



Care Alliance Ireland

Exchange

Spring 2017 Issue 54

Minister McEntee's Announcement Indicates Move towards Statutory Basis for Home Care

Minister Helen McEntee announced on 16 January that her department will launch a consultation process on the establishment of a new statutory homecare scheme. Minister McEntee said:

"My priority is to ensure that our older people get the best care possible. For many, that care can be provided in their own homes, surrounded by the people and communities that they love. Unfortunately, as a country, the only statutory scheme we have in place at present to care for our elderly is the Nursing Homes Support Scheme, a Fair Deal. I am determined to change this and to establish a new statutory homecare scheme.

"The Department of Health is currently engaged in a detailed process, which will determine what type of home care scheme is best for Ireland, in relation to both regulation and funding. Preparatory work has already been done in this area, including the HRB review of international best practice, which will be used to inform the development of a new statutory homecare scheme, and to regulate this important sector. Establishing exactly what type of scheme will work is a complicated process and while the Department will build on the success of Fair Deal we cannot simply copy it, or integrate homecare into it.

"In creating a new homecare scheme we need to plan for the projected increase in our older population and to devise a cost-effective and sustainable scheme and regulatory regime. In addition, we must also ensure that we don't damage what is already in place in homes across Ireland. I know from speaking to older people and their families that many have informal home care arrangements in place. We must ensure that any new scheme, which will contain new regulations, does not endanger or restrict the current informal arrangements which are in place."

You will find a link to the full statement [here](#).

Speaking in response to the announcement, Liam O'Sullivan, Executive Director said: "We welcome this announcement and look forward to reading the Health Research Board (HRB) report on how other countries provide a legal basis for home care. We will have an active role in the upcoming consultation and implementation process. In the meantime, we are calling on Minister Harris to ensure that the unmet need for home care provision are given priority as the year progresses and the need increases. Our research suggests (conservatively) that there are in the region of two million hours of unmet need in home care provision, with many overstretched Family Carers meeting this shortfall. In other cases, this unmet need is putting vulnerable people at real risk of neglect and injury."

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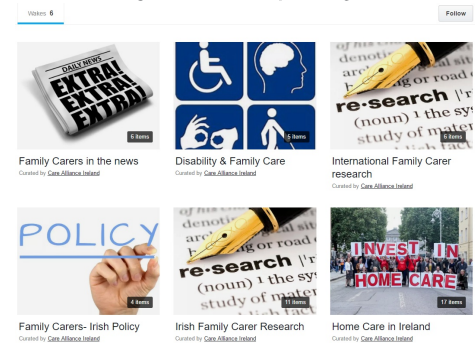


News

Care Alliance Ireland Research & Policy Round Up Launched

Care Alliance Ireland is delighted to announce the launch of the Care Alliance Ireland Research & Policy Round Up. This regularly updated online magazine aims to collate major news, policy and research matters related to family caring into one easily accessible place online. At launch, there are six sections:

- Family Carers in the news
- Disability and Family Carers
- Irish Family Carer research
- Irish Family Carer policy
- International Family Carer research
- Home care in Ireland.



This initiative replaces the Care Alliance Research & Policy E-zine with one which will be more responsive and timely, with regular updates and continual development. We encourage all our members to subscribe to the Round up. If you have any material which you feel should be included, or topics which are not currently covered, please contact our Policy & Research Officer Zoe (zoe@carealliance.ie).

To read and subscribe to the Roundup go to <https://wakelet.com/@careallianceireland>

Further Discussion Paper Published

We Need to Talk About It – Stigma and Family Care: Fifth in Series Published

Many Family Carers are happy for others in their circle of friends and family to be aware of their caring responsibilities. This is often easier when the "reason" that the person being cared for requires care is a condition which elicits an empathetic response – such as dementia, or a significant medical condition. However, not all conditions which necessitate family members becoming Family Carers fall under this category. In addition, Family Carers may find themselves subject to stigma for various reasons. This paper introduces a number of discussion points which link family caring and stigma, placing both within an Irish context and encouraging an open discussion of the issues.

Since its publication just over three months ago, it has already been downloaded more than 1,500 times. A small number of hard copies are available on request. If you have comments or questions about the paper, please contact Zoe (zoe@carealliance.ie), who would welcome feedback.

All discussion papers in the series are also available to download from our website www.carealliance.ie.



News

Young Carers Project Update

Empowering Professionals to support Young Carers (EPYC)



Our work with our European colleagues in Empowering Professionals to support Young Carers (EPYC) continues apace. Our co-ordinator, Denise Dunne, has been making contact with organisations working with young people and youth groups, and with our members whose work is focused on supporting Young Carers. We expect that this outreach will highlight the work of the estimated 56,000 young people in Ireland between the ages of 10 and 17 who provide regular, unpaid family care. We would be delighted to hear from you about your organisation's experience in this area.



The first Intellectual Outputs of the project, which involved gathering support materials and assessment tools used for Young Carers, are being collated at the moment and we expect to have an online database of these resources available in the coming weeks. We will update you when this tool is published on our website.

The six EPYC project partners met in early March for the second time at one of the partner agencies, the Istituto Versari Macrelli, close to Bologna, Italy. The meeting was very productive in helping partners understand the experience and knowledge of Young Carer supports across the partner nations.

For more information on the EPYC project, please contact Denise by phone on 085 806 2392, email at denise@carealliance.ie or visit the project website at www.ep-yc.org. The EPYC project is supported under the Erasmus+ funding programme.



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).

Resilience in Carergivers of People with Dementia – UCD/Care Alliance Research – Update



Since her appointment in November 2016, Sandra and the HRB project team have secured ethical approval for the next phase of this participatory action research project, the establishment of a Family Carers group. Sandra has been working closely with Care Alliance Ireland member organisations to recruit Family Carers of people with dementia to the group and it is anticipated that the group will be up and running by the end of March 2017.

Sandra can be contacted on 085 252 4978 or by email sandra@carealliance.ie.

News

Policy and Research Officer Reporting

Zoe continues to work with member organisations to increase collaboration across the policy and research brief of Care Alliance Ireland.



Zoe Hughes, Policy and Research Officer, Care Alliance Ireland, at the recent ABI Ireland Carers Conference in Croke Park

Work recently undertaken on research and policy includes:

- Launch of Discussion Paper 5 – “We Need to Talk About It - Stigma and Family Care” (see <http://bit.ly/2hMpHmf>).
- Continued participation with 16 other not-for-profit organisations in the “Invest in Home Care” campaign.
- Submission of multiple abstracts for presentation at the International Carers Conference, Australia (2017).
- Presentation at the February meeting of the Social Policy Network, on the topic of cross-cutting policy spheres (see <http://bit.ly/2kmpGG0>).
- Participation in the Eurocarers research sub-group.
- Launch of the Care Alliance Ireland Research & Policy Roundup (see further details on page 2).
- Attendance at the Acquired Brain Injury National Conference: "Building Resilience - Valuing Myself as a Carer" in February.
- Representation of Family Carer issues, along with colleagues from other local and national organisations, at the HSE National Patient Forum.
- 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 (zoe@carealliance.ie)

Care Alliance Ireland to Present on the Carer Needs Assessment at Upcoming Integrated Care Conference – May 2017



Following a successful collaborative abstract submission with the HSE, Family Carers Ireland and Rehab Care, we look forward to presenting on this topic in Dublin in May at the 17th International Conference for Integrated Care. For more details about the event see <http://bit.ly/2duDVXV>.

News

National Carers Week 12–18 June 2017

Now in its eleventh year, we look forward to another week of celebrations and recognition of the care provided by Ireland's 360,000 Family Carers.



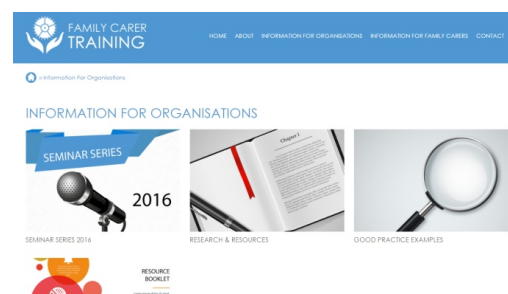
The first planning meeting is scheduled to take place on 21 March and we hope to make announcements in the coming weeks about new initiatives for this year's week.

Nine national organisations are partners in the week, and they will organise events around the country to acknowledge the valuable work and contribution that Family Carers make not only to their individual families but to Irish society more widely. Partners this year are: Acquired Brain Injury Ireland, Alzheimer Society of Ireland, Care Alliance Ireland, Family Carers Ireland, Disability Federation of Ireland, Inclusion Ireland, Irish Cancer Society, Irish Hospice Foundation and MS Ireland.

For details of events or tips on how to organise an event, see www.carersweek.ie or our Facebook page www.facebook.com/nationalcarersweek over the coming months.

Family Carer Training – New Website Reaches over 2,000 Family Carers

Part of our commitment to this project was the development of a new website www.familycarertraining.ie. Launched in mid-November 2016 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.



Since its launch there have been over 2,500 unique users. As part of the project we have committed to keeping the site updated throughout 2017. This project was funded under the Dormant Accounts (Carers Measure) and managed by Pobal.

AIHPC Carers Online Palliative Care Resource – Virtual Working Group Update

Led by the All Ireland Institute of Hospice and Palliative Care, (<http://aiihpc.org/>) the launch of the website is planned for the coming weeks. The content will aim to provide signposts for Family Carers through their caring journey.



All Ireland Institute of
Hospice and Palliative Care

Member News

"Walk in Our Footprints: A Dementia Carer's Journey"



"My father and I work together to care for my mum. He is 81, she is 68 and I am 33. At the moment, she is losing her ability to communicate clearly. Her words are completely jumbled most of the time. Due to stress and fear she needs someone to be with her all of the time. Breaks are so vital for releasing the tension. I try to go to the gym several times during the week. I also try to visit my friends. Our daily routine of getting out walking and meeting people is beneficial for her and me."

These are the words of Micheál Rowsome, a full-time carer for his mother Kate, who was diagnosed with dementia in 2014.

Micheál lives in Limerick and is a member of the Dementia Carers Campaign Network (DCCN), an advocacy group facilitated by the Alzheimer Society of Ireland. He shared his story as part of the "Walk in Our Footprints: A Dementia Carer's Journey" campaign, which was launched by the DCCN in late 2016.

Through this campaign six members of the DCCN shared their personal experience of caring for a loved one with dementia, highlighting the issues and needs that arise at different points of that journey.

Each of these powerful stories was shared through social media and a campaign leaflet containing extracts from the stories and information on relevant resources was widely circulated. Audio versions of the stories were also shared on SoundCloud, where they have been listened to over 1,100 times to date.

The campaign received good media coverage and was highlighted on RTÉ's 'Today with Maura and Dáithí' show, in a feature piece in the *Irish Independent* and through regional newspapers including the *Limerick Leader*.



Member News

Supporting Parents and Carers of Children with Epilepsy



Caring for a child with epilepsy can be a very challenging experience for parents and guardians as primary carers. In Epilepsy Ireland, we are regularly in contact with parents and carers of children and young people with epilepsy. Learning about the condition itself and understanding the healthcare system and how to progress through it for the child with epilepsy can be a daunting task.

In addition to this, the complexities relating to medication and their side effects, the struggle to get seizure freedom for the child, and understanding the risk and safety issues provides a challenge to carers. We make approximately 20,000 individual contacts per year through our services, both in one-to-one and in group settings, and of these, almost 50% are parents and carers of children with epilepsy. Our services span the country, with 10 offices nationally and community resource officers to support families in each office.

In 2015, we developed and designed a new programme specifically to support parents and carers of children with epilepsy. The programme was developed in collaboration with 10 healthcare professionals, including leading clinical psychologists, clinical neuropsychologists and paediatric epilepsy nurse specialists working in Ireland. It was designed to provide parents with both the epilepsy-specific information that they require to support their child, but also with information on aspects of care that can often be equally challenging. For example, information about what to expect and how to manage the child's educational requirements, or how to support the siblings of children with epilepsy in the best way. Siblings often become carers of the child with epilepsy, and we help parents to identify and reduce this occurrence. Other considerations we discuss with the parents relate to managing challenging behaviour and building self-esteem in their children. By building up the parents resources, we hope to impact on the child, the siblings and the wider family system. We include a module on stress management for parents and support with coping strategies.

The parents have provided incredibly positive feedback for our courses. We have completed 21 courses across the country and 145 people have attended. The courses are four sessions each. The parents and carers meet each other and share coping strategies and stories; they offer each other great support and insight into the difficulties they may be facing. The feedback identifies that the improvements in understanding epilepsy, risk and safety and managing seizures and children's emotional issues are all significant. In addition, people report that there is an improvement in their ability to talk about epilepsy and support their child the child's siblings and in their overall ability to care for their child with confidence.

One parent, living in Waterford, told us that 'this space has allowed me to feel normal again as a parent, as I had not met with any others in similar positions to myself before these sessions'. Another participant, living in Donegal, explained that 'since starting the course, I've approached my child's school about her learning and assessment because now I've got the knowledge to proceed with the school on a plan which will benefit her in her final years at primary school'.

Member News

Supporting Parents and Carers of Children with Epilepsy

Continued from page 7

Sharing with other parents and carers and being prepared for issues which may arise, not only currently but in the future, is an important function of the course. One parent explains that 'it was very interesting to hear other parents' experiences, and very good to highlight all aspects of epilepsy and to outline potential issues that we may come across as our child grows older with epilepsy'.

Epilepsy Ireland continues to strive to meet the needs of people with epilepsy and their families and carers. We offer online support groups, one-to-one support and toolkit sessions for those newly diagnosed and support groups for parents and carers. We also provide a Transition Advice Line for parents and carers of teenagers with epilepsy, as well as numerous events and activities for families around the country. Please check our website at www.epilepsy.ie for local events or phone (01) 455 7500 to speak to a community resource officer in your region.

Article by Wendy Crampton, Director of Services, Epilepsy Ireland

Update on Advance Care Planning



The role of advance care planning in the care of people with illnesses such as COPD, dementia, heart failure and neurological illnesses such as motor neuron disease, multiple sclerosis, Parkinsons and Huntingtons disease is increasingly being recognised, and this will be supported with the full commencement of the Assisted Decision-Making (Capacity) Act 2015. This new piece of legislation provides a statutory framework to support advance health care directives in the Irish context.

The HSE have recently appointed an assisted decision-making steering group and an advance healthcare directive MDT working group to make recommendations for the code of practice so that the Act can be fully commenced. However, in the meantime, while awaiting its full commencement and subsequent clear guidance, there is much anticipation and apprehension amongst Family Carers with regard to how their role as advocates and assistant decision-makers will be provided for in the Act.

In this uncertainty, the Irish Hospice Foundation has published a two-page fact sheet with information about advance care planning and related Irish Hospice Foundation activities and resources. An overview of the new legislation is provided together with information in relation to advance care planning and advance healthcare directives.

For more information about this visit: <http://hospicefoundation.ie/%20programmes/advance-care/> or email: Deirdre.shanagher@hospicefoundation.ie.

Member News

'Share the Care' Campaign Launched!

Launched in recent weeks, the campaign aims to make 2017 the Year of the Carer, and will highlight the vital role the 200,000+ Family Carers in Ireland play in our society. "Share the Care" will be supported by a range of nationwide awareness-building activities, events and research projects, and complemented by political engagement at all levels. The campaign will strive to give all carers a voice so that the issues facing them are heard.



One of the fundamental messages of the "Share the Care" campaign is that nobody should care alone. Caring should be a shared responsibility between a number of partners and parties including the person requiring care, the Family Carer, the wider family, the state and other relevant agencies such as service providers.

The present reality is that family carers prop up the health system through their dedication and are often expected to fill the gaps in resources in the system regardless of the cost to them – financially, socially, or in terms of their physical and mental health and well-being. "Share the Care" also calls on Family Carers to self-identify as carers and seek support from their wider family, the state and society, as some carers can find it difficult to reach out and ask for help.

Commenting on the launch, Catherine Cox, Head of Communications at Family Carers Ireland, said, "Our 'Share the Care' campaign that we launched today will run throughout 2017 and will create awareness of the work undertaken by family carers across the country. We also want to provide carers with a platform where they can communicate the issues that are facing them, and where they can get help and support."

Brendan O'Connor, journalist and TV presenter, has spoken openly many times about the challenges facing carers in accessing supports and services, in particular for children with disabilities. Brendan was on hand to launch the campaign today and he commented, "I'm delighted to be involved in Family Carers Ireland 'Share the Care' campaign. The issues the organisation are highlighting are ones which I feel very strongly about, and anything which can help to promote the difficulties facing carers and the lack of services available to them has my full backing. People with disabilities are not adequately taken care of in this country, in fact they are neglected, and it's time that we woke up to this reality and started to do something about it."

Throughout the course of 2017, Family Carers Ireland will aim to tell the stories of carers in society, across all age groups and demographics and in all corners of the country. The campaign will also focus on various issues of importance to carers, including carers' mental health and well-being, knowing your rights, keeping active, healthy eating and more. Complementing this awareness building will be advocacy and engagement with political parties at every level.

For further information on the "Share the Care" campaign and the year's activities please log on to www.familycarers.ie.

One of the key issues Family Carers Ireland has been advocating for and will continue to bring to the fore, particularly given Minister McEntee's recent commitment, will be for a statutory entitlement to homecare services which is demand led and available to all ages.

Member News

BodyWhys Workshop



New Maudsley Training

EATING DISORDERS

2 Day Family / Carers' Workshop Skills Based Caring in Eating Disorders

Specialist Training by:
GILL TODD RMN MSc

Date: Saturday 1st and Sunday 2nd April 2017

Venue Sponsored by:

Clayton Hotel, Leopardstown, Co. Dublin

Registration Day 1 @ 9am (pre-registration necessary)

Course 9:30am – 4:30pm each day

Cost: €100 Family/Carers €150 Professionals

Subjects covered will include:

- Explore how family relationship issues contribute to maintaining the Eating Disorder.
- Learn about the psychology of an Eating Disorder
- Practice makes perfect - we will practice the necessary communication skills to help improve your Loved Ones' self-esteem.
- Pre reading: 'Skills-based Learning for Caring for a Loved One with an Eating Disorder' *Pub. Routledge 2007.*

For further information and pre-registration, contact:
newmaudsleyworkshop@gmail.com

Research and Practice

Evaluation of Direct Payments in Residential Care Trailblazers Report



Evaluation of Direct Payments in
Residential Care Trailblazers
Second interim report

Danile Lombar, Research Officer within the Personal Social Services Research Unit at LSE, reports on the experience of direct payments in Residential Care in the UK.

Direct payments have been extended to people living in residential care in England for the first time, in a pilot programme initiated by the Department of Health (DH) in the UK. The payments are one method of delivering personalisation, an approach towards public services where support is tailored to the needs and preferences of individual people, in order to promote independence through greater choice and control. Direct payments, defined as a cash payment given to a person who has been assessed as having care and support needs, and being eligible for local authority support, have been available to people living in the community in the UK since the early 2000s. However, they haven't been adopted in long-term residential care.

A programme initiated by the DH gave care home residents in 14 local authority areas across England the opportunity to use direct payments. It was initially labelled a pilot, but was later renamed a trailblazer after the DH decided to extend direct payments in residential care nationally from 2016. The local authority social services departments participating in the programme designed new models of direct payments which could be used by care home residents, either to pay for activities or to cover the whole of the care home fee. The Policy Innovation Research Unit (PIRU), with a team of researchers from the Personal Social Services Research Unit at the London School of Economics and Political Science and the London School of Hygiene and Tropical Medicine, recently completed an evaluation of the programme (read full report here <http://bit.ly/2mBGIBF>). The evaluation, which was funded by DH, focused on three themes: the process of implementation; the outcomes for service users and other stakeholders; and the economic impact. From early in the programme it became clear that implementing the models was proving challenging for several reasons summarised below.

By the end of the trailblazer programme in autumn 2015, after it had run for two years, only around 40 care home residents were receiving direct payments – less than 10% of the numbers anticipated by councils at the start. The low numbers limited the amount of data that the research team could collect and the analyses that they could produce.

Across all of the 14 sites:

- 350 direct payments were offered to service users in care homes
- 70 people accepted the offer but not all of them actually received a direct payment
- 40 care home residents were in receipt of a direct payment when the scheme ended but by March 2016 only 29 of them were still in receipt of a direct payment

The most common client group taking part in the direct payments scheme was older people, followed by adults with learning disabilities, people with physical disabilities, and those with mental health problems.

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Research and Practice

Direct Payments Report, continued

Although the number of people accepting a direct payment in residential care was lower than expected, the evaluation has produced some insights into the potential benefits and disadvantages of the programme.

Findings from 68 completed surveys provided by service users and family members showed direct payments were used in different ways by people taking part in the programme. The most common uses were activities taking place outside the care home (such as trips to an art gallery or garden centre), activities within the care home, and meals outside the care home. The levels of satisfaction reported by people receiving direct payments and their family members were generally high.

During interviews, service users and family members who accepted a direct payment said they felt empowered to make choices about how service users' needs are met. One relative of a person holding a direct payment commented:

"We know that the money is not tied to that particular care home. We have got flexibility. If there is a problem and we need to move [the service user] for whatever reason, then we could."

Some relatives expressed views in interviews that using a direct payment made the care home fees more transparent to them, which improved their sense of confidence and control.

However, the results of the service user survey showed that, of the people who declined a direct payment, some were concerned that it would create additional work for them or their family. The most common reason for declining was that the people were happy with their current care arrangements.

In interviews, local government professionals involved in the programme described the process of setting up direct payments as lengthy and resource-intensive, requiring substantial co-ordination, co-operation and agreement between care home and council staff as well as service users and their families.

Some staff admitted that they lacked confidence to promote the scheme to others and many reported difficulties engaging care home providers.

Care home providers themselves, especially those who declined to participate in the trailblazer, said they were concerned it would risk the viability of their homes in the current financial climate. They also had concerns about whether direct payments would provide real benefits to residents and their families.

Next steps

The final report of the evaluation of the Direct Payments in Residential Care Trailblazers will be published in early 2017. An interim report is available here <http://bit.ly/2lvtXHU>.

Governance Corner

Good Governance Award

We were delighted not only to win the Good Governance Award in October 2016, but also to receive such an amount of good wishes from various stakeholders. More recently we received very detailed feedback from the judges on the content of our Directors Report and Audited Financial Statements. We will use this feedback to improve further on our reporting into the future.



Complaints Reporting

Per our agreement with the HSE, we submit a biannual statement of complaints. This was done in January.



Lobbying

In January we submitted our latest four-monthly report to the Register of Lobbyists. You can read our report here: <http://bit.ly/2lw6Gj>.



Audit 2016 Underway

We are currently working with our auditors DCON to prepare our 2016 Directors Report and Audited Financial Statements. We are aiming to have the audit considered by the Audit and Risk Subcommittee in late March, with a view to review and sign off by our Board of Directors at the 25 April board meeting.



Policies under Review

In recent weeks we completed a comprehensive update to our Social Media/Communications Policy. The board is currently undertaking its annual review of the Code of Conduct for Board Members, the Procedures for the Election of Directors and a number of other policies that are due for review.



Governance Compliance Numbers Continue to Rise

As of 1 March 375 organisations report being compliant with the Governance Code

1,031 organisations report being on the journey to adoption

For a full list of organisations go to <http://bit.ly/2mBz1v6>

Governance Corner

Changes to the Board of Directors

Resignation of Dermot Maguire. Following five and a half years on the Board, Dermot resigned from his position in February. In his time on the Board, Dermot, HR Director at VHI, brought both rigour and humour to the Board's deliberations and his contributions will be missed.



Resignation of Jimmy Duggan. Jimmy has stood down after three years on the Board. Originally nominated by Caring for Carers, Jimmy's contribution was grounded in his experience of directorships of other organisations and in his lengthy career in the Department of Health. We wish him the best for the future.

Co-option of Annie Dillon. Following nomination by the Alzheimer Society of Ireland, our Board co-opted Annie Dillon at the February meeting. Annie comes to the Board with over 40 years' professional experience, firstly in nursing, and more recently in practice development and quality assurance.



Annie works with the Alzheimer Society of Ireland and is currently the Project Lead for Quality, Safety and Practice Development. Previous roles in the Society include management of the national helpline and information service and project management of service development, research and funded pilot projects. She has represented the Alzheimer Society on steering and working groups including the National Dementia Education Project.

Annie has worked in health and education in Ireland and Australia, including older people's services. She has personal and professional experience of caring and supporting carers. Annie is a registered nurse and midwife with a MA and MSc (Education & Training Management).

Compliance with the Governance Code

Following the annual review of our organisation's current level of compliance with the Governance Code a number of outstanding issues were identified. The Executive Director is working with the Board and subcommittees with a view to addressing these issues over the coming months. It is anticipated that the Board will then reiterate its full compliance with the Governance Code.

Board Meetings 2017

(The first board meeting of 2017 took place on 21 February)

- 25 April
- 4 July
- 19 September (followed by AGM)
- 21 November

Recent Care Alliance Publications

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



Research News

The Open University Leading the Way in Carer Research

Carer research
and knowledge



Utilising carer-related research and knowledge:
a scoping review and information resource

Utilising carer-related research and knowledge: a scoping review and information resource

Currently underway in the Open University in an exciting new project which aims to identify gaps in current and recent Family Carer-related research. Its main focus is a comprehensive review of national and international carer-related knowledge and evidence. This will include 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 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 offering a synthesis of evidence.

Currently the least-researched topics in the field of family caring are Family Carers caring for those with HIV/AIDS diagnoses, and carers who identify on the Lesbian, Gay, Bisexual and Transgender (LGBT) spectrum.

Care Alliance Ireland was pleased to contribute our most recent research to be included in the review. To find out more about this project visit <http://bit.ly/2kv0YpS> or contact Dr Mary Larkin: mary.larkin@open.ac.uk.

Six Abstracts Submitted for 7th International Carers Conference

We in Care Alliance Ireland appreciate the high cost of attending international conferences. With this in mind, and keen to maximise the reach and impact of our research and other activities, we have submitted six abstracts for consideration at the upcoming 7th International Carers Conference, which is to take place in Adelaide, Australia in October 2017. Details of the abstracts are below. For further details about the conference go to <http://bit.ly/2ivrYWF>.

Title	Status	Document
Carer Needs Assessment Development - The Experience in Ireland	Submitted and Under Review	<input checked="" type="checkbox"/> Abstract Upload View
Do Leaflet Drops and Targeted Social Media Ads Increase Carer Identification	Submitted and Under Review	<input checked="" type="checkbox"/> Abstract Upload View
Having an Impact: Supporting High Quality Family Carer Training	Submitted and Under Review	<input checked="" type="checkbox"/> Abstract Upload View
Post-Caregiving: Family Carers' Experiences of Role and Identity Transition on Cessation of the Caring Role – Implications for Policy and Practice	Submitted and Under Review	<input checked="" type="checkbox"/> Abstract Upload View
Stigma Experienced by Family Carers	Submitted and Under Review	<input checked="" type="checkbox"/> Abstract Upload View
Supporting Professionals to Support Young Carers - an EU Experience	Submitted and Under Review	<input checked="" type="checkbox"/> Abstract Upload View

CONFERENCE SOLUTIONS

Contact: Carer's Australia Conference Secretariat P: + 61 2 6285 3000 E: carersaustralia@con-sol.com

Resources

Checklist for Carers – Citizens Information Board

www.citizensinformation.ie/en/reference/checklists/checklist_carers.html



Benefits and Entitlements

This comprehensive booklet from Family Carers Ireland outlines the main benefits & entitlements available to Family Carers in Ireland (updated January 2016). You can download a copy at <http://bit.ly/2mBtPaR>.



Benefits and Entitlements

HSE Carers Support Website

This dedicated section of the HSE website contains information and signposting which Family Carers may find useful – <http://bit.ly/2lld6Xr>.



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Member Profile

Western Alzheimers joined Care Alliance Ireland in November 2016. Áine Kilgallon from the organisation describes their work below.



Western Alzheimers was established in the early 1990s to provide help and support to carers and families of loved ones living with Alzheimers disease. Today Western Alzheimers provides a wide range of services across the counties of Galway, Mayo and Roscommon, which includes Residential Respite Care, Day Care, In-Home Support, Long-stay Residential Care and a Counselling and Information Service. The care provided by Western Alzheimers supports families impacted by dementia and allows the person living with dementia to lead a meaningful life in the community. Western Alzheimers believe that people impacted by dementia have the right to quality person-centred care based on respect, dignity and best-practice standards.

55,000 people suffer from dementia in Ireland, 5,000 of whom live in counties Mayo, Galway and Roscommon, which has the highest rate of dementia per head of population in the West of Ireland.

In summary they provide 360,000 hours of care per annum to approximately 350 families. Their facilities in Athenry, Co. Galway and Ballindine, Co. Mayo lead the way in the provision of services for people living with dementia and their families and carers.

Demand for all of their services continues to increase and it is anticipated that the number of dementia sufferers will treble in the next 25 years, which will lead to further demand for their services. Their aim is to meet the increasing demand for services to support people living with dementia through focusing their finite resources on areas where they can make the most impact in leading the fight against dementia in Counties Mayo, Roscommon and Galway.

Alzheimers is a heart-breaking disease that impacts not only the sufferer but also the extended family and carers. Western Alzheimers' vision is to reduce the impact of dementia through support and care in the community by sharing the burden of care with those who need their help.

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International News

IACO Update



IACO continues its solid growth in membership and activities.

In collaboration with Novartis, IACO is conducting a four-nation study of caregivers of persons with heart failure. The four nations are the United States, Canada, the United Kingdom and Australia. Participants will be asked a series of questions about the impact of heart failure on the caregiver and the care recipient and regarding caregiver experiences with health care providers. The information collected will be published in a report in September 2017. The report will be distributed to key policymakers in the four nations so they may use the findings to introduce legislation, modify regulations and possibly provide support services to caregivers of persons with heart failure. For further information go to <http://bit.ly/2kaLVkN>.

Thanks to funding from EMD Serono the work on the IACO Toolkit for nations without a formal NGO carer infrastructure is progressing.

The AGM has been planned to take place on the fringes of the 7th International Carers Conference in Adelaide in October.

For more about IACO see www.internationalcarers.org.

Chair of Care Alliance attends Carers Parliament in Glasgow



Donal McKenna (left, Chair, Care Alliance Ireland), with other delegates attending the 2016 Carers Parliament in Glasgow.

Also in the picture are Sebastian Fischer, Vocal Scotland, Benjamin Salzmänn, Pflege in Not, Johanne Powell, Family Carer, and Marian Mahon, Family Carers Ireland.

International News

EuroCarers Going from Strength to Strength

Now with a membership in excess of 60 carer organisations across Europe, Eurocarers is emerging as a leading voice for Family Carer issues in Europe.



A number of capacity-building and advocacy activities are planned for 2017. These include a Policy Working Group meeting and European Parliament Interest Group on Carers meeting to take place on 11 April in Brussels. The main objective of the working group is to align its policy messaging regarding promising and challenging policy developments at EU, national and local level in order to maximise the impact of its advocacy activities. Eurocarers will also host a second regional seminar (Mediterranean countries) on 9–10 May in Porto, Portugal. Eurocarers is playing a key role in supporting the 2nd International Young Carers Conference taking place from 29–31 May 2017 in Malmö, Sweden. Other events planned include the Eurocarers Annual General Assembly and Final Conference of the Training and Recognition of Carers' Skills (TRACK) project (20–21 June, Brussels).



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 providing information, developing research and policy in the field, sharing resources, and instigating opportunities for collaboration.

There are approximately 360,000 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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