20 Years of Family Carer Research in Ireland



Pre-"Family Caring" Terminology

- Limited State Welfare Struggling to feed family and get work
- Private Domain Family
- High levels of Institutionalisation
- Considered to be Women's Work

(Ref Care Alliance Ireland Discussion Doc 1 Oct 2015 http://bit.ly/1MVb8rc)



Emergence of NGO's? - (post Church led/founded orgs)

1960's – Beginnings of Disability Movement (KARE, NAMHI, Disability Federation of Ireland)

1970's - Independent Living Movement

1981 – National Council for the Aged (Semi-State)

1982 - The Alzheimer Society of Ireland

1987 – The Carers Association

1995 - Care Alliance Ireland



Early 2000's - Research Consortiums -TILDA/NCPOP

Some Figures on Carer Research in Ireland

- c 35 on our database (2008-2015)
- 19 (mostly ongoing) here at conference
- www.lenus.ie Open Access
- <u>€322,000</u> Significant primary research on Resilience of Family Carers of People with Dementia (HRB/UCD/Care Alliance Ireland)



Earliest Research Found (Internationally)

1982:

- Family Care of the Handicapped Elderly: Who Pays? M. Nissel and L. Bonnerjea. (Pp. 100; illustrated; £3.50.) Policy Studies Institute: London. 1982.
- Caring for the Elderly and Handicapped: Community Care Policies and Women's Lives. Equal Opportunities Commission.March 1982.

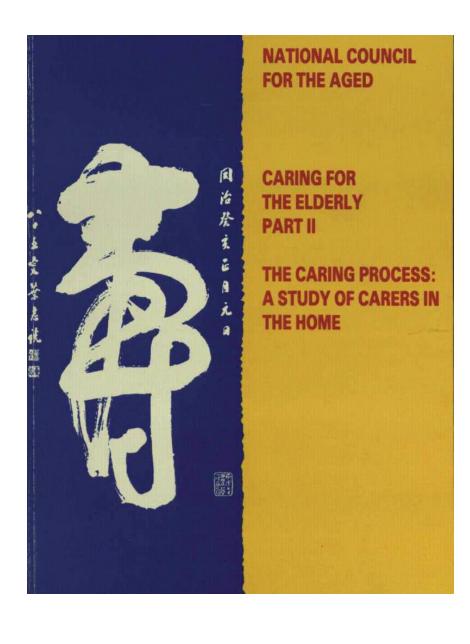
Ireland

Earliest Irish Research

- Who cares about the Carers. Noonan, M. Council for the Status of Women. Dublin. 1983.
- Caring for the Elderly at Home (National Council for the ElderlyO'Connor/Ruddle et al. (1988, 1994)
- O'Neill/Western Health Board (1999)
- Lane/South Eastern Health Board (2000)

(Focus on Caring for Older People – Mostly Descriptive – Some Surveys)





National Council for the Elderly



FACT SHEET NO. 1

CARING FOR THE ELDERLY AT HOME

PREPARED FOR THE NATIONAL COUNCIL FOR THE ELDERLY BY
PROFESSOR JOYCE O'CONNOR AND EILEEN MURPHY
TO ASSIST THOSE WITH A RESPONSIBILITY FOR THE WELFARE OF THE
ELDERLY AND THEIR CARERS
REPRINTED AND UPDATED JANUARY 1994



Review of the Carer's Allowance



Department of Social, Community and Family Affairs October 1998



Characteristics of Early Research

- Health Focussed (but reasonably wide collection of sub themes)
- Few published in journals
- Often once-off research (little follow up evident)
- Focus on Surveys and Scales



More Recent Foci

- Carers Health and Wellbeing CAI (2008, 2010);
 Carers Association (2009); Others
- Economic Cost of Caring -Visually Impaired, Dementia, MS. (Work ongoing re Cost of Disability)
- Condition Specific Dementia, Parkinsons (2010)
- Some Other Significant/Novel Research Caring/Elder Abuse, End of Life Care, Life After Care, Stress/Resilience, Telecare
- More recent focus on 'Lived Experiences'
- Looking at Trends 3 Census's (2002, 2006,2011)

Ireland

Health and Well-being of Family Carers in Ireland:

Results of a survey of recipients of the Carer's Allowance

Liam O'Sullivan

Care Alliance Ireland

Coleraine House, Coleraine Street, Dublin 7

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RESEARCH WORKING PAPER 2008/11

ISBN: 978-1-905485-72-7

November 2008







National Centre for the Protection of Older People

Research Findings Family Carers of Older People: Results of a

National Survey of Stress, Conflict and Coping

Dr. Attracta Lafferty, Prof. Gerard Fealy, Ms Carmel Downes & Prof. Jonathan Drennan

Fact File June 2014



Background

With the growing proportion of people aged 65 years and older worldwide and a desire by older people to remain living at home for as long as possible, there is an increasing reliance on families to provide care to older people living in the community.

For many carers, providing care to a family

Methods

The study design involved a cross-sectional national postal survey of family carers in receipt of a carer's allowance for care provided to a person aged 65 years and older. The survey was conducted using an anonymous self-completion questionnaire measuring stress, conflict and coping. A total of **2,311** carers completed and returned questionnaires yielding

403 NOPOP



Organisations for Family Carers



Parkinson's Association of Ireland

www.carealliance.ie

www.parkinsons.ie

Care Alliance Ireland and The Parkinson's Association of Ireland

The Caring Reality of Family Carers:

An exploration of the health status of Family Carers of people with Parkinson's disease

June 2010

Author: Ann Stokes/Care Alliance Ireland



Several Overview Reports/Lit Reviews

Are they Research in the purest sense? Does that matter?

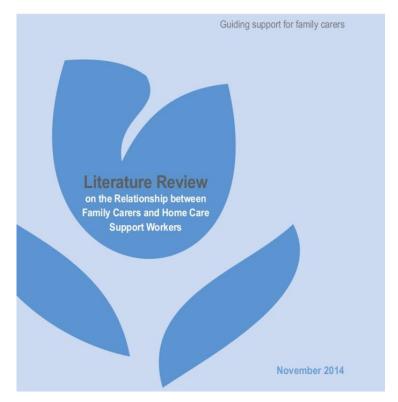
- Comhairle/ CIB (2002)
- Equality Authority (2005)
- Care Alliance (2010/2013/2015)

Literature Reviews -

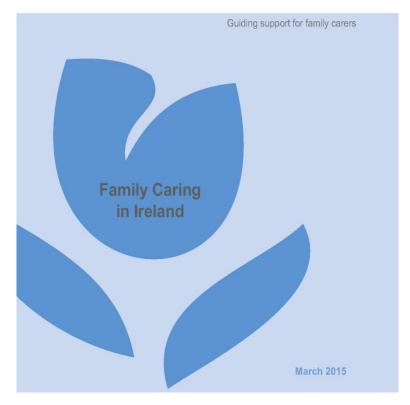
• CAI (2014) - Relationship between Family Carers, Paid Care workers, and Caree.













Current Drivers of the Research

- National Strategies? (NB Dementia)
 - But absent from 2012 National Carers Strategy
 - National Disability strategy, no mention of "family" or "family carer" etc in the whole document.
- Need for more evidence based interventions? (Funders, The right thing to do)
- Lobbying Actions need to be more evidenced/credible?
- EU/Eurocarers Young Adult Carers, Working Carers
- Care Alliance Ireland/Family Carer Research Group

Ireland

Sources of Funding

- State/Semi-State National Council for the Aged/NCAOP (RIP), IRCHSS (RIP), HRB,
- Self Funded Masters, Phd Students
- Philanthropy (eg; Atlantic Philanthropies, Trusts, Genio)
- Other Lottery Funds (via HSE/DOH)



Impact of Research - Cause and Effect?

 1988 Report Made 4 Recommendations - Have they been implemented?

- 1. Co-ordinator of Services for the Elderly
- 2. District Liaison and Information Officers
- 3. Respite and Intermittent Care Facilities
- 4. Information, Training and Counselling Services



Family Carer Research Group

- Information Sharing
- Peer Support
- Builds Momentum
- Encourages Collaboration
- Meet Quarterly in Dublin
- Next Meeting Jan 2016



Dissemination of Research

- Conferences
- Seminars
- eZines
- Media
- Journals
- Database

Who is the audience?



Gaps?

- Disability and Caring (Discussion paper, Care Alliance Ireland- Forthcoming)
- Carer Assessments Carer Experience, Impact
- Benefit Finding/Resilience/Stress/Self Management
- Inclusive research. Not just "including" carers in certain aspects but ground-up inclusive research for and with family carers
- Others??????

To the Future

- Bright
- Quality
- Collaborative



Some Questions to Pose

Research or Rhetoric?

Impact – Measuring



Thank You!

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www.carealliance.ie

https://twitter.com/CareAllianceIrl

https://www.facebook.com/nationalcarersweek

