

Care Alliance Ireland Exchange

Winter 2016 Issue 53

Care Alliance Ireland Wins Governance Award

On 18th October, The Carmichael Centre, in partnership with The Wheel, Volunteer Ireland, Charities Institute Ireland and supported by Davy, Mazars Ireland and Mason Hayes Curran, announced the winners of the inaugural Good Governance Awards. The awards highlighted governance excellence in the not-for-profit sector in Ireland.

Good governance is a key aspect of effective, sustainable and well-respected organisations and winning this award is a testament to the work of our volunteer board of directors, our staff and others who have helped us on the journey thus far. Sustaining the trust of the public, the state, our members, our collaborators and other stakeholders, both nationally and internationally, is important to us. It also gives confidence to our funders and those with whom we collaborate.

Speaking after the awards, Donal McKenna, Chair, said: "As a membership-based organisation we believe that our ongoing emphasis on good governance both reassures and encourages our 100 member organisations, who all support Family Carers in different ways. With a strong governance structure in place delivered by our Board, staff and volunteers, we will continue to be well placed to support the wider Family Carer community."



Pictured at the Good Governance Awards, L-R: Liam O'Sullivan (Executive Dir.), Donal McKenna (Chair), Zoe Hughes (Policy & Research Officer), Diarmaid Ó'Corrbaí (The Carmichael Centre), Dr. Gerry McCaffey (Outgoing Chair)

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Good Governance Award, continued

Other category winners in the awards included Jigsaw/Headstrong, Helium Arts and Concern. We are also delighted that one of our member organisations, The Migraine Association of Ireland, was shortlisted for an award.

The CEO of the Charities Regulatory Authority, Mr John Farrelly, spoke at the awards. His speech can be read [here](#). For more information on the Good Governance Awards please visit www.goodgovernanceawards.ie.

#InvestInHomeCare

In the Autumn of 2016, 17 not-for-profit organisations came together with one clear message for Budget 2017, namely to advocate for further investment in home care.

Home care is often seen and used as a solution to the hospital crisis, but it should be seen as an integral part of long-term care in its own right. The difference that appropriate home care can make to a family cannot be underestimated; it can support people to live well in the community, to stay out of hospital and long-term residential care, and to remain in their own homes with their families throughout their lives.

Home care is also vital in supporting Ireland's 200,000 Family Carers, who provide the vast majority of care for people at home. The system relies heavily on these carers, who provide nearly €4bn worth of care every year, and who need our support.

We were disappointed that only an additional €13.8m is being allocated to home care in Budget 2017, and will continue to push for the proper resourcing of this sector and for the introduction of a legislative basis for home care, so that families can be confident in their ability to access comprehensive home care in a timely fashion.

Our updated analysis of home care provision published on 3 October suggests that a deficit of in excess of 2m home care hours will emerge in 2017, with a projected increase in provision of 2.5%, insufficient to keep pace with annual demographic pressures of 4%. This means home care will become more difficult to access throughout 2017 unless further resources are found. To read our latest analysis of current home care provision see <http://bit.ly/2cNRM8B>.



Left: launch of
#InvestInHomeCare
campaign, Dublin, 27th
September

Right: Shirley Thornton,
Family Carer, speaking at
#InvestInHomeCare
campaign launch



Budget 2017

Increases in Income Support for Full-time Family Carers to Keep Pace with Projected Inflation



The €5 increase in the Carers Allowance/Benefit has been welcomed by many organisations. However, our analysis indicates that with a projected inflation rate of 2.1%, the increase will merely keep pace with the cost of living. With wages increasing by an expected 2% as well, it is reasonable to say that Family Carers by and large will be neither relatively better nor worse off in 2017. The failure to reinstate the telephone allowance has been criticised, whilst the reduction in prescription charges and the awarding of a medical card to all those in receipt of Domiciliary Care Allowance is a significant and well-flagged boost to such families. Finally, those whose careers enter nursing homes will now be able to keep their Carers Allowance for 12 weeks.

For details of the Department of Health allocation for 2017 read [here](#) (P 45-50) and summary [here](#). For details of the Department of Social Protection changes for 2017 [read here](#).

Some organisations' responses to Budget 2017 are below.

Family Carers Ireland - [read here](#).

"While Family Carers Ireland welcomes the announcement of an additional half a billion in the health budget, there is no indication that this will go towards home care services."



The Alzheimer Society of Ireland - [read here](#).

"We are deeply disappointed that no funding has been ring-fenced to provide home care supports for people with dementia in Budget 2017. People with dementia have the right to maintain their independence and the majority of people want the choice to live at home with their families."



THE ALZHEIMER
SOCIETY of IRELAND

Alone - [read here](#).

"ALONE has welcomed the increase to the state pension, announced as part of Budget 2017, but stated that the government needs to do more to support older people in the community."



Disability Federation of Ireland - [read here](#).

"After nearly a decade of cutbacks and retrenchment, and into the fourth year from the end of the recession, this first Budget Statement of our new Government fails to address the significant daily issues facing disabled people all around the country."



As is the practice each year, Care Alliance Ireland was involved in a number of pre-budget press briefings in collaboration with The Wheel, The Disability Federation of Ireland and other organisations. Our overall message was the need to continue to invest in the health and social care infrastructure. Our joint statements are available to read [here](#) and [here](#).

News

Resilience in Dementia Caregivers - Update

We are delighted to announce the appointment of Sandra McCarthy as Research Assistant with the Resilience in Dementia Caregivers project. Funded by the HRB and in collaboration with UCD, St Vincent's Hospital and others, Care Alliance Ireland is leading the carer engagement and research dissemination aspects of the three-year project.

Speaking on her appointment, Sandra said: "I am thrilled to be working with Care Alliance Ireland and their research partners on such an important and exciting project".

Sandra took up the post on 8th November and can be contacted by email on sandra@carealliance.ie



Martin Naughton - RIP

Martin passed away in recent weeks and we in Care Alliance Ireland will miss him. In our early days Martin supported us with the organisation of a conference and was professional and dignified in all he did. You can read his obituary [here](#).

"Although Martin never officially took credit for his involvement in the establishment of the Centre for Independent Living (CIL), it must be noted that he was indeed the initial driving force in ensuring that Independent Living became a reality for so many people living with disabilities in Ireland at that time and indeed at the present time also." (Hubert McCormack)



News

Young Carers Project Update

Empowering Professionals to support Young Carers (EPYC)



Co-funded by the
Erasmus+ Programme
of the European Union

Young Carers can be defined as children, teenagers and young adults who provide care, assistance or support to another family member, often a parent but also a sibling, grandparent or another relative who is disabled, has a chronic illness, mental health or addiction illness or other condition and who needs care, support or supervision. This caring responsibility is often unusual in their peer group, and may cause significant social, emotional and physical burdens. Based on research published recently, it is estimated there are in the region of 56,000 young people in Ireland between the ages of 10 and 17 years providing regular, unpaid care.

Empowering Professionals to support Young Carers (EPYC) is an Erasmus+ funded project which aims to support professionals working with young people — including teachers, healthcare professionals, youth workers, and social workers — to identify and support Young Carers. The first project strand has begun and is working to develop a basket of international tools which can be used by professionals to support these young people.

The six EPYC project partners represent five European countries – Austria, Germany, Italy, Ireland and Scotland – and will bring together the experience and knowledge in our respective countries to build the best possible resources for youth workers and other professionals. The group met for the first time in Berlin in September and will meet three more times over the next 18 months.

For more information on the EYPC project, please contact Denise Dunne by email denise@carealliance.ie or phone 085 806 2392.

More information can also be found on www.ep-yc.org, where the first newsletter of the project has been published.



Pictured at the first meeting of the group in September are representatives of the six partner organisations - Diakonisches Werk Berlin Stadtmitte e.V. (DE), Care Alliance, Ireland (IE), Anziani e non solo (IT), Carers Trust (UK), Austrian Red Cross (AT) and IPS VERSARI MACRELLI (IT).

News

Research and Policy Officer Reporting

Zoe continues to work with member organisations to increase collaboration across the policy and research brief of Care Alliance Ireland. If you would like to raise any issues with her, please don't hesitate to get in contact.



Recent work undertaken on research and policy issues includes:

- Participation with 16 other not-for-profit organisations in the “Invest In Home Care” campaign, calling for increased investment in Home Care in Ireland in Budget 2017.
- Participation in a number of pre-Budget 2017 statements; including not-for-profit umbrella organisations (coordinated by The Wheel) and disability umbrella organisations (coordinated by the Disability Federation of Ireland).
- Presentation of key pre-Budget “asks” to members of the Oireachtas, facilitated by Senator John Dolan and the Disability Federation of Ireland, in conjunction with other not-for-profit disability organisations.
- Publication of post-Budget 2017 analysis on measures which affect Family Carers (available at <http://bit.ly/2dNbR1C>).
- Participation in 2 key international events: International Expert Roundtable for Family Carers of People with Parkinson's Disease and the International Association of Caregiver Organisations (IACO) Annual General Meeting.
- Continued involvement in the Social Policy Network.
- Participation in Open Access Week 2016, along with continued involvement with the HSE Lenus Open Access interest group.
- Participation in the Eurocarers research sub-group.
- Launch of Discussion Paper 4 – “The Wisdom of Family Carers”.
- Continued availability to member organisations to consult on key policy & research issues.

For more information on these, or any other policy & research matters, please contact Zoe by email on zoe@carealliance.ie or by phone on 086 883 4942.

AIHPC Carers Online Palliative Care Resource – Virtual Working Group Update



All Ireland Institute of
Hospice and Palliative Care

Led by the All Ireland Institute of Hospice and Palliative Care (<http://aiihpc.org/>), the work of this group continues with a review of the draft website content currently underway. The content will aim to signpost Family Carers through their caring journey.

News

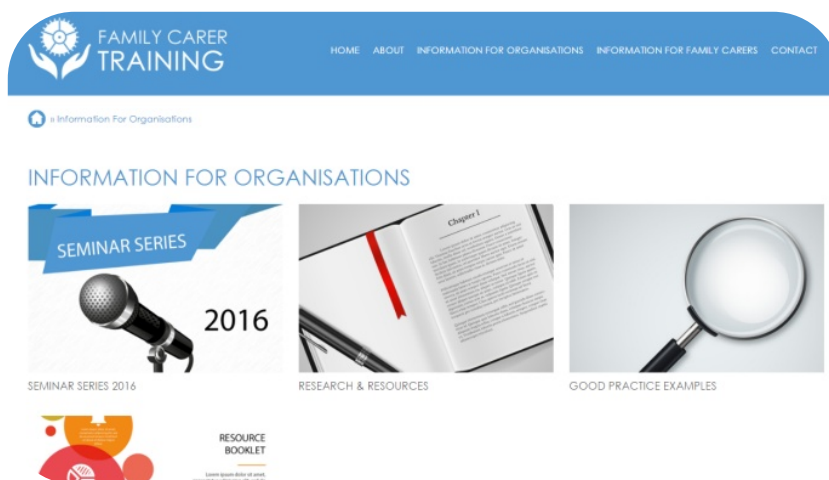
Final Family Carer Training Seminar Well Attended – New Website Launched

The third in our series of seminars took place on 7 November, with the participants reporting a high level of satisfaction with the opportunities provided at the seminar to network with peers and to share the learning from their own experiences in delivering Family Carer Training across the country over the past year. We also had a number of guests from Europe who presented on their own delivery of Family Carer training.



Part of our commitment to the project is the development of a new website www.familycarertraining.ie. Launched on the afternoon of the seminar, the website has two primary audiences; firstly it hosts a range of resources for those currently delivering or interested in delivering Family Carer Training; secondly it provides signposting for Family Carers to access local training and supports.

This project is funded under the Dormant Accounts (Carers Measure), with funds administered by Pobal.



www.familycarertraining.ie

Dementia Elevator – Free Dementia Training for Families and Carers



Dementia Elevator is a national dementia education project, working in partnership with the national dementia awareness campaign – 'Understand Together'. Understand Together is aimed at inspiring people from all sections of society to stand together with the 500,000 Irish people whose families have been affected by dementia. These projects aim to help individuals, communities and health services appropriately engage with and support people with dementia. We wish to ensure that there are people in the community with the right skills to make staying at home a more obvious choice than is currently the case. The Elevator project, based in Dublin City University has developed a range of free online training resources on dementia for anyone wishing to learn how to better understand and support people living with the condition. Among the suite of resources is the free, online **Dementia Coping Skills for Families and Carers programme**.

This comprehensive programme aims to provide carers with a range of skills which will enable them to support the person with dementia in their care, and to help them live well in their homes for longer. Participants will be taught to recognise the emotions, goals and coping strategies of the person with dementia, while learning about the importance of self-care.

The programme content is divided into five chapters:

1. Focusing on the person with dementia
2. The importance of self-care
3. Maintaining the relationship between carer and the person with dementia
4. Understanding and exploring the emotions of a person with dementia
5. Supporting the person with everyday activities.

(An additional chapter on will be available in December 2016.)



Members of the Dementia Elevator Roadshow.

The training aims to be interactive and engaging with features including:

- Interviews with people with dementia, Family Carers and professionals
- A range of video examples demonstrating the skills in everyday situations
- A personal narrator and use of characters
- A downloadable personal reflection journal
- Additional resources with each chapter
- A resource pack for group delivery.

Access the programme here: <http://elevator-carers-coping-skills.com/>.

Listen to some of the carers involved in the making of the programme www.youtube.com/watch?v=gKT85sd0aW0.

Other free online training resources include Dementia Awareness Training for public-facing services: retailers, financial services and transport services, and this is available using this link: www.elevator-pst.com/.

The project team embarked on a dementia roadshow in September 2016, promoting dementia awareness and highlighting the free training resources in cities, towns and villages around Ireland. The roadshow blog outlines highlights from our travels. <http://dementiaelevator.ie/wp-content/uploads/2016/10/Kates-Dementia-Elevator-Roadshow-Blog.pdf>.

The Elevator project is seeking to recruit local leaders around Ireland with an interest in promoting dementia awareness and delivering training within their community. For more information on how to get involved contact ann-marie.coen@dcu.ie or call 01 7006190.

To find out more about Dementia Elevator visit www.dementiaelevator.ie and to learn more about the Understand Together campaign visit www.hse.ie/eng/services/list/4/olderpeople/dementia/.

News

Blog by UK Caregiver and Partner Generates Significant Social Media Interest

A blog we in Care Alliance Ireland came across in recent weeks generated a lot of interest on the Facebook page that we manage, www.facebook.com/nationalcarersweek. The blog, titled [4 Things I Hate About Being a Full-Time Carer](#) is written by Bridget and Rob, aka The Bimblers. They describe themselves in the following way: “We are not like most travel bloggers, we’re older, travel slowly in a wheelchair, we prefer culture to clubbing and food to festivals.”

Speaking on the post, Zoe Hughes, Policy and Research officer said:

“Some posts just really take off and are shared widely by Partners in National Carers Week and others. This post generated scores of shares and comments, and is a testament to the reach and impact a well put together article by a Family Carer can have. It seems to have really struck a cord”.

The blog also has a section on accessible travel in Dublin/Ireland, <http://www.thebimblers.com/destinations/ireland/>.

Carers Northern Ireland – Getting Advice & Support from Carers NI

Caring can present all kinds of challenges, from accessing support to coping with emotions. Every year the Carers NI Adviceline hears from almost two thousand people who need help looking after a friend or family member. We provide information and advice on:

- Benefits
- Carer employment rights
- Carers’ assessments
- Support services available for carers
- How to complain effectively and challenge decisions.

With the introduction of welfare reform in Northern Ireland and the changes to the benefit system, Carers NI are increasingly hearing from carers who are worried about how this will impact on their already strained finances.

To help carers understand the changes, Carers NI has produced a Welfare Reform Briefing giving an overview of the main changes which may affect carers and the people they look after. It also includes information about the 'welfare supplementary payments' introduced to help mitigate the negative impact the changes may have. You can find our briefing by clicking [here](#).

Lesley Johnston, Advice and Information Officer, says: “The Adviceline often receives calls from carers only when they have reached crisis point. I would encourage any carer who is worried about their situation to seek advice as early as possible.”

If you need advice or support – or to find out more about how to navigate “the system”, Carers Northern Ireland is there to help – call them on 00 44 28 9043 9843 or email advice@carersni.org.

Member News

Irish Hospice Foundation Launch Seven Dementia Palliative Care Guidance Documents

There are about 55,000 people living with dementia in Ireland with the number expected to triple to 132,000 over the next thirty year as the population ages. People dying from dementia – with or without other illnesses – are a particularly vulnerable group. They require staff to have knowledge, skills and competence in both dementia and palliative care.

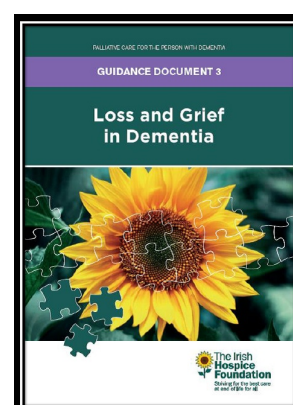
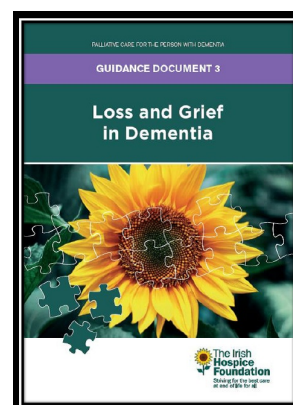
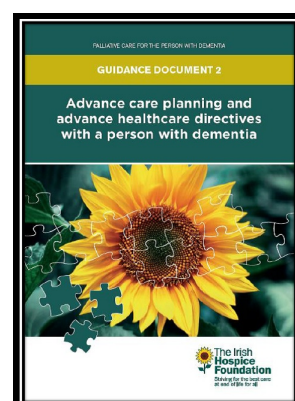
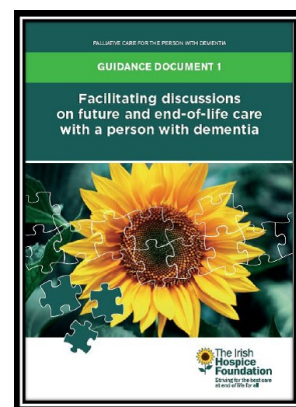
Broadcaster Valerie Cox who spent two years studying for a Master's Degree in End-of-Life Issues in UCC officially launched the documents.

She said: "I cannot imagine the amount of work that went into these documents. They are absolutely amazing. I love the message they send out: that all lives, whatever stage are valued, that there must be a respect and that capacity must be presumed, that there must be an autonomy-centred perspective. This I would say to medics and carers. In caring for a person with dementia you go far beyond their physical needs, you are dealing with their soul, that inner manifestation of personhood, that place that remembers the past, captures their dreams and their loves. You are in a position that can assist them in making those final choices in valuing their lives and restoring their dignity."

A new suite of guidance documents to help ensure all people with dementia get the appropriate palliative care they need throughout their illness were launched in University College Cork (UCC) on September 29th. The Irish Hospice Foundation (IHF) guidance documents are designed to support healthcare staff to improve palliative care for people with dementia. They were developed by the IHF in collaboration with researchers at UCC to fill an identified gap in practice guidelines for people providing palliative dementia care.

The guidance documents focus on the following key areas:

- Facilitating discussion on future end-of-life care with a person with dementia.
- Advance care planning and advance health care directives with a person with dementia.
- Loss and grief in dementia.
- Management of hydration and nutrition.
- Pain assessment and management.
- Ethical decision making in end-of-life care and the person with dementia.
- Medication and dementia: Palliative assessment and management.

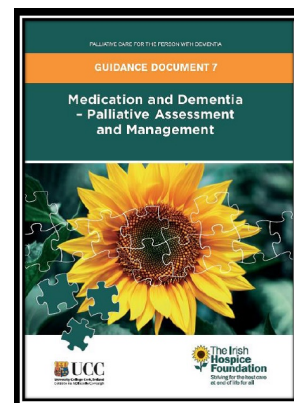
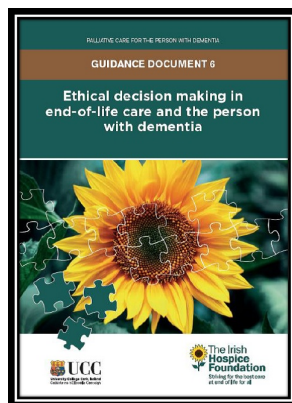
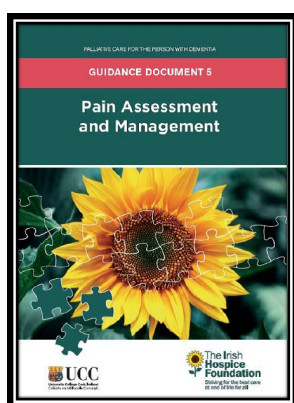


Member News

Irish Hospice Foundation Launch Seven Dementia Palliative Care Guidance Documents continued

Recent research conducted by the IHF shows that 4,200 people with dementia die in Ireland each year. About 2,310 people with dementia die in residential care settings in Ireland every year and a further 1,680 die in acute hospitals. However, it is estimated that only 210 people with dementia die in their own homes.

The guidance documents are available online to download for free and can be accessed [here](#). There is a fee payable for hard copies of the guidance documents which can be obtained by contacting: Deirdre.shanagher@hospicefoundation.ie.



MS Ireland Speaks Out on Home Care

MS Ireland in its recent publication called on the Government to do the following:

- Increase spending on Home Care Packages, Home Helps and Personal Assistance services.
- Establish access to supports with home care and independent living as a statutory right.
- Properly assess, map and cost the support needs of younger people under the age of 65 who are living with a long-term illness or disability, so that a robust plan for resourcing these services into the future can be developed.
- Develop a standardised assessment tool for accessing home care and Personal Assistant services and a protocol for prioritisation of resources so as to address the regional discrepancies that currently exist.
- Establish an age- and needs-appropriate equivalent to the Fair Deal scheme with ring-fenced funding which guarantees access to community-based care, and publish a plan with timescales for this. Funding for this scheme could be managed in a similar way to the Fair Deal, i.e. by drawing upon assets that the individual has access to, including property. As well as home care and Personal Assistants, examples of supports that people with MS might access through such a scheme include aids and appliances (including telecare and telehealth, environmental controls and mobile communication), home adaptations, respite care, and therapeutic supports such as physiotherapy and occupational therapy.

Read full report [here](#).

Member News

St. Michael's House

About St. Michael's House

Founded in 1955 by parents, St. Michael's House has grown to become Ireland's largest provider of community-based services for children and adults with an intellectual disability and their families.

Today, St. Michael's House has over 170 units throughout Dublin City and County and Navan, Co. Meath, providing supports and services to over 1,751 children and adults with an intellectual disability and their families.

St. Michael's House services include clinical, early learning, educational & vocational training, employment, residential, respite, alzheimer's supports, and social & recreational services.



Supporting Families

The continued increase in the number of children being referred to Early Services is now greater than ever. St. Michael's House emphasises the importance of group-based interventions and training courses for parents and family members. These include Early Bird training for parents of children with an Autism Spectrum Disorder and an intellectual disability. Specialised Lámh & Hannon courses are promoted to support the development of communication for young children.

Working in partnership with families, and in recognition of their vital caring role, our Social Work team aim to educate on the importance of 'Self Care'.

Supporting Individuals

St. Michael's House is committed to delivering individualised community-based services that:

- Reflect the individual needs and choices of service users
- Support individuals to develop meaningful relationships, to make a valued contribution and to become active members of their community
- Empower people to make choices about where they work, live and socialise
- Advocate for the improvement and development of services
- Are cost effective and accountable to service users, families and funding authorities.

Supporting Specialised Needs

St. Michael's House responded to the need to provide extra services for adults with autism and an intellectual disability. A new adult autism support services opened in 2016 to accommodate this need.

St. Michael's House also provides services to adult service users who develop Alzheimer's disease. "Cara" is the first purpose-built residential home in Ireland specialising in the care of people with an intellectual disability and Alzheimer's disease. Our goal is to support and help service users and their families to maintain a quality lifestyle, while adjusting to the difficulties associated with the progression of Alzheimer's.

Supporting Changes – Progressing Disability Services

St. Michael's House is in discussion with the HSE and other organisations in relation to the reorganisation of clinical services for children and young adults under the Progressing Disability Services national policy. The aim of the policy is to have a unified national approach to delivering clinical services to all children with a disability and/or complex needs in a defined geographic area, regardless of the nature of their disability.

Member News

St. Michael's House, continued

Home Sharing

The Family-based Respite Scheme was re-established in 2009 in St Michael's House. Family-based respite is run by the Social Work Department and we recruit, assess, and train families/individuals in the community to provide short breaks to a child or an adult with an intellectual disability, in their own home. A break could be an overnight stay, day care or a short holiday.

In line with the ethos of St Michael's House, the scheme is committed to delivering individualised community-based services, supporting individuals to develop meaningful relationships and become active members of their community. Currently we have 47 host families in the Leinster region providing supports to 77 individuals and their families.

From the host carer's perspective, Sylvia Callan, north Dublin, who has been a host family since 2012, states "it doesn't feel like work, both ladies are part of my family. They stay in my family home one night per week. All my extended family knows them now, I genuinely love it and my enthusiasm about the scheme has never wavered since the first day I applied to be a host family. I simply facilitate these two people's close friendship. When we are out and I see the conversation flowing between them, I say to myself this is what it is about."

Currently we are actively recruiting for more host families. If interested in applying to become a Host Family contact Fidelma Kelly, Social Work Team Leader on 01-8770500 or Bernie O'Reilly Social Worker on 01-2990500.

Useful References

www.nhsn.ie

www.smh.ie

www.hse.ie/eng/services/publications/disability/respitecarehomesharing

Contact us:

St. Michael's House, Ballymun Rd,
Ballymun, Dublin 9

T: 01 8840200

E: info@smh.ie

W: www.smh.ie



Governance Corner

Care Alliance Ireland wins Good Governance Award

To read the full story, see page 1.



New Chairperson Appointed

Following a short board meeting after the 2016 AGM, on 20th September, Donal McKenna was elected Chairperson. In accordance with good practice, two directors who had served on the board for six years moved on. Avril Easton (Director and Company Secretary) and Gerry McCaffrey (Director and Chair) provided wonderful support and direction to the organisation. Gerry's stewardship as Chair for the past three years was instrumental in bringing our governance standards to a high level.

Appointment of Company Secretary

Rosemary Daynes (Director) was formally appointed Company Secretary on 20th September.

Submission of Updated Details and Annual Report to Charities Regulatory Authority (CRA)

Our updated details, and relevant documents were submitted to the CRA on 19th October. Details on all charities are available to view [here](#).

Policies Under Review

Our board is currently reviewing our Complaints Policy and an updated Risk Register. The current complaints policy may be read [here](#). Updates to the Terms of Reference of the Risk and Audit Committee were presented at the AGM in September. These can be read [here](#). Operationally we are also currently preparing a comprehensive Social Media/Communications Policy.

Governance Code Updated

See main article on page 15. Website can be viewed [here](#).

Compliance with the Governance Code

As is done annually, our board will at its November meeting review our organisation's current level of compliance with the Governance Code and will reflect on the implications of the updated guidelines.

SORP Accounting on the Way

Speaking at the Good Governance Awards, John Farrelly, the Charities Regulator, strongly indicated that SORP Accounting (Statement of Recommended Accounting Practice) will be the required accounting format in the near future. For more details of SORP accounting see [here](#).

Governance Code Updated



The 25th October marked the publication of the revised Governance Code, following a year-long review. The Governance Code was developed by a group of organisations representing the community, voluntary and charity sector and was first published in 2012. Since then over 1,200 organisations have signed up, with 300 listed on the Code's register as fully compliant and a further 900 registered as 'on the journey' to compliance.

The Code is principles-based and is adopted on a "comply-or-explain" basis. It comprises a set of recommended practices for the boards of community, voluntary and charitable organisations. In late 2015 the Governance Code Working Group (GCWG) undertook a review of the Code to determine if it can be improved. After a widespread consultation that review is now complete and the revised Code has been published on www.governancecode.ie.

In summary the review found that:

- The Code's adoption journey requires a determined commitment and ownership by a board and takes a minimum of two years to complete.
- The majority of adopters interpreted the recommended practices to be rules with a minority seeing them as principles and practices to help a board set and oversee the achievement of their vision and objectives.
- Boards should be held to account for the veracity of their comply-or-explain declarations.
- These declarations should be open to verification and ratings by their stakeholders.
- Calls for the Code to be turned into mandatory rules should be resisted as that will only reduce governance to box-ticking compliance by board members with little affinity for the rules.
- Good governance requires a board to consciously align the organisation's culture and values with its strategy to ensure it achieves its objectives in an ethical manner.
- The Code's five principles and their recommended practices have proven to be very workable and as valid today as they were in 2012.

Based on these findings the 2012 Code is being re-issued today with its original principles and practices intact. However, changes have been made to the adoption processes but the big evolution is what accompanies the Code and that is, the Code Stewardship Guidelines.

These Guidelines are designed to empower stakeholders such as members, dependents, donors or funders to hold boards to account.

Continued on page 16.

Governance Code Updated

Alan McDonnell, chairperson of the GCWG said:

“The primary finding of our Code review was the need to empower stakeholders to hold boards declaring adoption of and compliance with the Code to account. We have done this by publishing detailed Code Stewardship Guidelines, which provide stakeholders, or their representatives, with a structured process and ratings methodology.

This solution means that boards can still undertake the adoption journey on a comply-or-explain basis, but with full awareness that the veracity of their declaration of compliance and explanations for divergence from the Code's recommended practices will be subject to closer stakeholder scrutiny. Governance is rapidly evolving with widespread international debates underway about the different board behaviours that result from rules-based versus principles-based models. The GCWG are avid contributors to this ongoing debate but at this point in time are of the firm view that the principles-based model with empowered stakeholder stewardship is most appropriate for the Irish community, voluntary and charity sector.”

For further information please contact the Chairperson of the Governance Code Working Group, Alan McDonnell 01 296 1008 / 086 831 8213 amcd@goodgovernance.ie
www.goodgovernance.ie.

**Carmichael Centre**
@CarmichaelCntr

Following

The Revised Governance Code is published today. carmichaelcentre.ie/content/revise ...
[@The_Wheel_IRL](#) [@boardmatch](#)
[@GGAireland](#) [@CiiTweets](#) [#Governance](#)


www.governancecode.ie

RETWEETS
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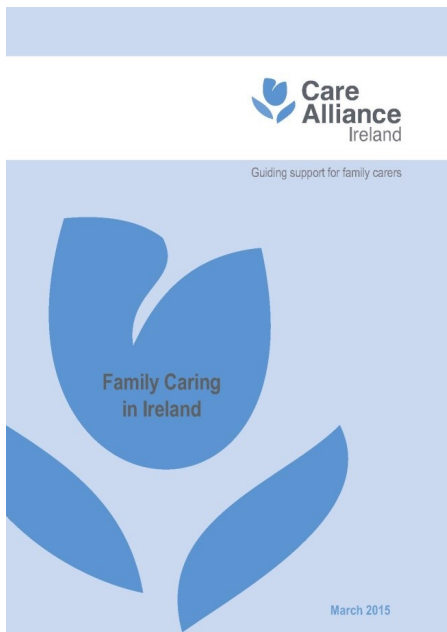
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Care Alliance Ireland Publications

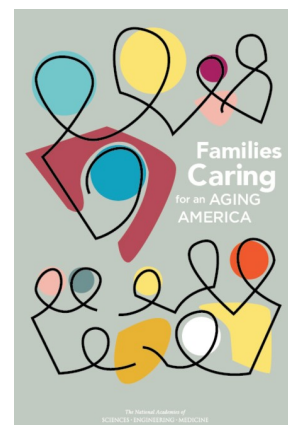
Our website has a range of research publications on Family Carer issues. Go to http://www.carealliance.ie/publications_resources.



International Research

Major Report on Carers of Older People in the US Published

At least 17.7 million individuals in the United States are providing care and support to an older parent, spouse, friend, or neighbor who needs help because of a limitation in their physical, mental, or cognitive functioning. The circumstances of individual caregivers are extremely varied. They may live with, near, or far away from the person receiving care. The care they provide may be episodic, daily, occasional, or of short or long duration. The caregiver may help with household tasks or self-care activities, such as getting in and out of bed, bathing, dressing, eating, or toileting, or may provide complex medical care tasks, such as managing medications and giving injections. The older adult may have dementia and require a caregiver's constant supervision. Or, the caregiver may be responsible for all of these activities. With support from 15 sponsors, the National Academies of Sciences, Engineering, and Medicine convened an expert committee to examine what is known about the nation's family caregivers of older adults and to recommend policies to address their needs and help to minimize the barriers they encounter in acting on behalf of an older adult. The resulting report, *Families Caring for an Aging America*, provides an overview of the prevalence and nature of family caregiving of older adults as well as its personal impact on caregivers' health, economic security, and overall well-being. The report also examines the available evidence on the effectiveness of programs and interventions designed to support family caregivers. It concludes with recommendations for developing a national strategy to effectively engage and support them under equality and work-life balance, health and safety at work, health care and long-term care".



For more information on this process see [here](#).

International News

IACO Hosts Meeting in Denmark



In early September, our Policy & Research Officer travelled to Europe to attend two meetings facilitated by the International Association of Caregiver Organisations (IACO). The first of these took place in Copenhagen, Denmark, on the topic of Family Care and Parkinson's Disease. The group, made up of experts in the field of caregiving, heard details of a number of international studies in caregiving and Parkinson's disease. A highlight of the meeting was a Q&A session with Marie Lenstrup, founder and Chair of Carers Denmark, who is a Family Carer for her husband who has Parkinson's disease. A plan of action from this meeting will be drawn up to progress services and research in this particular sector.

The following day saw the AGM of IACO take place in Malmo, Sweden. Present at this meeting were representatives from 17 international organisations representing Family Carers, with representation from across Europe, Canada, the United States, Australia, New Zealand, Japan and the developing world. IACO continues to go from strength to strength, having this year successfully gained consultative status at the United Nations to provide a single, unified voice at international level regarding policy matters. We look forward to continuing this international collaboration into the future.

International News

Mapping Carer Research – UK Taking the Lead

Dr Mary Larkin from the Open University (UK) is currently leading a research project which aims to map available research and evidence on adult carers.

They are working with partners across Europe and beyond with this project. If your organisation has published carer-related knowledge and evidence in priority research papers and evidence-based projects, you are invited to share this material with Dr Mary Larkin (mary.larkin@open.ac.uk), so that it can be taken into consideration within the scoping review she is leading. Publications from 2000 onwards, in English, concerning adults' carers only, are considered. Material should be shared as soon as possible, as a first synthesis report will be published on 1 February 2017, but addition at a later stage may be possible.

Speaking on this initiative, Dr. Larkin says:

“There are increasing numbers of carers and that caring affects most of us is now well-recognised. There has also been a steady growth in carer-related research and knowledge with the result that there is now a wealth of national and international material and research. Whilst this body of evidence can be credited with helping to raise awareness of carers' lives and caring issues, sources of knowledge and information are many and varied and located in many different places. Hence it is difficult to find, access and make use of the information that is ‘out there’. This fragmentation impedes the capacity of existing knowledge and research to inform research and social care practice and improve outcomes for carers and those for whom they care. This project aims to make a significant contribution to addressing this deficit. Its main focus is a comprehensive scoping review of national and international carer-related knowledge and evidence. This includes policy and practice documents, research findings/summaries, national surveys, information from carer charities, carer-related websites, relevant reports and consultations, and academic work including journal papers.

The nature of the scoping review is therefore potentially very wide in both breadth and depth. It is not concerned, for example, with focusing exclusively on efficacy of interventions for carers, or with answering a highly specific research question. Rather, it is attempting to map and delineate the landscape of knowledge and evidence in relation to informal carers. Hence we have applied some criteria to put some limits on the territory. These are:

- *Literature and material published since 2000.*
- *Literature and material produced in English language only*
- *Literature and material relating to care for adults.*

The review will be written up into a report that will, for the first time, pull together all carer-related knowledge providing an overview of its range, type, and nature and offer a synthesis of evidence.”

The review report seeks to achieve two other key aims:

1. It will help to inform the direction and nature of future research relating to carers and what we need to know; this is particularly important in light of the implementation of the (UK) Care Act 2014 and its drive to improve social care practice with carers.
2. The findings from the review will also inform the development of effective ways to support carers. To help achieve this aim the review outcomes will be publicised through a wide range of relevant networks.

International News

Mapping Carer Research – UK Taking the Lead

The specific approach of the project reflects Public and Patient Involvement (PPI) through:

- regular consultation with carers, those who use services, social workers, carer organisations, GPs, and a range of social care practitioners throughout the course of the project;
- use of the report findings to complement other accessible sources of information about carers that may have been developed, for example, those developed by carer organisations, research networks and (UK) NHS-funded information networks;
- in partnership with the Social Care Institute for Excellence (UK – SCIE), develop a new fully accessible carer digital resource, entitled 'Care Act 2014: a directory for carers and practitioners'. This will be launched in June 2017. It forms part of a suite of web-based resources designed to support the implementation of the Care Act 2014, and will provide particular support with the information requirements for carers and their relatives;
- These strategies will help to ensure that the scoping review informs commissioners, care workers, social workers, carers' organisations, carers' support workers, carers, people who use services and personal assistants, thereby supporting improvements in social care practice with carers.

Portuguese Carer Organisation Set Up

Portincarers – Cuidadores de Portugal, is a multidisciplinary and independent association that represents the caregivers of Portugal, established in January 2016 after five years' work in international and national projects focused on carers.



Its mission is to give visibility and voice to carers at national and European Union level. Portincarers participates in consultation and development of support services for the health promotion and quality of life of carers. It collaborates with numerous partners and organisations including universities, municipalities, companies, associations and research centres nationally and internationally. It is active in a number of fields including the promotion of Social inclusion, health technologies, health and digital literacy, evaluation of innovative solutions with caregivers, and active ageing.

Portincarers has established European Innovation Partnerships on active and healthy ageing and in order to address the challenges of work–life balance faced by working families, is currently working in collaboration with the National Psychology College Board, and is involved in the Porto4Ageing project (<http://www.porto4ageing.pt/>).

As a means of promoting the quality of life of informal caregivers, they strongly believe in the importance of participating in knowledge transfer networking systems. They report that one way to better boost and scale up innovation in care is through benchmarking and transnational cooperation.

International News

Carers Worldwide Impacting Positively on the Carer Community in India and Beyond



Carers Worldwide is the only organisation working exclusively and strategically with unpaid Family Carers in developing countries. They develop and promote cost-effective, sustainable and easily replicable methods of providing support to unpaid Family Carers in low- and middle-income countries. Since 2012, their work has directly impacted the lives of over 4,000 carers in Nepal and India. In turn, this has dramatically improved the lives of the relatives for whom these carers care.

They work in partnership with carers, cared-for, families, communities, local NGOs, national and international NGOs, governments and academics. Their work takes place both at grass-roots level and at the level of the decision makers. Using the Carers Worldwide model, they promote services that enhance the social, emotional, physical and economic wellbeing of carers. At the same time, they seek to influence government agencies, professionals and those leading in the health and social sectors to change their practices and policies. The ultimate aim is long-term change for carers, embedded in local systems.

They are currently partnered with five local organisations located across Nepal and India. They are training the staff of these organisations and through them working with over 4,000 carers who are looking after relatives with a disability or mental health condition. The majority of the carers are women, aged between 18 and 65, but they also work with older carers and a growing number of child carers. A recent survey that they conducted in India found that over 80% of carers themselves experienced ill health and 60% were unable to work due to caring responsibilities.

As well as expanding their work in Nepal and India, they are also developing plans to move into Bangladesh.

Each one of us, at some point in our lives, will either be a carer or in need of care. This is the same the world over, regardless of where we live. Carers in low- and middle-income countries currently go largely unrecognised and unsupported. Their goal is to change that.

For more information, please visit their website www.carersworldwide.org.



Carers Worldwide model ensures positive change for carers

International News

Carers Worldwide Impacting Positively on the Carer Community in India and Beyond, continued

“Now I can hope for the future...”

Sunita Thapa, aged 15, from a remote village in Baglung district in the Western Region of Nepal, was forced to drop out from school at the age of 10 to look after her mother who has bipolar disorder. Living in poverty in a cattle shed, the family could not afford medicine for Sunita's mother. As the only daughter, Sunita bore the brunt of caring for her as well as maintaining the household – cooking, cleaning, feeding cattle, collecting fire wood, all while she was just 10 years of age.

Her father was a daily wage labourer but contributed very little to the family and often was not around. The struggle for daily survival more often than not fell to young Sunita. Meanwhile, Sunita's mother's condition worsened and the family grew increasingly isolated. Help for Sunita and her family first came through intervention from LEADS, a local charity working with people affected by mental illness. They helped access medicine for Sunita's mother and her condition slowly stabilised. But Sunita remained at home, excluded from school due to the burden of maintaining the family and ensuring her mother's wellbeing. As a child carer, Sunita's plight went unrecognised until Carers Worldwide started to work in the area, in partnership with LEADS, raising awareness of the important role of carers, including child carers, and the need to take care of their needs as well as those of the relatives affected by mental illness or disability.

The priority was to get Sunita back into school and this was achieved by working with the school authorities and also the community. Neighbours now look out for Sunita's mother during the day. Sunita is back in school with uniform and school supplies provided by the Carers Worldwide project. Her teachers report she is excelling in her studies and has the potential to continue into further education. Carers Worldwide has set up a child carers club with the school and this allows Sunita space and time to socialise with her peers, share her troubles and get away from caring responsibilities for a while.

But getting back into school is not enough. Sunita cannot stay there unless the situation at home is improved. Carers Worldwide and LEADS supported the family's economic stability by providing them with two pregnant goats. These goats have gone on to produce a series of baby goats which the family sell at market. This money supports the family's household costs and also allows a little extra to pay for medicine, school fees, and a small savings pot.

Sunita still has huge responsibilities, caring for her mother and keeping the household running for her and her brothers. However, with the helping hand that has been extended to her, she is determined to fight for a better life. She has a vision to study further and wants to become a nurse. She says “Pain and struggle have been part of my daily life, but now I can hope for the future.”

For more information on Carers Worldwide see www.carersworldwide.org.



About Us

Care Alliance Ireland is the National Network of Voluntary Organisations supporting family carers. Our vision is that the role of family carers is fully recognised and valued by society in Ireland.

We exist to enhance the quality of life for family carers. We achieve this by supporting our member organisations in their direct work with Family Carers through the provision of information, developing research and policy in the field, sharing resources, and instigating opportunities for collaboration.

There are approximately 274,000 Family Carers in the Republic of Ireland. Family Carer support is provided by a number of organisations, including those dedicated solely to carer support and others who support carers as part of their response to individuals with specific conditions.

We work with our 104 member organisations and other agencies to support them in their work with Family Carers. Our membership includes all the carers organisations and virtually all the condition-specific organisations currently providing services to many of Ireland's Family Carers.

To apply for membership of Care Alliance Ireland, please [click here](#).

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10 Reasons To Join Us

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