

National Carers' Strategy Scorecard 2017



**Assessing
Government's Fifth
Annual Progress
Report from the
Perspective of
Family Carers**



Assessing progress on the implementation of the National Carers' Strategy in 2017 from the perspective of family carers.

About the Scorecard

Ireland's first National Carers' Strategy was published in 2012 with the vision that "Carers will be recognised and respected as key care partners, supported to maintain their own health and well-being, to care with confidence and empowered to participate as fully as possible in economic and social life". This vision was supported by 42 strategy actions, with responsibility for each action assigned to designated Government departments. The Department of Health has responsibility for the overall coordination of the strategy. Each year, departments report to the Department of Health on the progress they have made in implementing the actions assigned to them. This feedback is then collated into annual progress reports.

The National Carers' Strategy Scorecard, prepared by the National Carers' Strategy Monitoring Group (appendix 1), is an assessment of Government's annual progress reports, identifying the degree to which progress has been made with regard to each action. The Monitoring Group, led by Family Carers Ireland with membership from Care Alliance Ireland and a diverse group of family carers, uses an established methodology assigning one of five 'scores' to each action reflecting the progress they feel has been achieved during the review period.

Objective Achieved	Making a real difference for family carers
Good Progress	Positive results for family carers
Initial Progress	Some progress but slow pace/delayed start
No Progress	Nothing has been achieved
Regressive	Things have gotten worse

Overview of Scorecard 2017

There has been an overall improvement in the progress reported for 2017. Of the 42 actions, one received an 'Objective Achieved' score, meaning that the action has been implemented in full and is making a real difference to family carers; 21 actions received a 'Good Progress' score, meaning that there have been positive results for family carers; eight 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; nine 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; and finally three actions received a 'Regressive' score, meaning that the situation has worsened for family carers since the strategy was launched. Overall between 2016 and 2017, the scores assigned to 27 actions remained unchanged, 11 improved and four have gotten worse. The scores assigned in Scorecard 2017 were influenced by a number of significant events which took place during the year, specifically:

Highs

- » Allocation of €500,000 Dormant Accounts funding for information and training supports for carers.
- » Commitment to establish a statutory homecare scheme and the launch of a public consultation on homecare services.
- » Announcement of an additional €10m in funding towards the enhancement of respite supports for people with disabilities, €5m of which will go towards an additional respite houses in each CHO; €3m for additional respite houses in the greater Dublin areas; and €2m for alternative models of respite.
- » Carers in receipt of Carer's Allowance and Carer's Benefit to receive a GP Visit Card.
- » Medical Card for all children in receipt of Domiciliary Care Allowance.
- » Allocation of funding towards the implementation of a waste collection allowance for households where incontinence care is provided.
- » Completion of Ireland's first Carer Needs Assessment developed in collaboration with the HSE, InterRAI, Family Carers Ireland, Care Alliance Ireland and the Carer Reference Group.
- » Establishment of the Office of the Decision Support Service and the appointment of a Director of Decision Support to oversee the implementation of the Assisted Decision Making (Capacity) Act 2015.
- » Extension in the payment of Carer's Allowance from 6 to 12 weeks when the caring role ends due to admission to long term care.
- » Publication of Census 2016 Profile 9 on Health, Disability and Carers.

Lows

- » Access to respite remains problematic and is often dependent on the nature of the person's condition and where in the country they live, rather than on need. While respite is consistently identified as a key intervention to support the health and well-being of carers and is critical to the sustainability of caregiving efforts, funding cuts, staff shortages, bed closures and the transfer of respite beds to transitional care beds or long stay beds have combined to reduce respite availability.
- » Continued underfunding of homecare and the postcode lottery experienced by families trying to access supports.
- » Reliance by carer organisations on short-term funding and annual grants such as Dormant Accounts funding which prevents long-term planning and causes uncertainty in service delivery.
- » Practice of reducing homecare supports where a family member is in receipt of Carer's Allowance.
- » Findings from the National Patient Experiences Survey undertaken in May 2017 showed ongoing issues with hospital discharges, including poor discharge planning and inadequate consultation with family members.
- » The 'trolley crisis' continued and the total number of public hospital patients on some form of a waiting list surpassed the 600,000 barrier.
- » Failure to replace the Mobility Allowance and the Motorised Transport Grant withdrawn in 2013 with the long awaited 'Transport Support Scheme'.
- » An increasing number of carers and people with disabilities on the social housing waiting list and at risk of homelessness due to a shortage of accessible houses.

NCS Scorecard 2013-2017



The following table compares the scores assigned to all 42 strategy actions by the Monitoring Group for the 2016 and 2017 progress reports. The narratives explaining the rationale for each score are contained in the next section.

Action	2016	2017
National Goal 1: Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person they care for		
Better recognition of the role and contribution of carers	Good Progress	Good Progress
Carers' needs are considered in the development of policies that affect them	Good Progress	Good Progress
Build on Census 2011 to establish a statistical profile of family caring in Ireland	Good Progress	Good Progress
Continue to convene an Annual Carers' Forum	Achieved	Achieved
Support national organisations representing the interests of carers	Initial Progress	Initial Progress
Promote more proactive approach to identification of carers & addressing needs	Initial Progress	Good Progress
Promote carer self-identification initiatives	Initial Progress	Initial Progress
Involve carers as partners in care planning and provision	No Progress	Initial Progress
Identify carers and their involvement in discharge planning	Regressive	No Progress
Provide regular benefits advice sessions and information	Good Progress	Good Progress
Ensure carers can access benefits advice as early as possible	Good Progress	Good Progress
Publicise that the Carer's Allowance can be shared by two carers	Initial Progress	Initial Progress
Reduce waiting periods for processing of Carer's Allowance applications/appeals	Good Progress	No Progress
Review existing transition arrangements for carers at the end of their caring role	Good Progress	Good Progress

Action	2016	2017
National Goal 2: Support carers to manage their physical, mental and emotional health and wellbeing		
Raise awareness of the physical and emotional health issues carers experience	No Progress	Initial Progress
Encourage carers to attend their GP for an annual health check	No Progress	Good Progress
Develop and roll out SAT for older people and ensure carers' needs are included	Good Progress	Good Progress
Implement the recommendations of the Home Solutions Report (13) on telecare	Initial Progress	Initial Progress
Promote awareness of adult and child protection services	Good Progress	Good Progress
Review Fair Deal to develop an equitable system for community/long-term care	Good Progress	Good Progress
Implement national standards for homecare subject to inspection by HIQA	No Progress	No Progress
Raise awareness of the signs that children and young people are carers	Good Progress	Good Progress
Review how agencies respond to young carers/young adult carers	No Progress	Initial Progress
Identify supports needed by young carers and create mechanisms to contact service providers	Regressive	No Progress
Investigate the situation of children and young people undertaking caring roles	Regressive	No Progress
National Goal 3: Support carers to care with confidence through the provision of adequate information, training, services and supports		
Ensure frontline staff can signpost carers to other services as appropriate	Initial Progress	Good Progress
Investigate how more comprehensive carer information can be developed	Good Progress	Good Progress
Ensure that the information needs of sub-groups of carers are addressed	Good Progress	Good Progress
Collate and disseminate information about carer services available at a local level	Good Progress	Good Progress
Identify gaps in the content of current training programmes for carers	Initial Progress	Good Progress
Enhance the accessibility of education and training courses	Initial Progress	Good Progress
Prioritise funding for housing grants for older people and people with a disability	No Progress	Regressive
Identify good practice in assistive technology/ ambient assistive living technology	No Progress	No Progress
Review and update Transport Sectoral Plan under Disability Act 2005	Regressive	Regressive
National Goal 4: Empower carers to participate as fully as possible in economic and social life		
Promote a better awareness of the existence of the Respite Care Grant	Good Progress	Good Progress
Promote a range of person-centred and flexible respite options	Regressive	Regressive
Identify gaps in services and establish performance indicators for respite services	Initial Progress	No Progress
Promote carer friendly HR policies within Government departments and agencies	Good Progress	Good Progress
Promote awareness of the Carer's Leave Act 2001	Initial Progress	No Progress
Encourage work-life balance provisions to promote carer-friendly workplaces	No Progress	No Progress
Back to work and education training courses tailored to needs of carers	Good Progress	Good Progress
Review access by family carers to labour market activation measures	Initial Progress	Initial Progress

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

Response received: Department of Business, Enterprise and Innovation; Department of Children and Youth Affairs; Department of Employment Affairs and Social Protection; Department of Education and Skills, Department of Health and HSE.

No response: Department of Transport, Tourism and Sport; Department of Communications, Climate Action & Environment; Department of Justice and Equality; Department of Housing, Planning and Local Government.

Score: Good Progress

Explanation of assigned Score: 'Good Progress' continues to be made in strengthening awareness and recognition of the role and contribution of carers at national, regional and local level. In particular, the Monitoring Group acknowledges the efforts of the HSE to embed the voice of families and carers within the National Patient Experience Survey Programme, the establishment of Mental Health Area Leads in each CHO; the continued funding of TILDA; the investment of Dormant Accounts funding to support information and training provision for carers; the recognition of young carers by CYPSC and the ongoing efforts of the Workplace Relations Commission to support carers in the workforce. However, the Monitoring Group remains concerned that: (i) Despite all departments having a reporting requirement under Action 1.1.1, only six departments reported progress. Indeed some of the departments who did not report progress had in fact delivered very significant improvements for carers during 2017. (ii) Some progress reported has yet to materialise, for example the Department of Health's commitment to the drafting of primary legislation for a new Transport Support Scheme to assist those with a disability. (iii) We were not aware of some of the initiatives described, for example the age profiling of young carers by CYPSC or the request by SOLAS for ETBs to set out how training needs identified by carer organisations can be/will be addressed at local level.

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

Response received: Department of Business, Enterprise and Innovation; Department of Children and Youth Affairs; Department of Employment Affairs and Social Protection; Department of Education and Skills, Department of Health and HSE; Department of Housing, Planning and Local Government and the Department of Justice and Equality.

No response: Department of Transport, Tourism and Sport; Department of Communications, Climate Action & Environment.

Score: Good Progress

Explanation of assigned Score: The allocation of 'Good Progress' is 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 with a focus on the interim review of Better Outcomes Brighter Futures and the recognition of young carers in the '50 Key Messages' parental guidance documents. The Department of Education's ongoing review of the SNA Scheme and the publication of a report by SOLAS on Barriers to Participation in FET by Vulnerable Individuals also demonstrates significant progress in considering the needs of students with support needs as well as young carers transitioning from second to third level education. In the Department of Health, the allocation of €10m towards respite for people with disabilities was significant, as was the publication of the National Disability Inclusion Strategy 2017 - 2021. The ongoing engagement by the Department of Employment and Social Protection with the strategy overall has been positive and has contributed to the Good Progress score. The department's proactive engagement with the caring sector through the Annual Carers' Forum, as well as engagement with the Community and Voluntary Pillar organisations, continues to be exemplary (recognised in action 1.1.4).

The Monitoring Group is disappointed however that progress was not reported by the Department of Children and Youth Affairs in relation to the implementation of action 5.6 in the National Youth Strategy 2015-2020¹ to establish a cross-agency young carer working group. While the Group acknowledges the Department of Housing, Planning and Local Government's general support of consultation where appropriate, they would like to have seen more detailed progress reported by the department, particularly given the importance of housing supports and accessible living environments for people with disabilities, older people and their carers.

Of significant importance during 2017 was the ongoing work by the Department of Justice and Equality in relation to the Assisted Decision Making (Capacity) Bill 2015 and the establishment of administrative and support measures including the Office of the Director of Decision Support. While acknowledging the importance of this legislation and the very urgent need to establish the act fully, family carers remain sceptical about the practical application of the legislation and the need for provision to be made by the department to ensure the needs of decision-makers, most likely to be family carers, are also addressed.

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



Responsibility: CSO

Response received: Department of Children and Youth Affairs

No response: CSO

Score: Good Progress

Explanation of assigned Score: While the CSO did not report any progress, the Monitoring Group once again assigned a 'Good Progress' score in recognition of the publication in 2017 of the Profile 9 report from Census 2016 on 'Health, Disability and Caring' and the CSO's ongoing engagement with carer organisations in relation to Census 2021. The CSO failed to report on the work undertaken by the Census Advisory Group during 2017 and the public consultation on questionnaire content on Census 2021 launched in October, which included a focus on Q22 which captures information on caregiving. Carer organisations have made recommendations to the CSO as part of the consultation suggesting how Q22 could be improved to better capture the prevalence of caregiving and keep in line with other CSO surveys which show higher prevalence rates (10%) than those captured in the Census (4%). We are hopeful that the practical suggestions made will be reflected in Census 2021.

The Monitoring Group welcomes the Department of Children and Youth Affairs' analysis of Census 2016 data on young carers and looks forward to its publication.

¹ Action 5.6. 'To establish a cross-sector/cross-agency working group to consider the needs of young carers and to work towards aligning supports for young carers to help ensure an integrated and coordinated response to their needs'.

1.1.4. Continue to convene an Annual Carers' Forum to provide carers with a voice at policy level.



Responsibility: Department of Employment Affairs and Social Protection

Response received: Department of Employment Affairs and Social Protection

Score: Objective Achieved

Explanation of assigned score: The Monitoring Group has assigned an 'Objective Achieved' score in recognition of the Department of Employment Affairs and Social Protection's continued commitment to hosting an Annual Carers' Forum. The manner in which the department engages with carer organisations is exemplary; year on year they have liaised with carer organisations and sought to improve the forum's format. The department have also demonstrated an openness to participation from relevant not-for-profit organisations who had not been invited in previous years.

Despite the positive score, the Monitoring Group notes that the timing of the Annual Carers' Forum, traditionally hosted early in the year, has slipped in recent years taking place in the latter part of the year. The Group recommends that the forum be hosted in February or March each year, prior to prebudget deliberations. Likewise, the Group restates the importance of having officials from all relevant Government departments present at the forum.

1.1.5. Support national organisations representing the interests of carers



Responsibility: Department of Employment Affairs and Social Protection; Department of Health.

Response received: Department of Employment Affairs and Social Protection; Department of Health; HSE.

Score: Initial Progress

Explanation of assigned score: The Monitoring Group recognises the funding provided to national carer organisations which enables the provision of essential services such as respite, home care, training, information and advocacy. In particular, the Group acknowledges the positive impact of the Action Plan for Dormant Accounts which in 2017 provided funding to the Department of Employment Affairs and Social Protection of €0.5m 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. The Monitoring Group also welcomes funding received under the Scheme to Support National Organisations and recent increases in the funding allocation.

National organisations representing 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, particularly those caring for someone aged under 65. There are also regional inconsistencies in the provision and allocation of Section 39 funding, contributing to the 'postcode lottery' experienced by carers in some regions when trying to access supports.

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 carer organisations but they facilitate short-term (single year) action rather than contributing to the establishment of much-needed medium or long-term (multi-year) supports for family carers. An increase in core funding and a move to multiannual funding, as committed to in the 2016 Programme for Partnership Government (p. 131), would enable the provision of a more consistent service to family carers and an ability to plan for the future.

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: Department of Health; HSE; Department of Education and Skills.

Response received: Department of Education and Skills; HSE.

No response: Department of Health.

Score: Good Progress

Explanation of assigned score: The Monitoring Group assigned a score of 'Good Progress' in recognition of the very significant work undertaken by the Department of Education in promoting awareness of youth caregiving amongst students, parents and teachers, including the identification of young carers in the 'Personal Safety' guidelines for junior and senior cycle, and the ongoing work of the HSE in the development of a Carer Needs Assessment. The Group welcomes the completion of an agreed Carer Needs Assessment tool in December 2017, in collaboration with the HSE, InterRAI and representatives from the caring sector, and looks forward to the tool being made available to all carers. While not reported, the Monitoring Group also acknowledges the work of the HSE's National Patient Experience Survey's Oversight Group and the inclusion of families and carers in the development of quality improvement plans across hospital groups.

Notwithstanding the positive score, the Monitoring Group highlights delays in the identification of carers, with some carers reporting that they have cared for many years without finding out about supports that could be useful to them. To this end, the creation of a carer register and 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.

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



Responsibility: HSE

Response received: HSE

Score: Initial Progress

Explanation of assigned score: The Monitoring Group recognises the challenge presented by Action 1.1.7 and its focus on carers self-identifying to service providers which places the impetus on carers themselves. As highlighted in previous scorecard reports, whenever a carer applies for Carer's Allowance, Carer's Benefit, a Housing Adaptation Grant, respite care or home support they are in fact self-identifying to service providers. This presents an opportunity for departments/agencies to ask carers who apply for these supports whether they would like to be added to a carers' register 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 and/or referred to dedicated carer organisations for support (notwithstanding GDPR requirements).

The Monitoring Group acknowledges in particular the achievements of the Mental Health Engagement structures, the HSE carer webpage, the ongoing work of the CSO to improve question 22 wording on caregiving and Dormant Accounts funding as mechanisms through which carers are encouraged to self-identify.

Objective 1.2: Including carers in care planning and decision making for those that they care for**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**Response received:** HSE**Score:** Initial Progress

Explanation of assigned score: For the first time since the National Carers' Strategy's publication, the Monitoring Group has assigned a score of 'Initial Progress'. The score recognises the work being undertaken by the National Patient Experience Oversight Group and the Mental Health Division which encourages the involvement of family members in advancing the 'recovery based model' of mental health services, including the publication of the 'Recovery Framework for Mental Health Services'. While not reported, the score also reflects the first phase of a public consultation on the creation of a statutory homecare scheme and ongoing engagement with carer organisations.

Despite the improved score however, the Monitoring Group is concerned that 'respecting carers as partners in care' remains an ambition rather than a reality. The lived experience of many carers is that their expertise and practical knowledge is not taken into account by health professionals, nor is their ability or willingness to be included as a contributor to the care plan. Significant issues remain in relation to the rationing of home supports where a family member is present and the inclusion of family carers as the 'second' carer in packages of home support where two or more carers are required to satisfy health and safety regulations.

1.2.2. Identify carers and their involvement in discharge planning, including their details provided in discharge letters to GPs**Responsibility:** HSE**Response received:** HSE**Score:** No Progress

Explanation of assigned score: The score for Action 1.2.2. has improved from 'Regressive' to 'No Progress' to acknowledge the efforts of the Acute Hospital Division to ensure families and carers are included in the quality improvement plans developed by hospitals in response to results of the National Patient Experience Survey. The 2017 survey showed significant weaknesses in hospital discharge processes and the inadequate involvement of family carers in discharge planning. Family Carers Ireland has worked with the Acute Hospital Division throughout 2017 to support hospitals to better involve patients and their carers in care decisions; enabling patients to have the support of family members and loved ones during their hospital stay and ensuring they feel supported post discharge. The Monitoring Group acknowledges however that this work has yet to yield significant positive change and families still report feeling under pressure to take their loved ones home from hospital without adequate supports in place.

Similarly, while the HSE's National Healthcare Charter commits to "involving you and your family and carers in decision making about your healthcare and will take account of your preferences and values" and the explicit statement to involve service users and their carers in discharge planning (step 6 of the HSE's Integrated Care Guidance: A Practical Guide to Discharge and Transfer from Hospital) carers continue to report being excluded from decisions relating to the care of their loved one, even where they will play a significant caring role post discharge.

Objective 1.3: Recognise the needs of carers by provision of income supports.

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



Responsibility: Department of Employment Affairs and Social Protection

Response received: Department of Employment Affairs and Social Protection

Score: Good Progress

Explanation of the assigned score: The score on this action remains 'Good Progress' and, as with previous scorecards, the Monitoring Group recognises the ongoing engagement of the department with carer organisations throughout the year and the actions that have been taken to make applying for or appealing decisions on Carer's Allowance easier and more efficient. The amendments to written communication clarifying that Carer's Allowance is a taxable source of income and noting a possible entitlement to the Carer's Support Grant are good examples of progressive action here. The investment of Dormant Accounts funding into carer information resources and training have enabled carer organisations to deliver rights and entitlements supports to carers, which has also helped to progress this action, as have the regular information sessions hosting by the department's communications and customer service section. Of significance is the commencement during 2017 of a review of the Carer's Allowance application form, which aims to make the forms more accessible to all carers including those caring for a loved one experiencing mental health difficulties or with an intellectual disability.

While not directly related to action 1.3.1, the Monitoring Group expressed disappointment that the actions contained under objective 1.3 do not address the ambition of the objective, that is to 'recognise the needs of carers through the provision of income supports' but rather focus on raising awareness of the payments themselves. Only one quarter of all carers qualify for Carer's Allowance and as such more emphasis should be placed on extending income supports to reach as greater number of carers, for example by increasing the income disregard or the allowable hours of work/study.

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



Responsibility: Department of Employment Affairs and Social Protection

Response received: Department of Employment Affairs and Social Protection

Score: Good Progress

Explanation of assigned score: The score remains 'Good Progress' in recognition of the positive engagement of the department through the Annual Carers' Forum mentioned in previous scorecards and the signposting on the DEASP website to FCI's site. The allocation of Dormant Accounts funding to improve information and training for carers, including promoting the identification of carers early in their caring journey, has helped progress this action.

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: Department of Employment Affairs and Social Protection

Response received: Department of Employment Affairs and Social Protection

Score: Initial Progress

Explanation of assigned score: A score of 'Initial Progress' was awarded in recognition of the efforts of the department to increase awareness of Care Sharing arrangements with the addition of an information page on the department's website and within the Rates Booklet for 2017. While take-up of Care Sharing remains low, decreasing from 32 carers in the scheme in 2016 to 28 carers in 2017, this can in part be attributed to: (i) the scheme's criteria and the fact that it may not be an attractive option to many carers (ii) carers who qualify may be financially better off claiming another welfare payment and (iii) few, if any recipients of care receive residential care on alternate weeks.

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



Responsibility: Department of Employment Affairs and Social Protection

Response received: Department of Employment Affairs and Social Protection

Score: No Progress

Explanation of assigned score: The score of 'No Progress' reflects the ongoing challenge of keeping Carer's Allowance processing times at or below the target of 12 weeks. While the Department refer only to a reduction in waiting times in the progress reported, the minister clarified in her response to a PQ that waiting times reduced from 22 weeks in May 2016 to 17 weeks in December 2017, some five weeks off the 12 week target. The Monitoring Group is hopeful that the review of the Carer's Allowance application process and form undertaken in 2017, the recruitment of additional staff and continuing improvements in business process will yield improvements in processing times in 2018 and beyond.

While the Social Welfare Appeals Office's Annual Report 2017 shows a reduction in Carer's Allowance appeals of almost 18% between 2016 and 2017, waiting times for an appeal decision have increased from 17.9 weeks to 18.7 during the same period. Worryingly, the number of appeals for DCA has increased by 95% and Carer's Benefit by 15% during the same period, with a rise in waiting times from 23.3 weeks to 26.6 weeks for DCA and from 16.4 to 16.8 weeks for Carer's Benefit.

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



Responsibility: Department of Employment Affairs and Social Protection

Response received: Department of Employment Affairs and Social Protection

Score: Good Progress

Explanation of assigned score: The marked improvement in progress relating to transition arrangements for carers reaching the end of their caring role has continued. The extended payment of Carer's Allowance from 6 to 12 weeks after the death of a care recipient announced in Budget 2016 was matched in Budget 2017 by a similar extension being granted where a care recipient enters residential care.

Of significance is the focus of Dormant Accounts funding for 2018 towards supporting former carers. The funding, which was announced in December 2017, will enable carer organisations to roll out a number of initiatives across the country which support not only former carers, but also those who are preparing for the transition from the caring role. Family Carers Ireland specifically will use the €338,464 awarded to implement a national Plan C Programme to support former carers to manage the difficulties of transitioning from the caring role and adjusting to new circumstances. Modest HSE/National Lottery support of €5,707 for the printing and distribution of an updated booklet for former family carers, managed by Care Alliance Ireland, is also acknowledged.

As noted in the previous scorecard, the restriction imposed on all carers in receipt of any care-related social welfare payment to work or study no more than 15 hours per week acts as a barrier to carers remaining engaged with the workforce or further education and training. Indeed, many training programmes available to carers are in excess of the 15 hour ceiling. The Monitoring Group is hopeful that the department will increase the allowable hours of work/study to 18.5 hours in line with Government policy to achieve full employment in its Roadmap for Pension Reform.

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

Response received: HSE

Score: Initial Progress

Explanation of assigned score: The Monitoring Group awarded a score of 'Initial Progress' based on two specific initiatives – the completion of an agreed Carer Needs Assessment tool as reported by the HSE in the progress report and the decision to grant carers in receipt of Carer's Allowance and Carer's Benefit a GP Visit Card after the 'Carers in Crisis' documentary aired in December 2017 (which was unreported). Notwithstanding these initiatives, the Group remains concerned that despite being in the final year of the National Carers' Strategy, these are the only significant measures put forward 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 health issues. Indeed, for the Carer Needs Assessment to prove useful in progressing this action, it must be adopted by the HSE and made available to all full-time carers.

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



Responsibility: HSE

Response received: HSE and Department of Health.

Score: Good Progress

Explanation of assigned score: After four years of 'No Progress' the Monitoring Group is pleased to be able to increase the score assigned to action 2.1.2 to 'Good Progress'. This much improved score recognises the decision to grant carers in receipt of Carer's Allowance and Carer's Benefit a GP Visit Card. While regarded as an important step towards recognising the health and wellbeing needs of carers, the Monitoring Group cautions that only one quarter of all carers qualify for Carer's Allowance due to the strict eligibility criteria attached to the payment and as such, many deserving carers will not benefit from the announcement. We recommend that, to further progress this action, the GP Visit Card be extended to all full-time carers in receipt of the annual Carer's Support Grant. The score also reflects the inclusion of carers as an 'at risk group' for the flu vaccine who are entitled to have the vaccine provided free of charge.

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: HSE; Department of Health

Response received: HSE

No response: Department of Health

Score: Good Progress

There has been continued 'Good Progress' in relation to this measure with the ongoing rollout of the SAT for Older People across designated hospitals and CHOs. The Carer Needs Assessment, developed in partnership with the HSE, InterRAI and carer representatives as an addendum to InterRAI's suite of assessment tools, was completed in December 2017. The Monitoring Group recommends that family carers be given an entitlement to a Carer Needs Assessment, similar to the entitlement that currently exists in other jurisdictions including the UK.

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



Responsibility: HSE

Response received: HSE

Score: Initial Progress

Explanation of the assigned score: The Monitoring Group welcomes the allocation of €600,000 in Dormant Accounts funding over the two year period 2016/2017 to establish Memory Technology Resource Rooms across all nine CHOs. The Assistive Technology Library piloted in South Tipperary since 2011, and on which the Memory Resource Rooms will be based, has been a useful resource for people with memory difficulties and their carers. While not reported in the progress report, the score reflects the review of the Senior Alert Scheme and the introduction of a number of important changes during 2017 including the extension of the eligibility criteria to include elderly people who live on their own for long periods during the day and the introduction of free monitoring for the first year and a nationwide public awareness campaign in partnership with Pobal to increase a greater level of awareness, interest and participation in the scheme. The Monitoring Group recommends that the scheme be further extended to people of all ages and include basic assistive technology components.

While welcoming additional investment in the area of telecare, the Monitoring Group is cognisant of the specific recommendations set out in the Home Solutions Report 2011 - in particular that telecare should be regarded as a substantive ingredient of home care services especially for people with high levels of need and those who are assessed as likely to need residential or similar forms of care. To this end, the Group believes much more should be done to incorporate telecare and assistive technologies into packages of home support, using them as preventative measures against long-term residential care.

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



Responsibility: HSE

Response received: HSE

Score: Good Progress

Explanation of the assigned score: Good progress continues to be made in relation to the promotion of adult and child protection services. The Monitoring Group acknowledges the exceptional work undertaken across the HSE to raise awareness of the Children First Act 2015, HSE's policy that all staff irrespective of role, grade or position must promote the welfare of children and protect them from harm and the mandatory Children First e-learning module which must be completed by all HSE and funded agencies.

Significant progress has also been made in relation to the safeguarding of vulnerable adults with the establishment of Safeguarding Ireland in 2015 with representation from the caring sector; the publication of the office's first strategic plan in 2017; the creation of Safeguarding Committees and Safeguarding Teams at CHO level and the training of some 18,500 people in adult safeguarding. The work of the Safeguarding Office has done much to promote awareness of adult safeguarding in its relatively short history by highlighting the on-going need to strengthen incident reporting, improve governance and accountability and enhance monitoring arrangements.

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: Department of Health

Response received: Department of Health

Score: Good Progress

Explanation of the assigned score: While 'Good Progress' continues to be made, the Monitoring Group reminds the Department that action 2.1.6 refers specifically to the review of Fair Deal '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'. While the department has reported on the welcome progress in relation to advancing the recommendations set out in the Review of the Nursing Home Support Scheme 2015, there is no reference to any initiative that will support older people to remain at home.

While not reported, significant progress was made by the department during 2017 in relation to creating a statutory entitlement to homecare which would place homecare and nursing home care on an equal statutory footing. In January 2017, Government committed to the creation of a statutory homecare scheme and in July launched a public consultation on homecare services. The consultation was closed in October 2017, however organisations within the caring, older persons and disability sectors remain engaged with the Department on the development of the scheme and are united in calling for a scheme which is (i) sufficiently broad to encompass all potential users of long-term care services; (ii) incorporates a broad definition of home care and includes access to the gamut of services necessary to support and sustain people at home including respite; (iii) enshrines the principles of objectivity, transparency and consistency in the assessment of care needs and; (iv) provides for a proper independent regulatory system to ensure the quality and integrity of the homecare system.

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: Department of Health; HSE

Response received: Department of Health; HSE

Score: No Progress

Explanation of the assigned score: The Monitoring Group remains frustrated by the lack of progress that has been made in relation to progressing the development and implementation of national standards for homecare. The publication of the HRB report on the Financing and Regulation of Homecare in April 2017, while an opportunity for international learning, was questioned on a number of grounds by Family Carers Ireland, namely the choice of countries reviewed and their classification as 'framework' countries; the scope of the schemes explored and the basket of services provided; the degree of marketisation; and the role of family carers. While welcoming the standards required by successful HSE Homecare Providers, the Monitoring Group is concerned that private homecare providers remain unregulated, thus placing vulnerable people at risk within their own homes. Carers also express concern that where a homecare service is found to be in breach of standards, the service is withdrawn rather than replaced, thus penalising the family involved, not the provider. While the consultation on the establishment of a statutory homecare scheme is welcome, it must not delay the creation of national standards for home support services which are overdue and of immense importance.

The Group notes the reference to there being audit teams in each CHO area in respect of quality of home care services. We would expect that the findings of such audits would be published; reflective of a collaborative approach to quality improvement.

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

2.2.1. Raise awareness and understanding among education providers of the signs that children and young people have caring responsibilities and the impact of caring on them.



Responsibility: Department of Children and Youth Affairs; Department of Education and Skills

Response received: Department of Children and Youth Affairs; Department of Education and Skills

Score: Good Progress

Explanation of the assigned score: 'Good Progress' continues to be made in raising awareness of young carers and the impact of caring on their education. The Monitoring Group acknowledges in particular the Department of Education's inclusion of young carers in the Junior Cycle Booklets and the Personal Safety resources and the ongoing work of the Department of Children and Youth Affairs in implementing *Better Outcomes, Brighter Futures* which references young carers, as well as TUSLA's 50 Key Messages. The Group also welcomes the initial steps taken to establish a local young carer support network alongside a large ETB with a view to a national pilot and looks forward to future progress in relation to same. While not reported, in 2017 the Department of Children and Youth Affairs also launched a consultation on Targeted Youth Funding Scheme which enabled issues affecting young carers to be recorded. There is considerable disappointment that no visible progress has taken been made in relation to the advancement of action 5.6 in the National Youth Strategy 2015-2020 to establish a cross-agency young carer working group, particularly as we are now entering the final phase of the strategy.

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



Responsibility: Department of Health; Department of Children and Youth Affairs; Department of Education and Skills

Response received: Department of Children and Youth Affairs; Department of Education and Skills

No response: Department of Health

Score: Initial Progress

Explanation of assigned score: In the previous four scorecard reports, the Monitoring Group assigned a score of 'No Progress' for reasons relating primarily to the generality of the progress reported and the lack of detail in relation to how young carers would be responded to specifically. The Monitoring Group acknowledges the detailed response of both the Department of Education and the Department of Children and Youth Affairs and the actions underway and has assigned a score of 'Initial Progress'. While concerns on the generality of some progress reported remain, the Monitoring Group recognises the steps being taken to include young carers within the various strands of the departments' respective work. The Child and Family Support Networks and the Meitheal Early Intervention National Practice Model are both effective ways through which to meet the often complex needs of young carers and are welcome, as is the Department of Education's focus on student wellbeing. The Group accepts that young carers who are struggling within the education system should be identified within the NEPS programme and offered early intervention supports.

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

Response received: HSE

Score: No Progress

Explanation of assigned score: While acknowledging the progress reported by the HSE, the Monitoring Group has no evidence of any initiative(s) that responds directly to action 2.2.3, namely to identify the support needs of young carers and the creation of mechanisms through which they can contact service providers. Previous scorecards have made reference to research carried out by NUIG in 2010, and funded by the Office of the Minister for Children and Youth Affairs, which made a series of recommendations that have yet to be implemented. The report 'Research on Young Carers in the Irish Population' called for a coordinated cross-sectoral, multi-departmental and multiagency approach to identifying and supporting young carers; the establishment of young carer projects where self-referrals by young people is encouraged; dedicated young carer websites; targeted information campaigns; and initiatives to raise awareness of young carers amongst professionals.

The Health Behaviour in School-aged Children (HBSC) study, which was funded by the Department of Health and conducted by researchers in the Health Promotion Research Centre at NUIG in 2014, showed that 11.5 percent of 10-17 year olds surveyed (n=11,870) said they provide regular, unpaid personal help for a family member with a long-term illness, health problem or disability. Extrapolation from the sample to the national population would suggest that some 56,000 young people in the 10-17 year age-group alone provide regular unpaid care. While the majority of caring provided by this cohort will be a positive experience for the young people involved, those at the upper end of the caring spectrum will be adversely affected and must be supported through targeted interventions. For example, in the UK young carers have a right to a 'Young Carer Needs Assessment' which assesses the impact of caring on the young person's education, training and leisure opportunities and considers the additional supports they need. Like all carers, young carers with significant caring responsibilities need help in the home, respite and financial support. Similar initiatives are required if this action is to be progressed.

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



Responsibility: CSO

Response received: Department of Children and Youth Affairs

No response: CSO

Score: No Progress

Explanation of assigned score: The repeated delay in the analysis of data on young carers identified in the Census 2011 and 2016 is responsible for the 'regressive' score awarded. This fifth progress report again promises a report for 2018, as was promised in 2016. 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. This data could have been used to inform service delivery and strategic responses addressing young carers' roles. It is now over a full Census cycle for this information to be made available. This is disappointing as the delay diminishes the utility of the data.

While the CSO, who are assigned responsibility for action 2.2.4, reported no progress, Census 2016 data on the prevalence of caregiving, including young carers, was published in 2017.

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 signpost carers to other services as appropriate.



Responsibility: Department of Employment Affairs and Social Protection; Department of Health; Department of Environment, Community and Local Government (now Department of Housing, Planning and Local Government); HSE

Response received: Department of Employment Affairs and Social Protection; Department of Health; Department of Environment, Community and Local Government (now Department of Housing, Planning and Local Government); HSE

Score: Good Progress

Explanation of assigned score: The Monitoring Group is pleased to assign an improved score of 'Good Progress' to action 3.1.1. The score reflects the progress reported by all departments assigned responsibility for this action, in particular the comprehensive progress reported by the HSE. The dedicated carer section on the HSE website is welcome, however the Group notes that the page has become outdated with reference to Census 2011 rather than Census 2016 and is in need of review. 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 made available through the 'Your Mental Health' website represent tangible progress for carers, as does the inclusion of carers in the Understand Together campaign launched in 2017.

3.1.2. Review material (paper and Internet based) available to carers and investigate (in conjunction with carers' 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; Department of Employment Affairs and Social Protection; Citizens Information Board.

Response received: HSE; Department of Employment Affairs and Social Protection (includes CIB).

Score: Good Progress

Explanation of assigned score: The 'Good Progress' score recognises the ongoing achievements of the HSE and the Department of Employment Affairs and Social Protection, which includes the CIB, in improving the range of paper and internet information resources available to carers. Dormant Accounts funding, which aims to improve information and training provision for carers, has been essential in this regard. In 2017, the funding enabled the publication of a Carers Companion, a paper and PDF booklet containing important information on supports and services for carers; it allowed Family Carers Ireland to host 9 regional information forums for carers which all garnered large attendances; it facilitated the further training of volunteers and staff who run Family Carers Ireland's 24 hour Freephone Careline; and funded radio adverts to target carers who may not be aware of supports available to them. While 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 to family carers. While the Citizen's Information Board did not report progress, it remains an excellent source of information on supports for carers.

The progress reported by the HSE under 3.1.1 remains relevant here and deserves acknowledgement under this action. Progress has been made with the review of internet-based information. While not reported, of importance is the HSE's Healthcare Communications Working Group established under the auspice of the NPES Oversight Group and charged with improving healthcare communications between healthcare staff and patients/families. As well as reviewing all web-based information, the Working Group plan to roll-out training in pilot hospital sites in 2018.

The ongoing efforts of the Department of Employment Affairs and Social Protection continue to be commended, including its promotion of Carers Week, the Annual Carers' Forum, provision of online information and the commencement of a review/redraft of the application form for Carer's Allowance.

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

Response received: Department of Children and Youth Affairs; Department of Employment Affairs and Social Protection; Department of Education and Skills, Department of Health; HSE; Department of Housing, Planning and Local Government; Department of Justice and Equality.

No response: Department of Business, Enterprise and Innovation

Score: Good Progress

Explanation of assigned score: 'Good Progress' continues to be made in relation to addressing the information needs of some of the identified sub-groups of carers. The Monitoring Group in particular welcomes the fulsome progress reported by six Government departments and the HSE.

Highlights from the progress reported include the publication of the National Disability Inclusion Strategy 2017 – 2021 which identifies a number of actions concerning the provision of information to persons caring for a person with a disability; the establishment of Housing and Disability Steering Groups in each Local Authority to facilitate an integrated approach to meeting the housing needs of people with disabilities; mental health carer engagement teams and local Area Leads at CHO level; information leaflets provided by the Department of Education; the ongoing funding of SpunOut and dedicated carer sections on webpages or links to external carer pages. Funding from Dormant Accounts has also helped to address the information needs of sub-groups of carers listed in this action, particularly the Carers Companion and regional information forums held across the country thus reaching carers within their own communities. Family Carers Ireland has vibrant sub-groups of carers that meet regularly – Parents of Adults with Intellectual Disabilities, Carers of People with Mental Health Difficulties and a Young Carers Advisory Panel – that are always keen to work with departments towards achieving this action.

The Department of Justice and Equality did not report on the important progress being made in relation to the Assisted Decision-making (Capacity) Act 2015, including the establishment of the Office of the Director of Decision Support and the appointment of the Director of the Decision Support Service (DSS) in October 2017. The Director has a duty to inform the public about the act and about the supports available through the DSS to those who require assistance with their decision-making. Neither was progress reported by the Department of Community and Rural Development in relation to the role Public Participation Networks can play in giving a voice to socially excluded groups including family carers.

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



Responsibility: Department of Employment Affairs and Social Protection (CIB)

Response received: Department of Employment Affairs and Social Protection; HSE

Score: Good Progress

Explanation of assigned score: The progress reported in the other actions under Objective 3.1 remains relevant and so the score of 'Good Progress' continues. Funding provided under Dormant Accounts continues to be the main driver of achievements in the area of locally based information and training supports. 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 notes that there are still deficits in information relating to important supports for carers including respite, homecare, residential care, etc. as well as access to essential therapies such as occupational therapy, speech and language, community dieticians and physiotherapy for children. While the HSE initiated a national audit of respite provision in 2016, a final report has yet to be provided. The Monitoring Group recommends that a model similar to that undertaken in the mapping of dementia services by the HSE and ASI in 2016/2017 would prove useful if replicated for respite care services.

Objective 3.2: Provide relevant and accessible training opportunities for carers

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



Responsibility: HSE; Department of Employment and Skills.

Response received: HSE; Department of Employment and Skills.

Score: Good Progress

Explanation of assigned score: The Monitoring Group is pleased to assign an improved score of 'Good Progress' with progress reported relating to both training for paid homecare workers and family carers. In terms of paid homecare workers, the Group welcomes the data provided by the Department of Education's Skills Bulletin 2017 and the 10,500 beneficiaries of care-related training up to September 2017. We interpret the high turnover and transition rates presented as underpinning the transitory nature of such employment and the need to urgently address the poor terms and conditions that characterise the sector. While balancing the challenges of meeting the rapidly increasing demand for homecare with overhauling the unattractiveness of the sector extends beyond the Department of Education, we note that continuing to train homecare workers who will simply leave the sector is not sustainable. As such, inter-departmental efforts involving the Department of Education, Department of Employment Affairs and Social Protection and the Department of Health/HSE must be initiated to address the underlying issues affecting the homecare sector and the urgent need to address these, given the aging population.

In terms of the progress reported in relation to training for family carers, the Monitoring Group emphasises the importance of ongoing training for carers both at the onset of their caring role and throughout their caring journey as their loved one's condition and care needs progress. There is an opportunity for Public Health Nurses to be more proactive in supporting families to access basic training or indeed to demonstrate safe and effective personal care of a family member within the home setting.

While not reported, funding provided through Dormant Accounts has achieved significant progress in relation to action 3.2.1 by ensuring that training deficits could be identified and addressed by carer 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.



Responsibility: HSE; Department of Employment and Skills.

Response received: HSE; Department of Employment and Skills.

Score: Good Progress

Explanation of assigned score: 'Good Progress' has been made in enhancing the accessibility of education and training courses for carers. The Group welcomes in particular the Technology Enhanced Learning Strategy in Further Education and Training 2016-2019 to build capacity and good practice in technology-enhanced learning and the development of Technology Enhanced Learning Action Plans for each ETB. The Monitoring Group sees great potential for the ETBs and carer organisations to work together to expand the opportunities available to carers for training, upskilling and further education.

While not reported, funding from the Department of Communications, Climate Action and Environment under their Digital Skills for Citizens Programme has provided valuable support for carers enabling them to stay 'connected' by actively supporting them to get online and enjoy all that the internet has to offer. The scheme has enabled carers and older people with no computer skills to use and navigate the internet and access information online, potentially reducing isolation and giving many better confidence and new skills. Dormant Accounts funding also facilitated the development by Care Alliance Ireland of a website listing of resources and training courses available for carers as well as evidence informed resources for those seeking to deliver training to family carers.

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: Department of Housing, Planning and Local Government.

Response received: Department of Housing, Planning and Local Government

Score: Regressive

Explanation of assigned score: While funding for the HAGS has increased from €56m in 2016 to €60.5m in 2017, the allocation remains well below funding levels in 2010 of €95m. This is further compounded by the fact that the number of older people has increased by 36% in the 10 year period 2006 – 2016, while the number of people with a disability has increased by 63%. The Monitoring Group remains concerned that an outcome of the review of the scheme undertaken in 2014 means that the income of adults living in the household is now included, making it even more difficult for applicants with adult children living at home to satisfy the modest means test. Given the homeless crisis and the lack of affordable housing available to rent, it appears parents who facilitate adult children by allowing them to remain living at home are being penalised.

While the Monitoring Group recognises the department's plans to streamline the application process for the suite of housing adaptation grants and provide an easy read guide for applicants, we await the 2018 Progress Report to learn of actual progress in this regard.

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



Responsibility: HSE; Department of Housing, Planning and Local Government.

Response received: HSE; Department of Housing, Planning and Local Government

Score: No Progress

Explanation of assigned score: While the HSE refer to the establishment of memory clinics in each CHO as funded through Dormant Accounts, they also restate funding limitations as a reason for limited progress. In the 2016 progress report, the Department of Housing referred to a review of good practice models in service and housing provisions that was due to commence and it hoped should be completed by the end of 2017. However this review is not referred to in progress reported for 2017, nor is sufficient detail provided on how the Housing Agency will work with Genio to utilise assistive technologies to promote independent living.

The Monitoring Group restates that policies of deinstitutionalisation as well as the ambitions contained within Slaintecare to reorientate the health service towards care in the community, are only possible with the aid of assistive technologies. However, in the response provided, technology 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 under Horizon2020 which allocates R&D funding into assistive technology innovation.

3.3.3. Review and update Transport Sectoral Plan under Disability Act 2005



Responsibility: Department of Transport, Tourism and Sport.

Response received: Department of Transport, Tourism and Sport.

Score: Regressive

Explanation of assigned score: The Monitoring Group is disappointed to again assign a score of 'Regressive' to action 3.3.3. Notwithstanding the publication of the National Disability Inclusion Strategy, which contains a number of transport related actions, the fact remains that no action has been taken to review the Transport Sectoral Plan since 2011/2012 despite repeated commitments in previous progress reports that a review would be undertaken and would include a comprehensive consultation of which carer organisations would be part.

Notwithstanding that the focus of action 3.3.3 is on the Transport Sectoral Plan, the Monitoring Group uses the opportunity to express disappointment at the ongoing failure of the Department of Health to introduce the long awaited 'Transport Support Scheme' to replace the Mobility Allowance and Motorised Transport Grant which were withdrawn in 2013. The failure to introduce the Transport Support Scheme has left people with disabilities and their families unable to access transport links essential to their ability to live full and independent lives.

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

Objective 4.1: Enable carers to have access to respite breaks

4.1.1. Promote a better awareness of the existence of the Respite Care Grant (Carer's Support Grant).



Responsibility: Department of Employment Affairs and Social Protection.

Response received: Department of Employment Affairs and Social Protection.

Score: Good Progress

Explanation of assigned score: The rewording of letters sent from the Carer's Allowance section to inform unsuccessful applicants that they may be entitled to a Carer's Support Grant continues to promote better awareness of the Grant. While not reported, the Monitoring Group acknowledges that by extending the period for which Carer's Allowance continues to be paid after the death or admission to long term care of a loved one, carers whose caring role ends 12 weeks prior to the first Thursday in June will continue to receive the grant, rather than the six weeks previously stipulated. The group also acknowledges the facilitation by the department of retrospective applications from carers for the Carer's Support Grant for the previous year.

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



Responsibility: HSE

Response received: HSE.

Score: Regressive

Explanation of assigned score: The achievement of action 4.1.2 is contingent on 'person-centred, flexible respite' being available to carers and therefore overlaps with the subsequent action 4.1.3. The Monitoring Group therefore specifically considered efforts to 'promote' existing respite provision under this action and assigned a score of 'Regressive'. The Monitoring Group can find no evidence of the HSE actively promoting respite services. In fact, many carers remain unaware of the Residential Support Services Maintenance and Accommodation Contributions (RSSMACs) scheme which allows for 30 days free inpatient care, including respite in public centres in a 12 month period. Indeed, rather than promote respite, many carers experienced reductions or threats to their existing respite levels, with some respite beds converted to step-down or transitional care beds used to reduce hospital discharge pressures.

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



Responsibility: HSE

Response received: HSE

Score: No Progress

Explanation of assigned score: The Group has assigned the score of 'No Progress'. Despite the welcome investment of €10m to enhance respite services for people with disabilities, the announcement came late in 2017 and has yet to materialise. Likewise, the Monitoring Group notes that the investment was announced immediately after the 'Carers in Crisis' Prime Time Special which aired in December 2017 and therefore was a result of public pressure rather than planned political intention. The Group also notes the very significant reduction in the amount of respite available, reducing from 243,000 overnights in 2013 to just 158,000 nights in 2017. Until such time as respite is placed on a demand-led and statutory footing, access is likely to remain geographically inconsistent and inadequate to meet demand.

While carer organisations remain fully supportive of the department and HSE's plans to establish performance indicators for the provision of respite, the Monitoring Group is disappointed to learn from the progress reported by the HSE that an interim report from the Respite Review Group was completed during 2017. Carer organisations were directly involved in the early stages of the review and indeed hosted a carer consultation in 2016, however were not made aware of the report or its recommendations. At the time of writing (Q4, 2018) we are still not aware of this report.

It remains the case that the lack of appropriate and emergency respite is one of the greatest challenges facing family carers. Respite is essential and its improvement is an urgent matter. It is hoped that the work of the Review Group will bring about significant improvements in the measurement and performance monitoring of respite quality and provision.

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

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



Responsibility: All departments

Response received: Department of Business, Enterprise and Innovation; Department of Children and Youth Affairs; Department of Employment Affairs and Social Protection; Department of Education and Skills; Department of Health and HSE; Department of Housing, Planning and Local Government; Department of Justice and Equality.

No response: Department of Transport, Tourism and Sport; Department of Communications, Climate Action & Environment.

Score: Good Progress

Explanation of assigned score: The improved reporting and the promotion within departments of leave policies or work practices which accommodate carers has maintained a score of 'Good Progress'. According to the CSO, in Q1 2018 some 346,000 people were employed in the public service. Taking a carer prevalence rate of 10% (IHS, 2015) it can be assumed that some 34,000 of these workers balance their employment with caring responsibilities. It is therefore imperative that the State, as Ireland's largest employer, leads the way in nurturing and promoting carer-friendly work practices.

4.2.2. Promote Awareness of the Carer's Leave Act 2001



Responsibility: Department of Business, Enterprise and Innovation (WRC)

Response received: Department of Business, Enterprise and Innovation; Department of Children and Youth Affairs; Department of Justice and Equality

Score: No Progress

Explanation of assigned score: The Monitoring Group notes that there is little in the progress reported by either the Department of Business, Enterprise or Innovation or the Department of Justice that indicates any meaningful progress in promoting awareness of the Carer's Leave Act 2001. No reference was made to the Workplace Relations Commission who have a statutory responsibility for informing employees of their rights, including those relating to Carer's Leave and of investigating complaints in relation to Carer's Leave, nor has any progress been made on advancing the Family Leave Bill.

Because no central repository exists to record how many employees avail of Carer's Leave, the number in receipt of Carer's Benefit is used as a proxy measure. The Monitoring Group notes that take-up of Carer's Benefit remains low at just 2,763 recipients and has hovered in and around this figure for many years. The Monitoring Group believes more can and should be done to promote awareness of Carer's Leave and Carer's Benefit, including initiatives driven by the Department of Justice and Equality; Department of Business, Enterprise and Innovation (WRC) and the Department of Employment Affairs and Social Protection.

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



Responsibility: Department of Business, Enterprise and Innovation

Response received: Department of Business, Enterprise and Innovation

Score: No Progress

Explanation of assigned score: The Monitoring Group can see no evidence of progress being made in relation to encouraging work-life balance provisions for carers. Supporting working carers to remain in the workforce is of critical importance and will only increase in the future. With an ageing population and shifting dependency ratio, more and more workers will find themselves juggling caring obligations with full-time work. The future refreshed National Carers' Strategy will likely need more robust actions related to this issue. Family Carers Ireland has suggested that the Carer's Leave Act 2001 be reviewed to include the right to request flexible work. This is in line with the recent EU Directive on Work-Life Balance and the EU Pillar on Social Rights which would give the right to request flexible working arrangements (reduced working hours, flexible working hours and flexibility in place of work) to all working parents of children up to 12 and carers with dependent relatives.

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: Department Employment Affairs and Social Protection; Department Education and Skills

Response received: Department Employment Affairs & Social Protection; Department Education & Skills

Score: Good Progress

Explanation of assigned score: The score of 'Good Progress' has been maintained in recognition of the initiatives described by the Department of Education and Skills. In particular, the Monitoring Group welcomes the launch of the FET website in 2016 (www.fetchcourses.ie); SOLAS's review of barriers to FET; and broad range of training courses offered by the 16 ETBs that are provided at a various skills level and can be accessed in venues across the country. While not reported, Dormant Accounts funding has made available a range of practical information and training supports that will help carers who wish to return to the workforce.

As in previous scorecards, the Monitoring Group draws attention to the 15 hour ceiling placed on the hours a carer in receipt of Carer's Allowance, Carer's Benefit or the Carer's Support Grant can work or study. This is frequently identified by carers as the greatest barrier to their engagement in training or their ability to engage with the labour market. Indeed, as a consequence, some carers cannot avail of the ETB programmes described by the Department of Education. For meaningful progress to be made in relation to action 4.2.4, the hours a carer can work should be increased to at least 18.5 per week.

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



Responsibility: Department of Employment Affairs and Social Protection

Response received: Department of Employment Affairs and Social Protection

Score: Initial Progress

Explanation of assigned score: The Monitoring Group acknowledges the challenges associated with action 4.2.5 in particular, that for the vast majority of active carers, engagement with activation measures is not possible nor desirable. However, access to activation supports becomes more important as carers move towards the end of their caring journey and begin to consider the need to prepare for life after care and indeed when their caring role comes to an end. The extension in payment of Carer's Allowance from 6 to 12 weeks when caring ends was a significant move by the department in recognising the transitional challenges facing former carers, as was the allocation of Dormant Account funding to support this transition.

As noted in action 4.2.4, the restriction to 15 hours work or training for carers receiving a care-related payment hinders their ability to train in preparation for life after care and should be addressed. Likewise, carers should be able to engage in activation measures, should they chose to, during the 12 week period after their caring role ends but while they are still in receipt of Carer's Allowance. Some carers have reported that during this period, the Intreo office has prevented them from availing of activation supports as they remain classified as a 'carer'.

Appendix 1: Membership of the National Carers' Strategy Monitoring Group

Damien Douglas	Family carer
Johanne Powell	Family carer
Moira Skelly	Family carer
Tom Curran	Former family carer
Fiona Gallagher	Mental Health
Liam O'Sullivan	Care Alliance Ireland
Zoe Hughes	Care Alliance Ireland
Padraig McGrath	Young Carer Supports - Family Carers Ireland
Catherine Cox	Carer Engagement – Family Carers Ireland
Anne Flynn	Groups and Membership – Family Carers Ireland
Clare Duffy	Policy and Public Affairs – Family Carers Ireland
Marian Mahon	Carer Advocacy and Information – Family Carers Ireland
Pat Grogan	Regional Manager – Family Carers Ireland
Peter Cox	Area Manager – Family Carers Ireland



Family
Carers
Ireland
Fairness for Carers

National Freephone Careline:

1800 24 07 24

Website: www.familycarers.ie

Charity Number: CHY 10962

Family Carers Ireland
Unit 1, Heuston South Quarter
St. John's Road West
Dublin 8

EMAIL: careline@familycarers.ie

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