Care Alliance Ireland
The National Network of Voluntary Organisations for Family Carers

Care Alliance Ireland Exchange

Issue 27 Summer 2009

Inside this issue:

- Position paper on Report from An Snip Nua
- Law Reform Commission Consultation Paper
- National Positive Aging Strategy
- Member Profile

Contents:

Photographs from National Carers Week 3

Measuring Outcomes with Young Carers 8

Information on Family Carers from 2006 Census 9

Eurocarers 10

LAUNCH OF NATIONAL CARERS WEEK

This year National Carers Week had the theme of "Celebrating Carers – Because we're worth it!" With this theme we aimed to highlight the role played by the 161,000 Family Carers in Ireland .All too often the sacrifices and time given by Family Carers is unseen or unappreciated by the wider community.

With this in mind, 10 national voluntary organisations got together as partners to

promote the week.. The partner organisations are: The Alzheimer Society of Ireland, Aware, Brí, Care Alliance Ireland, The Carers Association, The Disability Federation of Ireland, Extra Care, Headway, The Irish Hospice Foundation and The Irish Red Cross. Working together over the year plans were made to celebrate the role of Family Carers. This year we introduced additional merchandise including pens and trolley coins and thousands of these were distributed nationwide.

Over 100 separate events were held during the week in all areas of the country. These included days out, pamper days, tea and coffee mornings and many more. (Please see www.carersweek.ie/events for a full listing)

Media coverage was extensive with over 30 regional and local radio stations covering the week. The website was given a complete overhall.

The launch of the week was held in the Mansion House on Monday 8th June. Speakers included, The Lord Mayor of Dublin – Cllr. Eibhlin Byrne, Liam O'Sullivan – Care Alliance Ireland, Colum Conway – Extra-Care, John Dolan – Disability Federation of Ireland, Enda Egan – The Carers Association, Una Crawford O'Brien – Actress and Catherine Keogh – The Alzheimer Society.

All the speakers spoke of the commitment of Family Carers and how hard this role can be. The focus was on commendation and appreciation for what Family Carers accomplish every day and the invaluable service they provide.

We would like to thank everyone who took part in what has been by far the most successful National Carers Week to date. A comprehensive review of the week took place in July and plans for National Carers Week 2010 are underway

OPINION

Care Alliance Ireland Position Statement on Report of An Board Snip Nua

Care Alliance notes the Report of the Special Group on Public Service Numbers and Expenditure Programmes and offers the following observations:

The recommendation to abolish the half rate Carers Allowance payment is not well considered and we oppose it.

The report argues for a blanket abolition of all secondary social welfare payments. We believe that the half-rate payment, currently worth up-to €109 per week to approximately 16,000 full time Family Carers represents good value for money. The Half Rate Carers Allowance was introduced in 2007. The changes announced to the Carer's Allowance Scheme allowed for more people who are caring for another person to receive a Carer's Allowance Payment. The changes meant that if an individual was in receipt of certain social welfare payments and providing full-time care and attention to another person, they could keep their main social welfare payment and receive a Half-Rate Carer's Allowance also.

The full rationale articulated by government for its introduction is available to view on http://www.welfare.ie/EN/Press/PressReleases/2006/Pages/pr121206.aspx

€109 equates to the cost of providing approximately 5 hours home care support per week.

1 This compares with an average of in excess of 60 hours per week, and often considerably more hours, provided by such Family Carers.

2 This half-rate payment enables over 16,000 dependent people to continue to be cared for at home. The estimated cost of nursing home care is in the region of €800-€1,000 per week, whilst the cost of acute hospital care is in the region of €5,000 per week

3. These weekly figures amount to €41,600-€52,000 per annum for nursing home care and €260,000 per annum for acute hospital care.

It is important to note that the current rate of payment of the full Carers Allowance is set at a rate a little above that of the supplementary allowance which is a right to eligible people with little or no income. For many Family Carers, Carers Allowance may be their only source of income. Both the full rate Carers Allowance and half rate Carers Allowance are heavily means-tested, meaning they only go to Family Carers on low incomes. In fact, full-time Family Carers in receipt of the full rate Carers Allowance only receive €16 more per week than an individual in receipt of the Jobseekers Allowance. This is an insult to Family Carers who choose to stay at home to care for a loved one. In many cases Family Carers remain on call 24/7, while also dealing with the additional costs associating with providing care in the home. Often, these individuals give up paid employment and a good salary to provide care at a considerable cost saving to the state.

Note: Further details on the background to and benefit of the Half Rate Carers Allowance can be found in an earlier Position Paper, available to download from our website: http://www.carealliance.ie/documents/Care_Alliance_Ireland_Position_Statement_on_Half_Rate_Carers_Allowance_Final_Jan15th.pdf

NEWS

Photos from National Carers Week Events Nationwide.
To see all the photographs we received please log onto www.carersweek.ie/gallery

NEWS

The Carers Association - National Carers Week 2009

Carers Week was another great success for The Carers Association with all our sixteen resource centres across the country carrying out a variety of events for family carers. The theme "Because we're worth it" was carried through these events and ensured that carers enjoyed themselves.

Two large gatherings of family carers took place during the week with one hundred and thirty carers meeting at Adare Village and one hundred and twenty carers meeting at the Cuisle Centre in Roscommon. Carers enjoyed the opportunity to meet up with other people in similar circumstances and the chance to share experiences while enjoying a day of relaxation, music and fun.

A survey undertaken by The Carers Association and Dublin City Council on family carers working in Dublin City Council was launched in the Mansion House during Carers Week. The report examines the strains and pressures of combining employment with caring for a loved one in the home. The Cork Family Carers Forum launched their new website www.corkfamilycarersforum.ie also during Carers Week.

Other successful events our resource centres ran during Carers Week were Information Mornings, Flower Arranging Classes, Bio Energy Sessions, Support Groups, Coffee Mornings, Serenity Healing, School Art Competitions, Social and Music Evenings, Certificate Presentations, Reiki, Massage, Beauty Therapy and Stress Management Classes plus many more.

Photos from our carers week events can be found on www.carersireland.com.

NEWS

LAW REFORM COMMISSION PUBLISHES CONSULTATION PAPER ON PROFESSIONAL HOME CARERS

CONSULTATION PAPER PROPOSES STATUTORY REGULATION OF PROFESSIONAL HOME CARERS BY HIQA

On Tuesday 28th July 2009: The Law Reform Commission's Consultation Paper on Professional Home Carers was launched by Dr Maureen Gaffney, Chair of the National Economic and Social Forum (and former Law Reform Commissioner), at the Commission's offices.

The Consultation Paper forms part of the Commission's Third Programme of Law Reform 2008-2014, and involves an examination of the extent to which the law should be reformed to ensure that appropriate legal standards are in place for professional home carers. The Consultation Paper makes 21 provisional recommendations for reform of the law.

The main recommendations in the Consultation Paper are that:

- HIQA should be empowered to regulate and monitor professional home carers (domiciliary care providers)
- HIQA standards it proposes for professional home carers should be specifically tailored for the home care setting, building on existing HIQA nursing home standards
- the proposed standards should ensure that home care is provided in a manner that promotes the well-being and independence of the service user in their own home
- the terms and conditions of the home care arrangements should be agreed and recorded in a care contract, in order to offer the maximum protection to the service user
- the care contract should contain clear policies and procedures in relation to the handling by the professional carer of money and personal property of the service user
- an individual who wishes to enter into an arrangement for the provision of professional home care services should have the option to contract with an intermediary, whether a State body (such as the HSE) or a private sector body, who would arrange for the provision of care and who would assume the responsibilities of an employer towards the professional home carer
- the Commission invites submissions as to whether a subvention arrangement, comparable to that for nursing homes in the Nursing Homes Support Scheme Act 2009 (the fair deal scheme), should be extended to professional home care
- section 469 of the Taxes Consolidation Act 1997 should be extended to provide tax relief for fees incurred by an individual in meeting the cost of professional home care
- the Commission invites submissions as to whether the form of protection for people who report concerns about incidents of possible abuse contained in the Protection of Persons Reporting Child Abuse Act 1998 should be

(Continued on page 6)

NEWS

(Continued from page 5)

extended to apply in the context of professional home care

- the Commission also invites submissions on the establishment of a specific register of professional domiciliary carers, which would be operated by HIQA, and which would set out specific requirements in relation to the registration and monitoring of professional domiciliary carers.

Those who wish to make submissions are requested to do so in writing by post to the Commission or by email to info@lawreform.ie by the 30th November 2009

Following a through review of the report and consultation with member organisations. Care Alliance Ireland will make its submission to the Commission

Hilton Foundation Awards €11,000 to Muscular Dystrophy Ireland

Muscular Dystrophy Ireland (MDI) were thrilled to receive funding of €11,000 from Hilton in the Community Foundation (HCF) following fundraising by team members at Hilton and Conrad hotels in Ireland.

The grant will support the provision of MDI's Youth Respite Service which consist of summer camps.

MDI would like to sincerely thank Hilton in the Community Foundation and all the staff who fund-raised for us.

(front row left to right)
Joe Mooney CEO of Muscular Dystrophy Ireland (MDI), Ciaran Purcell MDI, Donal Purcell MDI, (back row left to right) Ephrainn Purcell MDI, Laurens Zieren General Manager of the Conrad Dublin, Amy Bramley MDI.

Revamped National Carers Week Website

In advance of National Carers Week 2009, a complete overall of the website was co-ordinated by Esther Kavanagh in Care Alliance. In 2008 the site was a basic static page and there was a clear need to invest time and money to make an attractive and accessible website that would compliment the week and support the communication of the week to the wider public and the media. Several new pages were created.

Currently the website contains a list of over 100 events held during 2009, on a county by county basis, a gallery of photographs taken during Carers Week 2009, press releases and information on the partner organisations.

We also will be including a page of helpful tips for Family Carers so be sure to click on the link to see what is coming up.

This website can be found at www.carersweek.ie

Acquired Brain Injury Ireland
Maximising Ability, Changing Lives

NEWS

The Peter Bradley Foundation is now **Acquired Brain Injury Ireland.**

In March 2009, the Peter Bradley Foundation changed its name to **Acquired Brain Injury Ireland.**

Since its establishment in 2000, The Peter Bradley Foundation has made a significant difference to the lives of people living with Acquired Brain Injury (ABI) and their families. In the past eight years there has been significant growth across the organisation, in terms of the services provided, the number of people served and the regions in which they now operate.

This growth is no small achievement and is a tribute to everyone who works in, and supports, the Peter Bradley Foundation.

Barbara O'Connell , Chief Executive, says "On a personal level, it gives me and my family huge satisfaction that so many lives have been enhanced as a result of our determination to ensure that Peter could be enabled to live in his own home despite his brain injury. The organisation was built on one family's story, now there are so many similar family stories throughout Ireland".

Barbara O'Connell, continues "The reason for the name change is simple. We believe that our name should reflect the work we do and, unless one has a direct association with The Peter Bradley Foundation, or the sector, this is not immediately obvious in our current name".

The new name **Acquired Brain Injury Ireland** reflects the greatly expanded services now provided by the organisation.

The ethos which has made the Foundation so successful will be maintained. Staff will always be aware of Peter's own personal story and how it has formed the organisation. Acquired Brain Injury Ireland will continue to provide a personal service tailored to the individual needs of those using their residential, community or case management services.

Acquired Brain Injury Ireland's National Office is based in Dun Laoghaire, Co. Dublin. There are four regional offices in Galway, Kerry, Cashel and Dublin. ABI Ireland provides services in almost all counties in Ireland www.abiireland.ie

Headway & BRI - Because You're Worth It Carers Day

Headway and BRI are two organisations that support people affected by brain injuries. We held a Day Out for carers in the lovely surroundings of Airfield House in Dundrum on Saturday, 6th June 2009. Even though it poured out of the heavens, we had a great day, with 12 family members of people with acquired brain injuries attending.

Those who came are caring for family members who have had brain injuries from strokes, brain tumours, and head injuries, amongst other things. They had time, over coffee, lunch, and some relaxing activities, to share experiences and to get to know each other a bit better. Three talented facilitators worked with us: Clarissa, Eimear and Judith who taught us some origami and massage, and helped us to have a good sing-song to finish off the day.

Thanks to all the carers who came, and to Gillian from BRI, and Ruth and Ciaran from Headway, all of whom played their part in making the day a success.

There will be a **Group** for **carers** of people with brain injuries starting in Headway, Manor St, on Wednesday, 12th August (every Wednesday for four weeks). There will also be a new **Monthly Drop In** for family carers from the Dublin area, starting on Saturday 5th September, 11 am to 1 pm. Anyone interested in either of the groups should call Ciaran Nolan in Headway on 01 810 2098 or email him at: nolanc@headway.ie.

BRI's contact details are: www.briireland.ie and phone 01 2355 501

Research & Resources

Manual for Measures of Caring Activities and Outcomes for Children and Young People

by Stephen Joseph, Fiona Becker and Saul Becker,

published by The Princess Royal Trust for Carers

This practical 'hands-on' Manual is intended to provide researchers and practitioners in the field of caring with relevant and accessible instruments (or tools) for the assessment of caring activities and caring outcomes in children and young people ('young carers').

The tools can be used on a one-off basis for the purpose of assessment, or pre- and post-intervention to measure change and the impact of support. The instruments in this Manual have been developed and tested with over 500 young carers so can be used with confidence.

The Multidimensional Assessment of Caring Activities (MACA-YC18) is a questionnaire (an 18-item self-report measure) that can be used to provide an index of the total amount of caring activity undertaken by the young person, as well as six subscale scores for domestic tasks, household management, personal care, emotional care, sibling care, and financial/ practical care.

The Positive and Negative Outcomes of Caring (PANOC-YC20) is a questionnaire (20-item self-report measure) that can be used to provide an index of positive and negative outcomes of caring.

Additional resources include an extended version of the MACA-YC18 (the MACA-YC42), and two short questionnaires: 'What I like and dislike about caring', and 'Me and my young carers project'.

The Manual will be of interest to professionals in the fields of health and social care (including young carers workers, social workers, nurses, psychologists, psychiatrists, youth workers) as well as those researching care-giving, and caring organisations themselves. Published by The Princess Royal Trust for Carers in association with Young Carers International Research and Evaluation, School of Sociology and Social Policy, The University of Nottingham. ISBN 13 9780853582533

Available to download for free from The Princess Royal Trust for Carers website at: http://www.carers.org/professionals/young-carers/assessments,3063,PP.html

And for free from: http://saulbecker.co.uk/v1/downloads/young_carers/Young%20Carers%20Outcomes%20Manual%20April%202009.pdf

Professor Saul Becker
Head of School of Sociology and Social Policy
School of Sociology and Social Policy | The University of Nottingham | University Park
Nottingham NG7 2RD, UK
Email: Saul.Becker@nottingham.ac.uk

National Positive Ageing Strategy

We are currently in the process of preparing a joint submission with the Carers Association as part of the consultation phase for the development of a National Positive Ageing Strategy. It is envisaged that the strategy will set the strategic direction for all future policies, programmes and services for older people in Ireland. Family Carers are emerging as a growing sub-group within this population.

As members of Care Alliance Ireland, we would be very grateful of any comments or suggestions that you may have regarding the submission. We envisage that the focus of our submission will be on Family Carers as older people. Please forward on your suggestions to Ann Stokes at research@carealliance.ie by Monday August 31st 2009.

In addition, we would also encourage organisations to consider making their own submission as it is vital that as many views as possible inform the development of the new strategy.

Please forward on your suggestions to

Ann Stokes at research@carealliance.ie

by Monday August 31st 2009

Further Statistical Information on Family Carers from 2006 Census

GAMMA Consultants have been commissioned by The Carers Association to produce a new report entitled : Carers in Ireland - A Statistical and Geographical Overview.

The report was commissioned to provide a statistical profile of Family Carers in Ireland and those who receive care at an EU, constituency, national and county level. The information contained in the report is primarily derived from Census 2006, with supplementary information from the Department of Social and Family Affairs, the OECD and The Carers Association.

This report provides a valuable resource to all individuals working in the Family Carer sector .

A Pdf copy of the report is available to download from http://www.carersireland.com/library_of_documents.htm

European News

Eurocarers

Care Alliance Ireland is actively involved in Eurocarers, the pan European organisation advocating for Family Carers.

EUROCARERS aims to advance the issue of Family care at both national and EU levels through:

- Supporting the development of Carers organisations
- Providing a united voice at European level
- Influencing policy at national and EU levels
- Promoting awareness of Carers issues
- Dissemination of experience and good practice
- Developing an informed research agenda
- Providing information on relevant EU policy developments

The work of Eurocarers includes making policy submissions to the European Commission and other EU bodies together with providing member organisations with the opportunity to share good practice. Strong links have been formed with MEP's through the formation of an Interest Group on Carers in the European parliament. Several Irish MEPs have been to the fore in the work of this group.

There are 16 European countries represented with over 30 organisations from carer and research backgrounds.

There is an executive of 7, one of whom is Liam O'Sullivan of Care Alliance Ireland who is also the Treasurer. In addition, Frank Goodwin, Chair of The Carers Association of Ireland is the Secretary. Robert Anderson, of The European Foundation for the Improvement in Living and Working Conditions, is the Honorary President.

The executive will meet in Dublin in September for a 2 day planning and strategy meeting.

For more details on Eurocarers see www.eurocarers.org

Caring for Carers—Limerick Branch

Caring for Carers – Limerick Branch report a very busy start to 2009. A group of our carers are completing a First Aid Course under the auspices of the Irish Red Cross. We have just started a 12 week "Caring in The Home Course" in Newcastle West, West Limerick. This course is designed to suit family carers; the demand for spaces has been phenomenal this year. 24 carers are now doing the course. On completion they will have the opportunity to join the West Limerick Support Group. This is the first of four "Caring in the Home Courses" we will be running during the year.

Our Limerick Branch sent a group of 60 family carers to the **Caring for Carers Annual Respite Weekend & Conference** at the Gleneagle Hotel, Killarney the first weekend in March. The theme of the conference was "The Family Carer: Sustaining Care in Challenging Times". A number of our carers voiced their concern about the deferring in the publication of **A National Carers Strategy**. After all the campaigning for carers rights, this is a setback. As part of the conference there was a banquet

(Continued from page 10)

and other entertainment; among them, The Irwin School of Irish Dancing, who proved to be very popular. One of the Limerick Group of carers, Marion Keating won the Easter bonnet competition; this was great fun .The carers had a very relaxing weekend, many availing of the beauty treatments; other choosing to go on a tour or even a bit of retail therapy. This fitted in with our holistic approach to our carers and recognising the fact that carers need a respite break now and again.

Caring for Carers Limerick Branch weblog at. www.limerickcaringforcarers.wordpress.com

Member Profile

BODYWHYS
The Eating Disorders Association of Ireland

Bodywhys – the Eating Disorders Association of Ireland – is the national voluntary organisation providing support for people affected by eating disorders including friends and family members.

Eating disorders, including anorexia nervosa, bulimia nervosa and binge eating disorder, are serious mental health conditions that affect an estimated 200,000 people in Ireland.

Bodywhys is committed to the belief that people with eating disorders can and do recover. As such, the organisation strives to empower people affected by eating disorders to access information, support and treatment.

We work to ensure support, awareness and understanding of eating disorders amongst the wider community as well as advocating for the rights and healthcare needs of people affected by eating disorders.

Bodywhys provides a range of support services including a LoCall Helpline (1890 200 444), support groups in Dublin, Carlow and Galway, an email support service (alex@bodywhys.ie), online support groups, an under 25s forum and an information-rich website at www.bodywhys.ie

Care Alliance Ireland

The National Network of Voluntary Organisations for Family Carers

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 will achieve this by supporting organisation in their work with Family Carers through the provision of information, research, the sharing of resources and opportunities for collaboration..

Care Alliance Ireland was established in 1995 and our membership currently includes over 65 Voluntary organisations concerned with the needs of Family Carers.

To find about more about Care Alliance please visit our website www.carealliance.ie

or contact us by telephone or e-mail.

TEL: 01-8747776 E-mail: info@carealliance.ie

Care Alliance Ireland is a company limited by guarantee not having a share capital, registered in Dublin, Ireland, with registered office at: Coleraine House, Coleraine Street, Dublin 7

Family Carer Research Group

Care Alliance Ireland established a national research alliance on Family Carers issues in 2007, with the following key aims envisaged:

- To progress and develop an agreed research agenda within the Family Carer sector
- To facilitate relationship building between NGO'S/statutory agencies/ academics in relation to Family Carers research issues.
- To act as a means of sharing research information relating to Family Carers.
- To inform and update members of the group on research being carried out in other organisations, which may be relevant to their own work.
- To work together to develop and promote evidence-based research and publications on Family Carers, that can be used to support policy and to develop appropriate services.
- To identify possible gaps in research and help set priorities for new work in the area of Family Carers.
- To identify possible relevant research funding opportunities.
- To develop partnerships for possible future research.
- To promote the use of research to inform policy and practice in the Family Carer arena.
- To support members of the group in securing a more central recognition of Family Carers within their own organisations.

Membership is Open to all organisations/ individuals working on issues relating to Family Carers.
It is proposed that the Family Carer Research Group will meet on a quarterly basis in Dublin. Meetings normally last up to 2 hours and are hosted by Care Alliance Ireland. The next meeting of the Family Carer Research Group is due to take place on Tuesday 8th September 2009 at 10.30 am in the Hardwick Room, , Coleraine House, Coleraine Street. Dublin 7.
If you would like further information on the Family Carer Research Group or would be interested in attending the next meeting, please contact:
Ann Stokes, Research and Policy Officer, Care Alliance Ireland

Disclaimer: This Newsletter is provided as an information guide for voluntary groups supporting family carers only and does not constitute advice on, or endorsement of, any service or product referred to within this Newsletter. The views and opinions expressed within this Newsletter are those of the authors/represented organisations and are not necessarily shared or endorsed by Care Alliance Ireland. No responsibility is accepted for or on behalf of Care Alliance Ireland for any errors, omissions or misleading statements in this Newsletter or on any website, publication or advertisement referenced in this Newsletter. Whilst every effort has been made to ensure the reliability of any websites, publication or advertisement referenced in this Newsletter, this cannot be taken as an endorsement of those websites, publications or advertisements.