

Domiciliary Care Allowance Review

**Report on consultation undertaken for review of the
allowance**

21st December 2012

Final

TABLE OF CONTENTS

	PAGE
1. Introduction and overview on consultation	3
2. Summary of submissions received	4
3. Customer Survey	11
4. Consultation Seminars	12
<i>4.1. Parent consultation seminar.</i>	
<i>4.2. Consultation with disability organisations/support professionals.</i>	
5. Summary of main issues raised in consultation	19
 APPENDICES	 20
I List of submissions from Groups	
II List of submissions from individuals	
III Survey questionnaire and copy of letters issued to parents	

Chapter 1: Introduction and overview on consultation

As part of the review of the Domiciliary Care Allowance (DCA) scheme a consultation process was undertaken in the autumn of 2012. In keeping with the spirit and intention set out in the terms of reference, the working group undertook an extensive consultation process to facilitate those people who wished to contribute to and participate in the review of the DCA scheme. The consultation was undertaken in three phases:

Firstly, advertisements were placed in national papers in August seeking submissions from interested groups or individuals. At the same time, the Department wrote to all parents of children who were in receipt of the DCA informing them of the review process and inviting them to make submissions outlining their views on a number of suggested areas, including the objective of the scheme, application and assessment process, communications, reviews and appeals processes.

Secondly, a customer survey was undertaken, with questionnaires issued to 1,000 parents chosen at random. In preparation for this survey, the Department sought the advice of the National Disability Authority in relation to the questions to be asked and also involved the Statistics unit of the Department to assist in selecting the random sample to be surveyed. This ensured that the questions were targeted and that the survey sample, while randomly chosen, was representative of customers awarded since the Department took over responsibility for the scheme and also those awarded prior to 2009 by the Health Service Executive (HSE).

Thirdly, having analysed the submissions and survey data, two consultation sessions were organised as follows: One with parents and the second with advocacy groups/professionals working in the area to validate and further consult on the issues emerging. These consultation sessions were facilitated by National Disability Authority personnel, with the session involving parents held in the Pensions Office in Sligo and the second session held in the National Disability Authority premises in Dublin.

Chapter 2: Summary of submissions received

Following advertisement and the issue of a letter to each DCA recipient, a total of 323 submissions were received - 272 from individuals and 51 from groups/organisations. In inviting submissions, a number of headings were suggested under which people were asked to comment. The following is a summary of the issues raised, set out under the discussion headings used in the consultation process.

(a) The objectives or purpose of the scheme:

The main view expressed was that the allowance reflects the additional costs associated with the child's disability (196 submissions). On a similar theme, (68) of the submissions stated that the scheme should reflect the extra care given to a disabled child as opposed to another child without a disability. (41) submissions stated that the DCA is used to cover a multitude of expenses and costs associated with the care needs of the children.

Details from the remaining submissions on this point included the following: *[the number of submissions on the relevant point indicated in brackets]*

- DCA is NOT an income support such as Carer's Allowance - it is a family benefit, a universal payment similar to Children's Allowance (10).
- DCA recognises the extra care provided/contribution parents make in helping their children reach their full potential (9).
- DCA is an essential payment to families where the expenditure to meet the needs of the child far outstrips that required for a child without a disability/medical condition (7).
- Prescribing what the payment can be used for would restrict the benefit of the payment in meeting the child's individual needs and that of the family as a whole (2).
- The concept of what constitutes continuous care needs to be reconsidered (1).
- It is a cost of disability payment and should be titled as such (1).

(b) The application and assessment process:

The main views expressed included, that the application and review forms are biased towards physical disabilities and as such are not fit for purpose, needing to be amended to allow detail of non-physical disabilities to be documented. The application form needs to address social, socio-economic, behavioural, emotional, sensory and mental health issues (54 submissions).

Provision of clear guidance on the reports that should be submitted at claim and review stage was also highlighted as was the need to have a clear guide on how to complete the form (20 submissions).

Views were expressed that eligibility should be assessed based on:

- the level of extra care and costs (69); and
- the diagnosis and extra costs (55).

Submissions noted that applications should be supported by reports from GP's and Consultants/Specialists (132 submissions), with a further significant number saying they should be supported by assessment from other experts/professionals (65 submissions). It was considered that GP's may not be the most suitable professionals to complete the form as they may have limited contact with the child (25 submissions). The opinion that a report from the child's school describing the child's development and capabilities should be accepted as evidence was advanced (45 submissions).

Details from the remaining submissions on this point included the following:

- MA should have extensive expertise in the disability in question (32).
- GP's may not be best placed to complete the form - use other relevant professionals. Amend form to allow this (25).
- If a Medical Assessor (MA) is unsure of a claim, rather than refuse the allowance, he/she should contact the parent/professionals/therapists working with the child in question to gather the information required. This would reduce waiting times, paperwork and the need for a second review (11).
- Have status updates on applications available on-line - text a reference number when claim has been received (9).
- Share information between public bodies - eliminate the need for parents to get the same reports twice (9).
- Timely and courteous service with direct access to DCA staff (8).
- The professional opinions of experts provided in reports submitted should be given more serious consideration by the Deciding Officer (DO) in association with the opinion of the MA (8).
- The use of the term "mental retardation" is outdated and insensitive (8).

- The words “substantially in excess” and “severe” are subjective and should not be used in Guidelines. Also the words “continuous or continual” need to be more clearly defined (8).
- “More likely and less likely” guidelines are not fair (6).
- No problems with the application or assessment process (5).
- Department should be pro-active in informing parents of disabled children (4).
- The current levels of attainment contained in the Medical Eligibility Guidelines for DCA are outdated and unsuitable for purpose. Only covering to age 4 years (4).
- Papers supplied for DCA should also be used for Carer’s (1).
- Have an additional section on the claim form to be completed for ASD children (1).

What documentation/professional validation assessments should be used?

- The MA should have training/qualifications in the area of disability affecting the child (25).
- Diagnosis of a disability by a consultant/disability organisation should deem the child eligible (16).
- The MA assessment should be conducted by a panel of professionals qualified in different aspects of disability (12).
- Some disabilities should get a “straight through” passage to award (11).

(c) *How decisions are reached and communicated:*

The amount of detail provided on the reasons for disallowance was instanced in (104 submissions), with a suggestion that a checklist of what is passed and what is failed in the individual assessment should be included. At present, parents are only informed that in the view of the deciding officer their child does not require substantially more care and attention than a child of the same age without the disability. (49) submissions sought to have parents advised on the time required to make a decision, while a further (23) submissions suggested the Department make more use of e-mail to communicate with parents.

Details from the remaining submissions on this point included the following:

- Someone should be available to explain the rejection reason (23).
- Decision in a timely manner (12).
- Provide full details of the review/appeals process and critical dates (8).

- Each case should be assigned to case worker (5).
- When giving their opinion each MA should complete a detailed form indicating how his/her decision was reached (5).
- On-line tracking of where a claim is (4).
- The DO should complete a detailed form outlining their decision (3).

(d) How individual cases are reviewed:

There is a general acceptance that there will be a review policy on the DCA scheme, views on the frequency of reviews ranged from every 3 to 5 years (24 submissions) to every year (19 submissions), with a further (20 submissions) stating that it should depend on the type of disability. A large number of submissions (143 submissions) stated that children suffering from certain types of disability should never have their case reviewed.

Details from the remaining submissions on this point included the following:

How often should claims be reviewed and for what reason?

- All cases should be reviewed every 2 years (15).
- 2 yearly reviews as norm but disabilities that will not improve should be 5 yearly (2).
- Never review (9).

Format for review process:

- Medical personnel involved in the child's care should contribute to the review (16).
- Review should consist of an interview with family (9).
- There should be a more detailed review form asking specific questions about improvements and designed to map the child's improvements against the milestones of typically developing children of the same age (4).
- Review after 60 months - payment should continue until appeal heard (1).
- Parents who have been successful at appeal should not be reviewed for 10 years (1).
- 3 successful reviews = Do not review (DNR) again (1).
- Review only at age 16 years (1).

Documentation:

- A consultant's report should suffice to satisfy a review (29).

- Review should be based on a report by a consultant/specialist (14).
- All necessary/available papers should be provided (13).

Qualifications of reviewers:

- MA's reviewing cases should be qualified in the area of disability under consideration (38).
- The MA's setting review dates and undertaking review should have particular experience, expertise and knowledge of that disability (7).

Other comments:

- If the condition is permanent or degenerative - DNR again (22).
- Reviews are necessary but should be at reasonable intervals and based on the prognosis (10).
- Provide sufficient notice to allow parents to prepare their case properly (7).
- Review at primary and then secondary school age (4).
- Review temporary condition cases yearly, other cases, excluding DNR, every 3 years. (3).
- Improvements noticed at review could be due to the therapies paid for by the DCA, if DCA is lost and therapies stopped there will be a regression (3).
- Reviews should be carried out by an independent panel (3).
- Give to all children with Autism and review at set ages, e.g., 6 or 10 years old (2).

(e) *Should the rate of payment reflect the level of disability/care need of the child?*

(73 submissions) considered that the rate of payment should reflect the care needs resulting from the condition, with a further (28) saying that it should reflect the age of the child as costs rise with age. It should be noted that (88 submissions) recommended that the same rate should be paid to all recipients.

Details from the remaining submissions on this point included the following:

- The rate of payment should be individualised/reflect the level of care needed (11).
- Means test the allowance (10).
- Should reflect the actual costs incurred in the care of the child (4).
- Impossible/difficult to operate different rates (4).
- Basic level of DCA for all and a top up for exceptional/severe/deserving cases (3).
- Any changes to the rate of payment should reflect the reality of service provision (2).
- Three tiered approach looking at medical, physical and intellectual capacity with payment reflecting the level of care required due to each (2).
- DCA would not be needed if proper services for children with disabilities were available (1).

(f) *How the appeals process operates:*

Delays in the appeal process were highlighted as an issue, with (50 submissions) saying the process should take less than 8 weeks and a further (31) saying it should take less than 16 weeks. The transparency of the appeal process was instanced in (33) submissions, with (21) saying that details of the process should be published on the website.

More detail from the remaining submissions is set out as follows:

- Some claimants do not understand the appeals process - provide more information (14).
- If the current application and medical assessment processes were amended the number of files being sent to appeal would dramatically decrease (10).
- Give plenty of notice of an oral hearing (10).
- An advocate should attend if desired by the appellant (10).
- Any relevant reports or professional opinions should be made available to the Appeals Officer (AO). Contact parents to advise what to submit (7).
- AOs should meet with the child and their advocates (6).

- Consult with other professionals/support groups as part of the appeal process (6).
- Advise applicants what they are expected to provide in support of their appeal (5).
- AOs should have knowledge of the conditions being assessed (5).
- Look for further information before disallowing a claim, i.e. prior to a decision issuing (4).
- Email and on-line submissions to AOs (3).

Timeframe for Appeals:

- Appeals process should take less than 8 weeks (50).
- Appeals process should take less than 16 weeks (31).

Location of Appeals:

- Appeals should be close to the family's home location (21).
- Appeals should take place in the child's home (11).

Documentation:

- All necessary documentation should be provided by parents in support of appeal (49).
- Give up to 6 months to make an appeal and not 21 days (8).

Chapter 3: Customer Survey

Survey forms issued to 1,000 parents representing a randomly selected sample of DCA recipients. 512 replies were received by the closing date. 65% of respondents had been awarded DCA by the HSE. This accurately reflects the % of recipients currently in payment who had their claim awarded prior to April 2009. The average family size of those parents who responded was between 2 and 3 children. It should be noted that 450 families of the 512 respondents are getting DCA for 1 child; 50 for 2 children; 9 for 3 and 1 family had 4 children in receipt of DCA.

The following is a summary of the information provided by the survey;

- 94% felt DCA should be paid to 18 years.
- 77% felt that all ages should get the same rate of payment.
- 71% expressed their satisfaction with current medical assessment. (73% of DSP awarded customers were satisfied with medical assessment).
- 67% felt that the same rate of payment should be made, irrespective of the level of disability or care need.
- 65% people said their support needs were fully or mainly met by service providers.
- 64% of children are getting regular services from service provider.
- 61% of children in mainstream education; 29% in “special education”.
- Over 60% of respondents use the RCG for family holidays or day to day expenses.
- 55% of people pay for services privately.
- 55% of the survey respondents are in receipt of carer’s allowance in addition to DCA. (Overall, 46% of DCA recipients are also in receipt of CA).
- 50% thought the child should be seen by the MA as part of the application process.
- 60% use the respite care grant for family holidays/household expenses.
- 50% of people use respite care at some point each year.
- On improving communications, 40% considered that more information on reasons for disallowance should be given. More information on the process/appeals was an issue for 37% and a quicker process overall was raised by 23%.
- 34% felt that delays are the biggest concern with appeals.
- 26% of households were lone parent households - double the national average.
- 20% of respondents had been through the appeals process, with 63% of them stating that they were satisfied with the process.

Chapter 4: Consultation Seminars

To complement the consultation undertaken through the requests for submissions and the customer survey, the National Disability Authority facilitated two consultation sessions. One session with parents, which was held in Sligo on 5th November 2012 and one with a group of disability organisations and relevant support professions, which was held in Dublin on 7th November 2012. The following sets out the feedback received in these sessions.

4.1 Parent consultation seminar

Invitations were issued to 16 parents, of whom 9 attended. The meeting opened with a presentation giving an overview of the DCA scheme, the review process, outlining the progress to date, the issues being considered and provided an overview of the survey that issued to a sample group of DCA recipients. Parents attending were asked for their views and experience of the scheme particularly in relation to the following areas:

- the application form and application process;
- the medical assessment process;
- the appeals system and the communications issuing from the Department.

The following are the main points that arose from the discussion.

Impact of disability of the family:

- Unable to give appropriate time to their other children.
- No time to work or had to give up their work.
- Considerable amount of time spent taking their child to and from services/therapies.
- Trouble getting babysitters and child minders.
- Unable to leave child on their own in a room.
- Child can be more manageable at different times of year e.g. summer compared to winter.
- Every child with a disability requires extra care and money.
- DCA is not a substantial amount of money but a help.
- They feel the Department is only trying to save money by rejecting half of the applications.
- DCA is a gateway to Carer's Allowance enabling parent stay at home.

What the DCA money is used for:

- Additional costs in other areas of life.
- Only one salary – does not qualify for CA on means grounds – no margin for extras.
- Meeting extra costs of disability.
- Paying to go privately as long queue to get child's hearing seen to.
- Petrol for travel to multiple appointments.
- Paid to get learning support in school when child not eligible for same.
- Home support worker removed – now pay person privately to babysit.
- Skilled babysitter needed – not teenagers next door.
- Family not available to babysit child with disability, so needs to pay for this care.
- Buy stronger glasses frames than those supplied and extra hearing aids to keep as spares.

Application form and process:

- The current application form is difficult to complete, particularly for people with lower levels of literacy.
- Application is orientated towards physical disability.
- Parents sometimes feel embarrassment about the diagnosis.
- Problems expressing the care required in writing.
- Department should update customers weekly with status of their claim.
- They only hear about the suggestion of keeping a “daily diary” at the appeals stage.
- They feel Department is naïve about how much time a child with a disability requires.

Medical Assessment Process:

- Why does the MA question the Consultants reports?
- MAs should contact Consultants directly for further information.

Appeals process:

- 8 months waiting for oral hearing.

Communications:

- Not happy with decision letter - insufficient reasons for disallowance given.
- Can parents be sent a text to inform them of progress on application (e.g. where they are in a queue)?

Revised Claim Form:

An overview of the proposed revised DCA application form was given. The following points were raised:

- If the parent has a disability it should be taken into consideration.
- Not happy with word suicidal and would prefer other words to be used.
- Felt this new form would be a help for applicants.

Last contributions from the floor:

- Felt customers can be a victim of their success at a review. Their child has improved due to the therapies provided, but this results in DCA being stopped, so the services that helped to improve their child will be no longer be affordable.
- Because of the pressure some people are under, they do not have the time or the energy to be looking for reviews or appeals.
- Partial payments would be a benefit as anything extra they can get for their child is a help.
- The proposed changes to the application form will be an improvement.
- Decision letter has insufficient information regarding reasons.
- Happy to help and available for further surveys.
- Appreciate the opportunity and a real eye opener.

4.2 Consultation with disability organisations/support professionals.

This was held in National Disability Authority headquarters Dublin on 7th November 2012. A representative sample of ten groups and representatives of organisations were invited, with eight attending. The results of the parent survey were reported and a presentation on the medical assessment process for DCA was given by one of the Department's MA. This led to a wide ranging discussion on the issues that groups/professionals working in the area are coming across. These included the following listed below:

What is the allowance spent on:

- Paying HSE rates for babysitter for child with autism.
- Meeting costs of disability.
- Travelling to support groups.
- Promoting child's social inclusion.

Why numbers have gone up:

- Was DCA previously focused predominantly on physical not sensory disability?
- DCA numbers may have gone up because more people know about it.
- Children with disabilities are now living longer.
- When Cystic Fibrosis association does promotional activity they get more people inquiring about DCA.
- Parents with Enable Ireland do not have cash supports on their mind when they first get a diagnosis.

Eligibility:

- Are goal posts in the wrong place – historical carry over.
- Acknowledge that some areas of HSE granted DCA to a high percentage of applicants – this has now changed under the Department.
- Substantial care need goes beyond just medical area.
- Clarity needed about what does “substantial” and ‘care’ mean.

The overall process:

- Too many applicants turned down at first attempt. Social workers spending time assisting people with appeals.
- Get the process right first time -saves duplication of effort with appeals.

Application form:

- Have a user-friendly application form for non-national parents, in multiple languages.
- Current form is geared to parents with higher levels of literacy.

- Child may have high needs but parents who are not articulate may not convey that on the application form.
- Emotionally draining for parents to say how disabled the child is.
- Should cost of disability be captured on the form?
- Be more prescriptive on information being sought.
- Provide guidelines for multi-disciplinary teams about what information to give.
- Move information on getting help from Citizens Information Board to fill out form further up, towards the start of the form.
- New proposed form an improvement. Agree with rephrasing ‘suicidal’ – possible term ‘self-harm’.

Assessment:

- Is moderate intellectual disability not regarded as a ‘severe disability’?
- What weight is given to the parent’s part of the form?

Expert reports:

- Parents with autism can feel excluded because of cost of getting therapy reports.
- Expert reports may be needless – unless information there is relevant to ‘substantial care and attention’.
- One good report would save trouble.
- Reports from the school would be helpful for school-age children.
- Does attending a disability service such as Enable Ireland add to the likelihood of qualifying?

Multi-disciplinary input:

- Someone knowledgeable should be able to interpret therapy reports.
- Statutory Assessment of Need forms focus on strengths and goals, not on deficits, but deficit-related reports may be better in enabling people qualify for DCA.
- Multi-disciplinary reports from Daughters of Charity services are focused on future of child, not on deficits.
- Cannot ask busy multi-disciplinary team for another assessment.
- Should initial decision just be taken by medics?

- Have a mixture of doctors, multi-disciplinary professionals.
- Multi-disciplinary professionals to provide training for medical assessors in conducting assessments.

Standard assessments:

- Are there cases where assessments are inconsistent?
- Standard assessment tools would help.
- US Association of Child Neurologists has done a comparison of autism assessment tools.
- Medical assessors should review cases together if they are in doubt.

Social factors:

- Build in socio-economic and domestic circumstances at original stage.
- Are Medical Assessors sensitive to social aspects of care?
- Combined medical and social assessment.
- Are there situations where mild clinical need gives rise to substantial care needs?
- Should social circumstances be taken into account, e.g. being a lone parent?
- There could be two children with same clinical need but care need is higher in one family, e.g. lone parent.
- Hydrocephalus shunt – parent must get child into hospital within four hours if shunt comes out – parent gives up work.

Appeal process:

- Some appeals officers will not allow child attend the appeal – parent had no-one else to mind the child. Although bringing a child to the appeal is of no value if the child has a hidden condition.
- Parent reports of difficult meetings with appeals officers – e.g. reacted negatively to her child being there, appeals officer had not read the case.
- If appeals officer does not like you, does that affect the result of an appeal?
- Sense that refusal rate has gone up (Department says figures don't bear that out).
- Writing a daily diary leads to more success at appeal.
- Should appeals officer have medical qualifications?

- Successful appeals often relate to wider social circumstances.
- Assess trends in who gets DCA on appeal e.g. are there specific conditions that are more successful on appeal?

Communication:

- Old HSE system allowed for contact between social worker and medical officer – now no avenue of communication.
- Can social workers be allowed advocate on behalf of severe cases that have been refused.
- There should be more engagement with applicant and their advocate.
- Deciding officers should be given more detailed feedback from MA to be able to better communicate reasons for decision in any letters of refusal.

Issues around the DCA survey:

- Query whether younger parents knew extending age of DCA to 18 years would mean loss of Disability Allowance (DA). Survey question did not specifically mention trade-off of loss of DA.
- Tiered payments may be a good idea, but get current process right first.

Purpose of scheme:

- Meet costs of disability.

Other schemes:

- DA age raised to 18 would have implications for loss of secondary benefits.
- DCA eligibility should be sufficient to qualify for incapacitated child tax allowance.
- Dietary allowance form says if someone has cystic fibrosis they do not need to fill a form - but this is ignored by officials.

Chapter 5: Summary of main issues raised in consultation

The consultation feedback confirms that the main issues are those that had been highlighted in representations to the Department over the past year. These range from the purpose of the scheme and how the rules relating to qualification are set out and made known to parents to specific issues relating to process.

Based on the feedback there is need to clarify the purpose of the scheme. There appears to be a consensus that it differs from the Carer's Allowance and agreement that it is used to cover the additional cost associated with caring for a child with additional care needs. Defining the scheme and clarifying the qualifying conditions will be important in addressing the concerns of parents.

The main process issues emerging include the following:

- The application process.
- The medical assessment process.
- The review process and the frequency of reviews.
- Communications and the need to provide parents with as much information as possible on the reason for refusal of the allowance.
- The appeals system, including issues relating to delays.

Work undertaken by the review group to address these process issues, as reported in Chapter 5 of the Final Report, should ensure that parents have clarity and an understanding of the process and reasons for any action/decision on their individual claim.

Appendix I .Submissions made to Working Group from advocacy groups/Organisations

ORGANISATION	
People With Disabilities Kildare (PDK)	ASD Support Group (Cloghroe National School)
Midlands Regional Forum of People with Disabilities	Dóchas (2 submissions)
Laois Offaly Families For Autism (LOFFA)	Disability Education Network
Citizens Information Board	Cork Spina Bifida & Hydrocephalus Association
Carers Association Ireland	Regional Autism Spectrum Disorders Service
Care Alliance Ireland	Finian McGrath TD
Spectrum Alliance	Early Years Support Team
Aspire	Féach
Inclusion Ireland	Irish Association of Social Workers
Down Syndrome Limerick	Cottage Autism Network (CAN)
Special Hands Support Group	Fingal LEADER Partnership
Disability Federation of Ireland	Little People of Ireland
Special Needs Parents Association	Ennis Voices for Autism
DCA Warriors	Jack & Jill Children's Foundation
Spina Bifida Hydrocephalus Ireland	Arthritis Ireland Galway Branch
Prader Willi Syndrome Association Ireland	Children's Liver Disease Ireland
Cystic Fibrosis Association of Ireland	Special Needs Active Parents (SNAP)
Enable Ireland	Irish Autism Action
Autism Support Louth (2 submissions)	Northside Community Law & Mediation Centre
Brainwave Irish Epilepsy Association	National Sight Loss Agency (NCBI)
Wicklow Triple A Alliance	Heart Children Ireland
Down Syndrome Ireland	Diabetes Ireland
Midlands Dyspraxia Support Group	Midlands Border West Autism Support (MWB)
Dyspraxia Association of Ireland	Donegal Down Syndrome (2 submissions)
DeafHear	Daughters of Charity

Appendix II Submissions made to Working Group from individuals

<u>SURNAME</u>	<u>FIRST NAME</u>
Costello	Margaret
Kelleher	John
Cannon	Helen
Doyle	Julie
Jennings	Margaret C
Gillgarro	Mark and Michelle
Deegan	Donal
Casserley	Julie
Lynam	Nikita
O'Reilly	Martina
Whelan	Karen
Lee	Rock
Zoane	Marie Angele
Joyce	Mary Frances
Malone	Petria
Adekunle	Eniola
Malone	Peter
Mc Namara	Brian and Joan
Keane	Ann
Kelly	Norah
Grennan	Caitriona
Adeyemo	Yetunde
Hayden	Caroline
Graham	Madeline
Jerry-Onyi	Grace
Daskers	Marianne
Kelly	Eoin
Kevni	Florence
Tassara	Carlos Antonio
Penter	Gilbegta
Kelly	Aoife
Hand	Lisa
Drumm	Lurleen
Mohamad	Hiyam Wardah
Kiernan	Natalie
Solomon	Olayinka
Sequin	Daniele
Camon	Esther
Hare	Sarah
Alzuhairi	Bashar
Selim	Alaaeldin Hassan
Fitzgerald	Davina
Callaghan	Anne
Phelan	Marsella

<u>SURNAME</u>	<u>FIRST NAME</u>
Mc Kiernan	Clair
Galvin	Mary
Keating	Patrick and Yvonne
Scahill	Catherine
Iria	Juliet
O'Mahony	Ann Marie
Stasiau	Monica
Showoinmi	Bilikisu Sadu
Kilduff	Susan
Hobson	Lengiel
Devlin	Louise
Maher	Rosheen
Klukava	Sarka
Mc Carthy	James
Conneely	Sinead
O'Dwyer	Jacqueline
Rodgers	Anne
Parlane	Sarah
Byrne	Maria
Lakatosova	Kristina
Devane	Susan
Murphy	Nuala
Wise	Damien Matthew
Mc Cormack	Sandra
Molloy	Martina
Gibbons	Gertie
Ishola	Adetutu
Fitzgibbon	Diane
Balwin	Mark and Sharon
Redicca-Collins	Bridie
Long	David
Hossain	Motaleb
Quilter	Anne
Gallagher	Suzie
Ajmi	Fatima
Ogbomo	Osarieme
Hogan	Mary
Slater	Carol
Healy	Mary
Looney	Aengus
Mulcahy	Shirley
Dunne	Emily
Burns	Margaret
Mc Pherson	Sinead

<u>SURNAME</u>	<u>FIRST NAME</u>
Greene	Patricia
Flanagan	Mary
Yates	Dolores
Bowers	Deirdre
Michalik	Katarzyna
Barry	Helen Miranda
Howell	Nicole
Murphy	Caitriona
Scott	Ann
Sheeran	Margaret
Wilkinson	Kate
Adedewe	Rachel
Ramsay	Olive
Harmes	Christine
Ryan	Breda A
Kearney	Rose
Mc Mahon	Orla
Dickenson	Helen
Stivers	Dervila
Lwin	Yi Yi
Horan	Brian and Veronica
Fitzpatrick	Rebecca
Ogbehe	Mkilika Christina
Ferguson	Audrey
Ayere	Happiness
Worden	Thomas William
Preece	Mileen
O'Sullivan	Lorraine
Graham	Karen
Scott	Shane
Kennedy	Nicky
Stafford	Sylvia
Gleeson	Karen
Cuaresma	Shella Marie
Mc Donnell	Emma
Kaminska	Agniebaka
Gillespie	Lorraine
Murphy	Ethel
Donnelly	Mary
Kett	Deborah
Boylen	Claire
O'Driscoll	Martina
Coyle	Katie
O'Donnell	Alice
Nowat	Agmeszta

<u>SURNAME</u>	<u>FIRST NAME</u>
Sobczak-Grabarczyk	Agnieszka
Fitzgerald	Mary
Fydrych	Patryk and Monika
Mulvaney	Joan
Landingin	Jennifer
O'Mahony	Fergal and Catriona
Ryan	Anthony
Bevis	Karen
Hulton	Tom
Geoghegan	Sharon
O Connell	Lulu
Szabat	Daniel and Szabat
Asitashvili	Diana
Badigo	Temstope Y
Davy-Butler	Breed
Pacesiene	Laura
Stisz	Zaneta Maria
Defor	Mary Ann
O Reilly	Joanne
Jones	Sharon
Mcjyn-Igelige	Grace
Connolly	David and Ruth
Bandyk	Katarzyna
Machedou	Adam
Power	Deirdre
Lammond	Mary Bridgid
Lowther	Catriona
Godley	Kelly
Green	Susan
Boyle	Helen
Power	Nichola
Nolan and Doyle	Kim and Ciaran
Flannery	Deirdre
Fahy	Noreen
O'Leary	Paula
Brassil	Helen
Nizinga & Posiewka	Joao Paulo & Iwona
O'Brien	Ann
Burns	Anne
Doris	Brendan and Rani
Kemp	Jacqueline
Rushe and Kane	Jen and Chris
Crotty	Laura
Zovely	Nasrin Ahmed
Djomune	Jalqana

<u>FIRST NAME</u>	<u>SURNAME</u>
Carr	Anthony
Snow	Deirdre
Walsh	Kathryn
Wilson	Auveen
Burke	Lorraine
Hulton	Tom
Rennick	Maria
Murphy	Noleen
Ward	Maria
O Malley	Grainne
Murchan	Damien
Kinnahan	Karen
McLaughlin	Barry
Miley	Fiona
Cassley	Damian and Helen
Connolly	Meadhbh
FeeneySpellman	Norrie
O'Callaghan (Ward)	Regina
Maher	David and Mary
Hickey	Mary
Byrne	Jackie
Alauaiye	Omolola
Ryan	Mary B
O' Brien	Alan and Dorothy
Sweetman	Gert
Thorpe	Rosina
Gillespie	Patricia
Okolie	Vera
Okolie	Mildred
Austin	Linda
Bosonnet	Nuala
Doyle	Leon
Meade	Tracy
Whelan	Kievin
Ostoinska	Justyna
Bradley	Barry and Geraldine
Hartigan	Faye
Ryan	Claire
kwelele	Eji Judith
O'Donoghue	Patricia
Farrell	Colette

<u>FIRST NAME</u>	<u>SURNAME</u>
O'Keeffe	Alison
Kmita	Beata
O'Reilly	James and Gabrielle
Jordan	Maureen
Callaghan	Robert and Rosemary
Doherty	Harry and Teresa
Melvin	Siobhan
Doherty	John and Mary
Shovlin	Martin and Yvonne
Krusteff	Mira
Harty	Tom and Magdalene
Cahill	Suzanne
Kennedy	Deirdre
Young	Sandra
Curran	Deborah
Aylward	Elaine
Ryan	Alan
Maher	David and Mary
Spitere	Catherine
Flood	Suzie
Fisher	Elaine
Scully	Linda
O Reilly	Martina
O Donovan	Ann
Quinn	Emer
Grant	Regina
Connolly	Geraldine
Russell	John
McNally	Amy
Mc Guinness	Fionnuala
Olague	Edith
Walsh	Lisa
Fitzgerald	Veronica
Frawley	Emer
Bazante	Elena
Wasik	Wioletta
Mejer	Sylwia
Kearney	Tom
Asim	Mehreen Ali
Harrington	Caroline
Larkin	Deborah

Appendix III Letter to parents and survey questionnaire

An Roinn Coimirce Sóisialaí
Department of Social Protection



www.welfare.ie

Re: Domiciliary Care Allowance Review

Mrs Joan Sample

26 CCCCCCCCC

Ddijdn

Dublin 34

24th August 2012

Dear **Ms Sample**,

The Minister for Social Protection, Ms. Joan Burton T.D., recently announced a review of the operation of the Domiciliary Care Allowance (DCA).

While this review of the scheme is underway no further medical eligibility reviews of children receiving the payment will be undertaken.

A steering group, comprised of representatives of relevant departments together with nominees with relevant expertise and parent/advocacy group representatives, has been established and is due to report to the Minister by the end of the year. The review will examine, amongst other things, the policy objectives of the scheme, the administrative processes and consider any changes required.

The group recently advertised for submissions from individuals and groups representing children with disabilities, details of the submission process, including the headings to be used, can be found on http://www.welfare.ie/EN/Documents/DCA_ReviewSubmissions.doc

We are now contacting a sample group of parents, selected at random, to complete a survey which will help inform the group of the relevant issues around the allowance and help us obtain a wider understanding of the role than the allowance has in the care of children with disabilities.

You have been selected to participate in this survey and you are now invited to complete the attached questionnaire and return it in the enclosed freepost envelope by 28th September 2012. Your reply will be anonymous and will not be linked to your DCA claim in any way.

Yours sincerely

Roy Baldrick

Secretary to the DCA review group.

DSP, St. Oliver Plunkett Rd, Letterkenny, Co. Donegal. **Email: DCAReview@welfare.ie**

Domiciliary Care Allowance Review – Survey Questionnaire

You are invited to complete the attached survey. This will assist in informing the review group of the main issues concerning parents of children with disabilities and the payment of DCA. The information you give will be confidential and anonymous. It will not be linked to you, will be used purely for statistical purposes, and will not affect your claim in any way.

Q.1 When did you first claim DCA?

Before April 2009 After April 2009

Q.2 How many children do you have? _____

Q.3 How many children do you get DCA for? _____

Q. 4 Family circumstances

Are you: Living with spouse/partner Lone parent

Please answer Q.5 to Q.7 in respect of each child for whom you receive DCA:

	Child 1	Child 2	Child 3
Q.5 In what year did you first get DCA?	_____	_____	_____
Q.6 What is the relevant child's current age (in years)?	_____	_____	_____

Q.7 Are you currently getting Carer's Allowance?

Yes No

Q.8 Do you consider DCA and Carer's allowance are effectively the same type of payment?

Yes No

If NO, what difference do you see in the payments?

Q.9 What do you find DCA useful for? (Please tick all that apply.)

- General day-to-day living expenses
- Childcare for my child with a disability
- Respite care for my child with a disability
- Therapies/extra tuition/supports for my child with a disability
- Other extra-curricular activities for my child with a disability

(e.g. swimming, dance classes, etc)

- Extras for my other children
- Other purposes, (please specify) _____

Q.10 School - is your child with a disability (answer for each child under 16 with a disability)

	Child 1	Child 2	Child 3
	With a disability	With a disability	With a disability
• Not yet at school/preschool	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• At mainstream preschool	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• At special preschool	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• In mainstream primary education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• In mainstream post-primary education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• In special education – primary age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• In special education – post-primary age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Home schooled	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• None of the above	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(Please specify) _____

Application Process

Q.11 If you applied for DCA since April 2009, how did you find the application process? (Please tick all boxes that apply.)

1. Claim form was easy to complete
2. Claim form was difficult to complete
3. Not enough room on the claim form to detail my individual circumstances
4. Questions asked did allow me to detail my child's care needs fully

5. Detail what improvements you think should be made to the application process (Please specify):

Q. 12 Assessment of eligibility

(a) Do you think that medical evidence is best assessed by:

- A paper based desk assessment
- Child seen by a Medical Assessor
- Meeting with other Care professional

(b) Are you satisfied with how professional evidence is currently used to establish eligibility Yes No

If not, please specify

Q.13 How could the communication of the decision be improved?

- More information on the reasons for disallowance
- More information on the assessment /appeals process
- Timeliness
- Other (please give details):

Q.14 Does your child with a disability have (tick all which apply):

	Child 1	Child 2	Child 3
	With a disability	With a disability	With a disability
• A physical disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• A speech, sight or hearing disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• A psychological, mental health or emotional difficulty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• An intellectual disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Autism	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(please describe) _____

Q.15 Please tick which of these applies to your child with a disability, as compared with other children of the same age (tick all which apply)

	Child 1 With a disability	Child 2 With a disability	Child 3 With a disability
Needs to be lifted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Needs help with dressing/showering/bathing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Needs help with feeding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Needs help with toileting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Needs help with communication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Needs help at home with learning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Needs special exercises/physio at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Frequent medical appointments (e.g. every two weeks) or regular hospitalisation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Significant behaviour difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Needs care/support during normal sleeping hours or suffers significant sleep disturbance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Needs constant supervision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Access to supports

Q.16 Is your child with a disability registered with or receiving regular services from a disability service provider?

	Child 1 With a disability	Child 2 With a disability	Child 3 With a disability
Yes			
No			

Q.17 Does your child with a disability get the publicly-funded support services they require?

	Child 1 With a disability	Child 2 With a disability	Child 3 With a disability

Needs are fully or mainly met through the publicly-funded system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Needs are partially met through the publicly-funded system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Needs are not met through the publicly funded system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q.18 Do you access and pay for additional services privately?

Yes No

Respite

Q.19 How often do you use respite?

- Weekly
- Fortnightly
- Monthly
- 4-6 times a year
- 2-3 times a year
- Once a year
- Never –not used

Q.20 Type of respite services you use (please tick all that apply).

	Paid	Unpaid
Friends and family	<input type="checkbox"/>	<input type="checkbox"/>
Childminder in our home	<input type="checkbox"/>	<input type="checkbox"/>
Being minded in another family	<input type="checkbox"/>	<input type="checkbox"/>
Respite from disability service provider	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>

None/not applicable

Q.21 What do you use the yearly Respite Care Grant of €1700 for? (Please tick all that apply.)

- Providing respite care so rest of family can get a break
- Payment to disability service provider
- Payment for other respite arrangement
- Family holidays
- General household expenses
- None of the above

Appeal Process

Q.22 Have you been through the appeals process? Yes No

If NO, please continue to Q.23.

If YES, what was your experience?

- Satisfied with process
- Unhappy with process
- Please outline your concerns

Q.23 Should the rate and duration of payment reflect the level of disability/care needs of the child?

Yes, the rate of DCA should be tiered, with children with a more severe disability or who require most care getting a higher rate of payment.

No, all children that qualify should continue to be paid the same amount.

Q.24 Should the rate of payment reflect different stages of the care need of the child?

Should there be different rates at different ages? Yes No

If Yes, please indicate which age group you consider should get a higher rate!

	Lower rate	Higher rate
0-5 years		
5-10 years		
10-16 years		

Q.25 Do you think that DCA should be paid up to age 18 years? Yes No

Q.26 Suggest any changes to the operation of the scheme that would improve the service for parents:

Please return the completed survey in the enclosed envelope (no stamp needed) by September 28th 2012.

Thank you for your co-operation.