



UPDATED WITH CORRECTIONS JANUARY 2018

Family Carers' Scorecard

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

Family Carers' Scorecard

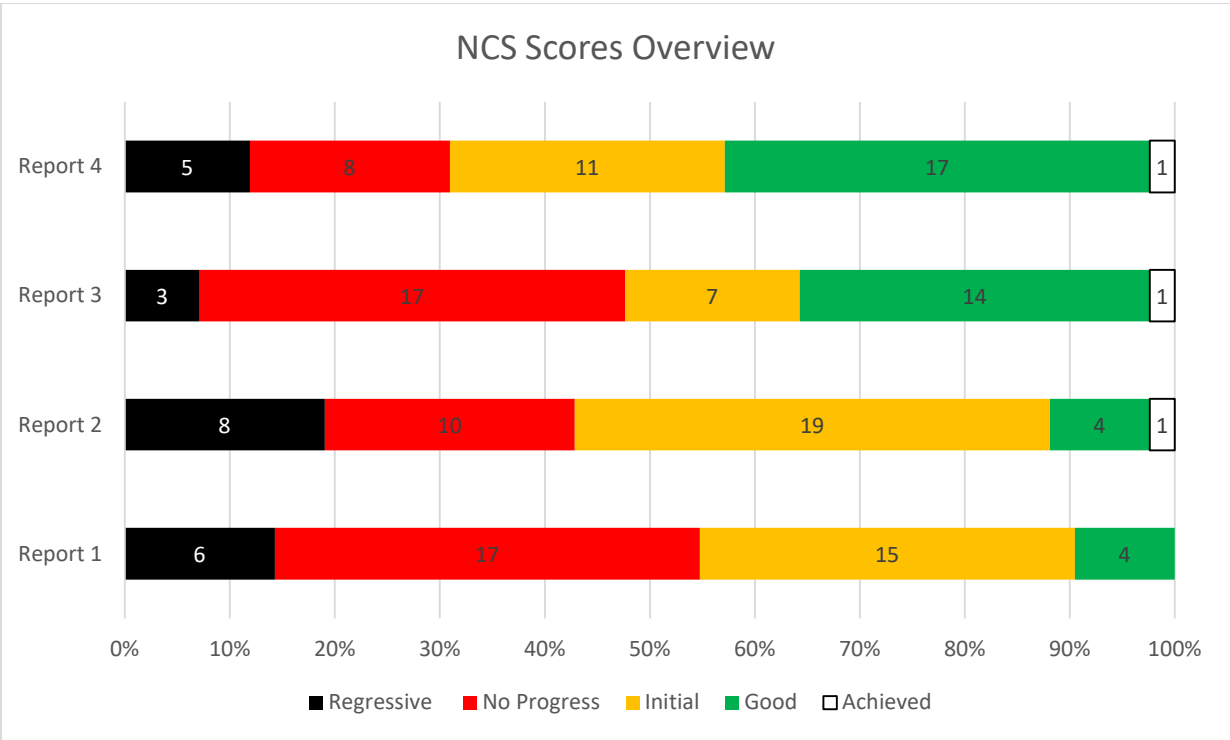
Assessing the Government's fourth report from the perspective of family carers

January 2018 update to Scorecard.

This version of the National Carers Strategy Scorecard was updated in January 2018. A number of errors were brought to our attention relating to our reporting on the Department of Education's performance in the first edition of this the fourth scorecard. We had incorrectly reported that the Department of Education failed to report under actions 2.2.1, 2.2.2 and 3.1.3. The Department had in fact taken meaningful actions in response to suggestions made in previous Scorecards and had reported on the same. We have corrected these errors and acknowledged those actions in this new updated Scorecard.

Overview

Of the 42 actions within the National Carers Strategy, one action received an 'Objective Achieved' score, meaning that the action has been implemented in full and is making a real difference to family carers' lives. Seventeen actions received a 'Good Progress' score, meaning that there have been positive results for family carers. Eleven 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. Eight 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, five actions received a 'Regressive' score, meaning that the situation has worsened for family carers since the strategy was launched.



With Progress Report 4 we have seen, once again, 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. However, there are a large number of actions that, from a carer's perspective, have not progressed at all or indeed have become worse. These scores are particularly disappointing as the lifetime of the first strategy has come to an end. These poor outcomes may be avoided in the next strategy by allocating appropriate ring-fenced funding. Below we set out the context for the awarding of scores, focusing on some of the more significant highs and lows throughout the year.

Highs and lows:

Positive:

2016 has seen a willingness and ambition to tackle the issue of financing home and community care.

- The Department of Health announced its intention to develop a new statutory home care scheme.
- The HRB commissioned an evidence review of the way in which homecare services are funded and regulated in other European countries.
- Importantly Minister McEntee announced a public consultation with a view to establishing a new statutory homecare scheme in January 2017. Though outside of the reporting period this action was so significant and was an expression of building momentum that it deemed appropriate to recognise here.
- During the year the Committee on the Future of Healthcare was established with the understanding "that the best health outcomes and value for money can be achieved by reorientating the model of care towards primary and community care where the majority of people's health needs can be met locally".
- This focus on homecare is very significant and comes after years of calling for the same by family carers. From a carers' perspective there are at least two elements that any future scheme must include. Firstly, people of all ages who require home care should be catered for, not just those over 65. Secondly, the scheme should include a suite of supports appropriate to needs of family carer and cared for person, rather than merely reconfiguring existing home help and home care packages.

[Relevant action: 2.1.6]

Negative:

In recent years a perfect storm of events has led to respite becoming almost non-existent. Funding cuts, staff shortages, bed closures as a result of HIQA inspections and the transfer of respite beds to transitional care beds or long stay beds have combined to reduce respite availability and deny carers this vital support. Respite services are essential, immediate investment is a must. Furthermore, there is no accurate picture of the reduction and impact nationally. While the establishment of a Respite Review Group to examine this issue is welcome, its work must include a thorough mapping exercise of respite services, proceed with urgency, and not delay the immediate investment required.

Relevant actions: 4.1.2, 4.1.3.

Positive:

In 2016 the Action Plan for Dormant Accounts provided funding to the Department of Social Protection of up to €1million to put towards projects to support locally-based training, awareness-raising information and related support services for carers. Though Dormant Accounts funding is short term and the information needs of carers are ongoing, during 2016 it has had a very tangible positive impact on many carers lives.

Relevant actions: 1.1.5, 1.1.7, 1.3.5, 2.1.4, 3.1.2, 3.1.3, 3.1.4, 3.2.1, 3.2.2, 4.2.4

Negative:

Despite the HSE's 'practical guides for discharge and transfer from hospital', the lived experience of discharge from acute hospitals to the home is very poor. Patients report 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. There are positive initiatives, such as the Patient Advisory Liaison Service (PALS) and Patient and Public Involvement (PPI) Ignite programmes; but again, feedback from family carers suggests they have yet to see the necessary changes that would mean their experiences and needs are adequately addressed alongside those of the care recipient.

Relevant action: 1.2.2

Positive:

The response by the Department of Social Protection to issues relating to carers' social welfare benefits is worthy of special recognition. Effective action has been taken during the year to make applying for or appealing decisions on Carer's Allowance easier and quicker. Furthermore, the extension of payment of Carer's Allowance from 6 to 12 weeks after the death of a care recipient in Budget 2016 was welcome, and was matched in Budget 2017 by a similar extension being granted where a care recipient entered residential care.

Relevant actions: 1.3.1, 1.3.5

Negative:

Problems with the Housing Adaptation Grant scheme persist around the country. Despite the older population having increased by 36 percent since 2006, eligibility for the scheme has been tightened, meaning many families in genuine need of an adaptation grant are not considered eligible. While funding is slowly being restored and currently stands at €56m, it is still significantly below the funding level of €95m paid in 2010. The problem of long waiting lists remains in some Local Authority regions with only high priority cases being progressed. Timeliness is an issue, as needs may increase or a condition deteriorate while an applicant is waiting for approval or for work to commence.

Relevant action: 3.3.1

Positive:

In relation to young carers' issues, engagement with the Department of Children and Youth Affairs has been positive. We note in particular the reference to young carers in the National Youth Strategy 2015-2020'.

There was also constructive engagement with Tusla during the reporting period; the involvement of

young carers in the development of the '50 key messages to accompany investing in families' is particularly worthy of recognition.

The Department of Education and Skills' explicit naming of young carers as a distinct group requiring specific support in junior cycle and senior cycle resources has been very useful in that it has proved an inroad for our Young Carer Development Officer to engage with teachers and students.

Given there is but one Young Carer Development Officer in the country it is vital that further positions be funded so that these opportunities might be maximised.

Relevant actions: 2.2.3, 2.2.4

Negative:

The description of how young carers are identified, as described by the HSE, 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, and we have no experience of individual Care and Support Plans being reviewed with young carers in mind. Referral systems should actively support young carers in a positive manner rather than only being used to respond to problems.

The waiting lists for the Child and Adolescence Mental Health Service (CAMHS) are a serious problem. For young people that need to use this service to access counselling and mental health supports, the enormous waiting lists are unacceptable and can cause serious regression.

Furthermore other departments, when reporting in relation to young carers list supports targeted at the children in general or vulnerable children with no articulation of how young carers in particular are identified and supported.

Relevant actions: 2.2.2, 2.2.3

Positive:

Previous years' scorecards had lamented an imbalance in the response by different departments in terms of reporting progress. This year we see a higher level of engagement from more departments. The Department of Social Protection, Department of Health, Health Service Executive (HSE) and the Department of Children and Youth Affairs (DCYA) maintain their positive interaction with family carers and organisations who represent them. There has been marked improvement in engagement by all of the other departments who in the past had not been as proactive in prioritising the strategy. The one exception to this is the Department of Transport who had insignificant input into the Progress Report.

Relevant action: 1.1.1, 1.1.2

[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. In the 2016 General Election support for a renewed and refreshed National Carers' Strategy gained popular support, with all of the major political parties committing to this goal. Support for the

strategy was enshrined within the programme for government and talks with Government officials on developing a second strategy with dedicated funding are progressing. It is clear that 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.

Background to the Strategy and the Scorecard

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. Four 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; the third recorded progress from September 2014–September 2015 and the fourth recorded progress from September 2015 to December 2016.

The National Carers' Strategy Monitoring Group is made up of staff and volunteers 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 2016, the Monitoring Group has met and carefully assessed Government's reported progress (as expressed in the fourth 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 Scores

Scores by Report No.

1.1.1. Promote a better recognition of the role and contribution of carers at a national level	1	2	3	4
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)	1	2	3	4
1.1.3. Build on the work begun in Census 2011 to establish a comprehensive statistical profile of Family Caring in Ireland	1	2	3	4
1.1.4. Continue to convene an annual carers' forum to provide carers with a voice at policy level	1	2	3	4
1.1.5. Support national organisations representing the interests of carers	1	2	3	4
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).	1	2	3	4
1.1.7. Promote carer self-identification initiatives and encourage carers to formally identify themselves to service providers	1	2	3	4
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	1	2	3	4
1.2.2. Identify carers and their involvement in discharge planning, including their details provided in discharge letters to GPs	1	2	3	4
1.3.1. Provide regular benefits advice sessions and information through the application process	1	2	3	4
1.3.2. Ensure that carers can access benefits advice as early as possible when their caring role begins	1	2	3	4
1.3.3. Publicise more widely that the Carer's Allowance can be shared by two carers providing care on a part time basis	1	2	3	4

- 1.3.4. Continue to work to reduce waiting periods for processing of Carer’s Allowance applications and appeals
- 1.3.5. Review existing transition arrangements for carers at the end of their caring role
- 2.1.1. Raise awareness among health and personal social service providers of the physical and emotional health issues that carers may experience
- 2.1.2. Encourage carers to attend their GP for an annual health check
- 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
- 2.1.4. Continue to implement the recommendations of the Home Solutions Report (13) on telecare
- 2.1.5. Promote awareness of adult and child protection services that are in place
- 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.
- 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).
- 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
- 2.2.2. Encourage statutory agencies to review the way that they respond 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
- 2.2.4. Investigate and analyse the situation of children and young people undertaking caring roles.
- 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

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- 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
- 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
- 3.1.4. Proactively collate and disseminate information about services and supports available at a local level for carers
- 3.2.1. Identify gaps in the content of current training programmes for carers (in conjunction with carer’s representative organisations)
- 3.2.2. Enhance the accessibility of education and training courses through the use of face-to face, on-line and distance learning options
- 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
- 3.3.2. Identify good practice in implementing assistive technology and ambient assistive living technology to support independent living and telehealth opportunities
- 3.3.3. Review and up-date Transport Sectoral Plan under Disability Act 2005
- 4.1.1. Promote a better awareness of the existence of the Respite Care Grant
- 4.1.2. Promote a range of person-centred and flexible respite options
- 4.1.3. Identify gaps in existing services and establish performance indicators for the provision of respite services.
- 4.2.1. Promote existing carer friendly HR policies within Government departments and agencies.
- 4.2.2. Promote awareness of the Carers Leave Act 2001.

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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: DTTS, DJE)

Progress continues to be good under this action. Previous years’ scorecards had lamented an imbalance in the response by different departments in terms of reporting progress. This year we see a more uniformly high level of engagement.

The announcement by the Department of Housing, Planning, Community and Local Government of a new round of the Scheme to Support National Organisations in the Community and Voluntary Sector is significant as carers’ organisations rely on such funding to support vital services in the community.

The engagement by the Department of Education and Skills of parents of children with special needs through its National Consultative Forum is a positive. As the forum is being reconstituted, it is an opportunity to formally include organisations directly representing family carers in the forum. Furthermore, the monitoring group is keen to work with and see the Department of Education and Skills take on a greater role in promoting and identifying young carers.

Another highlight has been the level of engagement by the HSE Mental Health Division with the Family Carers Ireland subgroup of carers for those with mental health difficulties.

Significant too is the inclusion within TILDA (Irish Longitudinal Study on Ageing) of a Carer’s Self Completion Questionnaire for carers of older adults with an intellectual disability living within family settings.

Engagement with the Department of Children and Youth Affairs has been particularly positive in this reporting period with a particular focus on the department’s annual plan.

The development by Tusla of the Child and Family Support Networks is a positive for children and families with complex needs but, as of yet, there are no specifics as to how young carers’ needs in particular will be addressed.

For carers who are in paid employment the Department of Jobs, Enterprise and Innovations' stated commitment to encouraging flexible workplaces, of which Carer's Leave is an important component, is notable.

The Monitoring Group however continue to be disappointed by the response of the Department of Transport whose only input into the Progress Report is the same wording used in the previous year's report, 'to undertake a review in 2017 of the actions under the current (transport) sectoral plan' with the changing of the year from 2016 to 2017. The input also shows a lack of progress in relation to the now overdue review of the Disability Sectoral Plan. We also note that the Department of Transport failed to meet with us during 2016.

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: DTTs)

The allocation of good progress is a recognition of the year-on-year improvement by departments in including carers in the development of policies that affect them.

Engagement with the Department of Children and Youth Affairs has been particularly positive in this reporting period with a particular focus on the department's annual plan. There was also constructive engagement with Tusla during the reporting period; the involvement of young carers in the development of the '50 key messages to accompany investing in families' is particularly worthy of recognition.

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 continues to be exemplary (recognised in action 1.1.4).

The establishment of Working Groups by the Department of Health to support the reform of disability services sounds progressive. Carer representative organisations expect and would appreciate inclusion in these Working Groups. Of particular interest is the 'People with Disabilities and Community Involvement' where carers are named as a distinct stakeholder.

The involvement of organisations representing family carers in the pilot of Consumer-Directed Home Care (CDHC) is positive in that it explores how to allow individuals in receipt of services and their carer to influence the design and delivery of their care. Carers will be keen to see how CDHC might allow them to exercise a greater degree of choice in what services are delivered, along with where and when those services are provided.

The engagement by the Department of Justice in relation to the Assisted Decision Making (Capacity) Bill 2013 has been very constructive with multiple presentations to groups of family carers. Saying this the implications of the Bill for family carers is still a source of uncertainty and fear.

Given the importance of the Department of Housing, Planning and Local Government's new Housing Action Plan, *Rebuilding Ireland*, to facilitate people to continue living independently in their own homes it would be useful to hear how family carers' needs were considered in the development of this policy.

In the context of 'ensuring that carers needs are considered in the development of any policies that might affect them', the Department of Education names 'a general call for submissions, including carers groups' about the development of its Special Needs Assistants Scheme. Family Carers Ireland have no record of any invitation being received and suspect that it was indeed a general public invitation. More proactive engagement of carer representative organisations would be appropriate given the importance of such measures for family carers.

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 Monitoring Group appreciates the CSO's proactive approach through the 'Carers Count' campaign to promoting Question 22 in advance of budget 2016.

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 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, as well as the 2015 Irish Health Survey, identified a substantially higher proportion of carers than the census has to date.

UNDERREPORTING: Significant too during this reporting period was the CSO's release of the results of the Irish Health Survey 2015. As referenced above these data increased our understanding of the numbers and situation of those providing care for family members in Ireland.

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 and 2016 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 fourth 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 to 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 very useful. However, from a carers' perspective any information awareness initiative can be eclipsed by frustration with huge gaps in supports (e.g. waiting lists for speech and language assessments and shortage of Special Needs Assistants).

The explicit naming of young carers as a distinct group requiring specific support in junior cycle and senior cycle resources has been very useful in that it has proved an inroad for our Young Carer Development Officer to engage with Teachers and students. We are happy to note that this inclusion has come about through the engagement between the monitoring group and the department on the National Carers Strategy.

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. Ultimately this tool should be made available to all carers, not just those caring for older people, as soon as is practicable.

Dedicated carers' notice boards in hospitals, health centres and GP practices are examples of simple, cost-neutral actions that could further this action. These notice boards could include a poster asking patients to inform reception staff, their GP or other staff that they are family carers. We urge the consideration of these actions.

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



Responsibility: HSE

It remains the case that when new to the caring role there is often a delay of a year or two before carers recognise themselves as a 'family carer'.

As referenced in Scorecard #3, this action focuses on carers self-identifying to service providers which places the onus 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 here 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 a carer's 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. 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.

Dormant Accounts Funding, though time limited, has supported this action directly. It has funded radio advertisements targeted specifically at family carers and it has enabled 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', it is hoped that the Census campaign will 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'. Despite the positive trend in Public Patient Involvement (PPI) in health research 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'."

The score on this action remains 'No Progress', and members of the Monitoring Group questioned whether there is not an element of talking at cross purposes regarding terminology here. Minimal consultation with a carer as to the content of a care plan when it is initially put in place, or simply sharing the plan with a carer, does not amount to involving or respecting family carers as partners in care. In reality, as one member of the Monitoring Group put it, there are two care plans: the one in place for home care workers coming into a home, or for accommodating a child in a school, and a second for family carers in the home who often must improvise and develop systems to cope with care recipients needs on a trial-and-error basis. It is strongly felt that the involvement of family carers in developing and implementing care plans on an ongoing basis is not sufficient and does not recognise the reality for family carers, who often are left without vital support, equipment and training in looking after their loved ones.

The Monitoring Group also noted however that there has been better engagement from those responsible for mental health services, and more acknowledgement of the problem posed by sharing or non-sharing of details of care or medication with carers. Family carers have yet to see concrete impact from this improved engagement, but it is positive.

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



Responsibility: HSE

The score of this action has been 'Regressive' over the lifetime of the National Carers' Strategy, and nothing like sufficient change has been accomplished to improve it. Carers still report feeling side-lined or uninformed, and underequipped to take on the role of caring for a loved one discharged from hospital, and that the existing 6-step HSE guide to discharge and transfer from hospital, referenced in the progress report, does not seem to them to be used.

There are positive initiatives which the Monitoring Group acknowledges and welcomes, such as the PALS and PPI Ignite programmes; but again, feedback from family carers suggests they have yet to see the necessary changes that would mean their experiences and needs were adequately addressed alongside those of the care recipient.

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



Responsibility: DSP

The score on this action remains Good Progress, and as with previous scorecards, the Monitoring Group recognises that effective action has been taken to make applying for or appealing decisions on Carer's Allowance easier and quicker. The amendments to written communication clarifying means assessments and noting a possible entitlement to the Carer's Support Grant are good examples of progressive action here.

The number of people in receipt of CA has been increasing year-on-year, and anecdotally Family Carers Ireland has seen a reduction in cases leading to appeals. Engagement from Dept. of Employment and Social Protection staff on this issue has also been positive, and the actions taken are again recognised in the score.

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



Responsibility: DSP

The score on this action remains Good Progress, in recognition of positive engagement through the Annual Carers' Forum mentioned in previous scorecards, and the signposting on the DESP website to FCI's site. The proactive provision of information on Carer's Benefit and Carer's Leave to unionised employees reported on here is also welcome, and an excellent example of the kind of work that could be done effectively to promote available benefits for family carers and to ensure more family carers self-identify as such as early as possible in their caring role.

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 Care Sharing remains low, but the score of Initial Progress has been awarded on the basis of DESP's addition of an information page on the option to the Dept.'s Rate Booklet for 2017.

The DESP has shared with FCI that only 29 people in April 2017 were availing themselves of Care Sharing. This low figure suggests perhaps that the option is not very attractive to most, and this may well be related as much to the fact that a person is restricted in their working hours even on the alternate weeks when they are not caring as to the fact that the arrangement requires that two people within reasonable distance be able and willing to share care. It was suggested by the Monitoring Group that this regulation be reviewed.

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



Responsibility: DSP

The work to reduce waiting periods has been effective, and the Department acknowledges in its reporting the increased waiting times associated with a rise in applications, and its work subsequently to reduce these. In response to a PQ in June 2017, it was reported that waiting times had been reduced from 22 weeks in May 2016 to 12 weeks in May 2017. The time taken for appeals to be processed is somewhat longer, but it is recognised that this process is independent of the DESP, and that there have been improvements here too: The average processing time of CA appeals in 2016 was 17.6 weeks for summary decisions and 21.6 weeks for oral hearings, down from 20.6 and 25.9 respectively in 2015 (PQ 28th March 2017).

The issue remains that CA applications are weighted toward documenting physical disability, and against mental health difficulties or not necessarily noticeable intellectual disabilities, and that the subjective nature of medical assessment (where on a scale between mild and profound disabilities a diagnosis places a person) is not controlled for.

The accomplishment of reduced waiting times is however acknowledged in again awarding this action a score of Good Progress.

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



Responsibility: DSP

The third scorecard showed a very significant improvement in scoring of this action, moving from 'Regressive' to 'Good Progress', and this has been retained. The extension of payment of Carer's Allowance from 6 to 12 weeks after the death of a care recipient in Budget 2016 was welcome, and was matched in Budget 2017 by a similar extension being granted where a care recipient entered residential care.

The restriction to 15hrs of work weekly for CA recipients has been identified as a significant barrier to carers remaining in touch with or re-entering the workplace. The score of Good Progress last year was in part based on indications from the DESP that this would be reviewed. Engagement with the Department on this important issue is ongoing.

The direction of Dormant Accounts funding into schemes focused on family carers is welcome and again acknowledged here, in particular as a strand of funding is for former carers. A statement from the previous two scorecards remains relevant, however: 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.

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 progress in relation to the Carers Needs Assessment is important and is recognised under the dedicated action 2.1.3. Underreported is the involvement of family carers in the National Patients Forum, this is important as it is intended that the forum become *“the first point of reference for HSE divisions and clinical care programmes when seeking an input from patients/service users in the planning, design and delivery of services and will act as a sounding board for implementation of new and existing national programmes”*¹. Also underreported is the inclusion of family carers in the National Patient Experience Survey, which offers a valuable opportunity for patients and their families to provide feedback on their experience of Irish hospitals.

Notwithstanding the above, the Monitoring Group scored this action as ‘No Progress’. Since the launch of the strategy there has been no significant initiative to address the substantial issue at the core of this action, namely the need to raise awareness amongst health and social care professionals about carers’ physical and emotional health issues. In its engagement with the department the Monitoring Group has shared suggestions for proactive initiatives that could progress this action. These were reiterated in the last Scorecard and are repeated below

- 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.

None of these suggestions were addressed in the Departments’ 4th progress report. This is disappointing as it represents a failure to engage with family carers.

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. However, the Departments’ response leaves many questions unanswered, what is the family carer component in staff training? Do all staff receive this training? We still do not have a clear picture of the coverage of other named initiatives nationwide. How specifically are carers’ needs raised with staff through Primary Care Teams, Home Care package Teams etc.? It is known that some parts of the country are well-served whereas others are not. Without this information it is impossible to gauge how impactful these initiatives are. Furthermore, in the last Scorecard the Monitoring Group asked for contribution on this action from the directorates of Mental Health, Health and Wellbeing and Health Promotion given their

¹ <http://www.hse.ie/eng/about/Who/QID/Person-Family-Engagement/National-Patient-Forum/>

remit to supporting family carers. None of the issues that were brought to the departments' attention in the last Scorecard were addressed in this progress report.

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



Responsibility: HSE

There is a distinction between a proactive annual health check as named in the strategy and initiatives aimed at the population to take care of ongoing health concerns. The former is not addressed by any of the responses by DOH or HSE.

The Monitoring Group has repeatedly rejected the original reframing 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.

The extension of free GP care to various age cohorts as reference in the DOH's response only relates to carers if they happen to fall within the different age ranges. There is nothing in this extension that relates to family carers in particular.

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. This point was made in the last Scorecard document but has not been addressed in this progress report.

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

There has been good progress in relation to this measure. As part of the rollout of the InterRAI single assessment tool for older people the Carer Needs Assessment was piloted in three areas during the reporting period.

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

The Monitoring Group welcomes the granting of €300,000 by DoH through Dormant Accounts with the intention of replicating the Assistive Technology Library, as piloted in South Tipperary, across all CHOs in 2017. This is important work but it is unclear what proportion of this €300,000 will go towards telecare technology. Telecare technology is only one component of assistive technology; others include orientation devices, prompts and reminders, communication devices, locator devices, leisure and reminiscence supports and home safety.

The scope of this action, framed as it is by the Home Solutions Report, refers to supports for older people alone; while this is important and valuable, the Monitoring Group emphasises the importance of providing telecare supports for all age groups who may need them in their own homes. Similarly, Telecare initiatives funded via Local Authorities and the Senior Alert Scheme administered by Pobal should be extended to allow people across the life course to avail of a broad range of telecare supports (beyond personal alarms and pendants).

The Monitoring Group's assertion from Scorecard 3 remains relevant here in response to the assertion that 'resource challenges continue to be a challenge in this area':

[S#3] 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 [S#3].

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



Responsibility: HSE

During the year the 'Grace Case' (1989-2009) came to prominence and served to remind what can happen when appropriate procedures and resources are not in place. The Conal Devine Report shone a much needed light on adult protection services and drew attention to the then shortages in appropriate staff and the less than ideal response to financial abuse.

The Monitoring Group acknowledges below the good progress made in relation to the promotion of adult and child protection services during the reporting period. The Group observes that awareness raising leads to an expectation that there will be an appropriate response.

Notwithstanding the increase in dedicated social workers WTE referenced in Progress Report 3, the Group queries whether there is a sufficient staff to older people ratio to ensure comprehensive service delivery.

The positive infrastructure referenced in previous Progress Reports (establishment of National Safeguarding Office; recruitment of social workers; increase in case workers for protection of older people; development of 'Safeguarding Vulnerable Persons at Risk of Abuse') and welcomed by previous Scorecards remains vital to adult protection. That 8,000 people received safeguarding training in 2016 is reassuring and the availability of information about protection teams is welcome.

The finalising of Child Protection and Welfare Policy in 2016 is welcome as is the development of the dedicated website and online e-learning programme. It is encouraging that this training is mandatory for all HSE/HSE funded employees.

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

Previous Scorecards have responded to the review of the Fair Deal system of financing home care published in 2015. From a carers’ perspective there was a failure to tackle whether and how the scheme could be adapted to improve home and community care. This resulted in poor scores.

2016 has seen a prioritisation of this issue and signs of a willingness and ambition to tackle the issue of financing community and long-term care. One caveat that the Group would offer is that it is vital that people of all ages who require home care should be able to avail of any future scheme, not just those over 65.

On 1 June 2016, the Dáil agreed to establish a Special Committee -- the Committee on the Future of Healthcare -- to achieve cross-party consensus on a single long-term vision for health care and the direction of health policy in Ireland, and to make recommendations to the Dáil in that regard. It was clear that the committee would work towards recommendations in support of the recognition “that the best health outcomes and value for money can be achieved by reorientating the model of care towards primary and community care where the majority of people’s health needs can be met locally”

There was engagement by Minister McEntee in a proposal by Deputy O’Dea that in certain cases funds from the Fair Deal scheme could be extended to those living in their own home.

The Department of Health announced its intention to develop a new statutory home care scheme.

The HRB commissioned an evidence review of the way in which home care services are funded and regulated in other European countries.

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]

The consultation on the establishment of a new statutory home care scheme is welcome but this should not delay national standards for home support services which are overdue and of high importance. Family carers would welcome higher standards of care in the home and the involvement of HIQA in 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.

Previous Scorecards raised the issue of certain care providers not having staff Garda vetted, and outlined instances where family carers were 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. The Monitoring Group understands that the turnaround for Garda vetting improved significantly over the year.

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

In an earlier draft of this Scorecard the Monitoring Group incorrectly reported that the Department of Education failed to report under this action, when in fact the Department reported in detail. During the year the Department took meaningful actions in response to suggestions made in previous Scorecards. Significantly, the Junior Cycle Personal Safety Handbook 2016 recognises caregiving as a core area relevant to personal safety, which should be acknowledged by teachers. This could be further improved by including in "Appendix 3: Support Organisations" the contact details for Family Carers Ireland's Young Carer support services and Freephone Careline.

The positive engagement with DCYA through the NCS review process has been lauded in previous reports with acknowledgement given to the recognition of young carers within the National Youth Strategy. On the ground DCYA staff have been engaging with Family Carers Ireland's Young Carer Development Officer with referrals going both ways. Given that there is only one Young Carer

Development Officer in the country, Family Carers Ireland is eager to continue to engage with DCYA to see how even more DCYA staff and young carers can be reached.

Engagement with Tusla in 2016 on the National Carers Strategy and about the role of young carers has been positive.

The Monitoring Group welcomes the inclusion in compulsory School Attendance Strategies that it be made clear how young carers will be supported. The deadline for these to be submitted is September 2017, the Monitoring Group hopes this will have a tangible impact on young carers in education around the country.

A small portion of Dormant Accounts funding during 2016 supported the production and dissemination of three different booklets targeted at young carers themselves, young carers' families and professionals working with young carers.

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)

In an earlier draft of this Scorecard the Monitoring Group expressed disappointment that the Department of Education failed to report under this action, in fact the Department did report and engaged positively with the Monitoring Group during the year. While most of the Departments' commentary relates to children in general rather than young carers specifically we do note that the Junior Cycle Personal Safety Handbook identifies caregiving as a core area relevant to personal safety and young carers are recognised and should be acknowledged by teachers.

In relation to DCYA's reporting, "some" Children and Young People's Services Committees (CYPSC) do indeed support work with young carers and include young carers in their annual plans. However, a strategy to standardise and roll out this approach would be welcomed by the Monitoring Group.

The development of the Child and Family Support Networks and the Meitheal Early Intervention National Practice Model is indeed progress for children and families with complex needs generally but there are no specifics as to how this will address young carers' needs in particular. The indication that this 'could' be used with young carers is too vague to be meaningful.

Similarly the bulleted list of supports that all young vulnerable people can avail of fails to articulate how young specifically would be identified and supported.

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.

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

Once again the description of how young carers are identified, as described in the HSE’s response to this action, bears little resemblance to the experience on the ground. We are not coming across young carers being identified by Primary Care Teams and the Public Health Nursing Service in the manner described in the fourth progress report. 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 proactively 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) raising the issue of waiting lists which the Monitoring Groups can attest to being a serious problem. For young people that need to use this service to access counselling and mental health supports the enormous waiting lists are unacceptable.

Saying this, Family Carers Ireland has 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.

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].

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



Responsibility: CSO (No Response: CSO)

The repeated delay in the planned analysis of children who reported in the 2011 Census that they undertook caring roles is unacceptable and is responsible for the 'regressive' score awarded. This, fourth, progress report promises a report for 2017 and at time of writing (September 2017) this has not been produced.

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 have been used to inform service delivery and strategic responses addressing young carers' roles. It is now over a full Census cycle and counting for this information to be made available. This is disappointing as the delay diminishes the utility of the data. A report from 2011 data will now not be acceptable or useful; it must also include 2016 data.

This is particularly disappointing given the good work DCYA and the CSO engaged in to include young carers in the Census. DCYA was central to the original inclusion of a question about carers in Census 2011. The CSO ran a strong Carers Count Campaign in 2011 to highlight Q22, the question relating to family care. This question also allowed 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; DHPLG; HSE

The development and roll out of the Dementia Coping Skills for Families and Carers programme as part of the National Dementia Programme and the carer-related supports through the ‘Your Mental Health’ website represent tangible progress for carers.

The response from DHPCLG does not make clear how its actions ensure 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.

The Department of Health’s dedicated section for family carers on its website is welcome, though an articulation of how front line staff are equipped with relevant information is needed. We also acknowledge the collaborative and inclusive manner in which carers’ organisations were included in the development of this web resource.

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. These suggestions speak to an active equipping of staff with information rather than a passive provision of information.

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 was awarded from Dormant Accounts to meet family carers’ information needs. For example, Dormant Accounts facilitated further training for those who run the Family Carers Ireland 24 hour Freephone information Careline. Radio adverts were also funded to target those carers who may not be aware of supports available to them. Though Dormant Accounts funding is short-term and the information needs of carers is ongoing, for the relevant period of time it is allowing organisations representing family carers to provide an enhanced information service.

The Citizen’s Information Board remains an excellent source of information for Government supports for carers. Indeed the March 2016 issue of *Relate!*, the Citizens Information Board's monthly journal, provided an overview of the main schemes and payments for carers. It included information on social welfare payments for carers, carers leave from employment, maintaining your PRSI record while caring and tax reliefs and credits for 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. Progress has been made with the review of the internet-based information. A similar review of paper-based information is also required.

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 calls for family carers to be represented in these reviews.

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; DHPLG, DTTS)

Funding from Dormant Accounts has helped 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.

The Government’s report describes information provision initiatives across departments seeking to meet the needs of sub groups of carers. Significant though not reported in the Governments report was the announcement during the year of the HRB and The Atlantic Philanthropies €4.5 million investment to benefit Dementia patients and carers. Within this will be specific research projects targeted at carers, one example being the project “Towards resilience in family caregiving for people with dementia”.

In particular the Monitoring Group appreciates and intends to take up the Department of Education and Skill's offer to disseminate relevant information about carers/young carers through its links with schools.

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. These groups are always keen to work with departments to work towards fulfilling this action.

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



Responsibility: DSP [CIB]

The funding provided through the Action Plan for Dormant Accounts has facilitated locally-based training, information and related support services for carers. It has also supported the dissemination of resource information for carers at local level.

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 play a role here alongside government bodies. The Monitoring Group proposed that the role of allied health professionals in supporting this action could be explored further.

The Monitoring Group does note that there are still large gaps in information about the quantum of key resources, such as respite care, occupational therapy and speech and language therapy. Through engagement with carers' organisations the HSE has initiated a mapping exercise of respite care provision at local level all over the country. The Department is also engaged in a mapping of dementia services which should yield useful information for a sub cohort of family carers.

Simple pragmatic 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 here.

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 speaks directly to this measure. The application process ensured that information needs of carers were assessed with the funded training aiming to fill identified gaps. The purpose of this funding was 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 was not long-term, for the relevant period of time it allowed organisations representing family carers to provide an enhanced training options to family carers.

Worth mentioning too is the funding from the Department of Communications, Climate Action and Environment under their Digital Skills for Citizens Programme will support many carers to enhance their ability to get online.

The response from the Department of Education focuses on the needs of care workers (Further Education and Training sector caring sector NFQ (National Framework of Qualifications) awards), while important and a feature of Family Carers Ireland’s engagement with the Department in September the National Carers Strategy explicitly states that formal care workers engaged under a contract of service are not included within its’ provision (page 8, National Carers Strategy).

Training for family carers should be provided in a timely manner and triggered by specific transition points such as the discharge of a patient from hospital to the home who may require bed sore prevention/management. Despite the initiatives named above most carers’ experience with the health system does not include appropriate and timely training supports.

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: DES, HSE

The reported progress from the responsible departments or agencies does not make clear that that the goals of the strategy action are being met. Some specific initiatives by these and other parties are not reported on, however, and these have pushed the score from ‘No Progress’ last year to ‘Initial Progress’ this year. These initiatives include:

The funding awarded to Family Carers Ireland under the Digital Skills for Citizens initiative (from the Dept. of Communications, Climate Action and Environment) is intended to reach carers and older people with no computer skills, and should give them the know-how to navigate online, potentially reducing isolation for some, and giving many better confidence and new skills. This scheme could also serve as a preliminary to courses run as part of the Technology Enhanced Learning Strategy, targeting learners from one and allowing them to segue into the other.

Dormant Accounts funding (DSP/Pobal) also provided for the establishment by Care Alliance Ireland of a website listing training courses available for carers in Ireland and abroad.

Neither the DSP nor the Dept. Communications &c. has responsibility for this action, but the Monitoring Group felt these initiatives should be acknowledged. Further, the DSP's receptiveness to examining the current cap at 15hrs p/w which a recipient of Carer's Allowance can work, extending this to 18hrs for training which helps carers in their caring role, is welcome. Again, this would make relevant training accessible.

Courses for carers of those with life-limiting illnesses run in Dublin, Limerick and Clare provided respite for the registered carers so they could attend: this is a great example of what accessibility for carers looks like.

There is some underreporting from responsible parties. There are now good online courses for people caring for those with dementia, which have developed with input from the HSE.

The Monitoring Group sees potential in the ETBs, and Family Carers Ireland will look to engage with them going forward to try and expand options available to carers for training, upskilling and further education.

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: DHPCLG

The specific recognition of older people and those with disabilities in the *Rebuilding Ireland* Action Plan is acknowledged and welcomed, but contact with carers and those with conditions that make independent living difficult indicate that problems with the HAG scheme persist around the country.

Again, 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.

There are restrictions on adaptations in local authority housing, but the threshold for eligibility for the grant is so low that many successful applicants will not be in their own homes. We note also that more grants does not necessarily mean more effective changes, and the rise in building costs must be taken account of in considering the amounts of individual grants awarded. The older population has increased and demand for adaptations under the scheme is rising, but eligibility criteria have tightened for many local authorities and funding has dropped. The problem of long waiting lists remains; many local authorities still open applications for only a short window during the year and are already dealing with a backlog, meaning only high priority cases are being progressed. Timeliness is an issue, as needs may increase or a condition deteriorate while an applicant is waiting for approval or for work to commence.

The Department in their response note that *Rebuilding Ireland* recognises “the value and social benefit of these grants”. The Monitoring Group shares the opinion that this is a very important scheme, which is very effective in improving the lives of those who manage to avail of it. The commitments in the Action Plan mentioned in the Department’s response, and the 10% increase in funding on 2015 are acknowledged, and mean that despite the problems adumbrated above, the score has remained static.

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



Responsibility: HSE; DHPCLG

The response notes the limitations on funding for provision of equipment and assistive technologies, but does not recognise the problem is compounded by a shortage of the relevant staff mentioned, i.e. primary care physiotherapists and occupational therapists.

As reported in 2.1.4., to which this response refers, the Assistive Technology Library in Tipperary is an example of good practice; feedback from the project has been very good and its success is acknowledged.

The Department of Housing Planning and Local Government notes that a review of good practice models in service and housing provisions will soon commence and is hoped to be completed by the end of 2017. There is no further information provided here: will the review look to international models?

It was noted by the Monitoring Group that recommendations on decongregation will likely only be possible with the aid of assistive technologies. This is an important way to realise the government goal of reorientation toward community care, but appears to be seen as a luxury or add-on rather than something that needs to be integrated into community care. There is no sense in the response that the relevant departments are abreast of or providing incentives for developments in assistive technologies, or liaising with Enterprise Ireland, who are the national contact points under Horizon2020, which allocates R&D funding into assistive technology innovation: <https://www.enterprise->

ireland.com/en/Research-Innovation/Companies/Access-EU-Research-Innovation-reports/Ambient-Assisted-Living-.html

As with previous scorecards, the withdrawal of the telephone allowance must again be raised, and the negative impact on many pensioners highlighted. The score remains at 'No Progress'.

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 Scorecards #2 and #3, 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.

The Dept. of Transport reported in the last progress report that the next review of the Transport Sectoral Plan will be undertaken in 2016, and forecasted a comprehensive consultation process, with opportunities for carers' organisations to input into the development of the next plan. The sectoral Plan review was not undertaken however, nor has there been any advance consultation with interest groups, and the continued delay on this matter accounts for a scoring on this action of Regressive.

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



Responsibility: DSP

Despite its falling outside of the reporting period for the last scorecard, the restoration of the Respite Grant in Budget 2016 to €1,700 was felt significant enough a step for the Monitoring Group to recognise it here as having a meaningful impact on many carers' lives and as the accomplishment of something that family carers have long called for. This, coupled with the renaming of the grant as a Carer's Support Grant, moved the score from 'Regressive' in the prior two scorecards to 'Good Progress'. This score has been retained, but the Group offered some caveats and suggestions. First, it was noted that evidence shows the Department of Employment and Social Protection is informally refusing anything beyond 2 Carer Support Grants, seemingly on the basis that three are felt too many, or that it is though unrealistic that a person could be caring for three separate persons full-time. It was suggested that the CSG could

be paid pro-rata, meaning those caring for someone who dies or enters a nursing home prior to June of the relevant year would also receive the grant. It was also suggested that better awareness could be promoted among carers of people with a mental health difficulty that they might be eligible for the CSG. The suggestion was also made that the grant be increased to average €40 a week (= €2,080), or that this could be rounded down to €2,000 (the current average is €32.64).

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



Responsibility: HSE

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”. Indeed, the 2016 HSE Annual Report confirms a reduction of over 4,000 respite overnights delivered. From a carer’s perspective this is the critical issue; respite beds and long-stay beds have continued to be reduced across the country, with some converted into long-stay or residential places, without replacement, resulting in the ‘Regressive’ verdict being awarded again.

The last scorecard mentioned the example of the Tír Na Nóg Respite House in Carlow, the services provided by which were not replaced after it was deregistered. The well-documented difficulties in respite centres in North Kerry this year similarly suggest a lack of overall planning.

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. It is hoped the work of the Respite Review group will provide direction in establishing more, and more flexible, respite options.

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



Responsibility: HSE

The establishment of the Respite Review Groups is very welcome, as is the initial consultation of this group with a carers focus group convened by FCI. The establishment of the group and its having begun

its important work has pushed the score on this action to Initial Progress. The focus group conducted with family carers in December 2016 was important but the Monitoring Group urges that the review proceeds with urgency (at time of writing, September 2017, tangible progress is not yet evident) and that its work does not delay the immediate investment required. It is expected that the review exercise, to be fully effective, will include a thorough mapping of respite services, including types of respite available and numbers of places, the availability of in-home and residential respite, what counties or localities represent ‘respite black spots’, where demand far exceeds supply and examination of what is working well in particular counties with a view to assessing its transferability.

It remains the case that respite shortfall is one of the greatest difficulties facing family carers. Respite services are essential, and their improvement is an urgent matter. This is not in dispute, and it is hoped that the work of the Review Group – which is not explicit in its terms of reference – will make effective recommendations which can be acted upon to improve respite provision.

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



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

The Monitoring Group acknowledges the extensive response from DJEI here, which has engaged with the NCS toward the close of its lifetime, and who met with FCI representatives in 2016. Awareness of the role of the Workplace Relations Commission in promoting flexitime and other measures for accommodating those with caring obligations and permitting them to remain in the workforce is also welcome. Similarly, Justice, which is responsible for Carer’s Leave legislation, reports on the numbers of its staff who availed themselves of Carer’s Leave in 2016, showing an increase from 5 to 10. The improved reporting and the promotion within departments of leave policies or work practices which accommodate carers has improved the score on this action from Initial Progress to Good Progress.

4.2.2. Promote Awareness of the Carers Leave Act 2001



Responsibility: DJEI (NERA)

This action has been awarded the improved score of Initial Progress, based on improved reporting from DJEI and the DCYA’s planned awareness campaign on Carer’s Leave to coincide with the launch of the new, 2017 staff handbook. It was also noted by the Monitoring Group that there was some under-reporting on this action of welcome activities, such as the DSP’s piece on Carer’s Leave and Carer’s Benefit published in the newsletters of SIPTU and other trade unions, and information provided at

conferences of trade unions (reported in 1.3.2). Though DSP are not listed as having responsibility here, the Monitoring Group believes these positive steps in promoting awareness of the provisions of the Act deserve acknowledgment here. More might however be done, whether by government departments of the WRC, to examine whether the relevant legislation is accomplishing its purpose, and suggestions for further promotion of the Act given in the last scorecard still stand.

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



Responsibility: DJEI (No Response DJEI)

This is an important issue, related to sustainability of the workforce, the importance of which will only increase in the future, with an ageing population and shifting dependency ratio meaning more and more workers are going to find themselves juggling caring obligations with full-time work. A future, refreshed National Carers' Strategy will likely need more robust actions related to this issue. The score remains 'No Progress', as the relevant department has not responded at all, and so there is no reported progress to assess. It has been suggested in FCI's pre-budget submission that the Carer's Leave Act 2001 needs to be reviewed to include a right to request flexible working time; this would be in line with the recent EU Directive on Work-Life Balance. The right of workers to call for flexible working time, and its encouragement as a way of facilitating employees' balancing of work with care obligations, is significant part of that Directive, and Family Carers Ireland would join Marian Harkin MEP in recognising this: Member Harkin wrote in her press release of April 27th 2017 of this and the proposed 5 days leave at sick-pay rates to care for or make arrangements for the care of ill relatives: 'it is [only] a start, but it will be a real achievement to get this in place'. It is also suggested that the Workplace Relations Commission as well as DJEI should be developing mechanisms to monitor the prevalence of flexible working arrangements within the Irish Economy; a report by Citrix suggests that most Irish-based business do not support mobile or flexible working (Citrix Ireland (2013) *Flexible Working in Ireland?*), and embracing trends toward flexible time will become more and more important to employees in all sectors of the economy.

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

The awarding of the 'Good Progress' score to this action is based, as with previously, on Dormant Accounts funding awarded to carers' representative and advocacy organisations much of which was devoted to a variety of information and training programmes.

As in previous scorecards, the Monitoring Group must again draw 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. This is frequently identified by carers 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. The DSP however has suggested that the permitted number of hours may be raised for carers undertaking training specifically related to their caring role. This allowance would be welcomed by carers.

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



Responsibility: DSP

The score has remained at 'Initial Progress', but the Monitoring Group acknowledges the improved reporting from DSP on this action. The observation regarding the action above and made in previous scorecards that family carers' restriction to 15hrs weekly excludes them from many training and work programmes stands. An action which allows recipients of Carer's Allowance to access activation services at the end of their caring role would be welcomed, but as indicated in the department's progress this is something which is only being considered in Pathways to Work 2017, rather than progressed.