

Past, Present and Future: Family Carer Research and Policy in Ireland

LIAM O'SULLIVAN, EXECUTIVE DIRECTOR, CARE ALLIANCE IRELAND

PRESENTATION TO 'TOWARDS A REFRESHED NATIONAL CARERS STRATEGY
- FROM RESEARCH TO POLICY, UCD, DUBLIN, NOVEMBER 14TH 2019

INFO@CAREALLIANCE.IE 087 207 3265 WWW.CAREALLIANCE.IE

@CAREALLIANCEIRL

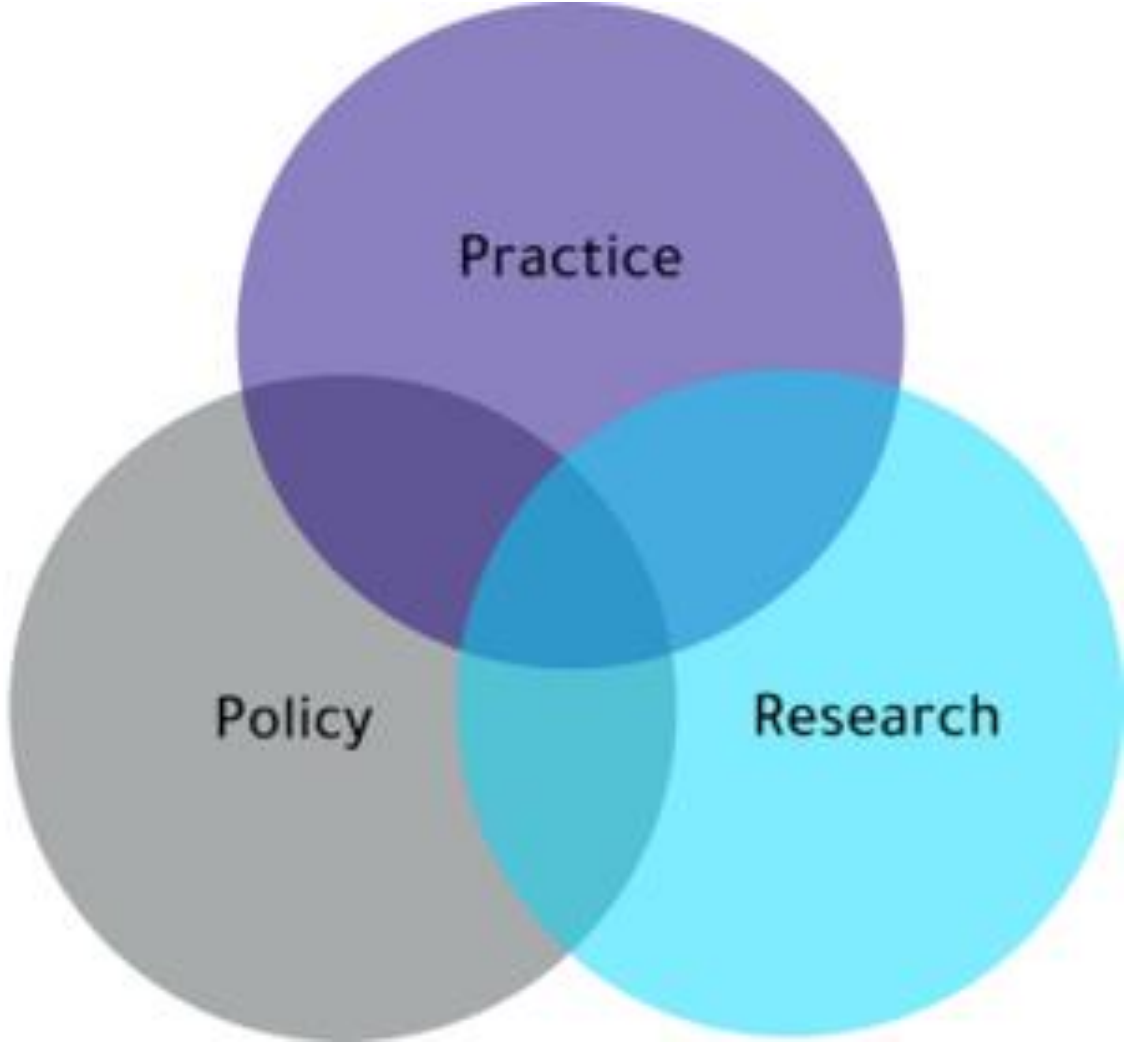
Presentation Outline

- What do we mean by Policy?
- The evolution of family carer policy in Ireland
- Key policy developments – including National Carers Strategy
- Recent policy documents and the effectiveness of strategies?
- Does having figures matter? What do we do with these figures?
- A call for 'Research for Societal Impact' – Impact on Policy?
- Implementation Challenges
- Case Study – Number of family carers
- What would success look like? And from whose perspective?

Policy

- What do we mean by Policy? (an approach to something....)
- Where does policy appear? (written, spoken, media)
- What are the drivers of Family carer Policy? (culture, lobbying, EU, economy, ideology)
- What does it influence? (resource allocation?, income, home care)
- How does it relate to practice, (supports, income, recognition?)

Research-Policy Relations

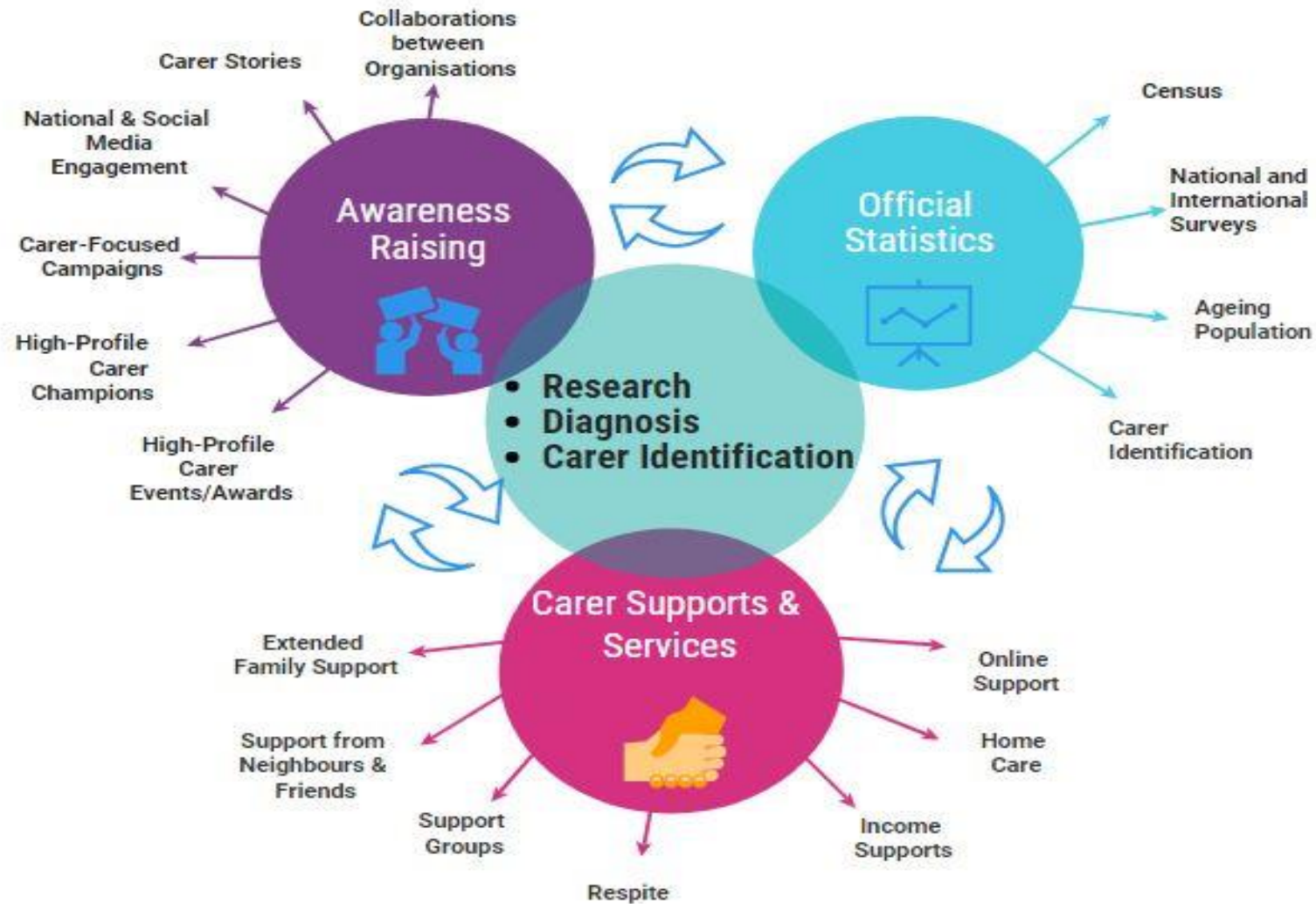


1. Research → Policy

2. Research ← Policy/politics

3. Research ↔ Policy

4. Research ↔ Policy



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

Past - The evolution of family carer policy in Ireland

- 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

Key Policy Developments

- 1970's - Prescribed relatives allowance
- (1980's – Setting up of NGO's/Carers Movement)
- 1990 – Carers Allowance introduced (€57) – 1999 – Respite Care Grant (means tested) – 2005 – RCP to all full time carers
- 2001: Primary Care Strategy – mentioned carers – commitment to 'care in home'.
- 2002: "Supporting Carers" – Comhairle (now Citizens information Board) – summarised research with regards to policy issues
- 2005: Implementing Equality for Carers – Equality Authority – practical recommendations for supporting carers
- 2006: Towards 2016 – commitment for the National Carers Strategy
- 2007: National Development Plan 2007-2013 – need for respite & day care
- 2007: National Action Plan for Social Inclusion 2007-2016 – formal recognition of family carers role in supporting govt policy

We need a National Strategy !

- The Holy Grail?
- Or just another tool to move things forward?



The National Carers Strategy

- c2000 onwards - Discussed – called for by NGO's
- Postponed in 2009 – due financial crisis
- Published in 2012 – 'cost neutral'
- Commitments to research and further policy developments



And so to the Present

Multiple – *sometimes competing* – policies relating to family carers

- National Disability Inclusion Strategy (2017-2021)
- A Vision for Change (2006 – under review)
- National Carers Strategy (2012)
- National Positive Aging Strategy (2013)
- National Dementia Strategy (2014)
- National Youth Strategy (2015-2020)
- Slaintecare (2017)

Family Caring in National Policy

Policy	"Family Carer"	"Family"	"Carer"	"Young Carer"
National Disability Inclusion Strategy (2017-2021)	0	2	1	0
A Vision for Change (2006)	5	95	151	0
National Positive Aging Strategy (2013)	2 (in references)	16	22	0
National Dementia Strategy (2014)	4	17	71	0
National Youth Strategy (2015-2020)	0	21 (7 of these in references or referring to job titles/ TUSLA)	4	3

Effectiveness of Strategies

- One document
- Legislative Basis ?
- Implementation Plan and Budget?
- Used by Opposition
- Benchmarking
- 'It's the policy' – 'it's not the policy'
- Shadow reports
- Scorecards

Research Impact on Policy

- **Hard to quantify** – can we be sure the research is being used? And to what effect.



- Can see certain 'researched issues' being pushed into **party manifestoes** and Members Bills (FF; Labour, Green Party)
- Who is responsible for **advocating research findings** into policy?

Income Support Policy Changes – 2000 to 2019

- 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 – now over 120,000 recipients
- Half-rate Carers Allowance (2007) – c35,000 recipients now
- Relaxed Income eligibility Limits for Carers Allowance (no further changes since (2008)
- Domiciliary Care Allowance – 10,570 to 32,000
- (Tax Relief on Home Care – €10k limit increased to €75k p.a limit- low take up 1,880 families)
- Working and caring – 15hours to 18.5hrs

Case Study

DEASP Expenditure – ‘Carer’ related Share of Income Supports

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

Carer Income Supports, 2000-2019

- A policy/practice that is readily measurable
- Carers Allowance – up 55% in real terms (wages up c25%)
- Numbers in receipt of one or more CA/CB/CSG/DCA – 35,000 to >120,000
- (Population and Paid Employment up c27%)

Source: Trends in Family Caring in Ireland in 2017: Review of Awareness, Self-Identification, Official Surveys and Income Supports. Care Alliance Ireland, (2017) Updated by CAI with own estimates to 2019

Figure 4: Carer's Allowance Recipients 1990 to 2018

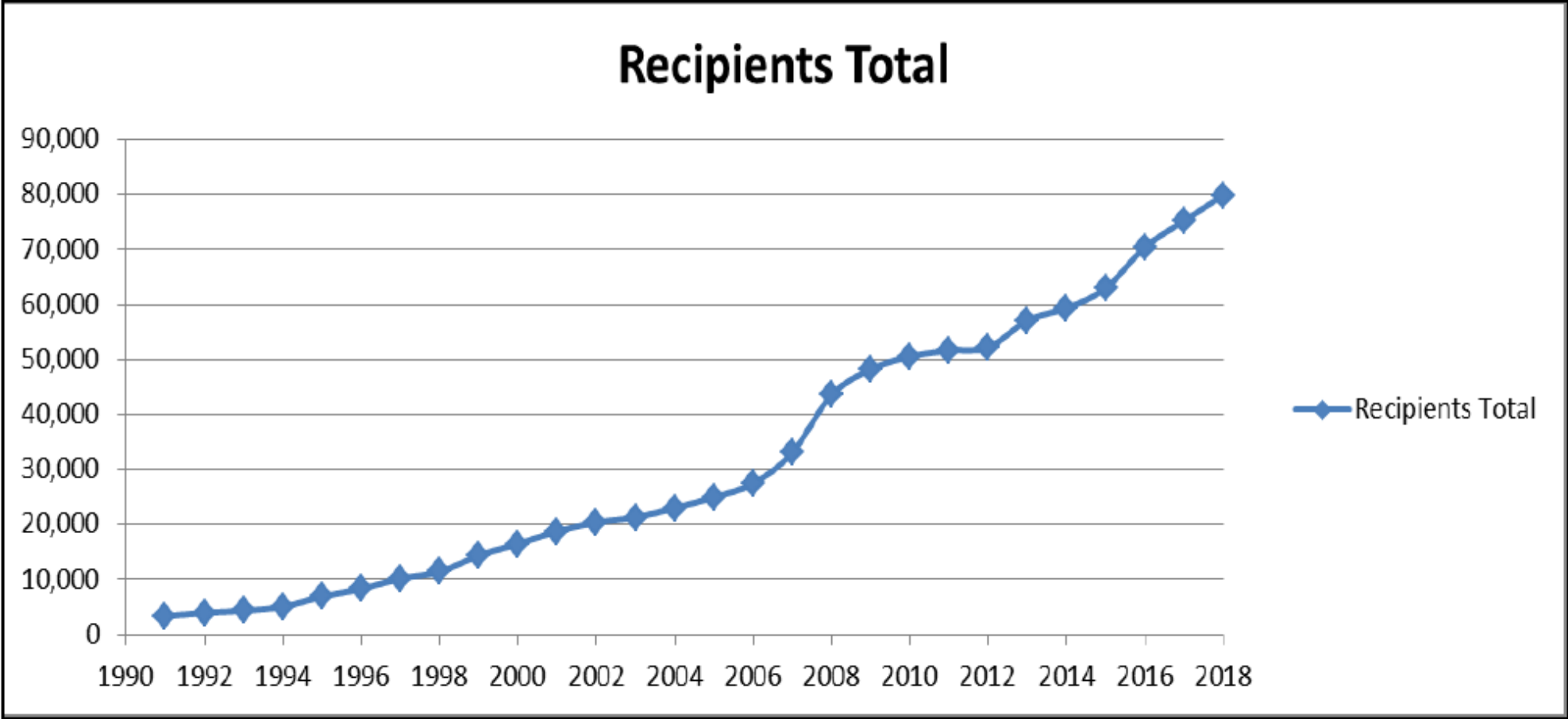
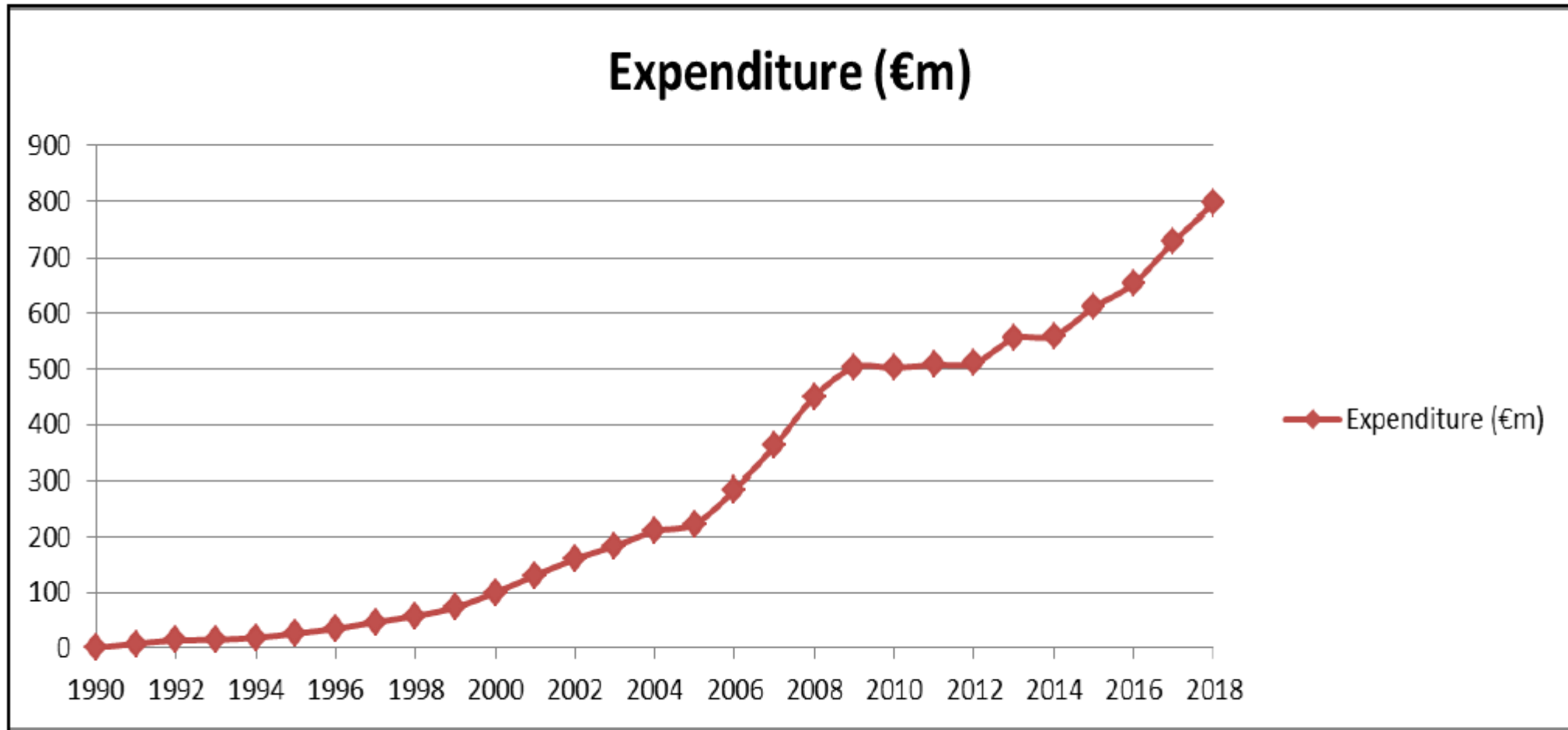


Figure 5: Carer's Allowance Expenditure 1990 to 2018

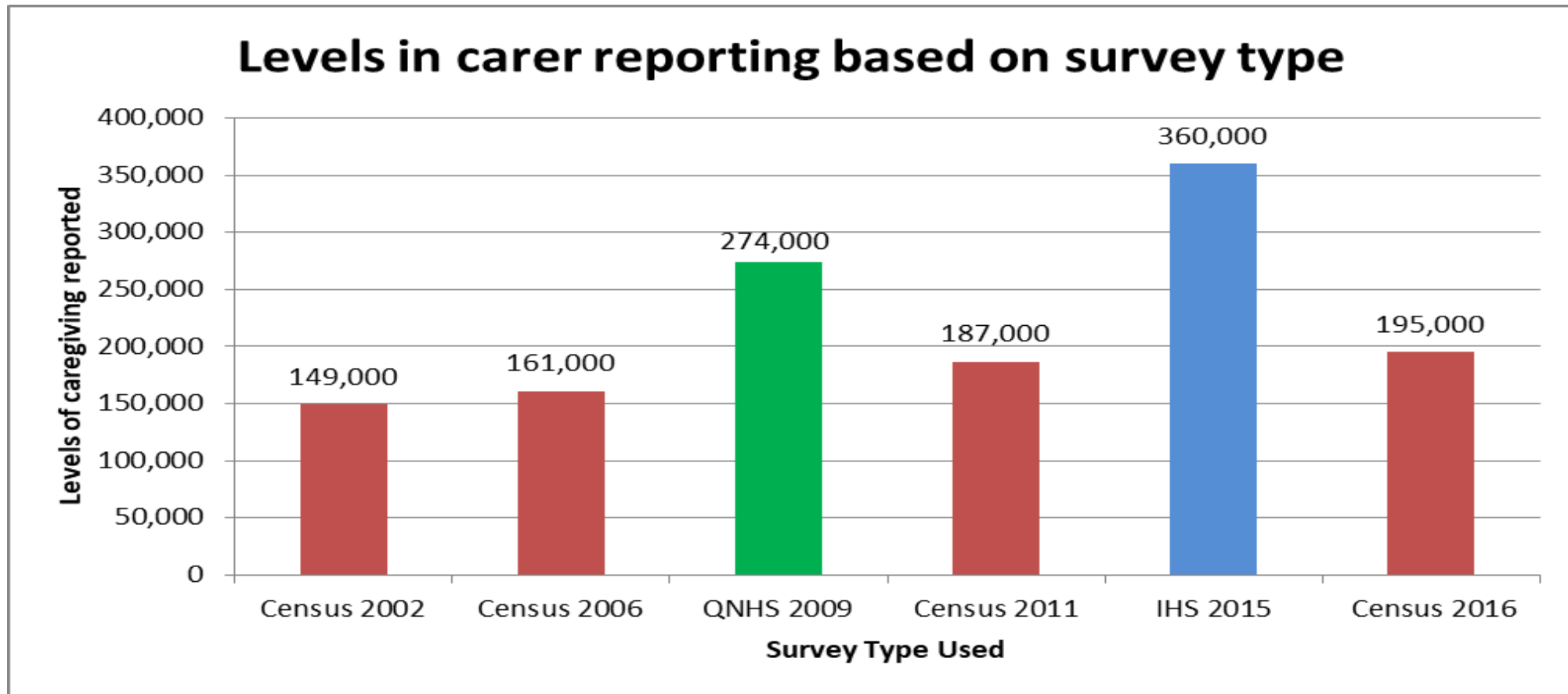


Source: Policy Review of Carer's Allowance 28 August 2019 DEASP.

Is the increase in income supports for Family carers witnessed over the past 20 years for Family Carers directly attributable to....

- Lobbying
- Self Identification
- Advocacy
- Media Coverage
- Economic Development
- An older population
- Diagnosing Practices
- Changes to Eligibility Criteria
- Lower morality rates
- Primary Research?
- All the above?

Trends in Irish Prevalence Data





Guiding support for family carers

**Estimates
for Numbers of
Family Carers
in Ireland**

October 2019

391,260

We have an
Implementation
Deficit Disorder!

Practice Implementation Challenges

- Why does it seem so difficult to demonstrate *and replicate* health and social care interventions that have a 'statistically significant' impact on family carers QOL?
- Is the legitimacy of health and social care organisations to deliver online supports to family carers through Facebook, in search of a reduction in stress & burden, seen to be of less value than the rights of people with dementia to absolute privacy? (See www.carealliance.ie news and events Nov 6th 2019)
- The information paradox

What do Family Carers Want/ Need?

When we ask them:

- **Recognition** - from the State, wider community, family and H & SC professionals
- **Information** – on the condition, what to expect
- **Access to specific supports** (home care, support groups, online)
- **Respite** (in home, out of home, flexible, quality)
- **Income support** (opportunity cost, costs of disability)

A call for 'Research for Societal Impact'

- 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/Past-projects>)
- Under- use of Grey Literature
- Open Access Movement (Lenus, HRB)– un-stoppable.

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 e.g. Journal article <https://bit.ly/2k0dWxZ>

What would success look like? And from whose perspective?

- Publication in 'impactful' peer reviewed journal articles?
- Carer centred research through a PPI approach
- Improved QOL for Family carers?
- Carers Income Higher?
- More carer friendly employment practices?

Future

- We need an updated National Carers Strategy
- Based on recommendations coming from research
- Cost-neutral no longer appropriate
- Dept of Health – considering a Health & Social Care Strategy
- Is this enough? Will this help to merge silo-ed sectors or cause carers issues to slip down the priority list?
- Need to collaborate more
- Winning over both the Hearts and the Minds
- This seminar will be part of this process – publish proceedings

Thank you

info@carealliance.ie

www.carealliance.ie

www.carersweek.ie

www.familycarertraining.ie

@CareAllianceIrl

<https://www.facebook.com/nationalcarersweek>