

Research for Societal Impact -Some experiences of an NGO

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The Lived Experience

- Reflective of a shift away from the hegemony of 'academic or expert knows best'
- ► Public Patient Involvement (PPI) See https://www.carealliance.ie/PPI-Ignite
- Co-creation (See https://personaloutcomescollaboration.org/carers/
- Documenting the process and experience of the lay participants (see https://www.carealliance.ie/Pastprojects

Publications as Currency



- Under- use of Grey Literature
- Open Access Movement (Lenus)- un-stopable.

Some Approaches we have Taken

- Develop our own research/publications (Briefing papers/ Discussion Documents) - Desk based - Positive Feedback - Awards
- Focus on Public Patient Involvement and Collaborative Research/Applied Projects (with Universities, NGO's, State Bodies)
 - Valuing others time
- Groups; Family Carer Research group (Ireland based); Student group via Slack (International for Post Graduate students)
- Care Alliance Ireland Research & Policy online resource https://wakelet.com/@careallianceireland
- Extensive use of Twitter to share others research and build relationships

Some of our Recent Research

- Discussion Paper Series (10 published to date)
 - Less discussed topics
 - Awkward/ sensitive topics
 - Desk-based (literature review & some secondary data analysis Census etc.)
 - Conclude with "Suggested responses" at practice, policy and individual levels
 - ▶ 2018: Difficult Relationships & Family Care; Family Care & Minority Populations; Rural Family Caring
- Briefing Papers/Overview Reports/Response Documents (c15 published to date)
 - Mix of literature review & secondary data analysis
 - ► Topical eg Home Care provision in Ireland, Carer Statistics, Response to Health Service Plans
 - ▶ Use of Freedom of Information requests etc. to access data for example needs assessment practice amongst health and social care practitioners.





Relationships Matter



- Trust
- Time

Co-Production/Co-creation



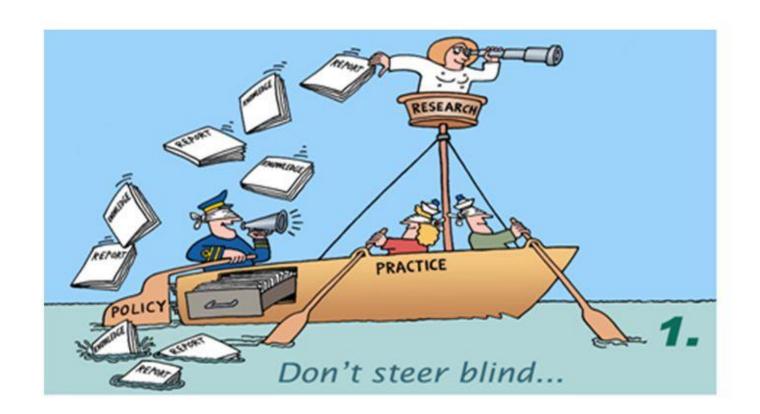
Open Access Research







Research — Policy — Practice







Presenting Research

- Chasing headlines or making an impact?
- Media Like Stats
- (Most) People Like Stats
- Officials more circumspect!
- Combine with personal stories
- No big bang usually incremental changes more likely



Family Carers in Ireland

Who Is a Carer?

unpaid personal help for a friend Someone who provides regular. or family member with a long-term illness, health problem or disability



How Do We Financially Support

What's the Kinship Between Them?

86% of Family Carers are Family Members. Most are caring for an ageing parent or a child with high



Full-time Family Carers? 44.6 hours Over 100,000 receive the Annual Carer Support Grant. 000,000

Is the Role Challenging?



Getting up in the night. (CANCE, 2009)

Are Carers Stressed?



What Is the Health Impact?

Over half reported having a medical problem, the most frequent being back injury, and over half also reported having a significant mental health problem, the most frequent being anxiety disorder. Most carers stated that they had no time for themselves and womied how the person they cared for would cope if they had to



What's the Gender Mix?

Do Children Provide

What Is Public Expenditure on Home Care

c€344m

What Share of the Social Welfare Pie do Family Carers Get?

5.3% Percentage of overall Department of Social Protection Budget spent on Income Supports for Family Carers

Are there More Older Carers? The number of older carers

has increased by over 50%

What Are Sandwich Carers?

What Is the Financial Contribution of Family Carers? €10bn per year eccom

Can Family Carers Combine Working and Caring? A third of Family Carers work full-time (550, 294)

- Access the International Conference on Termity Centry in Televal in 2017. Review of Assertness, Self-Identification, Official Surveys and Income Supports.

 Care Alliance Internat (2010) Analysis of Home Care Supports Funded by the HSE 2008/2016. Allowing for an estimated additional EZIIIn being allocated in 2017.

 Callaghan, M., Kener, E. & Mothol, M. (1906). Short Report HSES Credats, Young cares in the 2014 HSES Study.

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 Certral Statistics Office (2012) Cercus 2011 Police 8 Our Bill of Health, Dublin: Stationary Office.
- Certiral Statistics Office (2010) Quarterly National Household Survey, Quarter 3 2009: Module on Caring.
 Carers Association of Ireland and the Irish College of Psychiatrists (CAUICP) (2009) The Health of the Carer in Ireland Survey
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- Central Statistics Office (2016a) Irish Health Survey 2015.

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 Health Service Executive (2017) Social Care Operational Plan 2017.

 Social Protection, Department of (2017) Ministerial Briefing June 2017.

Can Family Carers Combine Working and Caring? A third of Family Carers work full-time (CSO, 2012) work

Are there More Older Carers?

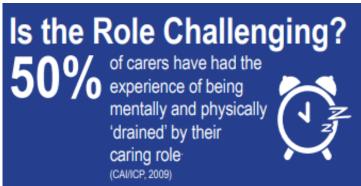
The number of older carers has increased by over

50% since 2006 (CSO,2017)









What Are Sandwich Carers?

Usually caring for young children and parents at the **same time**. The highest concentration of Caring in our population is in the 40–55 age group (CSO, 2012)

AWARD - CONTRIBUTION TO SOCIAL WORK PRACTICE



Challenges

- ► GDPR Data Protection Rights of family carers?
- Replicating Interventions bringing them to 'practice'
- ► Funding health and social care providers focussed on 'services to clients' not 'research about family carers'
- Responding to Third level Undergraduate/Post Graduate enquiries

Innovate ways of Doing Research

- 'Soft' Research Carers Week Survey June 2019 "Family carers use of Online Supports." See http://www.carealliance.ie/publications_researchreportsphp
- ► Freedom of Information Requests re service delivery, assessment approaches,
- Social Media Facebook page 20,000 Followers https://www.facebook.com/nationalcarersweek
 - Using the Facebook page to promote others research
 - Participant recruitment to undertake surveys of family carers
- Pushing Traditional Boundaries Principal Investigator Power/Money -Hypothesis V Story Telling eg Journal article https://bit.ly/2k0dWxZ
- Trust Funds Executive Director connections €400k x 3 Universities/Psychology body

Closing Messages - To All

- Make the case to funders to value Research Functions within organisations
- Collaborate not Control
- ► Share the knowledge accessibly
- Keep at it build the relationships
- Use the data consistently credibility matters

Thank You