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Hearing Family Carers: 'Going from Bad to Worse'

REPORT ON RESEARCH UNDERTAKEN WITH FAMILY CARERS IN CORK[1] IN 2008 AND 2013

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2014





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School of Applied Social Studies, UCC : The School of Applied Social Studies' mission is 'to provide an educational environment which promotes a culture of critical intellectual and practice enquiry in the social sciences based upon participation, inclusion and diversity'. This mission statement is underpinned by the objective of making equality an integral part of the intellectual, cultural, social and economic life of the University. The School believes that quality is best achieved through the pursuit of equality, based upon the principles of lifelong learning and open access. Many of its staff and students are engaged as active citizens in voluntary and community organisations, linking the School to civil society

The Carers Association is Ireland's national voluntary organization for and of family carers in the home. We Aim to provide family carers with emotional and practical support to promote the interests of Family carers and those receiving care in the home which including frail older people, people with severe disabilities, the terminally ill and children with special needs. We aim to do this through effective partnership, lobbying and advocacy and to gain recognition and social justice for carer's invaluable contribution to Irish society

The Association was established in 1987 to lobby and advocate on behalf of carers. While the government has begun to initiate some services for carers, we believe that the vast majority of Ireland's family carers still remain without vital services. These services, such as in-home respite, are essential to family carers. They allow us to continue in our roles as family carers, thus implementing government policy to care for people in their own homes for as long as possible.

Today, The Carers Association has 13 Resource Centres and two Service Bases from which it delivers our range of services

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PREFACE

This report provides an update to research conducted in 2008 on the experiences and access to supports available to family carers in Cork and published as *Hearing Family Carers* (O'Riordan, O'hAdhmaill and Duggan 2010). It includes additional research carried out in 2013 with some of the original participants who partook in the earlier research. Given the more recent changes in supports in the context of austerity measures it was considered necessary to consult carers again with reference to their more current experiences, supports and the challenges they face in their informal caring roles.

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INTRODUCTION

This report draws attention to the extent and dynamics of family caring, as seen through the opinions and experiences of carers located in and nearby Cork city. It details findings of research undertaken with family carers in Cork during 2007 – 2008. This research sought to elicit the views and experiences of family carers, and in so doing, to gain insights into their perspectives on family caring and on associated support mechanisms. The report also includes findings of research undertaken in 2013, which updates the earlier research. This new research was considered necessary in aftermath of a series of austerity budgets, which are perceived to have impacted substantially on family carers.

Three key themes emerged from the research itself. These are (i) the role and position of the family carer in society, (ii) the process of family caring itself and (iii) access to and knowledge of key support services. Issues arising are discussed throughout the report and it is hoped policy can draw on the observations made.

The report has the following structure. In the first instance we turn our attention to a discussion of family caring in Ireland, and associated supports more generally arising from the earlier research undertaken. This includes a discussion on key issues arising in the general discourse around family caring in Ireland and internationally, in order to provide a context from which to locate the experiences of carers involved in this research study.

Thereafter, we detail the methodology employed in the research studies, which followed a method of research enquiry that values the input of participants from the early stages of research focus and design, and which incorporated qualitative and quantitative methods of enquiry. The research was conceptualised and developed in conjunction with The Carers Association, Cork in keeping with an approach to social research that attempts to link academic and activist/advocacy interests. Its aims were to identify issues that family carers in the locality considered important, with a view to contributing to local knowledge, providing a forum for ongoing research, and to informing policy developments on carers.

The focus of the report then turns to profiling carers who participated in the earlier research, examining the care they provide, and discussing support they receive from family, friends and neighbours – from informal sources. A number of these carers took part in the updated research. The report then details results of the earlier research, focusing on access carers have to formal and public, community-based support services. We examine their experiences of, and concerns regarding some of these key services, and look at ways that such issues might be addressed. The next section concentrates on financial supports, a range of which are/were available to carers, for instance, to supplement income and to assist with home renovations. We look at their uptake and issues arising, again with a view to understanding and addressing them from the perspectives of the service users. Next, the report turns its attention to aspirations that carers have for themselves in terms of their own personal, training, and employment options. Attention is drawn to key issues discussed throughout and a number of key recommendations are made, aimed at addressing the voiced opinions and experiences of carers that have emerged through the research. Finally, we offer a summary of findings of the later research which draw attention to the manner in which people are experiencing more recent cutbacks on services available to them. These findings draw attention to the increased stress that carers are now under. They indicate that carers are dealing with increased levels of bureaucracy and highlight elements of confusion regarding the nature and availability of supports. The findings are worrying in that they indicate that reduced levels of service are at odds with stated home care support policy. Indeed, it was in discussing initial results with carers in November 2013, part of the title of this updated report - going from bad to worse -was suggested by carers to portray their more current experiences.

This update, then, illustrates the very real concerns of carers in the locality regarding diminishing supports for home-based care. It should be read in the context of the preceding discussions on the earlier research. However, while the context was harsh in 2008, conditions have severely deteriorated since and it is questionable to what extent home based care can survive without having detrimental impacts on those involved; carers and those for whom they care, unless there is an acute political change in perspective towards the provision of clear, transparent and accountable supports for home based and a willingness to place sufficient resources behind policy initiatives that recognise their value.

FAMILY CARERS AND SUPPORTS IN IRELAND: A REVIEW OF THE LITERATURE

The issue of caring for vulnerable people in society has led to a wide range of debates and research across Western states, particularly since the 1970s. Everyone needs care at some time in their life; in childhood, when ill, or when in need. However, some people due to disability, poor health or increased vulnerability need care on a long-term basis.

Advances in health care, healthier life styles and nutrition have led to a growth in life expectancy rates with increasing numbers living to an older age, often, although not always, with increased levels of disability and/or vulnerability and often in need of care and support (Robins 1988; Fahy and Murray 1994; Office for Social Inclusion 2007). The growing need for care is, in turn, placing tremendous burdens on carers and leading to increased demands for greater help and support from the rest of society. This combined with the advent of welfare states throughout much of the Western world, particularly since World War Two, has led to a large research literature focused on the issue of care and carers.

Who Cares ?

While some societies have attempted to place responsibilities for caring for their citizens on the collective – the State – others, such as Ireland, have tended to place responsibilities on family members, particularly female members (Timonen and McMenamin 2002). Whereas other societies talk primarily about informal care or personal care, in Ireland, this is referred to primarily as ‘family care’. Indeed, the term family carer is defined in the 2006 Census as ‘someone who provides regular, unpaid personal help for a friend or family member with a long-term illness, health problem or disability’ (CSO 2007:5).

It is argued, for example by Inglis (1998), that in Ireland Catholic ideology has historically had a major influence in the formation of family relationships, as well as the role of the state in welfare provision in Ireland. The Church’s concept of subsidiarity emphasised that the family should be primarily responsible for its own welfare, assisted by the Church. Indeed, this concept has become embedded in Ireland’s Constitutional framework where the primacy of the family is promoted in law as well as in tradition. Article 41.2.1 of this states, ‘In particular the State

recognises that by her life in the home, a woman gives to the State a support without which the common good cannot be achieved'. This is followed by article 41.2.2 which states that 'The State will therefore, endeavour to ensure that mothers shall not be obliged by economic necessity to engage in labour outside the home to the neglect of their duties in the home' (*Bunreacht na hÉireann* 1937). Both these articles are strongly prescriptive of women's caring role, place moral responsibility on women within the family to care, and neglect the increasing role that men are now playing in terms of providing family care. Concurrently, the State's involvement in 'family matters' has been minimised (Fanning 1999; 2006).

While the family has and is undergoing considerable change in Ireland in more recent years, it is reasonable to assume that ideas about privacy in the family and perceptions of the boundaries of relationship responsibilities and obligations continue to be viewed, in part at least, from a perspective of subsidiarity promoted by this Catholic ideology. Indeed, in Ireland, voluntary and statutory home care support services are conceptualised as additional to and subsidiary to informal family care.

The policy assumption that families and particularly women will continue to be the main providers of family care is being challenged by current demographic and economic shifts. In tandem with the growing need for care, as discussed above, women are now increasingly active in the Irish labour market and are, therefore, no longer available to provide unpaid/voluntary care to the degree that they once did. (O'Riordan 2005). This creates a challenge for service providers to respond adequately to the needs of those requiring care and their carers. Whereas the Welfare State made the bold claim to provide welfare for the people of Britain, from the cradle to the grave, no such claim has ever been made in Ireland, particularly in relation to caring.

Care and Support services in the community

The government's commitment to a policy of community care for older people, was stated as far back as 1968 in the *Care of the Aged* report 1968, and later in the *Years Ahead* report 1988. However, developments in provision and support for living in the community have been quite limited. Funding has continued to favour institution as opposed to community care. A Department of Family Community and Social Affairs report (2002 cited in Prendergast 2006) demonstrated that between 1993 and 1996

while expenditure on community services had risen by 8 per cent, spending on the nursing home subvention scheme increased by 422 per cent in the same period.

Despite this, the main stated thrust of policy in Ireland continues to be towards community care. Ahern (2001) stated that 'Government policy is strongly in favour of care in the community and enabling people to remain in their own homes for as long as possible ... the State cannot and would not wish to replace the personal support and care provided in the family and the community' (Dermot Ahern Dail Debates 24/5/01). The *National Action Plan on Social Inclusion* states that 'informal and family carers play a valuable role in our society particularly in enabling older people and people with disabilities to remain in their own homes for as long as possible' (2007:17). The National Economic and Social Forum (NESF) report 2002, *A Strategic Policy Framework for Equality Issues*, suggests that 'affective equality challenges us to, for example: develop a public focus on care, design supports to enrich caring and respond to the needs of carers and dependents' (NESF 2002 cited in NESF 2005:54). Carers themselves have indicated a range of needs which include practical help with caregiving, the provision of respite care, financial support, psychosocial support and the need for advice and information (O'Connor and Ruddle 1988; O'Shea 2000). In practice, however, services available to the carer from the State in Ireland tend to be *ad hoc* and difficult to access, are dependent on one's location, are provided largely on discretionary basis, and not as of right, and clear information on them is hard to come by. The following paragraphs briefly discuss a number of key community care support services in order to offer an overview of the landscape of caring supports available to carers in Ireland.

Day Care Services

Day services are a key support to carers however, there are insufficient places available (Joint Oireachtas Committee 2002, Haslett 2003) and that availability varies significantly across the country. The Joint Oireachtas Committee (2002) noted a lack of day-care facilities for care recipients with special needs including those with dementia, those with physical disabilities, or children and adults suffering with autism. *The Years Ahead: a Review of the Implementation of its Recommendations* (Ruddle, O'Donoghue and Mulvihill 1997) noted that day centres were low on the priority of health authorities and were provided on a discretionary basis. Waiting lists exist for many day centres (Haslett 2003) and this may impede carers from obtaining

the support of these services. Furthermore, Haslett (2003) and the Joint Oireachtas Committee (2002) note that the opening hours of day centres do not meet the needs of carers and do not assist carers who wish to work. Nevertheless, it is claimed that the provision of day care services to older people and disabled people who wish to continue to live at home is a central tenet of Irish health policy (Robins 1988; Department of Health and Children 2001).

Home Help Services

Again and again, research indicates that the home help service is a key community support for older and disabled people, and their caregivers in the community. Under the current legislative framework the service is also a discretionary one. The 1970 Health Act empowers, but does not oblige health boards (now the HSE) to provide a home help service (Section 61). The *Years Ahead* Report (Robins 1988) recommended that the provision of the home help service should be expanded substantially and given a statutory framework. Lundstrom and McKeown (1994 cited in Haslett et al 1998: 58) state that 'the personnel in the home help service -and the clients they serve- are not assisted in any way by lack of a clear legal mandate-they have to compete for a share of the health budget against service providers who are guaranteed funding because their service is mandated'. Worryingly however, programme managers interviewed in Haslett, Ruddle and Hennesey's study (1998) argued against underpinning the home help service with a legislative framework. They argued that legal obligation and quality do not necessarily go hand in hand, that obligation could bring a loss of flexibility and might discourage partnership in care between service providers and family members. This encapsulates an opposition to rights and entitlements to services by State providers and an adherence to the idea of state subsidiarity. The problems with a discretionary State service are highlighted in research that suggests that the service continues to operate with wide-ranging local and regional disparities (Larragy 1993). Furthermore, entitlement to home help service is not standarised across Health Service Executive areas (Lundstrom and Mckeown 1994; Citizens Information Board 2002,) and this creates difficulties for carers and care recipients who wish to access the service. Lundstrom and McKeown (1994) report that emergency services were only available in six health boards (HSE) areas and that some clients experienced lengthy waiting periods for the home help service, particularly where it was provided by a voluntary organisation. Provision of a home help service outside normal working

hours and at weekends as recommended by the *Years Ahead*, was available in most health board regions to only a minority of clients (Lundstrom and McKeown 1994). Furthermore, a wide variation existed between health boards in the provision of a home help service. Lunstrom and McKeown (1994:166) state 'accordingly it may not be unreasonable to conclude that some health boards are less responsive than others in providing a home help service outside normal working hours'. Recent cutbacks in health and community care spending has had an impact on community care services. A study by the Irish Association of Social Workers and Age Action Ireland (2008) found that Dublin south-east has no weekend cover for home helps and the freeze on recruitment had affected the provision of home help services in Donegal, DunLaoghaire, Cavan-Monaghan, Galway, Sligo Leitrim, North Tipperary/East Limerick, Kerry. Even more recently, the HSE themselves (2010) reported that Home Help services were 6.4% below their planned targets.

The home help service, like other statutory provision in the area, continues to be underpinned by the principle of subsidiarity. Lundstrom and McKeown (1994:167) note there is an 'underlying assumption that home help services should neither substitute nor supplement existing informal care arrangements'. In relation to the support of carers in the community, a study by Garavan *et al* (2001) found that requests for home help appear to be turned down where someone else appears to be fulfilling the role of 'home help. Others have argued that the home help service should not only operate for those who have little or not informal care, but also as a support for family carers. *The Future Organisation of the Home Help Service in Ireland* (Haslett, Ruddle, Hennessy 1998) points out that the majority view of all groups consulted in the study was that the home help service should be provided for older people whether they are supported by family or not. Garavan *et al* (2001) observe that independence from family and neighbours is emerging as a priority need among older people themselves. Carers themselves, indicated that what they need most from a home help service is respite from caregiving, as opposed to assistance with household tasks or with the personal care.

Home Care Packages

Quality and Fairness: A Health System for you (Department of Health and Children 2001) proposed the development of a home-based subvention scheme, in the name of home care packages, to provide financial help to purchase home help privately.

However, there is confusion surrounding their actual development, and access to them. Research (Prendergast 2006) indicates that funding was given directly people to enable them purchase required social care services in some HSE areas, while in others, the HSE paid the provider after the service had been supplied. Furthermore, there is little evidence of their integration with existing service provision.

HSE Managers have argued that direct payments to older people facilitate choice and empowerment (Prendergast 2006). Conversely, SIPTU (2006) argue that it would be more empowering if people were entitled to choose between direct provision of home care services by the HSE and the payment of a home care subvention. They also argue for statutory entitlement rather than the continuation of discretionary services.

Eligibility for home care subvention it is based on means-testing and is discretionary. In late 2005, according to Prendergast (2006), the main assessment criteria was based on weekly income, which for most older people constituted a pension, though whether spousal income was taken into account remained to be clarified. Prendergast (2006:64) also states that most home care packages were made available through hospital discharge committees and argued that the prioritising of hospital discharges had the unintended result of 'encouraging people to seek hospital admission'. Interviewees in the Prendergast study reported assessment procedures for home care packages to be inadequate and pointed out the need for 'non-standardised assessment tools' that are nationally implemented. A public health nurse pointed out the need to include carers' needs in assessments for supports (ibid). Another shortcoming of the home care packages schemes as identified by Prendergast et al's research was the lack of systematic review procedures.

Respite Care

The literature on respite services, again, illustrates the lack of a right to a service and its discretionary *ad hoc* composition. The Citizen's Information Board (CIB) (2002:21) points out that 'entitlement to respite care has not been clarified and that this needs to be 'more transparent and applied systematically to cater for ongoing caring situations as well as crisis interventions'. In addition to this the Joint Oireachtas Committee (2002) has called for the terms 'carer' and 'respite' to be explicitly defined. In addition, the Joint Oireachtas Committee on Social and Family Affairs (2002) stated that the 'lack of, insufficient or inappropriate respite care can

contribute to familial and marital difficulties, and to a deterioration in the carer / care recipient relationship, frequently leading to an earlier demand for long-term residential care' (Joint Oireachtas Committee 2002:18). However, the Committee found that there are an inadequate number of respite beds available to meet the needs of carers and that respite care services are '…minimal, unevenly distributed and inequitably apportioned…' (Joint Oireachtas Committee 2002:18). The report states that respite beds that are available are not always suited to the care recipient's level of dependency and the need to book respite beds in advance does not respond to the needs of carers, in that it does not account for unscheduled breaks. To meet carers' needs the Joint Oireachtas Committee (2002) proposed that in-home respite care be provided on a daily or nightly basis. This would enable carers to avail of shorter, more frequent breaks and, thus, add to the quality of their lives. The advantage of a system of home-based respite care would, according to the Committee, be that institutional respite care beds would be freed up for emergency use. For respite care services to be effective in responding to carers needs, the Joint Oireachtas Committee (2002) suggests that a tailor-made service is required to achieve an effective partnership between the statutory, voluntary and informal sector. Respite care services which emerge from this partnership should be 'standardised', 'flexible', and the element of choice for carers and recipients, should be at the heart of service provision (Joint Oireachtas Committee 2002:18). Measures that O' Shea (2000) suggests will support carers, are financial support and the provision of services such as respite care to provide a break from caring. He also suggests that training for carers around meeting the needs of people with cognitive impairment, is required and argues that day-sitting services and therapy services could be paid for through a care manager or through vouchers issued to carers.

Another issue that needs to be addressed is the impact of a long history of subsidiarity on carers themselves and prevailing attitudes in society towards care. For example, the Southeastern Health Board/Waterford Institute of Technology study (2000) found that many carers did not use respite services because of feelings of guilt or perceptions that services were not responsive to their needs or the needs of the care recipient.

Financial Supports

The debates around financial support revolve around entitlement, criteria for assessment and levels of payment. Supports as currently developed, tend to be based on employment participation, as in the Carers Benefit, or are means-tested, based on household incomes. They are all characterised by high levels of assessment criteria and have high rates of refusal (O'Connor 1998). No financial support has been developed in Ireland for carers, because of their role as carers *per say*. Indeed, the Carers Association (2005) estimates that there are a total of 125,488 family carers without any income support in Ireland and point out that Irish carers save the Exchequer up to €2 billion each year in terms of negating the need for substitute formal care. The Joint Oireachtas Committee (2002:16) states that 'There are economic and fiscal advantages to the State where the family are the key providers of care, but these savings to the State have not been re-distributed to the carers in an equitable manner'.

Research conducted by Timonen, Doyle and Prendergast (2006) on domiciliary care demonstrated a wide ranging diversity of opinion on co-payment for care. Opinions varied from the view that wealthier people ought to pay for care, to the concept that services should be universally free at the point of access to all on the basis of need. Timonen (2006:226) points out that 'while universal access to free services is in principle the most desirable option, this is unlikely in the context of a low tax/low spend welfare state such as Ireland'. According to this view, the most equitable solution would be to make a basic amount of services and or/financing universal and to make remaining services income-dependent. Such services would be funded from the tax take in the absence of a strong social insurance tradition in Ireland.

The Carers Allowance, Carers Benefit and the Domiciliary Care Allowance paid to the parents of children with disabilities are the main income supports for carers in the Republic of Ireland. The Carers Allowance is a means-tested benefit and the care recipient must require a high level of care for a carer to qualify. This stringent condition excludes many carers from obtaining the benefit. The Joint Oireachtas Committee state that means-testing is stressful for carers and this is connected to the threat of 'exposure of their financial situation and then losing control of the outcome' (2002:11). Carers who made submissions to the Committee's report found means-testing to be 'degrading' and the fact it is an allowance rather than a payment was

seen as ‘charity rather than a right’ (Joint Oireachtas Committee 2002:11). The Committee called for the abolition of means-testing for the Carers Allowance, based on the fact that Child Benefit is a universal payment and as such not subject to means-testing and also the Domiciliary Care Allowance is not means-tested against parents income. The need to make the Carers Allowance a universal payment has been strongly advocated by the Carers Association and other carers interest groups (CIB 2002). If means-testing is to continue, carers in the 2008 Carers Association report felt that there should be a disregard of spousal income. Payment of half-rate social welfare payments in addition to the Carers Allowance for eligible carers, was regarded as a welcome development, however the ‘knock on’ impact of this on the payment of other benefits needed to be taken into account (Carers Association 2008).

A further issue around benefits for carers is the existence of ambiguity around eligibility. Carers consulted for the *Listen to Carers* report highlighted the confusion that exists around how to apply for benefits and also the presence of inconsistencies in defining carers, particularly hidden carers, such as young people and those caring for people with mental health needs (Carers Association 2008). In respect of inconsistencies, the Joint Oireachtas Committee (2002) noted different rates of benefit paid to carers caring for different categories of care recipients by the Health Service Executive and Department of Social Community and Family Affairs (DFSCA). There were also different qualification criteria noted and these anomalies existed, according to the committee, because payment was not linked to needs assessments.

The Carers Benefit is a social insurance based scheme which allows an employee to take two years leave from employment to take up caring duties. The main shortcoming of this scheme is that it is restricted to those who have participated in the formal labour market and have made adequate insurance contributions. The time-limited nature of the Carers Benefit is another of its shortcomings and Combat Poverty Agency (2008) recommend that it be increased to three years, a call which has also been supported by the Carers Association (2008). In 2005, 24,970 carers were in receipt of the Carers Allowance and 867 received Carers Benefit (CSO 2008). The rate of payment of Carers Allowance and Carers Benefit is only about one-third of average net weekly earnings in Ireland (Carers Association 2005). This exposes many carers to poverty and social exclusion, however, this aspect of carers’ lives has not been researched to any great extent in the Irish context. The Combat Poverty

Agency (2008:6) state ‘the nature and extent of poverty amongst carers is not empirically established at national level in Ireland’. The Carers Association Report (2008) *Listen to Carers* found that many carers were of the view that current levels of welfare payments for carers were not an accurate reflection of the value of the work done by carers. Carers were in agreement of the need for higher payments but there was some division around whether this should be in the form of a wage or a compensatory payment (Carers Association 2008). The majority of submissions received by the Joint Oireachtas Committee recommended that the Carers Allowance ‘should be changed from being an income support to a payment for caring, with an associated assessment of the needs of the care recipient and the carer’ (2002:11). To adequately respond to the needs of Carers, the *Review of the Carers Allowance 1998* suggested that a system of needs assessment of the Carer and the care recipient be introduced. This process of assessment of need is strongly support by the Carers Association (2005, 2008).

NESF (2005) note that informal care is costly for carers as regards lost earnings and pension entitlements foregone. The Equal Opportunities Commission in Britain has noted two factors which are important in determining the financial cost of caring: 1) the financial costs of caring themselves 2) the restriction of employment opportunities for the carer and the extra costs to the household as a result of the needs of the person being cared for (cited in O' Connor and Ruddle 1993). O' Connor and Ruddle (1988) demonstrate the restriction of employment opportunities that carers experience. In their study twenty-eight per cent of carers said they would like to be in paid employment. Among female carers in the study 17% had given up employment in order to provide care while among male carers not in employment 38% had given up paid work to provide care. The Joint Oireachtas Committee (2002) point out that entitlement to pensions is a source of anxiety for carers, particularly those who have been caring long-term. If the care recipient dies, a carer who has been caring long-term and who does not have access to an occupational pension will not be entitled to other welfare payments and may be at risk of poverty. The Review of the Carers Allowance (DSCFA 1998) proposed the introduction of a continual care payment for those carers who care for highly dependent people however this has not been introduced. The Joint Oireachtas Committee in 2002 suggested the introduction of a Constant Care payment to compensate carers for the costs associated with Caring.

Similarly, CORI (2008) in their pre-budget submission have proposed the introduction of a Cost of Disability Payment and this would go some way to addressing the extra costs associated with caring for someone with extra requirements, such as heating and diet.

Carers and care work

At this point, it is worth turning attention to our understanding of informal care from a wider societal perspective. It is also worth noting that older people in common with other groups requiring care have expressed a strong desire for home-based informal care (Garavan, Winder, McGee 2001). How this caring labour can be encouraged and sustained is regarded as a key challenge for any social policy which prioritises community care. One of the problems identified above has been a growing population in need of care. Alongside this, value and worth are increasingly associated with participation in the public sphere, and a process of individualisation in society, based on neo-liberal and market-driven priorities. This contributes to the invisibility and undervaluation of family carers (Baker *et al* 2004; Lynch 2007). Within western traditions, caregivers are often excluded from participation in decision-making because of their role as carers, the gendered nature of caring, the low value that is placed on caring (Kittay 1999, 2002; Baker et al 2004; Lynch et al 2009; Williams 2009). In an age of increased expectations an identity based on a job is often what people need to feel valued as human beings. Many researchers have considered how caring or attitudes to it often causes people to feel excluded for society.

Women's positioning in these areas, and in particular within debates on care, has been crucial in distinguishing between the very different aspects of care (Lynch and MacLoughlin 1995; Badgett and Folbre 1999; Kittay 1999, 2002; Folbre 2008). Distinctions can be made between caring in the paid sphere of employment (Hochschild 1983) and that carried out in the private and domestic spheres (Lynch and McLoughlin 1995; Finch 1993; Kittay 1999; Kittay and Feder 2002). The significance of the historical association of care with women's *natural* work in the private, personal and domestic spheres is emphasised and its consequences are explored (Oakley 1974; Hochschild 1983, 1997; Kittay 1999, 2002). Such an association has reinforced the invisibility of care work, regardless of whether it is carried out by men or women. It has also supported approaches that have assumed it not to be of concern to social analysis, such as those espoused in classical sociological traditions that

simply ignored care as a subject of analysis and often relegated issues of concern within women's lives as *natural* or given (Mahon 1998a, 1998b; Lewenehak 1992; Crompton 1999, 2002, 2006; Baker *et al.* 2004; Williams 2004).

Furthermore, the association of care with the work of women in general and the associated under-valuation of women's work has meant that this caring has often acquired a value akin to unskilled work in the public sphere of paid work. It is placed at the lower levels of professions and work hierarchies. It is associated with poor and insecure working conditions, is badly paid, has little room for work and career progression, and often transgresses formal and informal forms of employment (Hochschild 1983, 1997; Folbre 1995; Himmelweit 1999; Crompton 2002; Williams 2004, 2009; Hammermesh and Pfann 2005).

Research has also suggested a link between caring and poor health (O'Connor & Ruddle, 1988; South Eastern Health Board; 2000; NESF 2005; CPA 2008). One third of respondents in the 1988 O' Connor and Ruddle study felt their health had suffered due to care-giving. In the UK, Carers UK (2004), reported greater levels of ill-health among carers than reported amongst the non-carer population, particularly for young carers. Maher and Green (2002) suggest a link between intensity of caring and ill-health. The health care needs of the carer have also been cited (O'Donoghue, 2003; Cullen *et al* 2004), particularly as it becomes apparent, that as people live to an older age, their family carers are also themselves growing older and exhibit similar vulnerabilities to ill-health and disability as the rest of the population. The South-eastern Health Board (2000 cited in Carers Association 2005) reported that a significant proportion of carers noted deterioration in their health subsequent to taking on the caring role.

More recently, O'Sullivan (2008) in a study involving family carers on low incomes, found that in comparison to the general population, family carers were less likely to report themselves in excellent or very good health. Carers also reported comparatively high levels of depression, back pain and anxiety. Blackwell (1992) found in relation to Ireland, that carers were nearly twice as likely to be at risk of depression compared to non-carers – something also reported by UK studies (Boden, 2002; Carers UK, 2006). O'Shea (2000) in his study of the costs of caring for people with Dementia and related cognitive impairments, reported that carers indicated a worrying level of psychological distress.

Furthemore, care-giving can generate tension and conflict. Carers in the O' Connor and Ruddle study (1988) reported adverse effects of care-giving on relationships with children (23% of respondents), spouses (16% of respondents), and family life in general (24% of respondents). They also found that 59% of carers experienced restrictions on their leisure and social activities. This is consistent with O'Sullivan (2008), whose research indicated that family carers often had restricted leisure hours and were at a high risk of being exposed to stress, emotional strain, and social isolation. The extent of limitation posed by caring on leisure/recreation appears to be a key factor both in likelihood of health suffering due to caring and in likelihood of low quality of life for carers.

The intention of this discussion is not to provide a fully comprehensive review of all the research literature on caring. It does, however, provide a flavour of some of the key and ongoing issues impacting on carers in Ireland today. It clearly demonstrates that a number of the concerns highlighted are long-standing ones which have been researched over a period of at least 30 years, but which still remain current.

METHODOLOGY

As stated this report draws on two research exercises, one undertaken in 2007-2008 and a later on undertaken in 2013. A mix of quantitative and qualitative methods was employed in carrying out the research – quantitative, to quantify different experiences across the population of carers consulted in the course of the research; qualitative, to allow for a more in-depth understanding from the perspective of the carers themselves. Data was gathered through a questionnaire, which is included in an appendix to this report, as well as a series of semi-structured interviews with a smaller sample of carers.

During a series of meetings in 2007 with the research team, the Carers Association Cork and focus group discussions with carers, the focus of the study was discussed and finalised and a questionnaire was drafted. The drafted questionnaire was piloted with 20 carers before the final version was ultimately agreed. This participatory approach provided both important local and specialist knowledge to the research team as well as a sense of ownership for the participants. The finalised questionnaire contained four sections focusing on (i) a description of the carer, (ii) the type of care provided and informal supports available; (iii) access to and quality of official supports and (iv) the needs of carers themselves.

The questionnaire was completed anonymously. However, those respondents who wished to engage further with the process, through in-depth interviews, were also requested to return their names and contact details on a form provided separately. Thereafter, this group were contacted by the research team and in-depth interviews with them were arranged. Interviews were recorded and following this all notes/tapes were transcribed. Participants were later offered the opportunity to review the written transcripts and make any changes they wished to make.

The questionnaires were posted to 500 carers drawn from the distribution list of the Carers Association, Cork in October/November 2007. Also included was a joint letter from the Carers Association, Cork and the research team explaining the nature of the research and requesting that people complete and return the questionnaire. This was followed up by a reminder letter in March 2008. A total of sixty-three questionnaires (12.6%) were completed and returned and twenty carers volunteered to participate in-depth interviews with the research team. The in-depth interviews were carried out

between February and June 2008 and analysis of the survey material took place concurrently. This analysis offers insight into the perspectives and opinions of this group of carers, in particular, and raises pertinent issues regarding their experiences of caring in the local context. However, issues raised often reflect those arising in other localities, and nationally, as is evidenced through existing literature and research in the area.

The update to the 2007 - 2008 research exercise took place in the context of a series of austerity measures put in place more recently. It took the form of a focus group discussion with family carers in Cork in August 2013 where they highlighted their more current experiences in accessing support services. This discussion was organised through the Carers Association, Cork and facilitated by the research team. The discussion was recorded, transcribed and, thereafter, analysed in the context of the earlier research undertaken. Preliminary findings were developed and presented by the research team at a Carers Forum meeting on 14th November 2013. During this meeting carers were invited to contribute and to discussions on these preliminary findings and elaborate on issues raised in order to deepen the understanding of their specificities.

WHO ARE THE CARERS?

In total, sixty-three carers completed the survey in the locality. While national figures indicate that almost two thirds of carers are women, and one third male (CSO 2010) in our study three quarters were women and one quarter were men. In age they ranged age from their mid-twenties to those in their eighties. However, the bulk of carers, 83%, were aged between forty and seventy.

Age	%
25-29	1.5
30-34	1.5
40-44	8
45-49	19
50-54	19
55-59	21
60-64	8
65-69	8
70-74	8
75-79	5
80+	1.5

Within this group, most were between 45 and 64 years, indicating a close association between caring and mid-life roles and responsibilities. Nationally, it is estimated that over half of carers are in this age group, (CSO 2010) whereas in our study they made up group made up 67% of those surveyed. It is also notable that 14% of carers were over seventy years thus questioning assumptions that link ageing with dependency and drawing our attention to the active contribution of older people in sustaining families and households. Almost 90% had been married or in co-habiting relationships at one time or another. At the time of our survey, two-thirds of the carers were currently married or co-habiting, 11% were widowed, and the remaining four were separated or divorced. Only 16%, 10 of the carers were single.

In keeping with existing literature in the area, the vast majority of carers were close family relatives of those for whom they were caring. Furthermore, the vast majority of carers interviewed (97%) were principle carers. Virtually all carers, 98%, cared seven days per week. In the vast majority of cases they did this without much assistance from anyone else. Nearly 50% said they cared for the person largely by themselves, while the bulk of the rest mentioned help from a partner (14%) or from other family members (33%).

Caring for whom?

Most carers, 94%, were caring for children, a parent and a spouse/partner, sometimes for over thirty years. Over ninety percent of carers said the person they cared for lived with them. Only a very small number, 6%, were caring for other, more distant relatives, neighbours or friends.

Nearly 30% of carers were a parent of the person being cared for, 38% were caring for a parent and just under this, 27%, were caring for a spouse.

Relationship to person cared for?		
	Number	%
Mother or father	24	38
Son or daughter	18	29
Wife, husband or partner	17	27
Other	4	6
Total	63	100

Fifty-seven percent of those being cared for were female and 43% were male. This probably reflects the longer life expectancy of females in the population. In terms of categories of disability/illness experienced by the cared-for person, the biggest single category mentioned was physical disability

(16%) followed by learning disability (6%). However, a very significant 24% (1/4) of all carers mentioned that the cared for person suffered from multiple disabilities/illnesses, ranging from physical disabilities to mental disabilities.

A significant 21% of those being cared for were under 20 years of age, and in these instances, they were usually being cared for by their parents. Another 20% of those being cared for were eighty years old or older, while 10% were aged between seventy-five and seventy-nine. The remaining 50% were spread relatively evenly among the age groups, twenty to seventy-four years.

Helping Hands?

In answer to the question ‘Do you get help from your spouse/partner’, 38%, or just over one third of carers said they did. Considering that two-thirds of carers interviewed had stated they were married or had a partner, and just less than this indicated that they were caring for a spouse or partner, this suggests that partners are an important source of support for those caring for people other than their partners.

Fifty-seven percent of carers indicated that they got some help from other family members, friends and neighbours. Where specified, this help was more likely to come from women than from men, indicating a continuation of gendered caring networks. It also reflects the nature of care in contemporary Irish society. The bulk of carers are female, (CSO 2007; Lynch 2008) but with a sizeable percentage of males, and virtually all of them are close family relatives.

Help in Caring		
	Yes	*No*
Partner	38%	63%
Other family Member	57%	43%

Of those who reported receiving help from these sources, 29% reported they received help from sisters and 27% received help from a female relative. Twelve percent received help from a brother and 13% from a male relative. Eighteen percent received help from a neighbour and 16% from a friend. However, it also emerged, particularly in the in-depth interviews that the process of seeking and getting such support was enmeshed in complex family dynamics. Carers sometimes felt guilty and frustrated about asking others for help. Also tensions could develop around this issue which could act as a barrier to asking for help at all.

Help from:	**%**
Sister	29
Brother	13
Female Relative	27
Male Relative	13
Friend	16
Neighbour	18

It might be worthwhile to develop family facilitation procedures, in conjunction community-based support services, to enable families to discuss the issues arising around caring for a family member. An added benefit would be that such interaction with professional expertise, which could help alleviate stress and conflict associated with increased care burdens, an identified risk associated with family caring (O'Connor and Ruddle 1998). This would also have the added advantage of highlighting caring contexts to such support services, rather than a current patient (cared for person) orientation, perhaps facilitating the development of a more flexible service provision. Only 10% of carers in total mentioned getting help from any other

sources in caring. The sources most mentioned were COPE foundation, St. Luke's Daycare Centre, Home help services and Public Health Nursers.

Almost half of carers, 46%, stated that they had other family responsibilities that could be affected by their caring role. These other responsibilities tended to involve children who were cared for or responsibilities they had for an elderly relative.

This paints a picture of caring which is almost totally provided by one close family relative with support primarily from other relatives. Support from statutory or other voluntary sources, as far carers themselves are concerned, are quite limited. This raises the issue about where responsibility within society should lie for helping those greatest in need, the role of the state, the community and the family. As is evidenced in our discussion on the development of policy and services on care in the community, opinions differ on this, from those that support the development of statutory rights-based service (Robins 1988; Hasslett, Ruddle and Hennessy 1998; Garavan et al 2001; SIPPU 2006) those that view care to be the responsibility of family members, with supporting services developed to make up any shortfalls (see Prendergast 2006).

What Caring?

As would be expected, caring involved a very wide range of tasks necessary to maintain and sustain daily living. Drawing on previous work in the area of caring we listed a range of tasks and asked carers to indicate with which they were involved, and on which, if any, they needed any they needed any advise. These included practical tasks geared towards everyday concerns, engagement with health services and medications, and more qualitative ones geared towards supporting well-being and social/psychological engagement.

The most common caring task that was mentioned by 95% of carers, was cooking. This is not surprising given our daily food and nutrition needs. This was followed by laundering 93%, shopping 92%, cleaning 90%, all of which relate to maintaining and sustaining daily living. Eighty-seven percent of carers reported that their care incorporated attending appointments 87%, while just under this, 83% assisted in giving medication. Other key tasks were managing finances and providing company for their relatives. Other key tasks were looking after house maintenance 82%, providing transport 80%, keeping the cared for safe 80%, motivating 73%, confidence building 72%, leisure activities 72%. Carers also dealt with aggressive behaviour

55%, dressing 52%, washing 57%, bathing 52%, toilet 38%, eating 32%, drinking 23%, providing support moving to bath/chair/bed, 37%, providing support walking in house 37%, moving on or off public/private transport 48%, pushing wheelchair 33%.

We can see from the scope and range of these tasks that caring incorporated a multitude of activities, oriented towards the other and attendant to their individual needs. While the tasks themselves offer a flavour of the diversity of activity involved in caring, their orientation and individualised focus are central in their execution.

Major Tasks Carried out by Carers	**%**
Preparing and cooking food	95
Shopping	92
Cleaning	90
Laundry	93
Providing/organising transport	80
Giving or monitoring medication	83
Dealing with difficult behaviour, Aggression etc.	55
Managing finances, bills, benefits, etc.	83
Company/activities at home	83
Reassurance, confidence building	72
Motivation	73
Supervising cared for doing tasks and keeping them safe	80
Attending leisure activities/family events with cared for	72
Attending meetings/appointments	87
Looking after the house/e.g. building maintenance	82
Help with dressing	52
Help with washing	57
Help with bathing showering	52
Help with getting on/off public / private transport	48
Help with using the toilet	38
Help with getting into or out of bed/chair/bath/toilet	37
Pushing wheelchair	33
Help with walking and moving indoors	37
Help with eating	32
Help with drinking	23

At least some of the tasks reflect what some writers have referred to as ‘love labour’ (for example, Lynch 2007) in that they recognise the needs of those cared for to be the recipients of love and experience emotional attachments.

It is clear that many of these tasks are very personal and may require the development of an ongoing empathetic relationship between carer and the cared for. Indeed it

could be argued that all the tasks need to be carried out in an empathetic manner respecting the dignity and human rights of those being cared for.

Since care appears to be primarily carried out by family members one question that arises here, however, is whether some of all of these tasks need to be carried out by ‘loved ones’ or family members and what would happen in the absence of such family members being able to provide such care? Another question which will be discussed later concerns how such a level of care affects the quality of life of carers and whether their needs are being catered for in society.

Access to Support Services and Financial Supports

Less than half the carers, 44%, stated that an official such as the Helath Service Executive had ever comprehensiviely assessed their needs or the needs of the person or people for whom they provided care. Considering that a number of the tasks listed above potentially require physical strength and skills associated with psychological counselling and leadership, it is worrying that over half respondents reported the absence of such needs assessments of their overall caring contexts.

People had varying access to community-social-based support services, as can be seen from the table below. This, again reflects a short-fall in service provision, as has been evidenced in earlier research in the area (Robins 1988; Lundstrom and McKeown 1994; Prendergast 2006): Fifty-eight of carers reported that they were in receipt of support from public health nurses and 46% had access to occupational therapists. Thirty-eight percent had home help support. Just under this, 35%, availed of respite services and about one quarter had access to a chiropodist and to day care services. While this indicates a high level of involvement of such services with home-base caring, it is also worth noting that a sizeable number of carers are not in receipt of these services. Given that some 98% of carers indicated that they largely cared for their relative/s on a full-time basis, including night times and weekends, there is then considerable room for expansion and development of such services. However, current indications are that community support services are most at risk of being cut back (HSE 2010).

Carers' Comments

I found it difficult to get my needs across and when we ran into difficulties, no one was there to help us

How can you make people understand what it is to care - 24 hours a day? … that inability to make people realise what it demands of you, morning, noon and night and the constant thinking of the other person…

Healthcare supports	In receipt of (%)
Public Health Nurse	58
Home help	38
Night nurse	2
Respite care	35
Day care	27
Chiropodist	24
Occupational Therapist	46

Support services for home-based carers can be key enabling factors in sustaining and maintaining caring relationships. Policy in this area indicates that a range of financial and community service supports are available and indeed the Primary Healthcare Strategy published in 2001, *Primary Care: A New Direction*, gives community-based care priority. As discussed, community care financial supports include Carers Benefit and Carers Allowance. They also include respite grants and financial assistance in home renovation. Care supports include home help services, currently being developed more into home care packages, public health nurses, occupational therapists, chiropodists, day care and respite centres and so on. In sum, they can be conceptualised as the range of financial, advice, and service supports that come together to sustain home-based care. However, in Ireland, responsibility for them is split between different government departments; the Department of Social Protection (previously the Department of Community and Family Affairs), in the case of Carers Benefit and Allowance; the Department of Health and Children with regard to medical oriented services; the Department of the Environment, Heritage and Local Government, in the case of home renovation supports. This is further complicated by age, with the Department of Education and Skills having responsibility for education for children and young people who are under 18, and the Health Service Executive having responsibility for the welfare of

CARERS' COMMENTS ON ACCESS TO SERVICES

What services are available for pensioners with a mental disability, that's what I'm trying to find out

Accessing services is so full of red take. It takes so long to get anything that sometimes you just forget about it

This house is not suitable for a wheelchair

It's difficult to get anyone to admit to being in charge of any particular service

My daughter is now 18. We are discharged for all services

children. Services are also often geared towards, either children or the elderly, rather than the needs of those requiring care, regardless of their age.

One of the issues that arose during the course of our research was the confusion and frustration that such split responsibility at State level causes. It negatively impacts on people's ability to access information about services, because, at first it is sometimes difficult to find out where, exactly, to find a particular service. People often referred to high levels of bureaucracy, they were confused about what, if any entitlements, they had and had difficulties in finding out about the existence of services. Furthermore, the issue of resources also came into play, with difficulties in contacting offices, and when they did, often their phone calls weren't answered for long periods of time. Such concerns yes again, question the actual priority that is being given to community- and home-based care, despite their stated policy priority, as discussed above.

The idea of a one-stop-shop has already been mooted, as a possible support/advocacy centre to help co-ordinate services and provide one place where carers and those they care for could look for comprehensive support. We asked carers if they supported such a proposal and requested their general opinions on such a centre. Eighty-one percent support such a development.

Importance of Such Services in Sustaining Home-Based Care

In general, carers were very appreciative of the supports that they did access. People contacted services through a number of sources, often through public health nurses, GPs, the Carers Association, the Citizens Information service, through support and advocacy groups that were generally illness based, through family and friends and by 'phoning around'. Some services and groups often then became the conduit for accessing other services and people often made very positive remarks about them, as can be seen from the extracts above. They meant more to carers than their respective names convey. Not only were they services within themselves, they also provided external connections, someone with whom to discuss issues arising, and respite from isolation, fear and worry; all issues pertaining to carers, that have been highlighted and discussed for some time (Hochschild 1983; O'Connor and Ruddle 1988; Maher and Green 2002). Such indicates the importance of identifying and publicising first or key points of contact through which other community services can be organised and through which social and psychological support can be offered, both to the carer and to the person needing care.

CARERS' COMMENTS ON SUSTAINING HOME-BASED CARE

And there was no support. The only thing we had was the GP. He was absolutely brilliant, but the isolation, the fear, the worry. It was very difficult for […] as the patient, for me as the carer

I find the public health nurse invaluable for setting up respite, accessing pads from community stores and helping get the stairlift and bathroom done

So it's working out now, but because I went to the Citizen's Advice and the Carers Association in Tuckey St.

It is a quick visit because they [public health nurse] have a lot of houses to call to

Right now I think I'm OK because I get a lot of verbal support from the OT, and the carers group ... I can phone if I'm feeling very stressed

They [public health nurse] came very quickly on leaving the hospital and were very supportive

When we needed it [public health nurse] I couldn't fault it

Issues Arising – general

The key community services to which carers had access were pubic health nurses, home help, respite and occupational therapists. As mentioned, carers were often very appreciative of assistance from these sources while being acutely aware of the limited resources available to services such as public health nurses, respite facilities and home

help. They often considered themselves lucky to have the support of those services with which they were in contact. A number of issues arose in accessing these services that are worth detailing in more depth. While some of these issues cross the range of community-based support services, we discuss them below with reference to particular key services in the first instance. Thereafter, we turn our attention to financial supports and the opinions carers expressed about them.

Public Health Nursing

According to documentation available through the Citizens Information Board (www.citizensinformation.ie) public health nurses are employed by the Health Service Executive (HSE) and work at local levels to provide community-based nursing to a range of people including older people, those with chronic illnesses, and people with disabilities. They work in health centres, day care and other community centres, schools and people's homes. The scope of the service includes planned weekend and palliative nursing and their role involves them in communication with a range of service providers in order to ensure that people's primary care needs within their communities are met.

For those who had public health nurse support, ease of access in the first instance varied, from immediate referral, usually post-hospitalisation, to four to five weeks post-hospitalisation, indicating a close association between hospitalisation and community health nursing. While carers generally indicated that they were satisfied with the service, this was in the context of knowing that their workloads were heavy 'it's a quick visit as they have a lot of houses to call to' (Carer's Comment).

CARERS' COMMENTS ON PUBLIC HEALTH NURSING SERVICE

District nurse is aware of my position but never talks to me. Now aware of what supports might be available

No one bothering to listen

They might have the office telephone number of their public health nurse, and could call if they needed assistance. However, carers expressed a wish that pubic health nurses call to them more often, as a re-assurance and as a way of connecting more comprehensively community support. Some suggested that a monthly call would be more than welcome, rather than the current practice, whereby it seemed that carers are visited by public health nurses only if they have a particular/acute need. This led some

to feel that they weren't being listened to and increased their levels of isolation, which has already been identified as a risk factor for carers (O'Sullivan 2008). Furthermore, there was no indication that the service operated at night time or at weekends. Carers commented that they were unaware that they could request night time support, although this was something that would have been very helpful - '[I] didn't know you could request a night nurse. If I did, I would have requested it, as I have to get up 2-3 times a night' (Carer's comment). Others, when they most acutely needed nursing support viewed and were informed that, their only alternative to doing it themselves, was to employ private nurses. 'When things were very bad I did all the nursing myself. I was told I would have to hire a private nurse' (Carer's comment). The implication of this is that the perception of public health nursing, and its practice, is one that operates outside of weekend and night time hours, and that any nursing support outside of these times is a private and not a State concern. It would seem, thus, that idea of subsidiarity is continued in this practice

At times, carers felt that their heavy workload encouraged pubic health nurses to deflect them to other services, as in an instance where a carer 'needed a nurse to dress my mother's infected toe, but they were not interested and tried to get us to go to a GP for dressing' (Carer's comment). This is an obvious task for the public health nurse service, and encouraging people to visit a GP for it highlights the stress on the service and the manner in which this stress can impact on the quality of the service. Visiting a GP with an infected toe would be a difficult thing to do; one might expect that such an infection would decrease the person's mobility and in such circumstances, the journey to the GP should, ideally, be avoided. That medical professionals would recommend such a course of action is worrying and calls into question priorities and quality in the service as well as supports and supervision mechanisms that are in place for community-based nursing. If this is in any way indicative of stress levels on workers who bear unduly heavy workloads, the HSE's adherence to best practice as an employer is called into question. It must ask itself to what extent it contributes to neglecting rather than nurturing and developing community based nursing services, and to what extent community nursing services are, in reality, as high a priority as they are purported to be in the myriad of State policies already discussed.

Home Help Support

The home help support is a community-based service that is geared to facilitating the maintenance of home-based care, through a range of non-medical activities, depending on the needs of carers/patients. As already mentioned, it is a discretionary service, meaning there is no actual entitlement to it, as such. The recommendation of the *Years Ahead* report (Robins 1988) that it be developed into a statutory rights-based service has not been realised. As currently constructed, it is organised through the HSE at local level, the eligibility criteria is not available publically and is determined at local level. Home help personnel are employed by the Health Service Executive, generally at hourly rates. More recent developments throughout the country indicate the privatisation of the service and its replacement with Home Care Packages, although this movement is unclear, does not follow any published guidelines and seems to vary from local health offices. In the latter instance, carer's/patients are allocated monthly allowances which can be used to employ support. In conjunction with such developments, a number of private companies have emerged in recent years, for example Home Instead and Home Comforters, just two of the private home care companies that now operate across Ireland. As mentioned above, the role of the carer is to manage the allocated amount, the HSE's role is one of allocating funds, and that of the private operator is as provider of care personnel.

CARERS' COMMENTS ON HOME HELP SERVICES

Just sorry we didn't apply ourselves sooner

I enquired about home help but I heard nothing about is since, though I'm sure we're entitled to it

Within our research, of those in receipt of home help service the level of support received ranged from one hour to twenty hours per week. Some had access to the service from the time they began caring, while others waited up to a year after requesting it, before they were allocated hours. Others, on requesting the service were informed that they were not entitled to it. Some others who had privately hired home help, and subsequently heard about and applied to the HSE, transferred to the public service. In all cases, the respite that it offered, even for small periods of time, for some, was the only time that they had for themselves during the week. Home helps also sometimes provided care that carers themselves, felt unqualified or unable to

carry out. Sometimes, this might involve more intimate caring; washing and so on. At other times, it might involve, extra cleaning in the house, or help with mobility.

However, a number of issues arose with regard to carers' experiences of the service. There was considerable confusion regarding people's entitlement to the service and the nature of the service. 'I don't know if I would be able to get a home help because my partner can get around the house, but at holiday time it would be great if I had a home help, but I don't know if I'd qualify.' (Carer's comment). As this extract indicates, the carer was unsure if the criteria for inclusion in the service included not being able to 'get around the house. Others thought that the service was means-tested, commenting 'I enquired but understand it is means tested and wouldn't be given it' (Carer's comment). More were told that they were not entitled to it because they had a private pension, and others were instructed that they could not be in the house while the home help was there. This combination of issues can only deter people from applying for home help assistance in the first instance, and fuels confusion and misinformation about it. It also contributes to the opinion that such care support is charity-based and not a right or entitlement, and thus is a further example of the State locating care responsibility primarily with family members.

CARERS' COMMENTS ON HOME HELP SERVICES

The person organising the home help would make you feel that you shouldn't be asking for help

I found it degrading to have to beg for this service but I needed to give my other children a chance to see me as a normal mother and spending time with them

When funding for assisted living came though they tried to take homehelp away but I wrote begging for it to be continued

You have to trust the person and the house is not private anymore, when you have people walking through it all the time

As well as inadequate and sometimes inaccurate information concerning entitlement to the service itself, and its scope, as discussed, further issues arising included problems with initial contacts, assessment of need, identifying appropriate personnel and sustaining the service.

Initial contact with personnel in the local health offices, who co-ordinate and organise the home help service was sometimes less than satisfactory. Some people reported that they felt humiliated and degraded in asking for this assistance. They indicated

that these feelings were fuelled by the responses to their enquires, sometimes making them feel like they were making excessive demands. It was only through their perseverance, and their need to find ways to make time for themselves and others in their families, that they did they gain access to the service.

At this point issues arose with regard to compatibility and personnel. Home-based care it just that; it is based in people's homes and, as such, when supported by paid workers, traverses the public and private spheres of life. People found it difficult to 'open up their homes' and would have liked more consultation regarding the selection of home help personnel.

This is a sensitive issue, but surely transparent and open communicative processes can be drawn up to address it. Furthermore, while some had very high regard for the home help service, others indicated that the service was uneven and poor, reflecting earlier research findings in the area (Lundstrom and McKeown 1994). There seemed to be little in the area of training and supervision, and standards varied. Again, this draws our attention to the seemingly immeasurable gap between written policy in the area of community support service and the reality of practice.

Respite and Day Care Services

Respite and day care services were other areas that carers indicated made a real difference to them in assisting them to sustain their care work. One carer stated that 'respite care is essential. I would not have been able to care for the past 10 years without it. It allowed me to give time to my family' (Carer's comment). Another, referring to day care stated that 'I would be dead without their help' (Carer's comment). As already stated, 35% of our respondents indicated that they had access to and used respite support, while 27% used day care services. Access to these

ACCESSED RESPITE CARE:

- After a long time of asking around, sister-in-law heard about it from a friend who is a nurse.
- PHN advised me
- Post office form
- Social worker
- Natural progression through school, rehab training, respite facility – all belong to COPE

ACCESSED DAY CARE:

- When my husband came out of the hospice, they arranged for him to come in twice a week.
- By ringing around various organisations
- District nurse
- Progressed from school to daycare centre

… my sister will be a pensioner in a couple of years and I'm not sure if the service will be suitable for her then

services also seemed to be connected with age, with those caring for children and young people under 18, often making contact through schools, while those caring for older people made contact in more *ad hoc* ways, Respite and day care were organised through a combination of HSE facilities as well as voluntary and religious groups, and it seems that children and young people who progress through the education system are more likely, to an extent, to access day care, often in the forms of training or sheltered employment.

Those caring for young people under 18, were often unsure about what facilities would be available to them once their, usually, son, daughter, brother or sister, turned 18 – 'Nothing in place after 18th birthday (Carer's comment). Where carers had

accessed respite and day care services and they and their relatives were comfortable in using them, they tended to organise around what was available to them. Some found that the need to plan ahead, often associated with respite care, was cumbersome and limited their flexibility, while others looked forward to respite that was booked, sometimes months in advance – 'I'm lucky to have respite care dates for the following year in December' and 'You have to plan so far in advance' (Carer's comment). However, there was a perception that respite and day care was organised, not so much with the needs of carers and those for whom they cared, but rather to suit institutional contexts. People commented that they availed of what was available, but considered it not to be geared towards their needs. 'They take [ ] for three days every month, depending on whether there is a place available' (Carer's comment). And, 'not flexible enough. I do not always require a full week, but that is what they provide. I usually just want an occasional day or weekend. (Carer's comment). 'I'm in the process of applying [for respite care]. Possibly I'll be offered a couple of days when it suits the providers, rather than me. (Carer's comment). Others thought that the change of surroundings or general environment in respite centres confuses those for whom they care, or do not engage patrons in activities, and therefore, when they need/want to spend some time away, they arrange family members to take over, although it was indicated that this was often difficult. At other times, those needing care didn't like the facilities available and in such instances, they were not considered an option. One carer commented on day care that had been available that the 'range of activities [was] inadequate [and spouse] would not agree to anymore,' (Carer's comment).

CARERS' COMMENTS ON RESPITE SERVICES

Haven't applied [for day care] mainly because he refuses to attend

He doesn't like to be around old people

My mother refuses to go into respite as she believes it's a long term nursing home

The service [day care] provides adequate support though not many skills are taught

This service [day care] was available to me but my mother wasn't interested

Once inside the centre [respite] there is no socialising. Clients are usually there at 7.30pm and in bed by 10.00 pm.

What is indicated through these comments is that the provision of day care and respite care services is makeshift, unplanned and disjointed, despite being essential and key supports for home-based carers and those for whom they care. These were all shortcomings identified, for instance, by the Joint Oireachtas Committee (2002). Care

can be excellent or can be poor; places might or might not be available; it might be possible or even mandatory to plan well in advance, and perhaps those plans will not have meaning, depending on available space. Services also seem to be organised around age groups: for those under 18, post-18 and under 65, all who seem to be channelled in various directions, that don't necessarily take into account physical as well as social needs and capacities. In cases where these needs are taken into account people are very appreciative of the scope and depth of the service offered, as expressed by this woman on the day care service which her husband attended. 'Great support for me. They collect my husband and bring him home again in the evening. Staff are great, husband loves going there and meeting other people. Gives him a chance to earn a bit of money' (Carer's comment). However, there seems to be only limited evidence of the development of more flexible respite care as recommended by Joint Oireachtas Committee (2002).

People needing care are drawn from all age groups and their care is not so much age related as ability and capacity related. Their need for care is one aspect of their lives. Respite and day care need to be attractive and cater for a wide range of needs, as well as providing a safe place to be. Particularly, those people who are over 18 and not yet 65, seem to fall between the gaps in the system geared towards the 'young' and the 'old', having some 47 years, to wait to quality for facilities geared towards elderly patrons.

Occupational Therapists

Quite a high number of people had accessed occupational therapists (OT), often with an initial visit coming between a few weeks to some months of requesting the service. However, again there were a number of instances where people were waiting longer, up to 14 months, and where the information they received indicated that public waiting lists were long and that opting to access the service privately would be their best course of action. These instances indicate, again, that information about, and access to occupational therapists could be organised in a way that is more transparent for users. Access to OTs was generally through schools, GPs, public health nurses and hospitals. Oftentimes, public health nurses or GPs made contact with the OT service and carers were then contacted directly by them. Carers found difficulty, however, in attempting to make direct contact with OT services themselves. Some people were in a position to have OT assessments organised through schools and found this to be valuable, 'Can be assessed at school, is very good. He can get OT assessment and speech therapy' (Carer's comment).

CARERS' COMMENTS ON OCCUPATIONAL THERAPIST SUPPORT SERVICES

Told [there was a] waiting list of 2½ years, so had assessment done privately to identify and fight for school support needs to be met

Not easy to access: 'you have to wait so long for them to get back to you

Received this support 2 months after assessment

I was told there was no OT living in the area

Those who assessed OT services found that it was invaluable to them. They generally commented that they had made very positive impacts on their lives and on the lives of those for whom they cared. They indicated that OT personnel with whom they had contact were dedicated to their work, and had expertise and knowledge, for instance, of assistive devises, that other professionals did not have. They not only worked with individuals, but they were also able to make useful and practical suggestions for adjusting home environments.

However, there were also indications that assessments, for instance, in accessing assistive devices, wheelchairs and in relation to home renovation, could take a long time. One carer commented that it took two months for an assessment to be completed while others opted to hire an OT privately in order to speed up the process of applying for home renovation. Others commented that public waiting lists were too long and

not enough OTs were employed by the HSE, making the whole assessment process a slow and laborious one. This comment largely sums up these concerns, indicating to us the value that carers ascribed to this service and its personnel. However, and unfortunately, it succinctly points to the poor priority given at State level, through the HSE, to the service - 'It is a service that is totally inadequate considering the value of the work' (Carer's comment). Carers valued the OT service, for the contribution it could make to improving the lives of those for whom they cared and their own lives, and they clearly point to the lack of resources afforded to it by the HSE. Once again, that such an essential service that can contribute so positively to sustaining home-based care is also characterised by long public waiting lists, difficulties in accessing it and lack of clarity surrounding it, can only lead to a conclusion that State support for home based caring remains wholly inadequate.

CARERS' COMMENTS ON OCCUPATIONAL THERAPIST SERVICES

My daughter improved so much when she started with OT it makes me think how well she could have done had she had this service earlier

My husband's OT could not do enough for him

Very good, when you get it

Very good, made improvements in the home

Currently clients are only reviewed when requested. Only OT knows of new products which may benefit client/carer

Other Support Services

Other public services, about which we specifically asked information, opinions and experiences, or which carers themselves, mentioned, include those of chiropodists, physiotherapists, psychiatrists, and behavioural specialists. As with the key services discussed above, similar issues arose. To detail them in the manner in which we have those above, would only engage us in a process of undue repetition. Access to them was often not transparent, and generally involved, as the axiom goes 'being in the right place at the right time', an often laborious process of finding an appropriate person to answer a query, and indeed, getting to know the specific question to ask.

CARERS' COMMENTS OTHER SUPPORT SERVICES

My husband needs a wheelchair. I phoned the OT… it took 2 months before she called and she said it would be December or March [8 or 11 months] before he's measured for chair.

Public waiting lists far too long

Having to wait so long to come out [to the house] and you cannot speak directly to an OT on the phone. You have to wait until they phone you for appointment.

It's too slow processing and provision of service took 14 months

Just could do with more of it, but they are so busy

Very angry that support system is not there for people needing assessment/ intervention and treatment

Access to Assistive Devices / Technical Aids

A total of 65% of all respondents were in receipt of some technical aid . These included wheelchairs, sometimes electrical and specially fitted ones. It also included colostomy bags, pads, hearing aids, walking aids/stick, protective sheets, commodes, oxygen, hoists, airbeds, a talking clock and various personal items. One third of respondents indicated that the aids to which they had access were adequate to their needs and some commented positive on their helpfulness, the flexibility of a service that recognised progression of illnesses and the differing needs and aids that might be needed. However, other comments highlighted difficulties in access to HSE stores, limitations in quantities of pads, and long waiting times, because of limited funding and resourcing of community services. Others commented that high levels of

bureaucracy and difficulties accessing personnel who had authority to sanction aids acted as barriers to pursuing access to the service in the first instance.

CARERS' COMMENTS ON ACCESS TO TECHNICAL AIDS

As the sickness progresses, my husband needs more aids

Health nurse called and got Mam basic things to make getting around the house better; handrails on stairs before stairlift, stick for picking up things, seat for toilet

When I need pads I have to drive to and from community stores at St. Finbarr's hospital – 40 mile round trip

We're only allowed 28 pads per week, that means four a day for a person with MRSA

Accessing services is full of red tape. It takes so long to get anything that sometimes you just forget about it

The chair doesn't seem to suit him, there's not enough support for his back. The OT has clarified this, but he has to wait 'til next year as they don't have the funding to get a new chair

Financial Supports

In terms of financial supports one of the biggest issues coming out of the research, again, was that although people seemed to have knowledge, to some extent at least, about some of the financial supports available to carers, their likelihood of applying for them did not match this knowledge. For instance 84% of carers reported that they were aware of Carer's allowance and only 66% of these applied for it and less than one fifth applied for a home care package.

There was also criticism of the criteria applied to Carers Benefit and Allowance. Due to the demands of caring, carers had generally, perhaps over a period of time, or perhaps more abruptly, discontinued their participation in paid labour. Thereafter, and with respect to their individual circumstances, spouses' income became subsumed into the household income, with no reference to their loss of earnings or previous financial contribution to the household. The impact of this was that eventually, spouses became ineligible for Carers Benefit and their access to Carers Allowance was decided on household income. This process angered carers since it led to the carer moving from being identified as a 'productive' member of society to an 'unproductive' member of society and in need of State assistance. It contributed towards their invisibility, continuing the association of invisibility with care work (Lynch and MacLaughlin 1995; Badgett and Folbre 1999; Folbre 2998) by denying their lost earning capacity and assuming their dependence on the State, while concurrently denying their unpaid caring contribution.

Financial Supports		
	Aware (%)	*Applied (%)*
Carers benefit	60	27
Carers allowance	84	66
Respite grant	81	76
Home care package	30	19
Home renovation assistance	35	25

With regard to home care packages, given that current policy throughout the country seems to be moving away from the provision of home help service by the HSE and more towards allocating Home Care Packages to people, the low level of

CARERS' COMMENTS ON RESPITE GRANTS

After a long time of asking around my sister-in-law heard about it [respite care grant] from a friend who is a nurse

Need to fill in the application form each time, when there is no change in caring needs at all

awareness and receipt of Home Care Packages is of concern. Furthermore, there is evidence that the move towards Home Care Packages is further privatising home-based care, since the onus is on the carer to manage the sum of money allocated by the State, through the HSE, to make sure that it covers all care costs. This is succinctly voiced by one of the respondents who indicated that 'I have two ladies coming in different nights from 10pm to 8am. They cost €50 per night and the homecare package is only €816, so I have to cover the rest myself' (Carer's Comment). Clearly, here the carer has taken on the responsibility to manage monies provided by the State and make up the shortfall privately.

Only one quarter of carers applied for home renovation assistance. This is also of concern, when we know that upwards of 50% of carers helped in physical tasks, indicating that those they cared for had some mobility difficulties. Furthermore, given the context of caring, it is likely that mobility difficulties will increase rather than decrease, highlighting a need for support for home renovation planning. It also feeds into existing criticisms that some supports, such as respite, home care packages and home renovation are *ad hoc* in their provision, often entail a lot of waiting, phone calls, form-filling and generally high levels of bureaucracy. Furthermore, knowledge about their existence and availability seems uneven and are sometimes sourced incidentally.

Supports Summary

In summary, then when we examine people's experiences of health/community, financial and technical supports to help and sustain home caring, the following key issues arise: an appreciation of available supports; identification of key support and referral services; high levels of frustration with the limitations in both the scope and level of community service support; and confusion around entitlement and access.

As discussed, we asked carers about their experiences of and access to a range of services including technical devices, a wide range of community health and support services and financial support measures and a majority of carers had access to some support service. In the first instance, carers are generally very appreciative of any service; health, technical and financial, that was available to them to support their caring, assist in daily living, and help themselves and their family members who are in need of support, to live as best they could. Access to public health nurses,

occupational therapists, home helps and respite were viewed as central in sustaining care over time. The public health nursing service was viewed as a critical one, in that it was often through public health nurses that access to other services was organised. This service was one that was often identified as a first point of contact after a GP consultation or hospital stay and was viewed as a conduit for information about and access to other services. Home helps were viewed as critical in assisting in everyday activities and occupational therapists were seen as invaluable in advising on technical aids, adjusting to and working with the limitations of different illness.

However, while access to these and other support services was viewed highly, all community support services were thought to be limited in their resources. People often referred to high workloads of public health nurses, claimed that they had to wait for long time periods to access occupational therapists and had only a small number of hours per week of home help service. Such limitations were evident in all community support services about which we enquired. This indicates that far from being a Health Service Executive priority, as indicated as early as 1968 in the *Care for the Aged* report, and as recently as 2001 in the Health Care Strategy, community support service resourcing is inadequate to the demand for them. Quite worryingly, there are indications that some of the consequences of under resourcing/heavy workloads raise issues related to poor medical practice. They also include quite limited access to technical aids, which are often essential to sustaining quality in daily life, such as wheel chairs and toiletry pads, without which it can be impossible to maintain a degree of dignity.

Views of and experiences of financial supports indicated that carers were either not fully aware of them, or that high levels of bureaucracy, and what was considered inappropriate criteria for assessment, led carers not to apply for them. There was particular criticism that carers were assessed on household income for carers allowance and that their own loss of earning potential was not taken into account. The comments that carers made on this emphasised their anger about the manner that this contributed to their invisibility. There was also considerable confusion on home care packages: on what they actually were and how to access them.

One key question that these discussions pose, is why, in an environment where telecommunications and information systems have never been so sophisticated, inexpensive, and having the capacity to reach out in so many ways, from printed

materials, to mobile communications, and world-wide-web based applications, cannot such information be clearly and transparently accessible in policy and in practice, including information on numbers of personnel employed, their expected workloads, waiting lists and so on?

The ‘fudge’ that characterises current practice across all State support services encountered in the research process draws attention away from the very good work in which personnel in each of the respective services are engaged. It hides bad practice and poor State resourcing in the sector. It places the onus on the individual carer to increasingly turn away from public service provision, where that is a possibility for them. It also seems to place the onus on the individual service provider and co-ordinator of individual services to encourage carers in this direction, in their efforts to ‘stretch’ their poor resource allocation – perhaps efforts in this regard would be better aimed at HSE and State levels for calls for more resources.

Focus on the Carers Aspirations for themselves

The focus of this research is on the experience of carers in the caring environment. Up to now the concentration has been their relationship and work with the person for which they care. However, it is also important to discuss the quality of life of carers themselves and whether they feel their aspirations in life are being fulfilled or not. One element in this must be the amount of time carers have to devote to their own needs and interests. Whilst it is clear from the research that most carers receive very limited support in their caring, particularly from statutory authorities, nonetheless a majority of those in the survey, nearly two-thirds, stated that they were able to get planned short breaks from caring for shopping, leisure activities and visiting friends or family, etc. Many of the comments however suggest that such breaks are limited.

CARERS' COMMENTS ON ACCESSING SHORT BREAKS

At weekends I go out for a drink or a meal if my family can mind my daughter

If my neighbour is free for an hour or two I can out to get shopping done

I only get breaks if I bring the person I care for with me

She goes to pre-school three times a week and I can go out then

Shopping and visiting family – I tend to bring my son with me as those are my only social outlets

These [breaks] are inclined to *ad hoc* and I have to put effort into planning full time weekend breaks

I can get two hours in the pub, 5.00-7.00 if someone comes in

I get breaks twice a week when my husband goes to the day centre

When she is at school I am free to get out and about

Of particular concern it that nearly one third of carers said they who were unable to get such planned short breaks.

DO YOU GET PLANNED SHORT BREAKS FROM CARING?	
Yes	62%
No	30%
No response	8%

Nearly two thirds of carers stated they couldn't get regular long breaks from caring, for weekends or longer holidays. One carer commented that they 'didn't get a holiday in 20 years'.

Do you get regular long breaks from caring (e.g. for weekends or longer holidays)?	
Yes	30%
No	62%
No response	8%

Even when it comes to the third of carers who stated they were able to get long breaks, it's clear from their comments that they sometimes do this by taking the person they care for with them. They, thus, continue to have caring responsibilities during such times. Others rely on family or friends, or respite care, as discussed in the above sections.

Carer's comments on the Breaks they get

If I needed one, I could get another member of my family to help out'.

I go as a helper once a year to Lourdes

I have to apply for respite breaks on an ad hoc basis, but it's very difficult to organise impromptu breaks.

I take a few short weekend breaks a year when I pay for someone to care for my mother, so it depends on finance

Once a year my mother goes to a nursing home for 1 to 2 weeks when we can arrange it

Despite this, the vast majority of carers said that they felt able to continue caring. It is clear from the comments made that a sense of love one of family responsibility were important motivating factors here along with the belief that there was no one else to do the caring. This feeds into expectations of obligations and family responsibilities associated with close family and intimate relationships.

Carer's Comments on the Sustainability of their Care

As a mother I will do this as long as it takes.'

'At times no, (don't feel able) but that's not an option'.

Many of the comments however, were also revealing in terms of the stress and strain being placed on many carers in having to continue with this responsibility.

CARER'S COMMENTS ON THE SUSTAINABILITY OF THEIR CARE

As one gets older it gets more difficult. If more aids were provided and the house was wheel chair friendly it would be easier

I'm 78 years old and I hope to continue as long as I can

At times it seems too much. It is the continuous need to give every day

It's getting harder as I'm 68 years old

I'm always tired as I have to get up 2/3 times a night

'I find it difficult as there is a lot of bending and lifting and my back is giving me trouble'.

I'm older now and my son is stronger. If he knew how much power he has in relation to strength, I'd be in trouble

These comments also reveal a worry held by many carers as they get older or weaker about how long they will be able to continue and what will happen when they cannot.

With regard to sources of emotional support for themselves, nearly 80% of carers felt they had someone in which they could confide for emotional support.

DO YOU HAVE SOMEONE TO CONFIDE IN FOR EMOTIONAL SUPPORT?	
Yes	78%
No	21%
No response	1%

Most commonly this was a friend (46%) or a family member (43%). About a third (30%) said that they got such support from the Carers Association, which reflects an important role played by that organisation in this regard. About a fifth (21%) mentioned receiving such support from another support group. Among those mentioned were – Ark House, Inismore Lodge Mayfield, Day Care Centre,

CARERS' COMMENTS

When I feel really down I visit my father's grave and I feel some comfort in this'

'One can feel really guilty about respite care but as one settles in for the long haul…'

Hospice, and their GP.

With respect to employment, about a third of the carers said they were in employment, the bulk of whom worked part-time. Only 6% were in full-time employment, indicating what could be interpreted as an incompatibility between the two roles.

ARE YOU IN EMPLOYMENT?	
Part-time	25%
Full-time	6%
Not in employment	67%
No response	2%

Indeed, the difficulties of combining employment with caring are captured in carers' comments about their availability for employment. It's clear that at least some of those not currently in employment would like to have been working. The biggest factor which such carers felt would help enable them to get into employment was 'more caring support' which was mentioned by 22% followed by 'more flexible employment hours', 18%. Training was mentioned by 13% as something that would help them to access employment and help with CV preparation by another 6%.

CARER'S COMMENTS ON EMPLOYMENT

I could only work when he is at school

I have to be at home when my daughter's at home

I would need to leave someone with my mother

A home help of any description is not available to anyone on carer's allowance

I am an artist but find it difficult to find sufficient time for my work

WHAT WOULD HELP ENABLE YOU TO GET INTO EMPLOYMENT?	
More caring support	22%
Flexible employment hours	18%
Training	13%
CV preparation	6%

Carers, however, face difficulties trying to get training, not just in terms of trying to find the time from their caring to do certain courses but also because the benefit system often militates against carers availing of training opportunities. This is voiced succinctly in the following comment made by a carer 'I would love to study a course but am unable to because it for 20 hours a week and I would lose Carers Allowance if I did it' (carer's comment). The long time away from paid employment was also felt to be an issue by some carers in trying to get employment. As one carer said, 'if recognition was given to caring as experience for similar employment this might make getting employment in the future easier' (Carer's comment).

CARER'S COMMENTS ON TRAINING

I've been out of work for a long time. I'd need re-training.

I have lost a bit of confidence in that regard'

I feel I could do with computer skills

KEY FINDINGS FROM 2013 RESEARCH – GOING FROM BAD TO WORSE

This section of the report provides an update to the research conducted in 2008. As previously stated, given the more recent changes in supports in the context of austerity measures it was considered necessary to consult carers again with reference to their more current experiences supports and the challenges they face in their informal caring.

For instance, in policy terms, individualised and flexible home care services are increasingly viewed as essential in supporting and sustain home based care. Home help services are considered fundamental to this in assisting those who are in need of long term care to remain in their own homes as is stated in the *Report of the Interdepartmental Working Group on Long Term Care* (2008). It is worthwhile recalling the Working Group's 2008 statement regarding the very centrality such services.

> The home help service is an essential foundation for any expansion of home support packages, by enabling many older people with lower levels of dependency to remain at home. Home help services will also normally form part of a home support package, possibly with additional hours beyond the standard level of provision. The Group considers that flexible and good quality home help services will continue to be at the centre of community-based care over the long-term, requiring continued prioritisation within the HSE (2006:7).

It is worth recalling that at the time this report was developed the average number of home help hours family carers received per week was five hours; considering its identified role as central in sustaining family based care, quite a small number? In its report, the Working Group recommended expansion of home help services and home help packages in consideration of their centrality in sustaining home care and limited capacity at the time. This report also recognised the importance of respite services, carer's allowance, support for carers, and housing in sustaining and supporting home based care. However, a NESF Review of Home Care Package Scheme in 2009 found a number of shortcomings in the development of Home Care Packages, including variation across local health offices, lack of clarity on financial and medical eligibility for home care packages, variations in their monitoring as well as delivery of packages by a range of different organisations. Such factors alongside poor budgeting,

communication and data collection combined to limit the effectiveness of home care packages and surrounds them with an element of confusion limiting their potential as core support services. These concerns were reiterated by the OECD (2008) and are associated with more general concerns regarding the range of austerity measures that served to contract social protection, welfare, health and public services since 2008 (Frazer, Murphy and Kelly 2013). Furthermore, according to an analysis of Budget 2013 carried out by the Carers Association, they are increasingly 'concerned about the cumulative affect of the cuts to social welfare and health services coupled with the imposition of the new Local Property Tax' (Carers Association, 2013: 1). Budgetary measures introduced in 2013 in areas of social protection that, for instance, reduce respite payments and support for utility allowances, increase medical costs, and herald the full rolling out of the property tax in 2014, place further pressure on carers, whose finances are often already stretched to the limit.

These findings, then, while based on issues arising for family carers in Cork, and specific to this locality can be held to be more generally applicable outside of Cork. They are summarised here under the following general headings: family caring, home help support, home care packages, assistive devices, respite, building grants, reviews, community based services, linking with hospital services and more general austerity measures. Key concerns regarding each of these factors are listed and quotations drawn from the focus group discussion are included to better illustrate these issues in the words of carers.

Family Caring

There is evidence of increasing expectation that carers will provide support while people are in acute hospitals, nursing homes, and when their loved ones are moving between nursing homes and specialist appointments and so on.

> The expectation is that the family will kick in. You are told that if you have other siblings or whatever that they should do their bit first
>
> People are being challenged, if you are in hospital and you are taking out someone you are being told you have x amount of family members

Issues identified included the requirement ancillary services/toiletries provided be paid when people are in respite/nursing home. Carers also highlighted an increasing expectation generally that family members *will* provide caring support, whatever their circumstances. They also reported that they felt

they and their homes were under surveillance of homes. Some concern was expressed that this more evident if a review of support needs was being undertaken. Consequences included of needs, and allowances, instilling fear into carers and contributing to undermining confidence.

Home Help Support

A number of carers indicated that their home help ours cut with little or no notice and little or no explanation. They indicated that is was now usual for carers to only hear about this informally and often at last minute. Furthermore, they spoke about being allocated home help support in units of ½ hour, which they considered too short a time. Some indicated that they had heard about people being reduced to units as short as ¼ hour. They also thought that it was unlikely that new allocations for home help were being considered, even where the need for them was very obvious. Some, however thought that there were indications that if a carer was completely desperate, then there was a possibility of accessing home help support.

> It's just cutbacks and this privatisation has a lot to do with it too. People are actually paying to have the hour'
>
> …top it [home help] up yourself, pay private for half an hour to make up the hour…
>
> 'tis an insult, to be honest with you, to give anyone a half an hour'
>
> the organiser would just say we haven't the time, and that is that
>
> 'tis only home helps were taken away in the last year'

Confusion associated with a lack of clarity regarding the type of support offered by the Home Help Service

> The policy is that it is personal care … well, the home help themselves [tell people this]
>
> Very hard to get things like that in writing

There is a perception among carers that home help support is confined to personal care, Furthermore, there is ambiguity regarding what is considered personal care and what is considered more general care – carers themselves, don't distinguish between the two and consider home help to be help they need in order to sustain the care required in their individual circumstances. This, along with the not difficulties in getting clarification in writing regarding what is currently supported under the home care service, is causing increased stress and ambiguity regarding this essential support.

Home Care Packages

With regard to home care packages there is considerable confusion regarding its current availability and the scope of the initiative, in general. For instance, there is hearsay that new home care packages are not being approved, that there are difficulties in the resourcing of home care packages, and speculation that people are not being encouraged to apply for same. However, again this hearsay and speculation cannot be confirmed and carers indicated that written information on the current status of home care packages is not available to them. However, this only fuels concern and confusion regarding its actual status. In practice, with reference to those for whom the initiative is aimed at supporting, confusion is created around it, and carers perceive that there is no point in applying for a home care package.

> there is no money there so there is no point in doing it [applying for home care package]

Assistive devices and supports

Here again, there is a perception that there is increasingly limited availability of disposable sheets and some carers indicated that their access to them had been stopped. Moreover, they voiced concern over the quality and availability of incontinence pads. Some indicated that their allocation of incontinence pads was insufficient, and others that the quality of the pads they received was very poor. Both these issues cause them and those they care for considerable distress and do nothing to uphold the dignity of those needing to use them.

> but they did stop the disposable sheets.
>
> Mine were stopped twice
>
> And mine were stopped (quotes from three different participants

However, on a positive note all were in agreement that the more recent practice of recalling and reusing equipment that they no longer needed is a very positive and practical move.

> Well that is a practical idea, when they took them back before they were dumped
>
> That is the most sensible thing to come out

Regarding access to building renovation grants, again there was a general perception among carers that funds available under this scheme are not very limited, leading to delays in getting approval for essential renovations. It is worth noting here that when renovations are needed in a

home caring context, they are generally needed immediately, in order to maintain good quality care and the dignity of the person needing care.

> If you apply for it, it depends on the funding that is available for it, the might tell you it is gone and you will have to wait until next year

Reductions in Respite

Carers indicated that they are being allocated shorter times for respite care and that, increasingly, there was an expectation that they would pay for respite services, in order to make up the these cuts in time. They also indicted that they thought that there was now even less choice than before on respite places and voiced concerns that care people were receiving while in respite care was not always adequate to the individual needs of those needing care.

> …this new thing, you know, reducing the respite and then [carers] paying for the other respite…
>
> We did have two weeks cut in respite in 2010 but we went to war there and got another … but you have to do all that sort of thing which is time consuming and emotionally draining, Being a carer was always emotionally draining but it is far worse now'

Reviews

The issue of reviews of caring needs and requirements arose as a concern for carers and one that they perceived to be more concerned with identifying possible cuts to supports available to them and those they cared for, than to review and put in place sufficient supports in line with ongoing and changing care requirements.

> people are being reviewed now and, I believe … the review has only one objective and that is to cut people off'
>
> I suppose more than ever now, in terms of austerity, we are seen as the easy target

Linking with Community Services

Carers though that community based services are now under a lot of pressure to sustain their activities. They thought that because of the problems they were experiencing in accessing home-bases supports there might be more demand for, for instance, day care services provided in the community. Some thought that the development of primary health care centres might be beneficial in this regard and

> I suppose, the demand for day care has gone up because, if the likes of home help are cut…
>
> 'I have never heard of a primary care centre. Sure, most of us here pay for our own chiropody. Oh, yeah

mentioned these in particular with regard to access to occupational therapy, chiropody and physiotherapy. However, carers had little or no direct experience of primary health care centres and indicated that, in practice, they were under pressure to pay for any such services required.

Continuing Concerns Regarding Care in Hospital Services

> [X] said "no way am I going out of here without [treatment] … otherwise we would have been sent out and it could have been years'
>
> 'You would nearly have to get someone to sit on the bed while you go and [attend to] her'

Carers voiced a number of concerns regarding their experiences in interacting with hospital services and generally spoke about engagements in hospital contexts in the context of ongoing struggles to be heard and to ensure quality of care. Some indicated that acute hospital services are often not geared towards complex and quite specific needs of those for whom they care. They said that they were unable to use equipment that was specially adapted for the care needs of the person they cared for, when they are in hospital. They indicated that this was even so when people were in specialised hospital units, and even when these supports were vital to their care and were not available in the hospital setting. They related issues arising to a perception that equipment used in one's home would not be clean enough for use in hospital settings and emphasized the cleanliness of the equipment they used in their homes. Carers also expressed concerns regarding cutbacks in capacity of hospitals and transport to from hospitals. They indicated that these brought further burdens on them in accessing acute care and particular treatments when required.

Generally, Austerity measures

In general, carers said that the ongoing austerity measures are placing them under severe financial pressure. These include higher costs for a range of utilities including gas, electricity, telephones, and home heating. They also include the introduction of a property tax and carers are very concerned regarding the proposed introduction of a water tax. Cuts in the respite care grant, more stringent criteria for eligibility for medical services and discussions regarding core benefits increase their anxiety and

place them under further pressure. An associated lack of clarity and increasing levels

> Yeah, it is only when you go to the chemist and they say "oh, it is more expensive tis week", you know'
>
> the policy, on what they [state services] claim, to keep people at home is certainly not their policy because they seem to do everything they can to obstruct it'

of bureaucracy, regarding initiatives and services is also leading to confusion and frustration among carers.

Together, these issues indicate that family carers feel under increasing intensity of pressure regarding numerous factors that intersect with their caring roles. They are finding it more difficult to deal with state services than in the past and are unsure regarding the nature of services as well as eligibility for entitlement. A dearth of written material on the actual state of service provision and direction accentuates their stress and contributes to increased vulnerability.

CONCLUSION

In conclusion, then this research indicates that in general individual carers were themselves responsible for the bulk of home caring responsibility, often combining this with other household and domestic responsibilities. Informal support from extended family members was evident, but to a limited extent only, and within the context of the latter's position within the family, their other responsibilities and geographical proximity. It is possible that a facilitation process for extended families could be set in place to discuss the dynamics of home caring in greater depth.

Formal support, delivered through health services, financial schemes and packages raise pertinent issues on the development of community support. As stated, in the first instance access to any service, whether financial, health related, or in the form of practical assistance, was welcomed by carers and access to these contributed positively to sustaining home-based care. However, limited resources, bureaucracy, lack of clear information and high workloads acted as access and delivery barriers. Such barriers have heightened considerably in more recent years.

Sometimes family members were caring for long periods of time without any knowledge of or access to support services and knowledge of them often came about in *ad hoc* ways. Developments in home-help and home care packages further fuelled confusion, and there was little clarity about the ways both services interact, if in fact, they interact at all. Furthermore, those in receipt of home care packages seemed to accept that it was up to them and family members to make up for any shortfall in funds allocated. The role of the HSE in such instances was viewed as limited to estimating the amount of the care package and providing those finances. This also feeds into existing criticisms that some supports, such as respite, home care packages and home renovation are *ad hoc* in their provision, often entail a lot of waiting, phone calls, form-filling and generally high levels of bureaucracy. That this situation exists highlights the importance of identifying and publicising first or key points of contact through which other community services can be organised and through which social and psychological support can be offered, both to the carer and to the person needing care. An associated factor that arose concerned high levels of confusion and frustration associated with identifying responsibility at State level. Carers commented that it was often very difficult to find who was in charge or where responsibility for a

particular service lay. It was difficult to find someone who had the authority to make a decision.

Recurring themes for each and every one of the particular services discussed, were (i) limited resources (ii) long waiting lists (iii) limited flexibility of service delivery (iv) lack of clarity on entitlement (v) high levels of bureaucracy. Combined, these issues led to difficulties in accessing support and articulating needs. They also contributed to a general association of such services with charity rather than with rights and entitlement. Eighty-one percent of carers consulted in the 2007-2008 indicated support for the development of a one-stop-shop, which would act as a first point of reference, information and support conduit to help co-ordinate services and provide one place where carers and those they care for could look for comprehensive support. Carers called for the development of a one-stop-shop again in 2013.

Furthermore, and quite worryingly, there was evidence that limited resourcing and cutbacks raised questions about the level and quality of medical and health related advice and assistance at community level, in some instances, as well as gaps in supports and supervision mechanisms for community-based nursing. Adherence to best practice by nursing professionals, and the HSE as an employer, is called into question. That these issues arise at all, questions the extent to which community nursing services are, in reality, as high a priority as they are purported to be. It questions the extent to which those working ‘on the ground’ have adequate support at organisational level to ensure high levels of service provision. Our attention is drawn to the seemingly immeasurable gap between stated policy in the area of community support service and the reality of practice.

Carers strongly objected to the practice of assessment for eligibility for Carers Allowance, which is based on household income. In particular, they were of the opinion that their own unfulfilled earning potential and contribution in kind, through their caring, were not taken into account; the system, instead, views them as dependents and ‘burdens’ on the State. This also fed negatively into their own feelings of self-worth and self-esteem. Furthermore, in the later research carried out in 2013 there was considerable uncertainty regarding care reviews along with perceptions that they were heralding further cuts in support rather than meeting care needs.

Turning to their aspirations for themselves, carers indicated that they felt they would continue in their caring role as long as they were able to do so. Almost two thirds had some form of emotional support, be it through close family members, friends, and a variety of ways they devised themselves to connect more spiritually to people with whom they had been close and so on. Thirty percent identified the Carers Association as an important source of such support and another 20% identified other, mostly, illness based, support groups as sources of emotional supports for them. Such support was important at times when carers tended to become overwhelmed, tired and guilty. Related to this, an issue that arose as important was how care would be continued when and if the carer became unable to provide it. This was a source of worry for a majority of carers, especially in cases where their caring involved a lot of lifting and heavy manual work, and where carers, themselves, were getting older. About two thirds of carers, again, were able to get short breaks, in the form of having time to go to the shops, some leisure activities and visiting friends and family. However, this was sometimes achieved through including their family member for whom they were caring in the particular activity. So, while it might represent leisure, be enjoyable and so on, the extent to which it can be considered a break from care is also limited.

Only 6% of carers were in full-time employment. However, one third were in part-time employment. They identified a wish to become more involved in employment and training, but in a way that would not interfere with their caring responsibilities.

In general terms, then the research offers a view of the complexity and dynamics of family caring as it is experienced in an Irish context. It draws attention to the manner in which community care supports are currently organised, seem to be prioritised, and practiced from the perspective of carers, as service users. Such knowledge can contribute to a better understanding of family caring and the development of services that are more in tune with those they are developed to accommodate.

RECOMMENDATIONS.

A number of key policy recommendations arise from the research undertaken which we now detail below. It is noteworthy that much of these recommendations reiterate those made previously, in different policy and research reports and strategies. (for instance Robins (1998), The Years Ahead, HeSSOP Report No 19, and 64) However, much as they are rooted in the experiences, opinions and expressed needs of carers, this research indicates that they continue to be necessary and as yet, undeveloped. Therefore, the importance of developing them is, yet again, worth restating.

- The bulk of family caring is provided by *one* close family relative with support primarily from other relatives, from statutory or other voluntary sources. It is recommended that the State take more proactive responsibility in developing care environments and supports that are actually flexible in nature and geared towards the needs of individuals needing care and their domestic contexts.
- Multiple barriers were presented that related to lack of information and clarity on service support provision currently in place. The development of One Stop Shop where information and appropriate supports could be obtained would ease the current frustration and confusion carers are experiencing in attempting to deal with numerous agencies.
- Associated with the above the identification of specific authority holders for each service would help to develop a culture of transparency and accountability in community support provision.
- It would be worthwhile to develop family facilitation service to explore the dynamics of caring in families.
- The development of more structured training and supervision for community support service workers, to ensure adherence to good practice, high levels of professional conduct and protection of workers from overloaded workloads.
- The development a rights-based community based access to community support services, rather than a discretionary access, as is currently the case.

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APPENDIX : QUESTIONNAIRE USED IN 2007 – 2008 STUDY

September 2007

This questionnaire is about you and your role as a carer. It is to help us to better understand the needs of carers in the Cork region. We hope that this will enable us to work towards contributing towards an understanding of caring, as experienced by those doing the caring: you, the carers. We hope that this information will help in setting out the views of carers and in lobbying appropriate state agencies for resources and supports for carers and those for whom you are caring.

We estimate that completing the questionnaire will take approximately 45 minutes to one hour to complete. If you wish to clarify anything within the questionnaire or would like assistance in completing the questionnaire, please let us know. You can call the Carers' Association on 021-4806397.

This questionnaire is confidential. Any information that you give to use will be treated in confidence.

Following this questionnaire, we will be asking people to discuss their experiences with us in a more in-depth way. If you would like to volunteer for this further exercise, please fill in your name and details on the attached sheet and place it in a separate envelope, so that we can contact you later on. Again, any information you give will be treated in confidence and no material that will be personal or identifying will be used in the final analysis.

Many thanks for your support and co-operation.

About You

1. Are you: Male Female

2. What age are you:

Under 20	20-24	25-29	30-34	35-39
40-44	45-49	50-54	55-59	60-64
65-69	70-74	75-79	80+	

3. Are you:

Married	Co-habiting with your partner		
Separated	Divorced	Single	Widowed

4. Are you the principal Carer: Yes No

The Care that You Provide

5. Is the person you care for : Male Female

6. What age is the person you care for:

Under 20 20-24 25-29 30-34 35-39

40-44 45-49 50-54 55-59 60-64

65-69 70-74 75-79 80+

7. What is your relationship to the person you care for?

Mother/Father Wife/Husband/Partner Friend/Neighbour

Son/daughter Other relative

Other (please describe) _____

8. How long have you been caring for this person?

9. Does the person live with you?

10. How many days (on average) per week do you spend caring? _____

11. Do you provide care principally :

Once a week Weekends only Several times a week

7 days a week

12. Do you care for this person:

On your own With a partner With family help

13. With Other Support (Please describe) _____

14. What support, if any, do you receive from your family / friends / neighbours in caring. (you might find this table helpful to use):

Help / Support	**Yes**	**No**	**Hours per week**	**Type of Help Provided**	**At whose discretion**	**Please make any further comments you might have here**
Spouse/ Partner						
Family Members						
Sister						
Brother						
Other Female Relative						
Other Male Relative						
Friends						
Neighbour						
Other (please specify) ……						

15. Do you have any other family responsibilities that are/could be affected by your caring? (Please describe)

16. What difficulties / disabilities does the person you care for have?

(Tick whichever boxes apply)

Physical disability	Hearing Loss
Visual Loss	Mental health
Dementia	Substance Misuse (Drugs/Alcohol)
Learning disability	Elderly Frail
Terminal illness	Other (please specify below)

_____

_____

_____

_____

17. Can you describe briefly how you became involved in caring?

18. The following table details different types of responsibilities involved in caring. Can you indicate which of these you are responsible for and whether you need help/advise on them?

Task	**Yes**	**No**	**Need help/ advice**
Prepare and cook food			
Shopping			
Cleaning			
Laundry			
Providing/organising transport			
Giving or monitoring medication			
Dealing with difficult behaviour, Aggression etc.			
Managing finances, bills, benefits, etc.			
Company/activities at home			
Reassurance, confidence building			
Motivation			
Supervising cared for doing tasks and keeping them safe			
Attending leisure activities/family events with cared for			
Attending meetings/appointments			
Looking after the house/e.g. building maintenance			
Dressing			
Washing			
Bathing / Showering			
Using the toilet			
Eating			
Drinking			
Moving and Handling Support you Provide :			
Into or out of bed/chair/bath/toilet			
Walking and moving indoors			
On or off public / private transport			
Pushing wheelchair			

19. Would you like to make any further comment?

Access to and Quality of Services

20. Has an *official state agency* such as Health and Social Services, ever comprehensively assessed the needs of the person you are caring for, and your needs as a carer, in order to identify your complete caring needs?

    Yes No

    If yes, please give details below:

21. Are you aware of the following financial supports?

Carers Benefit	Yes	No
Carers Allowance	Yes	No
Respite Grant	Yes	No
Home Care Package	Yes	No
Home Renovation Assistance	Yes	No

Any other financial assistance to support your caring (please describe):

22. Have you applied for any financial supports ?

Carers Benefit	Yes	No
Carers Allowance	Yes	No
Respite Grant	Yes	No
Home Care Package	Yes	No
Home Renovation Assistance	Yes	No

Any other financial assistance to support your caring (please describe):

If you haven't applied for any of the above, please state why you have not done so?

Carers Benefit

Carers Allowance

Respite Grant

Home Care Package

Home Renovation Assistance

Can you comment on services you receive support from as a carer? You might find that these questions are a little detailed and they might seem to repeat themselves. However, we hope to get a good idea *of your views of the various services* that are available through your answers. So please take time to consider your answers. Thank you.

Public health nurse *Yes* *No* *How Often* _____

Have you requested this support *Yes* *No*

If you receive this support

How long after requesting it did you begin to receive this support: _____

Do you consider that this level of service is adequate for your needs?

Can you comment on the quality of this service?

How did you originally access these services?

Did you find this an easy process? (Please explain a little)

Do you pay for fully or contribute financially towards this service?

Home help *Yes* *No* *How Often* _____

Have you requested this support *Yes* *No*

If you receive this support

How long after requesting it did you begin to receive this support: _____

Do you consider that this level of service is adequate for your needs?

Can you comment on the quality of this service?

How did you originally access these services?

Did you find this an easy process? (Please explain a little)

Do you pay for fully or contribute financially towards this service?

Do you have any other comments to make on this service?

Night nurse *Yes* *No* *How Often* _____

Have you requested this support *Yes* *No*

If you receive this support

How long after requesting it did you begin to receive this support: _____

Do you consider that this level of service is adequate for your needs?

Can you comment on the quality of this service?

How did you originally access these services?

Did you find this an easy process? (Please explain a little)

Do you pay for fully or contribute financially towards this service?

Do you have any other comments to make on this service?

Respite Care *Yes* *No* *How Often* _____

Have you requested this support *Yes* *No*

If you receive this support

How long after requesting it did you begin to receive this support: _____

Do you consider that this level of service is adequate for your needs?

Can you comment on the quality of this service?

How did you originally access these services?

Did you find this an easy process? (Please explain a little)

Do you pay for fully or contribute financially towards this service?

Do you have any other comments to make on this service?

Day Care Centre *Yes* *No* *How Often* _____

Have you requested this support *Yes* *No*

If you receive this support

How long after requesting it did you begin to receive this support: _____

Do you consider that this level of service is adequate for your needs?

Can you comment on the quality of this service?

How did you originally access these services?

Did you find this an easy process? (Please explain a little)

Do you pay for fully or contribute financially towards this service?

Do you have any other comments to make on this service?

Chiropodist *Yes* *No* *How Often* _____

Have you requested this support *Yes* *No*

If you receive this support

How long after requesting it did you begin to receive this support: _____

Do you consider that this level of service is adequate for your needs?

Can you comment on the quality of this service?

How did you originally access these services?

Did you find this an easy process? (Please explain a little)

Do you pay for fully or contribute financially towards this service?

Do you have any other comments to make on this service?

Occupational Therapist *Yes* *No* *How Often* _____

Have you requested this support *Yes* *No*

If you receive this support

How long after requesting it did you begin to receive this support: _____

Do you consider that this level of service is adequate for your needs?

Can you comment on the quality of this service?

How did you originally access these services?

Did you find this an easy process? (Please explain a little)

Do you pay for fully or contribute financially towards this service?

Do you have any other comments to make on this service?

Other (please Specify)

Yes *No* *How Often* _____

Have you requested this support *Yes* *No*

If you receive this support

How long after requesting it did you begin to receive this support: _____

Do you consider that this level of service is adequate for your needs?

Can you comment on the quality of this service?

How did you originally access these services?

Did you find this an easy process? (Please explain a little)

Do you pay for fully or contribute financially towards this service?

Do you have any other comments to make on this service?

23. Is the person that you care for in receipt of any of technical aids, such as a wheelchair, walking aids, pads, and so on?

Yes No

If yes, please specify:

Are these adequate for their need? Yes No

(Please comment)

24. Do you feel that the range of services you and the person you are caring for require adapt to suit your needs?

Yes No

(Please explain a little)

25. Can you comment on what further financial or other support services would be helpful in supporting you as a carer:

26. The idea of a *One Stop Shop* has been put forward as a possible support/ advocacy/ information centre, to help co-ordinate services and provide one place where carers and those they care for could look for comprehensive support. Do you think that the development of a *One Stop Shop for Carers and Caring* would be helpful?

Yes No

27. Please use this space to make any further comment you consider would be helpful in explaining your experience of services that are available to you as a carer.

Your needs

Thank you for taking the time to fill out this questionnaire so far. Now we wish to just briefly get a quick idea of some of your needs as you continue in your caring.

28. Do you get planned short breaks from caring (for example, for shopping, leisure, visiting friends/family)?

29. Do you get regular long breaks, for example for holiday (weekends, and longer holidays)?

30. Do you feel able to continue caring? (Please explain briefly)

31. Do you have someone or some organisation you can confide in for emotional support?

Yes No

If Yes can you please tick whichever is appropriate

Friend

Family Member

Carers Association

Support Group

Samaritans

Other (Please specify) _____

Are you in employment? Yes No

If Yes Full time Part time

IF NO

Would you like to be in employment? Yes No

If so, what would enable you to take up employment?

Training	Yes	No	Please Comment
Flexible hours			
CV preparation			
More caring support			
Other (Please specify?			

We thank you for your time and for giving your opinions and experiences. The Carers Association, Cork in conjunction with researchers at UCC will keep you updated on the progress we are making in bringing these opinions and experiences together, to make these experiences known locally and nationally.

Further to this questionnaire, we will be researching some of the concerns and issues that carers express concern about. These interviews will take the form of more in-depth conversations with individuals. We estimate that they will take about an hour to an hour and a half in time and can be arranged to suit your circumstances.

If you wish to be included in these further interviews please fill in your details below and we will be in contact with you later in this regard.

Please place your details in the separate envelope provided.

Thank you for your time and co-operation.

Name:

Address:

Telephone: Land line: _____ Mobile: _____

e-mail: _____

Best times for contact: _____