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Impact of the SSWB Act on Carers

Response to the Health, Social Care and Sports Committee Consultation

This response has been produced by the Centre for Innovative Ageing (CIA) Swansea University. We are pleased to offer this response and would be very happy to provide further evidence both written and oral to support the Committee's Inquiry. Our response has been compiled in the following way: Paragraphs 1 – 4 highlights the current work within the CIA that we believe is relevant to the aims of the Inquiry and that we would be very pleased to elaborate on further. What follows are we specific responses offered in relation to the issues raised within the consultation pertaining to: 1) information and data 2) other changes since the Act came into force and 3) broader Welsh Government policy on carers.

Introduction

This response has been compiled by [redacted] a PhD candidate at the Centre for Innovative Ageing the 3 year funded PhD has been awarded by the Wales School for Social Care Research. The overall aim of the PhD we believe is of particular interest to the Committee's current inquiry in relation to carers and the Social Services and Well-being Act. The PhD aims to contribute to a theorisation of the concept of well-being in relation to older family carers of people living with dementia, in order to support care policy and practice development that can deliver sustainable well-being outcomes for older family carers of people living with dementia in Wales.

The PhD research is of particular importance because recent evidence highlights that older family carers of people living with dementia are at particular risk of poor health and well-being outcomes. In comparison with the general carer population, carers of people with dementia are particularly vulnerable to high levels of psychological distress and stress, and levels of self-efficacy, subjective wellbeing and physical health are significantly lower in dementia care givers than in other caregivers (Brodaty & Donkin, 2009). The needs of this particular group of carers are growing, and the number of unpaid carers over the age of 65 is increasing more rapidly than the general carer's population; whilst the total number of carers has risen by 11% since 2001, the number of older carers rose by 35% (ONS 2011). In the UK, two thirds of people living with dementia are living at home and most are supported by unpaid family carers and caring for a person with dementia is associated with longer caring hours when compared with people cared for with other conditions. Welsh based data demonstrates the clear need to examine the experiences and challenges of carers of people living with dementia. The National Survey for Wales 2016-2017 'Volunteering and Caring Report' highlights that people who were caring for others were more likely than those who were not to have a limiting long-term illness, and were more likely to be in material deprivation. This relationship was strongest for those who spent more time caring and for those that provided more hours in a week, the proportion who were in material deprivation increased (Welsh Government, 2017 p. 11). Despite the increased risk of poorer health income and well-being outcomes, carers of people with dementia have been shown to be less likely to use services compared to the general carer population (Philp et al., 1995; Toseland, McCallion, Gerber, & Banks, 2002) Toseland et al (2002) found that enabling variables (which included such things as; knowledge of and barriers to service use, transportation, location) explained more variance in carers of people with dementia service use, than either need or predisposing variables (Toseland et al., 2002, p. 1261). Developing evidence based policy that supports service delivery for this particular group of carers is needed to tackle a growing number of the older population in Wales who are experiencing poor health and well-being outcomes.

- We recommend that in addition to gathering evidence on the level of take up of carers assessments in the broad carer population, that Welsh Government consider undertaking specific work that seeks to identify the barriers and obstacles that could be encountered when accessing services by family care givers of people living with dementia.

Sustainable Care: Connecting People and Systems

The PhD is formally connected to The Sustainable Care programme. The Programme is a multi-disciplinary ESRC-funded programme (2017-2021) exploring how care arrangements, can be made sustainable and deliver wellbeing outcomes. It aims to support policy and practice actors and scholars to conceptualise sustainability in care as an issue of rights, values, ethics and justice, as well as of resource distribution. Led by Professor Sue Yeandle, Sheffield University, the project brings together academics from eight universities, and is working with an extended network of international academic partners in fifteen other countries. The programme takes a future-oriented and internationally comparative look at current approaches to the care needs of adults living at home with chronic health problems or disabilities, examining these in the context of care systems, care work and care relationships. The PhD hosted within the CIA is connected to this programme through its' UK international network of PhD candidates, and as a named researcher on the work specifically in relation to work package 2 comparing care systems across the nations of the UK. We would welcome the opportunity to discuss further this substantial programme of work.

1) Whether local authorities and Local Health Boards have sufficient information on the number and needs of carers in their areas;

We are aware of significant data gaps in relation to carers and there is an absence of accessible and comprehensive data more broadly. Lack of coordination and large data gaps were identified across the 4 nations in a recent expert round table event ran by the Sustainable Care programme. Some of the key issues identified included the lack of a coordinated data strategy for social care and carers across the whole of the UK.

- A key recommendation from the expert roundtable is the establishment of a UK coordinating body for adult social care, this body would coordinate and summarise data trends for policy and research use.

The Centre for Innovative Ageing would be very happy to discuss the development of improving data collection on carers and through its close links with the Sustainable Care Programme is best placed to connect into work that is happening at the national and international level.

2) Other changes since the Act came into force which may impact on carers, for example changes to the services provided to people who are cared for;

Given the increase in population ageing, accompanied by increases in limiting lifelong condition such as dementia, and UK Government programme of austerity based social care reform older carer's needs are growing. There is now irrevocable evidence of the negative impact that caring for someone with dementia can have on individual health well-being and material circumstance. Sustainable systems of support are needed to alleviate these negative impacts and protect carers from old age exclusion and limited life chances.

It is not clear from the current literature how family carers of a person living with dementia in Wales are balancing increasing care demands with less welfare support, and no work to date has attempted to critically engage with the context of austerity driven care reform within the well-being in care paradigm in Wales. Notable exceptions to knowledge gaps do exist in Wales (Seddon et al, 2010; Shuie, 2015) but these studies do not provide a focus on the particular experiences of older family carers of people living with dementia, nor do they relate current systems to the promotion of older carer's well-being, or to the broader socio-political landscape in Wales and the UK.

3) Broader Welsh Government policy on carers

The Welsh Government approach to preventative social care services that promote individual well-being is welcome, however, well-being outcomes set for carers are based on measures of entitlements and rights. These measures do not adequately provide a clearer picture of the experiences of carers lives, particularly those carers who are particularly vulnerable to poor health and well-being outcomes such as older family carers of people living with dementia. The CIA has been recently commissioned by the Older People's Commissioner in Wales to carry out secondary data analysis of current well-being outcomes in relation to older people.

- We suggest that alternative methods of data collection in relation to carers are considered including the use of mixed method and qualitative research data to help build a deeper understanding of carer's lives.

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Appendix 1

'Well-being for older family cares of people living with Dementia – The Case of Wales'

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Supervisory team: [redacted].

A 3 year funded PhD programme (2017-2020) awarded by the Wales School for Social Care Research

This research is located at the interface between social care systems in Wales and the older family carer of persons living with dementia. The worldwide phenomenon of population ageing is a global success story; however, population ageing can bring challenges to nations particularly in relation to how families and Governments can reconcile the increasing need for long term social care for older living with long term health conditions.

Research aims and objectives

The overall aim of the PhD is to contribute to a theorisation of the concept of well-being in relation to older family carers of people living with dementia, in order to support care policy and practice development that can deliver sustainable well-being outcomes for older family carers of people living with dementia in Wales. In order to achieve this aim, the following objectives have been identified:

1. To advance understanding of the concept of well-being in care systems in relation to older family carers of people living with dementia in Wales, taking into account individual life course caring history, place based resources, policy influences (e.g. austerity), and social-cultural constructions of care.
2. Identify features and conditions of social care system that could contribute to well-being outcomes for family carers of people living with dementia.
3. Consider the implications of findings from objective 1 and 2 on well-being within social care policy making in Wales.

Research questions

The research will investigate the extent to which specific well-being legislation has generated positive well-being outcomes for family carers of people living with dementia. The research questions are as follows:

1. What is the state of knowledge in relation to well-being and older family carers of people living with dementia in Wales?
2. How do stakeholders (social care providers, policy makers, and carers) perceive of and experience well-being support systems in Wales?
3. What features of the care systems in Wales enhance well-being outcomes for older family carers of people living with dementia?

The research will be qualitative and conducted in three stages. Stage 1 will comprise of an in-depth literature review to inform the development of a theoretical framework and conceptualisation of well-being in relation to family carers of people living with dementia in Wales. During stage 2, primary evidence will be gathered through the use of participatory visual methods, written and audio diaries, in-depth interview and direct observation to elicit information to explore the views and experiences of older carers of people with dementia of social care services as well as practitioners and policy makers. Participants will choose which method they would like to use or a combination of methods to capture their views and experiences of interacting or their experiences of working within care support services over a one month period. Three focus groups will be held in phase 2 to explore themes identified by stakeholders and to identify common and divergent beliefs and experiences of well-being in care systems in Wales. During phase 3, the results from phase one and two will be analysed to develop a set of features that could enhance well-being for family carers within the socio-political context of Wales. These features will be tested with carers to arrive at a sustainable social care model for older family carers of people living with dementia in Wales.

For further information contact [redacted] [redacted]