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# Care Alliance Ireland

Welcome to the fifth Care Alliance Research & Policy E-zine. This special edition focusses on the first Care Alliance Ireland research conference which took place on 20 November 2015 in the Carmichael Centre in Dublin. This e-zine also takes a further look at the recently launched Care Alliance Discussion Paper Series (including a response to the first paper from a Family Carer), as well as information from Budget 2016.

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## **20 Years of Family Carer Research in Ireland: Conference Overview**



On 20 November 2015, Care Alliance Ireland welcomed oral and poster presentations from 24 key researchers and frontline workers in the Family Carer sector at a major research conference in the Carmichael Centre in Dublin.

The day began with a retrospective look at the field of Family Carer research, presented by Liam O'Sullivan, Executive Director of Care Alliance. His presentation outlined some of the key points in Family Carer research in Ireland over the last 20 - 30 years - including some issues which still remain unaddressed today.

### Session 1: Time & Space in Family Caring

Session 1 addressed the issues of location and geography over time. Dr Lazelle Benefield (University of Oklahoma Health Sciences Center and Fullbright Scholar, UCC) addressed the emerging (in Ireland) issue of distance caring, from a joint US and Irish perspective. Her presentation raised interesting issues about the challenges in coordinating care from a distance and navigating unsupportive family relationships.

Dr Ronan Foley (NUI Maynooth) introduced aspects of geography detailing the level of information in, and the usefulness of, maps using census data to understand the geographical spread of Family Carers. The applicability of these maps in intervention and support planning is clear. The maps are available [here](#).



## Session 2: Family Caring & Dementia

Session 2 specifically concerned issues around caring for someone with a dementia, from a number of different perspectives. Dr Emer Begley (Alzheimer Society of Ireland) began the session by raising the issue of how the community & voluntary sector can bring added value to Family Carer research. Her presentation encouraged those in the sector to understand the relevance of research to the everyday work of community & voluntary organisations, with direct examples drawn from the work of the Alzheimer Society.

Discussing some of the findings from the Actifcare project (ACcess to TIMely Formal Care), Dr Louise Hopper (DCU) focussed on some of the recurring issues which people with dementia and their families experience in their journey through dementia. These include divergences in the opinions of Family Carers and healthcare professionals in areas such as "Understanding Care Needs" and "The Impact of Caring".

Katie O'Donnell (TCD) and Jennifer Rogers (TCD) both presented findings from a project based on the NEIL project at Trinity College (NeuroEnhancement for Independent Lives), which investigated the experiences of spousal caregivers of people with dementia. Ms O'Donnell outlined the higher instances of depression and anxiety in this cohort of Family Carers, in comparison to other carers and the general population. Ms Rogers discussed the possible applications of "benefit finding" as an activity for spousal Family Carers, with greater benefit finding significantly associated with a lower caring burden and better psychological wellbeing.

## Session 3: Cross-cutting issues

Reflecting the fact that caring is an issue which cuts across age, gender, social status and a myriad other factors in society, session 3 included a number of presentations which addressed different health and social care sectors. Nora-Ann Donnelly (RCSI) presenting the findings of her study which looked at the factors influencing the admission of community-dwelling older people to long-term care. The main assumption in many studies has been that carer stress is a determining factor; however, Ms Donnelly's study contradicts this, with a wide variety of factors influencing the decision to access long-term care.

People with intellectual disabilities are living longer, healthier lives and Dr Damien Brennan and Ms Rebecca Murphy outlined some of the main points from the ongoing IDS TILDA (Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing) project in TCD regarding the family strategies

which enable long-term and sustainable environments for older people with intellectual disability.

Dr Niall Hanon (UCD & DBS) presented some of his work on masculinity and care, discussing some of the key points as they relate to the traditional view of caring as “women's’ work”, and how men negotiate a position within that framework.



#### Session 4: Future Directions

To close out the conference with an eye to the future of the sector, Moira O'Donovan (UCC) presented the results of a focussed literature review on the topic of families and hope, with specific regard to families supporting a person with a mental health difficulty. It is clear that this is an under-researched topic, and one which has the potential to have a significant impact on the way we view families where there is a mental health difficulty.

Finally, Dr John Baker (UCD & Basic Income Ireland) and Dr Anne Ryan (NUI Maynooth & Basic Income Ireland) wondered how having a basic income might benefit Family Carers, hosting a discussion with the delegates on the benefits and challenges such a system would provide.

In addition to the oral presentations outlined above, nine presentations were published in poster format, with topics including life after care, the inclusion of Family Carers in research and campaigning, the palliative care needs of Family Carers, the challenges faced by families and spousal carers where there is dementia and general support for Family Carers from various local perspectives.

Presentations and posters (where publishing restrictions permit) are available on the Care Alliance website.





## Budget 2016



On 13 October 2015, Budget 2016 was unveiled by Ministers Michael Noonan and Brendan Howlin. A range of measures were introduced and extended which will see a positive impact for Family Carers and those for whom they provide care and support. However, Care Alliance Ireland remains concerned at the overall lack of enhanced investment for people with disabilities, long-term illnesses and mental health concerns.



Family Carers often support their loved ones, on a 24-hour-a-day, 7-day-a-week basis, with an ongoing reduction in the supports available to them. Disability and Family Caring are two sides of the same coin. In particular, we are disappointed at the lack of reinstatement of the motorised transport grant, the mobility

allowance, or the telephone allowance as part of the household benefits package; initiatives which our colleagues in the Carers Association and other groups have highlighted as of particular concern to older people and their Family Carers.

Please see [here](#) for a full report on the key changes announced in Budget 2016 which will impact Family Carers.

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## **Care Alliance Ireland Discussion Paper Series launched- and a response from a Family Carer.**

Care Alliance Ireland was proud to launch a new initiative- the Discussion paper Series- on October 19. The purpose of the series - which will include six focussed papers over the next year - is to introduce new topics for reflection and consideration into the wider Family Carer discussion. These will include topics raised by Family Carers themselves, and will address less discussed and emotive topics.

The first such paper, entitled "Defining Carers" focusses on the topic of language use, and the term "Family Carer" itself. There are many different terms used by service providers, Family Carers themselves and policy makers to describe or "label" those who provide unpaid care at home for a friend or family member.

You can read the full paper [here](#).

Following the publication of the paper, we in Care Alliance were contacted by a Family Carer and member of 24/7 Family Carers (Manorhamilton), Annie McGuinness, with her thoughts and reflections on the issues raised in the paper. We are pleased to publish her response here. It is vital to include these reflections and understand more the views of Family Carers themselves if policy makers and service providers are to ensure that the support offered and available to those providing unpaid care at home is relevant and of high quality.

### A Response to Defining Carers Paper- A. McGuinness.

I provide ongoing significant support for my husband in our home due to illness. He suffers from a rare disease called Complex Hereditary Spastic Paraperises (CHSP).

Hereditary Spastic Paraperises is a neurological disorder that affects movement primarily in the legs, but as it progresses affects balance and coordination. My



husband is in a wheelchair. The complex form of HSP means he also suffers from a fairly rapidly progressing dementia.

I have been much exercised by the discussion paper recently published (Oct. 2015) by Care Alliance called 'Defining Carers'. I have always had a vague feeling of disquiet by the term 'carer' and this paper was able to articulate my nagging concern about it.

Whether we like it or not, labels/names do have a great influence on perception. So if I was to say I was an administrator in an office you would make a certain assumption about me and if I was to say I was a secretary in the office you would make a different (possibly less valued) assumption about me, though they could both refer to my occupation.

Why would I probably choose to call myself administrator if I had a choice? I would want people to think my work was valuable to the company or organisation. People wouldn't be able to specifically define my role so would not have a preconceived notion about me and my work. I would feel that being a secretary is "women's work" (therefore less valued) whereas administrator could be equally a man or a woman, thus gaining more respect.

I think the term 'Carer' is outdated, biased and outright paternalistic. Why do we use it? Well - it's the term that has always been used, the term the government uses. Though people who look after others on a full-time basis don't like it, they have no time to think about it much less do anything about it as their work is all consuming.

I would like to suggest another name altogether. One that I think describes a great deal of what we do, one that suggests that we are proactive and one that promotes our inclusion in decisions relating to the person we are supporting.

The name I suggest is 'Primary Advocate'. I see a 'Primary Advocate' as someone who is providing ongoing significant support for a person in the home due to illness or disability or frailty.

Talk to any person who looks after someone with significant needs in their home on a fulltime basis and they will tell you advocating is very high on their agenda. To fully understand the amount of time this takes I will provide a list of just some of the people, I, as a 'Primary Advocate', need to deal with on a regular basis - community nurse, home help providers, occupational therapist, physiotherapist, neurologist, GP, respite providers, chemist, mental health team, mental health nurse, members of my family, day care providers, government departments, wheelchair association, specialist personal care people, i.e. chiropodists, incontinence specialists, HSE departments and workers, home respite carers, home help workers.

You may ask what about the actual personal help in relation to the name Primary Advocate? That is implicit in the name. You can't do one without the other if someone is living in your home on a fulltime basis needing ongoing significant support.

For the substantial number of people who feel they have lost their principal identity with the term 'Carer', it would be possible to use the term 'Mother Primary Advocate' or 'Spousal Primary Advocate' etc., putting the relationship first then the job. Another great advantage of the term 'Primary Advocate' is that there is no gender expectation. Research has shown men have difficulty with the old term and it is my belief that the term 'Primary Advocate' does not need men to "resist traditional discourse surrounding masculinity" in their role.

One of the things I really relate to in this name is that is so positively proactive. To me a 'Primary Advocate' sounds like someone engaging with society and someone with the power to change things rather than someone who is kind, caring and –powerless. A Primary Advocate sounds like someone who leads the role rather than someone who is perceived to passively react to whatever comes their way. I do know that being a Primary Advocate is tiring even exhausting but this is exacerbated by the fact that we so often feel powerless due to our perceived role, the type of engagement afforded us by medical staff, government departments and friends and family.

There needs to be a move from the old name 'Carer'. In the term 'Primary Advocate' there is a great opportunity to develop a positive vision of the work and the people who do the work. There is no predetermined picture in people's minds and there is the freedom to start afresh redefining the job and the people who do it.

Names/labels have a great influence on expectation.

Finally, I would be proud to be identified as a 'Spousal Primary Advocate'

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If you would like to share research & policy work which is relevant to Family Carers, please do not hesitate to contact Research & Policy Officer, Zoe Hughes (zoe@carealliance.ie/ 0868834942).



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