

Guidelines on Disability Living Allowance for people with Williams Syndrome

Making a claim for benefits can be a confusing and dispiriting experience, especially when you already have so much to do without filling in lengthy, pedantic forms. Making a claim for Disability Living Allowance (“DLA”) for someone with Williams Syndrome (“WS”) can be particularly difficult because unlike Down’s Syndrome for example, most people have never heard of WS.

The fact that WS is not widely known, twinned with the vast spectrum of abilities and disabilities under WS mean applications, especially for the mobility component of DLA (“Mobility Component”) can have very varied outcomes. In the experience of the Foundation, WS applications for the care component of DLA (“Care Component”) are usually successful whilst some applicants have received Mobility Component at a higher rate yet some WS applications have been rejected altogether.

In this article I will attempt to clarify what is required for a DLA application specifically for a person with WS in the UK. (To keep things simple I will use “he” and “him” to refer to a person of either gender).

DLA-The Basics

There are 2 components of DLA- the Care Component (generally payable from age 3 months) and the Mobility Component (generally payable from age 3 years or 5 years depending on the circumstances).

An award for either can be made for a fixed or an indefinite period of time. An award of the two components will not be made for different fixed periods.

The awards are made on a weekly rate and if both the Care Component and the Mobility Component are awarded it will be the aggregate of the weekly rate of both.

There are various rules relating to age, residence and presence, which must be met.

For more information contact-
Disability Living Allowance Unit

Warbreck House
Warbreck Hill
Blackpool
Lancashire
FY2 0YE
Phone- 08457 123 456
Speech & hearing difficulties-Textphone 08457 224 433
Email- dcpu.customer-services@dwp.gsi.gov.uk
Website- http://www.dwp.gov.uk/lifeevent/benefits/dcs/contact_dcs.asp

The Care Component

To be entitled to this a person must be-

- A** So severely disabled mentally or physically that:-
- (i) he needs attention in relation to his bodily functions for a significant portion of the day;
- or**
- (ii) he cannot prepare a cooked main meal for himself if provided with ingredients (if 16 or over);
- or**
- B** So severely disabled mentally or physically that during daytime:-
- (i) he needs frequent attention in relation to his bodily functions throughout the day; **or**
 - (iii) he needs continual supervision throughout the day to avoid substantial danger to himself or others;
- or**
- C** So severely disabled mentally or physically that at night:-
- (i) he needs prolonged or repeated attention in relation to his bodily functions;
- or**
- (ii) he needs someone to be awake for a prolonged period or at frequent intervals for the purpose of watching over him in order to avoid substantial danger to himself or others.

If the person is **under 16**:-

- (i) his requirements as set out above must be substantially in excess of the normal requirements of someone (neuro-typical and physically able) of his age;
- or**

- (ii) he must have substantial requirements as set out above which younger people (ie neuro-typical and physically able children) would also have but not people (neuro-typical and physically able) of his age.

To be eligible for the Care Component the person must satisfy the above conditions for 3 months prior to the date of the award and must be likely to continue for another 6 months after that date.

There are 3 rates of the Care Component;-

Highest- if he meets requirements under B and C above

Middle- if he meets requirements under B or C

Lowest- in other cases

NB- Carer's Allowance

If you are making a Care Component claim for someone you look after you should also consider making a Carer's Allowance claim for yourself.

To be eligible to make a claim for Carer's Allowance-

- *you must be 16 or over*
- *you must live in Great Britain*
- *you must be looking after a disabled person for at least 35 hours a week*
- *the person you look after must get the middle or highest rate of the Care Component of DLA (or one of a number of other benefits).*
- *you must have an income that does not preclude eligibility*

For more information contact-

Carer's Allowance Unit

Palatine House

Lancaster Road

Preston PR1 1HB

Phone- 01253 856 123

Speech & hearing difficulties-Textphone 01772 899 489/ RNID Typetalk

Email- cau.customer-services@dwp.gsi.gov.uk

The Mobility Component

To be entitled to this a person must be:-

A Physically disabled so he is unable to walk or virtually unable to walk ie unable to walk or his ability to do so outside is so limited as to distance or speed or length of time or manner in which he can make progress by foot that he is virtually unable to walk;

or

B Blind and deaf plus other conditions (probably not relevant here);

or

C Severely mentally impaired, severe behavioural problems plus meeting the requirements under B and C of the Care Component above

- severe mental impairment - means he suffers from a state of arrested development or incomplete physical development of the brain resulting in severe impairment of intelligence and social functioning.

- severe behavioural problems - means disruptive behaviour which is extreme, regularly needs another person to intervene and physically restrain him in order to prevent him causing physical injury to himself or others or damage to property and is so unpredictable that he needs another person to be present watching over him when he is awake. This is generally the basis on which WS applications are made.

D Able to walk but so physically or mentally disabled that he cannot take advantage of his ability to walk outside without guidance or supervision from someone else most of the time.

This must not be because of fear or anxiety except where that is a symptom of mental disability and is so severe as to prevent him from taking advantage of his ability to walk in such circumstances.

If the person is **under 16:-**

- he must need substantially more guidance or supervision from someone else than mentally and physically able people his age would do; or
- mentally and physically able people his age must not need the guidance and supervision that he does.

To be eligible for the Mobility Component the person must satisfy the above conditions for 3 months prior to the date of the award and must be likely to continue for another 6 months after that date.

There are 2 rates of the Mobility Component;-

Higher- if he meets requirements under A, B or C above

Lower- in situations under D above.

NB- Blue Badge Application

If you look after someone with WS or are making a Mobility Component claim for someone you look after you should also consider making a Blue Badge Application.

A Blue Badge allows the vehicle in which a disabled person travels (but is not necessarily the driver) to park on disabled spaces and other special dispensations when parking. It sometimes exempts the vehicle from road tax and wheel clamping. If awarded the Blue Badge must not be abused.

A person is automatically eligible for a Blue Badge if they receive the higher rate of the Mobility Component of DLA (or meet one of various other criteria unlikely to be relevant here).

A person may qualify for a Blue Badge If he:-

- has a permanent and substantial disability ie he is unable to walk or has considerable difficulty in walking (or a temporary but substantial disability likely to last 12 months in Scotland);*

or

- is a driver with severe upper limb disabilities (probably not relevant here).*

Blue Badges are awarded to people over 2 years old (except in England and Scotland in the case of a child under 2 who has to be accompanied by bulky medical equipment)

Blue Badges are valid for 3 years and an application to renew should be made in good time (at least 4 weeks prior to expiry).

Local authorities award blue Badges and applications must be made on the correct form and accompanied by 2 signed passport photographs and the relevant fee.

A local authority decision to award a Blue badge, where the award is discretionary, will be made on the facts supplied in evidence by a person's doctor or other health professional on the medial form provided. The award depends on the person's ability to walk and no other issues will be taken into account.

For more information contact:-

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Zone 1/18
Great Minster House
76 Marsham Street
London SW1P 4DR*

Phone-0207 944 2914

Fax-0207 944 6102

Email- blue.badge@dft.gsi.gov.uk

Website- www.mobility-unit.dft.gov.uk

Form Filling

It is always a good idea to read application forms from start to finish before trying to fill them in. This gives you a chance to get together all the information you will need. It is also worth completing the forms in pencil first and working out what you are going to say for the detailed sections on another piece of paper before filling in the form itself. You may want to refer to this article so you can check the criteria that are being sought.

Lots of people agree that having to compile lists of the negative aspects of WS, personal details and worst-case scenarios can be a difficult and depressing exercise. Another off-putting factor is that many people think (wrongly) that you cannot make a claim for Mobility Component if a person can walk. If you are a new parent you may not feel that you have enough of a grasp on WS to make a comprehensive application, you may find it very upsetting when you are trying to stay up- beat about the challenges thrown up by WS or you may just find the forms a complete nightmare! Whatever your situation, the main thing to remember is that you are not alone. If it would help to chat through any of the issues raised here do not hesitate to contact the WSF on enquiries@williams-syndrome.org.uk