

The use of Census and other data on carer prevalence to make progress for family carers

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Presentation to Learning4Carers partners and Board of Directors of Care
Alliance Ireland Tuesday Sept 17th 2019

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There are three kinds of lies: lies, damned lies, and statistics.

- ▶ -a phrase describing the persuasive power of numbers, particularly the use of [statistics](#) to bolster weak [arguments](#). It is also sometimes colloquially used to doubt statistics used to prove an opponent's point.



Outline of Presentation

- ▶ Why defining ‘family carers’ matters
- ▶ Language
- ▶ Some Statistics of Family Caring in Ireland
- ▶ Use of Infographics
- ▶ Use of Statistics to Effect Positive Change
- ▶ Local Carer Identification Research
- ▶ Messages from our Experience

Why defining 'family carers' matters

- ▶ `Everyone seems to be in the 'caring' business
Reclaim the term 'carer'
- ▶ Agreeing a definition and a language
 - ▶ a step towards measuring
- ▶ Culturally acceptable wording
 - ▶ Informal care? - family carer? - Cultural norms - political landscape
- ▶ Messaging with media, politicians, general public
- ▶ Defining - then counting - then using the data

Background to Census and Carers

- ▶ Campaigning by Family Carers Ireland - led to inclusion in 2002 Census

- ▶ Impact (Speculative) -

- ▶ Including the Question gets people thinking
 - ▶ Creates more carer identification - by just asking the question
 - ▶ Credible figure
 - ▶ Used in media work extensively

- ▶ Under EU regulation, Ireland (and other EU countries)

- ▶ is(are) obliged to conduct a Census of Population in 2021.-

- ▶ but -

- ▶ European Statistical Code of Practice Principle 9, “*Non-Excessive Burden on Respondents*”, which also relates to respondent burden and the **need to limit statistical demands** on respondents to what is absolutely necessary.

No.	Variable description	Person or Household
1	Place of usual residence	Person
2	Location of place of work	Person
3	Size of locality	Person
4	Sex	Person
5	Age	Person
6	Legal marital status	Person

Defining - then counting Family Carers Nationally

- ▶ Increased as new census emerged - from 147,000 (2002) to 195,000 (2016) - ageing population, more normalised
- ▶ Figure low internationally - ref Eurocares/IACO - 10% more common figure
- ▶ 2016 - new Survey - Door to Door Survey - not self completed - 10% prevalence figure emerged. (391,000) -
- ▶ so
- ▶ “Be careful of What you Look for!”
- ▶ Ongoing dilemma of which figure to use
 - ▶ Which figure do you nail you coat to?
 - ▶ and
 - ▶ consistency matters.

The wording of a question can significantly affect how it is answered

- ▶ For example Census of Population (Ireland) 2016 -
- ▶ 4.1%
- ▶ Draft Census of Population 2021 -
- ▶ Added = “provision of ‘support’, caring for a neighbour and caring for person with ‘issues related to old age’”
- ▶ 5.7%
- ▶ Source: <https://www.cso.ie/en/census/census2021consultation/>

22 Do you provide regular unpaid personal help for a friend or family member with a long-term illness, health problem or disability?

Include problems which are due to old age
Personal help includes help with basic tasks such as feeding or dressing

1 ☐ Yes
2 ☐ No

If 'Yes', for how many hours per week?
Write in hours

23 Do you provide regular unpaid personal help or support to a family member, neighbour or friend with a long-term illness, health issue, an issue related to old age or disability?

1 ☐ Yes 2 ☐ No

If 'Yes', for how many hours per week?
Write in hours

Care provided on a 24 hour basis, 7 days a week equates to 168 hours

183,000 or 391,000??

Provision of informal care or assistance

- 50 Are you providing care or assistance at least once a week to one or more people suffering from any chronic condition or infirmity due to old age (exclude professional activities)? Yes ☐ No ☐
- If yes: Yes ☐ No ☐
- 51 Are the person or persons concerned family members?
- 52 How many hours a week do you give the care or assistance? Hours *Care provided on a 24 hour basis, 7 days a week equates to 168 hours.

YOU ARE HERE: [HOME](#) / [STATISTICS](#) / IRISH HEALTH SURVEY 2015

Irish Health Survey 2015



Digging deeper - Multiple Data Sources

- ▶ **Kinship:** 86% are family members
- ▶ **Intensity of Care:** Average of 44.6 hours care provided per week
- ▶ **Gender Ratio:** 61% women/39% men
- ▶ Emerging data - stress levels - employment status - cross tabulations from census data - county specific - even townland specific (ref local 'research')

(Sources - Irish Health Survey, 2015, Population Estimates April 2019, Central Statistics Office, 2016, TILDA, 2012)

Use of Statistics - Infographic

- Media Like Stats
- (Most) People Like Stats
- Combine with personal stories

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Tags # CARERS # DISABILITY # NATIONAL CARERS WEEK

'It's physically and mentally exhausting. I can't be off guard': The life of a single parent carer

Next week is National Carers Week, highlighting the experiences of thousands of family carers across Ireland that look their loved ones.

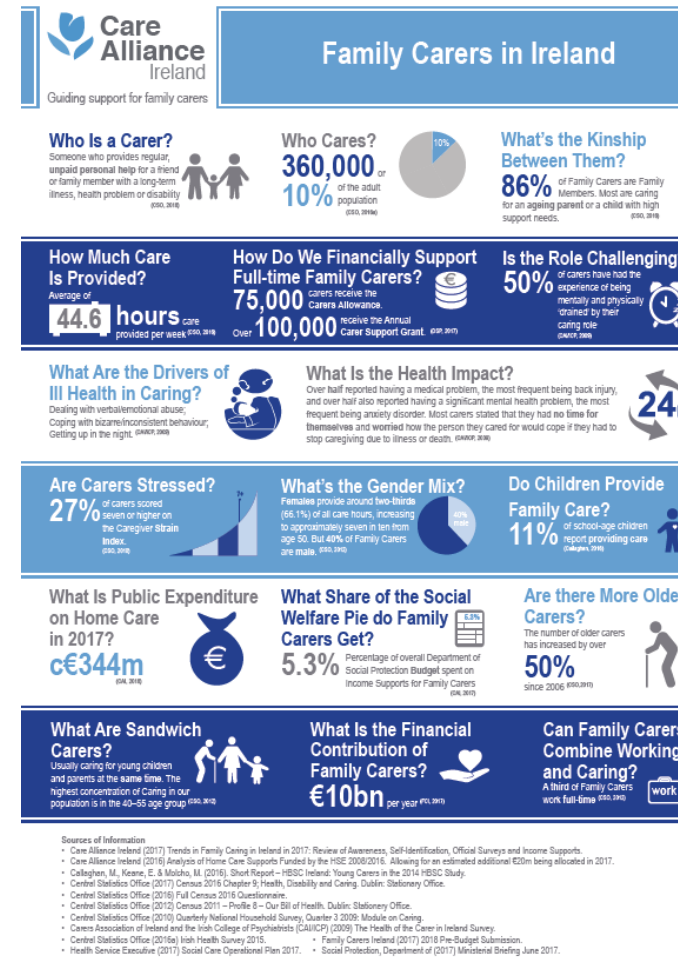
Jun 10th 2018, 9:01 PM 22,861 Views 41 Comments

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"PEOPLE TELL ME all the time that they don't know how I do it, but really, I have no choice. No carer has a choice."

Dubliner Louise O'Keeffe is the sole full-time carer to her four-year-old daughter Ella.

Ella O'Keeffe lives with a rare condition called Neurofibromatosis Microdeletion Syndrome. The condition causes tumours to grow throughout her nervous system, along with



Can Family Carers Combine Working and Caring?

A third of Family Carers work **full-time** (CSO, 2012)



Are there More Older Carers?

The number of older carers has increased by over

50%

since 2006 (CSO, 2017)



What Is the Financial Contribution of Family Carers?

€10bn per year (FCL, 2017)



Are Carers Stressed?

27% of carers scored seven or higher on the Caregiver **Strain Index**.

(CSO, 2010)



Is the Role Challenging?

50% of carers have had the experience of being mentally and physically 'drained' by their caring role

(CAI/ICP, 2009)



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)









Local 'Research/Intervention' on carer Identification.








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**We've received your order**
We're reviewing your advert to make sure that it meets our Advertising Policies. This usually takes less than 15 minutes.

Order summary
 You are targeting **women aged 45-54** who live in **1 location** and have **12 interests**.
Location: Ireland: Stillorgan Dublin
Interests: Alzheimer's disease awareness, Family caregivers, Parkinson's disease awareness, Alzheimer's Society, Caregiver, Alzheimer's Association, Parent, Home care, Dementia Awareness, Home Instead Senior Care, Elderly care or Stroke Awareness
Age: 45-54
Gender: Female
[Hide full summary](#)
 This promotion will run for **2 days**.
 Your total budget for this promotion is **€50.00**.
 **NATIONAL CARERS WEEK's Visa *8026** will be billed.

**National Carers Week**
Sponsored · 
Are you a Family Carer? Make your Mark with Question 22 in this Sunday's Census. If you provide regular unpaid personal care for a family member or friend it's really important that you make your mark on Question 22 and list your hours. For more information visit www.census.ie/carerscount


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Local 'Research/Intervention' on carer Identification.

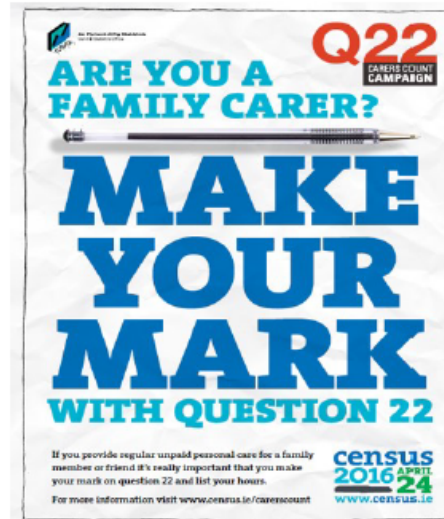
1. Background

Increasing Family Carer self-identification has long been hailed as a legitimate goal and a powerful actor in itself in the quest to improve the lives of Family Carers. We used the opportunity of a National Census in April 2016, which included a question on caring, to see if a local leaflet drop and geographically targeted paid social media posts increased such self-identification.

2. The Research Method/Intervention

- a) Suburban Area: house-to-house leaflet drop (n=269) & parallel use of geographically targeted paid social media posts (GTPSMP); (reach (r) 1,763, expenditure (exp) €4)
- b) Rural Area: Intensive GTPSMP (r 1,989, exp €20)
- c) Mixed Area: Dispersed GTPSMP (r 1,076, exp €19)

Leaflet



Census Question

22 Do you provide regular unpaid personal help for a friend or family member with a long-term illness, health problem or disability?
*Include problems which are due to old age.
Personal help includes help with basic tasks such as feeding or dressing.*

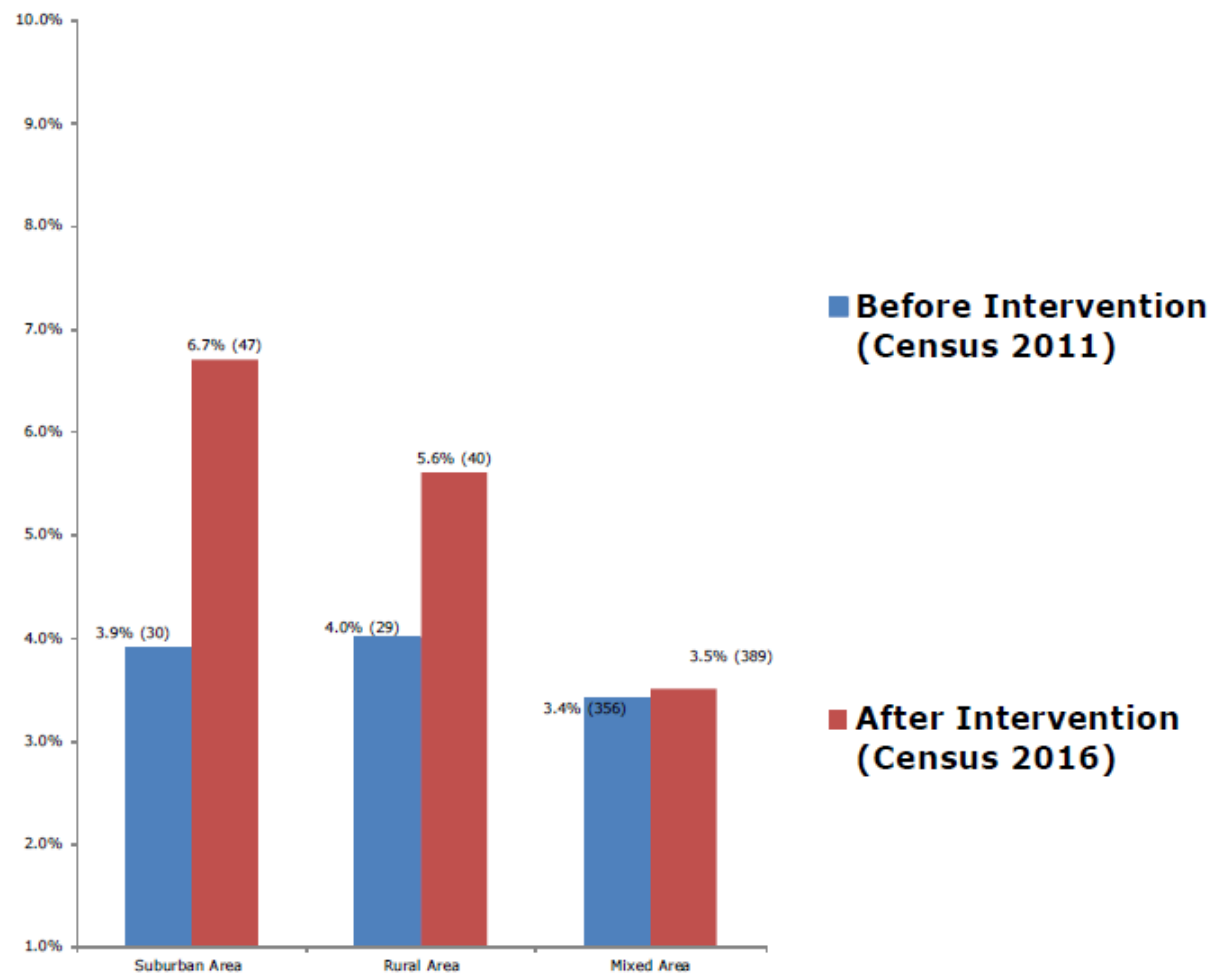
1 ☐ Yes
2 ☐ No

If 'Yes', for how many hours per week?
Write in hours.

Do Leaflet Drops and Targeted Social Media
Ads Increase Carer Identification?

▶ Yes - by 60% !

Self-reported Carer Identification



Closing Messages

- ▶ Build relationships - make the case
- ▶ Be involved in designing the wording - it matters
- ▶ Keep at it
- ▶ Get supporters at all levels - family carers stories, politicians, civil servants
- ▶ Use the data consistently

The background features abstract, overlapping geometric shapes in various shades of blue, ranging from light sky blue to deep navy blue. These shapes are primarily located on the right side of the image, creating a modern, layered effect. The rest of the background is a solid, very light blue.

Thank You