

NESC@50 - Dublin Castle, 23rd November 2023

A Thriving Ireland: Resilient, Inclusive and Protective

Comments made by Zoe Hughes, Senior Policy & Research Officer

Introduction from session Chair, Dr. Sara Burke

The need to ensure that all voices, are heard and listened to must also extend to family carers. There are over 500,000 family carers in Ireland. Almost three-quarters feel excluded from society in some way.

The terms 'inclusion' and 'protection' mean different things to different people. Sometimes they can be oversimplified and reduced to 'adequate supports and services'.

Zoe, from Care Alliance's point of view, in what ways are carers not included in the current approach, how are they excluded?

And what research, social dialogue, and NESC policy advice would help both the carers and the cared for?

Thank you Sara – to try and condense those answers into a few minutes is very tricky, but I'll do my very best.

As you said just now, there are over half a million family carers in Ireland, many of whom are caring or on call for caring 24 hours a day, 7 days a week.

They are caring for someone who has additional needs due to a disability, mental or physical health condition, or who are ageing. Some 50% of those carers are balancing work and care. 68% of family carers report being in financial distress, 23% are cutting back on essentials because of this.

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Only 43% report good health, vs 85% of the general population. 71% feel left out of society. They have a 38% higher chance of experiencing poor mental health than non-carers.

Those statistics are stark, and point to how excluded family carers are in many areas of society. Excluded from good emotional health, good physical health, good mental health, and good financial health. The solutions posed by many policy makers and health & social care professionals are often not feasible.

Going to your GP to discuss your mental & physical health? You probably need to find someone to take over the care for your loved one for a few hours during the day.

Taking a break or a holiday? 69% of carers report difficulties accessing respite.

Getting a good nights sleep? When you need to wake every 3 hours to ensure your child is breathing correctly, that’s impossible.

This is not to paint an entirely negative view of the experience of caregiving. Many carers find the experience of caring for a loved one to be a privilege, one that helps them become closer to their family, appreciate the time that they may have left with an ageing parent, or simply knowing that they are helping to keep their family members at home, in their community, contributing to society.

Unfortunately, to avail of the supports that do exist for family carers, you often have to concentrate on negatives.

In order to receive one of the Carers payments from the Department of Social Protection, you must show and write down in great detail just how much care is required, and in the case of the means-tested Carers Allowance payment, how financially stretched you are.

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If we were to replace each hour of care provided by families in this country, a conservative calculation of the cost of this to the Exchequer is €20 billion.

That does not include the lost opportunity costs of the skills and economic contribution of those providing care if they were in the formal labour market, using their skills and the qualifications they have, nor the long term health impacts of caring.

What could inclusion look like?

It could look like a radical overhaul of the system of financial supports for family carers. The means tested system we have is not inclusive, it is not respectful, and critically it is not protective. Family carers across the country remain at risk of poverty.

We need to rethink how we talk about carers at a societal level. We hear the words 'hero' and 'saint' and the phrase 'backbone of society' too much from our policy makers. Using these platitudes, without real thought about how to include family carers in the fabric of Irish society, risks assuming that families will always be there, because 'heroes' never shirk their 'duties'.

'Saints' always put others above themselves.

In speaking with my colleagues internationally, it is clear that in some ways, we are the envy of Europe. We actually have a National Carers Strategy, that provides guidance for how carers should be included in policy, services, and supports. However, that Strategy was published in 2012, and is woefully out of date.

There was no implementation plan included, nor was there a budget for different stakeholders in order to progress any of the 42 actions contained within the Strategy at the time of publication. Funding has been provided for various aspects

of supports over time, however the lack of commitment to a Budget at inception was problematic, and needs to be addressed in future iterations.

Government have committed to updating the Strategy within the current Programme for Government. However, what work was being done on this update a number of years ago seems to have stalled.

Putting in place a new National Carers Strategy that cross-references other relevant governmental strategies such as the National Disability Inclusion Strategy, the National Dementia Strategy, Sharing the Vision, and others, is critical. The silo-ing of national policies only leads to confusion in implementation, and so ALL policies must speak to each other and be the responsibility of all government departments in order to facilitate change.

The development of any new Strategy should be conducted in partnership with organisations like my own but more crucially, directly with family carers themselves. Perhaps then carers will experience what it is like to be seen as a 'key care partner', which is a phrase used in the current strategy, that to my mind, simply is not currently the case.

We need more research on innovative solutions to the challenges I have just briefly outlined.

Would a Universal Basic Income or Participation Income for family carers work?

How can we ensure carers are supported without perpetuating the paternalism that so often creeps in when we talk about those needing care and support?

How can we ensure that family carers from other socially excluded groups such as racial and ethnic minorities, the LGBTQ+ community, the travelling community and the disabled community, are not doubly or triply excluded from these conversations?

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How can we use technology to create innovative, evidence based solutions to the lack of supports for family carers across the country? Our own Family Carer Support Group, developed during covid, now supports over 7000 family carers across the country, many of whom never accessed other types of support for time or access reasons.

Finally, we need to ensure that family carers themselves are the drivers of any research, included at all levels, and part of any and all policy decisions that will impact them.

Inclusion must be meaningful and impactful, or we might as well not do it.

Thank you.

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