

Review Group on Domiciliary Care Allowance

Public Consultation

Submission from:

Individual

Parent/family of child with a disability Yes No

Other Yes No

Organisation

Disability organisation Yes No

Other NGO Yes No

Public body Yes No

Other Yes No

Name Special Needs Parents Association

Contact person Lorraine Dempsey Chairperson

Contact e-mail/phone no. info@specialneedsparents.ie /0877741917

Address

About your submission

Please make your submission under the headings below. If you do so, it is easier for the Review Group to analyse what the opinions and suggestions are. It is not necessary to make a submission under each heading if you do not wish to.

While the following are some suggested topics you may want to comment on, you are not confined to these.

Closing date for receipt of submissions is the 28th September 2012 and should be returned to:

Special Needs Parents Association

www.specialneedsparents.ie

CHY No. 19675

Roy Baldrick, secretary to the review group, DSP, St. Oliver Plunkett Rd.
Letterkenny, Co. Donegal.

Freedom of Information

You should be aware that the submissions will normally be available under Freedom of Information request.



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1. The objectives or purpose of this scheme

For example:

What is your opinion on what parents use the scheme for?

Do you feel the purpose of the scheme should be about acknowledging

- the degree of care and supervision required by the child relative to children in general
- the additional costs associated with having a child with a disability
- some other objectives?

Your submission:

1. Domiciliary Care Allowance is used to cover a multitude of **expenses/costs** incurred by a family unit, where a child has significant sensory, intellectual, medical, behavioural, physical or emotional disabilities.

1.1 Domiciliary Care Allowance is effectively a monthly payment to parents/guardians **to support families** where a child has a severe disability/condition. The scheme was originally established in recognition of the extra financial burden on families caring for a child with a disability/condition in their own home and is classed under EU Regulation 883/2004 as a Family Benefit and **not** an income support.

The report of the Commission of Inquiry on Mental Handicap (1965) stated "*some families need **financial assistance to cover the cost** of special food, medicines, of appliances required, the cost of excessive damage to bedding, etc. We recommend that health authorities should provide such **assistance for families** who suffer hardship in providing what is required from their own resources.*"

At the time of establishing the scheme in 1973, Minister for Health

Brendan Corish outlined the purpose and objectives of the DCA Scheme;

*"This is specifically designed to help parents of severely handicapped children under 16 years of age. Very often these have to be cared for at home at **considerable expense** to the parents".*

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1.2 Expenses incurred by parents can be substantial and varied depending on the individual needs of the child.

The list of examples is unlimited;

Housing Adaptations

House repairs due to damage caused by child

Equipment and therapeutic toys

Specialist clothing

Feeding/dribble bibs & specialist utensils,

Professionally recommended activities i.e. Hippo-therapy, swimming, social skills groups/outings

Special needs buggies/walking aids

Contenance care products

Private Therapeutic Interventions & Assessments

Therapy Dog maintenance (Vet bills & food)

Sibling support & counselling

Specialist childcare arrangements

Fuel, hospital accommodation & parking charges...etc.

2. The application and assessment process

For example

- How can this be made more user-friendly
- Should eligibility be assessed based on the child's diagnosis; the level of care and support needs; the additional costs for families; or other factors?
- What documentation/reports should support a claim
- What professionals should validate a claim
- Should assessments for other services be used to support a DCA claim

Your Submission:

2. Special Needs Parents Association is of the opinion that the application and assessment process can be made more user friendly by providing a more comprehensive guide to completing the application form for parents/guardians and reviewing the template of the application form itself and eligibility should continue to be based on the level of care and support needs which would generally have cost implications for the family unit as a whole.

2.1 Eligibility should not be based on the child's diagnosis, as children may be either awaiting diagnosis or diagnosis eludes healthcare professionals at that point in time. However, they may still require care well above the levels required for a child of a similar age. Parents are unsure as when to make the initial application as the legislation states child must have a severe disability and the presumption is that they require a diagnosis in order to apply for DCA. Parents report knowing from an early age the child has significant needs however, a long passage of time can lapse from the time parents seek referral for their child before it is actually confirmed that their child has a disability. This uncertainty has led to late applications and such a delay should not be viewed unfavourably by the Deciding Officer and Medical Assessor. Parent/Guardians may also make applications at a later date, due to not hearing or ever being told about the scheme or because financial circumstances have now changed and they can no longer absorb the added financial excesses of having a child with disabilities/conditions.

Eligibility should continue to be based on the level of care and support needs, which already incorporate a fiscal element in providing such a level of care as outlined in Section 1.2. However, there remains a level of ambiguity and subjectivity as to the measurement of "*continual or continuous care and attention substantially in excess of the care and attention normally required by a child of the same age*" (Social Welfare and Pensions Act 2008 Chapter 8A). This needs to be addressed and clarified in a more transparent and coherent manner by the Department taking into account, the personal impact of supporting a child with disabilities/conditions in the family home, which depends very much on access to external supports such as services, support from family members and the overall make-up of the family unit.

2.2 The Department has indicated that one of the predominant issues leading to a high rate of initial refusals on first application (circa 60% in 2011), is due to insufficient information being supplied by the applicant. A more comprehensive guide to completing the application form may rectify this and may possibly be used as a template for other social welfare entitlements that require medical and supplementary information to support application.

In general, GPs are not directly involved in assessing levels of disability and do not have any regular contact with children who are not ill as a result of their disability. Therefore where available, reports from professionals involved in assessing level of disability of the child should be used as 'medical' evidence and given due regard by Medical Assessors. The most comprehensive and common reports that parents/guardians may have in their possession are Assessment of Needs and Educational Psychological Reports. Neither may clearly identify a comprehensive picture of the level of care actually provided by parents/guardians in the home, as that is not entirely the purpose of such reports and the quality of some AON Reports is questionable and may not be substantial enough to meet the bar set by the current criteria for DCA despite reality in the home being very different.

Supplementary information by the parent/guardian is essential and should be given equal weighting by the Medical Assessors, as they are the individuals who provide for their children's needs and can more accurately reflect the level of care and incorporated costs.

Parents/guardians need to be facilitated in this process, by clearer guidelines and a more detailed format for self-assessment, such as assessment tools provided by Occupational Therapists. The current application form is limited in providing parents/guardians with a template to accurately describe the level of care that they provide and we would recommend that Part 4. of the application form contain a graded table of tick boxes from mild to profound (or other suitable spectrum) as is the case in Part 7, in areas of activities of daily living but in addition to existing sections, to also include behavioural, emotional, sensory and any mental health needs, as well as social skills and sleep.

A more holistic view needs to be taken on the impact of the child's disability/condition on the overall quality of life both of the child and of the family. It is therefore recommended that consideration be given to incorporating an impact of disability on family functioning in either GP Report (Part 6/7 on application form), Part 4 or by other professional reports.

Consideration should be given by the Department to drafting a supplementary information form that could be used in the application of other allowances such a Disability Allowance, Carers Allowance and any other Benefits/Allowances requiring supplementary information that would negate the need for inclusion of an often lengthy and over burdening diary.

2.3 Medical Assessors as it stands currently are qualified medical practitioners. Regular training by specialists in specific areas of disability are required to ensure that they remain up to date with the impact of behavioural, physical, emotional, sensory and intellectual disabilities on a child and their family.

A quality insurance mechanism/oversight of their decision making process is necessary to ensure that comparisons are not made between cases and the level of disability therein, but that every case is measured against a child of similar age without any disability/condition. Measurement tools must be robust and comprehensive for that purpose and the current use of Attainment Tables that do not cover up to and including sixteen years of age, are not robust enough.

3. How decisions are reached and communicated

For example

- What ways can communication with parents be improved
- How can the basis for decisions be made more transparent
- How can decisions be better communicated
- What level of detail should be included in communicating a decision

Your Submission:

3.1 Special Needs Parents Association welcomes the text confirmation service available from the Department confirming receipt of application. It is also welcome, that from earlier this year parents will be informed of a review date entered by Medical Assessor under section of Medical Officers opinion. A more comprehensive set of guidelines on filling out the application form, review and appeals process would aid parents in initial stages of application. The Department may consider an automated information line that lists out details of completing the application form and what supplementary information would be of benefit. This could be adapted for all other welfare entitlements and promote accessibility for those who are visually impaired.

3.2 It is requested that explanation on reason for refusal needs to be more clearly communicated. Currently refusals are been communicated to suggest the child involved does not require any more care and attention than a child of similar age, whilst recognising that they may require 'some level of care'. Again, this raises the issue of the subjectivity of what is the level of care actually given, where the experience of a Medical Assessor reading reports can be very two dimensional by comparison with the real life experiences of parent/guardian making the application for such a supportive payment as is DCA. Interestingly, the Social Welfare Appeals Office gives consideration to multiple factors including "Impact on family" and "school", which are areas that may not be considered as evidence by the Medical Assessors.

3.3 If further clarification is needed on a specific area or topic or report, this should be sought by the medical officer prior to giving an opinion to the Deciding Officer. This practice may in turn reduce the need for appeals or possible refusal due to lack of evidence.

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3.4 While we appreciate the high volume of applications that are processed by the Medical Assessors and Deciding Officers, a more detailed reply to applicants who are refused is required, which clearly outlines what the reasons are for refusal. The Medical Assessors may have some input on how those additional possible options can be incorporated in to the current system. A statement from the Deciding Officer is normally required by the Social Welfare Appeals Office should an application be refused. This statement should automatically be disclosed to the unsuccessful applicant, rather than the applicant having to obtain such a statement under the Freedom of Information Act 1997.



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4. How individual cases are reviewed

For example

- How often should cases be reviewed
- What should trigger a review
- When should cases be marked 'do not review again'
- What should be the format of the review process
- How can the review process be made more user-friendly
- What documentation/reports should support a review
- What qualifications should those conducting reviews have

Your Submission:

4. It is recognised by the Special Needs Parents Association, that all social welfare payments should be subject to a review, to ensure that the payments are allocated to those who continue to meet the qualifying criteria and it is welcomed that the Department took measures earlier this year to ensure that recipients would be informed of their case review date on receipt of DCA being awarded.

4.1 A review should be triggered by the date applied by the Medical Assessor only.

4.2 Cases should have a DNR Status if the child has a condition of a degenerative nature or where the level of impairment is unlikely to change as the child grows older.

Only cases where the condition is of a temporary nature and likely to respond well to medical interventions should be considered for a 12 month review date. This would not apply to the majority of diagnosed disabilities, but pertain more to certain medical conditions or trauma.

Other than the above exceptions, nothing less than a minimum three year review date would be recommended, as many of the professional reports remain valid for a 2-3 year period and parents should not be subjected to undue financial hardship by the Department requiring up to date reports from Healthcare professionals for the sole purpose of maintaining the DCA payment.

4.3 DCA recipients should be notified at least six months in advance of their review date in order to be given ample time to prepare any documentation/reports required and a reminder, one month prior to review date. Reminders can be by mail or via existing text service.

4.4 Where the parent states that a child's circumstances remain unchanged, and this is supported by either General practitioner or therapist by way of letter, a full professional assessment should not be called for, as this places undue pressure on HSE and service providers resources when a parent/guardian seeks an assessment and subsequent report, purely for the purposes of maintaining a welfare entitlement. For children of school going age, a letter from Principal/Teacher should be accepted as outlining the level of support required in school.

4.5 Any medical documentation supporting a recipients DCA review, should be examined by a Medical Assessor. Should the Medical Assessor deem that the information supplied is insufficient, this should trigger a request from the recipient for further information, prior to the Medical Assessor informing the Deciding Officer of their decision. Deciding Officers role in the decision making process of both initial application and review, should be confined to establishing if the applicant meets the criteria for habitual residency and age as set out in the legislation and they should not under any circumstances override the opinion of the Medical Assessor.

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

For example

- If you think there should be different rates, on what basis
- Should the rate of payment be related to degree of disability
- Should the rate of payment be related to degree of care required
- Should there be different rates at different ages?
- Should the payment be phased differently over the year?

Your submission:

The Special Needs Parents Association is of the opinion that the rate of payment should not be graded according to degree of disability, degree of care or age of the child.

The multifaceted nature of how a disability/condition and the resulting effects on an individual child, is not dependent on the age of the child, nor necessarily the degree of disability.

Quantifying degrees of care and setting thresholds, given the broad spectrum of disabilities and combinations of same, would be open to challenges on the basis of subjectivity on the part of the Assessor. For example, providing a lower degree of care without external or family supports can be as challenging to a parent as providing a higher degree of care with external and family supports.

Given the variation in expenses/costs incurred by parents in supporting their child with a disability/condition, phased payments at different times of the year, would reduce the ability of the parent to meet the individual needs of their child.

6. How the appeals process operates

For example:

- How can the appeals process be made more user-friendly
- What should be the timeframe for appeals
- Where should appeals take place
- What documentation should be required to support an appeal?

Your Submission:

6.1 There is much confusion as to the different pathways that an applicant can take should they be refused on initial application. Prior to refusal, it would be beneficial if the Medical Assessor triggered a request for further evidence to support a claim, thus potentially reducing the number of initial refusals sent out by the Deciding Officer, which in turn would reduce the numbers who request a review and appeal an unsuccessful decision thereafter.

The reason for refusal should be more clearly detailed to the applicant, including the full decision statement by the Deciding Officer, so that they can be better informed as to why the application was rejected. The existing Departments/Citizen's Information Leaflets on the Appeals Process should be sent out to all unsuccessful applicants, or a link to the relevant information included on the refusal letter.

6.2 The timeframe for appeals is currently dictated by the marked increase in the numbers of appeals in the system. Currently, unsuccessful applicants have a 21 day time frame to appeal the decision of a Deciding Officer. Any late appeals after that time period has elapsed may be accepted by the Chief Appeals Officer where valid reasons for late appeal are provided. Prior to an Appeals Officer reviewing an unsuccessful application, a Deciding Officer reviews the cases as does a different Medical Assessor than the one who made the initial decision. Should the decision not be revised in favour of the applicant, the request for an appeal is passed to the Social Welfare Appeals Office. In effect, were the applicant to be contacted prior to the initial refusal being made and a request for further supporting documentation been made at that early stage, there would be fewer requests for reviews and appeals.

Ideally, appeals should be no longer than a three month waiting time for a decision to be made. Currently the waiting times for a decision can be over a year, which causes difficulty for families where they have lost a DCA payment and have appealed the decision. Regardless of whether back payments are made should the appeal be successful, it does not make it any easier on families for the duration of the lengthy appeals process.

In order to achieve shorter waiting times for both DCA and other welfare related appeals, the Department must give consideration to re-designating staff from other areas from within the Department or other government agencies and retrain them to the standard required to carry out the roll of an Appeals Officer.

Parents/guardians should always be afforded the option to have someone accompany them to the appeal hearing.

6.3 In order to minimise the cost's associated with having appeals in a hotel, where possible, arrangements should be made to have appeals in existing government owned properties such as HSE centres or Social welfare centres, providing that there are adequate facilities at their disposal. Under exceptional circumstances and only where the case has been made, a parent/guardian should be able to request an oral hearing to take place in the family home.

6.4 Currently, parents who feel that they have provided all available reports with the initial application, resort to preparing lengthy diaries of their child's daily activities and care needs for the Appeals Officers. This is very time consuming for parents to draft up and for the Appeals Officers to examine. Again, guidelines provided by the Department on what type of information should be included would address this.

7. Suggestions for any changes to the operation of the scheme

- Give any other changes you would suggest to the scheme, and why

Your Submission:

Desk Assessment is a welcome recommendation from the Expert Group. The children subject of DCA applications have invariably through a number of assessments by various disciplines so to require them to be reassessed for DCA would be unfair to the child. However, considering the amount of assessments that may already have been carried out on such children it is difficult to understand how a medical assessor can form an opinion, that, contrary to reports furnished by relevant professionals familiar to the child stating otherwise, that the child does not meet the requirements of the scheme. While some parents would welcome a face to face assessment, it may not necessarily be in the child's best interests to subject them to an assessment that does not have any resulting therapeutic benefits.

There is cause for concern that Medical Assessors may be making comparisons between levels of disability demonstrated between different applications as opposed to making a comparison between the levels of disability compared to a typical child of similar age and that some disabilities are automatically granted DCA.

"Domiciliary Care Allowance is not awarded primarily on the basis of an impairment or disease, but on the resulting lack of function of body or mind necessitating a degree of extra care and attention required."

The Special Needs Parents Association has been very critical of the two tiered use of ICD10 codes which were developed into 'More likely/less likely' categories.

On the issue of Codes and Categories it is stated in the Medical Eligibility Guidelines for Domiciliary Care Allowance-Report of the Export Medical Group (2008) that, *"It was agreed by the Group that in order to ensure clarity and consistency in decisions codes and categories would be used"*. It is questionable as to how the use of codes and categories would ensure clarity and consistency in decisions considering DCA is not awarded

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according to diagnosis. Codes and categories may be useful in data collection just as the use of the multi axial diagnostic classification system may be too, in case of mental illness.

It is further stated in the report, *"It is important that codes, where available, are applied to the stock of claims which will be transferred from the Health service Executive. These codes will inform the review policy for these claims."* Again the use of codes can be helpful in gathering data but the suggestion that codes would inform review policy of claims is seriously worrying. Again DCA is not awarded on diagnosis so a system where awarding of DCA is suggested by condition or impairment more or less likely to require care and attention or condition or impairment denoted by addition of code to file being used to inform review policy firstly contradicts views expressed by The Expert Group themselves.

Any use of the ICD10 codes must be restricted to the development of statistical information only and the use of the two tiered categories should cease.

Currently, a parent/guardian needs to be in receipt of Domiciliary Care Allowance in order to qualify for Carers Allowance. While outside of the remit of the DCA Steering Group, we would recommend that the legislation regarding Carers Allowance be reviewed by the Department of Social protection and DCA be decoupled as a pre-requisite to applying for a Carers Allowance payment. According to the Departments own figures, circa 40% of DCA recipients are also in receipt of Carers Allowance. When a parent/guardian loses the DCA payment following a review, Carers Allowance, Respite Grant and Household Benefits package are also immediately terminated. Where families are dependent on the income support of the Carers Allowance due to one of the parents being unable to be available for gainful employment as a result of caring for a child with disabilities and significant needs, regardless of the Departments decision to withdraw DCA, the parent/guardian may continue to be in a position where they are unavailable for work.