C24

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr

Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers

Ymateb gan Gomisiynydd Pobl Hŷn Cymru

Response from Older People’s Commissioner for Wales

Older People's Commissioner for Wales
Comisiynydd Pobl Hŷn Cymru

Response from the Older People’s Commissioner for Wales

to

National Assembly for Wales, Health, Social Care and Sport Committee: Inquiry on the Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to carers

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About the Commissioner

The Older People’s Commissioner for Wales is an independent voice and champion for older people across Wales, standing up and speaking out on their behalf. She works to ensure that those who are vulnerable and at risk are kept safe and ensures that all older people have a voice that is heard, that they have choice and control, that they don’t feel isolated or discriminated against and that they receive the support and services they need.

The Commissioner's work is driven by what older people say matters most to them and their voices are at the heart of all that she does. The Commissioner works to make Wales a good place to grow older - not just for some but for everyone.

The Older People’s Commissioner for Wales:

- Promotes awareness of the rights and interests of older people in Wales.
- Challenges discrimination against older people in Wales.
- Encourages best practice in the treatment of older people in Wales.
- Reviews the law affecting the interests of older people in Wales.

National Assembly for Wales, Health, Social Care and Sport Committee: Inquiry on the Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to carers

Response by the Older People's Commissioner for Wales ('the Commissioner')

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Summary

- The Social Services and Well-being (Wales) Act 2014 provides carers with an equal right to an assessment – but there is concern that too few are accessing assessments, too few assessments are turning into support and it is unknown why assessments are being refused. There is a lack of intelligent data which prohibits meaningful evaluation of these statistics. The Welsh Government, Local Authorities and Health Boards need to collect more detailed information about assessments, including the reasons behind refusal and the type of support offered.

- Support for carers is often viewed only in relation to a narrow interpretation of respite. Perspectives of respite and the availability of alternative options are preventing carers from experiencing flexible and appropriate respite that contributes towards their well-being outcomes.

- Direct Payments should be widely offered as a route to respite that people are encouraged to explore and empowered to use. Local Authorities must increase their understanding and use of direct payments, ensure support is in place for carers, and promote flexible, meaningful use of direct payments for equipment and respite.

- Following the repeal of the Carers Strategies (Wales) Measure, health services must continue to focus on identifying and delivering for the needs of carers. Far more carers deal with health services than with social care as part of their caring role. However, health services, such as GP services, can be inflexible to the specific needs of carers. Awareness, identification and responsiveness to carers from health services is critical in supporting carers to continue caring and to maintain their own well-being.

- More needs to be done to ensure that carers’ needs for independent advocacy are being appropriately considered and met under the Act. Targeted awareness initiatives, such as information in GP surgeries and libraries, would ensure that those who are most vulnerable are made aware of independent advocacy, regardless of whether they are in contact with statutory services or identify as carers.

- The support needs and well-being outcomes of carers as individuals must be recognised in their own right, as well as recognising their caring role and the significant contribution this makes to health and social care services.

Introduction

Older carers in Wales

Across Wales, an estimated 370,000 carers are providing unpaid care and support to a loved one[1]. More than half of carers are aged 40 to 64 and a quarter of carers are aged 65 or over[2]. Carers provide the vast majority of care to people in communities across Wales, with 96% of care in communities being given by family and friends[3].

It is likely that the proportion of older carers is higher than these estimates and is likely to grow further, as is the number of older people receiving unpaid care and support from a loved one. For example, the data on the number of carers is from the 2011 Census. In those seven years, the demography of Wales has evolved, and the proportion of older people to younger people in Wales is now higher than the rest of the UK. The prevalence of dementia has also grown and is now one of the main causes of mortality in older people[4].

Furthermore, many older people will not recognise themselves as carers and will not declare themselves as such. For example, 55% of carers took over a year to recognise their caring role, and 24% took over five years to identify as a carer[5].

Whilst stating the estimated number of older people who may be carers across Wales is a starting point to understand the level and scale of unpaid support that is provided to loved ones – statistics alone do not delve into who these older carers are.

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[1] ONS, Census 2011

[2] Social Market Foundation, Caring for Carers, 2018

[3] Statement, Huw Irranca-Davies AM, Minister for Children, Older People and Social Care, 14 June 2018

[4] ONS, Deaths registered in England and Wales, 2017

[5] Carers UK, Missing Out: the identification challenge, 2016

It is important to remember that carers are not a homogenous group. Caring relationships are varied, diverse and not necessarily limited to a two-person relationship. Carers may be fulfilling one or multiple caring roles across and between generations, and they may be part of a wider caring network.

Older people are not simply always the recipients of care. Many older people are carers themselves, providing support to siblings, spouses, partners (and ex-partners), their children, parents and friends. Older carers may also provide support to more than one loved one. For example, the Commissioner's office has provided support to a woman who was a carer for both her disabled son and her husband.

In addition to the diversity of caring relationships and networks, there is diversity amongst carers. People with one or more protected characteristics may encounter a variation in their experience of caring. For example, familial responsibility for older people is expected in some cultures, and myths about BAME cultures may shape the outlook of a professional working within health and social care[6,7]. Furthermore, heteronormative assumptions can force LGBTQ older people and carers 'back into the closet' when interacting with health and social care professionals[8].

Section 6 (2) of the Social Services and Well-being (Wales) Act 2014 (the Act) outlines how a person exercising functions under the Act must have regard to an individual's views, wishes and feelings, their characteristics, culture and beliefs. The Act also includes a duty to have due regard to the United Nations Principles for Older Persons. A depth of understanding of who carers are is therefore critical to the achievement of these overarching duties in the Act.

The contribution of carers to our economy and our society is significant. The economic contribution of all carers in the UK is estimated to save £91 billion every year in potential care costs, with an economic value of £139 billion per year. In Wales, unpaid older carers save the Welsh economy an estimated £1.88 billion in care costs, predicted to rise to £2.44 billion by 2030. Other estimates indicate that the value of total

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[6] Health and Social Care in the Community, Barriers to access and minority ethnic carers' satisfaction with social care services in the community: a systematic review of qualitative and quantitative literature, Greenwood, Habibi, Smith & Manthorpe, 2015

[7] IRISS, Improving Support for Black and Minority Ethnic Carers, 2010

[8] Marie Curie, Hiding who I am – The reality of end of life care for LGBT people, 2016

carers' contributions in Wales could in fact be estimated at £8.15 billion per year[9]. The risks to the wider system, and society as a whole, cannot be underestimated if the well-being of carers is not supported.

Fundamentally, however, older carers want and need support to enable them to continue caring and to support their wishes to achieve their own outcomes and well-being goals in their own right as citizens under the Act.

Legal duties

It is positive that the the Act has placed carers on an equal footing with their loved ones. For example, carers have a legal right to an assessment and a legal right for support for eligible needs from a Local Authority following an assessment. The definition of a carer has also been broadened and Local Authorities must ensure that they have information, advice and assistance services in place, which are clearly signposted, so carers can get the right information at the right time[10].

There are duties within the legislation that make direct reference to carers, but there are also many other duties that impact on and protect carers as an individual in their own right. For example, the overarching principles of the Act should influence all interactions with a carer regarding their support needs. A Local Authority must have regard to an individual's views wishes and feelings, provide appropriate support to enable an individual to participate, and begin with the presumption that an individual is the best person to judge what is best for them[11]. As highlighted above, a person exercising duties under the Act must also have due regard to the United Nations Principles for Older Persons[12].

However, the Carers Strategies (Wales) Measure 2010 and other pre-existing carers legislation was repealed by the introduction of the Act. Although some of the provisions within the Measure have been passported across to the Act, this action was strongly opposed by carers organisations, as some of the provisions have been weakened. This is explored further below.

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[9] Bangor University, Living well for longer: The economic argument for investing in the health and wellbeing of older people in Wales, 2018

[10] Carers Wales, Track to Act, Briefing 2, 2017

[11] Section 6 Social Services and Wellbeing (Wales) Act 2014

[12] Section 7(1) Social Services and Wellbeing (Wales) Act 2014

Over two years on from the implementation of the Act, focus needs to shift from its content and onto its impact. It is not yet clear whether the Act is delivering upon its wide-reaching intent and whether the impact on carers has been positive. On the whole, there appears to be a concerning lack of robust information and data that can support us to conclude whether the duties within the Act are being met.

Welsh Government, Carers Ministerial Advisory Group & National Priorities

In 2017, the Welsh Government established three national priorities to guide work to enhance the lives of carers and announced an attached £1 million funding to support this[13]. A Ministerial Advisory Group (MAG) has also been established, and £95,000 has been allocated in 2018/19 to fund projects to drive forward a national approach to delivering against the priorities. Prior to this, the Carers Strategy 2013-2016 was being followed.

National priorities are not as substantial as a national strategy and these priorities do not include specific actions. It is therefore unclear whether the priorities in themselves constitute a strong enough commitment to ensure the needs of carers are met. For example, the priorities are all linked to duties already provided under the Act and it is currently difficult to see how they further progress the rights of carers and carer awareness across Wales.

Furthermore, the success of the national priorities in improving support and recognition for carers will depend on the effectiveness of the MAG to form the basis of a clear action plan for Wales.

It was disappointing to note that the funding linked to support for carers had already been allocated and objectives set before the MAG had met, with specific funds allocated to young carers support, an employment hub and respite[14]. Funding to meet the quality of life and outcomes of older carers was not explicitly named but is implicit in the £1m budget to raise carer awareness across GP practices in Wales and improve support for carers in relation to hospital discharge. It is vital that this funding is used prudently to benefit older carers in Wales. For example,

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[13] Welsh Government, Written Statement, A Carer Friendly Wales, 24 November 2017

[14] Welsh Government, Carers Ministerial Advisory Group, Terms of Reference

the consistent development and use of GP registers or more expedient discharge processes would contribute to ensuring that the needs and wishes of carers are recognised and responded to.

Carers’ Assessments

Legal duty to an assessment

The Act places a number of duties on Local Authorities relating to the assessment of a carer’s need for support. These include the right to an assessment, the ability to combine or separate assessments and care and support plans, a duty to assess a carer’s willingness and ability to provide care, and a duty to consider how the needs of a person with care and support needs would be met in the absence of a carer[15].

A carer can refuse to have a needs assessment under the Act if they so wish, but prior refusal does not prevent a carer from requesting an assessment again in future. Furthermore, a duty on the Local Authority to assess does not diminish if this is refused. For example, the Local Authority can assess a carer if they are satisfied that the carer lacks the relevant capacity, and an authorised person can make a decision on the carer’s behalf. If there is no authorised person, a Local Authority can assess if it would be in the carer’s best interest[16].

What matters conversations

When older people contact a Local Authority for help, information, advice or assistance, a ‘what matters’ approach should lead the discussion. The focus should be on ‘what matters’ to that individual and learning about that person, their strengths and support needs, with the presumption that they are the best person to judge what is best for them in relation to their well-being[17].

Once an individual has made contact with social services, this conversation should set the tone and direction for the whole of an individual’s access to support and the realisation of their rights. This approach is key to ensuring that older people are recognised as carers

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[15] Section 24, 28, 29 Social Services and Well-being (Wales) Act 2014

[16] Section 25 Social Services and Well-being (Wales) Act 2014

[17] Section 6(3)(a) Social Services and Well-being (Wales) Act 2014

(both by themselves and public services), and that their own needs are recognised and provided for through an assessment and an appropriate resultant plan.

Access to assessments

As set out above, carers should have access to a needs assessment under the Act, undertaken through a 'what matters' approach. Access to an assessment, and the quality of its undertaking, are both critical to the recognition of a carer's outcomes, well-being and support needs in their own right.

However, carers assessment rates are significantly lower than would be expected, given that there are an estimated 370,000 carers in Wales:

- In 2016/17, 6,207 carers' assessments were carried out during the year.
- Out of these assessments, 1,823 led to a support plan
- 6,864 carers refused an assessment[18].

Carers receiving or refusing an assessment accounted for less than 4% of the estimated number of carers in Wales and only 29% of those assessed received a support plan.

According to Carers Wales' State of Caring report, , it is concerning that over half (66%) of the 370,000 people in Wales providing unpaid care said they had not been offered or requested an assessment[19].

Serious questions therefore need to be asked regarding why so few carers are accessing assessments, why so few assessments are resulting in support plans and whether other forms of support are in place, to enable these figures to be interpreted in a meaningful way.

The Commissioner's office has provided support to an older carer who expressed her feelings that older carers were not given the same considerations as other carers, and were waiting longer for access to an assessment.

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[18] Stats Wales, Adults assessed by local authority and measure, 2016/17

[19] Carers Wales, State of Caring 2017, 2017

There are local and regional variations across Wales in the access that carers have to assessments. For example, Carers Wales' Track the Act report highlights that there is currently 'a 'postcode lottery' where carers in some areas will receive an assessment, whereas others won't'.[20] Furthermore, feedback from carers to the Commissioner shows that there is even variation in practice within Local Authorities and between social workers on the same team.

There are a number of possible reasons that sit behind the statistics for carers assessments: carers may be signposted to community or preventative services that are not recorded through a formal support plan, an individual may choose to refuse an assessment because of the perception that their ability to care is being assessed, or an individual may not recognise themselves as a carer or be recognised by health and social services as a carer to be able to access an assessment.

The data released by Stats Wales in relation to carers assessments is experimental, and there is some recording variation between Local Authorities. It is of concern that the data currently being recorded is not accurately reflecting the carer experience in relation to accessing assessments. For example, data recording does not include:

- Community/preventative support not included within a support plan
- Reason for refusing an assessment
- Whether the carer's outcomes are being met through support plans
- Feedback from carers on the assessment process

Identification of carers – relevance to assessments

In broad terms, Carers Wales Track the Act highlights a variance across Wales in strategic approach and delivery of services to identify and meet the needs of carers[21].

An individual identifying themselves as a carer, or the identification of a carer by social services [or through referral from health services] is critical to the access that a carer has to an assessment. There are many older people in Wales who may not recognise themselves as carers or who may care for a long time before recognising their role; in Wales,

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[20] Carers Wales, Track the Act, Briefing 2, 2017

[21] Carers Wales, Track the Act, Briefing 2, 2017

55% of carers took over a year to recognise their caring role, and 24% took over 5 years to identify as a carer[22].

The duties for carers' assessments under Section 24 of the Act are triggered 'where it appears to a Local Authority that a carer may have needs for support'. There is not a proactive duty on a social worker to seek out and identify individuals who may or may not be carers, and who may or may not have needs for support (as identified through an assessment).

Older people may therefore not be contacting their Local Authority to ask for support as a carer, as they do not recognise themselves as such. If individuals do not self-identify, the role of social services staff in recognising carers and communicating this relationship between being identified as a carer and accessing support to an individual becomes more important. For example, the Commissioner's office has provided support to an older man who was not considered as a carer for his wife and therefore could not access his right to an assessment because his wife had not yet been discharged from hospital and was under inpatient care.

Staff training of health and social care staff is therefore important to ensure the approach to individuals is consistent with the Act. Social Care Wales is developing a series of learning materials for social care workers and connected staff in relation to supporting carers and carers assessments. These resources are in development, but how they are rolled out and implemented could be critical in improving the awareness and identification of carers amongst social care staff and increasing the access that older carers have to assessments.

Population Assessments, as set out in Section 14 of the Act are a crucial part in a Local Authority's ability to understand the care and support needs of the people who live within their area, including carers, and the services needed to meet those needs[23]. This is one step towards improving carer awareness and recognition and, in turn, increasing assessments and support.

However, if the findings of the Population Assessments are going to move beyond an academic exercise, Local Authorities will need to undertake critical analyses of their findings against the reality of carers

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[22] Carers UK, Missing Out: the identification challenge, 2016

[23] s14 Social Services and Well-being (Wales) Act 2014

assessments and consider whether the carers assessments completed within their area are consistent and expected with the number of carers identified through their Population Assessment?

Assessments and support plans

Across Wales in 2016/17, 1,823 support plans were provided following 6,207 carers' assessments[24]; only 29% of those assessed received a support plan.

The number of support plans following an assessment may be low because support is sometimes merged with the needs assessment and plan of the person with care and support needs, support by informal community support or preventative services that do no feature in a plan, or eligibility criteria may not be clear enough and applied differently across Wales[25].

The Care and Support (Assessment) Wales Regulations 2015 state that a Local Authority must produce a written record of an assessment[26] and a copy of the written record of assessment must be given to the person[27].

However, older people have contacted the Commissioner describing how paperwork explaining support plans and other decision making are not always accurate, given in a timely manner, or not provided to carers. For example, the Commissioner's office provided support to an individual who was assessed as having no needs as a carer, but was not given a copy of the assessment for five months once requested. Once a copy was received, inaccuracies in the assessment were spotted and a new assessment took place which subsequently identified support needs.

Support for carers and respite

Carers Wales' State of Caring report, published in 2017, states that 1 in 5 carers caring for 50 hours or more a week receive or buy no practical

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[24] Stats Wales, Adults assessed by local authority and measure, 2016/17

[25] Carers Wales, Track the Act, Briefing 1, 2016

[26] Regulation 5(1) Care and Support (Assessment) (Wales) Regulations 2015

[27] Regulation 6 Care and Support (Assessment) (Wales) Regulations 2015

support at all to help them[28]. However, appropriate recognition and support is essential to maintaining and improving a carer's well-being, helping them to continue their caring role and supporting their life outside of a caring role.

There is a duty within the Act to provide preventative services, and this includes support services for carers[29]. Appropriate support and preventative services are essential to the achievement of the outcomes of carers, and preventative and support services for carers and people living with dementia have been proven to have a positive return on investment[30].

However, Social Care Wales found that the identification and recognition of carers by themselves and professionals, and the information, advice and assistance about rights, entitlements and services available to carers were key themes affecting access to preventative services[31]. Furthermore, services and support are not always designed or provided in a way that is most appropriate for those in need. For example, the Commissioner's 'Rethinking Respite' report found that a fundamental rethink in the design and delivery of respite services for carers is needed and that carers and people living with dementia need to be more involved and should be instrumental in the design of respite support services[32].

Information, advice and assistance

The Act places a duty on Local Authorities to provide information, advice and assistance (IAA) to citizens, including carers[33]. The provision of information advice and assistance is critical to the knowledge of, and access to support and preventative services that carers have. However, Local Authority IAA services across Wales will vary in structure and approach and could range from a telephone line, to a community hub.

Regardless of the type of IAA provision, when contacting an IAA service in Wales there is no duty within the Act to collect data about how carers are using the service. Carers Wales Track the Act report found that in the first six months of the Act's implementation, only 16% of carers had

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[28] Carers Wales, State of Caring 2017, 2017

[29] s15 Social Services and Well-being (Wales) Act 2014

[30] Bangor University, Living well for longer: The economic argument for investing in the health and wellbeing of older people in Wales, 2018

[31] Social Care Wales, Preventative support for adult carers in Wales: rapid review, 2018

[32] Older People's Commissioner for Wales, Rethinking Respite for people affected by dementia, 2018

[33] s17 Social Services and Well-being (Wales) Act 2014

received information from their Local Authority to support them in their caring role. This increased to 46% in the following six months. 78% of carers said that the information they had received was either useful or very useful[34].

However, whilst an indication, these figures are not national, official data. Improved data would mean a greater understanding about carers' needs and would help to identify gaps in support and IAA services, such as whether an individual is self-identifying as a carer or has been identified by IAA staff, the type of support requested, whether an individual is referred for an assessment, or the reasons behind a refusal for a carers assessment.

It is not currently possible to define the current success of IAA services in effectively signposting or referring carers to support services. Notwithstanding this, concerns have been raised with the Commissioner by third sector organisations that individuals using IAA services have been signposted back into the community where a further assessment may have been more appropriate.

Respite services

Respite is often seen as one of the most common forms of support for carers. However, it is often only thought of as an overnight stay or day visit to a care home for the individual with care and support needs.

The Commissioner's 'Rethinking Respite' report[35] found that respite should not be limited to this narrow choice, which does not always meet the needs of carers or those living with dementia. Whilst the report focused specifically on people living with dementia and their carers, many of the key messages are equally applicable to other people who need respite.

People need opportunities to have breaks together and apart, within the home and away from home, in line with their views, wishes and feelings. There is a clear need for more creative forms of respite, in partnership with a range of sectors, covering hospitality, the environment, sports, arts and leisure – such as the respitality scheme in Scotland.

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[34] Carers Wales, Track the Act, Briefing 2, 2017

[35] Older People's Commissioner for Wales, Rethinking Respite for people affected by dementia, 2018

However, current systems for monitoring, measuring and evaluating levels of ‘respite’ are not fit for purpose, as they relate to a narrow and one-sided definition of respite (e.g. the Welsh Government respite performance indicator only relates to overnight stays). Furthermore, information about respite options is not sufficiently accessible, delivered at the right time and in the right format, and there is insufficient support to make sense of the options available. Social services staff may not be fully aware of the options themselves.

The report also found that health and social care systems are not sufficiently responsive to people with multiple caring roles. For example, the Commissioner’s office has provided support to a woman who is a carer for both her husband and son. Whilst she receives infrequent respite support from social care workers who take her son out, she does not have any time for herself as she is still caring for her husband.

The Commissioner proposed a new respite outcomes map within the report, based on the outcomes that carers and people living with dementia stated that they wanted to achieve. This correlates to the National Outcomes Framework and has the potential to be a useful tool – for practitioners, regulators, policy makers, providers and people who use services – to promote the development of more meaningful respite alternatives and measure their impact.

The outcomes map has also been welcomed by the Carers Officers Learning and Information Network, carers organisations and professionals who have described it as a useful discussion point for making the National Outcomes Framework both meaningful and achievable in terms of personal outcomes.

Respite and the Dementia Action Plan

The Welsh Government’s Dementia Action Plan for Wales 2018-2022[36] (the Plan) was published in February 2018. An additional £10m a year will support the delivery of key actions within the Plan and progress against delivery of the plan will be overseen by a Dementia Delivery

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[36] Welsh Government, Dementia Action Plan for Wales, 2018

Assurance and Implementation Group[37], the minutes of which will be published for transparency[38].

The Plan recognises that there needs to be different options for respite care relevant to different age groups, includes a commitment to ensure that the new ‘teams around the individual’ approach enables families and carers to access respite care that meets the needs of the carer as well as those of the person living with dementia, and commits to learn from the ‘Rethinking Respite’ report. Progress against this plan will be ‘a key vehicle for demonstrating achievements and areas for improvement outlined within the Health and Care Standards for Wales’[39].

Carers and Continuing Health Care

Continuing Heath Care funding may be provided by a Health Board if an individual’s needs are assessed as being primarily health needs. However, once this funding and package of care is in place, there may still be a carer present who should be recognised and supported.

Local Authorities are responsible for assessing the support needs of carers, which includes carers of individuals receiving CHC funding[40]. However, when carers are involved in supporting an individual in receipt of CHC funding, the Commissioner is aware that in practice there can be a lack of clarity or action as to which public body is responsible for supporting the carer.

The Commissioner’s office provided support to an older man when a best interests decision was made to move his wife into a care home. The man expressed his desire to care for her in their own home, but to do so the Health Board advised him that he needed to provide a care plan to demonstrate how he intended to care for his wife. No support to develop such a plan was offered or accessible, and a further best interests meeting decided that he did not provide sufficient assurance that he was able to meet his wife’s needs, despite the fact that he had been a vital member of his wife’s care team when she was receiving treatment in hospital.

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[37] This group has now been renamed the Dementia Oversight, Implementation and Impact Group. Membership of this group will include people living with dementia and their carers and families.

[38] Welsh Government, Dementia, 2018

[39] Older People’s Commissioner for Wales, Rethinking Respite for people affected by dementia, 2018

[40] s24 (1)(a) Social Services and Wellbeing (Wales) Act 2014

Additionally, the Commissioner's office supported an individual when they disputed the removal of one-to-one support for their family member who received CHC funding. Following the Commissioner's intervention, the Health Board invited the carer to comment on new patient literature to prevent similar disputes from occurring. The carer expressed that they felt they had contributed to making a difference for other carers and that the Health Board had taken her feedback seriously.

In relation to respite, funding can be obtained for this where CHC funding is involved but older people have reported that it was difficult to obtain, and that they had to question or complain to the Health Board in order to access this.[41]

Direct payments

Direct Payments should be widely offered as a route to respite that people are encouraged to explore and empowered to use. Local Authorities must increase their understanding and use of direct payments, ensure necessary support is in place for carers to use direct payments, and promote their use for equipment and respite.

'Rethinking Respite'[42] found that direct payments can be an important vehicle to enable flexibility, choice and control in relation to supporting older carers. For example, a small number of people had used direct payments to organise respite support with positive results. These included paying for overnight respite in a place of choice, either on their own or as a family (either in a care home or within the hospitality sector), or paying for a 'buddy' for a few hours or days a week, to help support the person living with dementia with what they wanted to do, in or outside of the home.

However, there is very limited uptake of this option, particularly amongst older people and carers[43]. As demonstrated by the quotes below, the 'Rethinking Respite' report found that the majority of older people living with dementia and carers were unfamiliar with this route to support and

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[41] Older People's Commissioner for Wales, Rethinking Respite for people affected by dementia, 2018

[42] Older People's Commissioner for Wales, Rethinking Respite for people affected by dementia, 2018

[43] Social Care Institute for Excellence, Keeping personal budgets personal: learning from the experiences of older people, people with mental health problems and their carers, Newbronner, L., Chamberlain, R., Bosanquet, K., Bartlett, C., Sass, B. & Glendinning, C. 2011

said they had not been informed about direct payments by their social worker.

“Direct payments - here you have to fight for it.” Carer

“I have heard the Council now say that they will not pay carers direct payments now and that’s illegal.” Carer

Some carers who tried to use direct payments for respite did not have a positive experience, either because they did not feel adequately supported to manage them, the amount of money provided by Social Services did not cover the costs or because they could not find anyone to provide the service.

Carers are also entitled to seek support for themselves in the form of a direct payment. For example, a carer had used the payment for someone to mow the lawn, which was something he found difficult due to health reasons. It met the outcomes of having a break and sustaining him in his caring role:

“Helping with some of the difficult things I was finding to do – things that might alleviate that.” Carer

Carers access to advocacy

“[Advocacy] helped me know my rights.” – Carer and Advocacy User[44]

Upholding the rights of carers to access advocacy, where appropriate, is necessary to ensure they can access the services and support they need to continue in their role and is also a vital part of successful implementation of the Act.

However, the Commissioner’s report, ‘Making Voices Heard: Older People’s Access to Independent Advocacy in Wales[45]’ found that a

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[44] Older People’s Commissioner for Wales, Making Voices Heard: Older People’s Access to Independent Advocacy, 2018

[45] Older People’s Commissioner for Wales, Making Voices Heard: Older People’s Access to Independent Advocacy, 2018

significant number of older people are unable to access independent advocacy, both more generally and in relation to legislative duties.

“You don’t know what you don’t know.” – Older person living with dementia[46]

It suggests that more needs to be done to ensure that carers’ needs for independent advocacy are being appropriately considered and met under the Act. Targeted awareness initiatives, such as information in GP surgeries and libraries, would ensure that those people who are most vulnerable are made aware of independent advocacy, regardless of whether they are in contact with statutory services or identify as carers.

For many carers, a family member, friend or the person they provide care and support to may be able to provide informal advocacy to allow them to participate and have their views and wishes heard in the decision-making process. However, the number of carers who have received support from an informal advocate to assist them in their contact with social services is currently unclear. . Similarly, it is not clear how many carers have received an offer of statutory Independent Professional Advocacy (IPA) in line with the Act or how many carers have accepted the offer of IPA.

National data[47] shows that 762 people received an ‘advocacy’ service during 2016-17 as part of their care and support, but no further data is available to confirm the type of advocacy that was provided or the percentage of carers accessing advocacy support. In addition, whilst the Annual Report on the National Outcomes Framework shows that 71% of carers receiving support agreed that they had been involved in any decisions made about how their care or support was provided[48], it does not contain any further detail on the reasons why almost 30% of carers

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[46] Older People’s Commissioner for Wales, Making Voices Heard: Older People’s Access to Independent Advocacy, 2018

[47] Welsh Government, Adults receiving care and support in Wales, 2016-17 (Experimental statistics) ; Stats Wales, Children receiving care and support by local authority and age group, 2016-17 (Experimental statistics)

[48] Welsh Government, Measuring national well-being: A report on the national outcomes framework for people who need care and support, and carers who need support, 2016–17, 2017

did not feel involved in decisions made about them and whether their need for advocacy, statutory or otherwise, was a factor in this.

The lack of data to demonstrate whether a carer's need for advocacy has been considered is a concern. Carers were unanimous in their desire for specialist independent advocacy services to be available to them to ensure that they are aware of their rights, and the rights of the person they care for, so they can feel better informed and better able to continue to provide care and support.

The current lack of data collected in relation to the offer of advocacy during assessment process makes it unclear as to whether independent advocacy, or the lack of the carer having an effective voice during the process and not knowing their rights, may be a factor in the low number of Support Plans resulting from carers' assessments.

The report also found potential shortcomings in the level of training for staff working in statutory services on the legal requirements in relation to advocacy, resulting in a lack of understanding amongst professionals on people's rights to independent advocacy, which may act as a barrier to carer's access to advocacy.

Under the Mental Capacity Act 2005, those acting as informal advocates for the person lacking capacity, such as an unpaid carer, family member or friend, can receive support from an IMCA[49] to help support them perform the role of informal advocate. The extent to which this right is offered to informal advocates, and the use of IMCA at a national level is largely unknown. This is a concern as denying informal advocates the support of an IMCA to be effective in their role potentially undermines the voice of the person for whom they are advocating.

For example, the Commissioner's office has provided support to a family who disagreed with a best interests decision made about their family member. An IMCA referral was not considered as the individual already had family involvement. However, it is in situations like these where an IMCA could have been used to ensure the older person's best interests were protected.

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[49] The Mental Capacity Act 2005 states that where a person has an unpaid representative, a 39D IMCA must be instructed if a request is made by the person or their unpaid representative or the supervisory body believes that the person or their representative would benefit from the support of a 39D IMCA

The low level of uptake of support from a 39D IMCA by family or friends who are acting as an informal advocate for a person who lacks capacity is a concern. It calls into question the extent to which professionals are appropriately informing those undertaking the informal advocate role, many of whom will be carers, of this right. Whilst the latest monitoring report for Deprivation of Liberty Safeguards[50] shows that a higher proportion of challenges to DoLS authorisations were made when an IMCA was present, it states that use of IMCA in the DoLS process has remained relatively steady since 2015/16. The report shows that, of the 363 cases where an IMCA was appointed (out of a total of 13,627 DoLS applications made in 2016/17[51]), only 94 of these were a 39D IMCA. Given the important role played by an IMCA (including 39D IMCAs) in ensuring that the person's voice is heard when decisions about best interest are made, it is vital to ensure that people's rights to an IMCA (including informal advocates right to a 39D IMCA) are promoted more consistently.

Current and future need for independent advocacy

It is concerning that the current Population Assessments under the Act do not feature independent advocacy in any great detail, despite the requirement to do so. Whilst the Population Assessments identify several different groups within the reports – including people with a learning disability, people with a mental health condition, older people and carers, who potentially require independent advocates with different skills – there is no indication as to what different types of independent advocacy services may be required to meet this need.

It should be quite possible to analyse data on specific groups of people to estimate demand for independent advocacy; an increase in the number of people living with dementia, for example, will indicate a need for a proportionate increase in the number of independent advocates who are able to work in this area. It is concerning that this link has not been made in any of the Population Assessment reports.

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[50] CSSIW & HIW, Deprivation of Liberty Safeguards: Annual Monitoring Report for Health and Social Care 2016-17

[51] CSSIW & HIW, Deprivation of Liberty Safeguards: Annual Monitoring Report for Health and Social Care 2016-17

This is a significant missed opportunity and raises concerns about the effectiveness of the PAs as a tool to ‘ensure services are planned and developed in an efficient and effective way by public sector partners to promote the well-being of people with care and support needs’[52].

Broader Welsh Government policy

Health

Caring can have a negative impact on carer’s physical and mental health. Carers Wales’ State of Caring report showed that:

- Carers can find it a challenge to find time to take care of their own well-being whilst caring:
    - Over half of carers in Wales (53%) reported that they have reduced the amount of exercise they take because of caring and 47% reported that they have found it difficult to maintain a balanced diet.

- Carers are more likely to have physical or mental health conditions and often neglect those conditions:
    - 6 in 10 carers (59%) said their physical health was worse as a result of caring, whilst 70% of carers in Wales said they suffered from mental health problems.

- Carers are more likely to experience stress, anxiety and worse mental health:
    - Half (50%) of carers in Wales said their mental health has got worse as a result of caring, 8 out of 10 people (78%) said they feel more stressed because of their caring role, and 7 out of 10 (67%) said caring has made them feel more anxious[53].

In addition to their own health needs, far more carers deal with health services than with social care as part of their caring role[54]. Awareness, identification and responsiveness to carers from health services is therefore absolutely critical in

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[52] Paragraph 79, Part 2 Code of Practice (General Functions), Social Services and Well-being (Wales) Act 2014

[53] Carers Wales, State of Caring 2017, 2017

[54] Wales Carers Alliance, Assembly Member Briefing for the Stage 3 Debate of the Wellbeing of Future Generations (Wales) Bill, 2015

supporting carers to continue in their caring role and to maintain their own well-being.

Health & Carers Strategies (Wales) Measure 2010

The Carers Strategies (Wales) Measure 2010 (the Measure) and other pre-existing carers legislation was repealed by the introduction of the Act, on the basis that its provisions were intended to be passported across to the Act, an action that was strongly opposed by carers organisations at the time.

The Wales Carers Alliance raised concerns that the repeal of the Measure, and introduction of the Well-being of Future Generations (Wales) Act 2015 have diluted the role of Health Boards when jointly planning services for carers, and detailed guidance that sat under the Measure has been lost[55].

Under the Measure, Health Boards were designated as the lead agencies when developing local carers' strategies, the purpose of which was to deliver systematic carer identification and provision of information to carers[56]. This is now included within a more general requirement for Public Services Boards to complete assessments of well-being and publish a local well-being plan[57].

Whilst the impact of these legislative changes is currently unknown, the legal framework for recognising and providing information to carers that previously existed through the Measure has been dismantled, a change that has also been reflected in the dismantling of accompanying strategic roles[58].

Notwithstanding this, there are examples of good practice in relation to carers across Health Boards, such as schemes that aim to encourage and motivate practices to aspire to higher levels of information and support for carers, such as the 'Investors in Carers' scheme for GP practices across Hywel Dda University Health Board[59]. Furthermore, the role of a Carers Champion within GP services has been well

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[55] Wales Carers Alliance, Assembly Member Briefing for the Stage 3 Debate of the Wellbeing of Future Generations (Wales) Bill, 2015

[56] Carers Strategies (Wales) Measure 2010 ; Carers Strategies (Wales) Measure 2010 Guidance issues to Local Health Boards and Local Authorities, December 2011

[57] s37 Wellbeing of Future Generations (Wales) Act 2015

[58] Evidence gathered from Carers Officers Learning and Information Network for OPCW Rethinking Respite

[59] Hywel Dda University Health Board, Investors in Carers

implemented in some practices, but there has been a variation in the success and impact of this role[60]. However, the future of these schemes and action across each Health Board is now dependent on the will of each organisation opposed to requirements set out within the Measure.

GP services

The Commissioner published a report into GP services in 2017[61], in which almost 17% of questionnaire respondents identified as carers, and a number of issues were raised in relation to carers.

The report found that health systems can be inflexible and unresponsive to people's individual needs – for example when booking an appointment and a lack of recognition of the difficulty carers may face in attending last minute appointments. Carers talked about the challenges in getting a home visit, and the frustrations in having to explain their situation multiple times when requesting this.

"Difficult for carers to attend same day appointments as cannot get cover or help that quick - even volunteer car service may not be available at such short notice." – Carer at GP services engagement event

"The biggest problem is getting past the receptionist. We need home visits as my wife is housebound and I am her carer. It's like an interrogation every time - a minefield of questions demanding answers. There should be a flag on your file if you need home visits. Instead it's a battle every single time." – Carer at GP services engagement event

Overall, the feedback from older people appeared to show a positive shift in welcoming and recognising the presence and role of carers, and there were examples of good practice such as effective use of system flagging (with consent) to identify individuals who are carers, living with dementia, or specific communication needs.

"There is no problem bringing a carer. They talk to both of us. We are accepted as a couple - neither is excluded." – Carer at GP services engagement event

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[60] Older People's Commissioner for Wales, GP Services in Wales, 2017

[61] Older People's Commissioner for Wales, GP Services in Wales, 2017

However, a small number of older people felt that health professionals spoke to a carer or support worker instead of directly to them, and were not sufficiently responsive when keeping a record of an individual's status as a carer.

"I believe that the needs of (unpaid) Carers needs to be better addressed by my surgery. I handed in a Carer registration form but it is hard to see if anything has been actioned. I asked for a referral to my local Social Services (to receive Carer related information) but nothing has been received. I have not had any Carer related communication from my Surgery (e.g. invitation to flu clinic)." – Response to online questionnaire on GP services

Dementia Action Plan for Wales 2018-2022

The Welsh Government's Dementia Action Plan recognises the crucial role that carers play in supporting people living with dementia. It also recognises the right to a carers assessment, the need for flexible respite provision and introduces the principles of John's Campaign for carers to stay with the people they support in hospitals[62].

Carer involvement in in-patient care planning for people living with dementia is key to enable better outcomes following admission, whereas current hospital processes can mean carers are excluded from meaningful participation in supporting a loved one with dementia. The implementation of the strategy will therefore need to include carers, not only as an individual accompanying someone whilst in hospital, but as a key partner in the planning and delivery of care.

It is currently unknown how the Welsh Government will require Health Boards to report on the implementation of John's Campaign across Wales. However, any regional approach must ensure that carers rights to stay with their loved one are not diluted or left to chance.

Domestic abuse and caring

There is an increased risk[63] of people living with dementia experiencing abuse from a family carer. Similarly, carers are also at risk of being

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[62] Welsh Government, Dementia Action Plan for Wales, 2018

[63] National Centre for the Protection of Older people, Abuse of Older People with Dementia, 2013 ; Journal of Interpersonal Violence, Coercive control and physical violence in older adults, 2015

abused by the person they are caring for. Findings indicate a significant correlation between experiencing trauma, poor health, low levels of social support and living alone, with experiencing emotional coercive control by an intimate partner during one's lifetime, which are risk factors associated with an increased risk of physical abuse after the age of 60[64]. It is therefore essential that health and social care professionals are able to recognise the risks to a carer and the person they are caring for in a potentially abusive situation.

However, staff capacity issues may limit the opportunities that social workers have for developing positive, trusting relationships with older people. There is evidence in Wales that statutory agencies resort to case management by telephone[65], a practice that can inhibit the development of a 'person-centred' ethos within adult safeguarding and hinder the promotion of personalisation of adult care in general[66].

Local Authorities and Health Boards need to actively promote awareness of the hidden problem of domestic abuse experienced by older people, and recognise and implement a co-ordinated community response as the most appropriate strategy for tackling the complexity of domestic abuse[67].

Caring and finances

Being a carer can have a negative impact on personal finances. Carers may experience higher household costs, increased transport costs (especially for those in rural areas) and may not have access to flexible working, or be less able to work, due to their caring role[68]. An older carer may still wish to participate in work, but find this challenging due to their caring role, or may not be accessing the financial support to which they are entitled.

Carers Trust state that UK-wide:

- The employment rate for carers is at 67%; over half of those who are not working say that they want to do so. One in five carers gives up employment to care.

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[64] Journal of Interpersonal Violence, Coercive control and physical violence in older adults, 2015

[65] Older Peoples Commissioner for Wales, Access to support and justice, 2015

[66] British Journal of Social Work, Social work in the context of adult social care in England, 2010

[67] Journal of Gender Studies, Inching forward on domestic violence: The 'co-ordinated community response' and putting it in practice in Cheshire, Hague and Bridge, 2008,

[68] Carers UK, The Cost of Caring, 2013

- In a survey, 53% of carers have borrowed money as a result of their caring role.
- 60% have used all of their savings to cover the costs of caring.
- 35% of carers had missed out on state benefits because they didn't realise they could claim them. 9% had missed out on Carer's Allowance for 3–5 years, 10% for 5–10 years and 14% for over 10 years, because they did not realise they were entitled to it[69].

Attendance Allowance is a benefit available to people aged 65 and over who have a disability which means that they require care or supervision on a daily basis. It is claimed by 100,000 people in Wales, equating to 17% of people over 65 the age of 65 (at a cost of £400m). There are concerns that Attendance Allowance is not reaching all those who need it, and older people may not see themselves being entitled to claim benefits. For example, there is no correlation with the proportion of older people receiving Attendance Allowance and older people receiving non-residential care across Wales' Local Authority areas[70]. Raising awareness of benefits such as Attendance Allowance could be one step towards improving the financial situation of carers.

Caring and housing

It is well known that the quality and appropriateness of housing is a key factor in an individual's health and well-being. Warm, energy efficient homes can keep costs down and prevent problems related to cold and damp living conditions. Furthermore, accessibility and appropriate adaptation can greatly improve the quality of life of an individual with care and support needs and also their carer.

Housing issues experienced by carers include not being prioritised for housing, not being recognised as needing a separate bedroom, inheritance or tenancy rights not being recognised if a carer is not on the deeds/tenancy, and ongoing challenges in securing adaptations or an adapted home[71].

In taking forward the recommendations of the Expert Group on Housing an Ageing Population[72] and further housing policy, the Welsh

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[69] Carers Trust, Key facts about carers, accessed September 2018

[70] Bevan Foundation, Future of Attendance Allowance in Wales, 2016

[71] The Princess Royal Trust for Carers, Carers and Housing: Addressing their needs, 2010

[72] Welsh Government, Expert Group on Housing an Ageing Population, 2017

Government needs to be aware and responsive to the specific issues faced by carers.

Caring and technology

If desired, assistive technology could support both a carer and an individual with care and support needs to live more independent lives at home and when out in their community. There has been a rise in the types of technology available in recent years, which extend further than traditional community alarm systems. Today we use more electronic equipment than ever before, from remote control lighting to voice activated technologies such as Alexa or Google Home. These offer an opportunity to manage independence and can be linked to a variety of devices around the home, supporting things such as appointment management.

The Parliamentary Review into Health and Social Care also makes a recommendation to the Welsh Government and health and social care services to 'Harness innovation and accelerate technology and infrastructure developments"'[73].

Older carers need good quality information, advice and guidance about what assistive technology is available and how it can help maintain independence. This is frequently provided by Occupational Therapists and Physiotherapists, but more general advice through Social Workers and Information and Advice Services should be available to support the preventative aims of the Act.

However, digital inclusion, and the quality of broadband services across Wales are a barrier to the adoption of such technologies for many. Furthermore, technologies should always be seen as a support mechanism rather than a replacement for the human interaction and connectedness that is essential to our well-being.

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[73] Parliamentary Review of Health and Social Care, A Revolution from Within: Transforming Health and Care in Wales, 2018