

CLAIMING DISABILITY LIVING ALLOWANCE FOR CHILDREN WITH AN AUTISTIC SPECTRUM DISORDER/ASPERGER SYNDROME



Berkshire Autistic Society

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**This booklet is not intended to replace professional advice –
it is intended for guidance only. Please note that social
security law can (and does!) change.**



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Disability Living Allowance (DLA) can be paid to children under 16 who have care/supervision needs significantly higher than an “average” child of the same age.

The word “disability” in the name often puts many parents of children with an ASD off claiming. People often assume – wrongly – that this benefit is only for children with *physical* disability. This is not so – the benefit is intended for children with a wide variety of care and/or supervision needs.

Bearing in mind the levels of care/supervision that most ASD/Asperger children require on a daily basis, large numbers of these children *will* qualify for DLA.

How to use this guide :

Section 1 – outlines who may qualify, and how to claim.

Section 2 – guides you through the claim form page by page, giving you useful hints and ideas.

Section 3 - gives you other sources of information and help.

Section 1

DLA is a tax-free benefit processed and paid by a Department of Work and Pensions office based in Blackpool. It is not affected by your own earnings or savings, as it is awarded for the child.

Disability Living Allowance is made up of two parts (components). The **Care component** and the **Mobility component**.

The **care** component has 3 rates of payment – high, middle and low – depending on how much *looking after* the child requires because of their disability. The rates do not relate to the severity of the disability itself. Think of it like a 24 hour clock – if a child needs help for *portions* of the day or night then they would get the low rate. If they needed help all day *or* all night, then they would get the middle rate. But if they needed help all day *and* night, then they would get the high rate.

The rates for 2009/2010 are £70.35, £47.10 and £18.65 per week.

The **mobility** component has 2 rates of payment – high and low. The high rate is only for children over the age of 3 who have a significant physical problem that impairs their walking ability. The low rate is for a child over the age of 5 who needs to be supervised/guided when outdoors in places they do not know well. It is commonly the low rate that applies to ASD/Asperger children. The rates for 2009/2010 are £49.10 and £18.65 per week.

It is possible to receive a) the care component only, b) the mobility component only, or c) both components simultaneously.

It is not unusual for ASD/Asperger children to get both the Care and Mobility components.

Many parents of high-functioning ASD/Asperger children often look at the form and think “my child probably won’t qualify”. This is because even if you are coping comparatively well with your own child’s needs. You may overlook what the *average* child can do and forget the day-to-day efforts in *your* home that have become “normal” to *your* household. It is maybe the daily routines, which *you* are keeping to, that are enabling your child to cope reasonably well. *These rigid routines count as providing supervision.* What

would happen if you suddenly stopped implementing the routines?
Would chaos reign?

Completing a DLA claim form should not be viewed as a formal exercise – it is very emotional describing your child’s difficulties. So it is perfectly okay to write “emotionally”. It is good to *emphasise* your points by underlining or using exclamation marks. It is OK to explain if providing for your child’s needs is tiring, frustrating and sometimes distressing to cope with – feel free to make them understand that, but remember the claim is about what help your child needs not you! It is very important that they understand the difficulties you encounter caring for your child – that is the whole point of the claim. But do remember to keep focussed on the issues – a rant will make you feel better, but will not help the claim!

DLA claims are “processed” by Department of Work and Pensions officers – whose experience of disability matters will vary enormously. Autism is a very complex condition to understand, so it is unwise to assume the Decision Makers at the DLA unit will read between the lines or will understand any medical terminology you use. Parents often forget that *other* people have no idea what “gaze avoidance”, “theory of mind”, etc, actually mean. Take a step back and view what you have written from the viewpoint of someone who may know very little about autism.....

Priceless tip:

ALWAYS give examples wherever possible.

Remember that you are “painting a picture” of your child, describing them page by page so that the Decision Maker in Blackpool can imagine your child.

This officer will process a whole pile of claims every day – one after the other – faceless children that they will never actually meet. Your child needs to appear off the page from what *you* have described.

Examples are *hugely* effective at describing your child 3-dimensionally. For example, if your child is very literal in their use of language – give an example of a past misunderstanding of language that was perhaps upsetting or perhaps even tragically funny! A bit of ironic humour doesn’t go amiss in these claims – making a processing officer laugh out loud certainly gets their attention! Maybe your child says socially inappropriate things such as “why do you look so old?” “Why do you smell?” etc.

GIVE EXAMPLES!!!!

Adding extra sheets of paper: When completing the claim form, it is extremely common that you cannot fit everything into the small blank boxes provided. Staple another sheet of paper over the same page and carry on writing on that. Try to avoid the processing officer having to flick pages back and forth trying to find the end of your explanation.

Collecting information

If you prepare well and include supporting evidence, you have a better chance of success.

Collect as much supporting evidence as possible, for example, reports you may have from speech & language therapist, CAMHS, psychologist, paediatrician, etc. Reports from school can be helpful (if they understand your child!). If your child has a Statement of Special Educational Needs, you may also include a copy of this.

Remember, reports that detail what your child can do and how well they are coping, are not useful with a DLA claim – they need to know what your child *cannot* do!

You may want to start a “DLA diary”. See the NAS and Cerebra websites for more information (their contact details are at the back of this booklet in Section 3). Make notes of the help your child needed during a typical week – what help was needed and why, how long they needed help (day & night). This is very useful when you are struggling to recall the wide variety of their needs. It may also provide you with examples of incidents during the week that you can then include in your claim form.

Getting a claim pack

- Telephone the DLA office on 08457 123456 and ask for a DLA claim pack for a child under 16.

Or

- Telephone the Benefits Enquiry Line 0800 88 22 00 and ask for a DLA claim pack for a child under 16. The Enquiry Line can also answer questions for you, but please bear in mind that they are part of the DWP and therefore, the advice you receive is not independent.

Or

- The form can be downloaded from the DWP website or filled in online. See http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DisabilityLivingAllowance/DG_10011925. Be careful that you do not download the adult version of the form!

If you telephone for a claim form, you will have 6 weeks to complete and return it. Any successful claim will then be paid from the date you first phoned them. If you download a claim form or fill it in online, your claim can only be paid from the date the DWP actually receive your completed claim.

If you already have an award of DLA, you will automatically be sent a claim form 6 months before the end of the award period.

Frequently asked questions

How long will the benefit be awarded for?

Technically, a DLA claim can be awarded for 1,2,3,5 years or indefinitely. In childhood, claims are most commonly awarded for 2 or 3 years (as a child's needs can change significantly). When your child reaches age 16, they will need to claim as an adult. The adult claim form is slightly different, but the payment rates are the same.

What if my child's needs change?

If your child's needs change significantly, your DLA may need "reviewing". You should notify the DLA office. If your child's needs have increased, you might be entitled to a higher rate of payment.

Section 2

We have not given advice/tips for *all* parts of the form.

We have concentrated on the parts that are most commonly misunderstood, or cause the most difficulty, for ASD & Asperger children.

You should fill in *all* parts of the claim form that relate to *your* individual child.

Our questions are not exhaustive – each child is so unique - but they are designed to get you thinking as “broadly” as possible.

IMPORTANT:

Throughout the form you will see boxes asking you how many “days a week” your child needs help, or how many “times a day”, or for how many “minutes”. **These boxes have very little value for ASD/Asperger children. They usually need help with these tasks all the time!**

There are *some* tasks that *can* be measured to some degree – for example how long it takes to wash or bathe. Other tasks are impossible to measure or estimate, for example, helping the child with communication!

You need to bear in mind that the form is better designed for children with physical care needs. When the task is impossible to measure, cross out the boxes and write “**all the time**” where it says “days a week/times, a day/minutes”.

The following part numbers correspond to the sections on the actual claim form.

We will refer below to the child/young person as “him” rather than “him or her” within this booklet purely for simplicity.

Part 6:

Walking Outdoors

This part of the form is used to assess your child for the higher rate of mobility allowance and is about physical problems with walking. Your child must be at least 3 years old to qualify.

Your child may qualify for the higher rate if they regularly refuse to walk **or** they are autistic and need constant attention whenever they are awake because of extremely dangerous behaviour. If your child has both kinds of difficulty, include both.

Only a small percentage of children with autism qualify for the higher rate, nevertheless, **include any difficulty your child has with walking** to give a full picture of their difficulties.

- Do they have lax muscles which make the act of walking very tiring/make their legs ache?
- Do they stop walking to investigate their obsessive interest in lampposts for example and no amount of persuasion or discipline will deter them until their interest is satisfied?
- Do they refuse to move if overwhelmed by noise or crowds?
- Do they trip or fall often; do they need help on steps, stairs or uneven ground? How do they react when they fall over?
- Do you usually have to hold onto them or keep them on reins or in the pushchair, whenever you are outdoors?
- Do they run off frequently and unpredictably putting themselves or others in danger?

If your child regularly refuses to walk put '0' metres in the 'how far can they walk' box!

Part 7:

The child needs someone with them when they are outdoors

Part 6 asks about *physical* problems with walking, but Part 7 asks about *other* issues that may cause problems for a child or young person to get from A to B safely and unsupervised, *in places that he does not know*. Routes that have been learned repeatedly and have become familiar are not relevant.

This part of the form is used to assess your child for the lower rate of Mobility component. They must be at least 5 years old to qualify for this.

You need to take into account the age of your child when thinking about the questions below. What would be expected of another child of the same age as your child – socially and developmentally?

For example, all 5 year olds would need to be carefully supervised at all time, but does your child wander or run away unpredictably? Do they have no fear of getting lost or separated from you? Are they over-anxious when outdoors? Do they pick up rubbish or other inappropriate things? Do you have to hold their hand constantly or keep them on reins?

- What is your child's "road sense" like? Can he safely cross the road, or is he easily distracted/doesn't focus?
- Does he step into the road without regard for his own safety? (some children believe they will not get hurt because it has never actually happened to them before - they have difficulty understanding the concept of "possible" danger)
- Does he have difficulty judging when it is safe to cross, so is very cautious or indecisive but then crosses at the wrong time?
- Does he respond to verbal warnings?
- Does he walk into other people on the pavement? Trip or fall frequently? Trips on kerbs? Poor spatial awareness? Can he manage steps age appropriately?
- How does he cope with different outdoor environments, bustling crowds, noisy places? What about very busy times like Christmas shopping days? Do these environments over-excite him/upset him/make him want to go home/avoid them altogether? Does he hate supermarkets? Are there any noises/smells that upset or distress him?

- What if your child managed to get lost/wander off whilst outdoors, for example, whilst shopping/at the beach etc. Can he effectively ask strangers for directions? Would he approach appropriate strangers - maybe a woman with a pushchair - rather than the crowd of young people drinking alcohol?
- Would he understand or remember what directions/instructions someone gave him? Could he follow the directions accurately? Would he actually ask for help, or avoid asking? How would he feel if he got lost: anxious, worried or oblivious?
- Do you have other children to care for that he puts in danger, for example, he runs off so you have to leave a baby sibling unattended?
- Do you have to pre-prepare your child for a trip outdoors? Do you have to explain exactly where you are going, why you are going, how long you will be there, what shops you will be going into, who else will be there, what will happen whilst you are there, what time you will be coming back..... Sounds familiar?
- Do you have to protect him from angry/indignant reactions from strangers that he has been rude to, or who do not realise he has a disability and reprimand him for his behaviour

If you were filling in this page for a child in their early teens, it would be expected that an average child of the same age would have developed some independence skills by this time – perhaps it wouldn't be unusual that they could catch a bus into town to meet friends on their own, etc.

But does your ASD teen need to be accompanied by an adult or another responsible teen? Does he judge safe/unsafe behaviour accurately? Would he possibly do silly/dangerous things whilst outdoors if unsupervised?

What about other teenagers - is he liable to get caught up in a fight/argument? Do other teens laugh at him/wind him up? Do they trick or encourage him to do silly/dangerous/illegal things? Is he easily influenced to smoke/drink? Is he easily led because he wishes to make friends and be accepted by the crowd?

Part 8:

Someone keeping an eye on the child

This part is about safety/monitoring and the child's need for supervision.

- Does your child escape from your home?
- Does he fight with or hurt his siblings, or other children at school? Do you take steps to avoid sibling arguments for safety reasons?
- What precautions have you taken because of your child's lack of understanding of danger - doors & windows locked, stair gate, bed guards, things locked away for safety including unsafe things they may put in their mouth, or more extreme measures? You would expect all toddlers to need this help, but if your child is older, then these things are very relevant to the disability.
- Is there a risk to themselves, or others, when having a tantrum? What injuries have they had, or inflicted, because of their disability?

This page is also a good place to explain your child's needs for **rigid routines**. Be very clear about how essential this is to daily functioning - how is it achieved at home and at school? What happens when the child's needs for routine or predictability are not met? How does it affect their behaviour/emotions?

Holidays away, Christmas and times of illness, can all be major disruptions to daily routine schedules - how does your child cope with these?

Part 9 (page 9):**Has the child's development of physical and sensory skills been delayed?**

- Do they have clumsiness or dyspraxia?
- Do they have flawed spatial awareness, walk into people, step on your feet, fall over or injure themselves frequently?
- Do they have difficulties writing? Using cutlery? Doing up fastenings? If you have an OT report use the information from there and enclose a copy. Explain if the OT has recommended exercises for them
- Do they have sensory sensitivities – for example, upset by particular sounds or sudden noises? Do they hate the touch, smell or taste of certain things?
- Do they have a diagnosis of sensory integration disorder?
- Sensory hyper or hypo reactions, for example, covering their ears, refusal to wear certain clothes, extra vigilance due to high pain tolerance, feel sick if exposed to certain smells?
- Do they spin, rock, or constantly climb everywhere because they crave the feeling of movement? Do they refuse to go on any playground equipment because they cannot cope with the unsteadiness of being off the ground?
- Do they use ear defenders, special glasses, special pens/cutlery/sloping writing surface, or a feedback cushion?

Part 9 (page 9):continued**Has the child's development of learning skills been delayed?**

- Do they have difficulty understanding the world around them? Often confused by what they are supposed to do?
- Do they use PECS, Makaton, TEACCH or any other visual support? Is their learning non-transferable?
- Do they have extra help at school or are they at a special school? Do they have extra lessons to help them keep up?
- Do they have a statement of special educational needs?

- If they have difficulties with paying attention, say how this affects them – this is particularly important for children with a dual diagnosis of ADHD.
- Does your child have problems remembering more than one instruction at a time? Do you (or a teaching assistant) have to use simple language to help them understand? Do you have to repeat instructions several times?
- Are they impulsive and/or prone to going off at a tangent? For example, do they get so interested in how to write the date neatly that they do not get round to writing the story they are supposed to be doing!
- Do they feel overwhelmed or excessively anxious in school which prevents them from being in lessons or participating in them?

Part 9 (page 10):

Has the child's development of social skills been delayed?

This is obviously a key problem area for ASD and AS children!

- Do they have difficulty making friends? Do they want to interact, but get it wrong? Or prefer to be solitary? Do they understand what a friend is?
- Do they have problems understanding others? Do they have problems being understood? Do they have speech problems? (language difficulties are covered in detail in Part 14)
- Do you have to encourage and arrange social opportunities on their behalf? Do they avoid socialising because of social anxiety caused by their lack of social skills?
- Do they ask to have a friend round and then ignore them? Does the friend end up playing with your other children?
- Do they prefer to play with children much older or much younger than them?

Part 9 (page 10) continued:

Does someone need to help the child develop through play?

This tends to be more common with the younger children i.e. learning to take turns using play, etc. However, an older child might need you to help them interact with other children when playing, for example, to help them to remember their friend might not want to watch them playing on the computer for 2 hours!

- Do they need help to understand the rules of the game? Be encouraged to join in?
- Do you have to help them initiate play or show them alternatives? Do you have to model imaginative play?
- Do you use play to develop motor skills, or speech and language skills, or something else?
- Do they play alone, one to one or can they cope with groups?
- Do they need help not to dominate play, and to share ideas?

Part 10:

Waking, getting up and going to bed

This part is only asking about the time when the child is settling down for the night or waking first thing in the morning. The actual night-time needs are covered in Part 23.

- Does your child need a strict routine to settle them down? (Explain the routine and explain what happens if it goes wrong!) Do they need a particular toy/book/music? Do they like to be swaddled in blankets or a sleeping bag?
- Once in bed, do they have trouble falling asleep?
- Do they get in and out of bed repeatedly? Do they need cuddling/soothing?
- Do they understand they need to go to bed? Are they uncooperative? Will they only settle for one trusted adult?
- Are they hard to rouse in the morning because of poor sleep?

Part 11:

Washing and bathing

- Is their ability to wash age appropriate, or do they need extra help?
- Can they wash unaided or do you need to physically intervene? Do they co-operate?
- If they can wash/bathe/shower themselves, do you have to monitor what they are doing and prompt/remind them to do it? Do you have to check it has been done properly?
- Do they hate having their hair washed? Hate nit-combing? Hate having toenails cut? Can they dry themselves or their hair? Do you use visual aids?
- Is their behaviour in the bathroom unsafe in anyway? (Can it be managed by one adult?) Have you adapted the bathroom in any way for safety reasons?
- Do you have to buy particular products because of sensory issues?
- If you have a daughter, how does she cope with periods ? If she hasn't yet started her periods is she very anxious about what will happen?
- Do they wash obsessively? Do you have to encourage them to *stop* washing? Need to apply creams to skin because of over-washing?

Also - washing and bathing are not the only ways of looking after your body – how does your child cope with the dentist, hairdresser, doctor or visiting a chiropodist? Do you have to carefully prepare them for such appointments?

Part 12:

Getting dressed or undressed

- Does your child have physical difficulties dressing or undressing? Is he un-coordinated – gets tangled putting arms in or out of sleeves for example. Can they pull clothes on or off? Do they have problems with zips, buttons, school tie or shoe laces?
- Do they put clothes on inside-out or back-to-front or in the wrong order?
- Do they have sensory sensitivity about fabrics and clothes rubbing/touching their skin? Do they insist on all clothes labels being removed? Are there certain fabrics they will point-blank refuse to wear? Do they dislike shoes – preferring to be barefoot? Do they dislike the feel of socks or toe seams?
- Do they remove their clothes inappropriately, for example, at the shops?
- Do they wear the wrong clothes for the season/weather – shorts in winter and wellies in summer? Do they have difficulty understanding why certain clothes are for certain occasions – like dressing formally for weddings? Do they hate wearing school uniform? Do they insist their clothes should be very baggy or very tight? Do they constantly wear hoods?
- Will they insist on wearing the same items of clothing over and over until it is filthy and has to be sneaked away in the night to be laundered or until they no longer fit or are threadbare?
- Does your child refuse to try on clothes when shopping or hates to have their feet measured for shoes?

Part 13:

Help with toilet needs

- Has your child achieved toilet-training yet? If not, is it age appropriate or older? Do they wet the bed? Do you have to dress them in dungarees so they can't get their hands into their nappy? Do they co-operate with nappy changes?
- If they are old enough, can they clean themselves after using the toilet or do you still have to do it? Do they smear faeces?

- If your child is toilet-trained, do they still need reminding to remember to use the toilet (for example, if they are absorbed in a game, they might forget to go until it is too late?).
- Do they need support/reminding to use the toilet at school or do they point-blank refuse to use the toilets at school because they consider them unpleasant?
- Is your child very obsessive about washing after using the toilet or do they refuse to wash? If you have an older child, do they have to be constantly reminded to flush the toilet and/or wash their hands?
- Do they have an obsession with toilets and have to visit all of them wherever you go! Do they suffer from diarrhoea or constipation?
- Are public toilets a problem? For example, if you are a mum of a 12 year old boy, do you still have to take him into the ladies toilets with you because you are afraid of his vulnerability alone in the men's toilets?

Handy tip – if your child is successfully awarded Disability Living Allowance, you can apply for a RADAR key for them – this unlocks public disabled toilets and your child can use the toilet safely and independently.

For more information see the website <http://radar-shop.org.uk/>

Part 14 (page 15):

It is particularly essential to give actual examples throughout part 14 of the form – try to recall incidents when your child has misunderstood or struggled to understand. Most parents usually have some rather spectacular examples!

Communicating with other people

Does the child need help *understanding* other people?

Don't be afraid to remind the DWP here that this claim is for a child with a social and communication disorder!

- Do you need to frequently/constantly explain to your child what someone else was trying to tell them or ask them?
- Do they constantly ask "what does that mean" or do they just repeat the question back?
- Do they take everything painfully literally – often misunderstanding the situation?
- Does your child avoid looking at someone's face when talking?
- Do they understand how to have a conversation?
- Do they get confused if more than one person is talking at the same time or find it difficult to converse if there is a lot of background noise or distractions?
- Do they have difficulties listening, if what is being said is not of interest to them? Are they often in their own world? What do you have to do to get their attention?
- Do you use PECS, Makaton, etc?

It is important to explain that your child would have problems understanding metaphors, similes, rhetoric – and that these aspects of language can be mystifying/confusing for the child.

To help you think, would your child understand these metaphors, "To grab the bull by the horns" or "to break the ice"? What about the similes "as strong as an ox" or "he fights like a lion"? Or if asked the rhetorical question "Do you think I'm stupid?" would they tell them!

Also explain that they struggle with understanding body language, facial expressions or changes in the tone of voice. A child is

regarded as needing help with communication no matter *who* the person is they are talking to – it does not have to be someone official like a teacher or doctor, etc – it might be their own siblings, a friend or a grandparent.

Does the child need help being understood *by* other people?

- Do they have speech?
- Do they have any speech difficulty that makes it hard for others to distinguish their words/sounds?
- Does your child often offend people with the direct or literal things they say or by not listening to what the other person has to say?
- Do they find it difficult to take turns when having a conversation? Do they talk obsessively about their favourite topics? Do they dominate a conversation?
- Do you have to constantly explain what your child actually meant?
- Are they reluctant to speak at all? Do they speak too quietly, too loudly, too fast or too slow? Do they not realise when they have been asked a question, and need prompting to listen and respond?
- Is their conversation meaningful, or do they repeat favourite phrases? Remember proper communication is not just speaking words. Do you act as an interpreter for your child, guessing what they want from their behaviour?
- Do they have odd, or flat, body language/facial expressions which make it hard to understand them?

Part 14 (page 16):

Is the child unwilling to communicate with other people?

- Is your child unwilling to communicate?
- Or does your child want to interact but finds it difficult to achieve successfully? What happens when your child tries and it goes wrong? Do they get upset, shout or just refuse to speak anymore or just wander off and lose interest?
- Does your child not interact at all?

- Maybe they will only interact with certain people or in certain situations? Perhaps the usually silent child will become very animated when they come across their latest obsession.
- Will they only communicate on their terms or only about topics they are interested in?
- Does it occur to them to ask for help when they need it? Do they understand that other people can help them?

Part 15:

Eating and drinking

- Is your child rigid about what they will and will not eat? Do they dislike certain textures?
- Will they insist upon having the same food all the time? Or do foods have to be prepared in a very particular way (for example, foods not touching, sandwiches prepared and cut in a particular way, will only eat from a purple bowl, etc)?
- Will they completely refuse to eat if the food is not "right" and would rather go hungry than be forced to eat it? If forced to eat something will they actually vomit?
- Do you have to stick to precisely the same recipe every time when cooking a family favourite? Will they only eat certain brands or insist that you must buy things that they have seen advertised on the television?
- Does your child dislike eating with others or dislikes seeing others chewing their food?
- Are they anxious about "contamination"?
- Maybe your child is obsessive about eating too much food or the wrong foods and finds it hard to control?
- Do you follow a special diet for them or do they have food allergies?
- Are they very messy eaters or eat with their fingers? Do they overfill their mouths?
- Won't they come up to, or stay, at the table?
- Do you have to cut up their food or do they use special cutlery which is easier to hold?

Part 20: **The child's mental health**

This part makes more sense if you think of it in terms of your child's *emotional health*.

- What kind of things makes your child happy?
- What things make them upset or anxious?
- Do they dislike being touched or cuddled? Do they seek out or avoid displays of affection?
- Do they find it hard to make or retain friendships?
- How do they react when someone upsets them? Get angry/cry/retreat/go quiet?
- How do they react when their routine is interrupted? For example, how do they cope when away from home on holidays? Or cope at Christmas time when lessons overlap with school celebration activities?
- How do you settle or comfort your child? What works for them in particular? How do you calm them after a bad day at school?
- How do you settle a conflict with them?
- Do they have difficulties expressing how they feel or what they want? How do you interpret what they are thinking?

Part 23:

When the child is in bed at night

This Part is not referring to the process of *getting* your child to sleep – that should have already been discussed in Part 10. It is about the household shut-down time when everyone should be asleep. Different households have different routines, some shut down late and wake late or vice versa. The times the DLA unit are looking at are the times you (the adult) would normally be asleep. Or would *wish* to be asleep if only the children were not waking you up!! For example, if you would normally *wish* to go to bed at about 11pm and wake at 7am that would be regarded as *your* household's normal shut-down time.

If your child wakes you up frequently or for a significant length of time during those hours, then you *must* explain this in your claim. Children who significantly disturb their parent's sleep because the parent has to get up or stay awake to attend to them, might qualify for the highest rate of the Care component (as long as the child needs care/supervision throughout the daytime as well).

Examples:

In the following 3 examples, we will *assume* that all of these households usually shut-down for the night from 11.30pm to 7.30am.

- a) Sophie aged 8 has frequent nightmares and wakes crying 3 or 4 times a night. Each time her mother has to soothe her and cuddle her back to sleep – this can take between 30 minutes and an hour each time. Her nightmares can be even worse at times of change such as the start of new school terms. *Sophie is likely to qualify for the high rate because her mother has to attend to her several times during the night for significant periods of time.*
- b) Jonathan aged 4 gets to sleep quite well at around 8pm, but he wakes nearly every morning around 4am and *refuses* to go back to sleep. His parents take it in turns to sit with him in his room whilst he plays. They do this to ensure he is safe because he has little awareness of common dangers and to ensure he does not wake his siblings. *Jonathan is likely to qualify for the high rate because his parents have to attend to him for a single but long period of time during the night.*
- c) Craig aged 12 has great difficulty getting to sleep at night. He gets in and out of bed repeatedly, asking for drinks and snacks, and tries to switch on his Xbox or the television, even when he has been told it is not allowed. He gets grumpy and irritable, and his father has to go up and down the stairs to his room repeatedly trying to settle him until he eventually falls asleep – usually at around midnight. He then sleeps through the night until morning. The evenings are exhausting and frustrating for his parents and Craig is often tired at school. *Craig is unlikely to qualify for the high rate because he has only prevented his father from sleeping between approx 11.30pm and midnight.*

Part 24 (pages 25 and 26):

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

This page is asking about activities/hobbies that the child can only do with some help or assistance. For example, do they attend swimming lessons, music lessons, karate, Brownies/Cubs, go to church, etc?

- Does your child need extra help to enable them to take part in these activities? Maybe your child needs someone to sit with them at Brownies? Maybe they cannot go to large group swimming lessons and you have to pay for them to go to a smaller group or one-to-one teaching? Maybe they can only go to special needs groups where the staff are more experienced or understanding?
- What about other types of social activities outside of the home? A teenager being accompanied to the cinema rather than going on their own? Help to play in the park safely? etc.

Remember..... Explain *all* of the help they need, from preparation beforehand, to calming down afterwards!

Part 25 (page 26):

Who would you like to tell us about your child's disabilities?

Choose carefully. You cannot put down anyone else already included later on in the form, for example, your paediatrician. It is essential that they know your child well, and be able to describe their difficulties and the help they need.

Schools tend to emphasise what the child *can* do, rather than what they *can't* and may only see *some* of your child's difficulties, particularly if your child happens to enjoy the structure of school. It is admirable that schools will often want to highlight positive aspects of the child's abilities – that is very much what should be expected in a positive education environment. **But** DLA is intended for children with greater needs than other children and unfortunately the DLA office need to know the negatives not the positives!

Some people put down a recent or current teacher here or teaching assistant and ask the SENCO to be the contact for the school. Other people have asked Health Visitors or Speech and Language

therapists or friends who are professionals, for example, church or activity leaders.

Part 26 (page 27):

Anything else that affects the child

Do not forget to enter information here about how your child copes at school or pre-school. You will have noticed that none of the form asks about schooling and yet children spend most of the week there! Also school can often be the biggest cause of stress and anxiety!!

If your child has a Statement of Special Educational Needs and/or a written record of extra help they get at school, often called an Individual Education Plan (IEP), then do enclose a copy if it is going to be helpful to the claim. Also any reports from Educational Psychologists or CAMHS are very useful indeed. Do not send documents that are more than 12 – 18 months old, unless you have nothing more recent.

Explain about any time you spend at meetings, or in self-education/training to help your child.

Part 27:

About the child's condition

The dates here are important because you cannot claim unless your child has had significant care/supervision needs for the past 6 months or longer. This is *not* the date of diagnosis, but the approx date from when they needed extra care - quite often this will be from birth!

Part 32 (page 30):

The child's school or nursery

It is not unusual for the DLA unit to write to the school for more information/verification. Enter the name of the staff member who *knows your child best*. Inform that member of staff that they might get an enquiry from the Blackpool DLA unit and would they please discuss any content with you. It might even be helpful to give them a copy of your completed claim, so that they can see what you wrote. An informed and accurate reply from the school can make a claim - a rushed or inaccurate response can break it!

Most schools try their best to understand and support special needs children. However, sometimes, parents feel that their child's school does not understand their child's needs. In this situation you need to make sure the DLA unit knows this. Write (in red pen) next to the school address something like "I believe the school does not understand my child's needs. I would prefer that you did not request any information from them. If you do request information, it is likely I may challenge the content of any reports they provide to you".

Part 36:

Statement from someone else who knows the child

This is an optional page and it is not critical to have it completed. However, if you do have another person (who has not already been mentioned in your form) who knows your child very well, then it would be a good idea to get this statement filled in. This can be a friend, neighbour or relative.

Always photocopy your form before posting it

If it gets lost in the post, you won't want to fill in the 40 page form from scratch!

Photocopies are also very useful for future claims – if your current claim is successful, it will be paid for the next 1, 2 or 3 years (sometimes longer), but it will then need to be renewed. At that time you will have to do the claim form again. However, it is *much* easier to look at your previous photocopy and carefully update the information you gave before (also adding anything new), rather than starting completely from scratch.

Send it Recorded Delivery so you can prove the date it was posted and received.

APPEALS

If your child's claim is refused (or awarded a lower rate than you expected), you have the right to challenge the decision.

The DWP booklet "If you think our decision is wrong" explains what to do. You should get a copy with your decision letter, if not; your local Jobcentre will have some.

It is not as complicated to do as you might think and a significantly large number of appeals succeed, so it *is* worth pursuing.

The internet link below will also provide you with more information, or you can seek help from the Citizen's Advice Bureau or a local advice agency.

<http://www.dwp.gov.uk/advisers/ni260/appealprocess/>

Section 3

This section tells you where you can go for more advice and some advantages to you if your child is successfully awarded DLA.

The advice agencies mentioned below are local to our area in **Berkshire**; they may not be able to help you if you live elsewhere. Your local Citizen's Advice Bureau should be able to help you wherever you are or they can inform you of specialist advisers in your area.

Written guides and websites

www.nas.org.uk

They have 2 excellent information sheets. "DLA (Disability Living Allowance): What is it?" and "DLA: keeping a diary".

www.cerebra.org.uk

Type "DLA" into their search box, and you can access the Cerebra guide to filling in the claim form. It is very extensive and applies to all children with a brain related condition.

Telephone help

National Autistic Society 0845 070 4004

Benefits Enquiry Line 0800 88 22 00. Please note that this line is run by the department of Works and Pensions, and is not independent.

Community Legal Service 0845 345 345. May be helpful if your claim is refused and you qualify for legal aid. You can get confidential and independent legal advice.
www.communitylegaladvice.org.uk

Face to Face

Berkshire Autistic Society	0118 9594 594 Phone to make an appointment.
Princess Royal Trust for Carers (Berkshire)	0118 950 3941 or helpline@prtberks.plus.com www.carers.org/berkshire
Citizen's Advice Bureau	Reading 0845 071 6380 (carers & disabled people line) Wokingham 0844 499 4126 West Berkshire 0844 477 9980 Slough 0845 120 3712
Reading Welfare Rights Unit	0118 955 1070 www.readingcommunitywelfareunit.co.uk
Slough Welfare Rights Unit	01753 875399

IF YOUR CHILD IS AWARDED DLA, YOU MAY BECOME ENTITLED TO OTHER TYPES OF HELP TOO:

Carers Allowance

Carers Allowance is a taxable benefit that can be paid to a parent/carer of a child that receives the middle or higher rate of DLA Care component. You can claim if you are not working, *or* you earn less than £95 a week (2009/10) after certain deductions have been made (such as Income Tax). Carers Allowance is currently £53.10 per week in 2009/10.

Claims can be backdated for up to 3 months, if you fulfilled all of the qualifying criteria during that period.

Claim forms can be obtained in the same way as DLA forms and it's very straightforward to claim. For further details on eligibility go to

http://www.direct.gov.uk/en/CaringForSomeone/MoneyMatters/DG_10012522. If in doubt, claim!

If you wish to download the form, or to use the online e-service to claim, go to http://www.direct.gov.uk/en/CaringForSomeone/MoneyMatters/CarersAllowance/DG_10012547 and follow the links.

Remember – if your family receives Child Tax Credit, Income Support, Income-based Jobseekers Allowance, Income-based Employment Support Allowance, Pension Credit, Housing Benefit or Council Tax Benefit, you *must* tell these departments if you are awarded Carers Allowance.

Child Tax Credit

If you get Child Tax Credit you *must* tell them if your child is awarded DLA. Depending on your household income, you *might* receive extra Tax Credit payments. Some families can qualify for up to £69.00 per week extra! Contact them on 0845 300 3900.

Housing Benefit and Council Tax Benefit

If you get one, or both, of these benefits, but do not currently receive 100% benefit, you may get increased benefit. Call your Housing Benefit department and tell them that your child has been awarded DLA.

Motability Scheme and Blue Badge Scheme

If your child is awarded the highest rate of the Mobility Component of DLA, you may qualify for the Motability Scheme which provides cars for people with disability. See www.motability.co.uk. You would be exempt from road tax and you can also apply for a Blue Badge for disabled parking.

Cinema Exhibitors Association Card (CEA Card)

Does your child enjoy the cinema? If your child gets DLA, they can apply for a CEA card. The child still needs to buy a ticket, but their CEA card entitles the parent/carer accompanying the child to get in *free*. It costs £5.50 and lasts for a year (you can use it as many times as you like). See www.ceacard.co.uk for application and details of participating cinemas in your area.

Family Days out

Most large family visitor attractions offer discounts on entry costs for DLA children and their carers. *Always* check their websites before you go! *Just a few examples:*

- Longleat Safari Park does half-price Passport tickets for both DLA child and a carer.
- Beale Park has half-price for DLA children and cost reduction for carers.
- Marwell Zoo has reductions on DLA child ticket entry.
- Legoland admits a carer free.
- London Zoo admits a carer free.

A note from the authors:

We decided to write this booklet to help parents to claim DLA, as we felt there was nothing quite like this currently available. All 3 of us are mothers of children on the autistic spectrum. Ruth and Simone have also worked professionally with ASD families for many years. We wanted to share what we have learned by writing this from our unique "parent *and* professional" perspective.

We hope you find it useful!

Best wishes,
Ruth, Nicola and Simone

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