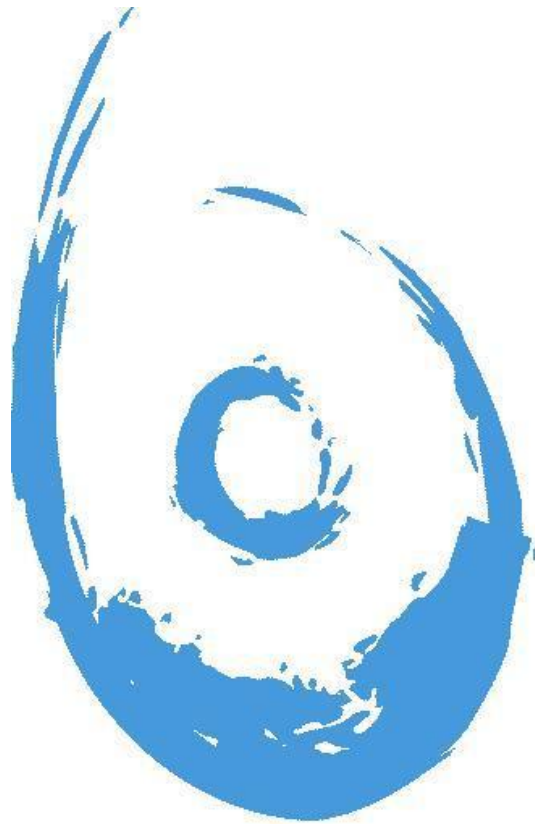


# **Inclusion Ireland**



**Inclusion Ireland Submission to the  
Domiciliary Care Allowance Review Group  
- September 2012**

## **Inclusion Ireland Submission to the Domiciliary Care Allowance Review Group**

### **Introduction:**

Inclusion Ireland is the national advocacy organisation for people with an intellectual disability. The Vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights as citizens to live the life of their choice to their fullest potential. Inclusion Ireland works to ensure that people with an intellectual disability have their voices heard, are not isolated or segregated and can lead more independent and healthier lives.

Inclusion Ireland provides a central forum for its members to identify priorities and formulate nationally agreed policies to present to government, statutory bodies, other relevant groups as well as the general public. Inclusion Ireland campaigns for changes in services and legislation that will improve the quality of life and participation of people with an intellectual disability in Irish Society. Inclusion Ireland also provides advocacy for people with a disability and their families.

The Minister of Social Protection, Joan Burton, T.D., has recently announced a review of the Domiciliary Care Allowance (DCA) scheme. A steering group has been established to review the scheme and report back to the Minister by the end of the year. This steering group will examine:

- the objectives of the scheme;
- how the application process operates;
- if any improvements can be made to make the scheme more user-friendly.

To enhance the review, the steering group has asked for submissions from interested individuals and groups that represent children with a disability. This document sets out the position of Inclusion Ireland.

### **Summary of observations**

- The application process itself is heavily based on the medical model of disability. This is not consistent with government policy. Parents are asked to explain how their child is so 'severely disabled'. Medical practitioners are asked to detail the applicant child's medical history including hospitalisation and surgery. Most people with a disability are very healthy, but do have additional care needs.

- The application and appeals process are lengthy and bureaucratic.
- The process itself and appeal if needed are not transparent enough. If an application for DCA is refused there needs to be a full report detailing what criteria was not met, the appeal process available and that the parent can avail of representation in appealing the decision.
- DCA is a cost of disability payment and should be recognised as such.

## **1. The objectives or purpose of this scheme**

The purpose of the scheme should be about acknowledging the extra care that a child with a disability requires in the home over and above other children their own age. Children with an intellectual disability can require a significant amount of additional care and investment (emotional, educational, therapeutic, financial, etc) to give them the greatest opportunity to live their lives on an equal basis with other children. Parents currently use the DCA payment to cover a range of additional costs in meeting the additional care needs of their child.

These expenses include:

- The cost of private interventions and assessments such as physiotherapy, speech and language therapy, occupational therapy, psychology, etc.
- Communication devices such as iPads or computers and associated software.
- Specialist therapeutic and educational toys.
- More frequent replacement of above aids.
- The additional cost of specialist social groups.
- The cost of replacing home wares due to challenging incidents or poor motor skills.
- The cost of any home adaptations. The current grant scheme is means tested and poorly funded.
- Cost of motor fuel to HSE appointments, schools, social groups and outings.
- Many children have special dietary requirements that incur extra expense including specialist foods, supplements and vitamins.
- Toileting is an issue for many children affected by disability. Additional costs include: additional nappies/pads (HSE supply is often insufficient), wipes, creams, constant laundering, bed protection and replacement.
- Cost of special buggies, rain wear for same and wheelchairs.
- Baby sitting/child minding is more expensive, often costing HSE care rates.

- Care needs often affect a parents ability to work outside the home (not all receive carers allowance)
- Additional costs with other children eg: sibling workshops/therapy, outings.

This list is not exhaustive but merely an indication of some of the expenses incurred on a regular basis by the families of people with an intellectual disability.

## **2. The application and assessment process**

To begin, the documentation is adversarial in nature, and takes a medical perspective on disability. The phrase 'severe disability' is used on three occasions in the information on DCA. In essence, the form is asking parents to write down information about their child that proves they are 'severely disabled'. This can be a traumatic task in itself. A parent should have to demonstrate the amount of additional care, attention and expense that they put into ensuring their child has the best chance of living as inclusive and fulfilling a life as possible, not how 'severely disabled' they are.

**Part 2 Question 18** should have at least a hint for a parent to answer. Why did you not apply on the date of additional care being recognised?

No formal diagnosis\_\_\_ or Waiting on assessment of need\_\_\_ or Did not know of DCA\_\_\_ , etc.

**Part 4** could mention the importance of this particular section. Here a parent needs to be as detailed as possible to successfully apply for DCA; this should be emphasised on the form or an accompanying booklet. Would it be beneficial if a parent kept a diary of care over a number of days to illustrate the level of care they administer? . In our experience parents find this section of the application daunting.

This section also includes a list of reports that can be included, and questions if the child is attending any particular therapeutic services. Many HSE areas do not have these services available; does the fact a child is not attending speech and language therapy count against them? It may even pressurise a parent to have a report commissioned privately, believing it may enhance their chance of being approved. Clarity is needed on the importance of additional assessments.

**Part 6**, the section for the GP to complete is heavily weighted to the medical model of disability. This is an outdated perspective of disability and is not consistent with current government policy. People who have been diagnosed with a disability are not sick and therefore, do not necessarily require medical intervention, surgical history, clinical findings or hospital admissions. Does a lack of historical illness count against a DCA application?

**Part 7, Question 9** is proposing that the GP is expert in the areas of psychology, speech and language therapy and occupational therapy in addition to general medicine. Ratings on mental health/behaviour and learning/intelligence should surely be completed by a psychologist with a recognised assessment tool to determine what level the child is at. In addition, behaviour relates to much more than mental health and learning and intelligence are two different concepts. Again, with the involvement of the GP the DCA application is delving further into the medical model of disability.

In essence, the ideal assessment tool for eligibility should be the assessment of need. This is however only available to children under 5 on a statutory basis. In the absence of an assessment of needs the application should take account of what ever reports and professional opinion are available (a parent should not be punished for a lack of service in their area) and also the parents own assessment of the additional care they provide. The opinion of the GP should not weigh heavily on the outcome as they are not expert in assessing mental health, behaviour, intelligence or learning.

### **3 How decisions are reached and communicated**

The application process is extremely lengthy. There should be an indication of the length of time the application will take. This reduces the anxiety of a prolonged waiting period.

Before refusing any application due to a lack of information, the DSP could contact the parent allowing them to forward this information, and then reconsider the application fully. If an application is refused, a detailed explanation should be furnished to parents (perhaps they forgot to include some vital information). This explanation should detail why the child does not fit the criteria of not having significant, additional care needs.

The appeals procedure should be made clear to a parent if their application is refused. This should include a timeline, and that they can have representation if they so wish.

To ensure transparency throughout the process the DSP needs to communicate with parents during the application process and if there is a refusal a detailed reasoning behind the decision.

#### **4 how individual cases are reviewed**

Reviews of any welfare payment are necessary, and should be conducted at reasonable intervals. A review should occur at two to three year intervals with the first review being at least three years after initial application. A review in most cases should be done as a matter of course, as therapeutic and educational interventions can have a substantial effect on a child's development and how their disability affects their daily living and care needs.

Any review should be conducted by a suitably qualified professional with expertise in the disability in question. There should be a review of the progress of the child via any reports that are available. However, services are patchy and not all children get regular reports from services. This should not place undue pressure on parents to commission expensive private reports. Obtaining reports from HSE staff familiar with the case could place additional pressure on the already over stretched services.

As stated before, the format to be user-friendly should keep the parents informed at all times. Why is the review being carried out, by whom, the procedure and what to expect? Communication is the key to allaying the fears of parents whose usual experience of review means a cutting of service.

#### **5 Should the rate of payment reflect the level of disability/care need of the child**

Ideally all supports that are in place for children and families should be based on the needs of the child in question. The process of defining the level of payment based upon the child's care needs would be fraught with difficulty, as there is presently great difficulty with determining eligibility let alone linking the degree of the disability to the level of payment. The payment should not graduate according age. Age is not one of the determinants of how severely a disability will affect any person. How a disability impacts upon an individual's life will improve with intervention, not age.

## **6 How the appeals process operates**

Firstly the applicant should be made aware of exactly why their application has failed. Many applications fail due to insufficient information on the form. A parent can only supply the DSP with the information required if they know exactly what is needed upon appeal. Perhaps additional reports are required, or the section on the care needs of the child was not comprehensive enough. Again, communication with the family is the key. Parents should be advised they can avail of advice in the form of an advocate if needed.

The appeal should be carried out as expediently as possible, but should also not be restrictive in time in a case where an additional report is required.

The appeals officer should be very familiar with disability, the care needs of people with a disability and how these needs affect the family. If a parent is dissatisfied they should have the option of input into the process by a suitably qualified professional with extensive experience of disability.

## **7 Suggestions for any changes to the operation of the scheme**

The process must move away from the medical model of disability to be consistent with DSP policy. Phrases such as 'a disability so severe' and 'lack of function of body or mind' could be stated in a much more positive manner. These phrases only serve to undermine the applicant. The input of the GP is also questionable considering there are probably reports from specialist therapists accompanying the application and that many individuals with a disability do not have medical needs or an extensive medical history.

The entire scheme needs to be completely transparent. The DSP should inform parents at what stage their application is at, is more information needed and if it was unsuccessful, for what reason. Any refusal must be detailed to allow the parent to collate the appropriate information needed for an appeal. The appeals process must also be completely open for parents with a full report detailing why an appeal was unsuccessful.

A lack of professional reports should not count against the application. If the reports are critical the process should be paused until the HSE furnish such reports. An application should not be simply refused or parents should not feel pressurised to obtain expensive private assessments. Inclusion Ireland calls for the DSP to state how important these reports are in an application for DCA.

The application form and accompanying literature must emphasise the importance of the section where a parent details the care needs of their child. A successful application can hinge on this information and its importance can not be stressed enough. Inclusion Ireland recommends that the DSP produce and easily understood, comprehensive guide to completing a DCA application. This is inline with the DSP customer charter “we will: provide you with full and clear information”.

At present the DCA is being reviewed in the context of inadequate data or knowledge within the DSP on the real cost of disability throughout the life course. Inclusion Ireland believes it is imperative, in the interests of equity that the Department works with others such as the NDA, people with disabilities, family members and advocacy groups to gain an understanding of the real cost of disability. This will enable the DSP to provide a full range of income supports on an equitable basis.



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