



**26<sup>th</sup> BIC Summit, Glasgow, 17<sup>th</sup> June 2016**

**CARERS: Supporting people who provide unpaid care in the home**

The Council is invited to:

Discuss and note the following paper prepared by Social Inclusion work sector officials including the following key points:

- Carers are an integral part of society, caring for family, friends and neighbours affected by physical or mental illness, disability, frailty or substance misuse. Whilst caring can be a positive and rewarding experience, high-intensity caring can result in poor carer health, both physically and mentally. Carers' policy sits within a wider context of tackling economic, health and social inequalities and, with regard to young carers, within the holistic, child-at-the-centre context. A decisive shift towards preventative approaches rather than crisis-led responses should be accompanied by greater integration of services at a local level.
- Member Administrations agree that further action is required to support carers. Member Administrations commit to working together in order to further their knowledge and understanding of what works in supporting carers, especially with regard to young carers and older carers; carer identification; and telecare, telehealth and assistive technology. Member Administrations will work with partners in the statutory and third sectors, in communities and in academia to take forward this agenda.

It is agreed that this paper will be published on the BIC website and made available for interested stakeholders.

**BIC Social Inclusion Work Sector  
17 June 2016**

## **INTRODUCTION**

At the British Irish Council (BIC) Ministerial meeting on 11 March 2015 Ministers confirmed their interest in the issue of unpaid carers. They tasked officials, working with the BIC Secretariat, to begin consideration of how best the Member Administrations can support carers by looking at best practice, new and creative policy responses and community actions across the eight Member Administrations.

The work sector group of officials met for the first time in Edinburgh on 24 September 2015. It has since met on three occasions and also by teleconference.

The meetings have enabled Member Administrations to hear about each other's policies on carers. They have also provided opportunities for presentations from third sector carer organisations and from statutory bodies and for discussion and learning.

## **BACKGROUND**

Carers<sup>1</sup> provide care and support to family members, friends and neighbours. The people they care for are affected by disability, physical and mental ill health, frailty, substance misuse and other conditions, often in combination.

Carers comprise people of all ages, female and male and from urban and rural communities. They are in education, employment, caring full-time, unemployed and retired. Each will have their own specific circumstances.

Young carers are children and young people under the age of 18 who have a role in caring for someone else. Most young carers care for a parent or sibling or for both. Member Administrations agree that it is important that a holistic child-at-the-centre approach is taken with young carers, ensuring that young carers do not undertake inappropriate caring. They should be children and young people first and foremost.

Young adult carers are usually between the age of 18 and 25 although the exact age varies across Member Administrations. Planning for becoming a young adult carer will often start

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<sup>1</sup> In this paper, when the term "carers" is used, it means both adult and young carers. The paper makes clear if adult or young carers are being discussed separately.

before the age of 18. They often take on additional responsibilities that can make the transition from childhood to adulthood especially challenging.

Older, frail carers can provide long hours of care whilst their own physical and mental health deteriorates. This can result in a breakdown in their ability to continue caring.

The term “sandwich carer” is often used to refer to those looking after young children at the same time as caring for older parents. It can also be used more broadly to describe a variety of multiple caring responsibilities for people in different generations.

## **CHANGING DEMOGRAPHIC**

The proportion of the population in Member Administrations over the age of 75 years is predicted to rise considerably over the next decade and beyond. More people will be living with long-term conditions, and may have multiple conditions and complex needs.

Changing demographics and an aging population are likely to lead to an increased demand for both paid and unpaid care with potentially less supply as more carers continue to work into their 60s and beyond. Family migration patterns can also have an impact on the supply of unpaid care especially in remote and rural areas and in all of the smaller Member Administrations. The increasing number of people providing sandwich care also has an impact. There is a predicted ‘family care gap’ by 2017, whereby the need for care will outstrip the number of family members able to provide it.<sup>2</sup>

There is a marked social gradient for the intensity of caring. Carers living in the most deprived areas are much more likely to provide intensive care compared with those in the least deprived areas.<sup>3</sup>

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<sup>2</sup> Examples of research/data include:

A Growing Care Gap? The supply of unpaid care for older people by their adult children in England to 2032, - Pickard, Linda, 2015

<http://eprints.lse.ac.uk/51955/>

The Generation Strain: Collective Solutions to Care in an Ageing Society – the Institute for Public Policy Research – 2014

<http://www.ippr.org/publications/the-generation-strain-collective-solutions-to-care-in-an-ageing-society>

<sup>3</sup> For example, in Scotland, 47% of carers in the most deprived areas care for 35 hours a week or more. This is almost double the level in the least deprived areas where 24% of carers care for 35 hours a week or more. (Scottish Household Survey)

## **ECONOMIC IMPACT**

It is estimated that the economic value of the contribution made by carers in the UK is £132 billion per year.<sup>4</sup> Based on 2011 census figures, the replacement cost of the care provided by Irish carers is €4 billion per annum.

## **CHANGING ATTITUDES**

The societal attitude to caring has changed over time. Historically, people's general view was that caring, especially by adult carers, was something to be done dutifully and without any public sector support. Over time, this largely outdated view was replaced with society recognising and valuing carers for the work that they do but still without much practical support. The 1990s heralded a change in attitude with some Member Administrations producing carers' strategies and with initial support being delivered to carers. By 2016 Member Administrations are supporting adult carers, and in some cases, young carers.

In the case of young carers, some caring demands, for example, the quantity of time spent caring, or the nature of the caring tasks should not be expected of any child. However, appropriate caring by young carers can have positive effects and enhance the child or young person's maturity, sense of responsibility and resilience.<sup>5</sup> Member Administrations agree that caring by young carers is unacceptable where it is detrimental to the young carer's wellbeing, or prevents them taking up similar opportunities in life as their non-carer peers. With many young carers, the focus should be on ensuring that the family is supported so that this caring is no longer required.

## **IMPACT OF CARING**

Member Administrations agree that progress has been made in recent years in recognising the impact that caring can have on carers' own lives. However, carers are vulnerable to a wide range of inequalities. Studies<sup>6</sup> show that caring can be a predictor of poor mental

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<sup>4</sup> Valuing Carers 2015 – The rising value of carers' support – Carers UK report

<http://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015>

<sup>5</sup> For example: in Scotland, Getting it Right for Young Carers, 2010-2015

<http://www.gov.scot/Publications/2010/07/23153304/42>

Emotional Support for Young Carers – Children's Society, 2008

<http://www.rcpsych.ac.uk/healthadvice/parentsandyouthinfo/youngpeople/emotionalsupport.aspx>

<sup>6</sup> For example: State of Caring 2015 – Carers UK report

<http://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2015>

wellbeing particularly where caring is intensive and for long periods of time. Those most at risk of psychological distress are carers in more demanding care situations. Young carers are much more likely to report that they have a long-term mental health problem than their non-carer peers. Caring brings financial stress and due to the impact of caring, carers may have to leave employment, are unable to take up work or are working fewer hours.<sup>7</sup>

## LACK OF OPPORTUNITIES

Member Administrations recognise that caring can also limit opportunities to pursue education, employment, leisure and recreation or to have fulfilling relationships and friendships. Carers can feel isolated from their peers and sometimes experience loneliness. Many carers do not feel that they have any choice but to adopt a caring role.

Caring responsibilities are often cited as a key reason for labour market exit amongst older workers. People in the 50-64 age bracket have higher rates of caring than other age groups.<sup>8</sup> Across the UK the public expenditure costs of carers feeling unable to continue working are estimated to be £1.3 billion a year.<sup>9</sup>

Member Administrations agree that being in work may sustain a carer in their role by providing an income and sense of fulfilment and enabling them to take a break from caring. However, employment may not ensure adequate income and financial security for some carers, with many of those caring more intensively in poorer paid employment.

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The Health and Wellbeing of Unpaid Carers: Where Can Digital Skills and Community Support Add Value? – Tinder Foundation 2015

<http://www.carersuk.org/for-professionals/policy/policy-library/the-health-and-wellbeing-of-unpaid-carers>

Young Adult Carers at School: Experiences and Perceptions of Caring and Education – University of Nottingham 2013

[https://professionals.carers.org/sites/default/files/young\\_adult\\_carers\\_at\\_school-8\\_11\\_13-1\\_proof\\_4\\_final.pdf](https://professionals.carers.org/sites/default/files/young_adult_carers_at_school-8_11_13-1_proof_4_final.pdf)

<sup>7</sup> State of Caring 2016 – Carers UK report

<http://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2016>

<sup>8</sup> Scotland's Census 2011, Table DC3301SC – 'Provision of unpaid care by general health by age' <http://www.scotlandscensus.gov.uk/news/census-2011-release-3f-detailed-characteristics-health-scotland>

<sup>9</sup> Public Expenditure Costs of Carers Leaving Employment – Linda Pickard et al, London School of Economics and Political Science (LSE), 2012

<http://blogs.lse.ac.uk/healthandsocialcare/2012/04/25/dr-linda-pickard-public-expenditure-costs-of-carers-leaving-employment/>

## **SUPPORT TO CARERS**

### ***Overview***

Member Administrations agree that it is important that support for carers is sufficiently flexible to ensure that as many as possible can meaningfully engage with the support available.

Support to carers can take many forms. At a national level, having a flourishing economy and tackling health inequalities supports carers as citizens. Carers can also be supported by wider programmes such as those relating to employment, skills, training, student bursaries and so on. Support targeted specifically at carers is important. This includes short breaks (respite), training, emotional and practical support, advocacy, emergency and future planning and income maximisation, including income support.

Member Administrations agree that preventative approaches to supporting carers are vital in order to prevent or minimise escalating need with carers reaching crisis point before they are supported. It is necessary for statutory bodies and the third sector to work on a preventative basis in order to achieve optimum results.

### ***Self-directed support***

Greater access to self-directed support is being promoted across some Member Administrations. This is where individuals (carers and cared-for people) can exercise more choice and control over the funding that is allocated to meet their needs, directing the spend and in many cases receiving the money as a direct payment to make their own arrangements. Carers benefit from flexible and personalised services that can be adapted around their individual caring duties, and accessing self-directed support can be a helpful way of enabling this.

### ***Short breaks (respite)***

The opportunity to have a short break (respite) is very important for carers, particularly those who are providing high levels of care. Short breaks' provision is being taken forward in all Member Administrations.

### ***Benefit system***

Carers can also be supported by the benefits system. For example a carer's allowance is available to carers meeting certain conditions in each of the BIC Member Administrations.

### ***Leave for working carers***

Most Member Administrations also have special leave arrangements for working carers. Any employed person meeting certain conditions (including carers) in the UK, Scotland, Northern Ireland and Wales Member Administrations can request flexible working and have reasonable time off for emergencies.<sup>10</sup> In Ireland<sup>11</sup> employees are legally entitled to leave their employment temporarily to provide care for someone in need of full time care and attention. Whilst carers' leave from employment is unpaid, legislation ensures that those who take carers' leave will have their jobs kept open for them for the duration of the leave.

## **WIDER INITIATIVES**

There are strategies, policies and practice developments both at national and local level that are relevant to improving outcomes for carers. Member Administrations agree that strategies for dementia, mental health, autism, learning disabilities and sensory impairment amongst others demonstrate the determination to assure high quality care and support services that improve people's lives, including the lives of carers. Improvements to the economy, employment rates, access to training and employability schemes, civic participation and so on can all benefit carers as citizens. Improved services to cared-for people will indirectly support carers.

## **THE CHALLENGES AHEAD**

The shift in the balance of care from institutional care to more care being provided for in the community, is welcome but brings further challenges for carers.

The role of carers will become increasingly significant and should therefore become a central consideration in the commissioning, planning and delivery of care services.

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<sup>10</sup> Work and Families Act 2006 <http://www.legislation.gov.uk/ukpga/2006/18/contents>

<sup>11</sup> Carers Leave Act 2001. Employees are entitled to take carer's leave of at least 13 weeks up to a maximum of 104 weeks. <http://www.irishstatutebook.ie/eli/2001/act/19/enacted/en/html>

There are implications of increased demand on unpaid carers in the context of a care system that is also facing challenges recruiting and retaining the workforce.

As children with multiple and complex conditions live longer, parent-carers will be caring for longer as they themselves move into old age with their own health and care needs to deal with.

The public sector now has a growing role in supporting carers both directly and indirectly although families and friends and volunteer-led befriending and community-based networks have a crucial role to play.

## **ADDRESSING THE CHALLENGES**

Member Administrations agree that in challenging financial times, there needs to be an impetus on innovative ways of supporting carers, and more widely on building communities ('carer-friendly/supportive/literate') that are inherently more conducive to caring. There is a greater role for community capacity building and volunteering which is presently supporting carers on a small-scale.

Member Administrations agree that we can help and support carers by tackling health inequalities, ensuring a fair and prosperous and economically resilient society and by furthering participation in communities.

It is also important that carers are fully involved in decisions at local level about strategic planning decisions of concern and interest to them. This takes various forms in Member Administrations and is more developed in some Administrations than in others.

Using an assets-based approach where the focus is on the strengths of carers and their wider familial and community networks, rather than on deficit, need and service-led responses is increasingly the way forward.

The goal in the longer term (beyond the scope of the social inclusion/carers work stream) is ambitious – that Member Administrations are recognised as progressive societies demonstrated by a culture of positive, proactive and preventive care and support in communities at all levels. Every level of society would understand the health and socio-economic benefits of supporting carers, would understand its role in supporting carers, and deliver that support. This goes beyond designated "carer support" structures and reaches



across all of society. Caring should have a positive impact on health and wellbeing in more carers. The negative impacts of caring should be identified early and minimised through person-centred support. More people should live independently at home, for longer, supported by their carers and services that they have helped design and commission.

## **COLLABORATION**

The British-Irish Council plays an important role in facilitating and fostering collaboration among Member Administrations. It provides a forum where support to carers can be discussed, debated and strategies agreed for driving forward the agenda in Member Administrations. It is recognised that whilst the agenda is more developed in some Administrations than in others, there is nevertheless a mutually beneficial and reinforcing aspect to the work. It is important that the collaborative effort takes this fully into account and acknowledges, respectfully, that all Member Administrations can learn from each other. There is value in the diversity of approach as well as the similarities.

## **NEXT STEPS**

Officials have proposed priorities to focus on for the remainder of this work stream. It is recognised that the proposed priorities comprise groups of carers, a type of support and identification of carers. The priorities are cross-cutting but mutually reinforcing.

It is further proposed that there should be a flexible approach to this work to enable new ideas and proposals to come forward but without compromising work on the priorities.

The proposed priorities are:

- young carers – Ministers agreed at the Ministerial meeting on social inclusion/older people and preventative support that within the carers theme, they particularly wanted a focus on young carers. The policy and legislative focus in some Member Administrations is on children in need who may have caring responsibilities and other needs whilst in other Member Administrations, the focus is on children and young people who are young carers within a wider context of support for children and young people. The approaches are nuanced. However, it is agreed that some of the support and interventions applicable to adult carers are relevant to young carers too whilst there are also crucial differences in the lives of adult and young carers and the policy and legislative responses;

- carers of older people, including older carers – with the demographic challenges there will be more older people in society, including the frail elderly, and increasing numbers of older carers who will require particular attention;
- identification – carer identification is the first step to supporting carers. However, some people do not wish to be identified as carers whilst others will identify later on in the caring journey when the caring role intensifies. Some young carers may fear family break-up if they are identified whilst others will wish to be identified. The paid workforce has a role in identifying carers. There are particular issues around carer identification of certain groups of carers, including those from Black and Minority Ethnic (BME) and gypsy, traveller and Roma communities; and
- telecare and telehealth services and assistive technologies – technology-enabled solutions and assistive technologies can help cared-for people to live independently but the services and technology support carers too. This theme would be explored within the wider context of digital inclusion.

In relation to the four priorities, the work going forward will focus on:

- establishing a baseline of information in each Member Administration;
- sharing policy, research and practice;
- cross-learning and development; and
- putting new ideas into practice to further support carers.

## **CONCLUSION**

Member Administrations agree that further action is required to support carers who are providers of care to the people they care for.

Member Administrations commit to working together in order to further their knowledge and understanding of what works in supporting carers, especially with regard to young carers and older carers, carer identification and telecare, telehealth and assistive technology.

Member Administrations will work with partners in the statutory and third sectors, communities and academia to take forward this agenda.

**BIC Social Inclusion Work Sector**  
**17 June 2016**