

# Full Report



## Family Carers' Scorecard

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



## Family Carers' Scorecard

Cover photo: Anne McGrath, Carer of the Year 2010, and her daughter Tamara.

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## 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.

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**

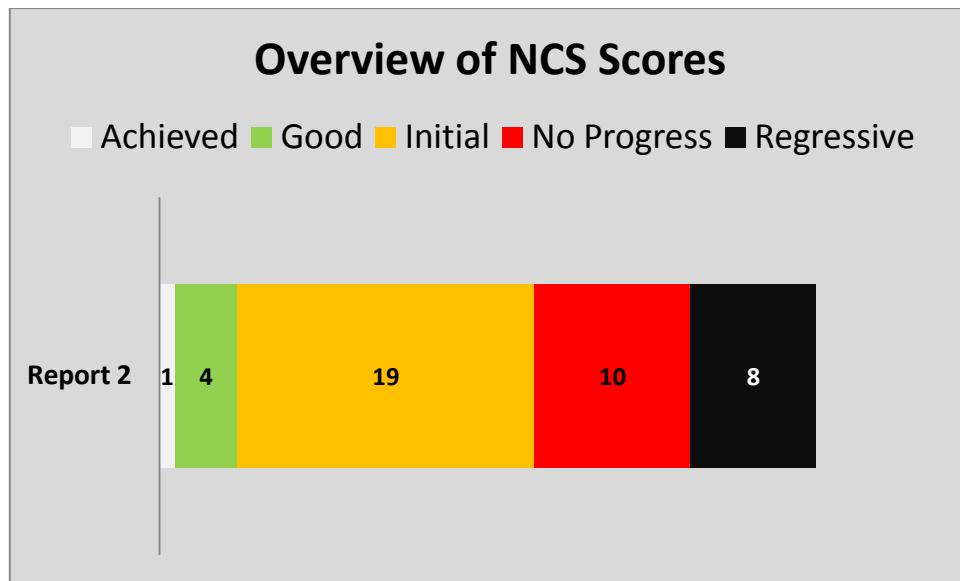
**Verdict: Initial progress. But slow pace/delayed start**

**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.

<b>Regressive</b>	1.3.5. Review existing transition arrangements for carers at the end of their caring role
<b>Regressive</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>	4.1.2. Promote a range of person-centred and flexible respite options
<b>Regressive</b>	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

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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.

Below 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 remits 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 have 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.

The 5-page chart overleaf outlines the verdicts assigned to all 42 Strategy Actions. Following this each of the Strategy Actions is considered in turn. A narrative is provided which explains why each score was assigned by the Monitoring Group.

## 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	Initial, But Slow, Progress.	Good Progress
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)	Initial, But Slow, Progress.	Initial, But Slow, Progress.
1.1.3. Build on the work begun in Census 2011 to establish a comprehensive statistical profile of Family Caring in Ireland	Good Progress	Good Progress
1.1.4. Continue to convene an annual carers forum to provide carers with a voice at policy level	Good Progress	Objective Achieved
1.1.5. Support national organisations representing the interests of carers	Initial, But Slow, Progress.	Initial, But Slow, Progress.
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).	Initial, But Slow, Progress.	No Progress
1.1.7. Promote carer self-identification initiatives and encourage carers to formally identify themselves to service providers	Initial, But Slow, Progress.	No Progress
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	No Progress	No Progress
1.2.2. Identify carers and their involvement in discharge planning, including their details provided in discharge letters to GPs	Regressive	Regressive

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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	Initial, But Slow, Progress.	Good Progress
1.3.2. Ensure that carers can access benefits advice as early as possible when their caring role begins	Initial, But Slow, Progress.	Initial, But Slow, Progress.
1.3.3. Publicise more widely that the Carer's Allowance can be shared by two carers providing care on a part time basis	Initial, But Slow, Progress.	No Progress
1.3.4. Continue to work to reduce waiting periods for processing of Carer's Allowance applications and appeals	Good Progress	Initial, But Slow, Progress.
1.3.5. Review existing transition arrangements for carers at the end of their caring role	Regressive	Regressive
2.1.1. Raise awareness among health and personal social service providers of the physical and emotional health issues that carers may experience	No Progress	Initial, But Slow, Progress.
2.1.2. Encourage carers to attend their GP for an annual health check	No Progress	No 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	Good Progress
2.1.4. Continue to implement the recommendations of the Home Solutions Report (13) on telecare	Initial, But Slow, Progress.	Initial, But Slow, Progress.
2.1.5. Promote awareness of adult and child protection services that are in place	Initial, But Slow, Progress.	Initial, But Slow, Progress.
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.	No Progress	Regressive
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).	No Progress	No Progress

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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	Initial, But Slow, Progress.	Initial, But Slow, Progress.
2.2.2. Encourage statutory agencies to review the way that they respond to children and young people with caring responsibilities	No Progress	No Progress
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	No Progress	No Progress
2.2.4. Investigate and analyse the situation of children and young people undertaking caring roles.	Initial, But Slow, Progress.	Initial, But Slow, Progress.
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	No Progress	Initial, But Slow, Progress.
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	Initial, But Slow, Progress.	Initial, But Slow, Progress.
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	No Progress	Initial, But Slow, Progress.
3.1.4. Proactively collate and disseminate information about services and supports available at a local level for carers	No Progress	Initial, But Slow, Progress.

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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)	No Progress	Initial, But Slow, Progress.
3.2.2. Enhance the accessibility of education and training courses through the use of face-to face, on-line and distance learning options	No Progress	Initial, But Slow, Progress.
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	Regressive
3.3.2. Identify good practice in implementing assistive technology and ambient assistive living technology to support independent living and telehealth opportunities	Initial, But Slow, Progress.	Initial, But Slow, Progress.
3.3.3. Review and up-date Transport Sectoral Plan under Disability Act 2005	Regressive	Initial, But Slow, Progress.
4.1.1. Promote a better awareness of the existence of the Respite Care Grant	Regressive	Initial, But Slow, Progress.

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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	Regressive	Regressive
4.1.3. Identify gaps in existing services and establish performance indicators for the provision of respite services.	No Progress	Regressive
4.2.1. Promote existing carer friendly HR policies within Government departments and agencies.	No Progress	Initial, But Slow, Progress.
4.2.2. Promote awareness of the Carers Leave Act 2001.	No Progress	No Progress
4.2.3. Encourage work-life balance provisions that are needed to ensure that working arrangements are carer friendly.	No Progress	Regressive.
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.	No Progress	No Progress
4.2.5. Review access by Family Carers to labour market activation measures.	Initial, But Slow, Progress.	Regressive.

## Analysis of Individual Strategy Actions

**National Goal 1: Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they caring for**

**Objective 1.1: Strengthen awareness and recognition of the role and contribution of carers at national, regional and local level.**

### 1.1.1 Promote a better recognition of the role and contribution of carers at a national level

#### Verdict 1<sup>st</sup> Report: Initial progress. But slow pace/delayed start

- The 1<sup>st</sup> Progress Report includes updates from Department of Health and the HSE, with no updates from other departments.
- CSO Carers Count Campaign in 2011 was very positive and significantly helped to secure recognition nationally of Family Carers' role. The campaign sought to ensure that Family Carers were aware of a new question, question 22, which related to their caring role, and that they recorded their contribution appropriately. The statistics generated from this campaign are still generating very useful information about Family Carers, in particular Young Family Carers.
- The 1<sup>st</sup> Progress Report focuses solely on DISCOVER SKILLS for Carers and, whilst this represents some progress, the Monitoring Group notes that caring sector organisations have not been asked to contribute to the development of the Discover Skills platform.
- Whilst the publication of the National Carers Strategy itself represented recognition of the contribution of carers at a national level, there is clearly still some way to go to ensure Family Carers are recognised across Government Departments. It was disappointing to note that Family Carers are not referenced at all in HSE Service Plan 2013.

#### Verdict 2<sup>nd</sup> Report: Good Progress. Positive Results for Family Carers

- Engagement with the strategy by most Departments has improved significantly. During the year, the Monitoring Group met with all of the Departments responsible for delivering the Strategy with the exception of the Department of Jobs, Enterprise and Innovation which is yet to engage.
- An interdepartmental meeting on the Strategy is scheduled for May 2015. This is significant as delivering the strategy will require working across as well as within Departments.
- DSP: UNDERREPORTING. The Department of Social Protection consulted with the Monitoring Group as to how the 2015 annual carers' forum could be better structured and what kind of agenda would enhance the utility of the forum. The ambition to shape the event into as meaningful an exchange as possible is very encouraging. The DSP frequently engages with caring sector organisations; the involvement of Family Carers in the review of Domiciliary Care Grant, for example, was emblematic of this practice.
- DOH and HSE: The annual HSE National Service Plan outlines key changes to health service delivery. Encouragingly, the 2015 plan includes references to ensuring the views of Family

Carers are central to the design and delivery of health services; this is specifically outlined with regard to mental health services, disability services and dementia care.

- DOH and HSE: On 26 February 2013, the Department of Health announced that the Mobility Allowance scheme and the Motorised Transport Grant would be closed to new applicants. A review of both schemes is being carried out, but the reality is that there has been a complete closure of both allowances to new applications with no alternative in place. This decision was taken with no consultation with those affected or representative groups.
- DES: the Monitoring Group welcomes the fact that Parents caring for children with special needs are represented on the Consultative Forum of the National Council for Special Education, and recommends that Young Carers also be represented in the forum. The educational needs of other cohorts of carers such as those caring for their spouse or older loved one should also be considered by this Department.
- DECLG: The Monitoring Group recognises the funding provided by the Department to support carers' organisations through the Scheme to Support National Organisations.  
UNDERREPORTING: The Monitoring Group also recognises that in the early plans for the implementation of water charges a subsidy was to be given to Family Carers to offset the increased water use that comes with caring for someone at home. While the implementation of water charges has since changed this signalled important recognition and accommodation by the Department. The Monitoring Group expects that the Department will apply a similar subsidy for Family Carers with high essential water needs when the cap on water charges is lifted in 2019.
- DJE: In recent months the Department of Justice and Equality has been forthcoming in engaging with the group and Family Carers. In particular, the Department has briefed carers on the implications of the Assisted Decision-Making (Capacity) Bill for them and for their loved ones.
- DCYA: The Monitoring Group welcomes indications given by the DCYA during recent meetings 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.

**1.1.2. Ensure that carers' needs are considered in the development of any policies that might affect them (e.g. Review of Disability Policy, NPAS, Children & Young People's Policy Framework)**

**Verdict 1<sup>st</sup> Report: Initial progress. But slow pace/delayed start**

- Whilst in agreement with the 1<sup>st</sup> Progress Report that there are good examples of carers' needs being considered in the development of key policies, such as the National Positive Ageing Strategy and National Dementia Strategy, it was disappointing to note that Family Carers were not referenced at all in the latest HSE Service Plan. Similarly, *Future Health, A Strategic Framework for Reform of the Health Service 2012 – 2015*, a document which focused on the movement of health services to the community, makes no significant reference to Family Carers, who play a vital role in care provision at home and community level.
- The Monitoring Group acknowledges the launch of "Better Outcomes, Brighter Futures: the National Policy Framework for Children and Young People 2014-2020" on 16<sup>th</sup> April 2014.

Whilst Young Carers weren't specifically mentioned in the document, the 1<sup>st</sup> Progress Report signposts the need to give 'due regard' to the "situation of Young Carers and their need for support". The Monitoring Group looks forward to the detailing of how Young Carers' concerns in particular will be taken account of.

- Department of Health have a fundamental role in ensuring that Family Carers are considered in the roll-out of health-related policies. Unfortunately, however, the level of engagement between the Department, the HSE and caring sector organisations has not been as proactive as it could be.

**Verdict 2<sup>nd</sup> Report: Initial progress. But slow pace/delayed start**

- The progress on this action acknowledged in the Monitoring Group's response to the 1<sup>st</sup> Progress Report is still valid.
- The Monitoring Group welcomes indications given by the DCYA during recent meetings that Young Carers would be recognised in the forthcoming National Youth Strategy as a target group with specific support needs.
- DSP carries out a social impact assessment of the main welfare and direct tax measures in each Budget. It estimates the likely distributive effects of policy proposals on income and social inequalities. To date, Family Carers have not been included in this profile. The Monitoring Group recommends that the social impact assessment of future Budgets include an analysis of how Budget changes will affect Family Carers.
- Regarding the approach used in other jurisdictions, including Australia, the Monitoring Group recommends the creation of a one-page document which outlines how the National Carers Strategy relates to other strategies such as the National Positive Ageing Strategy, the National Disability Strategy, the National Dementia Strategy and the National Youth Strategy.
- The Monitoring Group suggests that the DoH host an annual forum which would bring together representatives responsible for all national strategies and facilitate their working together on progressing common objectives. To date the Monitoring Group is not aware of any such coordinated action having taken place.

**1.1.3. Build on the work begun in Census 2011 to establish a comprehensive statistical profile of Family Caring in Ireland**

**Verdict 1<sup>st</sup> Report: Good Progress. Positive Results for Family Carers**

- The Monitoring Group acknowledges DCYA's role in requesting that the Central Statistics Office include a question in the Census of Population 2011 concerning carers. The CSO Carers Count Campaign in 2011 was very positive, and significantly helped to secure recognition nationally of Family Carers' role. The campaign sought to ensure that Family Carers were aware of a new question, question 22, which related to their caring role, and that they recorded their contribution appropriately. The statistics generated from this campaign are still generating very useful information about Family Carers, in particular Young Family Carers.

- The Monitoring Group welcomes and looks forward to the publication of statistical profiling of the 6,449 young people identified as Young Carers in Census 2011

**Verdict 2<sup>nd</sup> Report: Good Progress. Positive Results for Family Carers**

- The progress on this action acknowledged in the Monitoring Group's response to the 1<sup>st</sup> Progress Report is still valid.
- The Monitoring Group welcomes and looks forward to the publication of statistical profiling of the 6,449 young people identified as Young Carers in Census 2011.
- A 'Carers Count' campaign was run through a partnership of The Carers Association and 9 other voluntary organisations in the caring/disability sector, and with the support of the CSO, in advance of Census 2011, to make carers aware of question 22 and to encourage carers to self-identify. Given that Census 2016 will be an unchanged Census carrying the same question on caring responsibilities, the Monitoring Group suggests that a similar campaign be run again to ensure the accurate enumeration of carers in Census 2016. Comparisons in census data across countries which examine caring responsibilities in their Censuses show that Ireland has a very low level of carer self-identification.

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

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

- The Department of Social Protection-hosted annual Carers' Forum continues to be an important platform for engagement. This initiative could be strengthened further by greater representation from all departments which engage directly with Family Carers.

**Verdict 2<sup>nd</sup> Report: Objective Achieved**

- The Department of Social Protection consulted with caring sector organisations as to how the 2014 Annual Carers' Forum could be better structured to ensure the maximum participation of Family Carers, representative organisations and Government bodies and to ensure a genuine sharing of information. The ambition to shape the event into as meaningful an exchange as possible speaks to the spirit of this action as well as following it to the letter.

**1.1.5. Support national organisations representing the interests of carers**

**Verdict 1<sup>st</sup> Report: Initial progress. But slow pace/delayed start**

- The Monitoring Group acknowledges the Government funding to national carer organisations which enables the provision of essential services such as respite, home care, training, information and advocacy.
- The reality is that funding to national carers' organisations representing the interests of Family Carers has been cut by between 3% and 5% year on year since 2008.
- Funding provision is not consistent throughout the country and is piecemeal in nature.

**Verdict 2<sup>nd</sup> Report: Initial progress. But slow pace/delayed start**

- The Monitoring Group acknowledges the Government funding to national carer organisations, as detailed in the 2<sup>nd</sup> Progress Report, which enables the provision of essential services such as respite, home care, training, information and advocacy.
- The Monitoring Group acknowledges the positive potential of the Action Plan for Dormant Accounts 2014, which will provide funding to the Department of Social Protection of up to €1million to put towards projects to support locally-based training, information and related support services for Carers.
- National organisations representing the interests of carers rely on Section 39 funding to support service provision. While greatly valued, the short-term and precarious nature of this funding makes it difficult to expand services where necessary and respond to support demands from Family Carers.
- Caring sector organisations and the HSE are involved in a number of innovative pilot projects around the country to support care in the home. Quite often, however, funding restrictions and/or a lack of a national perspective prevent these progressive projects being rolled out nationwide. This contributes to regional inconsistencies or disparities in service provision.

**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).**

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

- Notwithstanding a number of individual and isolated initiatives, there are no *national* proactive approaches to identifying carers or to addressing their needs amongst relevant professionals.
- The five posts of Carer Development Officer (Sligo, Kerry, Donegal, Longford/Westmeath, Galway) offer very practical ways of identifying and supporting Family Carers. However, we are concerned about the limited geographic coverage of these posts. The current status of all five posts is unclear, i.e., whether the posts are filled on a full or a part-time basis, or whether all five posts are currently operational.
- The Monitoring Group is aware of instances where Family Carers are being discouraged by healthcare professionals from applying for supports due to a lack of resources to meet support needs.
- Carers Support Groups are potentially a very powerful means of engaging with Family Carers and identifying their needs; however, support for the groups is not consistent across the country.
- Under this Strategy Action the 1<sup>st</sup> Progress Report references Carers Databases. The Monitoring Group would welcome the sharing of statistics from the Databases at a macro level, especially where Family Carers could not be identified, the better to inform the provision and planning of services among not-for-profit, for-profit and public service providers.

**Verdict 2<sup>nd</sup> Report: No Progress**

- The points outlined in the Monitoring Group's response to the 1<sup>st</sup> Progress Report remain relevant.
- In its engagement with the Departments, the Monitoring Group suggested simple, cost-neutral steps that would help health and social service staff to identify Family Carers. This positive engagement happened in the latter half of 2014, but to date these recommendations have not been taken up; if implemented, they could lead to real progress that can be recognised in future reports.
  - One example of such a measure would be to encourage the creation of dedicated Carers' notice boards in hospitals, health centres and GP practices. These notice boards could include a poster asking patients to inform reception staff, their GP or other staff that they are Family Carers
- The 2<sup>nd</sup> Progress Report outlines a number of regional projects with a component which encourages staff to identify carers and their needs. While the Monitoring Group welcomes the projects outlined, it also laments the lack of ambition to roll these out nationwide. Indeed the proliferation of individual regional initiatives points to a gap that is not being addressed nationally.
- Under the strategy this action was allocated to DOH, HSE and DES; the Monitoring Group however considers that all departments have a role in identifying Family Carers, and would encourage responsibility under the strategy being extended accordingly.
- While the DES's information leaflet for parents of children with special educational needs about National Educational Psychological Service is welcomed, we feel compelled to highlight the extremely poor access to supports and therapies for young children with special needs, with waiting times now in excess of 2 years.
- It is not clear that or how Government Departments and organisations such as the HSE record the number of Family Carers identified or supported. Such baseline measures are key to measuring progress in this area.

**1.1.7. Promote carer self-identification initiatives and encourage carers to formally identify themselves to service providers**

**Verdict 1<sup>st</sup> Report: Initial progress. But slow pace/delayed start**

- The monitoring group acknowledges the Carers Count Campaign in advance of Census 2011. This was very positive and significantly helped to secure recognition nationally of Family Carers' role. The campaign sought to ensure that Family Carers were aware of a new question, question 22, which related to their caring role, and that they recorded their contribution appropriately.
- The Monitoring Group notes that Census 2016 will be a 'no change census', not permitting any revisions to Census questions. The extension of question 22 in the 2011 census to include Young Carers represented significant progress but could benefit from revised wording due to concerns around under-reporting and recording of caring roles and caring hours. Given the 'no change census' in 2016, the opportunity further to improve the question will be lost.

- The 1<sup>st</sup> Progress Report makes reference to “Carers Co-ordinators” and “Carers Development Officers (where available)” as a key mechanism for identifying carers. The next, 2<sup>nd</sup> Progress Report should clarify the status of these roles (geographic coverage, part time full/time basis, etc.).

**Verdict 2<sup>nd</sup> Report: No Progress**

- The 2<sup>nd</sup> Progress Report outlines a number of regional projects with a component which encourages carers to self-identify. While the Monitoring Group welcomes the projects outlined, it also laments the lack of ambition to roll these out nationwide. Indeed the proliferation of individual regional initiatives points to a gap that is not being addressed nationally.
- Furthermore, the projects outlined are skewed towards the care of older people. Some of these are very innovative, but what is being done for other cohorts of carers?
- This action requires a national carer awareness campaign. The benefits to the health system are clear; carers that self-identify can avail of supports which should raise the standard of care in the home and decrease the pressure and isolation felt by Family Carers.
- Our response to the 1<sup>st</sup> Progress Report above recognises the importance of question 22 which seeks to record caring roles. However, when we compare Ireland with other countries that record Family Carers in their censuses (UK 10%, Canada 25%), the positive response to the question appears very low. Given that this is to be a ‘no-change’ census, it would be very important that the CSO repeat the ‘Carers Count’ campaign in conjunction with caring sector organisations in advance of Census 2016.
- Under the strategy this action was allocated to the HSE alone; in reality, all Departments have a responsibility to encourage carers to self-identify and formally to identify themselves to service providers. DSP has a particularly important role to play as they are often the Department a carer has first contact with. The Strategy should be amended accordingly.

**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**

**Verdict 1<sup>st</sup> Report: No Progress**

- The recalibration of services from institutional care to care in the home is predicated on the availability of Family Carers; despite this, there has been no national initiative to require Family Carers to be partners in care.
- Whilst the Monitoring Group acknowledges the value of local initiatives described in the 1<sup>st</sup> Progress Report, these are piecemeal and not available nationwide.
- As reported in the 1<sup>st</sup> Progress Report, the involvement of two Family Carers on a Steering Group for a research project is positive but does not represent a shift in national policy to a greater recognition and involvement of Family Carers as partners in care planning and provision.
- In particular, the involvement of Family Carers in the planning and provision of care for care-recipients with Mental Health issues remains problematic and poor.

**Verdict 2<sup>nd</sup> Report: No Progress**

- Considerable effort has been put into outlining specific regional projects that have an element which will encourage the appropriate involvement of Family Carers as partners in care. While the Monitoring Group welcomes these innovative projects, it also laments the lack of ambition to roll these out nationwide. Indeed the proliferation of individual regional initiatives points to a gap that is not being addressed nationally.
- Furthermore, the projects outlined are skewed towards the care of older people. Some of these are very innovative, but what is being done for other cohorts of carers?
- From a Family Carer's perspective, care plans are very hit-and-miss, dependent on the interest and commitment of individual professionals and teams. Carers often report poor follow-up from and coordination between professionals after a patient is discharged from acute care.
- The 1<sup>st</sup> Progress Report refers to the possibility of Family Carers attending primary care clinical meetings where appropriate. The Monitoring Group questioned whether this was common practice, as it did not reflect the experience of many carers.
- The Monitoring Group expressed the concern that, in the Mental Health arena in particular, care plans are overly medical in nature and do not take into account the psychosocial needs of the patient and family on discharge from an acute setting. Furthermore, there is a concern that confidentiality is too often being used as an excuse not to involve Family Carers as key partners in the care plan of their loved one. The Monitoring Group believes that, where appropriate and with facilitation, consent from the patient to full disclosure of information could be encouraged and a holistic Family Care Plan put in place.

**1.2.2. Identify carers and their involvement in discharge planning, including their details provided in discharge letters to GPs**

**Verdict: 1<sup>st</sup> Report: Regressive**

- The Monitoring Group finds the one-line reporting on this element of the NCS disingenuous.
- The reality is that crisis discharge is the norm and that the situation is regressing. Many Family Carers are being put under unfair pressure to assume a caring role regardless of the supports available to them to perform that role adequately.

**Verdict 2<sup>nd</sup> Report: Regressive**

- The Monitoring Group recognises the number of individual initiatives around the country designed to improve the discharge planning process. There is an urgent need for the standard and administration of discharge to improve nationwide. While the HSE references its new guide for discharge and transferring from hospitals, from a Family Carer's perspective this has yet to improve standards across the country. This past year has seen a serious crisis in hospitals, with insufficient beds available to meet needs and patients being treated on trolleys. In this context the Monitoring Group still hears of frequent crisis discharges, where Family Carers are receiving loved ones discharged from hospital without a

practical plan or necessary supports to perform their caring role in a safe and dignified manner.

- The HSE's response recognises this disparity, noting that "the level of engagement / involvement may vary depending on circumstances". Given how crucial appropriate discharge is to the health of the patient and the dignity of the carer, as well as to the more efficient administration of the health system, the Monitoring Group believes dramatic change is required.
- The Monitoring Group seeks clarification on the wording and intent of this Strategy Action, 'Identify carers and their involvement in discharge planning, including their details provided in discharge letters'. What mechanism does the HSE intend to use to seek permission from carers to include their personal details as part of this action; how will it be recorded; and with whom will it be shared?

### **1.3.1. Provide regular benefits advice sessions and information through the application process**

#### **Verdict 1<sup>st</sup> Report: Initial progress. But slow pace/delayed start**

- In most instances Department of Social Protection staff are very informative and helpful when contacted by Family Carers. The Monitoring Group acknowledges that there have been significant improvements in how the Department processes applications and manages calls. Notwithstanding this progress there remain significant opportunities to improve the system further, for example by introducing a Freephone line and reducing call-holding times, and by creating an online application and tracking process.
- Frontline staff should refer Family Carers to support organisations to enable these organisations to provide practical information to carers on entitlements and the relevant application processes.

#### **Verdict 2<sup>nd</sup> Report: Good Progress. Positive Results for Family Carers**

- There has been good progress in relation to this Strategy Action.
- 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. DSP has further amended its communication better to draw attention to the fact that Carer's Allowance is a taxable source of income.
- The Monitoring Group acknowledges the positive potential of the Action Plan for Dormant Accounts 2014 which provides funding to the Department of Social Protection of up to €1million to put towards projects which provide locally based training, information and related support services for Carers. The purpose of this measure will be to help carers up-skill to provide the best care possible, but also to reduce the risk of injury to the carer and to help them cope with the emotional and psychological aspects of their role. Funding will also be made available to provide for the dissemination of resource information for Carers and to provide supports to reduce the social isolation experienced.
- UNDERREPORTING: The Monitoring Group welcomes the DSP's commitment to improving the transition arrangements for children moving from Domiciliary Care Allowance to

Disability Allowance at age 16, and the subsequent review of arrangements for Carer's Allowance. Caring sector organisations look forward to working with the Department on implementing these improvements.

### 1.3.2. Ensure that carers can access benefits advice as early as possible when their caring role begins

#### Verdict 1<sup>st</sup> Report: Initial progress. But slow pace/delayed start

- It is very often the HSE or healthcare professionals who are the first point of contact at the beginning of the caring process. There is a clear responsibility for frontline HSE staff, particularly those involved in discharge from acute settings, to refer Family Carers new to their role on to the right support agencies.
- Whilst Citizens' Information Centres provide a very good service, they are often not the first point of contact for Family Carers. Frontline staff including healthcare professionals and social welfare staff should refer Family Carers to support organisations that can support them with their broader needs and provide practical advice on form completion, eligibility, entitlements, etc.

#### Verdict 2<sup>nd</sup> Report: Initial progress. But slow pace/delayed start

- The points outlined in response to the 1<sup>st</sup> Progress Report still stand. The HSE and other key government departments have a clear duty in relation to this action, but were not assigned any responsibility and as such have offered no response. The Monitoring Group recommends that responsibility for this action be extended to include other key departments, including the DoH and HSE, the better to facilitate the early identification and support of Family Carers.
- The verdict remains at 'Initial Progress'. There has been positive engagement with the DSP, to whom the Monitoring Group suggested specific actions which if implemented could lead to real progress that could be recognised in future progress reports.

### 1.3.3. Publicise more widely that the Carer's Allowance can be shared by two carers providing care on a part time basis

#### Verdict 1<sup>st</sup> Report: Initial progress. But slow pace/delayed start

- Whilst a Banner Headline within the Department's Website will provide good direction for those already on the website, more proactive online methods, including the creative use of social media channels and targeted advertising, could increase awareness amongst Family Carers that Carer's Allowance can be shared by two carers providing care on a part-time basis.
- Many Family Carers do not have access to the internet. The Carer's Allowance application form should be amended to include a footnote to explain how it can be shared between two carers.

**Verdict 2<sup>nd</sup> Report: No Progress**

- Awareness of the possibility of sharing Carer's Allowance is very low. No proactive awareness measures have been taken since the Strategy was launched; the link on the Department's Website, while welcomed, is a passive action targeting those already on the site.
- A positive first step would be to publish the figures on the number of carers availing of care sharing arrangements and to use this as a baseline to measure progress going forward.
- Awareness of care sharing should also be raised through the Carer's Allowance application form.
- The Monitoring Group recognises that caring sector organisations share a responsibility with the Department and Government Agencies to highlight the possibility of sharing Carer's Allowance and are keen to work together to raise awareness.

**1.3.4. Continue to work to reduce waiting periods for processing of Carer's Allowance applications and appeals**

**Verdict 1<sup>st</sup> Report: Good Progress. Positive Results for Family Carers**

- The Monitoring Group acknowledges the "major service delivery modernisation project" which has yielded significant reductions in waiting periods for processing of Carer's Allowance applications. This represents good progress and it will be important to ensure that this reduction in waiting time is maintained.
- Waiting times for appeals, particularly oral hearings, remain problematic; it is not uncommon for waiting times to take up to one year.

**Verdict 2<sup>nd</sup> Report: Initial progress. But slow pace/delayed start**

- The Monitoring Group acknowledged the positive developments made in the 1<sup>st</sup> Progress Report with a 'Good Progress' verdict. Significant service delivery modernisation was implemented to achieve a reduction in waiting periods. However, there has been a slippage in these waiting times and the reduction in the score reflects that. The Monitoring Group acknowledges the new processes and the effort on these issues and hopes that this will lead to times being reduced again.
- UNDERREPORTING: The Monitoring Group welcomes the DSP's commitment to improving the transition arrangements for children moving from Domiciliary Care Allowance to Disability Allowance at age 16, and the subsequent review of arrangements for Carer's Allowance. Caring sector organisations look forward to working with the Department on implementing these improvements.

**1.3.5. Review existing transition arrangements for carers at the end of their caring role**

**Verdict 1<sup>st</sup> Report: Regressive**

- The removal of the Bereavement Grant shows a lack of awareness of the significant cost to families on the death of a loved one. The solution offered of asking Family Carers to apply

for an exceptional needs payment at a point of personal loss and vulnerability shows a lack of understanding at odds with the goals of the strategy to recognise, support and empower.

- No information has been shared on what the review of transition arrangements will involve.

### Verdict 2<sup>nd</sup> Report: Regressive

- The points raised in relation to the 1<sup>st</sup> Progress Report about the impact of the removal of the Bereavement Grant on Family Carers who have lost a loved one are still valid.
- The Monitoring Group suggested a range of practical solutions that would help alleviate some of the difficulties experienced by carers who reach the end of their caring role, but none of these has been implemented.
- DJEI, who have yet to engage with the strategy, should review their supports to ascertain how they can better support Family Carers to return to the workplace after their caring role ends.
- DES: DES should similarly review the training they provide to assess whether it is meeting the needs of those whose caring role has ended and who may require up-skilling and support to re-enter the workplace.
- DSP: The recently introduced Back to Work Family Dividend (BTWFD) supports families to move from social welfare to employment. Those qualifying will receive any increases for qualified children that were being paid on jobseeker or one-parent family payment for the first year of employment. An opportunity was missed by not extending the scheme to include Family Carers and accommodate their transition back into employment at the end of their caring role.
- The long-term financial penalties that arise as a consequence of a caring role can be significant. The immediate cessation of Carer's Allowance on the admission of a care-recipient to a nursing home does not do justice to those who have been caring for decades. Similarly, greater awareness of the Homemaker's Scheme could assist carers who hope to qualify for a Contributory State Pension.

### National Goal 2: Support carers to manage their physical, mental and emotional health and well-being

#### Objective 2.1 Promote the development of supports and services to protect the physical, mental and emotional health and wellbeing of carers

##### 2.1.1. Raise awareness among health and personal social service providers of the physical and emotional health issues that carers may experience

### Verdict 1<sup>st</sup> Report: No Progress

- The 1<sup>st</sup> Progress Report response to Strategy Action 2.1.1 is piecemeal and anecdotal. There is little evidence that the 1<sup>st</sup> Progress Report comprehensively and robustly captures the national reality. This does not befit a report on a National Strategy. The Monitoring Group used the word 'disingenuous' to describe this written response.

- Under this Strategy Action the 1<sup>st</sup> Progress Report makes reference to “Carer Departments”, “Carers Co-ordinators” and “Carers Development Officers” in the context of disseminating information at a local level. However, there is a lack of clarity regarding these resources; the 2<sup>nd</sup> Progress Report should clarify the status of these roles (scope of role, geographic coverage, part-time/full-time basis etc.)

**Verdict 2<sup>nd</sup> Report: Initial progress. But slow pace/delayed start**

- The pioneering progress in relation to the InterRAI suite and the development of a Carer’s Needs Assessment, as recognised under Strategy Action 2.1.3 below, will also serve to raise awareness among health and personal social service providers of the physical and emotional health issues that carers may experience. It is worth bearing in mind that this will only benefit those caring for an older person; an indication of whether and when this will be rolled out to other cohorts of carers would be beneficial.
- The Monitoring Group recognises the detail provided by the HSE in response to this Strategy Action. Numerous individual projects are outlined; however, the concern outlined in our response to the 1<sup>st</sup> Progress Report remains; we still do not have a picture of supports nationwide. Projects in five counties are mentioned, but Family Carers in other counties will wonder whether there are projects to support them in their regions. With a national strategy, we should strive to provide this information. Specific figures on the number of carers supported in all regions would be beneficial.
- The projects outlined are skewed towards older people. Some of these are very innovative, but what is being done for other cohorts of carers?
- One way of raising awareness amongst health professionals would be to include a carer representative on multidisciplinary teams.

**2.1.2. Encourage carers to attend their GP for an annual health check**

**Verdict 1<sup>st</sup> Report: No Progress**

- The 1<sup>st</sup> Progress Report response to this Strategy Action 2.1.2 is piecemeal and anecdotal. 1<sup>st</sup> Progress Report response begins with: *“Approaches taken to encourage carers to attend their GP for an annual health check vary from one HSE area to another”*. There is no sense that the report is reflective of the national reality. Aside from reference to ‘Carers Week’ as an important mechanism for raising awareness, there is no evidence of attempts to progress this Strategy Action ‘nationwide’ as one would expect from action relating to a National Strategy.
- The Monitoring Group took issue with the Strategy Action as framed in The NCS, noting that the core issue is not that Family Carers need to be ‘encouraged’ to attend their GP; rather the issue of Family Carers’ often poor self-care is related to support and funding. A voucher to see their GP once a year is an example of a measure which would adequately meet this Strategy Action.
- The lack of progress on this Strategy Action has a detrimental impact; Family Carers continue to neglect their own physical and mental health.

**Verdict 2<sup>nd</sup> Report: No Progress**

- It is unclear whether the DOH's response is focused on encouraging the cared-for person or carers themselves to attend the GP. The latter is the focus of this Strategy Action. In response to the points made:
  - From Family Carers' perspective, the restoration of discretionary Medical Cards previously withdrawn, referenced in the 2<sup>nd</sup> Progress Report, represents the remedying of a disastrous decision. The net result is at best neutral, and not something that can be construed as progress.
  - The proposal to provide universal GP care free at point of access to those under 6 and over 70 will be welcomed by those who fall into those cohorts. However, those between the ages of 7 and 69 with frequent GP visits and high medical bills would be better served by a mechanism that responded to medical need. It is not clear how this action relates to the objective of this Strategy Action, actively to encourage (and support) Family Carers of all ages to attend their GP.
- The cost of Family Carers attending their GP is to be understood in the context of related costs such as prescription charges, which have increased fivefold since they were introduced in 2010.
- The HSE's response is exactly the same as the previous year; accordingly the assessment and score remain the same.

**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**

**Verdict 1<sup>st</sup> Report: Good Progress. Positive Results for Family Carers**

- There has been good progress on this Strategy Action. The HSE has taken a very innovative approach. Ireland is to be the first country to develop a Carer's Needs Assessment as part of the InterRAI suite.
- The HSE has been proactive in engaging with Family Carer representative groups on Strategy Action 2.1.3 The Monitoring Group described this as 'a model of good practice'.
- Despite some delays, this Strategy Action has the potential to have significant positive impact on Family Carers' lives, subject to being properly resourced.

**Verdict 2<sup>nd</sup> Report: Good Progress. Positive Results for Family Carers**

- As recognised in our response to the 1<sup>st</sup> Progress Report, the development of a Carer's Needs Assessment as part of the InterRAI suite is innovative and pioneering.
- The Monitoring Group recommends that Family Carers be given an entitlement to a Carer Needs Assessment similar to the entitlement that currently exists in other jurisdictions including the UK.
- The Monitoring Group suggests that, once implemented, the Single Assessment Tool and Carer Needs Assessment be evaluated with a view to extending their availability to the wider population.

#### 2.1.4. Continue to implement the recommendations of the Home Solutions Report on telecare

##### Verdict 1<sup>st</sup> Report: Initial progress. But slow pace/delayed start

- So far, there has been a positive impact on the small cohort of Family Carers that have been involved in the innovative telecare pilot projects.
- However, the 1<sup>st</sup> Progress Report asserts that 'resources are an issue in terms of this roll out nationwide. National roll-out remains a pressing concern.'
- The prioritisation and implementation of this project nationwide would provide a much needed tool assisting older people to live well in their own homes for as long as possible. The Home Solutions Report demonstrated that the telecare service was highly effective in supporting older people with significant needs to remain at home. The Report reached the conclusion that a telecare service should be regarded as a substantive component of home care services. The assurance and confidence offered by telecare made a considerable contribution to the decision of the older people who took part in the study to remain at home. The resource issue must be overcome if care in the home is to be truly supported.
- The withdrawal of the Telephone Allowance as a component of the Household Benefits Package in Budget 2014 undermines Family Carers' ability to avail of such innovative telecare projects.

##### Verdict 2<sup>nd</sup> Report: Initial progress. But slow pace/delayed start

- The Monitoring Group recognises that there are many positive projects around the country not referenced in the 2<sup>nd</sup> Progress Report. While the 2<sup>nd</sup> Progress Report does refer to 60 assistive technology packages in Inishowen, a comprehensive account of telecare projects around the country would provide a useful benchmark.
- 'Resource challenges' are again mentioned as a challenge to the implementation of the recommendations of the Home Solutions Report.
- With the understanding that assisted living technology projects will always be complementary to and not a replacement for face-to-face care, the Home Solutions Report underlines how important access to such projects is: "*Telecare should be regarded as a substantive ingredient of home care services especially for people with high levels of need*". The Report specifically finds that funding telecare projects is effective and represents a good return on investment: "*telecare is likely to contribute to the appropriate use of limited and specialist resources, and support the most effective use of finances*".
- The progression from regional pilot projects to nationwide provision is vital if we are to remedy the current situation where an element of geographic lottery can determine access to telecare supports.

**2.1.5. Promote awareness of adult and child protection services that are in place**

**Verdict 1<sup>st</sup> Report: Initial progress. But slow pace/delayed start**

- The Monitoring Group recognised that there were clear improvements in this Strategy Action where it relates to older people; however, there is no mention at all in the reporting of child protection services.
- There has been marked progress in the areas of Elder Abuse, Child Abuse and Garda Vetting. There has been positive collaboration with the Community and Voluntary sector and significant public awareness campaigns around Elder Abuse in particular.
- The work of the NCPOP has been to the fore in highlighting the issue of Elder Abuse. The Monitoring Group noted that funding for NCPOP is coming to an end and expressed the hope that momentum on elder abuse awareness is maintained in the face of funding challenges.
- Whilst Elder Abuse research, practice and support services have indeed developed, the same could not be said regarding the issue of child protection and Young Carers. Young Carers should be explicitly named within child protection guidelines.
- Related to awareness of services is the quality of the adult and child protection services themselves. The Monitoring Group expressed concern at the lack of capacity to provide adequate vacation/sick cover for adult and child protection staff.

**Verdict 2<sup>nd</sup> Report: Initial progress. But slow pace/delayed start**

- While there have been positive actions in relation to this Strategy Action in the past year, the revelations about abuses such as those committed in Áras Attracta have left Family Carers very upset and eroded confidence in adult protection services. Accordingly, the score for this Strategy Action remains as 'Initial Progress'.
- The 2<sup>nd</sup> Progress Report outlines an increase in the number of case workers for the protection of older people and describes a number of important initiatives aimed at preventing elder abuse.
- The development of 'Safeguarding Vulnerable Persons at Risk of Abuse' by the HSE's social care division has provided an important overarching policy for all agencies which work with older persons with a disability.
- The establishment of Tusla, The Child and Family Agency, in January 2014, is a welcome move and the Monitoring Group is hopeful that the new agency recognises Young Carers as a cohort requiring their support.
- The appointment of a Health Service 'Children First' Lead is welcomed by the Monitoring Group, as is the mandatory training programme for all HSE employees in 'Children First'.

**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.**

**Verdict 1<sup>st</sup> Report: No Progress**

- The 1<sup>st</sup> Progress Report refers to the Programme for Government's commitment to review Fair Deal with a view to developing a system for financing community and long-term care

which supports older people to stay in their own homes. The report states that it will be completed by early 2014. This completion date has now passed and the review has not been published. Communication in relation to the review has been poor. Furthermore, apart from public consultations, organisations representing Family Carers have not been engaged with directly. Given the intricacies of this issue, and its direct impact on Family Carers, this is regrettable.

### **Verdict 2<sup>nd</sup> Report: Regressive**

- The Monitoring Group cannot emphasise enough the importance of providing affordable options for families to provide care for loved ones in their own homes. The review of 'Fair Deal' with a view to financing the same is of vital importance. The timeline for the review has been missed, and there still remains an imbalance between the entitlement to nursing home care and the lack of entitlement to care in the home. This imbalance can best be redressed through legislation affording a statutory entitlement to home care services. Movement on this issue is critical as it has the potential to release pressure on those waiting for discharge from acute settings.
- The 2<sup>nd</sup> Progress Report indicates that the review is expected to be completed 'in the coming months'. The Monitoring Group hopes this will result in the development of progressive options for financing care in the home.

### **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).**

#### **Verdict 1<sup>st</sup> Report: No Progress**

- Nothing has been reported under this Strategy Action in the 1<sup>st</sup> Progress Report.
- National standards for home support services are overdue and of high importance. The laudable shift towards more care being delivered in the home adds urgency to this Strategy Action. The failure to report any progress here is a concern.

#### **Verdict 2<sup>nd</sup> Report: No Progress**

- The DOH's response outlines that primary legislation is required to progress this Strategy Action. However, there is no sense of urgency in relation to moving this forward: "*This is being progressed in the context of overall legislative and resource priorities*".
- The HSE outlines the Quality Standards that successful tenders must meet to qualify for the National Tender for Enhanced Home Care Packages. However, those who receive private care or statutory home care are not protected by the same level of Quality Standards. It is imperative that families can expect the same quality of home care regardless of the source.
- The Monitoring Group acknowledges the work of the Migrant Rights Centre Ireland in leading a national project to examine home care standards, and the representation on the committee of key stakeholders including HIQA, HSE, TCA and SIPTU. This work has however

been initiated by the voluntary sector and funded by the Irish Human Rights and Equality Commission, rather than by statutory bodies.

**Objective 2.2. Support children and young people with caring responsibilities and protect them from the adverse impacts of caring.**

**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.**

**Verdict 1<sup>st</sup> Report: Initial progress. But slow pace/delayed start**

- As forecasted in the 1<sup>st</sup> Progress Report, the Monitoring Group looks forward to the development of national guidelines by the National Education and Welfare Boards on School Attendance Strategies, which will include measures to support children with caring responsibilities.
- The 'Study of Young Carers in the Irish Population' (October 2010) calls for targeted information campaigns in primary and secondary schools. Whilst no such targeted information campaigns yet exist, the Social Personal and Health Education (SPHE) Development Team were briefed by the Carers Association's Young Carers Development Officer on 1<sup>st</sup> December 2013 about raising awareness of Young Carer issues as part of the new Personal Safety modules. SPHE is for children in primary and secondary schools, and incorporating modules on Young Carers into this curriculum would represent progress.
- The Monitoring Group acknowledges funding from DECLG to fund the position of Young Carers Outreach and Development Co-ordinator with The Carers Association for a two year period from 2012 to 2014. This initiative had a positive impact and also produced a toolkit for those working with Young Carers. These guidelines have been incorporated into the National Youth Council of Ireland's 'Access All Areas: a diversity toolkit for the Youth Work Sector'. To maintain positive momentum, a similar toolkit could be developed and rolled out among education providers nationwide. This is in line with research carried out by NUIG and funded by the Office of the Minister for Children and Youth Affairs in 2010, which identified understanding and assistance from teachers as a clear support need for Young Carers.

**Verdict 2<sup>nd</sup> Report: Initial progress. But slow pace/delayed start**

- DCYA: While the verdict remains the same, the Monitoring Group recognises that there has been very positive engagement which it is hoped will lead to real outcomes that can be recognised in future reports. Relationships with the newly formed TULSA have been established, and it is to be hoped the links between TULSA and the DES will lead to coordinated responses to Young Carers' needs. In meetings with DCYA, there was an indication that Young Carers would be recognised in the upcoming Youth Strategy as a specific group with specific support needs; this would be a real positive.
- DECLG: A Young Carer Development Officer position was funded by DECLG on a pilot basis in one region. This post is key to developing supports for Young Carers; funding for additional development workers would allow for this to be done on a national basis.

- DES: The 2<sup>nd</sup> Progress Report provides good information on how young people in general are being supported, but provides little specificity on how Young Carers in particular will be supported.

### 2.2.2. Encourage statutory agencies to review the way that they respond to children and young people with caring responsibilities.

#### Verdict 1<sup>st</sup> Report: No Progress

- The Monitoring Group questions the framing of this Strategy Action, particularly the use of the word 'encourage', from which it is difficult to measure any real outcomes. As many Statutory Agencies' capacities are stretched to breaking point, it is difficult to see an action encouraging reviews yielding any results.
- The Monitoring Group is not aware of any reviews conducted by statutory agencies about the way they respond to children and young people with caring responsibilities.
- We welcome the establishment of the Child and Family Agency on 1<sup>st</sup> January 2014. To date, organisations representing Family Carers have not been consulted with regard to the Agency's strategic planning. Whilst recognising that it is early days for the agency, this Strategy Action outlines that such engagement is vital.

#### Verdict 2<sup>nd</sup> Report: No Progress

- Neither the DOH nor the DES has responded to this Strategy Action. Given their key role in responding to the needs of children and young people with caring responsibilities, this is very disappointing.
- DCYA references "One Child, One Team, One Plan" as a strategic initiative by the Education Welfare Service of TULSA aimed at providing an enhanced response to the needs of children, families and schools. There is no indication of how this will meet the needs of Young Carers in particular.
- As recognised elsewhere (SA 2.2.1), there has been positive engagement with DCYA and TULSA. This is the beginning of a process from which we anticipate we will be able to recognise real progress in future reports.
- **Underreported:** The Monitoring Group welcome indications given by DCYA during recent meetings that Young Carers would be recognised in the forthcoming National Youth Strategy as a target group with specific support needs.

### 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.

#### Verdict 1<sup>st</sup> Report: No Progress

- Research carried out by NUIG in 2010, and funded by the Office of the Minister for Children and Youth Affairs, made a series of recommendations relating to awareness-raising among young people and supporting Young Carers that have yet to be implemented nationwide. 'Research on Young Carers in the Irish Population' called for a coordinated cross-sectoral, multi-departmental and multiagency approach; raising public awareness of children and

young people as carers; proactive identification of Young Carers where there is already a known care need; development of referral pathways to supports; ensuring Young Carers have a voice in issues that affect them; and development of suitable materials to inform young people about caring.

- Recommendations from this research relating to mechanisms for young people to make contact with service providers, each of which is yet to be implemented, include: 'Young Carer projects' where self-referrals by Young Carers can be encouraged by establishing dedicated Young Carers' websites and organisations; targeted information campaigns in primary and secondary schools; increasing the profile of potential caring responsibilities of young people among professionals in statutory and non-statutory bodies; identifying and raising awareness about the characteristics of young people who act as carers.
- The 1<sup>st</sup> Progress Report recognises that "In some areas, the Carers Association has developed a contact service for children and young people with caring responsibilities". The Roscommon Young Carers Group provides a once-monthly respite for Young Carers from their caring role; however, similar supports are not available nationwide.
- The Carers Association has developed a toolkit for professionals working with Young Carers. This toolkit has been incorporated into the National Youth Council of Ireland's 'Access All Areas: a diversity toolkit for the Youth Work Sector'. To maintain positive momentum, this toolkit should now be rolled out nationwide for professionals working in the areas of education, health and social care.

#### **Verdict 2<sup>nd</sup> Report: No Progress**

- There has been no attempt to respond to the core of this Strategy Action. The description of one positive support in a single geographic area gives no indication of the strength and weaknesses of support services nationwide. Throughout the document, reporting by the HSE on supports relating to Young Carers is weak.
- The Monitoring Group's comments in response to the 1<sup>st</sup> Progress Report remain valid and have not been addressed.
- The responsibility for this Strategy Action should be extended to other Departments, rather than being that of the DOH alone.

#### **2.2.4 Investigate and analyse the situation of children and young people undertaking caring roles**

#### **Verdict 1<sup>st</sup> Report : Initial progress. But slow pace/delayed start**

- The inclusion of a question in the Census of Population 2011 concerning carers and Young Carers was a positive development; however, the framing of Question 22 in the census could be improved more accurately to capture the number of Adult and Young Carers. Notwithstanding the need for improvement, the Monitoring Group understands that this will not be possible in Census 2016, as Government has confirmed that no change will be permitted to any of the questions. Despite this, the Census 2011 questions are still generating very useful information about Family Carers, and Young Family Carers in

particular. The Monitoring Group welcomes and looks forward to the publication of statistical profiling of the 6,449 young people identified as Young Carers in Census 2011.

- Our understanding of Young Carers is still poor. Whilst the 'Study of Young Carers in the Irish Population' (October 2010) represented a first step in developing an understanding of Young Carers, certain cohorts of Young Carers, such as those in more vulnerable situations, were not captured at all due to difficulties in securing their participation in the study. Further research and deeper analysis are required.

**Verdict 2<sup>nd</sup> Report: Initial progress. But slow pace/delayed start**

- The positive changes to Census 2011 recognised in the Monitoring Group's response to the 1<sup>st</sup> Progress Report are still valid. Indeed, the statistical profiling of Young Carers identified in Census 2011 is warmly anticipated, and the Department indicates that it will be published shortly.
- The anticipated profiling of Young Carers will provide very useful quantitative information; there is also merit in complementary qualitative studies to be carried out in order to build up a picture of the challenges and barriers Young Carers face. This would require extension of responsibility for this Strategy Action beyond the CSO.
- In advance of Census 2016, the Monitoring Group encourages the Government to support a similar campaign to that run in the last Census to raise awareness around the new questions relating to caring and Young Carers (Q22). Caring sector organisations would be willing to support such an initiative; it is certainly warranted, as we know there are more Young Carers than are being captured by this question.

**National Goal 3: Support carers to care with confidence through the provision of adequate information, training, services and supports**

**Objective 3.1. Promote the availability of user friendly and timely information and advice.**

**3.1.1. Ensure frontline staff in key 'first contact' agencies such as local authorities, local health offices and personal social service providers have the correct information to be able to sign-post carers to other services as appropriate.**

**Verdict 1<sup>st</sup> Report: No Progress**

- No new progress has been reported under this Strategy Action; in the 1<sup>st</sup> Progress Report, only existing initiatives and intention to pursue actions in the future is outlined.
- The 1<sup>st</sup> Progress Report response to Strategy Action 3.1.1 is piecemeal and anecdotal. The 1<sup>st</sup> Progress Report response states that: "Approaches to ensuring that frontline staff have the correct information to sign-post carers to other services as appropriate vary from one HSE to the next depending on local resources". There is no sense that the report is reflective of the national reality, as one would expect from a report on a National Strategy.
- The Monitoring Group acknowledges DECLG's future plans to pilot Housing Advice Centres as part of a coordinated approach to providing integrated and accessible advice. Whilst this may lead to improvements in time, from a Family Carer's perspective there has been no

discernible improvement since the launch of the NCS in the standard and accuracy of information provision and referral.

- The Monitoring Group is aware of instances where Family Carers have been given incorrect information by staff interfacing with carers. Failure to refer on to support organisations can lead to carers not being aware of and so not availing of much needed supports.

**Verdict 2<sup>nd</sup> Report: Initial progress. But slow pace/delayed start**

- There has been positive engagement on this issue across departments and, as noted in the Government's 2<sup>nd</sup> Progress Report, modest practical steps have been taken towards its implementation. However, further progress is required to ensure a high standard of signposting by frontline staff. The Carers Association has offered its services to train frontline staff in referring carers to relevant supports, and this offer remains available to all departments.
- Carer Coordinators are referenced in the HSE's response as one of the frontline staff with responsibility for signposting. In response to the 1<sup>st</sup> Progress Report, the Monitoring Group requested that the HSE clarify the status of these roles (geographic coverage, part-time/full-time basis etc). The Monitoring Group understands that a number of the Carer Coordinator positions have been wound down, or the post remains vacant following the departure of previous staff. Carer Coordinators are referenced here again without this requisite contextualising information.
- In its response the DECLG references its instruction to Local Authorities to establish Housing and Disability Advice Steering Groups. Ensuring Family Carers are represented on these Steering Groups would be a positive in the context of this Strategy Action.

**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**

**Verdict 1<sup>st</sup> Report: Initial progress. But slow pace/delayed start**

- Under this Strategy Action the 1<sup>st</sup> Progress Report does not report any new progress, referring only to existing initiatives and intention for future action.
- **Underreported:** The DSP's recent review of the Domiciliary Care Allowance application and review process was a good example of ongoing improvements in materials available to Family Carers, yet was unreported in the 1<sup>st</sup> Progress Report.
- Very significant information resources exist within carer organisations and offer a good starting point from which to review the materials available. To date there has been no review. Caring sector organisations are willing to work with Departments in this regard.
- Under Strategy 3.1.1 we outline our concern about the referencing of "Carer Departments", "Carers Coordinators" and "Carers Development Officers" where clarification of the nature and status of these roles is required (scope of role, geographic coverage, part-time/full-time basis etc.).

**Verdict 2<sup>nd</sup> Report: Initial progress. But slow pace/delayed start**

- DSP has engaged positively on this issue, hosting a themed meeting in November with the Monitoring Group to discuss information-related suggestions and making modest practical changes.
- **UNDERREPORTING:** Following discussions with representatives from the Monitoring Group, the DSP has made a number of welcome amendments to their letters and communications with Family Carers; these however remain unreported
- The HSE's response does not refer to the core of the Strategy Action, which is to 'review' relevant material and investigate how more comprehensive material dedicated to carer's needs can be developed and distributed.
- The Monitoring Group's queries from 1<sup>st</sup> Progress Report regarding "Carer Departments", "Carers Coordinators" and "Carers Development Officers" have not been answered.

**3.1.3 Ensure 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**

**Verdict 1<sup>st</sup> Report: No Progress**

- The projected timeframe for this Strategy Action has passed and the 1<sup>st</sup> Progress Report fails to describe any progress from any of the Departments. The Monitoring Group is not aware of any initiatives that speak to this Strategy Action.

**Verdict 2<sup>nd</sup> Report: Initial, But Slow. Progress**

- DOH and DCYA have added links on their website to sites such as [www.carersireland.com](http://www.carersireland.com) and to [www.youngcarers.ie](http://www.youngcarers.ie) which provide information and support to carers. The recent engagement with DSP has been positive and will, it is hoped, lead to concrete outcomes.
- The Monitoring Group acknowledges the funding provided to organisations that represent Family Carers. While this is a positive in that these organisations strive to meet the information needs of subgroups of carers, each Department still has a responsibility to be proactive in supporting the information needs of these carers in relation to the services and supports they provide. While many of the information initiatives listed by the HSE are positive, the Monitoring Group emphasised that all courses for carers should include advice on meeting carers' own needs (self-care, stress management, etc.) in addition to meeting the care needs of their loved ones.
- Furthermore, many of the examples listed deal with those caring for older people. This is an important cohort of carers, but it is not clear how the information needs of other subgroups of carers (e.g. children and young people with caring responsibilities, carers in rural areas) are being met. Again, reporting on a number of positive examples does not allow us to build a picture of national coverage, which makes it impossible to say whether the information needs of carers all over the country are being addressed. There is no indication of any ambition to take these positive individual regional initiatives and roll them out nationally for the benefit of all carers regardless of geography.

- This Strategy Action applies to all Departments, yet there is no response from the Department of Transport, Tourism and Sport, the Department of Education and Skills, The Department of Social Protection or the Department of Jobs, Enterprise and Innovation (the last has not engaged at all around the Strategy).

### 3.1.4. Proactively collate and disseminate information about services and supports available at a local level for carers

#### Verdict 1<sup>st</sup> Progress Report: No Progress

- At a national level, the Monitoring Group acknowledges the provision of a range of funding measures which allows organisations like The Carers Association to collate and disseminate information about services and supports at a local level for carers.
- Notwithstanding this, the 1<sup>st</sup> Progress Report fails to describe any new progress under this Strategy Action, outlining only intentions for future action.
- Under this Strategy Action the 1<sup>st</sup> Progress Report makes reference to “Carer Departments”, “Carers Coordinators” and “Carers Development Officers” in the context of collating and disseminating information at a local level. There is a lack of clarity regarding these resources; the 2<sup>nd</sup> Progress Report should clarify the status of these roles (scope of role, geographic coverage, part-time/full-time basis etc.)

#### Verdict 2<sup>nd</sup> Report: Initial, But Slow. Progress

- Engagement with the DSP has been positive in relation to this Strategy Action, with potential for concrete progress on foot of the themed meeting which took place with the Monitoring Group in November and ongoing discussions with the department.
- **Underreporting:** The Monitoring Group acknowledges the positive potential of the Action Plan for Dormant Accounts 2014 which provides funding to the Department of Social Protection of up to €1million to put towards projects which provide locally based training, information and related support services for Carers. The purpose of this measure will be to help carers up-skill to provide the best care possible, but also to reduce the risk of injury to the carer and to help them cope with the emotional and psychological aspects of their role. Funding will also be made available to provide for the dissemination of resource information for Carers and to provide supports to reduce the social isolation experienced.
- In the HSE’s response, the naming of undefined resources such as “Carer Departments”, “Carers Coordinators” and “Carers Development Officers” is repeated in this progress report despite queries/concerns raised after the 1<sup>st</sup> Progress Report by the Monitoring Group as to their national reach and impact. As no clarification has been provided, this response is of little value.
- The NCS names the HSE and DSP as responsible for delivery on this Strategy Action; the Monitoring Group however sees the proactive dissemination of information as important for all Departments, and believes all Departments should report on this action.

### 3.2.1. Identify gaps in the content of current training programmes for carers (in conjunction with carer organisations).

#### Verdict 1<sup>st</sup> Report: No Progress

- The 1<sup>st</sup> Progress Report states that SOLAS will support the delivery of integrated education and training that is relevant to individual needs, “including those of carers”. Many of the programmes supported by SOLAS are focused on ‘pathways to work’; the report contains no information on measures to identify gaps in the content of current training programmes for Family Carers. Nor does it outline plans to engage with carer organisations on this issue.
- The increase in the numbers of people with intensive care needs being cared for at home must be matched by an increase in the training available for Family Carers around high-dependency care, condition-specific training and palliative care. Similarly, the transition from a long-term caring role to employment requires specific retraining options.
- While the 2013 Momentum Training Programme made specific provision for the training of Family Carers, the Momentum 2014 programme does not.

#### Verdict 2<sup>nd</sup> Report: Initial, But Slow. Progress

- The Monitoring Group acknowledges the support given to caring organisations from Government Departments and agencies to provide training for Family Carers. It also recognises the responsibility shared with Government Departments and agencies to identify gaps in the current training programme for Family Carers. The HSE refers to a number of positive regional initiatives in response to this Strategy Action. For example, the HSE’s response provides figures on the numbers of carers reached in the Galway initiative. In order for gaps in the content of current training to be identified, such figures should be available at a national level. There is no acknowledgment of the ‘postcode lottery’ when it comes to training for carers, nor any indication of an ambition to roll out successful initiatives nationally.
- **Underreported:** Action Plan for Dormant Account 2014 commits €1 million of funding to the DSP to provide ‘structured training programmes on relevant subjects for Family Carers’. The 2<sup>nd</sup> Progress Report acknowledges this potentially transformative funding under Strategy Action 1.1.5 and 1.3.1, but not here.
- Furthermore, the Monitoring Group understands that the Carer Needs Assessment tool to be included within the InterRAI suite will help identify the training needs of carers caring for older people. Neither of these initiatives are yet in effect, but both have potential for positive impact in the future.
- The initiatives listed by the HSE are skewed towards carers of older people, leaving unaddressed the question of what is available for those caring for people with mental health issues, children with disabilities or Young Carers.
- This Strategy Action is vital for a functioning health system. The Monitoring Group believes that comprehensive training for Family Carers should be a condition of discharge from an acute setting to the home, and embedded within transfer of care protocols.
- The issue of Momentum training no longer making specific provision for the training of Family Carers still stands.
- The Department of Education and Skills’ response names Education and Training Boards [ETBs] as responsible for delivering on this Strategy Action with no indication as to whether ETBs are meeting the goals of the strategy. The Monitoring Group understands that where agencies (like ETBs) are working under the Department, the Department is responsible for reporting about progress in relation to the Strategy Action.

**3.2.2. Enhance the accessibility of education and training courses through the use of face-to-face, on-line and distance learning options.**

**Verdict: No Progress**

- The 1<sup>st</sup> Progress Report states “There are a range of tuition models available to adult learners including online and blended learning options”. This response does not indicate what range of models exists; whether they are available around the country; and whether these options suit Family Carers’ needs. This response is piecemeal and anecdotal. There is no sense that this response is reflective of the national reality, as one would expect from a report on a National Strategy.

**Verdict 2<sup>nd</sup> Report: Initial, But Slow. Progress**

- The Monitoring Group acknowledges the support given to caring organisations from Government Departments and agencies to provide training for Family Carers. It also recognises the responsibility shared with Government Departments and agencies to enhance the accessibility of education and training options.
- The response in the 2<sup>nd</sup> Progress Report lacks a focus on the **accessibility** of training provided and moves to enhance this for Family Carers. The needs of subsets of Family Carers such as Young Carers are not addressed in this response. The Monitoring Group’s Action Plan suggested steps that could be taken to progress this action, but there is no indication that these suggestions have been taken on board. Caring sector organisations are keen to work with Departments and agencies to further these actions.
- **Underreported:** As noted in response to Strategy Action 3.2.1, the €1 million Dormant Accounts funding for training for Family Carers has the potential to be transformative and to provide training in accessible formats for Family Carers.
- The Department of Education’s response names Education and Training Boards [ETBs] as responsible for delivering on this Strategy Action with no indication as to whether ETBs are meeting the goals of the strategy. The Monitoring Group understands that where agencies (like ETBs) are working under the Department, the Department is responsible for reporting about progress in relation to the Strategy Action.

**Objective: 3.3 Promote the development of accessible living environments for all**

**3.3.1. Prioritise funding for the operation of the suite of housing grants for older people and people with a disability and ensure they can be accessed in a timely way.**

**Verdict 1<sup>st</sup> Report: Regressive**

- Housing Grant Schemes (including Mobility Aids Grants), which are an essential piece of the jigsaw in making care in the home viable, have had their funding halved from €79m in 2011 to just €38m in 2014; further, changes to the scheme announced in January 2014 will mean that even less people are now eligible.
- Poor scheme management along with reduced funding allocations means that each year Local Authorities run out of money, forcing grants to be suspended indefinitely and leading to a vicious cycle where in reality only low-income, crisis applicants have any real hope of

securing a grant. The practice of closing off or suspending applications during the year distorts scheme figures and prevents the true extent of demand being monitored.

### **Verdict 2<sup>nd</sup> Report: Regressive**

- The Monitoring Group acknowledges and welcomes the introduction of a disregard for Carer's Allowance in calculating the household income for the schemes operated by DECLG. However, the issues outlined above in relation to the 1<sup>st</sup> Progress Report persist. Accordingly, the score for this Strategy Action remains 'regressive'.
- There remain unacceptable waiting times for housing grants to be awarded. The Monitoring Group understands that, in County Offaly, 70 people are on the waiting list for HAGs, and are being told they will have to wait 3-5 years for grant to be awarded.
- The Monitoring Group regrets that no organisations representing Family Carers were included as members of the Review Group which reviewed the Housing Grant (Review of the Housing Grants for Older People and People with a Disability, June 2013, Appendix 1).
- Some of the changes made to the operation of the HAGs scheme are regressive from a Family Carer's perspective. For example, the lowering of the maximum grant available for the Housing Adaptation Grant for People with a Disability disadvantages those who require more significant adaptations to make their home a safe environment to live in. Furthermore, the 'total household income' will now be taken into account when assessing eligibility for grants. Appropriate housing options in urban areas are not currently meeting demand, while the cost of renting is escalating. In this context, an older couple in need of a housing grant may be penalised if their adult daughter or son is living with them, even if on a temporary basis.
- The inadequacy of the HAGs and MAGs schemes to meet demand has a real negative effect on Family Carers and those they care for, and is at odds with Government Policy to support people remaining in their own homes for as long as possible.

#### **3.3.2. Identify good practice in implementing assistive technology and ambient assistive living technology to support independent living and telehealth opportunities.**

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

- The Monitoring Group acknowledges the importance of assistive technology and telehealth pilot projects currently in place. In accordance with the goals of a National Strategy, efforts should focus on mainstreaming these projects, raising the quality of and access to assistive technologies and telehealth across the country as a whole.
- It is worth noting again that the withdrawal of the Telephone Allowance as a component of the Household Benefits Package in Budget 2014 undermines Family Carers' ability to avail of innovative telehealth projects.

### **Verdict 2<sup>nd</sup> Report: Initial progress. But slow pace/delayed start**

- The Monitoring Group commends the projects named by the HSE in response to this Strategy Action; however, there is no indication of ambition to progress from successful pilots to national programmes. Similarly, there do not seem to be structures in place to

measure success of disparate projects to develop best practice in the area. A national lead in coordinating such information would be useful.

- A National Strategy demands an accurate picture of supports across the country. This has not been provided.
- DECLG: The delay in the implementation of a pilot project to test good practice in sustainable communities for people with disabilities is particularly regrettable when Government are pursing care in the home as a preferred model of care.

### 3.3.3. Review and up-date Transport Sectoral Plan under Disability Act 2005

#### Verdict 1<sup>st</sup> Report: Regressive

- Whilst, as stated in the 1<sup>st</sup> Progress Report, the review of the Transport Sectoral Plan was completed, updated and published by August 2013, from a Family Carer's perspective Transport supports have diminished since the National Carers Strategy was published. The closure of the Mobility Allowance scheme and the Motorised Transport Scheme to new applicants without clarity about replacement schemes is a step backwards for Family Carers and those that they care for.
- In addition, following the ruling by the European Court of Justice in April 2013, the excise relief on the fuel element of the Disabled Drivers and Disabled Passengers scheme will be discontinued on 31<sup>st</sup> December 2014. The Government has proposed replacing the Disabled Drivers and Disabled Passengers scheme with a Fuel Grant Scheme, but it is unclear whether members of the former scheme will lose out under these arrangements.

#### Verdict 2<sup>nd</sup> Report: Regressive

- While we acknowledge that the DTTAS has reviewed and updated the Transport Sectoral Plan, there have been a number of actions outside the Plan and outside the control of DTTAS that undermine the goals of the plan to provide accessible 'Transport for All'. These regressive moves relating to the Mobility Allowance Scheme, the Motorised Transport Scheme and the Disabled Drivers and Disabled Passengers Scheme are outlined in our response to the 1<sup>st</sup> Progress Report above. A year has passed and the negative impact of these changes has materialised for Family Carers; accordingly, the score for this action remains 'Regressive'.
- Transport is a vital issue for Carers and those they care for, and this Strategy Action provides the only opportunity for comment on these issues within the NCS.

### National Goal 4: Empower carers to participate as fully as possible in economic and social life

#### Objective 4.1 Enable carers to have access to respite breaks

##### 4.1.1. Promote a better awareness of the existence of the Respite Care Grant

#### Verdict 1<sup>st</sup> Report: Regressive

- The 19 percent cut to the Respite Care Grant imposed in Budget 2013 was very regressive. This payment is given to allow Family Carers take a much needed break from their often round-the-clock caring role. In reality, it is also used for respite from financial worries and to cover the hidden costs of caring such as increased electricity, fuel and medical bills. The

stress and anxiety this cut has caused Family Carers cannot be understated. Consequently, this Strategy Action has been given a ‘Regressive’ verdict.

- The Department included a prominent banner on the DSP website during National Carers Week highlighting the Respite Care Grant. Whilst a banner headline within the Department’s Website will provide good direction for those already on the website, more proactive online methods, including the creative use of social media channels and targeted advertising, could increase awareness of the Respite Care Grant further. Similar proactive offline methods for promoting the Grant could be put in place such as alerting those refused Carer’s Allowance or Half Rate Carer’s Allowance to their possible eligibility for Respite Care Grant.
- The Respite Care Grant is designed so that Family Carers can use the Grant in whatever way they wish; it can be used to pay for respite care, but does not necessarily have to be spent in this way. The Monitoring Group understands that in some areas Carers are being told that it must be used for buying in respite care. The Department’s efforts to promote the Respite Care Grant must clarify that the Grant is intended for discretionary use by the Family Carer, and that they are in no way required to use it to pay for respite services
- Under this Strategy Action the 1<sup>st</sup> Progress Report makes reference to “Carer Departments”, “Carers Coordinators” and “Carers Development Officers” in the context of promoting better awareness of the Respite Care Grant. There is a lack of clarity regarding these resources; the 2<sup>nd</sup> Progress Report should clarify the status of these roles (scope of role, geographic coverage, part-time/full-time basis, etc.)

### Verdict 2<sup>nd</sup> Report: Regressive

- The failure to reverse the 19% cut to the Respite Care Grant in Budget 2015 was very disappointing, particularly in light of the fact that the Government has begun the process of reversal of arbitrary cuts from Budget 2012. As outlined in our response to the 1<sup>st</sup> Progress Report above, respite care is vital for Family Carers. This remains a pivotal action within the Strategy, and a failure to move on this action will have a disproportionately negative effect on Family Carers.
- The score for this Strategy Action remains ‘Regressive’ because of the continued negative impact of the cut on Family Carers. This is despite the positive engagement the Monitoring Group has had with the DSP on other elements of this Strategy Action.
- **UNDERREPORTING:** On the recommendation of the Monitoring Group, DSP has amended the standard letter sent to Family Carers who have been refused Carer’s Allowance on the grounds of means, notifying them that they may be entitled to apply for the Respite Care Grant. This action was a direct result of positive engagement with the Monitoring Group as part of the NCS process. More Family Carers will now be made aware of their potential eligibility for an important support of which they may have been previously unaware.

#### 4.1.2. Promote a range of person centred and flexible respite options.

### Verdict 1<sup>st</sup> Report: Regressive

- Vital respite hours have been cut, and the number of respite beds reduced, while the numbers of people being cared for at home increases. Research has repeatedly shown that

access to respite care is essential in reducing carer stress, helping prevent instances of elder abuse and supporting carers to continue in their caring role.

- Under this Strategy Action the 1<sup>st</sup> Progress Report makes reference to “Carer Departments”, “Carers Coordinators” and “Carers Development Officers” in the context of disseminating information at a local level. However, there is a lack of clarity regarding these resources; the 2<sup>nd</sup> Progress Report should clarify the status of these roles (scope of role, geographic coverage, part-time/full-time basis etc.)

### Verdict 2<sup>nd</sup> Report: Regressive

- The Monitoring Group acknowledges a strand in the [Genio Project](#) (part-funded by the HSE) which is exploring flexible respite options and developing innovative models for those caring for older people. This is important and pioneering work.
- However, respite beds and long-stay beds have continued to be reduced across the country, resulting in the ‘Regressive’ verdict being awarded again. The Monitoring Group is aware of individual accounts of reductions in services regionally, but there is no accurate picture of the reduction and impact nationally.
  - Examples have been put forward of instances where the actual physical respite beds are available but the staff are not available adequately to support these facilities and so respite cannot be given.
  - The Monitoring Group is aware of a situation where an entire respite house was closed to all its regular adult patients because a child with a profound disability had to be housed there, the HSE not being allowed to provide respite to children and adults at the same time.
  - The Monitoring Group understands that a respite centre in Claremorris, Co. Mayo will close for remedial works for 6 months, and the local manager confirmed that no alternative arrangements for its day-care or respite patients will be put in place during this time – while not detrimental in and of itself, it does indicate the lack of priority assigned to respite care by the HSE across the board.
  - Anecdotally, respite beds that were in the system for those caring for someone at home are now less available as these beds are being used as step-down for those in acute hospitals who do not have appropriate supports to return home
- The Monitoring Group is also aware of individual examples from around the country indicating reductions of in-home respite. Can the HSE share relevant data about in-home respite, the numbers of families receiving this support and the amount of hours they are receiving? We are hearing the following:
  - Families receiving in-home respite report having their hours cut; weekend respite in particular is frequently reported as being reduced
  - Reports of families being awarded home care packages including in-home respite care but there being no funding available to provide it
  - Concern about the rationing of home supports to households where a Carer’s Allowance is being paid
- We do have figures from one county, County Louth, and these illustrate the impact of cuts in one area. We understand that the number of long-stay beds in County Louth declined by 22% from 180 in 2011 to 139 in 2015. While the number of step-down beds increased from 3

to 23, we understand that many of these were formerly respite beds. Furthermore, Our lady of Lourdes Drogheda frequently experiences long Emergency trolley lists, in part because of the inability of the hospital to discharge patients who no longer need acute care.

- “An Irish National Survey of Dementia in Long-Term Residential Care” (launched January 2015) also revealed the extent of the undersupply of respite beds for those with dementia. Some 30,000 people have dementia nationally, and there are 66 respite beds available across 54 specialist care units in nursing homes. This equates to just one respite bed for every 450 people with dementia in Ireland.
- Furthermore, the HSE Service Plan indicates that “The 2015 Social Care Operational Plan will include an expanded range of KPIs which include non-overnight respite and no. of people in receipt of more than 30 overnights continuous respite. It is anticipated that there will be a reduction in overnight respite as services move in line with person centred models are delivered. Data validation will be carried out as transition is made to the new KPIs”. This anticipation of a reduction in overnight respite services requires further explanation. The Monitoring Group seeks an explanation of these KPIs and what impact they will have on service delivery.

#### **4.1.3. Identify gaps in existing services and establish performance indicators for the provision of respite services.**

##### **Verdict 1<sup>st</sup> Report: No Progress**

- 1<sup>st</sup> Progress Report states “This Action is to be progressed in 2013/2014”; however, no detail was given on how it was to be progressed. Notwithstanding one known project working towards the establishment of performance indicators for respite services in Wexford, the Monitoring Group is not aware of any efforts at national level.

##### **Verdict 2<sup>nd</sup> Report: Regressive**

- By the HSE’s own reporting, this Strategy Action has regressed: ‘This Action was due to be progressed in 2013/2014, however, this action will roll over to 2014/2015’.
- In the HSE’s National Service Plan 2015, delivered respite services (measured as number of overnights, with or without day respite, accessed by people with a disability), at 182,887, fell significantly short of the NSP 2014 expected activity/target of 243,260. Worryingly, the expected activity/target for 2015 for the same indicator has been reduced to 190,000. The Monitoring Group is concerned that the delivery of respite services is not keeping pace with carers’ needs or the complexity of care routinely provided in the home, and that 2015 targets are being set in the context of the previous year’s under-delivery rather than current and future demand.
- The Monitoring Group acknowledges and welcomes the HSE Service plan to deliver 190 ‘intensive home care packages’. The development of supports to assist older people with complex needs to remain at home is very much needed. However, in the context of the overcrowding and delayed discharges in acute hospitals in the last year, the Monitoring Group is concerned that this will not be sufficient to address the issue. Furthermore, the

funding from this initiative comes from monies allocated to the Fair Deal scheme, which is itself already overstretched, raising concerns about the sustainability of this funding model.

- Furthermore, the Service Plan indicates that: "*The 2015 Social Care Operational Plan will include an expanded range of KPIs which include non-overnight respite and no. of people in receipt of more than 30 overnights continuous respite. It is anticipated that there will be a reduction in overnight respite as services more in line with person centred models are delivered. Data validation will be carried out as transition is made to the new KPIs*". This anticipation of a reduction in overnight respite services requires further explanation. The Monitoring Group seeks an explanation of these KPIs and what impact they will have on service delivery.
- A dramatic increase in the availability of respite services is urgently required, as more and more people with complex needs are being cared for at home; the demand for respite is also being magnified by other changes, such as the welcome closure of institutions and transition to community living for people with disabilities.

**Objective 4.2: Enable carers to remain in touch with the labour market to the greatest extent possible**

**4.2.1. Promote existing carer friendly HR policies within Government Departments and Agencies**

**Verdict 1<sup>st</sup> Report: No Progress**

- The response in the 1<sup>st</sup> Progress Report to this Strategy Action names existing carer-friendly HR policies but fails to describe any efforts to promote these to staff within Government Departments and Agencies. The Monitoring Group is not aware of any initiatives that address this Strategy Action.

**Verdict 2<sup>nd</sup> Report: Initial progress. But slow pace/delayed start**

- The reporting on this Strategy Action has improved, with Departments providing detail about existing policies and describing where information about them is to be found.
- As yet there has not been a focus on the 'promoting' element of this Strategy Action, which will be key to raising awareness amongst staff in Government Departments and Agencies. The Monitoring Group encourages Departments to take the opportunity that Carers Week presents to take more proactive measures to highlight their carer friendly HR policies.
- The Department of Jobs, Enterprise and Innovation has not engaged with the NCS or with the Monitoring Group. This is particularly disappointing in the context of this Strategy Action, where it should be a key player.

**4.2.2. Promote Awareness of the Carers Leave Act 2001**

**Verdict 1<sup>st</sup> Report: No Progress**

- The response under this action describes passive provision of information about the Carers Leave Act, and not the proactive promotion that this Strategy Action implies.
- The Department of Jobs, Enterprise and Innovation had not engaged with the Monitoring Group about the NCS.

**Verdict 2<sup>nd</sup> Report: No Progress**

- The Monitoring Group acknowledges the positive engagement from the Department of Justice and Equality, which took responsibility for Carer's Leave under the Family Leave Bill. From meetings with the Department, the Monitoring Group was heartened by the Department's acknowledgment of the low take-up of Carer's Leave and the need to increase awareness of the same.
- The Department of Jobs, Enterprise and Innovation has not engaged with the NCS or with the Monitoring Group. One consequence of this is that there is no reporting on efforts to promote awareness of the Carers Leave Act amongst private sector employers and employees.

**4.2.3. Encourage work-life balance provisions that are needed to ensure that working arrangements are carer friendly**

**Verdict 1<sup>st</sup> Report: No Progress**

- The 1<sup>st</sup> Progress Report states that "This Action is to be progressed in 2013/2014". The Monitoring Group is not aware of any progress regarding this action, and the Department of Jobs, Enterprise and Innovation has not engaged with the Monitoring Group on the NCS.

**Verdict 2<sup>nd</sup> Report: Regressive**

- The Department of Jobs, Enterprise and Innovation has not engaged with the NCS or with the Monitoring Group. The blank response to this Strategy Action does a disservice to Family Carers who are struggling to balance employment commitments whilst caring for a loved one.

**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 workplace**

**Verdict: No Progress**

- The 1<sup>st</sup> Progress Report indicated that 'existing arrangements will be reviewed during 2013/14' by DSP. Carers' Representative Groups have not been informed about what this review will encompass or whether the process has actually begun.
- The Monitoring Group acknowledges the success of the MOMENTUM Enhanced Homecare Training Programme initiative providing free education and training projects for 6,500 jobseekers. Momentum (indirectly) supports Family Carers by supporting workers who provide care relief and care support in the home. However, it is unfortunate that the eligibility criteria prevent Family Carers themselves from availing of this valuable training initiative.

**Verdict: No Progress**

- The Monitoring Group acknowledges the themed meetings with DSP during which we explored this Strategy Action under five separate headings. Though concrete progress has not yet been delivered, engagement has been positive.

## Family Carers' Scorecard

- The limit on the number of hours recipients of Carer's Allowance, Carers Benefit and the Respite Care Grant are permitted to engage in training is currently set at 15 hours per week. This is the biggest barrier preventing Family Carers from up-skilling with a view to returning to the workforce. There has been no movement on this limit. As a consequence, many Family Carers cannot avail of the ETB programmes described under this Strategy Action.
- The Monitoring Group acknowledges the Back to Work Family Dividend (BTWFD) scheme announced by Minister Burton as part of Budget 2015, which allows jobseekers returning to work to retain the element of the welfare payment which they receive for their children. While positive for those who will benefit under the scheme, the Monitoring Group sees this as a missed opportunity to extend a similar support to Family Carers who wish to return to employment after a caring role.

### 4.2.5. Review access by Family Carers to labour market activation measures

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

- The Monitoring Group acknowledges the success of the MOMENTUM Enhanced Homecare Training Programme initiative providing free education and training projects for 6,500 jobseekers. Momentum (indirectly) supports Family Carers by supporting workers who provide care relief and care support in the home. However, it is unfortunate that the eligibility criteria prevent Family Carers themselves from availing of this valuable training initiative.
- Again, under this Strategy Action the 1<sup>st</sup> Progress Report indicated that 'existing arrangements will be reviewed during 2013/14' by DSP. Carers' Representative Groups have not been informed about what this review will encompass or whether the process has actually begun.
- There are many additional ways in which Family Carers' access to labour market activation measures could be improved; however, these opportunities are missed in the progress reported.

#### Verdict 2<sup>nd</sup> Report: Regressive

- The limit on the number of hours recipients of Carer's Allowance, Carers Benefit and the Respite Care Grant are permitted to engage in training is currently set at 15 hours per week. This limit is preventing many Family Carers from up-skilling with a view to returning to the workforce. There has been no movement on this limit.
- Increasing the limit to 19.5 hours would allow Family Carers to access potentially transformative Community Employment schemes.
- The 15 hour per week limit also extends to employment for those in receipt of the above named supports. Many part-time and job-sharing opportunities are set at half the 39 hour working week. Extending the limit to 19.5 hours would allow Family Carers to apply for such positions. For Family Carers such as those caring for a child with a disability who spends part of the week in school, such a change could be transformative.
- In previous years, Family Carers availed of health and social care training through Momentum. This is no longer a core focus of Momentum 2015, and as a consequence there

## Family Carers' Scorecard

are fewer opportunities for Family Carers to translate their care experience, through training, into employment.

