



GUIDELINES TO CLAIMING

DISABILITY LIVING ALLOWANCE

From birth to 3

April 2007

This information is updated every year.

information

INDEX TO GUIDELINES

	PAGE
How to use these guidelines	3
Introducing Disability Living Allowance	4
How does Disability Living Allowance work?	4
Making a first claim for a child from birth to 3	5
Making a renewal claim for a child from birth to 3	5
When to claim for a child with Down's syndrome	6
The claim form	7
Disability Living Allowance - the care component	10
The care component – the rules	10
The care component – filling in the form	16
Other information about DLA	24
The non-disability conditions	24
Revisions, supersessions and appeals	25
Length of award	27
Renewal claims	27
Appointees	27
What rate should my child get?	28
DLA and other benefits	28
Useful addresses	30

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 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. 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.

The mobility component

Children under the age of 3 can't get the mobility component. So we don't give information about mobility in these guidelines. If your child is coming up to 3, ask for the DSA Guidelines to claiming Disability Living Allowance ages 3-8.

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 disability or long term illness.

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 savings or income 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.

We do not give information about the mobility component in these guidelines. If your child is coming up to 3, ask for the DSA Guidelines to claiming Disability Living Allowance ages 3-8.

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 10-15.

There are also '**non disability conditions**' and these are explained on page 24.

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 first claim for a child from birth to 3

Most people looking at these guidelines will be making a claim for the very first time. To get a DLA claimpack, call 0800 882200 – ask for a DLA claimpack for a child.

When you receive it, it will have 2 dates stamped on it. The top one will be the date you rang them, the second will be a date 6 weeks later. If you return the form before the second date, your claim can be considered from the first date stamp on the form – as long as your baby is at least 3 months old at that date. If you send it back after the second date, your claim may only start from the date they receive the form.

Making a renewal claim for a child from birth to 3

Most children get DLA for a limited period. This means you have to make a renewal claim when it runs out. Lots of children get a first award of 1-2 years.

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 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 your child is coming up to 3

Lots of awards finish on a child's 3rd, or 5th, birthdays. This is so that you can claim the mobility component at the right time. So if your child's award finishes at

3, and you are making a renewal claim for them when they are 2 ½ or older, you need information on the mobility component. Ask for the DSA Guidelines to claiming DLA ages 3-8.

If you are making a renewal claim for a child approaching 3 years of age, you will usually have to answer the questions on both the care and the mobility components.

WHEN TO CLAIM FOR A CHILD WITH DOWN'S SYNDROME

People are given confusing information about when they should make a first claim for the care component of DLA.

Three months is usually the earliest that it is possible to get DLA because of the qualifying periods (see page 24 of these guidelines - you may be able to get it earlier if your child is very ill). Some children with Down's syndrome do get DLA at 3 months.

We suggest that the earliest you send in the claim form is when your child is 3 months old. This stops the DWP refusing you simply because "your child hasn't satisfied the qualifying period". It also gives you a chance to get to know your child and their developing needs.

When you decide to claim will depend on your child. Children with Down's syndrome have different needs. **You need to ask yourself if your child needs more care than most other children of the same age** (see pages 10-15 of these guidelines). We feel that most parents claim sometime between 3 months and 1 year old.

However, the earlier you apply for your child, the more strict the conditions. The younger the child, the greater the need for attention and supervision for most children, and therefore the harder it is to show that your child needs more help. Claim when you feel that your child has extra care needs (like the suggestions given in pages 16-23 of these guidelines). Most children with Down's syndrome get DLA by the time they are one.

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 claim pack, you are asked to get another person to sign the form. 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, 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. Having "a severe learning disability and severe behavioural problems" is about getting the higher rate of the mobility component and is not relevant to children in this age range.

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.

But 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. For example, a child might have sticky eyes which need cleaning 2-3 times a day. It may only take 5 minutes each time - but it's worth putting in.

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 a child 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 24).

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, feeding); or
- it is different in some way (some kind of help not needed by most other children, for example, physiotherapy, portage, 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 16-23.

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.

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 time taken to have a bottle **AND** extra time taken teaching your child to walk, etc, are added together to meet the "frequent attention" condition.

Continual supervision

All children from birth to 3 need a lot of supervision to keep them safe. Children with Down's syndrome under 2 may not need extra supervision unless they have another medical condition, such as a heart, lung or bowel problem. To qualify for the 'extra test', you would have to show that your baby was more at risk if left alone in another room than a child of that age would normally be. For example, a baby with a severe heart defect or breathing problems may need careful watching. There has to be a real danger of harm - parental anxieties are not taken into account. If your baby has a naso-gastric tube or a catheter, you may have to watch for them pulling it out and so this may count.

Over 2, children with Down's syndrome may need more supervision than other children of their age because of their learning disability. For example, they may be much slower to learn about common household dangers (such as banging into furniture), or they cannot be left alone to play in the same way that another child of the same age could be, or they still aren't responsive to spoken commands but need to be physically stopped or removed from danger.

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.

However, all babies will wake during the first year and 'normal' waking and feeding routines cannot be taken into account. But if your child takes a lot longer to feed than other children, or still needs night feeds at an older age than most children, or is a lot more wakeful than most children, then these needs may

qualify. If you are having to tube feed your baby or attend to a catheter or other technical procedure, these are outside the range of what is considered normal and will be taken into account.

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.

Remember, it is usual for young children to need attention at night, and to count, the attention your child needs has to be different, or take longer, or be attention that usually only a younger child would need.

"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 with sleep apnoea or a heart defect who might stop breathing. (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

Walking outdoors

If the child needs someone with them when they are outdoors

These questions are about the mobility component. They do not apply until your child is 3 years old. You can leave them blank.

Someone keeping an eye on the child

This question is about “supervision” during the day and “watching over” at night – see pages 10-15.

During the day

All children with Down's syndrome from birth to 3 will need “continual supervision throughout the day in order to avoid substantial danger to themselves or others”. In order to qualify, your child has to need a level of supervision greater than most other children of the same age.

Your child may need more supervision than other children because

- they have a serious health problem and would be at risk if left unattended for even the shortest time
- 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 to play 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.

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, or they tend to throw their covers off. Remember, nappy changes and feeds that most other children would also need don't count.

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 be slower in learning to roll over, get head control, sit up by themselves, hold things and co-ordinate their eye to hand movements. When they are a little older, they may be slower in learning to walk, jump or run. They may walk unsteadily with a lot of falls, at an age when most children are walking well. 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 page 16 - Help with Therapy. If you choose to give full details on page 16, say so here.

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 starting to finger feed (usually around 7 months) or hold a feeding cup by themselves. Have they started babbling yet? Can they roll over by themselves? Have they started to crawl or walk?

Again, if information here overlaps with other questions (for example, page 9 - Washing and bathing, or page 10 - 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 12-13 - 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 3 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. 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. If they have very low muscle tone, and are not yet sitting up independently when most other children are, they may need to be held differently. 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. Most children will be able to co-operate when being dressed from about 18 months. Your child may not have the muscle control to do this, or may still not understand. Your child may need more changes of clothes than other children, perhaps because they are still in nappies, or tend to have more accidents than other children.

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 still be in nappies at an age when most children are toilet-trained. They may have more accidents as they are learning. It may take more time and effort to teach them to use the toilet. Once they are toilet trained, 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?

All children in this age range need help to communicate. However, most children in this age range with Down's syndrome have a delay in their development of language and need extra help. Even before any child uses words, your child may need extra help, for example, in learning to take turns, or to babble. By the age of 15 months, most children use 2-6 words and understand simple instructions. Give details about your child's understanding and speech. How many words do they use, if any? 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. If your child is talking, 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. Babies may take a long time to breast feed or finish a bottle. Usually it would take a baby 15 – 20 minutes for a feed, so anything over that would be extra. Your child may also need feeding more frequently than other children. A child who needs tube feeding definitely needs extra attention. Your child may not be able to tolerate lumpy food and stay on pureed food for longer than would be considered “normal”. They may be slower to hold a bottle or lidded cup or to finger feed.

Your child may need a lot of help learning to use a spoon and feed themselves. 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 solid food, or 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 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 portage worker (unlikely for older children in this age range)
- 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 ‘Communicating with other people’.

Physiotherapy – you may have chosen to give details on pages ‘ About the child’s development’ or ‘Movement and co-ordination and Moving about indoors.’
Portage – as for physiotherapy.

Psychologist – you may have chosen to give details on pages ‘ About the child’s development’ or page headed ‘ 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 everything for different therapies together. 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, panicky or frustrated, or shows difficult behaviour.

Movement and co-ordination

You will probably already have given details on previous 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 on previous pages '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 from page 5. Again, most children need some help at night when very young – why is the help your child needs “extra”?

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 (or any help they need to live “a normal life”) counts for DLA. They are not really relevant to very young children with Down's syndrome. You can leave them blank.

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 nursery here. If your child is over 2, do they have a statement of special educational needs? Do they have extra help at nursery, like a 1:1 carer?

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 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 5th 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. Childrens' needs vary so widely. However, we feel that if a child with Down's syndrome over the age of 1 year is only getting the lower rate of the care component, 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.

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.

Child Tax Credits

An award of DLA can affect the amount of tax credits that you are paid. It can lead to an increased amount, depending on your level of income. DLA flag up cases where tax credits may be an issue. A computer alert is issued to the tax credit office. However, it may be worthwhile notifying the tax credit office yourself to make sure that they have been informed of this.

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.