit) or ring the Tax Credit Helpline on 0845 300 3900.

Motability

If your child gets the higher rate of the mobility component (for a period of 3 years or more), you can get a new or used car by hire purchase through the organisation Motability (address on page 40).

Road tax exemption

If your child gets the higher rate of the mobility component, you will be sent forms to apply for exemption from road tax (vehicle excise duty). If the car is used mainly for the purposes of your child, then you don't have to pay road tax.

Blue Badge (this used to be the Orange Badge)

The Blue Badge scheme is run by local councils (in England and Wales). A Blue Badge means you can park in some, but not all, parking restricted areas.

You may get an Blue Badge if your child is aged 2 or over and:

- your child gets the higher rate of the mobility component of DLA **OR**
- your council accepts that your child has a "permanent and substantial disability which causes inability to walk or very considerable difficulty in walking".

So your child doesn't have to get the higher rate of the mobility component of DLA.

If you are refused, there is no formal right of appeal, but you could speak to a local councillor to see if they will change their mind.

USEFUL ADDRESSES

Disability Living Allowance Unit

Warbreck House

Blackpool

Lancashire

FY2 0YE

Tel: 0845 712 3456 (local call rate)

Down's Syndrome Association

The Langdon Down Centre

2A Langdon Park

Teddington

Middlesex

TW11 9PS

Tel: 0845 230 0372

Carer's Allowance Unit

Palatine House

Lancaster Road

Preston PR1 1HB **Tel: 01253 856123**

MENCAP National Office

123 Golden Lane

London

EC1Y 0RT

Tel: 020 7454 0454

Motability

Goodman House

Station Approach

Harlow

Essex

CM20 2ET

Tel: 0845 456 4566

DWP Enquiry Line

for people with disabilities:

0800 882200

They can send out claim forms. Cannot give information about individual claims; general advice only.