



**Discussion
Paper 9**



**Family caring
and minority
populations**

September 2018

1. Introduction

This is the ninth 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.

There are up to 360,000 family carers caring for friends and family members in Ireland¹ with a particularly high concentration among women in their 40s and 50s². Across the country, organisations supporting and advocating for family carers are naturally focussed on providing the best supports for the greatest number of family carers. However, the risk is that such an approach will be less successful in addressing the specific needs of minority group carers such as members of the Travelling Community, ethnic and religious minorities and members of the lesbian, gay, bisexual, transgender and/or queer (LGBTQ) community.



Across the country, organisations supporting and advocating for family carers are naturally focussed on providing the best supports for the greatest number of family carers

Family carers, in general, experience myriad challenges due to their status as family carers. These include (but are not limited to) social isolation and loneliness³, along with mental health difficulties such as increased likelihood of depression and anxiety^{4,5,6}. There is increased likelihood that family carers will experience negative

¹ Central Statistics Office, 'CSO Releases Irish Health Survey Results', 16 November 2016, <http://cso.ie/en/media/csoie/newsevents/documents/pressreleases/IHS2015.pdf>.

² Central Statistics Office, 'Census 2016 Summary Results – Part 2' (Central Statistics Office, 2017).

³ Liam O'Sullivan, 'Health and Well-Being of Family Carers in Ireland: Results of a Survey of Recipients of the Carer's Allowance' (Combat Poverty Agency, 2008).

⁴ Christina Aggar, Susan Ronaldson and Ian Cameron, 'Self-Esteem in Carers of Frail Older People: Resentment Predicts Anxiety and Depression', *Aging and Mental Health* 15, no. 6 (2011)

⁵ Brennan et al., 'De-Stress: A Study to Assess the Health & Wellbeing of Spousal Carers of People with Dementia in Ireland'.

⁶ O'Riordan and Kelleher, 'A Fine Balance: Mental Health and Family Caring'.



physical health effects, such as back and muscular problems, high blood pressure, heart problems, and stroke⁷, as well as the possibility that existing health conditions will be exacerbated during caring⁸. Family carers are more likely than the general population to live in poverty, with many family carers experiencing a sharp decrease in their earning ability – perhaps needing to give up work entirely – as well as bearing the costs of caring and disability^{9,10,11,12}.

For minority groups within family caring, these effects are likely to be compounded by other issues connected with their minority status which they may have been experiencing before the onset of caring responsibilities. Examples include social exclusion, poorer-than-average mental and physical health, lower educational attainment, poorer employment status and poor access to housing.



Much of the knowledge of the experiences, challenges and support needs of Irish family carers are based upon the assumption that the average family carer in Ireland is a white, Catholic, middle-aged heterosexual woman

Much of the knowledge of the experiences, challenges and support needs of Irish family carers are based upon the assumption that the average family carer in Ireland is a white, Catholic, middle-aged heterosexual woman. Whilst this assumption does have statistical merit¹³, this stereotypical portrayal of family carers does not take account of other caring situations.

The aim of this paper is to introduce some of the particular issues which family carers who are members of minority populations face. To date, very little work has been undertaken within these specific groups in an Irish context, and although

⁷ Ann Stokes, 'The Caring Reality of Family Carers: An Exploration of the Health Status of Family Carers of People with Parkinson's Disease', 2010, <http://www.carealliance.ie/userfiles/file/FullReportFinal.pdf>.

⁸ Allie Anderson, 'When Looking after a Loved-One Is Too Much: Caring for Carers', *British Journal of Community Nursing* 22, no. 5 (2017).

⁹ Carers UK, 'The Cost of Caring: How Money Worries Are Pushing Carers to Breaking Point' (Carers UK, 2011).

¹⁰ John Cullinan, 'The Economic Costs of Disability for Families', *Frontline: The Irish Voice of Intellectual Disability*, no. 97 (2015), <http://frontline-ireland.com/economic-costs-disability-families/>

¹¹ John Cullinan and Sean Lyons, 'The Private Economic Costs of Adult Disability' (2014)

¹² E O'Shea, 'The Costs of Caring for People with Dementia and Related Cognitive Impairments' (National Council on Ageing and Older People, 2000)

¹³ Care Alliance Ireland, 'Trends in Family Caring in Ireland in 2017: Review of Awareness, Self-Identification, Official Surveys and Income Supports' (Care Alliance Ireland, 2017).

more work has been undertaken in the UK and US, our knowledge of these issues remains low. We know that disability and illness, and consequently family caring, are cross-cutting issues which effect individuals across age, race, gender, sexuality and religion. There is evidence (discussed below) that certain groups are more likely to experience certain conditions that require care (for example mental health difficulties etc.) – and there is also evidence that certain groups experience proportionally much higher levels of disability and care, even if the actual numbers remain low in comparison to non-minority populations.



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It is important to note that when the term ‘minority’ is used in this document, it denotes that a population is in the minority when compared with the majority white Catholic population in Ireland.



2. Minority Groups in Ireland

Historically, Ireland has been an agrarian, Catholic country. However, following Irish accession to the EEC in the 1970s (subsequently the European Union), overseas investment began to develop, with Ireland positioning itself as an international hub of technology and communications, taking advantage of both a highly educated workforce (with free primary and secondary education for all citizens) and an advantageous geographical location between mainland Europe and the United States. What followed, from the mid 90s until 2008, was an unprecedented economic boom. Unemployment fell to historically low levels, with some sectors unable to fill positions from the population. Ireland became an attractive place to live and work, with immigration levels at an all-time high. This dramatic reversal of the traditional Irish migratory pattern ensured that Ireland became a multicultural society; in 2006, for example, there were 420,000 non-Irish nationals living and working in Ireland – which equated to 10% of the population¹⁴. This compares to approximately 230,000 in 1991¹⁵ and 137,000 in 1971¹⁶, and represented a near doubling of the percentage of people living in Ireland with a nationality other than Irish, as found by Census 2002¹⁷. During this time, Ireland was named the ‘most globalized country in the world’ three years running¹⁸. Even now, after the latest economic crash, which severely impacted employment opportunities in many sectors, 18% of the population identified as other than ‘white Irish’ when asked in Census 2016 about their ethnicity¹⁹.

The age profile of minority groups, in particular minority ethnic groups, generally skews younger than the white Irish population. Just over 57% of people in ethnic groups other than white Irish were under 35. Almost 5% of people in these ethnic groups were 65 or older, compared with 13% of the white Irish group²⁰.

¹⁴ Central Statistics Office, Census 2006 (Central Statistics Office, 2006).

¹⁵ Central Statistics Office, Census 1991 (Central Statistics Office, 1991).

¹⁶ Central Statistics Office, Census 1971 (Central Statistics Office, 1971).

¹⁷ Central Statistics Office, 2006 Census Of Population -Principal Demographic Results (Central Statistics Office, 2007),

<https://www.cso.ie/en/csolatestnews/pressreleases/2007pressreleases/2006censusofpopulation-principaldemographicresults/>

¹⁸ Susannah Bowyer, ‘Queer Patriots’, *Cultural Studies* 24, no. 6 (2010): 801–20.

¹⁹ Central Statistics Office, Census 2016 Summary Results – Part 1 (Central Statistics Office, 2017),

<https://www.cso.ie/en/media/csoie/newsevents/documents/census2016summaryresultspart1/Census2016SummaryPart1.pdf>

²⁰ Ibid.

3. Ireland's Minority Family Carers

Whilst it has been recognised by researchers that many of the issues facing carers from minority groups will be the same as or similar to those faced by carers from majority populations, those same issues can be compounded by the carers' minority status²¹.

The types of caring that minority groups may be doing are likely to differ in distinct ways. For example, research undertaken in the UK²² suggests that compared to other carers, black and minority ethnic (BME) carers are:

- More likely to report that they struggle to make ends meet
- More likely to be caring for their children, particularly children aged 20–25
- Less likely to be caring for someone over the age of 85
- More likely to be caring for someone with a mental health problem



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The UK, as a former colonial power, has a significantly different migratory pattern to Ireland – many Caribbean migrants arrived in the UK in the 'Windrush' era of the 1940s and 1950s, along with residents of other former British colonies such as India and Pakistan. However, it is possible that many of the same issues affect BME carers in Ireland, as the structure of the UK and Ireland is broadly similar in terms of their being Western welfare states with similar Western policy and legislative structures in place.

In some cultures, although the concept of caring for family members experiencing disability, illness, etc. does exist, there is no formal word or term equivalent to the term 'family carer', which is used with increasing frequency in Irish and UK society. Therefore, family carers in these communities are undertaking caring responsibilities without formal acknowledgement of the role or identification as carers. We know from past research that the term 'carer' or 'family carer' is often a contested one for family

²¹ Carers UK, 'Half a Million Voices: Improving Support for BAME Carers' (Carers UK, 2011).

²² S Yeandle et al., 'Diversity in Caring: Towards Equality for Carers' (Carers UK and University of Leeds, 2007).



carers regardless of ethnicity²³; however, for Western family carers the choice is theirs as to whether or not they wish to accept the terminology. Family carers from other communities may not have that choice. As it is often necessary to know that you are a family carer to maximise your engagement with family carer supports, those who choose not to identify as carers or who are simply unaware of the terminology may be at a disadvantage in accessing support^{24,25}.

There is evidence that some of the traditional supports provided by family carer support groups are inappropriate for, or unwanted by, certain cultural and ethnic groups. For example, work in the UK with BME (black and minority ethnic) carers has highlighted that many BME carers

emphasised how important it was for them to feel part of their ethnic community and consistently described their preference to spend their time participating in shared culturally relevant activities rather than pursuing 'leisure' activities such as clothes shopping, going to the gym or library, attending coffee mornings, meeting for lunch, going to pubs or clubs, walking, or even hobbies such as train spotting or bird watching.²⁶



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This is not to say that BME carers do not enjoy leisure activities, but that as so many of the social activities offered by family carer organisations across the country fall into such categories, it may be difficult for minority family carers to socialise with other carers and get information through those networks if the activities being offered are not experienced by them as relevant.

²³ Zoe Hughes and Liam O'Sullivan, 'Defining and Profiling Family Carers: Reflections from Ireland', *International Journal of Care and Caring* 1, no. 3 (2017): 421–27.

²⁴ The Ireland-Poland Cultural Foundation, 'Hidden in Our Midst: Carers from Minority Ethnic Backgrounds in Newry & Mourne' (The Ireland-Poland Cultural Foundation & Diversiton, 2013).

²⁵ Victoria Molyneaux et al., 'Reconsidering the Term "Carer": A Critique of the Universal Adoption of the Term "Carer"', *Ageing and Society* 31, no. 3 (2011): 422–37

²⁶ National Black Carers & Carers Workers Network, 'Beyond "We Care Too": Putting Black Carers in the Picture' (AfiyaTrust, 2008).



Family carers who do not speak English will find it almost impossible to effectively navigate a complex health and social care system

varying degrees, there will be a proportion who do not. Those carers are likely to be at increased risk of isolation. Being a family carer is often an isolating role, but add to that an inability or limited ability to speak the working language of the country well, and it is easy to see how isolated a family carer could become.

In addition to isolation, family carers who do not speak English will find it almost impossible to effectively navigate a complex health and social care system, such as the one we have here in Ireland. Research in the UK and elsewhere has highlighted the difficulties faced by those who cannot access information in the language that they speak. Depending on the situation, this can often mean that family carers and people with a disability are forced to find a translator – often a younger family member such as a child – which in turn may lead to a child hearing health details about their loved one which may be inappropriate for their age²⁸. Access to official translators can be difficult, and in times of crisis or out-of-office hours, access to translators for lesser spoken languages may be non-existent.

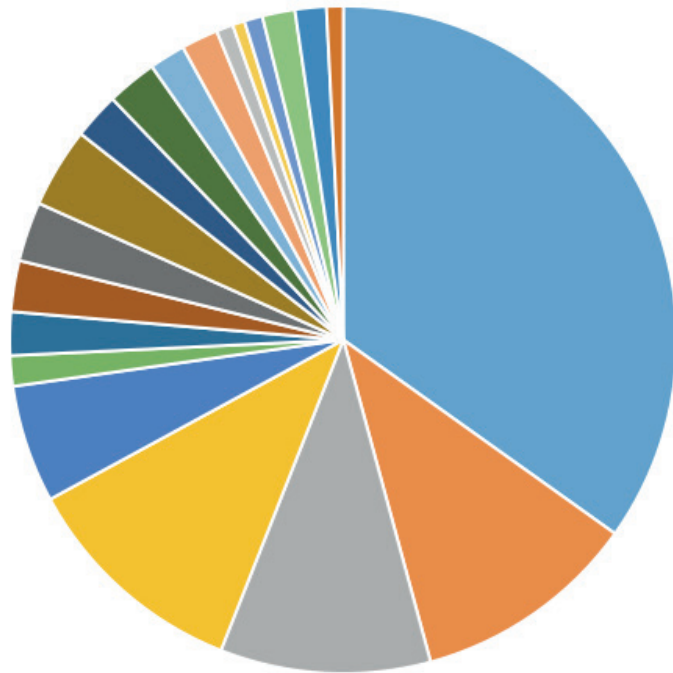
With regards to religion, Catholicism is by far the dominant religion in Ireland, with 82% of carers identifying as Catholic in Census 2016 - this, however, is down from 87% in Census 2011. This means that just about one-fifth of family carers in Ireland are not Catholic, which is marginally higher than the rate of Catholicism in the general population (which stands at 78%). 5% of all family carers specifically note having 'no religion', which is just about half the rate of the general population (which is just under 10%).

By far the greatest proportion of those who identify as non-Catholic, are those who have 'no religion' (8.8% of all family carers). However the chart below shows that there is a wide array of religions practiced by family carers in Ireland, who are not Catholic. This is important because many of these religions — in particular many non-Christian religions — will have particular needs regarding health and social care which may seem 'unusual' to general family carer support organisations, and indeed to health and social care professionals in Ireland who are used to working with Catholic and Christian religions. Many hospitals and hospice teams have a pastoral team in place, however these will be predominately Catholic and/or Christian in nature.

²⁸ Savita Katabama et al., 'Do They Look after Their Own? Informal Support for South Asian Carers', *Health and Social Care in the Community* 12, no. 5 (2004): 398–406.

Family Carers in Ireland (Census 2016) - those identifying as having a religion that is not Catholic

- Church of Ireland, Church of England, Anglican, Episcopalian
- Muslim (Islamic)
- Orthodox (Greek, Coptic, Russian)
- Other Christian
- Presbyterian, Church of Scotland
- Hindu
- Apostolic or Pentecostal
- Evangelical
- Buddhist
- Lapsed Roman Catholic
- Atheist
- Jehovah's Witness
- Methodist, Wesleyan
- Agnostic
- Lutheran
- Protestant (no details)
- Baptist
- Spiritualist
- Pagan, Patheist
- Born Again Christian



Many of these religions — in particular many non-Christian religions — will have particular needs regarding health and social care which may seem 'unusual' to general family carer support organisations



5. Key Issues for LGBT Carers

Ireland's view and acceptance of individuals who identify as lesbian, gay, bisexual, transgender and/or queer (LGBTQ) has changed significantly in the last 25 years. Following campaigns throughout the 1970s and 1980s, homosexuality was decriminalised in 1993, with various pieces of legislation to equalise access to services and protect against discrimination following. In 2015, Ireland became the first country in the world to introduce equal marriage by popular vote. However, despite this legislative and policy progress, many members of the LGBTQ community are still a 'vulnerable' population, with increased likelihood of mental and physical health problems^{29,30}. LGBTQ individuals may be unable and/or unwilling to access appropriate healthcare for fear of discrimination³¹, or because healthcare professionals are not appropriately educated on the particular health issues that are impacted by sexuality and/or gender identity. With regard to young LGBTQ family carers, for example, a study in 2016 by Carers Trust (Scotland) reported that young LGBTQ carers felt even less supported by the National Health Service than did young LGBTQ people who did not have caring responsibilities³².



Organisations that support family carers appear to be ill-prepared to work specifically with older LGBTQ people, with some studies citing that up to 60% of older people's support groups did not feel the need to address LGBTQ issues specifically

Whilst a significant literature review is outside the scope of this paper, it is clear from work to date that specific challenges face LGBTQ family carers. Older LGBTQ adults were found to be serving as caregivers almost twice as often as the general population³³. Yet organisations that support family carers appear to be ill-prepared to work specifically with older LGBTQ people, with some studies citing that up to

²⁹ S Cochran, J Sullivan, and V Mays, 'Prevalence of Mental Disorders, Psychological Distress, and Mental Health Services Use among Lesbian, Gay and Bisexual Adults in the United States', *Journal of Consulting and Clinical Psychology* 71, no. 1 (2003)

³⁰ Agnes Higgins et al., 'The LGBT Ireland Report: National Study of the Mental Health and Wellbeing of Lesbian, Gay, Bisexual, Transgender and Intersex People in Ireland' (GLEN and BeLonG To, 2016).

³¹ Grayce Alencar et al., 'Access to Health Services by Lesbian, Gay, Bisexual, and Transgender Persons: Systematic Literature Review', *BMC International Health and Human Rights* 16, no. 2 (2016).

³² Paul Traynor, 'Young People Caring OUT There: Experiences of LGBT Young Adult Carers in Scotland' (Glasgow: Carers Trust Scotland, 2016).

³³ Catherine Croghan, Rajean Moone, and Andrea Olson, 'Friends, Family and Caregiving Among Midlife and Older Lesbian, Gay, Bisexual and Transgender Adults', *Journal of Homosexuality* 61 (2014): 79–102.

60% of older people's support groups did not feel the need to address LGBTQ issues specifically³⁴. Where there are faith-led support services, some LGBTQ family carers experience being overtly blocked from those supports due to a conflict in religious 'ethos'³⁵. This is perhaps less likely in the Irish context given our equality legislation; however, in the context of the number of supports for people with disabilities, for example, run by Catholic faith-based organisations in Ireland, it is worth mentioning. Some LGBTQ family carers provide care for individuals who now or in the past expressed hostility or displayed homo/transphobia towards them, such as unsupportive parents^{36,37}. Often it is assumed that the last female in the family to remain single will take on the role of family carer³⁸. The fact that many LGBTQ relationships are not recognised, or may only recently have been viewed as legitimised through the establishment of marriage equality (in an Irish context), may have an impact on how family care responsibilities are organised within families. At a higher, policy level, the ubiquity of heteronormative attitudes can create a reluctance on the part of LGBTQ family carers to engage with existing carer supports, because of how they are structured. If an LGBTQ person does not see their experience reflected in the promotional material or content of these support groups, they are less likely to engage, even when there is a lot of overlap in the support needs of LGBTQ family carers and their 'straight' peers³⁹.

In the UK and Ireland, much of the work to date on this topic has taken place within the not-for-profit sector, in the UK primarily by organisations such as Carers UK, Carers Trust and LGBT organisations. Most of the 'academic' work located has been conducted in the United States and Australia, which have different legislative, policy, and health service structures to Ireland.

There has been relatively little research to date on the specific experiences of family carers who identify as a member of the LGBTQ community. A recent scoping review, undertaken by researchers in the Open University, identified a mere 18 pieces of research concerning this cohort of carers in the UK and Ireland since 2000 – out of 3,434⁴⁰. With estimates that there are 360,000 family carers in Ireland⁴¹, there are potentially tens of thousands of members of the LGBTQ community providing care for a loved one.

³⁴ Ibid.

³⁵ Catherine Barrett and Pauline Cramer, 'An Extra Degree of Difficulty; An Evidence Based Resource Exploring the Experiences and Needs of Older LGBTI Carers and the Carers of Older LGBTI People' (Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia, 2015).

³⁶ Ibid.

³⁷ Care Alliance Ireland, 'Difficult Relationships and Family Care', 2018.

³⁸ Karen Fredriksen, 'Family Caregiving Responsibilities among Lesbians and Gay Men', *Social Work* 44, no. 2 (1999): 142–55.

³⁹ Callum Banbury, 'LGBTI – Carers: Issues and Challenges' (Carers Australia, 2017).

⁴⁰ Melanie Henwood, Mary Larkin, and Alisoun Milne, 'Seeing the Wood for the Trees: Carer-Related Research and Knowledge: A Scoping Review', 2017.

⁴¹ Central Statistics Office, 'CSO Releases Irish Health Survey Results', 2016.



6. Key Issues for the Travelling Community

The Irish Travelling Community was granted minority ethnic status in 2017, making history in the process. As of Census 2016, 1,273 members of the Travelling Community provided care to a friend or family member, up from 1,105 in Census 2011.

Whilst we are not aware of any research that has been undertaken in Ireland to date with members of the Travelling Community about family caring, such studies have taken place in the UK, and it is worth noting some of the issues faced by Travellers in that jurisdiction, as they are likely to be broadly similar to those faced by Irish Travellers.

The main study of note in this sector is that undertaken and published by MECOPP (Minority Ethnic Carers of People Project) in Scotland, in 2012⁴². That project and subsequent study found that although Travellers, and in particular family carers within that community, are generally viewed as ‘hard to reach’, that is not necessarily the case – often it is simply that family carer support organisations are ill-equipped and occasionally unwilling to include this group as a specific target group for supports.



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With regard to Travellers’ ability to access supports for the people they care for, many of the Travellers in the study had experienced cultural insensitivity from health and social care workers. This includes feeling like they were being blamed for causing their own problems, as if it was their ethnicity that was the problem, rather than an inappropriate service or lack of flexibility. In common with non-English-speaking carers from other ethnic communities, the lack of information for those with literacy difficulties was a significant problem. This makes it even more difficult for people to navigate the often-complex health and social care system in an effort to obtain supports for both the person they care for and themselves.

⁴² MECOPP (Minority Ethnic Carers of People Project), ‘Hidden Carers Unheard Voices: Informal Carers within the Gypsy/Traveller Community in Scotland’ (MECOPP (Minority Ethnic Carers of People Project), 2012).

7. Responses

As always in these Discussion Documents, a range of responses to the issues raised can be identified – both at policy level and at direct-support level.

Policy Level

The current National Carers Strategy (NCS) (2012) does not directly acknowledge minority carers in any way, in particular those groups discussed in this paper. The closest that the NCS comes is to acknowledge the existence of caring ‘sub groups’ such as young carers, male carers and rural carers. Of course, supports directed at these particular groups are important; however, none of these supports will adequately address the specific issues experienced by family carers from cultural and ethnic minorities. Any new or refreshed National Carers Strategy should include direct actions which address the specific issues faced by family carers from minority groups. Understanding of diversity and cultural competency are values which health and social services must operate with.

Likewise it is important that health-related literature be available in as many languages as possible, or at least that steps be taken to ensure key messages are available in those languages spoken by family carers and those they care for. Information must be made available in order for family carers to make informed decisions on care.

It is vital that the Irish health and social care systems recognise that Ireland is very much a multicultural society, and that although many of the problems facing minority ethnic and LGBT carers are the same as those facing the mainstream family caring community, the solutions will be different⁴³.



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⁴³ National Black Carers & Care Workers Network, ‘Beyond “We Care Too”: Putting Black Carers in the Picture’, 2008.



Support Organisations

Given the pressure on services for people with disabilities and services for family carers to support the largest number of people in the most financially efficient way, it is not surprising that providing specialist supports for minority family carers has not been at the forefront of service provision. However, in light of the increasing number and visibility of family carers who are members of ethnic, cultural, religious or sexual minorities, it is clear that thought must now be given as to how to most appropriately support family carers who do not fit the traditional picture of an 'Irish family carer'.

This could be as simple as ensuring that carer groups celebrate non-Christian religious holidays such as Eid or Passover, or that gender-inclusive language is used when discussing how to support partners. Many activities and resources for family carers are provided along gender-specific lines (for example, groups for women which involve makeovers, and activities for men based around sports or DIY), which for many in the LGBTQ community may not make sense or be comfortable, or fit with their experiences and preferences.

8. Conclusion

As discussed above, it is to be expected that as the actual number of family carers who are members of minority groups is low, carer organisations and health and social care professionals, both in terms of policy and support, have been slow to address them directly. However, Ireland is increasingly multicultural and diverse, with changing family structures likely to impact on how family care is provided now and in the future. It is important that we understand and acknowledge that what works as a support for a white Catholic Irish carer may not work for a Chinese Buddhist carer. The challenge moving forward for those of us who support family carers is to begin to understand the assumptions we make about carers in Ireland – which are not always correct – and how we as a sector can ensure that all family carers in Ireland are supported in the way that works best for them, no matter what their race, religion or sexual identity.



Guiding support for family carers

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