





**Discussion
Paper 5**



**“We Need to
Talk About It” –
Stigma and Family Care**

December 2016

1. Introduction

This is the fifth 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 or perhaps controversial topic for discussion within the wider community of academics, not-for-profit organisations and other interested parties.

Many Family Carers are happy for others in their circle of friends and family to be aware of their caring responsibilities. This is often easier when the “reason” that the person being cared for requires care is a condition which elicits an empathetic response – such as dementia, or a significant medical condition. However, not all conditions which necessitate family members becoming Family Carers fall under this category. In addition, Family Carers may find themselves subject to stigmas for various reasons. This paper introduces a number of discussion points which link family caring and stigma, placing both within an Irish context and encouraging an open discussion of the issues.



This paper introduces a number of discussion points which link family caring and stigma, placing both within an Irish context and encouraging an open discussion of the issues.

Worth noting is the relative unavailability of studies specifically addressing the issue of stigma directly related to family care. Consequently, this paper is exploratory in nature, and is based upon discussions with professionals and Family Carers. Where reference material is available, it has been included; however, material was not available for all topics under discussion in this paper.



2. Stigma

2.1) What is stigma?

Whilst the notion of “stigma” has developed and changed – and is still under debate – since it was first developed in the 1960s (Goffman, 1963), in general it can be seen as set of misguided opinions about a group of people, built upon assumptions which have developed over time. Difficult to truly “define”, the word itself is indicative of a group’s struggle to be understood and to create a positive impression.



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2.2) Stigma in Ireland

Ireland and stigma have a long history. We are all familiar with the influence which the Catholic Church had for decades in Ireland, until the recent past – with the Church arguably still holding some power in certain spheres of social policy. There is the long history of the Magdalene Laundries for unmarried and pregnant, or troublesome, young women. The Church also ran asylums and workhouses for the poor, the unemployed and those with mental health concerns, institutions for people with intellectual disabilities, and reform schools for troublesome children (Whyte, 1971). It was relatively easy to admit a person to these church-run and state-supported institutions without their consent, and they were used to house groups of people who were misunderstood and who could not be cared for elsewhere. Many families of people with intellectual disabilities, for example, would hide the fact they had a child in an institution; parents would send pregnant teenage daughters to a laundry and tell family and friends that they had gone to the countryside to look after a fictional aunt or grandmother. It may seem as though we have come a long way since this was routine, but discussions with people with disabilities, single mothers, those on the LGBTQ spectrum and other marginalised and stigmatised groups would suggest otherwise. How, if at all, does this impact Family Carers?

3. Condition stigma

When first exploring the idea of stigma as it relates to family caring, what comes to mind is often the stigma which people with a specific condition or disability, and their families, may experience. This is, however, not the only type of stigma which Family Carers experience on a routine basis.

3.1) Mental health

Stigma in mental health is a well-discussed topic. Those who experience poor mental health, and their families, face high levels of stigma. People who experience poor mental health are less likely to be in employment (Amnesty International, 2011). According to a significant survey undertaken in 2015, just 53% of Irish people believe those with a mental health problem are trustworthy, at least two in three (67%) view a person's requiring treatment for a mental health issue as a sign of personal failure, and 29% of people would not trust a person who had suffered a previous mental health problem to babysit their child (Condon, 2015).



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Due to the stigma attached to mental health, Family Carers¹ of those with such conditions are often concerned with the impact of – for want of a better word – “outing” the person they support as having care needs. Acknowledging a role as a Family Carer, although allowing a person to access supports from the State and the voluntary sector, will indicate to those in contact with the family that there is someone receiving care – as a Family Carer cannot by definition exist without someone to care for. Due to the stigma which people with mental health concerns experience (as discussed above), many choose not to reveal their difficulties to the public at large, and in some cases not even within their immediate circle of friends or family. This of course increases the pressure on their key supports to hide the caring responsibilities, denying carers support for themselves. This has a wide impact, given that Family Carers are more likely than the general population to themselves experience a mental health difficulty, such as anxiety, depression or insomnia (O’Riordan & Kelleher, 2016;

¹ We acknowledge that the use of the term “Family Carer” when discussing mental health causes difficulty for many people. However, in this case we use the term to refer to anyone who has a role in caring for or supporting, or who is otherwise involved in the lives of, individuals experiencing poor mental health. For a further discussion regarding terminology, please see the first paper in this series, entitled “Defining Carers”, available on www.carealliance.ie.



Stokes, 2010; The Carers Association of Ireland & Royal College of Psychiatrists, 2009; Vermeulen B et al., 2015).

3.2) “Self-inflicted” conditions

Although a difficult topic to discuss, we are aware of the stigma attached to certain illnesses and conditions which may be perceived as being “caused” by the person in need of care and support. Examples include physical injuries or disabilities caused by road traffic accidents (which may be due to error or irresponsible driving by the person experiencing the injuries) or drug and alcohol use and abuse.

In no way is it acceptable that Family Carers, or the individuals requiring care are, or feel, stigmatised in this manner. The counterpoint to this type of stigmatisation is equally problematic: there are multiple examples of people with disabilities or certain “good” or “worthy” conditions being glorified for overcoming their “suffering” (this is sometimes referred to as “inspiration porn”²), whilst Family Carers may be “deified” for their selfless “sacrifices”³. This dichotomy – the stigmatisation of certain conditions, such as mental health, and the admiration of others – simply makes it more difficult for Family Carers in these difficult areas to look for and accept help.



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It is also possible, although significant work has not been undertaken on the topic⁴, that the Family Carers of individuals who come within this category may carry significant resentment towards the person they care for, due to the attributable cause of the disability, unlike in cases of genetic conditions or accidents. This gives a focal point for the negative emotions which Family Carers often carry with them. With resentment comes blame, and often guilt, in a cocktail of negative emotions, exacerbating feelings of isolation and anger. It has been shown that Family Carers who resent having to provide care (not specifically for the reasons mentioned in this section) are susceptible to anxiety and depressive symptoms (Aggar, Ronaldson, & Cameron, 2011).

² The term “inspiration porn”, coined by activist Stella Young, describes when people with disabilities are represented as inspirational solely or in part on the basis of their disability. For more information about this problematic construction of disability, see <http://the-toast.net/2016/04/14/disability-representation-inspiration-porn/>.

³ For a recent example of this, see <http://www.irishtimes.com/life-and-style/health-family/minding-my-disabled-daughter-i-don-t-want-to-do-this-any-more-1.2872341>

⁴ That we are currently aware of.

3.3) Caring for a person with an infectious condition

Infectious conditions have a history of stigmatisation – an example which resonates across the world is that of the stigma experienced by those who contracted HIV and/or AIDS during the crisis of the 1980s and 1990s (Mahajan et al., 2008). For many reasons, encompassing homophobia (both personal and structural); highly negative attitudes towards drug use, sex work and other stigmatised activities; and misunderstanding of the condition for a significant period when first discovered, HIV and AIDS patients were hugely stigmatised, with health professionals and the wider public greatly reticent to have physical contact with someone who had been diagnosed.

This, of course, has huge repercussions for those who care for a person with an infectious condition such as HIV/AIDS or Hepatitis. By extension, Family Carers of such patients are often seen as “infectious by association”, further isolating them from friends, family and the wider public. Significant misinformation persists regarding infection and transmission rates for many of these conditions, and indeed regarding details such as the sectors of society most likely to contract such conditions. What all this means is that a Family Carer providing care for someone with an infectious condition may experience extra marginalisation and isolation, as compared to Family Carers who care for people with more common conditions. Similar issues arise as regards “outing” a person with this type of illness as arise in relation to those with a mental health condition, discussed above.



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A person’s acknowledgement that he or she is a Family Carer is a significant statement about the health of the person for whom care is required – which is not always appropriate, appreciated or understood by family, friends or the general public.



4. Welfare stigma

Whilst society at large has an understanding of the work which Family Carers do, thanks to significant advocacy and publicity campaigns by the State and by the voluntary sector, there is still a lingering impression that Family Carers, particularly those with long-term caring responsibilities which keep them out of the paid workforce, should be regarded with, at the very least, mild suspicion. In a 2015 large-scale survey⁵, some Family Carers identified this issue as problematic:

“[There’s] no appreciation from society, you’re seen as being jobless and on the dole by the social welfare and government”

“We are seen as dole bludgers. Or people who get top ups aren’t we lucky. Especially the respite care grant, there is a lot of jealousy about that.”

“I think that carers are often patronised, believed to be welfare frauds, and live in fear a lot of the time...”

It is clear from these comments that there is a perception, at some level, that those in receipt of Carers Allowance are somehow committing fraud, or at the very least are managing to get “money for nothing”. The truth is, of course, far from this perception, with Carers Allowance being the only social welfare payment requiring proof from recipients that they work the equivalent of close to fulltime employment hours, with recipients not allowed to work more than 15 hours outside the home in any week. As a result of this attitude, some Family Carers choose not to apply for Carers Allowance or ancillary social welfare benefits, a choice which has a significant individual economic impact.



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⁵This study was conducted online via SurveyMonkey.com in March 2015, with over 800 respondents. The survey was publicised through Care Alliance member organisations and the National Carers Week Facebook page.

5. Age stigma

According to the most recent Census figures (2011), there are 4,228 children aged less than 15 years who are engaged in providing care to others, accounting for 2.3% of all carers. More recent data from the Health Behaviour in School-Aged Children (HBSC) study of school pupils in Ireland indicates that 11.4% of 10- to 17-year-olds identify as a carer (Callaghan, Keane, & Molcho, 2016). On the other end of the caring spectrum, Carers aged 65 years and over represent 22% of those providing at least 43 hours of care per week. In line with a recent set of figures released by the Central Statistics Office (Central Statistics Office, 2016), it is expected that both of these figures will increase when details of Census 2016 are released in 2017.

When confronted with these figures – in particular those which relate to young carers – the most frequent reaction of those not working in the health or Family Carer-support fields is one of disbelief that so many young people have such significant caring responsibilities. However, many organisations and other professionals feel that these numbers are underestimated – with a prime reason for this underestimation postulated to be the effects of stigma.



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Census data in Ireland is collected via a paper form which, although untraceable by design, remains unsealed when collected by a contracted enumerator, who is often someone living locally. Many individuals remain sceptical regarding the safety of their data, and due to the sensitive nature of the health- and caring-related questions in particular, may not wish to admit that their child is caring for them or for another member of the family on a regular basis (Care Alliance Ireland, 2015). Of course, some families see this kind of care as simply something that all families do, and to some extent that is correct. However, due to the stigma particularly surrounding a family that relies on young children to provide intimate and personal care to other members of the household, many of these young carers remain unacknowledged. This often continues throughout school and college, with young carers at risk of early school leaving, bullying, poor educational attainment and poor mental health (Becker & Becker, 2008).



6. Gender stigma

Caring is a gendered activity. That much is clear from the basic statistics which indicate that just under two-thirds of Family Carers are female⁶ (Central Statistics Office, 2012). Care and caring has long been established as a female occupation, with the work of caring and the attributes of caregivers being feminised and consequently of low status, and receiving little recognition (Hanlon, 2015).

Due to this feminisation of caring, and the resultant lack of status and recognition for caregiving activities, male Family Carers may experience significant stigma, not unlike the stigma faced by fathers who wished to become more involved in their children's care and development in previous decades. There are many who see a man who engages in caregiving activities as weak, or feminine, regardless of the relationship to the cared-for person. In addition, there have been cases of young male carers experiencing homophobia (regardless of their sexuality) due at least in part to their caregiving role.



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7. Institutional stigma

For many families, a point comes where it is no longer possible or appropriate to provide care at home, in particular where there are significant medical or psychiatric needs. In these cases, many families choose to access – if available – some form of long-term residential care for their family member. However, some Family Carers in this situation report feeling stigmatised for the decision to choose such care, as well as feeling guilty (Boland, 2016). This is not always the case; however, there is anecdotal evidence that “putting your Mum into a home” is seen as an abandonment of a child's duties to an ageing parent, and that accessing residential care for family members with a disability or mental health concern attracts similar stigma. This decision is a source of significant guilt for Family Carers, who often wish to continue to play a role in their loved one's care (Argyle, Downs, & Tasker, 2010).

⁶ The full breakdown in 2011 was: male carers 39%, female carers 61% (Central Statistics Office, 2012).

8. Responses

So far, this paper has highlighted a number of situations in which Family Carers find themselves stigmatised, for reasons ranging from age and gender to mental health and infectious diseases. So little work has been undertaken on this subject that it is difficult to outline these issues accurately without running the risk of descending into hyperbole and mere hearsay. However, as the purpose of these papers is to stimulate debate and introduce difficult or little-discussed issues into the wider conversation for Family Carers and the organisations which support them, such discussion is justified. However, in addition to outlining some of the issues, it is important to outline some of their possible implications – and some recommendations for policy, organisation and research responses.

8.1) Further exploration

From our brief discussions with Family Carer organisations, condition-specific groups, advocates and Family Carers themselves, it is clear that these issues, whilst affecting differing numbers of Family Carers, **are** currently being experienced. What is concerning is how little we know about how stigma affects the lives of Family Carers on a daily basis, and what the real effects of stigma emanating from society and even from health and social care professionals truly are. In order to begin addressing these issues, it is vital that more robust research is carried out, with specific questions relating to the issues outlined above.



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Many professionals working with Family Carers may not be fully aware of the effects which certain types of stigma can have on the lives of those they support. This is not to say that such professionals are ignorant as regards the issue, but without a specific acknowledgement of stigma, it may be difficult to get to the root of concerns which families are experiencing – in particular as in some instances Family Carers themselves may not be aware that stigma is an issue for them.



In particular, the issue raised regarding stigma experienced by those caring for someone who is viewed as having “caused” their need for care is a particularly sensitive one to address with Family Carers.



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8.3) Tackling stigma on a wider scale

It is clear from the work that has been done regarding stigma and mental health that despite significant efforts by organisations in the not-for profit sector and by the State, stigma continues to be a significant issue in modern Ireland. It is vital to address this issue at a societal and policy level.

Caring continues to be viewed as “women’s work”, and in Ireland the value of women’s work is up to 20% less than that of men’s work (Morgan McKinley, 2016). This exacerbates the stigma for men of doing what is traditionally seen as “women’s work”.

Large sections of society continue to be misinformed as to how infection and infectious diseases such as HIV/AIDS are spread.

People with mental health concerns and their families continue to be thought of as less trustworthy, or less safe to be around.

Addressing these issues at policy level is crucial. Continuing the work being undertaken under the auspices of the National Disability Strategy, A Vision for Change, the National Youth Strategy and others will go some way towards addressing and rebalancing the stigma felt by Family Carers across Ireland.

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