



Teenage Life

Disability Living Allowance

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Disability Living Allowance (DLA) is a benefit to help with personal care and/or getting around.

DLA is available to children up to their 16th birthday who have a disability. (Post-16 it is possible that you will be able to claim Personal Independence Payment, see below).

If your child needs help or support with things like washing, dressing, going to the toilet and getting around outdoors or because they need someone to keep an eye on them during the day and night, then you should apply for DLA.

There is nothing in law to say you must have a written diagnosis to apply for DLA. Whilst having a diagnosis probably makes things easier, you can apply regardless if your child has autistic like behaviour or you are waiting on an autism assessment

DLA is non- means tested – it is not related to your income or savings

Anyone with a disability can apply for DLA regardless of their or their parents' income, savings and other benefits.

DLA can be a 'passport' to other benefits

Claiming DLA can increase your entitlement to other benefits, such as Carer's Allowance (see later section), council tax benefit/reduction. Depending on the allowance awarded, it can also lead to the awarding of a Disabled Persons Parking Badge (Blue Badge) for parents and exemption from Vehicle Excise Duty (car/road tax). It can help with getting a bus pass and cinema card (www.ceacard.co.uk). If you get high rate mobility you can use that money towards a vehicle on the Motability scheme.

DLA is divided into two parts or 'components'

The *care component* and the *mobility component* - both of which are claimed using the same application form.

These components are divided into further levels, according to the applicant's own level of need. For 'mobility' there are two levels; *lower* and *higher*; and for 'care' there are three levels; *low*, *middle* and *high*.

Although you can claim the care component of DLA for a child from birth, you can only claim the mobility component from age three. At this age, a child can only receive the higher rate of the mobility component - they can qualify for the lower rate of mobility from age five.

The higher rate of mobility can be harder to obtain than the lower rate as it is mainly aimed at children with severe physical problems as opposed to behavioural problems.

How much will I receive on my child's behalf?

If you are successful in your claim you could receive anything from about £24 to over £150 per week, depending on your child's care and mobility needs. If DLA is awarded it will normally be reviewed when your child reaches the ages of 5 and 11, but it varies.

Post-16 it is possible that you will be able to claim Personal Independence Payment. (If you are over 16 and wish to claim PIP call 0800 917 2222.)

How do I make a claim for DLA?

For a DLA form, call **0800 121 4600**.

Alternatively, you can complete the DLA form online at:

<https://www.gov.uk/government/publications/disability-living-allowance-for-children-claim-form>

You should hear whether your claim is successful or not within about 10 weeks. You can always call 0800 121 4600 to chase up your claim if you have not heard back by 10 weeks.

Many people prefer to complete the paper version of DLA by phoning to ask for the DLA form because then the claim if successful is backdated to when you made the phone call.

Once you have received the paper DLA claim form you have six weeks to complete it and return it to:

Disability Benefit Centre
4 Post Handling Site B
Wolverhampton
WV99 1BY

Get advice about filling in the form

It can be exhausting, frustrating and time consuming to apply for DLA so get help from someone who knows how to complete the form. Sometimes it can be helpful to discuss the wording with other parents at your local NAS branch, support group or carers' centre who have experience of making successful claims, or to seek advice from your social worker or benefits agency.

Useful UK contacts

Contact a Family

0808 808 3555

www.cafamily.org.uk

National Autistic Society

www.autism.org.uk/DLA

NAS Autism Helpline 0808 800 4104

Cerebra

www.cerebra.org.uk

Has excellent DLA Guide

Carers' Centres

0844 800 4361

www.carers.org

Scope

0808 800 3333

www.scope.org.uk

Give as full as picture as you can

Do not assume that the decision maker who reads your application will know how autism affects your child. Fill in the form with as much detail as possible about the difficulties your son or daughter has with daily living tasks.

Do add on extra pages if you need more space than is provided by the boxes on the form (but be sure to add your child's full name and date of birth on the top of these additional pages). Do not let the form's questions restrict what you write - if you need to add more information, do so!

Remember that you may take for granted all the help you give your child, so think carefully about all the extra support and care you have to provide to ensure your child develops to their full potential. Sometimes it helps to ask other people outside your immediate family to comment, as they may be able to remind you what extra support your child requires. They may also wish to complete the section towards the back of the DLA form which asks for a statement from someone who knows the child.

Write about what your child actually needs (not just the support they already get)

When you are filling in the form, write about what your child *actually needs* regardless of whether those needs are being met at the present time. For example he or she may require one-to-one support at all times at school and when outdoors, so write this even if, in reality, your child is not given much support at school and you are unable to provide constant supervision when he or she is playing outdoors.

What makes for a successful claim?

The most important factor for DLA is time. You need to write in detail about the extra time you spend on supporting your child with daily living and mobility tasks. This will give you more chance of making a successful claim for DLA.

The second piece of advice is (as previously stated) get advice from someone who regularly completes DLA forms.

There is no particular phrase or terminology which can be used when applying for the benefit that will result in an automatic award of DLA. A detailed claim form with specific examples and as much relevant information as possible, together with supporting evidence, is the best approach to take when making a claim or disputing a decision.

Photocopy or save the DLA form before you submit it

This is *very* important. Make sure that you have a spare copy in case the original form gets lost in the post. It is also useful to keep a photocopy for your own reference when the DLA office asks you to reapply in the future. If you have completed the form online you should make sure you have saved a copy of it and that it is safely filed away.

Some parents who complete a paper DLA form prefer to photocopy it and write notes over the copy version before transferring the information onto the original form.

Some parents write their own 'report' in a separate file and save it to their computer with their answers following the numbering in the DLA form. They then can add any additional notes to the DLA form making sure they reference their answers to their separate report.

Whichever way you decide to complete the DLA form, the key thing is to save a copy of all your answers. You will need this saved copy when your child's DLA claim is 'reviewed' a year or two or more later.

Write about the worst days

Do not water it down - you need to stress your case as clearly as possible. Remember, although it can be distressing to write about the difficulties your son or daughter faces, there is likely to be a positive outcome. Financial support can be used to help him or her develop become more independent, and have social opportunities. It is also your child's right to make a claim.

Keep in mind, however, that if your child's behaviour and needs fluctuate it is important to mention this on the form to give a balanced overall picture to the decision maker.

If your child is not awarded DLA ask for a review/reconsideration (and possibly an appeal)

If your claim is unsuccessful, you will receive a letter back from the DLA office giving brief details of why you were not awarded the benefit. If you wish to dispute the decision then follow the relevant instructions within the letter and explain that you wish to have the decision reviewed/reconsidered. Call the NAS Autism Helpline on 0808 800 4104 or look up one of the other organisations for more help eg Cerebra, Contact a Family, Scope, Carer's Centres.

Sometimes, the first claim submitted by parents does not fully reflect their child's needs. If this is the case for you, there is nothing to stop you re-applying. Try again with a more accurate description of your child's circumstances.

If a review takes place but the original decision is not reversed, you may decide to request an appeal. You generally have to make this request within a month. You can opt for a paper-based hearing or an oral hearing but, statistically, oral hearings have a higher success rate. If you opt for an oral appeal, it will involve you going to discuss your child's case with the Independent Appeals Tribunal Service. The appeal tribunal includes a professional with a legal background (who is usually also the chairperson) a person with an understanding or experience of disability, and a medical professional.

Your decision to take your child to the tribunal will depend on your individual circumstances and whether his or her presence will help or hinder the claim. There is no requirement for a child to attend a tribunal and you should consider carefully whether they will find it distressing.

You are entitled to take someone to represent and support you at the tribunal. This could but does not have to be someone from your local NAS branch or a Carers' Centre.

Err on the side of caution to YES or NO questions

Some questions ask you whether a behaviour occurs or does not occur. Please err on the side of caution. For example, if the question is can they cross the road safely? and your child is mostly ok with roads but not always, then the answer is NO.

Or, if a question asks, 'are they anxious out of the home?' and they are often anxious but not always anxious, then the answer is YES.

Keep a diary before you actually fill in the form

Before completing the DLA form, some parents choose to keep a short diary (or make notes on a photocopy of the DLA form) for a week or two. This way, they can jot down quick notes about the extra support they have to give their child, and the needs that cannot currently be met, throughout the day and/or night.

However clearly an event sticks in your mind at the time, you may forget it at a later stage, so write it down. When you come to complete the actual form on paper or online, you will already have lots of information ready to use.

Write what the support was and how many minutes it took.

Wherever possible, you should include examples of your child's behaviour to illustrate particular points - extra sheets of paper can be added for this purpose and sent with the completed DLA form. Mark any extra sheets clearly with your child's name and date of birth in case they get separated from the form.

Prepare carefully for a medical examination

Once you have completed the DLA form and sent it back you may then have an assessment of your child's needs by a Department for Work and Pensions commissioned Health Care Professional (HCP).

The purpose of this visit is to check whether everything in your DLA form is verified when the HCP assesses your child. The HCP will have a medical background but may have little knowledge of autistic experiencing and thinking.

If you have a face to face assessment, make sure you take certain precautions. Firstly, ensure you have another adult with you if possible. This will make you feel more confident and give you time to consider what to say.

The HCP will need to ask questions to determine whether or not your child meets the criteria for DLA. Do not sign anything unless you are completely happy with what the HCP has written. If you wish to amend what you have said, do so, and if you disagree with what the HCP has written, ask him or her to re-write it. If you are still not satisfied, do not sign and say you will seek further advice. Phone the NAS Autism helpline on 0845 070 4004 or Cerebra on 0800 3281159. Not signing will not stop you receiving DLA.

Carer's Allowance

If you are successful in your child's claim for DLA (Care component at mid or higher rate) you or another carer could get Carer's Allowance (CA) if they:

- are aged 16 or over, and
- spend at least 35 hours a week caring for a disabled child
- not earning over about £120/week

The child must be awarded DLA at the middle or the highest rate of care before the CA claim is made.

Other CA claim conditions apply. Even if you cannot claim Carer's Allowance you may still be able to claim Carer's Credit (National insurance contributions).

CA should be claimed within 3 months of the DLA decision being made or the carer could lose benefit.

Whether or not to claim Carer's Allowance /Carer's Credit can be complicated so call:

0800 731 0297

Also look up Cinema Card www.ceacard.co.uk and talk to Contact a Family 0800 808 3555 about other benefits or entitlements if your child starts receiving DLA.

Ask for 'supersession', if your son or daughter's difficulties increase

If you think the rate of DLA your child is receiving is too low because their circumstances have changed, then you may wish to ask for the claim to be re-examined. For example, your son or daughter may have been receiving middle rate care, but then developed disturbed sleep patterns at night, so s/he now requires the high rate of the care component. This reassessment is known as 'supersession' and will usually involve you completing a 'change of circumstances' form (DLA434).

Remember that whenever you ask the DLA office to re-examine your child's level of benefit, it is possible that they may decide it should be lowered as well as raised, so be sure to get advice before re-applying.

Phone 0800 121 4600 and ask for DLA434 form, if you wish to apply.

Completing the DLA application form

Before completing your DLA application form, visit www.autism.org.uk/dla and make sure you have read this Handbook thoroughly.

Don't feel you need to complete the form all in one go! Do it a few questions at a time but be aware if it is a paper version you only have six weeks to return it (or you might lose your entitlement to those six weeks worth of DLA).

Describe your child's behaviour as clearly and simply as possible, however negative/difficult/embarrassing/terrifying it may be. It is not a pleasant experience to have to concentrate on what your child cannot do, but for the purposes of the form this is precisely what is required. It may lead to getting DLA and this means money to help your child become more independent.

The DLA form has a lot of useful tips on how to complete the form and this takes up the first 22 pages.

NB- In this Handbook we have not given detail on every question as some are self-explanatory, or usually require less guidance.

Questions 1 -13

These are mostly questions you need to fill in with your family details.

Question 14 - in the last 12 months, has the child seen anyone apart from their GP about their illnesses or disabilities?

In this question you are asked to provide details of health/NHS professionals your child has seen in the past 12 months. Although it requests a 'health' professional it allows you put down the details of any other professional that has the best understanding of your child (eg school nurse, learning support assistant, educational psychologist, social worker, previous year's class teacher). See also question 20.

Question 15 - Name of the child's GP

This question asks for details of your child's GP. In some cases, your GP may have limited contact with or understanding of your child. If so, you may wish to ask the DLA office to also

Speak to another NHS professional, such as a paediatrician, speech therapist or occupational therapist, who knows your child better and is 'on your side'. Make sure you write this clearly on the DLA form, as follows: 'Dr [insert name here] is my child's GP but please also speak to [name and contact number of the other health professional] as s/he knows my child better'.

You may wish to inform your child's GP that you have applied for DLA and if possible make an appointment to discuss your child's claim with them.

Question 17 – Do you have any reports, letters or assessments about the child's illnesses or disabilities?

When you submit your DLA application form you may wish to include some supporting evidence from professionals who know your child. However, do ask for any supporting letters to be sent to you first. Make sure whatever they write actually does support your claim. A letter saying your son or daughter has no difficulties and is progressing very well may not accurately represent the true picture or support your claim.

Question 18 – Name of the child's school or nursery

The DLA office may contact your child's school. Always inform your child's school that you have applied for DLA and if possible make an appointment to discuss your child's claim with them. Read the *Cerebra* guide to claiming DLA at www.cerebra.org.uk/download/disability-living-allowance-dla-guide or call Cerebra helpline on 0800 32 81 159 for more advice on this.

The main form starts on page 23 with Question 1 and the section titled: **About the child**

Question 19 – Does the child have or are they waiting to hear about an Educational Health and Care Plan (EHCP), Individual Education Plan (IEP), Individual Behaviour Plan (IBP) or statement of Special Educational Needs (statement)?

This question is asking what formal support your child's school or other educational setting provides. You do not have to provide any evidence if it does not give a true picture of your child's needs. However if you have an EHCP it is likely to support your case and do send this on (as the DLA office request). Get advice from an experienced DLA form filler, if you are unsure what to send to DLA.

NB- The wording in this question is out of date now (School Action and School Action Plus are terms no longer used) and it contains an abbreviation error ("EHP").

Question 20 – Statement from someone who knows your child

This question allows you to add the details of any other professional who has the best understanding of your child, eg school nurse, learning support assistant, educational psychologist, social worker, or previous year's class teacher.

It is entirely up to you who you pick so choose someone who you know really understands your child and their difficulties. Importantly it does not have to be a professional - it can be a family friend who is involved in your child's care in some way.

Question 21 – Consent

This section is asking for your consent to contact:

- GP
- School
- Someone who knows your child (see question 20)
- Anyone else you have listed for DLA to contact (eg speech and language therapist or paediatrician)

If there are good reasons why you would prefer the DLA to not contact one or more of the above people/organisations, you are within your rights to withhold consent.

It is generally seen as sensible to let DLA contact those people so get advice from an experienced form filler if you are unsure of the best approach to take.

The Motability scheme

This is asking you if you want to be sent information on Motability.

It is worth ticking yes, if you think your child has significant mobility issues eg physically moving about or has behaviour out of the home that makes them dangerous, very vulnerable, or they are very anxious.

Motability is only available to those who get *high rate DLA mobility*.

Question 22 - About the child's illnesses or disabilities

List all and any of the diagnoses your child has and any that are suspected by yourself or others. Autism is a lifelong developmental difference so state that it has been present 'from birth'.

Question 23 – Does the child use, or have they been assessed for, any aids or adaptations?

You can list almost any aids your child uses such as visual supports, timetables, whiteboards with task reminders, tick lists, adapted cutlery, pens, computer, seating, beanbags, fidget toys, weighted items, soft bed light or trampoline. The aids do not have to be highly technical or assessed by a professional. Any aids you make use to help your child develop and become more independent count.

Question 24 - When the child needs help

This has a single question – do your child's needs vary or are they more or less the same every day.

Most parents tick "is the same most of the time", because autism is not a variable condition – your child is always autistic in thought and feeling. Their behaviour may vary but not their needs!

If you wish to state in the free text box that some days are better than others that is fine but it needs to be stressed clearly that autism does not have an off switch.

Mobility questions

This section about Mobility.

Mobility can mean:

1. physical movement – for example can you child actually walk
2. safety and confidence outside the home – for example can your child be safe outside and /or do they experience anxiety

In answering this section, you must talk about why it is so difficult for your child to move around, how long it takes them, and in what manner your child walks.

Question 25 - Can they physically walk?

State here whether your child can walk or not.

Question 26 - Do they have physical difficulties walking?

Describe any difficulties.

Question 29 - Please tick the box that best describes the way they walk.

If your child has an unusual walking style, write this in the box provided on the form. If you need to tick more than one option do so. Don't worry that it says only tick one box.

Question 31 - If you want to tell us why you have ticked the boxes, how their needs vary or anything else you think we should know, use the box below.

Many children with autism get very tired walking because of the way they hold themselves when they walk or other physical difficulties. So make sure if this is the case you mention the problems here. For example because they are always tensed up and 'over-thinking' about how they look to other people this causes tiredness and aches in their joints.

Question 32 - Do they need guidance or supervision most of the time when they walk outdoors?

These are a series of YES/NO options. Remember if your child even sometimes does have difficulties tick either YES or NO depending on the way the question is asked. Err on the side of caution. For example, your child may be able to sometimes find their way around places they know well, ask for and follow directions, walk safely next to a busy road, cross a road safely and understand common dangers outdoors, however if they sometimes cannot do these things then tick NO.

Question 34 and Question 35

These are free text boxes to complete. You need to use the following information to explain fully the difficulties your child has.

Take as much space as you require, though you'll notice the text size gets smaller, as you write more. So if you want to write more than you have space for on the form then type your own answers separately on your computer and save a file called DLA evidence. Then you can make your own evidence report to print off and send to DLA.

Here are some things to consider writing about in the Question 34 and 35 boxes:

Your child may:

- exhibit challenging behaviour when outside, such as sitting down and refusing to move or shouting at passers-by
- have to follow certain routes or routines when walking (eg touching every lamp post, asking questions of people they see in the street, insisting you take them to their favourite place)
- walk extremely slowly and refuse to speed up.

You might provide an example of a regular journey that you might normally walk but which you are usually forced to take by car or bus because it is the only feasible method for your child.

Does your child listen and respond to your instructions when you are out?

Or will they:

- ignore you even when you are near busy roads or in dangerous situations
- deliberately disobey you or fail to comply with reasonable requests, making it difficult to go out if there is just one adult or if there is more than one child?

Further points to consider for questions 34 and 35:

- Are you ever unable to go out because of the way your child behaves or because it might be dangerous?
- Do you have to provide constant reassurance and encouragement to your child in order to travel by unfamiliar routes?
- Does your child have any sensory difficulties, such as acute hearing, that makes going out difficult?
- Is your child afraid of busy places and noisy people, requiring extra supervision and reassurance? Does this restrict the places you can go?
- Is he or she easily distracted by what is going on around them?
- Do they insist on always walking by a certain route and become aggressive if this route is not followed?
- Do they always have to carry certain objects with them before they will leave the house?
- Do you have to use any special equipment, such as an adapted buggy or reins?
- Is your child paranoid that people are staring at them? Do they get distressed and need reassurance as a result?
- Do they refuse to get out of the car once you reach a destination, or when you arrive home again?
- Do they get lost in the supermarket or park?
- Do you have to avoid certain places, noises, or people because of their fears/phobias/intense reactions? (Eg Do they panic if they see a dog?)

Make sure you write about the help your child needs in unfamiliar places. If they can go to a local shop and back, that does not count - use this section to write about the help they need, or would need, if they were going somewhere new.

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

Why do you need to be with your child when they are outdoors?

Does your child have a sense of danger?

Does your child understand danger but find still them self easily distracted should something else come along? For example, they might normally be fine on the roads but will run across a busy street to get a better look at a double decker bus.

Does your child need your help even if a situation or a journey is familiar? Do they need reassurance?

Do they have limited spatial awareness? Are they unable to tell right from left, follow more than one simple direction at a time, or travel beyond end of the road? Do they get mixed up and panic?

Does your child forget to use mobile or ask an adult? Are they too afraid to do this?

Are you unable to tell your child to be back at a particular hour because he or she loses track of time, has no concept of time or cannot read a watch?

How vulnerable do you think your child is?

Does your child understand stranger danger?

Can your child's knowledge of stranger danger easily be overridden? For example, if he or she is offered a favourite treat.

Can they assess the risks involved in situations?

Would your child hand over money to strangers or other children if asked?

Will your child do whatever other children tell them to do? For example, throwing stones at passing cars.

Does your child make personal comments when in public? For example, "why are you so fat?"

Does your child strip their clothes when out?

Do you need to provide a near constant commentary when you are out to reassure your child and to explain what is going on? Will they become anxious or aggressive without this?

Does your child understand that certain rules can be broken? For example, once they have learned to wait for the green man to indicate it is safe to cross the road, can they then learn that sometimes ambulances or fire engines go through red lights?

Does your child's outward appearance make them a potential target for attack? Does he or she make comments about others, or push/strike other people if they come too close? Would your child always let you know if something had happened to them?

Question 36 - When did your child's mobility needs you have told us about start?

Put a date in here. For some children with anxiety about leaving the home this may have started before they started pre-school.

Care questions

Question 37 – Do they need encouragement, prompting, or physical help to get into or out of or settle in bed during the day?

Make sure you write about waking up, getting up and going to bed in the free text box. Use the following questions to help you think about their needs:

Does your child have difficulties waking, getting up, or going to bed? When completing this section, it is important to outline any routines or rituals that your child may have. Consider the following questions.

- Do clothes need to be laid out the night before in a special sequence to ensure your child will get dressed?
- Is getting dressed a lengthy process?
- How soon does your child have to start getting ready for bed? This could be several hours before bedtime and might involve saying goodnight to everyone, choosing a book, pouring a glass of milk, talking through what is happening the next day etc.
- Does your child have to be woken in a particular way by a particular person, pet or toy to ensure a good mood? Is it a constant battle to get them up in the morning, involving lengthy explanations of why it is important to get up?
- Do you have to let your child snooze for a while before they will get up?
- Can you trust your child to stay in their room and occupy them self if they are awake in the night?

- What happens if you don't see to your child immediately in the morning? Could your child do something disruptive (eg set off the burglar alarm, wake siblings), wander into the kitchen without supervision, be destructive (eg strip wallpaper, pull up the carpet) or do something dangerous such as bang their head or jump out of the window?

Question 38 - Do they need encouragement, prompting, or physical help to go the toilet during the day?

Make sure you use the space in the free text box to write about any using the needs your child has with using the toilet.

Include as much detail as possible about any bowel or bladder problems and/or difficulties using the toilet that your child experiences.

- Does your child have difficulty coping with his or her toilet needs?
- Is he or she able to stay clean and dry? Does he or she have poor toilet hygiene?
- Is your child likely to smear? Do you have to help with wiping to avoid bad smells?
- Does your child follow a specific diet to avoid bowel problems? How easy is this to implement? What happens if they eat wrong foods and does this affect toileting?
- Do they hide poo around the house or have it under their fingernails?
- Do they have an awareness of needing to use a toilet or do they just relieve themselves anywhere?
- Are they unaware of being wet and unmotivated to use the bathroom, making them difficult to toilet train?
- Does your child wash their hands in the toilet or play with and drink toilet water?
- Are they obsessed with the flush or putting toilet paper down the toilet pan?
- Is your child hyper-sensitive? For example, do they only use certain toilet tissue, refuse to be wiped or dislike being touched?
- Does your child lock him- or herself in the toilet?
- Is he or she unable to go to the toilet by him- or herself, even though they are too old for a parent to accompany them?
- Do they have phobias about the toilet, such as a fear of the flush? Do they forget or refuse to wash their hands?
- Do they have a fear of hand dryers, making it difficult to use public conveniences?

- Will they talk to strangers in public toilets or ask for help from strangers with toileting needs?
- Does your child have sensory issues relating to toileting? Do they dislike the smell of toilets, air fresheners or chemical cleaners?
- Does your child have to sit down, so cannot use urinals? Do they need a foot rest because of balance problems?
- Will they only use certain toilets? For example, do they refuse to go at school or away from home? Do they have to carry paper toilet covers or antiseptic spray?
- Are they afraid of germs, preventing them from touching toilet doors or parts of the cistern/lift seat?
- Do they have dietary problems such as constipation, or pain that needs medication?
- Does your child have loose bowel movements? Do they have accidents? And does this mean that toileting takes longer to clear up and laundry costs more?
- Do you need to be in the bathroom with your child to prevent other undesirable behaviour?
- Do you ever have to get up in the night to help your child go to the toilet?

Question 39 - Do they need encouragement, prompting, or physical help to move around indoors, use stairs or get into or out of a chair during the day?

Many children with autism have physical co-ordination difficulties. If your child has a diagnosis of dyspraxia, developmental co-ordination disorder or sensory integration difficulties, state this on the application form along with full details of who made the diagnosis. Even if your child does not have a formal diagnosis, it is worth stating any difficulties they do have.

Many children with autism have sensory integration and processing difficulties affecting their balance, sensitivity to movement and awareness of their body position, Your child may also have visual difficulties, such as finding it hard to track movement or having limited depth perception, all of which make getting around more of a challenge.

Thinking about the following questions will also help you when defining your child's difficulties.

- Do they dislike stairs, lifts, kerbs or door thresholds, requiring encouragement to step up or down and negotiate new environments?
- Does your child bottom shuffle down stairs?
- Do they often accidentally break objects in the home?
- Does your child need to lean against objects or people because of poor muscle tone?
- If they do have weak muscle tone does this result in other difficulties with physical activities and independent living skills?
- Does he or she have tactile problems such as a low threshold to pain?
- Does he or she have problems with falling over?
- Does your child have an unusual or awkward walking style (or 'gait')?
- Does your child have an obsessional behaviour about doorways and going into rooms eg rituals they have to perform before they can enter another room?
- Do they have difficulties catching a ball because of poor visual tracking?
- Does your child have difficulties riding a bike or swimming?
- Do they have difficulties playing games and sports or running?

Remember to highlight any support you currently give your child, or any that they need but don't get. The support you provide your child could be to offer encouragement and advice, or it could consist of specific exercises to develop muscle tone, and co-ordination. Without support to develop his or her abilities with movement and co-ordination, your child might become depressed, feel left out, have accidents, be in pain, or stop trying new activities.

Some children's movement and co-ordination problems can cause difficulties around the house. This question focuses on your child's mobility needs within the home and at school; so if they have physical difficulties that affect them indoors, write these here.

Does your child:

- have difficulties going up or down stairs?
- refuse to use the shower because of balance difficulties?
- need to lean against objects?
- have lots of accidents as a result of poor balance?

- move very slowly?
- panic when using stairs or uneven surfaces?
- require hand rails?
- require constant supervision due to their movement and balance difficulties?

Remember to include details of what would happen if your child did not receive support, aids or encouragement with moving around indoors. For example, would they become distressed if not helped?

Question 40 - Do they need encouragement, prompting, or physical help to wash, bath, shower and check their appearance during the day?

Does your child have difficulties washing or having a bath or shower? Or is your child capable of washing him- or herself but still avoids doing it without parental supervision? Remember that even if your child does not need physical assistance with washing and bathing, he or she may still need support and prompting to keep clean.

You should consider the following questions when describing your child's bathroom routine.

- Does your child have difficulty with sequencing the washing/bathing routine?
- Do you have to be present when your child is washing?
- Do they need the bathroom warmed before use?
- Do they refuse to enter the bathroom?
- Does your child need verbal prompts at each stage?
- Does your child resist being touched or rubbed by a towel, resulting in challenging behaviour?
- Do they have difficulties with motor skills which might, for example, make it difficult to get toothpaste onto a toothbrush?
- Is your child hypersensitive to touch or taste, making it difficult and unpleasant to brush teeth, have a shower or brush their hair?
- Does your child know when he or she is being scalded or when the water is too cold?
- Is there a danger of flooding in the bathroom if they are unsupervised?
- Does your child refuse to get in or out of the bath, because they either love or hate it?
- Does your child insist on following the same bath-time rituals?

- Do they have an obsessive compulsive hand-washing problem?
- Do they need help to flush the toilet because they hate the sound of it?
- Do they stuff toilet paper down the toilet unless supervised?
- Does your child understand the health benefits of keeping clean?
- Is your child likely to make a real mess in the bathroom?
- Does your child wash properly and hygienically without prompts?
- Can they use conventional soap or shower gel or do they need unperfumed non-allergy products to avoid skin reactions? Do they need supervising to ensure they use the correct washing materials?

Question 41 - Do they need encouragement, prompting, or physical help to dress, undress during the day?

The following questions may be relevant when completing this question.

Does your child have difficulties getting dressed or undressed?

- Is he or she unable to choose appropriate clothes (with regard to season/occasion) without assistance?
- Does your child have difficulty with the routine of getting dressed? For example, do clothes go on inside out or in the wrong order, putting socks over shoes?
- Do your child's fine motor skills make doing up buttons and zips and tying laces difficult?
- Does your child refuse to wear clothes that have even a slight mark on them?
- Does your child chew clothing?
- Does your child tear clothes?
- Does your child need to change clothes several times a day?
- Does your child refuse to throw away old clothes (due to sensory, attachment to objects or other reasons?)
- Is your child resistant to change, such as wearing new clothes?
- Does your child have rituals about getting dressed that mean it takes a long time to be completed?
- Is your child unable to wear school uniform, due to sensory reasons?
- Does your child soil clothing (eg constipation leakage, diarrhoea or menstruation)

Sometimes a child's routines or obsessions will affect what he or she wears. Do any of the following relevant points apply to your child? If so, make this clear in your application.

- They will only wear certain colours.
- They only tolerate certain fabrics (eg due to sensitive skin.)
- They require special clothes (eg weighted vest or lap blanket.)
- They only wear certain fashion or brand labels.
- They refuse to wear clothes indoors.
- They strip their clothing in public places.
- They become distressed when their favourite clothes wear out or need washing.

Question 42 - Do they need encouragement, prompting, or physical help to eat and drink during the day?

Children on the autism spectrum often have difficulties with diet. This can be due to a range of problems, such as finding it difficult to chew or having sensory difficulties with texture, smell, taste.

Consider whether any of the following apply to your child when completing this question.

- Does your child not have an appetite due to anxiety?
- Does your child not receive interceptive (internal hunger signal) information about needing to eat?
- Does your child have difficulty using cutlery? For example eat with their fingers?
- Does your child have rigid ideas about what is safe or unsafe to eat?
- Does your child have difficulties with chewing food?
- Is he or she likely to regurgitate food if not properly supervised?
- Does your child need to follow certain routines about plates or cutlery?
- Do they constantly get up from the table, or only eat whilst walking around?
- Do they require monitoring to prevent them bolting their food and getting indigestion?
- Do they eat non-food items (a condition known as 'pica') and therefore need supervision when they are in the bathroom, kitchen or outside?

- Is your child aware that he or she needs to eat to survive? Are they at risk of dehydration/headaches because they only drink when reminded?
- Will your child only eat certain brands of food?
- Are they intolerant of people talking during meals?
- Do they dislike other people eating near them – perhaps because of the noise or a fear of germs?
- Do they eat meals alone because they do not like people looking at them while they eat?
- Will he or she refuse to eat in certain places, such as school?
- Does your child know about the need for a balanced diet?
- Does your child dislike eating foods with certain colours or textures?
- If they are old enough, do they understand about food safety and sell by dates?
- Does your child have a specific diet (eg casein or gluten free) that requires their meals to be constantly monitored?
- Do they have any other specific food allergies that require you to be constantly vigilant? (Explain what happens if they eat the foods they are allergic to.)
- Is your child prone to eating disorders (either over or under eating as a reaction to anxiety and wanting control?)

Question 43 - Do they need encouragement, prompting, or physical help to take medicine or have therapy during the day?

If your child is undergoing, or needs, any kind of therapy (eg occupational therapy, physiotherapy, speech therapy, sensory integration, music, drama or art therapy) you should provide details.

Your child may have had an assessment which recommended that they undertake specific exercises. If so, provide details of these, including how long they take (even if you do not always have time to complete them.)

Also consider the following questions.

- Do they forget their medicine or refuse to take it?

- Do they need considerable encouragement to undertake any recommended specialist exercise advice from occupational therapy or speech therapy? This could include social skills training?
- Do you have to conduct any therapies at home? These may have become part of everyday life, but are still over and above the typical routines of family life.
- Are there speech or language exercises you can do or have been recommended?
- Have you been given any exercises to do relating to sensory needs? These might include getting your child used to different sounds to develop their tolerance or giving them exercises to develop their food tastes and improve their diet.
- Do you have to help your child with movement or co-ordination exercises?
- Do you have to use special techniques to prevent head-banging or other self-injurious behaviours?
- Would your child benefit from regular massage and deep pressure techniques to reduce stress and anxiety and make him or her more alert, relaxed and able to concentrate?

Question 44 and 45 are about poor sight or hearing. If your child has difficulties in these areas write about their needs.

Question 46 - Do they have difficulty speaking?

This question is nearly always relevant to children with autism. For example, if your child finds talking out loud difficult to other people they don't know very well.

If your child finds speaking to others difficult give the details in this question.

- Does your child find other people too anxiety provoking to talk to?
- Do they have problems knowing what to say when people talk to them?
- Can they speak? Do they have a limited vocabulary or get their word order mixed up? Do they repeat words and phrases that they have heard (echolalia)?
- Is their speech unclear? Do they talk in mumbles or grunts or only use forms of communication that family members can understand?
- Do they find words too difficult to process so tend to switch off to cope?
- Do they have attention difficulties? Do you need to be in same room, at the same level or in their line of sight to get their attention? Perhaps you always need to use

their name first or need to gently hold their chin so they direct their eyes towards yours?

- Does your child respond to his or her name?
- Do they use eye contact or look down nearly all the time?
- Does the stress of talking mean that they avoid people to avoid meltdown?
- Will they only respond to certain phrases, voice tones or people?
- Do they get their words mixed up?
- Do you use any form of non-verbal communication with your child, such as gestures, signs, visual cues or PECS?
- Does he or she have to use visual supports to understand or express thoughts?
- Do you have to use specific communication methods, such as slowing down speech, ensuring your child is facing you, gaining attention first or only using short simple phrases to get any response?
- Does your child understand when other people are addressing him or her?
- Do they refuse to talk to some people (eg elective mutism)?
- Does he or she have problems talking to other children because of social difficulties?
Does he or she become nervous or anxious as a result?

Question 47 – Do they have difficulty and need help with communicating?

This is the core difficulty faced by autistic people, so ensure that you write about **all** the specific help your child is getting and **all** the help they require with communication, interaction and social skills in and outside school (even if they don't always get it). The following questions will help you to develop a clear picture of your child's difficulties and needs.

- Does your child need help understanding other people?
- Is your child unwilling, or simply unmotivated, to communicate with other people?
- Will they only respond to certain phrases, voice tones or people?
- Does your child have a short attention span which makes communication difficult?
- Are they unable to communicate need, becoming angry or sick but not being able to express this?

- Does he or she have auditory processing difficulties? In other words, does he or she take a long time to process information and respond to it? Do you have to slow down your speech, break down instructions and wait for him or her to reply?
- Are they rude to people they do not know? For example, do they swear at strangers?
- Do they become paranoid about what others are thinking and get angry/anxious/aggressive?
- Do they communicate through physical means by, for example, grabbing, pulling or pushing other people to get their needs met?
- Can they process facial expressions in other people? Can they tell if you are happy or sad?
- Do they find eye contact difficult and therefore find it hard to follow a conversation?
- Does he or she misunderstand other people regularly and do you have to provide an interpretation of what other people mean? For example, do they fail to understand jokes and get angry if people are not precise in what they say?
- Do they fail to stay on topic? Do they talk too slowly, loudly or quickly?
- Does your child fail to understand the rules of conversation? Do they communicate impolitely or blank people who say hello to them?
- Do they talk about one topic obsessively?
- Does your child make false assumptions about what people might already know and get confused, angry or paranoid as a result?
- Do they lack empathy? Are they unable to read social situations or interpret non-verbal behaviour correctly?
- Does your child place the wrong interpretations on what is said? Do they take things very literally or become easily upset by teasing?
- Does your child want to be more sociable but not know how to? Is he or she susceptible to bullying because of naïvety?
- Does he or she make tentative efforts to be sociable but give up very easily if these are ignored?

In your written response to this question of the DLA form, explain that without adequate support, your child will become more isolated and their social development will be affected. They need to learn social skills in order to make friends and get on with other people.

Go into detail about the support your child needs with social and communication skills. Do you find yourself having to do any of the following:

- Being there to sign, gesture or interpret for your child?
- Helping your child to be understood by other people?
- Using a favourite toy or food to motivate your child?
- Helping him or her to recognise facial expressions and body language?
- Reassuring your child to prevent anger and frustration?
- Reminding your child to change topic?
- Telling them how to say hello and be polite?
- Requiring social skills training for your child in the home and when out in town?
- Needing to give your child lots of encouragement to join in socially?
- Avoiding social situations such as parties or outings with other children, due to your child's lack of understanding or interest or their fear of socializing?

Question 48 is about seizures and fits. These are relatively common in autistic children. So if your child suffers these make sure you give details.

Question 49 – Do they need to be supervised during the day?

The extent to which your child needs to be monitored during the day depends on how well they can be occupied by their own interests and what they are likely to do if unoccupied. Ask yourself how long can you safely leave your child unsupervised?

You could:

- write how often you need to physically check up on your child, even if this just means staying in the next room or within earshot
- give examples of specific incidents. For example, "s/he appeared to be playing quietly in the kitchen but when I went back five minutes later s/he had removed half the contents of the freezer."

Even if your child is quite able, he or she may still need a lot of supervision. Your child might, for example, be interested in how electricity works and could take apart the television in

minutes, or put fingers into sockets and light fittings. Do you have to use special gates, plug covers, locks etc?

When working out how much time you can leave your child unattended, ask yourself if you feel comfortable leaving them unattended at all. If you find your child doing something inappropriate, how long does it take you to:

- stop the behaviour?
- deal with the consequences?
- make repairs safe?
- clear up?
- deal with the meltdown/anger?
- distract your child with another activity?
- encourage your child to behave differently?
- explain to your child why the behaviour is inappropriate/dangerous?

Give details of how long this whole process takes from start to finish.

Can your child cope with changes to daily routine eg new route to school? Different breakfast cereal? New class teacher or assistant? Not able to watch favourite programme? Being told to hurry up and let someone else use the bathroom?

xxxxxxxxxx

Question 50 – Do they need extra help with their development?

Does your child have a delay in their development of physical or sensory skills? This may include gross or fine motor skills or hyper/hyposensitivity to sensory stimuli.

Does your child have a delay in their development of learning skills? They may learn skills but forget them the next day or be unable to generalise them to other situations. Others may have a patchy range of skills or only use acquired skills when prompted or encouraged to do so.

Does your child have a delay in their development of social skills? Concentrate on the inappropriateness of your child's social behaviour and describe whether it is active but odd, passive or aloof.

Also, consider the following points when completing this section.

- Does someone need to help your child develop through play?
- How much time does it take to explain about how to play successfully with others? Eg say hello, don't go and hide in your bedroom when your friend arrives
- How much time does it take to explain what other people are thinking and feeling? Eg if your child is too blunt and honest how that can hurt someone's feelings.
- Can your child play imaginatively or is he or she dependent on your input?
- Do you have to regularly intervene in play to redirect or motivate them?
- Once your child has accepted an activity, how long can they entertain them self or maintain their attention to the task?
- Does your child's play constantly demand adult involvement?
- Will your child only be interested in activities that demand your involvement (eg rough and tumble play, trampolining)?

Remember to provide examples to illustrate all your child's developmental difficulties.

Question 51 – Do they need encouragement, prompting or physical help at school or nursery?

In this question write down anything that your child gets help with (*or needs help with and does not get*).

You may wish to include details of any special educational needs, for example Education Health and Care Plan (EHCP) or other support like a support plan or individual education plan. Explain in detail what help they actually require.

As we know not all schools are able to provide the support that your child needs, so make sure you write what a good school what be doing to help your child.

This might include:

- A classroom assistant for most of the day to help them understand what they need to be doing and how to manage their class work?
- Peer mentor to help them manage the playground?
- Extra time to do exams?
- Social skills groups?
- Help to cope with PE?
- Let out of lessons early to navigate the school campus?
- Use of staff toilet due to fears about germs?
- Lunch club to avoid queues and other people eating?
- Help with handwriting?
- Help with dyslexia/dyscalculia?
- Quiet room to use when overwhelmed?
- Help to make friends?
- Reminders to take the right books to the right lesson?
- Support to get around the school?
- Help to work in groups within the classroom?
- Special pen or seating?
- Allowance to leave school early to avoid crowds?

Question 52 – Do they need encouragement, prompting or physical help to take part in hobbies, interests, social or religious activities?

This section is about the help your child requires with social and leisure activities at home or elsewhere. Any or all of the following difficulties are relevant, if they apply to your child.

- Spending lots of time at home and not having many friends.
- Not attending clubs or other after-school activities.
- Missing out on social events such as birthday parties and sleep-overs.
- Needing lots of encouragement to leave their room or the house.
- Needing three or four visits to any new social activity to help them feel relaxed enough to stay
- Requiring your presence at their social events to give them confidence to cope
- Needing you to discuss what will happen at a new leisure activity
- Needing you to explain what the rules or expectations are for their social activities

- Needing to take them shopping with you to buy things related to their interest, because they cannot be safely left alone.

As well as describing your child's difficulties, you also need to write about what your child could do if they had the social skills, confidence and one-to-one support they require after school. Think about what your child could attend and get involved with, if extra support was available:

- Gaming shops
- Cubs/Brownies
- Playing in the park
- Climbing wall
- Country walks
- Swimming
- Visiting friends or family members
- Anime meeting
- Comic shops
- Dr Who exhibition
- Train visits
- Football match

Some of the following means of support may be relevant to include here.

- Driving to and from a venue.
- Encouraging your child to go in the first place.
- Finding ways to build their self confidence so they might try a new activity.
- Staying during the activity to ensure it runs smoothly.
- Having someone to help your child communicate with other children.
- Supervision to prevent your child getting into arguments, fights or dangerous situations.
- Reminders to use toilet.
- Reminders of how to play appropriately.
- Supervision to monitor teasing/bullying or aggression.

Remember that this section is not just about social and leisure activities outside the home.

You should also use this opportunity to write about:

- the need to fill 'unstructured time' by keeping your child entertained. (Will your child just do repetitive activities unless given supervision? Is he or she unable to decide on new activities or make independent choices?)
- the structured activities and visual supports you have to follow with your child
- your constant supervision of sibling relationships to ensure that activities are positive and don't end in fights
- the structures you have to put in place to prevent rituals and obsessions taking over
- becoming involved in games because siblings cannot understand their brother or sister's behaviour.

Question 53 – Do they wake and need help at night, or need someone to be awake to watch over them at night?

Case law defines 'night time' as between approximately 11pm and 7am (roughly the hours when you (parents) go to bed), so if your child is up and about during those hours, that will usually count towards a claim of night time needs.

Many children who are autistic do not sleep particularly well and some seem to get by on far fewer hours than the average child. If your child goes to sleep after the adults then this counts as disturbed sleep.

Ask yourself if any of the following questions are relevant when completing this section. Does your child:

- have a fear of night, dark, sleep or closing their eyes?
- have any specific phobias or fears, such as not wanting to touch the covers, insisting that the duvet cover has to be exactly straight, having to follow a particular routine or always having certain objects or toys with them?
- need visual supports to guide them through the night-time routine, such as reminders to close their eyes, visual sequences to show them sleeping and waking at certain times or reminders to stay in their bedroom until a specific time?
- take a long time to settle, meaning that it takes you longer to get them to sleep?

- get up very early and disturb the rest of the household?
- sleep walk or have night terrors and anxiety attacks? If so, how long does he or she take to settle again?
- require particular rituals to be followed in order to settle?
- have sensory difficulties requiring, for example, total black out or a background noise from a radio or fan?
- require a deep pressure routine before bedtime in order to settle, such as being rolled in a rug, given a massage, put in a sleep suit, tucked in tightly or placed under a weighted blanket?
- have difficulties with bed wetting or soiling at night?
- have any medication to take at night, such as melatonin?

Describe your child's night time needs in the same way as you did for the daytime. Do problems that occur during the day also happen at night? Even if they occur less frequently, they are still worth mentioning.

Other problems that you may want to mention, if applicable, include:

- not sleeping if the sun has not set or if there is a half- or full-moon
- not sleeping more than a few hours each night
- being up and moving around the home during the night
- waking siblings by calling out
- waking in the night and being disorientated so needing settling
- wanting to eat food or have a drink in the night
- waking and not being able to re-settle unless they sleep in your bed or you stay with them in their room/ beside or in their bed
- needing to follow a certain routine that goes on past 11pm (eg watching a certain DVD)
- needing to keep the light on
- needing total blackout of all lights
- needing a fan, radio or TV switched on in order to sleep

- having all household appliances switched off due to hyper-sensitive hearing
- sleep walker or night terrors
- being unable to settle unless all other members of the house are asleep.

Once they are awake, how do you get your child back to sleep?

- Do they insist on following a routine before returning to bed?
- Is it possible for them to go back to sleep? Do they wake and start playing in their room?
- Does your child ever enjoy unbroken sleep? Is this a common occurrence?

Question 54 – Extra information about care

Use this free text box to add any other information you think might be relevant.

The following areas may be useful to consider for your child:

It is important to report your child's emotional difficulties resulting from autism. If your child has a diagnosed mental health difficulty it is important that you state this on the application form, but even if they have not been diagnosed, they may well experience fears, phobias, low mood, obsessive routines and anxiety. They may also display impulsive, destructive, self-harming or threatening behaviour.

Any medication that your child does take in relation to his or her mental health difficulty should be stated in this section, including the dosage and how often he or she has to take it. State also any side effects which are difficult to manage.

Consider if any of the following points apply:

- Does your child become anxious in and out of the house? Do you need to be careful where you can take them? What can happen if your child becomes too anxious?
- Is your family limited in what it can do because of your child's need for routine? For example, does your child take over the TV and lounge area?

- Does your child spend more time than average in their room and require coaxing to join in social activities? Can they bear to have any object touched in their room, or have things moved into the 'wrong place' around the house?
- What effect do the difficulties have on other family members?
- What happens if there is an unexpected change of plan? What does he or she do?
- Does he or she have panic attacks? Does this limit what you can do and where you can go?
- Does your child have any paranoid thoughts? Do they avoid going out for fear of being talked about and attacked or of people knowing their thoughts?
- Do they display self-harming behaviour? If so, describe it. Do you need to spend extra time supervising your child to make sure they do not self-harm?
- Does your child cause damage to property? Do they make threats of violence?
- Do you need to spend a lot of time using de-escalation (ie trying to calm him or her down) when your child has a meltdown due to their inability to express feelings safely?

Question 55 – When did the child's care needs you have told us about start?

The form asks you from what age your child has needed this help. In truth, your child has needed this help from the day they were born, regardless of when they were diagnosed, so many parents write 'from birth', or at least by 36 months onwards.

Questions 56-69 are asking for personal details including bank account.

Question 70 – Extra information

You can always add more information here but always relate it as evidence to a particular Question on the form.

Further information

Across the UK

NAS Autism Helpline

Tel: 0808 800 4104

Web: www.autism.org.uk

Cerebra

Tel: 0800 328 1159

Web: www.cerebra.org.uk

Useful UK contacts

Contact a Family

0808 808 3555

www.cafamily.org.uk

National Autistic Society

www.autism.org.uk/DLA

NAS Autism Helpline 0808 800 4104

Cerebra

www.cerebra.org.uk

Has excellent DLA Guide

Carers' Centres

0844 800 4361

www.carers.org

Scope

0808 800 3333

www.scope.org.uk

DLA and Child Tax Credit

Child Tax Credit is a payment for families with children. If you have children and a household income of less than a certain amount (check for an up-to-date figure) you may be eligible for Child Tax Credit. You do not have to be working in order to claim.

If you are eligible for Child Tax Credit and your child also receives DLA care, you should be receiving a disability or severe disability element as part of your Child Tax Credit calculation.

To ensure you get the correct Child Tax Credit calculation, call the Inland Revenue **Tax Credit Helpline** and tell them about your child's DLA,
0844 856 9912