

# Family Carers' Scorecard

Assessing the Government's third National Carers' Strategy report from the perspective of family carers



[National Carers Strategy Monitoring Group](#)

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# Family Carers’ Scorecard Number 3

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## Assessing the Government’s third report from the perspective of family carers

The National Carers’ Strategy was a commitment by Government to better support family carers. This ‘scorecard report’ is a carer-proofed assessment of 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 wellbeing and to care with confidence. They will be empowered to participate as fully as possible in economic and social life”.

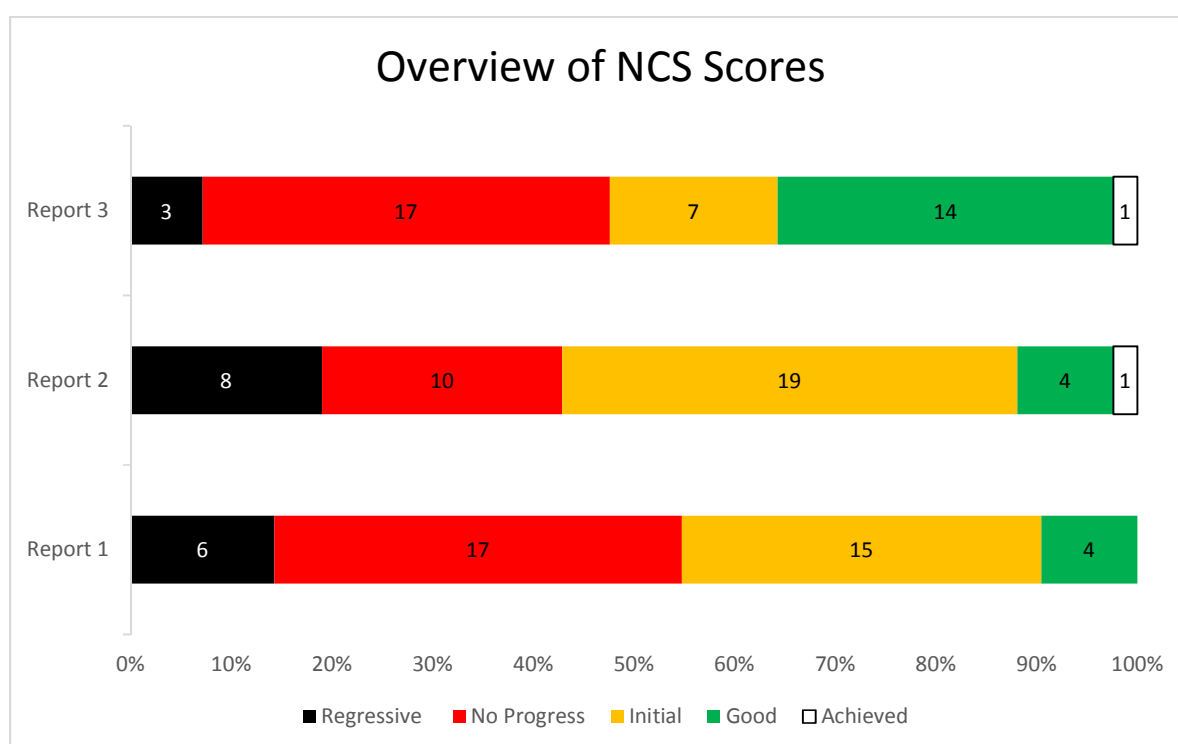
This vision was supported by 42 actions. Responsibility for each action was assigned to relevant Government departments. The departments committed to producing an annual Progress Report documenting progress in relation to the strategy. Three of these reports have been produced to date: the first Progress Report recorded progress from September 2012–September 2013; the second Progress Report recorded progress from September 2013–September 2014 and the third recorded progress from September 2014–September 2015.

The National Carers’ Strategy Monitoring Group is made up of representatives from Family Carers Ireland, Care Alliance Ireland and most importantly family carers themselves. The purpose of the Group is to monitor and encourage delivery of the national goals, objectives and actions contained within the Strategy and to do so through meaningful and positive engagement with Government departments and statutory bodies. Since early 2015, the Monitoring Group has met and carefully assessed Government’s reported progress (as expressed in the third Progress Report) in line with the stated goals, objectives and actions named in the National Carers’ Strategy. The key question the Group asked itself 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 in full and is making a real difference to family carers' lives. Fourteen actions received a 'Good Progress' score, meaning that there have been positive results for family carers, and the actions have the potential to be fully implemented within the lifetime of the strategy. Seven actions received an 'Initial Progress' score, meaning that there have been steps in the right direction but this progress is slow and requires an increase in the pace of implementation. Seventeen 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, three actions received a 'Regressive' score, meaning that the situation has worsened for family carers since the strategy was launched.



On the whole, we have seen a considerable year-on-year increase in the number of 'Good Progress' scores, for actions that have had a significant positive impact on the lives of family carers. Similarly, there has been a marked reduction in the number of 'Regressive' scores assigned. There are a large number of actions that, from a carer's perspective, have not progressed at all. Below we set out the context for the allocation of the scores, focusing on some of the more significant highs and lows throughout the year.

## Highs and lows:

**Positive:** The Action Plan for Dormant Accounts 2014 had a significant positive effect on the scores for the third progress report. It will provide up to €1 million through the Department of Social Protection and Pobal to caring organisations to provide family carers with information and training, helping them to

provide the best possible care for their loved ones. While the funding is not long-term, it did give a boost to most of the scores relating to information provision, training and those targeted at sub-groups of carers.

**Negative:** Despite the HSE's relatively new '*practical guide for discharge and transfer from hospital*', the lived experience of discharge from the acute sector to the home is very poor. Patients are being discharged from hospital without a documented care plan or the necessary supports in place to help families perform their caring role in a safe and dignified manner.

**Positive:** The engagement by departments with the strategy and the Monitoring Group has, in many cases, been meaningful and has yielded tangible results. The Department of Social Protection's (DSP) engagement through the Annual Carers' forum has been exemplary, as has its willingness to engage with the Monitoring Group. Practical improvements in how the department communicates with carers, including improvements in the wording of letters, has offered practical support to carers at no extra cost to the department. Direct positive engagement with the Department of Children and Youth Affairs (DCYA) on this action has resulted in the recognition of Young Carers within the National Youth Strategy. There has been particularly positive and meaningful engagement with the Health Service Executive (HSE) in relation to the provision of information for carers by online means. At a macro level, continued meetings of the HSE Cross-Departmental Group on the NCS signal a positive commitment to the strategy.

**Negative:** While engagement with some Government departments has been exemplary, others have been less proactive in delivering actions contained within the NCS and which they have been assigned responsibility. The Monitoring Group would welcome greater involvement of the Department of Jobs, Enterprise and Innovation (DJEI) in particular, with a focus on better supporting the large number of working carers. Similarly, reporting from the Department of Education and Skills (DES) names Education and Training Boards [ETBs] as responsible for delivering on specific measures with no indication as to whether or how the needs of young carers and young people with a disability are being met. More detailed reporting from the ETBs delivered via the DES would be welcomed.

**Positive:** While technically outside of the reporting period, the restoration of the Carer's Support Grant (formerly the Respite Care Grant) in Budget 2016 to €1,700 was so significant that the Monitoring Group felt it should be recognised in this Scorecard; it will have a meaningful impact on many carers' lives and is the accomplishment of something that family carers have long called for. Furthermore, the renaming of the Respite Care Grant as the Carer's Support Grant is also a positive, as it makes clear the fact that the grant is for the carer to use in any way they see fit.

**Negative:** The provision of home care services and of centre-based respite is well short of demand across the country. One figure that encapsulates the situation is that there is only one respite bed for every 450 people with dementia in Ireland. Similarly, and as acknowledged by the Department of Health (DoH), Home Help and Home Care Package provision falls well short of the hours required. A dramatic increase in the availability of respite, home help and home care services is urgently required, as more and more people with complex needs are being cared for at home.

Until home and community care is put on a statutory footing similar to that of the Nursing Homes Support Scheme, it will remain underfunded and insufficient.

### [The future of the National Carers' Strategy](#)

The National Carers' Strategy was published in a time of austerity, and it was understood that the implementation of its actions would be on a cost-neutral basis. What has been achieved by the strategy represents the first steps toward securing fair and equitable treatment of and support for family carers in Ireland. The Monitoring Group expects a timely renewal of the strategy with the allocation of ring-fenced funding and resources necessary for the full implementation of any new strategy's objectives. All of the major political parties were canvassed on this issue in advance of General Election 2016, and all gave positive commitments to renew and provide dedicated funding for a second NCS. The limits of a cost-neutral strategy have now been reached, and the engagement facilitated through the first strategy has primed any future, renewed and appropriately funded strategy for success.

## Overview of Scores

	1 <sup>st</sup> Progress Report	2 <sup>nd</sup> Progress Report	3 <sup>rd</sup> Progress Report
1.1.1. Promote a better recognition of the role and contribution of carers at a national level	<b>Initial, But Slow, Progress.</b>	<b>Good Progress</b>	<b>Good Progress</b>
1.1.2. Ensure that carers' needs are considered in the development of any policies that might affect them (such as the Review of Disability Policy (DoH), the National Positive Ageing Strategy (DoH, forthcoming) and the Children and Young People's Policy Framework 2012-2017 (DCYA, forthcoming)	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>	<b>Good Progress</b>
1.1.3. Build on the work begun in Census 2011 to establish a comprehensive statistical profile of Family Caring in Ireland	<b>Good Progress</b>	<b>Good Progress</b>	<b>Good Progress</b>
1.1.4. Continue to convene an annual carers' forum to provide carers with a voice at policy level	<b>Good Progress</b>	<b>Objective Achieved</b>	<b>Objective Achieved</b>
1.1.5. Support national organisations representing the interests of carers	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress</b>
1.1.6. Promote more proactive approaches to the identification of carers and to addressing their needs among staff and organisations that are likely to encounter individuals in caring situations (e.g. health and personal social service providers, and particularly primary care team members, community and education professionals).	<b>Initial, But Slow, Progress.</b>	<b>No Progress</b>	<b>No Progress</b>
1.1.7. Promote carer self-identification initiatives and encourage carers to formally identify themselves to service providers	<b>Initial, But Slow, Progress.</b>	<b>No Progress</b>	<b>No Progress</b>
1.2.1. Involve carers, as appropriate, as partners in care planning and provision by health and personal social service providers and particularly by the primary care team	<b>No Progress</b>	<b>No Progress</b>	<b>No Progress</b>
1.2.2. Identify carers and their involvement in discharge planning, including their details provided in discharge letters to GPs	<b>Regressive</b>	<b>Regressive</b>	<b>Regressive</b>

	1 <sup>st</sup> Progress Report	2 <sup>nd</sup> Progress Report	3 <sup>rd</sup> Progress Report
1.3.1. Provide regular benefits advice sessions and information through the application process	Initial, But Slow, Progress.	Good 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.	Good 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	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.	Initial Progress
1.3.5. Review existing transition arrangements for carers at the end of their caring role	Regressive	Regressive	Good Progress
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.	Initial Progress
2.1.2. Encourage carers to attend their GP for an annual health check	No Progress	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	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.	No Progress
2.1.5. Promote awareness of adult and child protection services that are in place	Initial, But Slow, Progress.	Initial, But Slow, Progress.	Good 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	No Progress
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	No Progress

	1 <sup>st</sup> Progress Report	2 <sup>nd</sup> Progress Report	3 <sup>rd</sup> Progress Report
2.2.1. Raise awareness and understanding among education providers of the signs that children and young people have caring responsibilities and the impact of caring on them	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>	<b>Good Progress</b>
2.2.2. Encourage statutory agencies to review the way that they respond to children and young people with caring responsibilities	<b>No Progress</b>	<b>No Progress</b>	<b>No Progress</b>
2.2.3. Identify support services needed by children and young people with caring responsibilities and create mechanisms for young carers to contact service providers	<b>No Progress</b>	<b>No Progress</b>	<b>No Progress</b>
2.2.4. Investigate and analyse the situation of children and young people undertaking caring roles.	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>	<b>No Progress</b>
3.1.1. Ensure frontline staff in key 'first contact' agencies such as local authorities, local health offices and health and personal social service providers have the correct information to be able to sign-post carers to other services as appropriate	<b>No Progress</b>	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>
3.1.2. Review material (paper and Internet based) available to carers and investigate (in conjunction with carer's representative organisations) how more comprehensive information materials dedicated to carers' needs can be developed and distributed to service providers likely to be a carer's first point of contact	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>	<b>Good Progress</b>
3.1.3. Ensure that the information needs of sub-groups of carers, such as older carers, children and young people with caring responsibilities, carers in rural areas are addressed	<b>No Progress</b>	<b>Initial, But Slow, Progress.</b>	<b>Good Progress</b>
3.1.4. Proactively collate and disseminate information about services and supports available at a local level for carers	<b>No Progress</b>	<b>Initial, But Slow, Progress.</b>	<b>Good Progress</b>



	1 <sup>st</sup> Progress Report	2 <sup>nd</sup> Progress Report	3 <sup>rd</sup> Progress Report
3.2.1. Identify gaps in the content of current training programmes for carers (in conjunction with carer's representative organisations)	<b>No Progress</b>	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress</b>
3.2.2. Enhance the accessibility of education and training courses through the use of face-to face, on-line and distance learning options	<b>No Progress</b>	<b>Initial, But Slow, Progress.</b>	<b>No Progress</b>
3.3.1. Prioritise funding for the operation of the suite of housing grants for older people and people with a disability and ensure that they can be accessed by families in a timely way	<b>Regressive</b>	<b>Regressive</b>	<b>No Progress</b>
3.3.2. Identify good practice in implementing assistive technology and ambient assistive living technology to support independent living and telehealth opportunities	<b>Initial, But Slow, Progress.</b>	<b>Initial, But Slow, Progress.</b>	<b>No Progress</b>
3.3.3. Review and up-date Transport Sectoral Plan under Disability Act 2005	<b>Regressive</b>	<b>Regressive</b>	<b>No Progress</b>
4.1.1. Promote a better awareness of the existence of the Respite Care Grant	<b>Regressive</b>	<b>Regressive</b>	<b>Good Progress</b>

	1 <sup>st</sup> Progress Report	2 <sup>nd</sup> Progress Report	3 <sup>rd</sup> Progress Report
4.1.2. Promote a range of person-centred and flexible respite options	<b>Regressive</b>	<b>Regressive</b>	<b>Regressive</b>
4.1.3. Identify gaps in existing services and establish performance indicators for the provision of respite services.	<b>No Progress</b>	<b>Regressive</b>	<b>Regressive</b>
4.2.1. Promote existing carer friendly HR policies within Government departments and agencies.	<b>No Progress</b>	<b>Initial, But Slow, Progress.</b>	<b>Initial Progress</b>
4.2.2. Promote awareness of the Carers Leave Act 2001.	<b>No Progress</b>	<b>No Progress</b>	<b>No Progress</b>
4.2.3. Encourage work-life balance provisions that are needed to ensure that working arrangements are carer friendly.	<b>No Progress</b>	<b>Regressive.</b>	<b>No Progress</b>
4.2.4. Explore how back to work and education training courses can be tailored to the needs of carers who wish to return to the workforce.	<b>No Progress</b>	<b>No Progress</b>	<b>Good Progress</b>
4.2.5. Review access by family carers to labour market activation measures.	<b>Initial, But Slow, Progress.</b>	<b>Regressive.</b>	<b>Initial Progress</b>

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**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, regional and local level



**Responsibility: All Departments (No Response: DJEI, DTTS, DJE, DECLG)**

Progress continues to be good under this action. The Monitoring Group had good engagement with most departments. In the past year, the Department of Social Protection, the Department of Health and the HSE have been particularly proactive. On the other hand the Monitoring group would welcome greater involvement by the Department of Jobs, Enterprise and Innovation, with a focus on better supporting the large number of working carers. Similarly, reporting from the Department of Education and Skills names Education and Training Boards [ETBs] as responsible for delivering on specific measures with no indication as to whether or how the needs of young carers and young people with a disability are being met. More detailed reporting from the ETBs delivered via the DES would be welcomed.

There has been particularly positive and meaningful engagement with the HSE in relation to the provision of information for carers by online means.

Continuing meetings of the HSE Cross-Departmental Group on the NCS signal a positive commitment to the strategy.

The cross-departmental Annual Carers' Forum facilitated by the DSP continues to be a good space for a focused discussion on issues important to carers.

The Monitoring Group is keen to see progress on the Transport Support Scheme. The DoH reports the issue moving through various legislative stages, but two years after the schemes were closed there is still no replacement for the Motorised Transport Grant and Mobility Allowance (those who were in receipt still receive payment, but no new applicants are being processed).

The report references the establishment of the Office of the Head of Service User Family Member & Carer Engagement by the HSE Mental Health Division in 2014. The Monitoring Group would welcome a briefing on the remit of the Office and an opportunity to engage with the Office.

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)



**Responsibility: All Departments (No Response: DJEI, DTTS, DECLG)**

The allocation of good progress is a recognition of the work of departments that have engaged with the Monitoring Group and have taken positive steps in progressing this action. Overall the Department of the Environment, Planning and Local Government, Department of Education and Skills and Department of Jobs and Enterprise did not engage in the same manner as other departments. The strength of other departments' performances increased this score to 'good progress'.

The Monitoring Group's overarching recommendation from scorecard 2 still stands:

[S#2] 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 [S#2].

In the interest of cohesion and coherence across relevant national strategies, the Monitoring Group recommend that designated leads for each national strategy meet periodically to discuss crosscutting issues and actions

Direct positive engagement with the DCYA on this action has resulted in the recognition of young carers within the National Youth Strategy, published October 2015, as a target group with specific support needs. "Outcome 5.6: Establish a cross-sector/cross-agency working group to consider the needs of young carers and to work towards aligning supports for young carers to help ensure an integrated and coordinated response to their needs".

Engagement by the DSP with the strategy overall has been positive and proactive and has contributed to the good progress score. The DSP's engagement through the Annual Carers' forum is exemplary and recognised in action 1.1.4. Worth repeating is the recommendation from last year's scorecard:

[S#2] 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 [S#2].

The Monitoring Group welcomes the DoH's establishment of a reference group to devise a national participation framework for service users. It goes on to state that "carers will be considered in the

course of all work undertaken by this Working Group”. The Monitoring Group is interested to hear more about this working group and how best carers’ organisations can engage with it.

The Department of Justice engaged positively on the new Assisted Decision-making (Capacity) Act 2015. DoJ met carers’ organisations and informed a subgroup of carers (parents of adults with intellectual disabilities) about the Act. While carers still have concerns about the implications of the legislation, the communication relating to the development of the Act was positive.

The National Carers’ Strategy was published in a time of austerity, and it was understood that implementations of its actions would be on a cost-neutral basis. What has been achieved by the strategy represents the first steps toward securing fair and equitable treatment of and support for family carers in Ireland, valuing their contribution to, and enabling them more fully to participate in, Irish society. The Monitoring Group anticipates a renewal of the strategy with the allocation of ring-fenced funding and resources necessary for the full implementation of its objectives. All of the major political parties were canvassed on this issue in advance of General Election 2016, and all gave positive commitments to renew and provide dedicated funding for a second NCS.

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



#### **Responsibility: CSO (No Response: CSO)**

Once again the Monitoring Group assigned good progress to this action. The only factor preventing this from achieving a higher score of ‘objective achieved’ is the fact that this was a ‘no change’ census so there was no opportunity to amend the phrasing of Q22 which seems to be capturing a lower total than the actual number of family carers in Ireland. A 2009 Quarterly National Household Survey carried out by the CSO identified a higher proportion of carers than the census has to date.

It is important to recognise the detailed statistical analysis of the Census 2011 data on family carers carried out as part of “Census 2011 Profile 8: Our Bill of Health – Health, Disability and Carers in Ireland”. These data are invaluable to those working with family carers, and the Monitoring Group looks forward to the Census 2016 data being added to this profile. It will be interesting to see what trends in family care are reflected in the data.

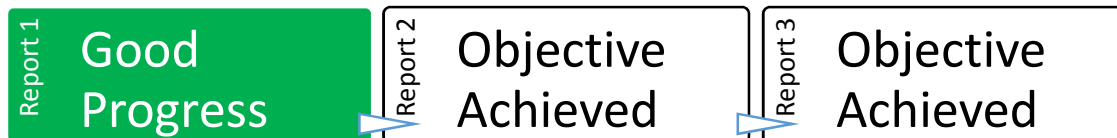
As acknowledged in the first scorecard, the CSO was central to the inclusion of a question about carers in Census 2011. The CSO ran a very successful Carers Count Campaign in 2011 to highlight Q22, the question relating to family care. In advance of the 2016 Census, the CSO worked very closely with organisations representing family carers to create an information leaflet, posters and a dedicated



section on their website with accessible information about Q22. The CSO also provided some funding to Family Carers Ireland to engage family carers about Q22 in the months in advance of the census through face-to-face and online methods.

The Monitoring Group appreciates the CSO's proactive approach to promoting Q22 and looks forward to an opportunity to discuss improving the accuracy and scope of Q22 in future Censuses.

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



#### Responsibility: DSP

The Department of Social Protection continues to convene an Annual Carers' forum. The manner in which the department engages with carers' organisations is exemplary: year on year they have liaised with carers' organisations and sought to improve the Forum's format. Our first scorecard recommended that the forum be strengthened by representations from all relevant departments and this happened in subsequent forums. In the 2015 forum, carers' organisations were involved directly in setting the day's agenda. It is worth repeating our assessment from the last scorecard

[S#2] 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 [S#2].

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



#### Responsibility: DSP; DoH

The Monitoring Group acknowledges the Government funding to national carer organisations, as detailed in the second Progress Report, which enables the provision of essential services such as respite, home care, training, information and advocacy. We also recognise the very welcome multiannual nature of funding received under the Scheme to Support National Organisations. As detailed below, carer organisations rely on a plethora of additional but intermittent funding streams to provide a meaningful service to family carers. An increase in core funding and a move to multiannual funding, as committed to in the 2016 Programme for Government (p. 131), would enable the provision of a more consistent service to family carers and an ability to plan for the future.

The Monitoring Group acknowledges the positive impact of the Action Plan for Dormant Accounts, which in 2016 has provided 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. While not designed to support national organisations, it is, for the relevant time period, allowing national organisations to provide an enhanced service to family carers.

National organisations representing the interests of carers mainly 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. There are also regional inconsistencies in the provision and allocation of Section 39 funding. This funding is very restrictive, designed as it is to support older people, as it precludes the provision of respite to carers under the age of 65.

Caring sector organisations utilise CE schemes and, while this assists in the running and operating of local offices it also contributes to a high turnover of staff and a less than ideal service for family carers. National Lottery Funding, HSE Grant Aid and Dormant Accounts Funding are highly valued and widely utilised by carers' organisations but they facilitate short-term (single year) action rather than contributing to the establishment of much-needed medium for long-term (multi-year) supports for 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).



**Responsibility: DoH; HSE; DES (No Response: DoH)**

Family carers still report that it can be a number of years after they start a caring role before they find out about supports that could be useful to them.

The Department of Educations and Skills' highlighting of their relevant information booklets is useful but leaves the Monitoring Group wondering about the proactive element of this action. How are the needs of parents and guardians of children with special educational needs identified and addressed?

The status of engagement on this issue remains as stated in the last scorecard:

[S#2] 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 [S#2].

The HSE makes reference to work towards developing a specific Carer Needs Assessment as part of the InterRAI Single Assessment Tool. Once established, this assessment will assist in identifying those caring for older people and assessing their needs. The positive work towards developing the Carer Needs Assessment is recorded under the dedicated action 2.1.3.

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.

Finally the following comment from the second scorecard remains relevant:

[S#2] 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. [S#2]

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



#### **Responsibility: HSE**

Similar to the observation in 1.1.6, when family carers look back over their years of caring they see that there is often a delay of a year or two before they come to recognise themselves as a 'family carer'.

This action focuses on carers self-identifying to service providers which places the impetus on carers' themselves. In fact whenever a carer applies for Carer's Allowance, Carer's Benefit, a Housing Adaptation Grant, Mobility Aid Grant, respite care or home help they are already self-identifying to service providers. There is an opportunity being missed for each of the relevant departments to ask carers on these forms whether they would like to be on a carers' database so that they can be better supported. Given that carers' first point of contact is often with a health service provider or a social welfare official there are many opportunities for carers to be recorded. The Monitoring Group suggests that establishment of a carers' database be explored.

The assumption underlying this action is that self-identification will lead to a positive outcome for the carer, for example a referral to a local carers' support group where peer support can be invaluable, or securing Carer's Allowance, home help or respite hours. However, in some areas of the country home help, respite or special education supports are in short supply or not available at all. The Monitoring Group suspects that this lack of a perceived benefit may be one of the reasons some carers are not self-identifying. Events like National Carers' Week and the Carer of the Year Awards attempt to link identification as a carer with positive outcomes. A national awareness campaign is required if this action is to be achieved. The Monitoring Group suggests that in addition to positive self-identification measures, an increase in self-identification will be realised if supports and services for carers improve.

The positive impact of Dormant Accounts Funding has been recognised under other actions; worth mentioning here is that a limited portion of this will enable the printing of information booklets and posters aimed at encouraging those for whom it is relevant to self-identify as a family carer.

The positive support provided by the CSO through the 'Carers Count' campaign to encourage carers to self-identify in 2016 is recognised under action 1.1.3. and, while not directly related to this action, which is about self-identifying to 'service providers', the Census campaign may have a positive knock-on effect.

#### 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



#### Responsibility: HSE

The core aim of this action is that carers be treated as 'partners in care'. The lived experience of most family carers is that their expertise and practical knowledge of the patient is not taken into account by health professionals and as such they are not respected as 'partners in care'.

"All CHOs report that carers are involved in care planning where appropriate and with the client's permission".

This assertion, articulated in the HSE's report, does not chime with carers' reported experiences. HSE staff are in a position proactively to encourage patients to give consent for their carers, where appropriate, to be involved in care planning. Carers sense that this is not promoted, and that patient confidentiality is too often cited as a reason not to involve carers rather than viewing care planning something to be negotiated between health professional, patient and carer. As articulated in previous scorecards, this is a particularly pronounced problem in the mental health arena.

Health professionals are often extremely busy and carers' experience is that a brief conversation in a hospital corridor is the limit of engagement with a care plan – an experience which falls well short of being treated as 'partners in care'.

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



**Responsibility: HSE**

The Monitoring Group’s assessment of the state of discharge as articulated in scorecard #2 remains relevant:

[S#2] 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. [S#2]

In June 2015, Care Alliance Ireland carried out an exercise on the National Carers’ Week Facebook page, where the HSE’s 9-step discharge policy was shared and carers were asked what their experience of discharge was like. The response was very grim, with most carers reporting a very poor discharge experience. Family carers’ lived experience of hospital discharge is a world away from that described in Government’s response to this action, and is not reflective of the referenced discharge planning process, HSE’s *Integrated Care Guidance: A Practical Guide to Discharge and Transfer from Hospital*.

The Monitoring Group notes with anticipation the HSE’s assertion that “*proactive approaches to working in partnership with carers will be explored as part of the proposed plans on patient and public partnership across the hospital groups*”. Given the importance of safe and comprehensive discharge, a positive change in how the caring responsibility is transferred from hospital to home cannot happen soon enough.

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



**Responsibility: DSP**

In past scorecards, we have recognised how well informed and helpful DSP staff are when contacted by family carers or organisations working on their behalf. We also welcomed the proactive measures the department has taken to improve communication with family carers, e.g. amending written communication with family carers so that those refused Carer's Allowance on the grounds of means were alerted to the fact that they may have an entitlement to the Carer's Support Grant. Year on year engagement with the department on this action has been meaningful and impact-orientated.

The Monitoring Group recognises 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. Recipients are now alerted earlier about the implication of moving beyond the 16 years of age threshold with more information being provided at this point.

The Monitoring Group understands that some parents have experienced problems transitioning from DCA to DA despite their child having a significant medical condition or disability.

The review of the Domiciliary Care Allowance was proactive and yielded positive changes to the application process. Caring sector organisations are keen to work with the department on any future reviews such as that of the Carer's Allowance application process.

Dormant Accounts funding will have a significant impact on the dissemination of practical information and support to family carers. In addition to providing dedicated training, a portion of Dormant Accounts funding will enable the dissemination of resource information and will provide supports to reduce the social isolation experienced by many carers.

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



#### Responsibility: DSP

There has been positive engagement with the DSP on this action via the Annual Carers' Forum. Part of the Annual Carers' Forum included a discussion with family carers and stakeholders on how to ensure carers can access information and support as early in the caregiving journey as possible. The Monitoring Group has suggested specific actions which, if implemented, could lead to real progress. The linking to Family Carers Ireland website from the Department of Social Protection site is also positive.

It is often the HSE or healthcare professionals who are the first point of contact at the beginning of the caring process. However, only the DSP has been assigned to this action. The Monitoring Group asks that the DoH and HSE also report under this action. 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

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

**Responsibility: DSP**



Awareness of the possibility of sharing Carer's Allowance is very low. 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.

Attendance by the DSP at the Care & Mobility Show 2015 provided an opportunity to publicise information about care sharing to those present. The Monitoring Group acknowledges that the Carer's Allowance section within the department is considering other cost-effective methods of publishing this information.

The Monitoring Group calls for care sharing to be analysed and reviewed. The reason for the low take-up may not be lack of awareness alone; rather, the way in which the support is structured may not be best designed to support those who wish to share a caring role.

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



**Responsibility: DSP**

DSP reports that waiting times have increased for processing Carer's Allowance during 2015, struggling to keep pace with the increase in numbers applying.

The Monitoring Group understands that where there are significant delays in the processing of Disability Allowance: where a child at 16 years of age is waiting for Disability Allowance to be approved, having previously received the Domiciliary Care Allowance, there can be a lengthy knock-on effect on the parent's application for Carer's Allowance.

The engagement with DSP has been very positive, with proposed changes on the website and application forms designed to encourage applicants to supply sufficient information in their initial submission to give a full picture of their caring role.

Another positive is that the new system that has been introduced will now accept email queries from applicants.

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



#### Responsibility: DSP

The Action Plan for Dormant Accounts 2014 will provide funding to the Department of Social Protection to support locally-based training, information and related support services for carers. This should allow carers to plan, by upskilling through training, for a future transition from their caring role. There is also a specific strand of training within Dormant Accounts targeted at former carers.

In previous scorecards the Monitoring Group drew attention to the limit on the number of hours recipients of Carer's Allowance, Carer's Benefit and the Carer's Support Grant are permitted to engage in training, which is currently set at 15 hours per week. The Monitoring Group identified this as a significant barrier preventing family carers from upskilling in advance of their caring role coming to an end. In a very welcome move, the Department of Social Protection has acknowledged this issue and has invited Family Carers Ireland to submit a proposal on a pilot project which would allow a small cohort of carers to increase the hours that they work or study from the current 15-hour limit.

Both of these measures have contributed to the 'Good Progress' verdict this year. The suggestions put forward in the previous scorecard, but not acted upon, remain relevant:

- DJEI should review their supports to ascertain how they can better support family carers to return to the workplace after their caring role ends.
- 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 upskilling and support to re-enter the workplace.
- DSP: The 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.



- The Monitoring Group welcomes the Budget 2016 measure which extends the retention of Carer’s Allowance from 6 weeks to 12 weeks after the death of the person being cared for.

**National Goal 2: Support carers to manage their physical, mental and emotional health and wellbeing**

**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



**Responsibility: HSE**

The pioneering progress in relation to the InterRAI suite and the development of a Carer 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, as it is currently proposed, 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 range of activity provided by the HSE in response to this Strategy Action. Carers’ organisations recognise their own role in delivering on this action too.

Worth recognising as particularly impactful are the Alzheimer’s cafés, a HSE-led initiative, run in collaboration with carers’ organisations, which provide a welcoming and accessible space for people with dementia, their family and friends to meet with social and healthcare professionals and exchange ideas and learning.

However, we still do not have a clear picture of the coverage of these initiatives nationwide; it is known that some parts of the country are well-served whereas others are not.

There are divisions within the HSE from which, given their remit, it would be appropriate to hear how they are meeting carers’ needs. The Monitoring Group would welcome contributions to future NCS reports from the directorates of Mental Health, Health and Wellbeing and Health Promotion.

In its engagement with the department the Monitoring Group has shared suggestions for proactive initiatives that might progress this action. These suggestions still have merit and some are repeated here.

- Provide funding towards the development of a training initiative or training DVD to help general practitioners, front-line healthcare staff and allied health professionals identify carers and to recognise when they are suffering from poor physical and emotional health and help them to locate and obtain support.
- Develop a free Carers e-Learning Programme to help GPs and Primary Care Teams better understand and support carers. The programme could include interactive educational sessions designed for health and social care professionals, which could be completed online.
- Develop a ‘carer protocol’ for use in general practice which will actively identify carers (including young carers): routinely direct identified carers to local support services: deliver improved outcomes for carer's health and emotional wellbeing and ensure carers are involved, consulted and enabled to participate in commissioning of local services, agreeing service priorities and influencing service design.

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



**Responsibility: HSE**

Worth repeating is the assessment of the Monitoring Group of the original framing of this action:

[S#1] 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 [S#1].

The Monitoring Group believes that an annual health check for carers should be provided without charge and should be holistic in line with National Goal 2, covering physical, mental and emotional health and wellbeing.

In its response the Department of Health references the Government’s policy of moving towards universal GP care free at the point of access.

Those lucky to fall within the age cohorts where GP care is free at point of access, under 6 and over 70, welcome and value the entitlement. 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. Most carers are of working age and do not benefit from this initiative.

The HSE references “household contacts of at-risk persons” as being a priority group for influenza vaccination. The Monitoring Group understands that in some HSE areas the cost of the vaccination is

borne by the family carer and in other areas the HSE covers the charge. It would represent some progress if across the country family carers were not charged for such vaccinations.

### 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



#### Responsibility: DoH, HSE

The development of a Carer Needs Assessment as part of the rollout of the InterRAI single assessment tool for older people is pioneering and warmly welcomed by the Monitoring Group. The Monitoring Group understands that pre-testing of the InterRAI suite took place in October 2015, with a larger-scale international pilot currently underway. We look forward to the launch of the Carer Needs Assessment in Ireland by late 2017.

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; it further 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



#### Responsibility: HSE

We know there has been a positive impact on the small cohort of family carers that have been involved in innovative telecare pilot projects.

However, for the third report in a row “resource challenges” are again mentioned as a barrier to the implementation of the recommendations of the Home Solutions Report. National roll-out remains a pressing concern.

The prioritisation and implementation of relevant projects 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 and 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 was a considerable factor in 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.

Only the HSE has been assigned responsibility for implementing this action, but the Home Solutions Report clearly names the DECLG as also being responsible for the implementation of its recommendations. Accordingly it would be important for the DECLG to report on this action.

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



#### Responsibility: HSE

The third Progress Report references the establishment of a National Safeguarding Office led by a senior manager from Older Persons' Services. The recruitment of an additional 21.7 Social Worker WTEs for the Safeguarding teams in the nine CHOs is also a significant development. The second Progress Report outlined 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. Furthermore, 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 who work with older people and people with a disability. Cumulatively, these measures will enhance adult protection services significantly.

As acknowledged in the second scorecard report:

[S#2] 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 [S#2].

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' policy and legislation.

#### 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.



#### Responsibility: DoH

The review of the Fair Deal system of financing nursing home care was published in July 2015. The review was long overdue and failed to make any clear decisions in relation to financing “community and long-term care which supports older people to stay in their own homes”.

The review has been criticised for failing to address the unsustainability of Fair Deal as a means of financing nursing home care and for failing to outline whether and how the scheme could be adapted to improve home and community care. (“Government’s lack of courage fails us all, but more importantly, our oldest and frailest citizens”, *Irish Independent*, July 21<sup>st</sup>, 2015).

The review recommends better coordination within and standardisation of the home care system, and addressing the uneven availability of home care (pp. 64, 67-8), and notes the need to support family carers, and to implement the National Carers’ Strategy (pp. 90. 92). It also recommends that the HSE Review of Home Care Services proceed as a priority.

While the review sketches the standard options for financing residential and community care – increased personal contribution, mandatory social insurance or hypothecated taxation – it refrains from making solid recommendations or expressing a preference for any one option. While it notes the progressive nature of the NHSS, it is also clear that it is not sustainable in its current form, given the projected demographic changes and consequent rise in costs of both residential and home care provision.

In its report the Department of Health describes a process where an Interdepartmental/Agency Working Group will present a first annual report to a Cabinet Committee in June 2016 to include details of the progress achieved in improving the assessment of income and assets, including home ownership, and the validation of associated declarations by applications. This is a welcome development and the Monitoring Group looks forward to engaging with this working group in the near future.

It is disappointing that the review of the Fair Deal did not come out with more tangible recommendations for the financing of community care to support older people to stay in their own homes.

Furthermore, the reported progress from the Department of Health relating to the working group does not make clear how it will address the specifics of this action. The initial work plan seems to relate to the operation of the Fair Deal and not the future financing of 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).



**Responsibility: DoH, HSE**

The following commentary from the Monitoring Group’s second scorecard report still remains valid:

[S#2] 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. [S#2]

Issues remain relating to certain care providers not having staff Garda vetted, and there are instances where family carers are unable to leave the home while respite care is being provided in-home due to concerns about the quality of care or the ability of allocated staff to deliver a safe and appropriate care service.

National standards for home support services are overdue and of high importance. Family carers would welcome higher standards of care in the home and the involvement of HIQA in the same. One concern that family carers have raised is that they do not want to see further instances of what currently tends to happen when a respite service is found wanting in terms of meeting appropriate standards, i.e. the complete loss and non-replacement of a service within an area and the ensuing hardship for family carers. Should a home care service be found lacking, it is imperative that an acceptable and appropriate alternative be promptly provided. Family carers actively seek the raising of standards of care in the home, but do not want to be left to 'take up the slack' should a home care service fail to meet appropriate standards.

#### 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.



#### **Responsibility: DCYA; DES (No Response: DES)**

Direct, positive engagement with the DCYA on this action has resulted in the recognition of young carers within the National Youth Strategy for the first time. The National Youth Strategy, published October 2015, recognises young carers as a target group with specific support needs. "Outcome 5.6: Establish a cross-sector/cross-agency working group to consider the needs of young carers and to work towards aligning supports for young carers to help ensure an integrated and coordinated response to their needs". As key stakeholders, organisations representing family carers look forward to direct engagement with this cross-sector/cross-agency working group.

An element of the Action Plan for Dormant Accounts 2014, which will provide funding to the Department of Social Protection to support locally-based training, information and related support services for carers, may also have a positive impact under this action. A small portion of the funding will support the production and dissemination of three different booklets targeted at young carers themselves, young carers' families and professionals working with young carers.

School Attendance Guidelines are reported as being complete and currently being published by the Educational Welfare Service of TUSLA. However, as far as the Monitoring Group is aware the guidelines have not been disseminated to schools. This delay is disappointing. The Monitoring Group has not seen a copy of the guidelines and doesn't know whether a mechanism to identify young carers is contained within these guidelines.

The National Carers' Strategy assigned responsibility for this strategy to DCYA alone. The Monitoring Group sees this as an oversight. The Department of Education and Skills should be reporting under this action too as they have a direct responsibility to deliver on it. One example of what potential proactive measures by the DES under this action could look like would be incorporating young carer awareness, self-identification and referral elements into the Personal Safety modules of the Social, Personal and Health Education Curriculum. Knowing how and where to get timely help and support is a critical life skill that can benefit all young people, particularly those with caring responsibilities. Such a measure would support the recommendation in the 'Study of Young Carers in the Irish Population' (October 2010) which called for targeted information campaigns in primary and secondary schools. At third level the DoE could encourage colleges and universities to incorporate a Student Carer Policy into their Admission and Student Support systems.

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



#### **Responsibility: DCYA, DoH, DES (No Response: DoH, DES)**

DCYA reference the Donegal Young Carers' Support Group in its response to this action. The Monitoring Group can attest to the positive impact that the Donegal Young Carers' Support Group is having on engagement with young carers and the links with key youth services. Unfortunately this is a standalone example; to our knowledge, none of the other Children and Young People's Service Committees (CYPSC) has developed a group that operates in this manner. The description of one positive support in a single geographic area gives no indication of the strength and weaknesses of young carers support services nationwide. Ambition to standardise and roll out this initiative nationwide would be welcomed by the Monitoring Group.

The Monitoring Group looks forward to the establishment of a cross-departmental Young Carer Working Group, as committed to in the National Youth Strategy, which will bring together key departments and agencies with a responsibility for supporting young carers.

The National Carers' Strategy assigned responsibility for this strategy to DCYA alone. The Monitoring Group sees this as an oversight. The DES should be reporting under this action too as they have a direct

responsibility to deliver on it. The Monitoring Group raised this point in the last scorecard, and are disappointed DES have again not engaged. The Monitoring Group calls on departments to clarify the respective roles and responsibilities of TUSLA, DCYA, DES and HSE in relation to children and young people with caring responsibilities.

### 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.



#### Responsibility: HSE

The Monitoring Group's assertion in scorecard 1 is unfortunately still valid here:

[S#1] 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 [S#1].

Unfortunately, the description of how young carers are identified, as described in the HSE's response to this action, bears no resemblance to the experience on the ground. In our experience, Primary Care Teams and the Public Health Nursing Service are not identifying young carers in the manner described, and we have no experience of individual Care and Support Plans being reviewed with young carers in mind. Family Carers Ireland has not received any referrals from this system. Perhaps referrals are being made only where child welfare or social protection issues arise? If this is the case, it is a missed opportunity. Such a referral system should act actively to support young carers in a positive manner rather than only being used to respond to problems.



The HSE refers to the work of the Child and Adolescence Mental Health Service (CAMHS), mentioning actions to reduce waiting lists and to extend the service to 16 and 17 year olds. For the small cohort of young carers that use this service to access counselling and mental health supports, it is vital. Family Carers Ireland has also worked with CAMHS in a small number of areas to run Community Outreach Programmes targeting young carers and assisting them to look after their mental health. Such initiatives should be rolled out on a nationwide basis.

Finally, the toolkits and booklets referred to in 2.2.1 above will also play a positive role in that they will raise awareness amongst young carers about mechanisms they can use to contact service providers.

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



#### **Responsibility: CSO (No Response: CSO)**

DCYA reference the National Strategy for Research and Data on Children’s Lives, published by the Department in November 2011. The third Progress Report states that an analysis of young children identified in Census 2011 is due to be published in early 2016. As of May 2016 this has not been published. Given that the second Progress Report stated that ‘this report is now finalised and will be published shortly’ the Monitoring Group cannot help but be frustrated at the delay in its publication. These data could be used to inform service delivery and strategic responses addressing young carers’ roles. It has taken a full Census cycle for this information to be made available. This is disappointing as the delay diminishes the utility of the data.

As acknowledged in the first scorecard, DCYA was central to the original inclusion of a question about carers in Census 2011. The CSO ran a very successful Carers Count Campaign in 2011 to highlight Q22, the question relating to family care. This question also allows for young carers to be identified. For the 2016 Census the CSO worked very closely with organisations representing family carers to create an information leaflet, posters and a dedicated section on their website with accessible information about Q22. The CSO also provided some funding to Family Carers Ireland to engage family carers, including young carers, about Q22 through face-to-face and an online means.

The Monitoring Group anticipates that once established the cross-departmental Young Carer Working Group’s work programme will include investigating and analysing the situation of children and young people with caring roles to build an evidence base better to address their needs. The Young Carer Working Group will bring together key departments and agencies with a responsibility for supporting young carers.

#### **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.



**Responsibility: DSP; DoH; DECLG; HSE**

The assessment of progress recognised in Scorecard #2 remains relevant here:

[S#2] There has been positive engagement on this issue across departments and...modest practical steps have been taken towards its implementation. However, further progress is required to ensure a high standard of signposting by frontline staff. Family Carers Ireland has offered its services to train frontline staff in referring carers to relevant supports, and this offer remains available to all departments [S#2].

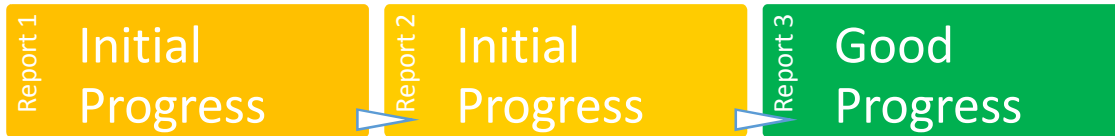
The Monitoring Group welcomes the DoH’s creation of a dedicated section for family carers on the department’s website. We also acknowledge the collaborative and inclusive manner in which carers’ organisations were included in the development of these resources.

The HSE’s reporting of CHO staff accessing “presentations by Family Carers Ireland, staff training, team meetings, sharing of local knowledge of supports and services” speaks to a more proactive approach.

Full completion of this action would involve additional, proactive measures for all frontline staff in key ‘first contact’ agencies across all Departments. This could involve including carer-specific information as part of induction, human resource management, continuing professional development and information days to equip frontline staff with the necessary referral information for family carers.

The DECLG’s report on the establishment of Housing and Disability Steering Groups and the future setting up of Housing Advice Centres clearly represents progress for people with disabilities. It is unclear how carers’ specific needs, as distinct from those they care for, are being addressed in this process. Is it possible for family carers to become involved, perhaps by invitation to sit on these steering groups as suggested in Scorecard #2? Moreover, this report, though interesting, does not respond to the specific action. The Monitoring Group is interested to hear how DECLG ensures its frontline staff are equipped to sign post carers to other services as appropriate. This is particularly important for Local Authority staff administering the Housing Adaptation and Mobility Aids Grant Schemes.

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



**Responsibility: HSE; DSP (CIB)**

Significant funding has been awarded from Dormant Accounts to meet family carers’ information needs. As part of this process, successful grantees reviewed existing paper and internet-based material and funds have been provided to enhance these resources. While this funding is not long-term, for the relevant period of time, it will allow organisations representing family carers to provide an enhanced information service to family carers.

The progress the HSE and DoH have made in terms of online information reported under 3.1.1 is relevant here and deserves acknowledgement under this action too. Headway has been made with the review of the internet-based information. A similar review of paper-based information is also required. The fact that many carers are not online underscores the importance of this action.

The DSP also outlines improvements to online information provision and flags its intention to review/redraft the application form for Carer’s Allowance and to update the Carer’s Allowance and Benefit operational guidelines. Given the importance of these supports to carers’ lives, the Monitoring Group asks whether representatives of family carers could be involved in these reviews. These reviews mark a positive trend within DSP continuing from progress recognised in Scorecard #2:

[#S2] 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 [#S2].

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



**Responsibility: All Departments (No Response: DJEI; DJE, DECLG, DTTS, DES)**

The significant funding forthcoming from Dormant Accounts will do much to address the online and hardcopy information needs of subgroups of carers listed in this action. While this funding is not long-term, for the relevant period of time it will allow organisations representing family carers to provide an enhanced information service to family carers.

In their responses each of the departments name information items relevant to carers with frequent reference to publishing the strategy itself and links to caring sector organisations.

DCYA commits to future actions under the National Youth Strategy. The inclusion of specific actions for young carers is very welcome.

With the exception of the Dormant Accounts funding which is tailored to meet the information needs of named subgroups of carers, the departmental responses don't specify how their actions meet the information needs of subgroups of carers "such as older carers, children and young people with caring responsibilities, carers in rural area". An exception to this is the HSE's detailed description of how it meets one subgroup's needs, namely the needs of those caring for older people. Laudably, the DSP's approach to organising their annual forum is shaped with subgroups of carers in mind. A similar approach by the DSP and all Departments to meeting the differing information needs of subgroups of carers would be welcomed.

Family Carers Ireland has vibrant subgroups of carers that meet regularly; Parents of Adults with Intellectual Disabilities, Parents of Children with Special Needs and a Young Carers Advisory Panel to name just three. Such groups would be keen to work with departments to work towards fulfilling this action.

Finally, commentary from Scorecard #2 is just as relevant to this report:

[S#2] This action applies to all Departments, yet there is no response from the Department of Transport, Tourism and Sport, the Department of Education and Skills or the Department of Jobs, Enterprise and Innovation (the last has not engaged at all around the Strategy) [S#2].

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



**Responsibility: DSP [CIB], (No Response: DSP)**

The funding provided through the Action Plan for Dormant Accounts has significant potential to advance this action as it will provide funding for locally-based training, information and related support services for carers. The purpose of this measure will be to help carers upskill 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. This funding will be instrumental in assisting caring sector organisations in making progress related to this action. While the impact of this funding will not be felt until 2016, the call for this funding was

issued and signed off within the reporting period of Report #3 and so the Monitoring Group acknowledges this progress here.

The list of healthcare professionals and resources included in the HSE’s response to this action does include those in a good position to engage with family carers at a local level. Carers’ representative organisations clearly have a role to play here alongside government bodies.

Carers’ lived experience is that these measures are still not entirely effective at reaching them early in their caring life. Many carers report that it can be years before they become aware of resources that could support them in their caring role.

Simple actions, such as carers’ notice boards in primary health centres and hospitals, or the introduction of a carer-friendly hospital pilot, could have a positive impact.

The commentary below from Scorecard #2 is just as relevant to this report; the HSE was the only department to respond to this action this year.

[S#2] The NCS names the 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 [S#2].

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



#### **Responsibility: HSE; DES**

The funding provided through the Action Plan for Dormant Accounts has potential to advance this action as it will provide significant funding for locally-based training for carers. The application process for Dormant Accounts funding ensured that information needs of carers were assessed with the funded training aiming to fill identified gaps. The purpose of this funding will be to help carers upskill 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. While this funding is not long-term, for the relevant period of time it will allow organisations representing family carers to provide an enhanced training options to family carers.

The positive steps taken by the DOH and HSE in relation to this action have contributed to the increase in this score. However, the action may well have received an even higher score were it not for the lack of engagement or progress reported from the Department of Education and Skills.

The DES's response repeats the same shortcomings as last years' report:

[S#2] 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 [S#2].

It is unclear to the Monitoring Group how the Expert Group on Future Skills Needs (EGFSN) takes cognisance of carers' and sub groups of carers' training needs.

The scoping exercise of training courses available to carers carried out by Care Alliance Ireland and referenced by the HSE is certainly positive. The monitoring group hopes this will be followed by steps to fill the gaps identified in the content of these courses and in the availability of the courses geographically.

The following points from Scorecard #2 remain relevant:

[S#2] 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. [S#2]

[S#2] 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. [S#2]

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



#### Responsibility: HSE; DES

The impact of Dormant Accounts funding will have a positive impact on this action. The impact of Dormant Accounts has been well recognised in the preceding scores. The poor score in this action is by way of marking the lack of engagement or progress from the Department of Education and Skills. The DES's response repeats the same shortcomings as last years' report:

[S#2] 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 [S#2].

Once again, departments' responses fail to get to the core of this action, accessibility. The scorecard commentary from last year remains relevant:

[S#2] The response in the 2nd 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 [S#2].

### **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.**



#### **Responsibility: DECLG**

DECLG reports that it spent 10% more on Housing Adaptation Grants in 2015 and describes the exchequer funding increase and number of grants awarded accordingly.

The Monitoring Group acknowledges the additional €13 million allocated in 2015. However, the €50m spent by the exchequer on these grants in 2015 is still significantly less than the €95.46m spent in 2010.

The Monitoring Group believes that the overall spend is out of step with fact that the number of people requiring care in the home has increased over this time period.

There are mixed reports about the operation of these grants around the country. Those who receive supports are very appreciative and rely on them to adapt their home and make it an appropriate place to care for a loved one. However, we continue to receive reports of unacceptable waiting times.

In Scorecard #2 we outlined an example of delays in County Offaly. Reports from County Wicklow indicate that grants awarded in 2015 were for applications made in 2013.

It is worth repeating that the review of the Housing Adaptation Grant scheme actually made many people ineligible for these grants:

[S#2] 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 Aid for Older People disadvantages those who require an adaptation to make their home a safer 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 [S#2].

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



#### **Responsibility: HSE; DECLG (No Response: DECLG)**

The development of the Royal College of Surgeons’ MyHealth app which provides credible health information is particularly welcome given that it is available nationwide to those with the mobile technology to download it.

Referring to equipment and assistive technologies, the HSE acknowledges that “budgetary limitations exist for the provision of such equipment / technologies”. This is related to the response the Monitoring Group has given in previous years about individual examples of progressive pilot projects with no plan or budget to mainstream those supports. In this context it is worth repeating the recommendation in Scorecard #2:

[S#2] 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 [S#2].

The withdrawal of the Telephone Allowance still has relevance under this action:

[S#1] 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 [S#1].

Unfortunately DECLG did not report under this action this year, and so we have no update on the implementation of a pilot project to test good practice in sustainable communities for people with disabilities. The second report named a delay in the project’s implementation and the scorecard underlined the importance of this project given that Government are pursuing care in the home as a preferred model of care.

In previous years the Monitoring Group focused on digital technology and failed to consider physical aids like wheelchairs and crutches as ‘assistive technology’. The World Health Organisation’s definition



of 'assistive devices and technology' is very clear that they are central to the concept (<http://www.who.int/disabilities/technology/en/>). This year's negative score reflects the fact that there are people waiting up to 18 months to be reassessed for wheelchair suitability.

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



#### Responsibility: DTTS

It is worth repeating the Monitoring Group's perspective on this action as outlined in Scorecard #2, and the reason we allocate a score for transport as a whole, rather than the Transport Sectoral Plan alone:

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.

DTTS report that the next review of the Transport Sectoral Plan will be undertaken in 2016 and forecasts a comprehensive consultation process. It indicates this as an opportunity for carers' organisations to input into the development of the next plan.

Such an opportunity would be most welcome as transport supports have diminished since the National Carers' Strategy was first published in 2012. There have been a number of actions outside the plan and beyond the control of DTTS that undermine the goals to provide accessible 'Transport for All'. These regressive moves relate to the closure of the Mobility Allowance scheme and the Motorised Transport Scheme to new applicants without clarity about replacement schemes.

Worth noting is that, since January 2015, those who qualify for the Disabled Drivers and Disabled Passengers Scheme are now eligible for a Fuel Grant. This grant replaced the repayment of excise duty on fuel which was discontinued on 31<sup>st</sup> December 2014 due to a ruling of by the European Court of Justice in April 2013. The Monitoring Group welcomes the introduction of the Fuel Grant and the Department of Finance's assurances that recipients of the scheme would not lose out financially as a result of the Court of Justice ruling.

Transport is a vital issue for carers and those they care for, and this action provides the only opportunity for comment on these issues within the NCS.

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



#### Responsibility: DSP

The regressive scores for Scorecard #1 and #2 are reflective of the negative impact the 19% cut to the Respite Care Grant in Budget 2013 had on family carers. It is worth noting that the repeated failure to reverse the original cut overshadowed some positive engagement by the DSP related to this action such as the department amending 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. The Monitoring Group recognised this in the narrative of previous scorecards but it could not be reflected in the score awarded.

While technically outside of the reporting period, the restoration of the Respite Grant in Budget 2016 to €1,700 was so significant that the Monitoring Group felt it should be recognised in this scorecard as it will have a meaningful impact on many carers' lives and is the accomplishment of something that family carers have long called for.

Furthermore, the renaming of the Respite Care Grant to the Carer's Support Grant is also a positive in that it makes clear the fact that the grant is for the carer to use in any way they see fit. This was always the case, but the renaming removes any doubt about the issue. It also indicates that the department is listening and responding to carers' concerns about the supports that underpin their caring role.

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



#### Responsibility: HSE

As recognised in previous years, the Monitoring Group acknowledges a strand in the Genio Project (part-funded by the HSE, previously a standalone project now subsumed into the HSE) which is exploring flexible respite options and developing innovative models for those caring for older people. This is important and pioneering work though as yet is not available nationwide.

In its response to this action the HSE lists a range of flexible responsive respite services that it provides, but this is qualified by the statement: "The respite service is not a demand led scheme and the HSE must deliver services within budget". From a carer's perspective this is the critical issue; 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. This in itself is a failing.

- 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.

- 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.
- HIQA are appropriately closing down respite centres that fail to meet the required standards; however, family carers are being put under much strain as appropriate alternative services are not readily available. Examples include Tír Na NÓg Respite House in Carlow and St Patrick's Centre residential unit in Kilkenny. Both services provided overnight respite services to children with disabilities and when de-registered families were not offered suitable overnight alternatives (day and evening respite was offered) or emergency respite cover; in the latter case, families were instructed to bring their children to A&E or to a nursing 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.

"An Irish National Survey of Dementia in Long-Term Residential Care" (launched January 2015) 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.

The HSE's Social Care Operational Plan 2016 indicates that 'new funding' of €1 million will be allocated to respite with host families in a community setting. Respite with a host family is where a child or adult with a disability is offered a short break / holiday with a host family in the community. A combination of day and / or weekly respite will be provided, benefiting approximately 300 service users. This announcement is a positive but as the service has not yet been delivered it cannot be recognised until next year's scorecard.

While there are a number of positive actions as acknowledged above, the overall shortage of services justifies a regressive score again this year.

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



**Responsibility: HSE**

The HSE's response to this action announces the intention to establish a HSE multidivisional Review Group to review respite services. The HSE's Social Care Operational Plan specifies that this Review Group will be tasked with determining the requirements for respite care and identifying the gaps in service provision. The Monitoring Group is very interested in this initiative and would welcome the opportunity to engage with this Review Group given the pressing need promptly to provide adequate respite services. The establishment of the Review Group is all to the good and necessary, but from a carer's perspective another year has passed and gaps in respite services have increased while the number of people requiring those services has also increased.

According to a recent research paper developed for TDs, referring to Home Help and Home Care Packages:

"The Department of Health acknowledges that the service supplied often falls short of the hours required – the HSE estimated that supply fell 10% short of demand in 2015. It is estimated that an extra 1,600 people will need home care in 2016. However, the HSE plans no increase in the number of home help hours or clients, or the number of HCPs in 2016. There will be 649 more people supported by the NHSS (on a weekly average basis). This implies that the rising demand for care will be met by residential rather than home care. The HSE is due to establish waiting lists for home help and HCPs this year – these are already an established feature of the NHSS." A. Timoney, "Home Care for Older People" in "Research Matters for the 32nd Dail and 25th Seanad" (April 2016) p. 19. A paper published by Care Alliance Ireland in June 2016 suggests a deficit in home care support of between 8% and 20%, equating to several million home care hours, depending on which baseline year is used ([http://www.carealliance.ie/Briefing\\_Papers](http://www.carealliance.ie/Briefing_Papers)).

From a family carer's perspective this analysis reflects their lived experience of Home Help and Home Carer services falling well short of demand. 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. Furthermore, the Monitoring Group is concerned about the phenomenon of patients being discharged from hospital without an appropriate package to bring them home. In some instances, families are taking their cared-for person home where it is unsafe to do so due to lack of appropriate supports. Finally, the practice of 'care cramming',

awarding of very short (as little as 30 mins) care packages is an inefficient use of resources, prevents any meaningful service being delivered and is insulting to both carer and care recipient.

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



**Responsibility: All Departments/Agencies (No Response: DSP, HSE, DJEI, DTTS)**

The Department's reporting on this action is exactly the same as it was in Progress Report number 2. Given that nothing has changed the score remains the same.

It is worth repeating here the Monitoring Group's assessment in Scorecard #2:

[S#2] 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 [S#2].

Finally, the Department of Jobs, Enterprise and Innovation has still 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



**Responsibility: DJEI (NERA)**

Unfortunately, the responses under this action describe passive provision of information about the Carer's Leave Act, and not the proactive promotion that this Strategy Action implies.

It would be very useful if all Departments were to report on the number of employees who have availed of the Carer's Leave Act year-on-year since it was established.

It is disappointing that the Department of Justice and Equality have not responded, despite responsibility for the Family Leave Act, which entails Carer's Leave falling within the remit of the department.

The Monitoring Group welcomes the establishment of the Workplace Relations Commission (WRC) by the Department of Justice and Equality on the 1<sup>st</sup> October 2015. Family carers who balance their caring role with paid employment are an important and large cohort of carers who need additional support. While a welcome development, it does relate to redress and enforcement and is not aimed at increasing the number who avail of Carer's Leave which is very low. The Monitoring Group also recognises that a representative of the WRC participated in the Annual Carers' forum hosted by the DSP.

The Monitoring Group has made a number of suggestions as to how this action might be progressed in the proactive way that the term 'promote' indicates:

- Promote greater levels of public awareness of the provisions of the Carer's Leave Act amongst caregivers, and bodies supporting carers, trade unions and employers.
- Identify and address barriers to the take-up of the provisions of the Carer's Leave Act 2001
- Identify the benefits and cost-effectiveness of incorporating a period of paid leave for caregivers.

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



#### Responsibility: DJEI

The Department's response is to "see 4.2.1. and 4.2.2" above, this is understandable as the actions are closely related.

The Monitoring Group's response to the preceding two actions is relevant here too. As detailed above, the Monitoring Group sees the actions described as falling short of the proactive measures that are needed to encourage more carer-friendly workplaces. A good starting point would be if each department reported just how many people avail of the work-life balance provisions they make available and attempted to analyse what impact these measure are having.

The Monitoring Group has suggested meaningful actions that would progress this action which have, as yet, not been taken up:

- Introduce new rights for carers on the grounds of their caring role, including protection from discrimination in the workplace.
- Improve the provision of information to employers to enable them to support carers in their workforce, including through a page on their website offering advice for employers.
- Undertake research to explore the difficulties as well as solutions associated with the reconciliation of paid work and family care

- Address barriers and disincentives for carers to remain in employment or re-enter the workforce after their caring role comes to an end.

#### 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



**Responsibility: DES, DSP (No Response: DSP)**

The Action Plan for Dormant Accounts 2014 will provide funding to the Department of Social Protection to support locally-based training, information and related support services for carers. The programme includes specific education and training courses tailored to the needs of family carers.

In previous scorecards, the Monitoring Group drew attention to the limit on the number of hours recipients of Carer’s Allowance, Carer’s Benefit and the Carer’s Support Grant are permitted to engage in training or work, currently set at 15 hours per week. The Monitoring Group identified this as the greatest obstacle preventing family carers from upskilling with a view to returning to the workforce. As a consequence, many carers cannot avail of the ETB programmes described under this action in previous progress reports. In a very welcome move, the Department of Social Protection has acknowledged this issue and has invited Family Carers Ireland to submit a proposal for a pilot project allowing a small cohort of carers to work in excess of the allowable 15 hours.

It is disappointing, however, that the Department of Education and Skills did not respond to this action as it relates directly to their brief.

#### 4.2.5. Review access by family carers to labour market activation measures



**Responsibility: DSP**

Relevant under this action is the Department of Social Protection’s willingness to consider the feasibility of a pilot project extending the hours those in receipt of specific carer supports can engage in training or work from the current 15-hour ceiling. In previous scorecards, the Monitoring Group drew attention to the limit on the number of hours recipients of Carer’s Allowance, Carer’s Benefit and the Carer’s Support Grant are permitted to engage in training which is currently set at 15 hours per week. Many part-time and job-sharing opportunities are set at half the 39 hour working week and so family carers cannot apply for such positions. The Monitoring Group identified this as the greatest obstacle preventing family

carers from upskilling with a view to returning to the workforce. As a consequence, many carers cannot avail of the ETB programmes described under this action in previous progress reports. Consequently, this pilot programme has the potential to have a big impact for carers looking to return to the workplace. For 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.

Other suggestions the Monitoring Group has made under this action include:

- Extend and promote the services offered through Intreo to include family carers who may wish to secure part-time employment or return to employment when their caring role ends.
- All mainstream activation measures must provide equality of access to carers in receipt of Carer's Allowance and people on disability payments, where this is appropriate and desirable for the individual.