

Trends in Family Caring in Ireland in 2017: Review of Awareness, Self-Identification, Official Surveys and Income Supports



Guiding support for family carers



19 September 2017

Liam O'Sullivan, Executive Director,
Care Alliance Ireland



'Guiding support for family carers'

Outline of Presentation

- A brief summary of the family carer movement
- Explore terms 'awareness' and 'identification'
- Use of 'reliable statistics' and 'personal carer stories' to secure attention.
- Review of Irish statistics and international data
- Reasons for the large discrepancy in family carer numbers reported in different studies?
- Review trends in state income supports since 2000. Drivers of these trends?
- Connection between family carer identification, family carer prevalence statistics and supports for family carers ?
- Can specific awareness campaigns can have population-level impacts?
- Public preferences 'apparent demand' for care.



'Guiding support for family carers'

Limitations of Paper

- Has not looked at important areas such as;
 - home care provision (ref 2016 Care Alliance Ireland paper <http://bit.ly/29eKgYh>)
 - carer support groups
 - educative interventions
 - residential respite care
 - extended familial support
 - online peer support



'Guiding support for family carers'

Brief History of the Family Carers Movement

- Ireland – 1980's – Family Carers Ireland – Care Alliance
- UK – 1963 – Mary Webster – Carers UK
- US – Australia
- Cross-national Alliances – Eurocarers – IACO
- Connections with Disability and Independent Living Movements



'Guiding support for family carers'

Awareness Raising

- In the promotion of a cause in the not-for-profit sector, 'awareness raising' is often seen as key to success.
- Individual self-identification NB important.

*"Achieve greater public **awareness** of and support for Family Carers and care issues Promote greater **self-identification** by Family Carers."*



Source: Family Carers Ireland Strategic Plan 2013–2020

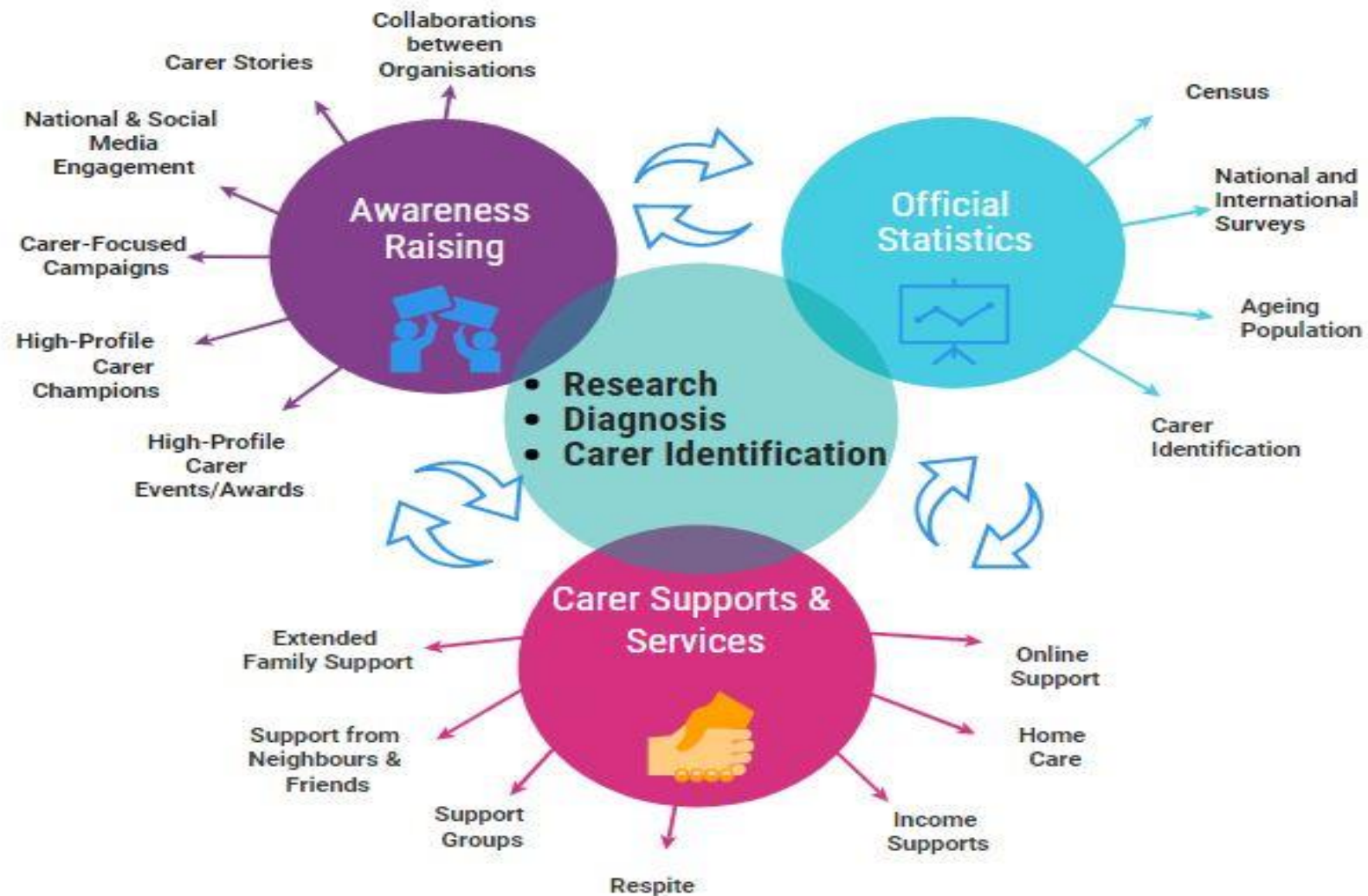
'Guiding support for family carers'

Identity and Labelling

- 'the gateway through which supports are accessed'
- 'a key and almost cathartic event in their process of successful engagement with family carers is when such individuals identify as family carers'
- Clear link between awareness raising at a societal or macro level, individual carer self-identification and access to services.
- A dearth of published material specifically discussing these connections.



'Guiding support for family carers'



Does Having Figures Matter?

- Importance of having reliable quantitative data on family carer numbers
- Raised awareness - via figures, personal stories, recruitment of public champions and the benefit of a relatively free, liberal and uncritical media.
- Policy makers or politicians
 - different responses?



'Guiding support for family carers'

Carer Prevalence and Self-Identification

The Origin of Carer Prevalence Statistics in Ireland

- *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 and dressing.)

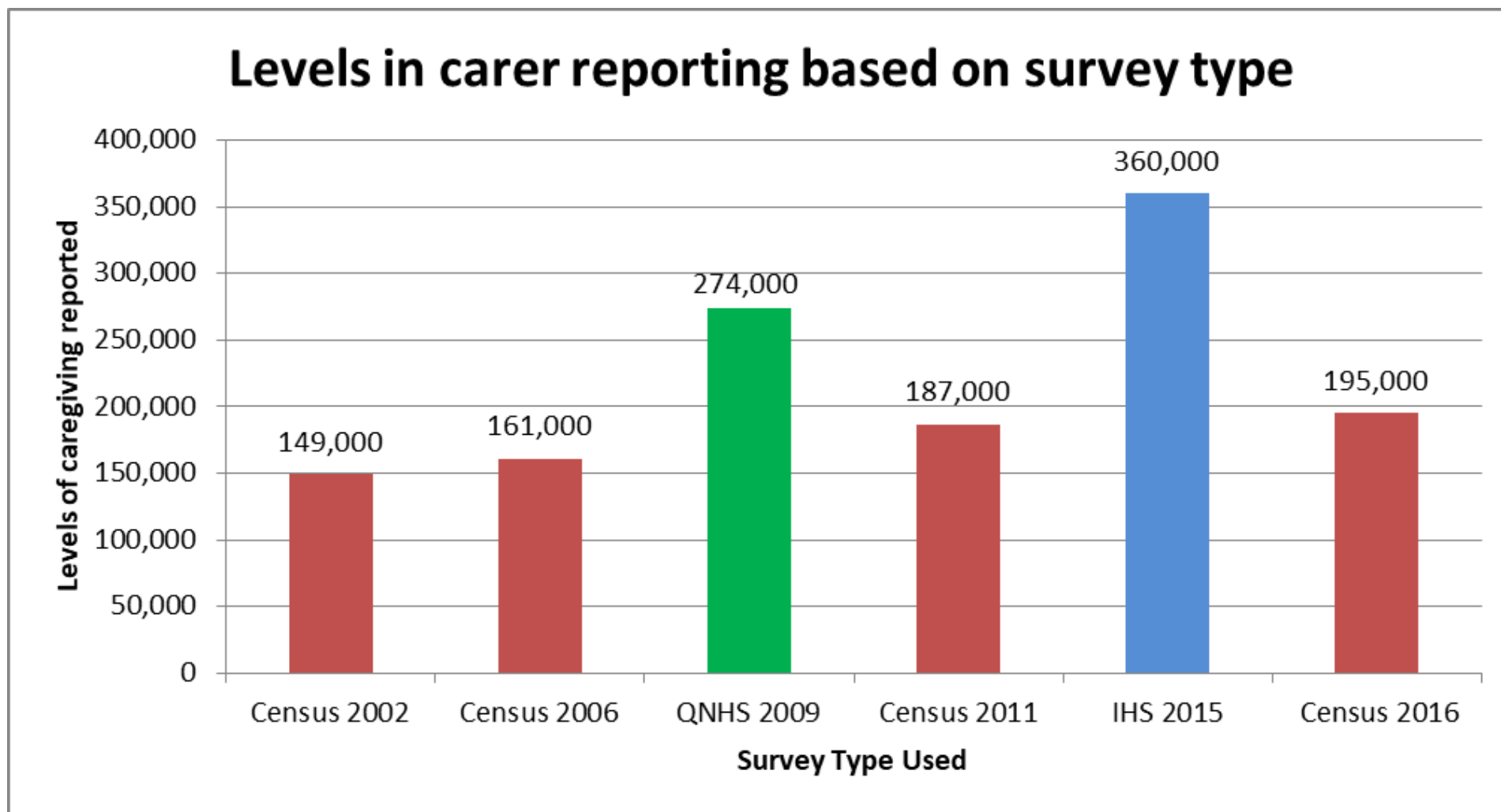
If yes, for how many hours per week? Write in hours.

(Question on caring in 2016 National Census of Population in Ireland)



'Guiding support for family carers'

Trends in Irish Prevalence Data



Why the Differences?

1. The wording of the survey question

'personal care' (4% of population)

'look after or give special help to' (8% of adult pop.)

'providing care or assistance' (10% of adult pop.)

ADL's /IADL's ?

1. Different response rates

Census (>99%) QNHS (?) HIS(40%)

2. How the surveys are completed and by whom?

Enumerator or self completed? Stigma ?

Intensity of caring

- Differences not very large between surveys
 - 40 hours per week (Census)
 - 45 (IHS)
 - ??(QNHS)
- Internationally(?)

International Comparisons

- UK – Census – 10% (NI 12%) 'look after'
- Australia – 11.6% - 'informal assistance' (detailed guidelines for enumerators ref ADL's etc.)
- Europe – large variations – 0.4% to 21.3%
- US – 18.2% - only 34% lived with person

Income Supports–Trends since 2000

- Support that is readily measureable
- Carers Allowance – up 53% in real terms
(wages up c20%)
- Numbers in receipt of one or more
CA/CB/CSG/DCA – 35,000 to >100,000
(Population and Paid Employment up c25%)



'Guiding support for family carers'

Income Supports–Trends since 2000 (cont.)

>65 age group increased by 60%

>85 age group increased by 65%

So why have Census data prevalence changed only modestly from 3.8% (2002) to 4.1% (2016)?

Policy Changes – 2000 to 2016

- Carers Leave Act (2001) – Carers Benefit – 425 to 2,710
- Carer Support Grant (Respite Care Grant) – removal of means test (2005) – rate increased €380 to €1,700
- Half-rate Carers Allowance (2007) – 25,000 recipients
- Relaxed Income eligibility Limits for Carers Allowance
- Domiciliary Care Allowance – 10,570 to 32,000
- (Tax Relief on Home Care – 10k to 75k p.a- low take up 1,880 families)



'Guiding support for family carers'

Share of Income Supports

Year	Total Social Welfare Budget	Carer Income Supports	% of Total Welfare Budget
2000	€ 6.8bn	€ 115m	1.8%
2008	€ 17.8bn	€ 657m	3.7%
2012	€ 20.8bn	€ 772m	3.7%
2017	€ 19.9bn	€ 1,048m	5.3%



'Guiding support for family carers'

A look at the Drivers

- Changes in eligibility criteria
 - Less restrictive means testing (CA)
 - Move towards universal payments (CSG)
 - Removal of one state income support payment(1/2 rate CA)
- Reduced mortality(infant and general)
- Ageing population (>85)
- Increasing diagnosis (Spectrum)
- De-institutionalisation?(ageing and mental health)

But...

- Increased opportunity costs for Family Carers
- <10% of Family Carer contribution



'Guiding support for family carers'

Other Drivers? 'Apparent Demand'

- Higher expectations of what family care means today?
- Increasing societal and state emphasis on health and safety and specifically a more prevalent 'avoidance of risks' attitude
- In the past those with care support needs may have received limited supports and were perhaps less closely supervised but now there may be an element of providing too much 'care' for some individuals at the risk of inhibiting their autonomy.



Does Policy Influence Self-Reported Carer Prevalence?

- Strong evidence that the introduction of the half-rate Carers Allowance in 2007 is associated with a very large increase in those aged 65 and over reported as providing care. 36% increase between 2006 and 2011, v's 14% pop increase. This increase has continued in recent years, albeit at slower rate

Carers 2011 to 2016 (Number) by Regular Unpaid Help, Sex, Age Group and Census Year

	2011	2016
All carers		
Both sexes		
65 - 69 years	9,587	11,037
70 - 74 years	6,483	7,813
75 - 79 years	4,770	5,375
80 - 84 years	2,588	3,310
85 years and over	1,318	1,776

- More acceptable to identify as a Family Carer?
- Impact reducing over time?



'Guiding support for family carers'

Do Specific Campaigns on Carer Awareness Have Population-level Impacts?

- 2011/2016 Censuses, Family Carer NGOs engaged with CSO
- Prevalence went from 3.6%(2006) to 4.1% (2011) to 4.1% (2016) Impact was most significant in first campaign? Or was it the ½ rate CA driving change?



'Guiding support for family carers'



Q22
CARERS COUNT
CAMPAIGN

**ARE YOU A
FAMILY CARER?**



**MAKE
YOUR
MARK
WITH QUESTION 22**

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

census
2016 APRIL
24
www.census.ie



'Guiding support for family carers'

Local Initiative

- Local leaflet drop + geographically targeted paid social media posts
- Increased self-identification by between 40% and 60%, using the 2011 Census data as the baseline.
- This suggests that there is an opportunity for specific awareness campaigns to significantly increase individual care identification at population level.

Source: 'Do leaflet drops and targeted social media ads increase carer identification?' Liam O'Sullivan, Care Alliance Ireland. Poster presentation at 7th International Carers Conference, Adelaide October 2017 (upcoming).



'Guiding support for family carers'

Discussion and Conclusion

- The wording matters!
- Cultural, demographic or welfare model variations are unlikely to be key determinants of self-reported family carer prevalence rates.
- Ireland - large variation in reported prevalence rates.
- More Family Carers – drivers multifaceted
- Disconnect between the census data and the increase in the rate of applications for Carers Allowance and the Domiciliary Care Allowance.



'Guiding support for family carers'

Discussion and Conclusion (2)

- 2000 Low base and low priority
- 2017 - €1bn in current income supports is significant – min wage/equivalent wages?
- Attribution difficult - family carer movement important
- The general goodwill of state officials and politicians?



'Guiding support for family carers'

Some Unanswered Questions

- What proportion of our national resources can we collectively agree to direct towards care supports? Priority?
- Do we respond first to those who shout the loudest?
- or to those who vote in greater numbers?
- Are the types of supports and interventions provided based on the strongest evidence for impact?
- or spread widely to please as many groups as possible?
- How has the way we define, conceptualise and measure unmet needs changed in recent decades?
- What implications, if any, does this have on the apparent 'demand' for services and supports?



'Guiding support for family carers'

Thank You!

info@carealliance.ie

www.carealliance.ie

@CareAllianceIrl



'Guiding support for family carers'