1. Introduction

This is the tenth paper in the Care Alliance Ireland Discussion Paper Series. The papers in this series are not intended to present a definitive account of a particular topic, but to introduce a less-discussed, sensitive or perhaps controversial topic for discussion within the wider community of practitioners, policy-makers, researchers and other interested parties. This often takes the form of a literature review (where possible), along with a discussion of views which have been shared with the Care Alliance team, either by our member organisations or by family carers themselves. In some cases the topic will be one which has been raised and shared in the media or social spaces online.

Traditionally, the majority of the population of Ireland have lived in rural areas outside of large towns and cities. However, this has changed over time, and in 2016 just over 37% of the population lived in an ‘aggregate rural area’ – which is an area of less than 1,500 inhabitants. The percentage of family carers living in these same rural aggregate areas is higher, at almost 42%.

In 2016 just over 37% of the population lived in an ‘aggregate rural area’ – which is an area of less than 1,500 inhabitants. The percentage of family carers living in these same rural aggregate areas is higher, at almost 42%.

Work published by Dr. Ronan Foley in 2008 found that rural counties in the west of Ireland such as Galway, Mayo and Roscommon had a higher instance ('Location Quotient' – LQ) of family carers, per head of population, than the national average. Conversely, the lowest concentration of family carers occurred in urban centres such as Galway city, Kildare and certain areas of Dublin. This of course does not mean that there are more family carers in these rural areas, merely that the relative incidence is higher than that in certain urban centres. It is not clear why this is so. Using the same calculation method with 2016 Census data, we can see similar results for predominately rural areas, with patterns remaining constant over the ten years from 2006 to 2016.

---

Many thanks to Dr. Ronan Foley, Maynooth University, for recalculating this using 2016 Census data upon request.


The National Carers Strategy (2012) identifies ‘rural carers’ as a ‘sub-group’ of family carers (along with male carers, young carers and older carers) whose needs must be specifically addressed. Specific challenges face family carers living in rural or sparsely inhabited areas. While there are family carer support organisations across the country, operating and providing supports nationwide, not all of the challenges facing family carers can be addressed by support organisations alone.

Figure 1 shows that counties with predominately rural areas have the highest location quotient (coloured red and orange), and a person living in those areas is therefore more likely to be a family carer than those in predominately urban areas (coloured blue and green). This is borne out in international research which has similarly indicated that there is likely to be a higher proportion (for the population level) of older people in particular providing care in rural areas.

The National Carers Strategy (2012) identifies ‘rural carers’ as a ‘sub-group’ of family carers (along with male carers, young carers and older carers) whose needs must be specifically addressed.

This paper outlines some of these key issues, investigates some of the international research and responses to rural family carer challenges, and sets out some additional responses which are necessary in an Irish context.

---

4 Many thanks to Dr. Ronan Foley, Maynooth University, for recalculating this using 2016 Census data upon request.
2. Characteristics of Rural Family Carers

Understanding and classifying ‘rural family carers’ is, as can be imagined, quite difficult. Defining who is and is not a family carer is the subject of much research. When you add the necessity to define and delineate what constitutes ‘rural’, these challenges are increased. In general ‘rural’ can be taken to mean a household which is located in a relatively low-population area – for example, an area with less than 1,500 people, as defined by the Central Statistics Office for the purposes of the Census.

Much of the research to date regarding the challenges and characteristics of rural family carers has been conducted in jurisdictions other than Ireland – for example, in countries which have significant rural populations that are particularly isolated due to the geographical extent of those countries. This includes the United States, Canada and Australia, where journeys to access specialist services can take many hours.

When looking at how rural family carers differ from their urban counterparts, there appear to be some differences in how they typically approach some of the challenges of their role. For example, research in the US in 2017 suggests that carers from rural areas approach their role differently – appearing to be more focussed on ‘taking life as it came’, in contrast with family carers from urban areas, who more frequently expressed frustration at the loss of independence caused by their role. Likewise, rural carers seemed to put more emphasis on the ‘we’ of caring – being part of a team of family and friends involved in providing care, unlike urban carers who more frequently used the word ‘I’, and who framed their experiences with regard to personal experience and loss. This may be due to a higher likelihood of those in rural areas living within extended family circles, or at least in close proximity to other members of their family. This may contrast with the typically more independent way of life in urban areas, in particular in larger urban centres such as cities.

Rural carers seemed to put more emphasis on the ‘we’ of caring – being part of a team of family and friends involved in providing care, unlike urban carers who more frequently used the word ‘I’

---

A recent study in Northern Ireland\textsuperscript{10} showed that caregivers in remote areas with limited access to shops and services were also at a significantly increased risk of mental health difficulties, as evidenced by prescription rates for antidepressants. This study also showed that the effects of this remoteness seemed to be stronger for those family carers providing more intensive levels of care (>19 hours per week).

The links which rural communities in general cultivate and the close-knit nature of those communities also play a part in the experience of rural family carers. For example, many of those who work in rural communities in the health and social care sector such as nursing, care work, etc., have a ‘contextual knowledge’ of patients, as they live, work, shop and socialise in the same communities, often over periods of many years with little change\textsuperscript{11}. This can mean the fostering of local links leading to positive outcomes for patients and their family carers.

---

\textsuperscript{10} Doebler et al., *Ibid*

3. Access to Services (in Particular Health Services)

Given the geographical isolation of many carers in rural locations, access to services has always been, and likely will continue to be, a critical issue. For some, over an hour’s drive to get to a hospital for outpatient procedures is the norm, and car ownership is a necessity for many in isolated areas due to inadequate public transport links. A local GP or pharmacy may be upwards of 30 minutes’ drive away. This can be experienced by rural dwellers as unsatisfactory. It is clear that the geographical isolation of a percentage of our population, generally those living on the fringes of the western sea-board, does make it more time consuming to access GP and pharmacy services (see Figures 2 and 3 below). This can have particular impact on family carers, as they are more likely to require these services on a frequent basis. This paper has not assessed the extent to which regular GP home visits and prescription delivery services are available to those living in particularly isolated areas. The recent introduction of 140 rapid response teams, along with the development of Community Intervention Teams across the country, attempts to address some of the challenges of accessing emergency health care in rural areas. However, there is a level of anxiety about timely access to emergency health care which some organisations say is contributing to further rural depopulation. In addition, 24/7 home/respite care is not available in all parts of the country, which has been highlighted by some of our member organisations as problematic.

The AIRO mapping tools allow investigation of average journey times to existing services. It can be seen from Figure 2 that a drive of 90+ minutes is required to get to a hospital in significant areas of the country, with 30+ minutes required to get to a pharmacy or GP surgery (Figures 3 and 4).

---

12 These times have been collated from Census 2016 – see http://airomaps.nuim.ie/id/AccessMap/
13 See https://www.icrr.ie/
14 See https://www.hse.ie/eng/services/list/3/cits/
Figure 2: Drive times to a full (24-hour) and partial emergency hospital, Ireland (AIRO and Central Statistics Office: Source: Census 2016)

Figure 3: Drive times to a pharmacy, Ireland (AIRO and CSO: Source: Census 2016)
This is significant because family carers are likely to need these services not only for the person they care for but also for themselves. Such significant travel times for some residents of rural Ireland, coupled with lack of access to home and respite care supports, may lead family carers to neglect their own health and wellbeing. If replacement care cannot be found to allow them to complete a trip to their GP, which could take up to two hours including travel time, they may not be able to do so. While there have been some advances in the development of telehealth services, they remain below optimum levels, with difficulties in resourcing evident, as noted in relation to the National Carers Strategy\textsuperscript{16}. This means that telehealth as a support to family carers and those they care for is not always a viable option.

The most recent interim report of the National Dementia Strategy has acknowledged that people with dementia and their families are ‘still dealing with inadequate services and supports’\(^\text{17}\). Following on from this, the Alzheimer Society of Ireland has produced a series of county-by-county factsheets outlining the investment necessary to bring each county up to minimum standards\(^\text{18}\). These factsheets make clear that a number of the counties with the highest investment requirements are counties with the highest levels of rural occupation. Discounting Dublin (which requires a significant development investment of €2.5m, with 247 additional dementia-specific supports and services needed due to its large population), counties such as Cork (€522k, 151 additional services needed), Donegal (€154k, 56 additional services needed) and Galway (€232k, 56 additional services needed) are in need of significant development and investment.

A study in the US which compared access to supports for palliative caregivers in rural and urban areas found that, perhaps unsurprisingly, rural caregivers had greater unmet support needs in the domain of tangible support than those living in urban areas\(^\text{19}\). However, no significant differences were observed in that study regarding the emotional or informational support needs of carers across rural or urban lines. It is possible that this is a matter of perception – rural family carers are likely to have adjusted expectations regarding services and supports in general, in comparison to their urban counterparts, and so those self-reporting their satisfaction with their existing situation may have done so unconsciously.

Rural family carers are likely to have adjusted expectations regarding services and supports in general, in comparison to their urban counterparts, and so those self-reporting their satisfaction with their existing situation may have done so unconsciously.

An unfortunate effect of budget prioritisation and the focus on ‘value for money’ within the Irish health service has meant that the priority of funding is often to provide the greatest support to the greatest number of individual family carers –


\(^{18}\) This work is the result of a mapping exercise undertaken by ASI along with the HSE. All of these county-by-county factsheets can be seen on their website: http://www.alzheimer.ie/Get-Involved/Campaigning/Current-Advocacy-Campaigns/Pre-Budget-Submission-2019/Dementia-In-Your-Area.aspx

with the natural result that services are clustered in areas with higher population densities. However, this means that many family carers have to travel some distance to access a family carer support group or attend an event. A regular criticism of support organisations is that support services and events are held in Dublin or other cities and large towns, making it difficult for a large number of family carers to access them, in particular as replacement care cover may need to be sourced to allow a carer to attend\textsuperscript{20}. It is much more likely that such cover – in particular if provided within the family carer’s circle of informal support such as friends and other family members – could be provided in the evening or at weekends, when others who are in paid employment may be freer to spend time with the person requiring care.

The availability of respite care has been a contentious issue for many years, in particular since the recent economic downturn in 2008. It is common knowledge that availability of respite care (whether that be in the form of overnight stays, day centre places and services such as home help and home care) was reduced as part of cost-saving measures during that period, with consistent reports showing that family carers are finding it increasingly difficult to access respite care for their loved ones. For example, data from HSE annual reports suggests there has been a reduction of approximately 35\% in overnight respite care between 2013 and 2017, from 243,000 overnights to 158,000\textsuperscript{21}. Ireland’s economy has begun to recover significantly, yet the latest figures show that the provision of respite care remains well below what is required, and there is evidence that provision has dropped in the first half of 2018 in comparison to the same period in 2017\textsuperscript{22}. It appears that rural areas are among the worst affected by this continuing fall in provision.

\textbf{Data from HSE annual reports suggests there has been a reduction of approximately 35\% in overnight respite care between 2013 and 2017, from 243,000 overnights to 158,000}

\textsuperscript{20} An example of this is a recent series of workshops for family carers of people with dementia which Care Alliance Ireland organised and facilitated alongside University College Dublin. Funding was applied for and received to pay for replacement care costs to enable family carers to come to the workshops.


\textsuperscript{22} Family Carers Ireland, ‘Family Carers Ireland Express Concern as Emerging Figures Show Provision of Respite Care Is on a Steady Decrease’, August 15, 2018, https://familycarers.ie/dramatic-drop-in-respite-care-sessions-since-2017-is-unacceptable/
There are widespread fears regarding access to GPs in rural Ireland, with many areas struggling to find adequate numbers of doctors willing to locate practices in rural areas. Multiple state programmes have been mooted to address this problem; however, in 2017, the chairperson of the Irish Medical Organisation GP Committee warned that many rural areas were experiencing severe GP shortages, with the threat of further depletion as retiring professionals were not being replaced at any acceptable rate\(^\text{23}\). The ongoing development and negotiation of the renewed GP Contract will no doubt affect these issues into the future.

A common issue affecting many family carers across rural Ireland is the increased push towards online information and application processes by government departments and state organisations such as the Department of Employment Affairs and Social Protection and the Health Service Executive. We understand the focus on cost-saving in relation to moving access to services online; however, in our experience of talking to family carers, it is not always appropriate to do so, as it may prevent some carers from accessing services.

As discussed in our previous paper on the subject\(^\text{24}\), while information for carers and those they care for is increasingly being pushed online, the infrastructure allowing rural populations to access information online is not necessarily present. While Ireland exceeds key EU targets for access to basic broadband, there are spots where there is no such access, and access to fast broadband is lower. We acknowledge that the absolute numbers affected by these issues is small; however, those affected are most likely to be living in rural areas and the impact on life in these areas should not be understated because of low numbers\(^\text{25}\). Figures\(^\text{26}\) from 2017 estimate that 89% of households have access to the internet. However, although 95% of those in the 16–25 age group had used the internet within the three months prior to the study, only 48% of individuals in the 60–74 years age category had done so, and 46% of individuals in the 60–74 years age group have never used the internet. Given that over 23% of family carers in Ireland are aged 60+, this is worrying.

\(^{23}\) Claire McCormack, ‘Rural Ireland Losing Another Lifeline as up to 50pc of GPs to Retire’, \textit{Irish Independent}, July 11, 2017.

\(^{24}\) Care Alliance Ireland, ‘Online Supports for Family Carers – Options & Experiences’ (Care Alliance Ireland, 2016).

\(^{25}\) Care Alliance Ireland: IBID.

4. Transport

The lack of transport links, in particular accessible transport links in rural areas, has long been a topic of concern for disability and family carer advocates. The Rural Transport Scheme, under the direction of the National Transport Authority, is working towards creating better transport links for rural populations; however, latest figures note that just 62% of service journeys taken under the scheme are partially or fully accessible to those with limited mobility\textsuperscript{27}.

Furthermore, car ownership is a necessity for many in rural areas, and is a significant cost. If no accessible transport is available, then access to private transport is vital – in particular for those caring for people with significant health difficulties which necessitate regular trips to GPs and/or hospitals. As seen in the illustrations in the previous section, in significant areas of the country considerable travel distances are involved in accessing such facilities.

The lack of an alternative to the Motorised Transport Grant (closed to new applicants since 2013) is disappointing. This particularly affects rural and isolated family carers who did not apply for the scheme before it was closed five years ago. Many of our member groups support individual family carers and family groups who are isolated because of the combined lack of a replacement scheme and of accessible public transport. A new scheme has been promised since 2013, but little information is available about what such a replacement scheme would contain. At time of writing (November 2018), the Minister responsible for the scheme has indicated a preferred timeline for a new Bill in the coming parliamentary session; however, a memo to that effect was withdrawn from Cabinet briefings and it is now not known when the Bill will be retabled\textsuperscript{28}.

\textsuperscript{27} See https://www.nationaltransport.ie/public-transport-services/rural-transport-programme/

5. Social Isolation

Research has clearly established the impact of isolation on family carers regardless of geographic location\(^{29}\). Isolation can be compounded for rural carers, although some research suggests that the experience of isolation may not be as significant for rural carers as might be assumed\(^{30}\).

As discussed earlier, family carers in some rural areas experience significant travel times to access health services, and it is reasonable to assume that these carers are also likely to face similar travel times to access other services, such as face-to-face social supports in the form of a family carer support group or other social activities\(^{31}\). In previous work undertaken by Care Alliance, anecdotal feedback from family carers indicates that they feel isolated due to their caring role\(^{32}\). While it is not possible to say for certain that rural carers are more socially isolated, it is not an unreasonable assumption. It does appear that rural family carers experience negative outcomes at least in part due to their physical location\(^{33}\).

There are significant barriers to carer social participation, which include issues of travel, lack of appropriate supports in the area (particularly relevant for family carers from minority populations), lack of time due to the intensity of their caring responsibilities and lack of respite options\(^{34}\). Again, these issues are not exclusive to family carers in rural areas, but can be exacerbated by the rural and possibly isolated nature of their location. Often, attendance and involvement with local carer support groups is mooted as an appropriate outlet to combat family carer social isolation, and to foster and create a local support system for family carers. However, some family carers and those they care for report feeling uncomfortable sharing personal troubles and private information at local support groups due to the small size of the population in such areas\(^{35}\). This is of course an issue that all family

---


\(^{31}\) Winterton and Warburton, ‘Models of Care for Socially Isolated Older Rural Carers: Barriers and implications’.

\(^{32}\) A survey was undertaken of over 800 family carers via the National Carers Week Facebook page in 2015. Previous papers in this series have highlighted some of the responses, addressing loneliness and isolation, in particular when it comes to accessing supports online (see Discussion Paper 3 – ‘Online Support for Family Carers: Options & Experiences’ at http://www.carealliance.ie/discussionpapers).


\(^{35}\) Hussain, Wark, and Ryan, ‘Caregiving, Employment and Social Isolation: Challenges for Rural Carers in Australia’ Ibid.
Some family carers and those they care for report feeling uncomfortable sharing personal troubles and private information at local support groups due to the small size of the population in such areas.

---

36 Care Alliance Ireland, “We Need to Talk About It” – Stigma and Family Care’, 2016.
Focus on Rural Family Carers at National Policy Level

Although, as previously outlined, rural family carers are identified within the current National Carers Strategy as a particular ‘sub-group’ of family carers needing particular attention, it is not clear that enough attention has been paid to them overall. The action in the Strategy covers young carers and older carers as well as rural family carers, and most of the reported responses from the various government departments over the lifetime of the Strategy do not specifically address rural carers, focussing instead on the other sub-groups, in particular young carers. Subsuming sub-groups of carers and minority carer groups into one or two actions within such a strategy makes it unlikely that concrete actions will be taken to address their specific needs. We would recommend that an updated National Carers Strategy contain a specific action addressing the particular needs of rural family carers.

Ensure a Range of Appropriate Information Dissemination Channels

Access to fast, reliable broadband in rural areas is not adequate for the situation where state services and family carer support organisations continue to focus closely on web-based services as a means of information dissemination.
Older carers are particularly at risk of further isolation as they are less likely to have the ability or the technology to access the internet to obtain support. We welcome the recent creation of internet points in post offices with the aim of alleviating this type of isolation and allowing older and rural carers with inadequate internet connectivity to seek information and apply for state schemes with assistance from staff. However, it is vital that local health centres, GP surgeries, community libraries, etc. continue to make information available in more traditional non-technical settings.

Internet Use

The other side of the argument for the internet as a means of communication and information dissemination is that it is increasingly useful for support organisations in reaching isolated rural family carers. This is particularly so for younger age groups who are familiar with technology and likely to have access to the internet via smartphones and tablet computers. While visiting every town in Ireland to provide information about new schemes or training courses would be cost-prohibitive, the creation of ‘online versions’ of such events and workshops is increasing. Often this can be done with an internet connection and a smartphone or tablet, and the event can be broadcast live via Facebook, Twitter or any number of online platforms. This allows isolated carers to watch and participate if they are unable to leave the house to attend, or to watch at a later time.

A good example is a recent webinar which Care Alliance Ireland facilitated in conjunction with UCD for a Health Research Board-funded project for family carers of people with dementia. In that case, we struggled to find attendees who were able to leave their caring duties for sufficient time, on the designated day, to attend face-to-face workshops in the local area. We were able to create
an online space that allowed far more carers to take part and others to watch later at a convenient time. For example, only two family carers could attend a face-to-face workshop in Limerick, and only one in Cavan. However, for a much lower level of investment, we reached 25 attendees in the online webinar. We acknowledge however that face-to-face support has unique impacts that may not be replicated in online interventions.

Studies have shown that supported Information and Communications Technology (ICT) usage with older and rural carers can increase quality of life and reduce social isolation. Other studies indicate that access to supports online leads to a decrease in depressive symptoms and social isolation for rural family carers. This is promising and needs to be examined in an Irish context more thoroughly.

Reintroduction of the Motorised Transport Grant and Mobility Allowance Scheme

Following the onset of the economic downturn in 2008 significant and distressing reductions were made to certain schemes and allowances on which family carers and those they care for depended. While many of these have been reintroduced in one form or another (not necessarily at the same rates or in the same guise), the Motorised Transport Grant and the Mobility Allowance Scheme have remained closed to new entrants since 2013. For several years it has been stated that a replacement scheme is ‘being devised’; however, this has yet to come to fruition. We recommend that a replacement scheme be established without delay to meet the needs of the sub-group ‘rural carers’, identified by the National Carers Strategy as having unique needs.

38 Madeline Blusi, Kenneth Asplund, and Jong. ‘Older Family Carers in Rural Areas: Experiences from Using Caregiver Support Services Based on Information and Communication Technology (ICT)’, European Journal of Ageing 10, no. 3 (2013).
Increased Funding for Home Care Supports

As discussed in our most recent Briefing Paper\textsuperscript{40}, significant investment in home care across Ireland is needed, along with a consistent approach to assessment and allocation of home care hours across the various Community Healthcare Organisation (CHO) regions. The waiting times for accessing home care averages 3.3 months; however, in some cases the wait can be up to two years. We estimate an injection of €110m in 2019 would allow supply to meet assessed need\textsuperscript{41}. While this action is not aimed specifically at rural carers, ensuring an equitable system of access to healthcare, in particular by reducing variations in waiting times, would go some way towards easing some of the issues of access raised earlier.

Developing Compassionate Communities

It is likely that the bulk of support for rural family carers will develop from ‘formal’ sources, including family carer organisations and government initiatives. However, Ireland has a long tradition of compassion within communities. One of the key positives for those caring in rural communities is how local communities rally around and support their members at times of crisis and throughout ongoing difficulties. Encouraging the development of these innate characteristics – while not a substitute for adequate health and social care services and regular established supports for family carers – may contribute to making rural family carers feel supported and more positive about their caring experience.

One of the key positives for those caring in rural communities is how local communities rally around and support their members at times of crisis and throughout ongoing difficulties

\textsuperscript{40} Care Alliance Ireland, \textit{Briefing Paper 2: Public Provision of Home Care in Ireland – Update}, October 2018.

\textsuperscript{41} Ibid; 23.
7. Conclusion

It is clear that there are specific challenges unique to family carers living in rural locations, along with specific positives, as outlined through the paper. Various studies have outlined that rural family carers are likely to experience mental health difficulties more acutely than those in urban areas, but given the correct supports this can be mitigated. Long travel times and lack of services add to the challenges. Responses to these issues are necessary from senior policy-makers at local and national level, and from family carer support groups around the country. Creative responses must be developed.

It is of note that many carers in rural Ireland do enjoy supportive local communities, which should be encouraged.

While no one response will resolve the challenges experienced by rural family carers, addressing issues such as transport, access to services and social exclusion will support rural family carers in caring well not only for their loved ones but also for themselves.

Acknowledgements

We would like to thank everyone who helped with this publication.

We would like to thank Zoe Hughes, Care Alliance Ireland for authoring the report.

Thanks to Liam O’Sullivan (Care Alliance), Dr. Ronan Foley (Maynooth University), Deirdre Shanagher (Irish Hospice Foundation & Chair of CAI Research Sub-Committee) and Annie Dillon (Alzheimer Society of Ireland & CAI Research Sub-Committee) for their comments on the draft report.

Thanks to Máire O’Dwyer (www.perfectlywrite.eu) for proofing and editing; Ruth Cahill (www.duckblue.ie) for design; and Dogget Print for printing (www.doggetprinters.com)