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 Consortiaums –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

• €322,000 – Significant primary research on Resilience of Family Carers of People with Dementia (HRB/UCD/Care Alliance Ireland)
Earliest Research Found (Internationally)

1982:


Earliest Irish Research


• *Caring for the Elderly at Home* (National Council for the Elderly/O’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 AGED

CARING FOR THE ELDERLY
PART II

THE CARING PROCESS: A STUDY OF CARERS IN THE HOME

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

Care Alliance Ireland
"Guiding support for family carers"
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’
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
Colaraina House, Colaraina Street, Dublin 7
info@careralliance.ie

RESEARCH WORKING PAPER 2008/11
ISBN: 978-1-905485-72-7
November 2008

The Caring Reality of Family Carers:
An exploration of the health status of Family Carers of people with Parkinson’s disease

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

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 member or friend with Parkinson’s disease can be both rewarding and challenging. It is important to consider the emotional, physical, and financial impact that caregiving can have on the carer.

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 the questionnaire, including those who were at risk of burnout.

Fact File June 2014

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
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
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