DOWN'S SYNDROME ASSOCIATION

A Registered Charity
No. 1061474

information

GUIDELINES TO CLAIMING

DISABILITY LIVING ALLOWANCE

Age 16+

April 2007
This information is updated every year.

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INDEX TO GUIDELINES

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

Your child is coming up to or has reached the age of 16. The DWP always looks at DLA again at this age. Your child will now be assessed under the “adult” rules for DLA. Although you have probably filled in the forms several times by now, it can be difficult at this stage. The “adult” rules are slightly different. Also your child may be more independent and may need different sorts of help now. These guidelines are to explain the rules and to help you fill in the form.

The first section gives a general outline how the benefit works, and how to claim it. 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 though your child has been getting DLA.

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 disability or long term illness.

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

Claiming as an adult at age 16
At the age of 16, a young person is considered to be an adult, claiming in their own right. The DWP assume that the young adult will be dealing with their claim themselves. But young people with Down’s syndrome will probably not be able to deal with their claim themselves at 16. In most cases, a parent (or other carer) becomes an appointee for their child. This means that the DWP will deal with the appointee instead. See p 34 for information about becoming an appointee.

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 savings or income are.

Will getting DLA reduce other benefits you get?
Getting DLA does not reduce the amount of other benefits you or your child may get. It is paid on top of other benefits and may increase the amount of benefit you get.

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 10-14.

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 20-24.

There are also **'non disability conditions'** and these are explained on page 30.

Will someone 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.

Renewal claims at 16

If your child is already getting DLA, you should be sent a claim form to make a renewal claim about 6 months before their DLA runs out. The form should be for a person over 16 – even though your child isn't 16 yet. 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 and that your child will be 16 shortly.

When do I have to send the forms 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 young person at 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 the person you're claiming for. **DON'T** think that because they have been getting DLA, you don't have to give full information.

It is always a good idea to keep a copy of your completed form.

Claiming Incapacity Benefit and Income Support at 16

At age 16, your child may be able to claim other benefits, in their own right. These are Incapacity Benefit and Income Support. Most young people with Down's syndrome can claim these benefits at 16. Disability Living Allowance is paid on top of these benefits. See the DSA information sheet **Benefits at 16** for more information.

However, if your child claims in their own right, they no longer count as a dependent, or a member of your household. You will stop getting Child Benefit for them. If you yourself are claiming benefits (such as Child Tax Credit or Income Support), your child claiming in their own right will affect the amount of money you receive. Your family could end up with less money overall.

Don't claim benefits for your child in their own right until you have checked your own situation.

This does not apply to claiming DLA. Your child getting DLA will not reduce your other benefits.

THE CLAIM FORM

The claim form for a person aged 16 or over is different to the claim form for a child.

Most young people with Down's syndrome will already be receiving DLA. Renewal claims are usually sent several months before DLA runs out. So your child may not yet be 16 when you get the renewal claim form. But if they are coming up to 16, you do need to fill out the adult claim form for them. Just describe their present needs.

How is the adult form different?

The main difference is that the questions on the adult form are phrased as if the young adult with Down's syndrome were answering for themselves.

You can chose to answer as if it's the young adult describing themselves. You can get them to sign the form, if you feel that they are able to deal with their own claim.

However, many 16 year olds with Down's syndrome are not able to deal with their DLA claim. On page 2 of the form, there is a section **For people signing this form for someone else.** If you know that you are going to be dealing with the claim on your child's behalf, it may be easier to tick one of the boxes in this section. You can then fill in the form for your child, even though the questions are addressed to "you." For example, in answer to the question "Do you have physical problems walking? you can answer: "Michael has problems walking because….."

If you fill in the form on your child's behalf, the DWP will get in touch with you about becoming their "appointee". See p 33 for more information.

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 sombodys' 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 the form. Anyone who knows the young adult can sign either of the statements, but it is probably a good idea to get a professional (GP, teacher, speech therapist, etc) to sign

About you

Fill in information about the person you're claiming for, not yourself.

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. It may be relevant to some people with Down's syndrome. Other boxes may be relevant, particularly problems with hearing or speech. Some people 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 13 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 needing supervision, it is obvious that if the need exists, help will have to be more or less all the time.

However, if help is needed at mealtimes, 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 the young adult 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 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 the person you’re claiming for 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 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, someone 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 someone fits into the qualifying conditions. Someone may have serious problems with walking, but not fit the rules well enough to get it.

An adult 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 the person you're claiming for meets more than one of these conditions.

Unable to walk

Someone will get the higher rate of the mobility component if they cannot walk at all.

Virtually unable to walk

To get higher rate mobility under this condition, you need to show that although the person you're claiming for **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 someone can walk
- How fast they 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 encourage them 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 the person you're claiming for can't walk at all, they get it. If they can take steps, it is then a question of looking at all the factors, distance, speed, time taken, and manner of walking.

Distance
If someone 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 the person you're claiming for 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 encouraging them to carry on. How long this takes is very important.

Manner of walking

The person you're claiming for 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.

Behaviour problems with walking

Some adults 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 the adult with Down's syndrome must not be "consciously" refusing to walk. Someone who walks to places they like, but refuses on other occasions, would not qualify. A young adult who regularly, for no apparent reason, refuses to walk regardless of where they are or where they're going, may qualify.
- On a average day, the refusals to walk must limit their walking seriously enough in terms of distance, speed, time taken, etc.
- If they stop, and then can be encouraged 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.

Remember, problems with keeping someone 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. The person you're claiming for may stop walking because they're tired. Or you may stop them 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 adults with Down's syndrome do have medical problems like these. You would need supporting information from a doctor.

Severe mental impairment

To qualify under this condition, remember that someone 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 themselves, 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 the person you’re claiming for meets a number of rules. They have to satisfy all of them in order to get it.

- They have to be receiving the **highest rate** of the care component.

- They have 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”.

Adults 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. Instead, you can give information about the level reached in reading, writing and numeracy. What sort of school or college do they attend? If it’s mainstream, how much extra help do they get? Information about how independent they is in daily routines (eating, washing, dressing, going to the toilet, etc) will be useful. How much supervision do they need to help them in daily tasks? Information about their speech will also be useful. This will help the decision maker assess their “social functioning”.

- Somone has to “exhibit disruptive behaviour” which is “extreme”.

Disruptive behaviour can range from aggression such as hitting, kicking, slapping, spitting, etc, to shouting, 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, being destructive of furniture, or simply behaving in any way that is inappropriate and risks upsetting or disturbing other people. There is no suggestion that they are deliberately being malicious. You will need to describe what the person you're claiming for does, in as much detail as possible, giving details of incidents.

- Someone'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 do they 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, someone 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.

- Someone'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 someone 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 the person you're claiming for alone in another room more than you feel happy about. But if so, do give details of anything that has happened while they have 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 may qualify for the lower rate if:

They cannot go to a place they don't know without someone with them to help and guide them.

In the experience of families who contact the Association, everyone with Down's syndrome gets 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. The mobility questions are on pages 6-9 of the claim form.

You will notice that the questions on the adult form are phrased as if the young adult with Down's syndrome were answering for themselves. See p 7 for discussion about this.

Walking outdoors

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

Do you have physical problems 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.

The person you're claiming for may only be able to walk a short distance or very slowly. This may be because of:
- Low muscle tone or loose ligaments, leading to tiredness, aches and pains, etc
- Problems because of poor vision or hearing, for example, tripping or stumbling
- Other medical conditions, such as a heart or chest problem
- Behavioural problems

Describe in your own words the problems you have and the help you need with walking

This is where you can explain the young adult's limitations in walking. Read the information on "Virtually unable to walk" and "Severely mentally impaired" – pages 10-14. Which condition do you think they qualify under? It could be more than one.

Virtually unable to walk
You need to give detailed information about:

- Why the person you're claiming for 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 someone not being able to walk far. Do they 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 people? Do they have trouble because of other conditions (a heart problem, or problems with seeing or hearing?)

- Why 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 they stop because they are in discomfort of any kind.

- What happens then – can they be encouraged to walk further?

- How many interruptions to walking (pauses, refusals) are there during this distance? How long do they last?

- The 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. What happens? Does it happen every day? Does it happen in every situation?

Severely mentally impaired

You need to give details about:

- The young adult's level of social and intellectual functioning. Do they still need help getting dressed and undressed, going to the toilet, at mealtimes? (Help includes prompting, reminders and encouragement as well as hands-on help.) What's their speech like? What level have they reached with reading, writing, numeracy?
- You will need to give 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 them physically
- Whether they can be left alone at all.

If you think that the person you're claiming for may qualify under this rule, you are going to have to get further information from other people, for example, a letter from someone who knows how they behave, 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 13) to send with your form, please contact the Welfare benefit advisers at the DSA on 0845 230 0372.

If you are giving information about “severe mental impairment” you may need to continue on a separate sheet of paper.

Tell us about anything you use to help you walk

Most adults with Down’s syndrome will not use any special equipment, but some may, for example, a wheelchair, or special shoes.

If the effort of walking would be dangerous for you, tell us about this

Some adults with Down’s syndrome 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 the cardiologist about exercise and exertion limitations. You will need evidence from the consultant. The majority of adults with a heart condition will be able to walk without damaging their health.

Tell us roughly how far you can walk before you feel 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 they 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 the person you’re claiming for 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 the person you’re claiming for only manages to walk when they are very tired, or breathless, or otherwise uncomfortable.

They may not stop because of severe discomfort. They may simply stop. Just give the distance they walk.

Tell us how long on average it takes you to walk this far

Normal walking speed is around 6 km or 3-4 miles per hour. Roughly it takes just over a minute to walk 90-100 metres. If you're not sure how long it takes the person you're claiming for 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.

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

How many days a week do you have this amount of difficult walking?

This question is designed to find out if walking difficulties occur for the majority of the time. Remember that it is the help needed 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 they went out? If the answer is yes, then put 7 days.

Having someone with you when you are outdoors

Look at the information on the lower rate of the mobility component – page 14. The person you are claiming for may be able to go to places they know on their own. But if they couldn't go somewhere they didn't know without someone with them to guide or supervise them, they may get the lower rate.

Do you need to have someone with you when you are out of doors?
Why does the person with Down's syndrome need guidance or supervision when they go to an unfamiliar place?

Do they need someone to show them or tell them the way? Would they be fully alert to danger from traffic if they didn't know the roads well? Would they become confused? If they got lost, could they cope? Would they be able to communicate well with strangers, for example, asking for directions? Would they understand what people told them? Would they get upset or very anxious? Could someone take advantage of them? Are there particular situations or events that upset them so they would need someone with them to calm them down?

Falls or stumbles

Falling or stumbling could be the reason why someone needs guidance or supervision in unfamiliar places. This could be caused by epilepsy, or dizzy spells, or poor vision.

Someone with Down’s syndrome may also have epilepsy, or may have poor eyesight.

If your child has problems with falling or stumbling, give details here.

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 30).

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 the person you’re claiming for can’t use public transport, or needs so much help you can’t work, but these do not help in getting DLA.

The different rates of the care component

It is when help is needed, how often and how long for, which decides which rate an adult with Down’s syndrome will get.

- They will get the lower rate if they need attention for about an hour during the day or they can’t prepare a cooked main meal for themselves.
- They will get the middle rate if they need attention or supervision during the day, or during the night.
- They will get the highest rate if they need attention or supervision during the day, and during the night.

The rules for the lower rate

The person you’re claiming for may get the lower rate if:

- They cannot prepare a cooked main meal for themselves if they had the ingredients

or

- they need "part time day care", that is, attention in connection with their "bodily functions" for a significant portion of the day

The cooking test
The test is about cooking a fresh meal on a traditional cooker (not about heating something up in a microwave). It includes planning the meal, preparing vegetables and meat, using taps, using cooking utensils, using a cooker, lifting hot or heavy pans, being able to tell when food is cooked. It’s a test about being able to do these activities, in theory – not about whether someone can or does actually cook. For an adult with Down’s syndrome, difficulties in reading a recipe, or understanding the correct order to do things, or planning, would count. Or they might be at risk if they used a cooker, or hot water, without supervision.

Part time day care
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 the person you're claiming for needs help throughout the day, they might qualify for the middle rate.

The rules for the middle rate

The person you're claiming for may get the middle rate if they need attention and/or supervision **either** during the day, **or** during the night.

The day time conditions

- they need frequent attention throughout the day in connection with their "bodily functions"

and/or

- they need continual supervision throughout the day in order to avoid substantial danger to themselves or others.

They only need to meet **one** of the daytime conditions to get 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 needed spread out at intervals through the whole day. There can be gaps in the day when they don't need help but the pattern must be over the whole day. This is why it is so important to include all the help needed, since the DWP look at how often help is needed, as well as what kind of help it is.

Help can be prompting, reminding and encouragement, as well as actual hands-on help. For example, your child might now be independent in washing and dressing routines, but might need constant reminding about personal hygiene and appropriate clothes.

Different kinds of help are "added together". For example, time spent checking your child's bathing and dressing in the morning **AND** help with dressing appropriately for the weather when going out during the day **AND** the help they need to participate in social and leisure activities in the evening are added together to meet the "frequent attention" condition.

Remember, it is the help needed by the adult with Down's syndrome that's important. Who gives the help is not. So think about help they need during the day if they’re not at home (at school or college or work) as well as the help you give at home.

Continual supervision

Many people with Down's syndrome will need supervision because of their learning disability. What risks would they face if they were left on their own – at home, on the street? Are they able to cope with the unexpected? How good is their judgement about time? Can they keep to a daily routine without reminders? Would they be vulnerable to danger from other people? Can they cope with common household dangers – hot water, the cooker, ironing? Have you set up a routine so they can be as independent as possible? But what if this routine was changed? You may be so used to the supervision you give that you don’t notice any more.

The night time conditions

- they need prolonged or repeated attention in connection with their "bodily functions" at night

and/or

- they need 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.

They only need 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 starts from when you and other adults in the household have gone to bed and the household closes down for the night.

"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.

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 seven, or one week out of four. For example, if your daughter needs help at night during her menstrual period, but not at other times, this would not be enough to qualify.

"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. 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, the person you’re claiming for has to meet one of the daytime conditions **or** one of the night time conditions.

The rules for the highest rate

The person you’re claiming for will get the highest rate if they need attention and/or supervision **both** during the day **and** during the night.

In other words, they qualify 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, they could need continual supervision during the day, and need “frequent attention” at night.

THE CARE COMPONENT - FILLING IN THE FORM

The “time” questions

The questions “How long do you need help each time?”, “How many days a week”, and “How many times a day?” can be very difficult to answer, especially if it varies from day to day.

- You can give an average.
- You can give a range of times, for example, “it can be 5 minutes, but more often it takes 20-30 minutes….”
- For help with supervision, or communication, you may want to put “all the time.”
- The person you’re claiming for may only have a bath three times a week. But if they would need help every time they had a bath, put 7 days a week.

Moving about indoors

Some adults with Down’s syndrome may have problems moving around indoors - for example, using the stairs, or getting in or out of the bath - because of poor balance and co-ordination, or a heart or lung problem. Some people with Down’s syndrome may use a wheelchair indoors.

Remember, help includes prompting and encouragement, as well as physical help.

Getting out of bed in the morning and into bed at night

Probably not many people with Down’s syndrome will need physical help getting in and out of bed. But if they need reminding or encouragement, rather than physical help, tick “yes”.

It’s more likely that they may need reminding or encouragement to get up or go to bed. It may be that they are not very good at telling the time. Or they may want to get up and be active during the night, not realising most people are asleep. Perhaps they like keeping to a very set routine at bedtime that involves someone else being with them and get anxious or upset if it’s not followed.

Remember, help includes reminders and encouragement.

When you are in bed

This question is about attention or watching over that is needed at night.

Most of the examples given on the form are about physical help. But attention can also include reassurance if someone wakes up, or helping someone go back to sleep.

If the person you're claiming for needs help at night with having a drink or a snack, or with coping with their toilet needs, mention it here, but you can put details on other pages as well.

Help with your toilet needs

Remember, help includes reminding or prompting someone to use the toilet, and checking that they have cleaned themselves.

Washing, bathing and looking after your appearance

Remember, help includes coping with shaving, and coping with menstrual periods. And it includes prompting, reminders and encouragement.

Getting dressed or undressed

Remember, help includes prompting and reminding, for example, to wear clean clothes, or clothes that are suitable for the weather or the day's activities.

Preparing a cooked main meal for yourself

Would you have problems because of your illness or disability if you prepared a cooked main meal for yourself?

Why would the person you're claiming for have problems cooking a meal? Could they read a recipe? Would they get confused about where they were up to, and what to do next? Could they safely use hot pans and the cooker? Could they plan so different parts of the meal were ready at the same time? Could they tell if food was cooked?

How many days a week would you have these problems?

Remember, it's not asking how often the adult with Down's syndrome actually cooks. If they would have problems whenever they cooked, put "7 days".

At mealtimes

The person you're claiming for probably won't need physical help with eating and drinking. But they may need prompting and reminding to eat regularly and keep to a routine. Remember to explain if they need any help with drinks or snacks during the night.

Help with medical treatment

Most people with Down's syndrome won't be on regular medical treatment but some will be. If they need any help with taking medication, or anything else, give details here.

Someone keeping an eye on you

It is important to answer this question in detail. Many adults with Down's syndrome will get DLA because they need "continual supervision to avoid substantial danger to themselves or others" (see pages 20 and 23).

Why does the person you're claiming for need supervision? What might happen if they were left on their own? How would they be at risk? Would they keep to a daily routine without prompting and reminders? How well can they tell the time? How well can they plan their activities on their own? Could they cope with the unexpected? Can they cope with common household dangers – hot water, the cooker, the iron? Would they become confused or anxious? Do they need someone to explain what's happening, if they are in an unfamiliar situation? What about outside the home – how good is their understanding and speech? Would they be vulnerable to being taken advantage of? What about road safety?

It's important to think about how long they need supervision for – it has to be "continual" to count for getting DLA.

Remember, you have to be awake to count as "watching over" someone at night.

Dizzy spells, blackouts, fits, seizures or something like this

Most people with Down's syndrome won't be affected by blackouts, etc.

The way you feel because of your mental health

Some adults with Down’s syndrome (like other people) will experience depression and anxiety. This may happen as they find they are treated differently, or see brothers, sisters and friends having different life experiences. Some people with Down’s syndrome have autism as well. Give details here, if the person you’re claiming for experiences unusual sadness or anxiety or frustration.

Communicating with other people

Many people with Down’s syndrome will have some problems with communicating. Their speech may not be clear. Or they may have difficulty understanding other people. It may be hard for them to speak to or to understand people they don’t know well.   Do they need someone to explain what’s happening, if they are in an unfamiliar situation? They may also have problems reading letters or dealing with forms, and need someone to help them.

If the person you’re claiming for has a lot of difficulty with communicating, you may want to put “all the time” in answer to “How long do you need help each time?” Otherwise, try to think about their daily life – how often do they need help on an average day? You may be so used to giving them help you don’t notice it any more.

Help you need when you go out during the day or in the evening

The person you’re claiming for may need help with social and leisure activities, both at home and when they go out. This help counts towards getting DLA. They may need help with planning what they’re going to do, organising meeting up with other people, getting there (if it’s outside the home), and help during the actual activity.

More about the way your illnesses or disabilities affect you

There is space here to put anything else you want to say. You could write a summary of the information you’ve put on the form. Or you could use the space here to give more details about the person with Down’s syndrome, such as giving examples of what happens in their daily life.

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, someone 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**
- 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

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

So you have to wait 3 months from when someone's needs increase, before they can start to get a higher level of DLA.

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, you may not be happy with the DWP decision.

- The person you're claiming for may be refused completely
- They may be given a rate you are not happy with
- They 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

If you want to get their 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 the 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 often known it to happen for people with Down's syndrome.

However, people's needs do change – for example, they could stop needing so much help at night and this could affect their DLA.

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, the 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.

It is also useful to send supporting letters from health or education professionals who know the person you're claiming for.

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, 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.**

Supersessions

If it is more than **one month** after you have received a decision on DLA, and you are not happy with the benefit, you need to ask for a supersession. However, you can only get a supersession for certain reasons, such as the person's needs have increased, or you think the original decision was wrong. If you would like to know more about the grounds for a supersession, 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, 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 supersessions 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 supersession, 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 can 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 supersession.

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.

After the age of 16, awards are usually given for several years, at least.

RENEWAL CLAIMS

Most people are awarded DLA for a limited period. 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. Sometimes the DWP want to visit and meet the young adult with Down’s syndrome.

WHICH RATE OF DLA SHOULD SOMEONE WITH DOWN’S SYNDROME GET?

It’s impossible to say. Needs and abilities vary so widely. However, if someone is on the lower rate of the care component, get advice to check they’re not missing out.

DLA AND OTHER BENEFITS

Carer’s Allowance

If the person you’re claiming for 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 included in your benefits while your child gets DLA, and still counts as a member of your household (that is, from 16 to 19 if they are still in education). 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.

Remember, if your child claims Incapacity Benefit and/or Income Support in their own right at 16, they stop counting as a dependent member of your household and the amount you get will change (see p 6 for more information).

Motability

If the person you're claiming for 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 36).

Road tax exemption

If the person you're claiming for 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 the person with Down's syndrome, 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:

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

So someone doesn't have to get the higher rate of the mobility component of DLA to get a Blue Badge. But it makes it much easier.

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.*