

# Family Carers' Scorecard

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What has the National Carers' Strategy Achieved? An assessment of progress from the perspective of Family Carers.





## Introduction

This report gives a Family Carer's perspective on the impact the National Carers' Strategy (NCS) has had on Family Carers' lives since its launch in July 2012.

This is a summary document. It contains an overview of the assessment of the National Carers Strategy and describes the verdicts assigned to all 42 strategy actions. The narratives explaining the rationale for assigning each score are contained in the full report which is available for download on [www.carersireland.com](http://www.carersireland.com) or from any of The Carers Association's resource centres.

The National Carers' Strategy was launched with the following vision: "Carers will be recognised and respected as key care partners. They will be supported to maintain their own health and well-being and to care with confidence. They will be empowered to participate as fully as possible in economic and social life".

This vision was supported by 42 actions. Responsibility for each action was assigned to relevant Government Departments. The Departments committed to producing an annual Progress Report documenting progress in relation to the strategy. Two of these reports have been produced to date; the 1st Progress Report recorded progress from September 2012–September 2013 and the 2nd Progress Report recorded progress from September 2013–September 2014.

The Carers Association assembled a National Carers' Strategy Monitoring Group made up of Family Carers, Carers Association staff with a range of expertise, and included representation from Care Alliance. Since early 2014, the Monitoring Group has met and carefully assessed Government's reported progress (as expressed in the 1st and 2nd Progress Reports) against the stated goals, objectives and actions named in the National Carers' Strategy. The key question the Group asked itself again and again was whether there had been any identifiable impact on Family Carers' lives. The Monitoring Group assigned the colour-coded scores below to each of the actions contained within the strategy.

**Verdict: Objective Achieved. Making a real difference**

**Verdict: Good Progress. Positive results for Family Carers**

**Verdict: Initial progress. But slow pace/delayed start**

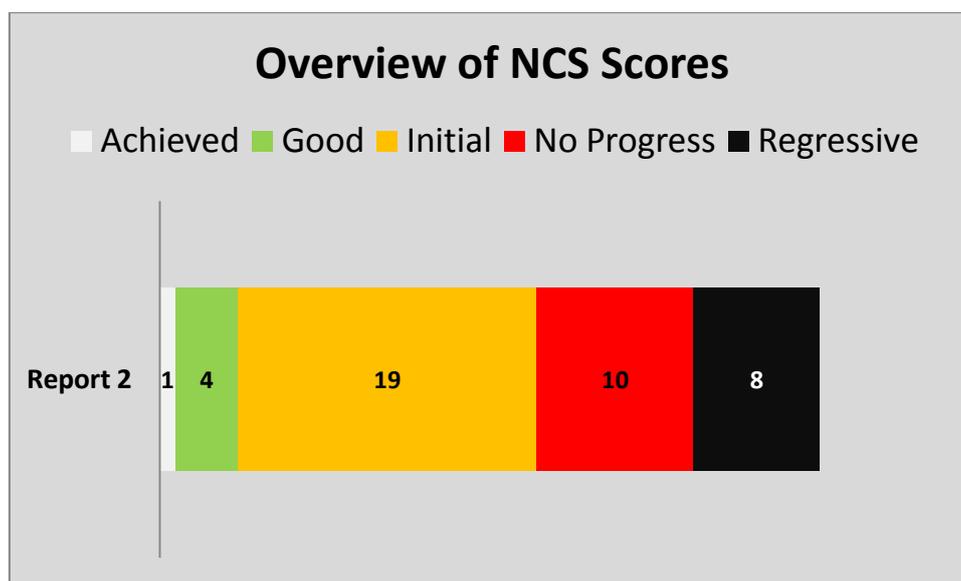
**Verdict: No Progress**

**Verdict: Regressive**

## Overview

Of the 42 actions within the strategy, one action received an 'Objective Achieved' score, meaning that the goal of the action has been implemented to full effect and is making a real difference to Family Carers' lives. Four actions received a 'Good Progress' score, meaning that there have been positive results for Family Carers, and the actions have the potential fully to be implemented within the lifetime of the strategy. Nineteen actions received an 'Initial Progress' score, meaning that there have been steps in the right direction but, given the short lifetime of the strategy, this progress is slow and requires an increase in the pace of implementation. Ten actions received a 'No Progress' score, meaning that there was no evidence that any change has taken place that would have an

impact on Family Carers' lives. Finally, 8 actions received a 'regressive' score, meaning that the situation has worsened for Family Carers since the strategy was launched.



On the whole, the level of progress across the strategy is poor. From the outset the strategy was designed to run over a short period of time and to be cost neutral, with modest, achievable objectives. While over half of the actions show some progress, most of these were stamped with 'initial progress: but slow pace/delayed start'. While an 'initial progress' score would be considered positive in year one of a short term strategy, with our now being over half way through the lifetime of the strategy this verdict becomes less acceptable. The fact that a significant minority of the strategy actions did not move forward or actually regressed is very disappointing.

### Highs and Lows

The report outlines in detail how each strategy action was scored and the rationale for each score. Here we give a sample of some of the highs and lows within the strategy.

Areas where we have witnessed regression include cuts to respite services and supports. Particularly disappointing was the 19% cut to the respite care grant in Budget 2012; poor discharge planning and consultation with family carers when their loved one moves from hospital to home care; and the halving of funding for Housing Grant Schemes from €79 million in 2011 to €38 million in 2014. Understandably, actions related to these negatives were awarded our poorest score of 'Regressive', as the situation has worsened for Family Carers since the report was launched.

- Regressive** 1.3.5. Review existing transition arrangements for carers at the end of their caring role
- Regressive** 3.3.1. Prioritise funding for the operation of the suite of housing grants for older people and people with a disability and ensure that they can be accessed by families in a timely way
- Regressive** 4.1.2. Promote a range of person-centred and flexible respite options
- Regressive** 4.1.3. Identify gaps in existing services and establish performance indicators for the provision of respite services.

Areas of good progress within the strategy include: the development of a single assessment tool for older people which contains a detailed carer's needs assessment; the imminent release of €1 million

funding from Dormant accounts for training and information provision for family carers; and the hosting of an Annual Carers Forum by the Department of Social Protection, in particular the positive engagement provided for by the structure of this forum in meeting the needs of family carers.

Good Progress

2.1.3. Develop and roll out a single assessment tool for older people and ensure that the views of carers as well as the people they care for are taken into consideration

Good Progress

1.3.1. Provide regular benefits advice sessions and information through the application process. €1 million funds from Dormant Accounts will be released to support locally-based training, information and related support services for Carers.

Objective Achieved

1.1.4. Continue to convene an annual carers forum to provide carers with a voice at policy level

It is worth remembering that not all scores are equal and some of the strategy actions have a bigger impact on Family Carers' lives than others. For example, Respite Care Grant and Transition Arrangements are particularly important, and the poor state of affairs in relation to both is very disconcerting to Family Carers.

### Inadequate Resourcing

While the overall level of progress that the Monitoring Group could recognise is disappointing, it is worth remembering that the strategy was published in a time of austerity and was designed to be "cost-neutral". As noted below, active engagement with the Strategy by Departments has increased; the lack of dedicated resources, however, may well be impeding progress.

Now that Ireland is moving out of austerity, it is time for Government to resource the implementation of the National Carers Strategy and, by doing so, make a real positive difference to the lives of our family carers.

### Positive Engagement and Potential

It is important to bear in mind that the scorecard only captures progress that has been implemented, not plans for future action or positive engagement. The scorecard process and the engagement it has yielded with Government Departments may well be the catalyst for significant positive change that Family Carers require. Government Departments have been remarkably open to taking suggestions as to how real progress for Family Carers can be achieved within their areas of responsibility. Engagement with Departments peaked just before the 2nd report was produced. In many cases, there would not have been time between these meetings and the production of the report for many of the discussed items to be acted upon and so recorded as progress in the scorecard. We anticipate that these positive exchanges will continue, and will lead to real progress that will be recorded in the next NCS scorecard. The one exception to this positive engagement is the Department of Jobs, Enterprise and Innovation, which has yet to engage with the Strategy or the Monitoring Group in any way.

Next we give a brief sense of each Department's engagement with the Strategy.

**Department of Health (DoH):** DoH is the lead department for the National Carers Strategy, and has responsibility for coordinating the compilation of the annual progress report from submissions for all departments. Encouragingly, the DoH is coordinating cross-departmental meetings which will be

vital if progress is to be achieved for Family Carers whose concerns often fall within the remit of numerous departments.

Engagement by Health Service Executive (HSE) in its own area of responsibility has been positive, particularly so in recent months. The DoH and the HSE have a very large brief, and engagement from some sections has been better than others. The response from the older person's section has been particularly strong. One example of this is work in relation to the InterRAI suite and development of a Carer's Needs Assessment, which is pioneering and will be of great value to those caring for older people.

It is not clear, however, how the needs of other cohorts of carers are being met. These include young people with caring responsibilities; carers for those with disabilities or mental health issues; and carers of young children with special needs. Future reports should rectify this.

More generally, reporting from the HSE and DoH often falls short of what one would expect of a National Strategy. Frequently, a number of isolated positive examples are given to show progress in relation to a specific action. This approach does not allow us to build a picture of national coverage, and makes it impossible to say whether the needs of carers all over the country are being addressed.

**Department of Social Protection (DSP):** The engagement by DSP with the NCS Monitoring Group has been good. This open communication has led to practical outcomes. On the recommendation of the Monitoring Group, DSP has amended standard written communication to those refused Carer's Allowance on the grounds of means to indicate that they may have an entitlement to the Respite Care Grant. Furthermore, the Department's Annual Carers Forum is a good template for open and transparent engagement. This year, the Department reshaped the forum in consultation with The Carers Association so that it might be even more effective. Elsewhere, the Department made initial gains in reducing the waiting periods for Carers Allowance applications and appeals. This was recognised in our scoring of the first report; waiting times have however slipped more recently. It is clear on the whole that the Department's "major service delivery modernisation project" represents a concerted effort to improve their service to Family Carers.

**Department of Children and Youth Affairs (DCYA):** The engagement relating to the NCS with DCYA has been particularly useful and timely. Most welcome are the indications given by DCYA on foot of meetings with the Monitoring Group that Young Carers would be recognised in the forthcoming National Youth Strategy as a target group with specific support needs. This was born out of positive engagement with representatives from the NCS Monitoring Group.

Worth recognising too is that relationships with the newly-formed TUSLA have been established, and it is to be hoped the links between TUSLA and the Department of Education will lead to coordinated responses to Young Carers' needs. Such responses are necessary, as "One Child, One Team, One Plan", the strategic framework for the Education Welfare Service of TUSLA, aimed at providing an enhanced response to the needs of children, families and schools, does not indicate how it will meet the needs of Young Carers in particular.

**Department of Education and Skills (DES):** The Monitoring Group meeting with the Department of Education and Skills was useful. The 2<sup>nd</sup> Progress Report provides information on how young people in general are being supported and about general further education and training initiatives. However

there is little specificity on how Young Carers and young people with a disability are being supported. The Monitoring Group appreciated the opportunity to emphasise how important it is that the Department make explicit and prioritise its support for these groups. While Education and Training Boards have a remit to deliver on specific strategy actions, the Department's report does not give an indication as to whether ETBs are meeting the goals of the Strategy. Given the Department's role in reporting on progress for all agencies working under its auspices, the Monitoring Group anticipates a clearer picture of this work in future reports.

**Department of Justice and Equality (DJE):** The Monitoring Group acknowledges the positive engagement with the Department of Justice and Equality, which has taken responsibility for Carer's Leave under the Family Leave Bill. From meetings, the Monitoring Group was encouraged by the Department's acknowledgment of the low take-up of Carer's Leave and the need to increase awareness of the same. In the latter months of 2014, the Department of Justice has been forthcoming in engaging with the Monitoring Group and Family Carers. Specifically, the Department has briefed carers about the implications of the Assisted Decision-Making Capacity Bill for them and their loved ones.

**Department of Transport, Tourism and Sport (DTTS):** Engagement with DTTS has been useful. DTTS gave assurance that many of the actions within the NCS relating to ensuring accessible transport options for Family Carers and those they care for would be covered by the Transport Sectoral Plan 'Transport Access for All', and the work of the National Disability Strategy Implementation process. DTTS displayed openness about sharing this work with the Monitoring Group, and flexibility in framing and progressing transport issues raised in the NCS through the Department's agenda.

While we acknowledge that DTTS has reviewed and updated the Transport Sectoral Plan, there have been a number of actions outside the Plan and outside the control of DTTS that undermine the goals of the plan to provide accessible 'Transport for All'. Regressive changes relating to the Mobility Allowance Scheme, the Motorised Transport Scheme and the Disabled Drivers and Disabled Passengers Scheme, though transport related, are actually the remit of other Departments. The negative impact of these changes is now affecting Family Carers; accordingly, the score we awarded to many transport-related actions is poor.

**Department of Jobs, Enterprise and Innovation (DJEI):** Despite repeated requests to do so DJEI has yet to engage with the National Carers' Strategy. It is not clear that they recognise the importance of the strategy at all. DJEI has not contributed to either of the Government's Progress Reports, or yet agreed to meet with the Monitoring Group. This is especially disappointing given the role DJEI has been assigned in the strategy to support Working Carers and Former Carers who wish to return to the workforce after their caring role comes to an end. Given the focus contained within the NCS's vision statement on 'empowering carers to participate fully in economic life', the involvement of the Department in the implementation of the strategy is of utmost importance.

### Overview of Scores

The 5-page chart overleaf outlines the verdicts assigned to all 42 Strategy Actions by the Monitoring Group. The narratives explaining the rationale for assigning each score are contained in the full report which is available for download on [www.carersireland.com](http://www.carersireland.com) or from any of The Carers Association's resource centres.

**Chart 1: Overview of Scores**

	1 <sup>st</sup> Progress Report	2 <sup>nd</sup> Progress Report
1.1.1. Promote a better recognition of the role and contribution of carers at a national level	<b>Initial, But Slow, Progress.</b>	<b>Good Progress</b>
1.1.2. Ensure that carers' needs are considered in the development of any policies that might affect them (such as the Review of Disability Policy (DoH), the National Positive Ageing Strategy (DoH, forthcoming) and the Children and Young People's Policy Framework 2012-2017 (DCYA, forthcoming)	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>
1.1.3. Build on the work begun in Census 2011 to establish a comprehensive statistical profile of Family Caring in Ireland	<b>Good Progress</b>	<b>Good Progress</b>
1.1.4. Continue to convene an annual carers forum to provide carers with a voice at policy level	<b>Good Progress</b>	<b>Objective Achieved</b>
1.1.5. Support national organisations representing the interests of carers	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>
1.1.6. Promote more proactive approaches to the identification of carers and to addressing their needs among staff and organisations that are likely to encounter individuals in caring situations (e.g. health and personal social service providers, and particularly primary care team members, community and education professionals).	<b>Initial, But Slow, Progress.</b>	<b>No Progress</b>
1.1.7. Promote carer self-identification initiatives and encourage carers to formally identify themselves to service providers	<b>Initial, But Slow, Progress.</b>	<b>No Progress</b>
1.2.1. Involve carers, as appropriate, as partners in care planning and provision by health and personal social service providers and particularly by the primary care team	<b>No Progress</b>	<b>No Progress</b>
1.2.2. Identify carers and their involvement in discharge planning, including their details provided in discharge letters to GPs	<b>Regressive</b>	<b>Regressive</b>

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	1 <sup>st</sup> Progress Report	2 <sup>nd</sup> Progress Report
1.3.1. Provide regular benefits advice sessions and information through the application process	<b>Initial, But Slow, Progress.</b>	<b>Good Progress</b>
1.3.2. Ensure that carers can access benefits advice as early as possible when their caring role begins	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>
1.3.3. Publicise more widely that the Carer's Allowance can be shared by two carers providing care on a part time basis	<b>Initial, But Slow, Progress.</b>	<b>No Progress</b>
1.3.4. Continue to work to reduce waiting periods for processing of Carer's Allowance applications and appeals	<b>Good Progress</b>	<b>Initial, But Slow, Progress.</b>
1.3.5. Review existing transition arrangements for carers at the end of their caring role	<b>Regressive</b>	<b>Regressive</b>
2.1.1. Raise awareness among health and personal social service providers of the physical and emotional health issues that carers may experience	<b>No Progress</b>	<b>Initial, But Slow, Progress.</b>
2.1.2. Encourage carers to attend their GP for an annual health check	<b>No Progress</b>	<b>No Progress</b>
2.1.3. Develop and roll out a single assessment tool for older people and ensure that the views of carers as well as the people they care for are taken into consideration	<b>Good Progress</b>	<b>Good Progress</b>
2.1.4. Continue to implement the recommendations of the Home Solutions Report (13) on telecare	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>
2.1.5. Promote awareness of adult and child protection services that are in place	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>
2.1.6. Review the Fair Deal system of financing nursing home care with a view to developing a secure and equitable system of financing for community and long-term care which supports older people to stay in their own homes.	<b>No Progress</b>	<b>Regressive</b>
2.1.7. Progress the development and implementation of national standards for home support services, which will be subject to inspection by the Health and Information Quality Authority (HIQA).	<b>No Progress</b>	<b>No Progress</b>

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	1 <sup>st</sup> Progress Report	2 <sup>nd</sup> Progress Report
2.2.1. Raise awareness and understanding among education providers of the signs that children and young people have caring responsibilities and the impact of caring on them	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>
2.2.2. Encourage statutory agencies to review the way that they respond to children and young people with caring responsibilities	<b>No Progress</b>	<b>No Progress</b>
2.2.3. Identify support services needed by children and young people with caring responsibilities and create mechanisms for young carers to contact service providers	<b>No Progress</b>	<b>No Progress</b>
2.2.4. Investigate and analyse the situation of children and young people undertaking caring roles.	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>
3.1.1. Ensure frontline staff in key 'first contact' agencies such as local authorities, local health offices and health and personal social service providers have the correct information to be able to sign-post carers to other services as appropriate	<b>No Progress</b>	<b>Initial, But Slow, Progress.</b>
3.1.2. Review material (paper and Internet based) available to carers and investigate (in conjunction with carer's representative organisations) how more comprehensive information materials dedicated to carers' needs can be developed and distributed to service providers likely to be a carer's first point of contact	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>
3.1.3. Ensure that the information needs of sub-groups of carers, such as older carers, children and young people with caring responsibilities, carers in rural areas are addressed	<b>No Progress</b>	<b>Initial, But Slow, Progress.</b>
3.1.4. Proactively collate and disseminate information about services and supports available at a local level for carers	<b>No Progress</b>	<b>Initial, But Slow, Progress.</b>

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	1 <sup>st</sup> Progress Report	2 <sup>nd</sup> Progress Report
3.2.1. Identify gaps in the content of current training programmes for carers (in conjunction with carer's representative organisations)	<b>No Progress</b>	<b>Initial, But Slow, Progress.</b>
3.2.2. Enhance the accessibility of education and training courses through the use of face-to face, on-line and distance learning options	<b>No Progress</b>	<b>Initial, But Slow, Progress.</b>
3.3.1. Prioritise funding for the operation of the suite of housing grants for older people and people with a disability and ensure that they can be accessed by families in a timely way	<b>Regressive</b>	<b>Regressive</b>
3.3.2. Identify good practice in implementing assistive technology and ambient assistive living technology to support independent living and telehealth opportunities	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>
3.3.3. Review and up-date Transport Sectoral Plan under Disability Act 2005	<b>Regressive</b>	<b>Initial, But Slow, Progress.</b>
4.1.1. Promote a better awareness of the existence of the Respite Care Grant	<b>Regressive</b>	<b>Initial, But Slow, Progress.</b>

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	1 <sup>st</sup> Progress Report	2 <sup>nd</sup> Progress Report
4.1.2. Promote a range of person-centred and flexible respite options	<b>Regressive</b>	<b>Regressive</b>
4.1.3. Identify gaps in existing services and establish performance indicators for the provision of respite services.	<b>No Progress</b>	<b>Regressive</b>
4.2.1. Promote existing carer friendly HR policies within Government departments and agencies.	<b>No Progress</b>	<b>Initial, But Slow, Progress.</b>
4.2.2. Promote awareness of the Carers Leave Act 2001.	<b>No Progress</b>	<b>No Progress</b>
4.2.3. Encourage work-life balance provisions that are needed to ensure that working arrangements are carer friendly.	<b>No Progress</b>	<b>Regressive.</b>
4.2.4. Explore how back to work and education training courses can be tailored to the needs of carers who wish to return to the workforce.	<b>No Progress</b>	<b>No Progress</b>
4.2.5. Review access by Family Carers to labour market activation measures.	<b>Initial, But Slow, Progress.</b>	<b>Regressive.</b>