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Health, Social Care and Sport Committee
National Assembly for Wales
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18 September 2018

Ref: Health, Social Care and Sport Committee inquiry into the Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers: Alzheimer's Society Cymru response

Alzheimer's Society Cymru



Website

alzheimers.org.uk

Dear Dr Lloyd,

I am pleased to respond on behalf of Alzheimer's Society Cymru to the [Health, Social Care and Sport Committee inquiry into the Impact of the Social Services and Wellbeing \(Wales\) Act 2014 in relation to Carers](#). Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia. Alzheimer's Society Cymru welcomes the Committee's interest in the impact of the Social Services and Wellbeing (Wales) Act 2014 on Carers. Evidence for this document was collected by a mixture of desk based research and anecdotal evidence collected from Alzheimer's Society frontline staff in the period 13 August to 10 September 2018. The evidence was collected from across Wales.

Overview

- 1.1 The evidence provided by staff suggests that Carer's Assessments are seen as inconsistent and tokenistic.
- 1.2 The well-publicised issues around funding continue to persist in Wales.
- 1.3 Statutory Service staff and unpaid carers are doing the best job possible in the current climate.
- 1.4 The sharing of information between Local Health Boards, local authorities and third sector organisations is poor and in need of improvement.
- 1.5 Guidance from Local Health Boards, local authorities and third sector is in need of standardisation to prevent confusion.
- 1.6 There are not enough services, and those services do not have enough resource.

Assessments of Need

- 2.1 The Adults receiving care and support in Wales Report, 2016-17 from Statistics Wales reported that 6864 carers refused an assessment.¹
- 2.2 Further discussion with Statistics Wales revealed the reasons for these refusals were not reported on, or not recorded.

¹ Adults receiving care and support in Wales, 2016-17 (Experimental statistics), Statistics Wales, 31 October 2017. First Accessed August 2018

2.3 Anecdotal evidence from Alzheimer's Society frontline staff revealed that most local authorities have a long waiting list, and it is often a case of "take a ticket and wait for your number to be called."

2.4 Evidence also suggested that the assessments are being done over the telephone as opposed to face to face, meaning that the assessor is not getting the full picture and situation of the carer being assessed.

2.5 Staff also reported that often carers are asked what they want out of an assessment and that carers often come away with a carer's passport or carer's card.

2.6 Reasons given by staff for this included the stigma of talking to Social Services; the fear that Social Services will remove the person being cared for if the carer cannot cope and that Social Services are seen as an extension of a figure of authority and carers are afraid to question or fight for something they need.

2.7 This has been echoed by staff across Wales who have commented that Social Services have passed the responsibility onto the carer. One example came from North Wales where staff commented that Social Services are asking carers to complete the 'What Matters' form, something that Social Services used to do themselves. Staff reported that this has led to an inconsistent service and inequitable access.

2.8 Evidence from staff also suggested that the new system has put greater expectation on carers to meet the needs of the person being cared for themselves.

2.9 However, comments from other staff indicated that Social Services have become easier to deal with and there has been an attitude change towards making things easier for the carer to be assessed and access the support needed.

2.10 Overall, staff expressed concern that whilst the new system has led to some improvements, it is patchy at best, and often feels inconsistent and tokenistic to the person being assessed.

2.11 Staff were also concerned that the Carer's Assessments only focussed on the immediate position of the carer and not any potential needs in the future.

Provision of support, including respite care

3.1 The overarching thread that emerged from evidence given by staff and from desk research is that Social Services staff are doing all they can to support carers and the people they care for in a challenging situation.

3.2 Evidence from staff indicated that in theory everyone understands the need for the community to do what it can before statutory services step in, but in practice people generally only ask for help when they are really in need and cannot do any more.

3.3 An example was given where respite wasn't approved for a Carer of a Person with Dementia who is prone to violent outbursts as the Council and carer were unable to fund the respite place despite the chosen facility having space and the service user wanting to go there due to past positive experiences.

3.4 An example was also given of Denbighshire cutting their respite care provision to half, with the Council outlining that the full eight weeks are only available in exceptional circumstances.

3.5 This has led to a situation where volunteer led services are attempting to fill in the gaps in the care, with befriending services asked to go in and provide respite care. Staff have said that there is an over reliance on this.

3.6 Concerns have also been raised about making sure that respite care is age appropriate. What is considered appropriate for older people living with dementia is not always appropriate for those living with early onset dementia.

3.7 Worries have also been raised on the accessibility of respite care, particularly in rural areas; with our report 'Dementia in rural Wales: The lived experiences' highlighting the issue, with one carer saying that: 'They say he can go to a residential setting for respite, but that I need to take him to it and pick him up. By the time I've driven there and back, it's not really giving me a break or for the purpose it's intended.'²

3.8 Anecdotal evidence on taking respite together was also heard, with staff commenting that often, carers and the people they care for would like to have a holiday or break together, but are unable to do so due to a lack of options or availability of help whilst on the break.

3.9 Evidence from staff suggested that this gap is growing due to funding pressures on local authorities, with suggestions that those who can afford to pay for respite care are getting a more comprehensive service than those who cannot.

3.10 Issues were also raised with the state of respite facilities available to carers and people they care for, with staff giving examples of carers refusing to take up respite due to negative experiences in respite homes.

3.11 This has led to safeguarding issues coming to the fore in discussions around respite, with concerns that care plans are not being put in place and followed for respite care.

3.12 There were also concerns raised with the speed of response to advance requests for respite care, with an example given of a carer who had put in a request for respite for a pre-planned trip, but not hearing if respite was granted until 48 hours before the trip, adding to concerns about the person being cared for.

3.13 Finally, staff expressed bewilderment that self-neglect is not recognised as a form of abuse in Wales, and expressed a wish that this should be recognised as soon as possible.

Provision of information, advice and assistance

4.1 Staff reported that the information that exists currently is of good quality, but the people trying to either provide it out or make use of the information are being hamstrung by systems, regulations or funding.

4.2 An example of this was given whereby an assessor asked for signposting advice from the third sector as they didn't know what services were available in their area. Whilst the information was available, joined up access to it was not, leading to this confusion.

4.3 A further example was given of trying to contact the C1V service in the Vale of Glamorgan. The caller wished to report a safeguarding issue, but was faced with a 15 minute wait and a staff member, who, whilst trying their best, were unable to understand the full issues due to a lack of information.

4.4 Evidence from staff suggested that this lack of information, and joined up access to it, has led to a much deeper questioning of the carer's ability to provide care and the carers wider support network.

4.5 This line of questioning simply adds to their burden. People feel obliged to agree to providing support which they are not able to fulfil and get closer to crisis, despite information about helpful services existing.

4.6 Where this information exists, but is held by the third sector, staff evidenced that whilst there was a need to show a connection with the third Sector, it felt like a tick-box exercise as consultations with potentially valuable allies were going on after the majority of a plan or assessment had been finalised.

² Alzheimer's Society Cymru – Dementia in rural Wales The lived experiences - https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_in_rural_wales_the_lived_experiences.pdf - First Accessed September 2018

4.7 Finally, staff also evidenced that there have been occasions when safeguarding complaints have not been upheld as they have been told that “carers can just walk away.” This comment was echoed by staff working in various local authorities.

Information collected by local authorities and Local Health Boards on carers and their needs

5.1 The overwhelming evidence given by staff here is that third sector organisations and Local Health Boards & local authority services are speaking different languages. Staff evidenced that this includes different policies and different structures and suggested that there is a need for some form of standardisation.

5.2 Evidence also emerged that there is a lack of signposting and that it of ten seems that services are talked about and offered to people on a ‘need to know basis.’

5.3 An example of this was given of a multi-disciplinary team meeting where each person at the meeting had their own agenda and were actually arguing amongst themselves to fight for their own services, as opposed to offering and producing the best services for the person in need.

5.4 A further example of this disconnect came from Rhondda Cynon Taf where people who have been diagnosed with dementia don’t know the type of dementia they have been diagnosed with. Staff commented that this lack of sharing of information leads to increased service pressures.

Broader Welsh Government Carers Policy

6.1 Evidence from staff suggested that carers are struggling to have their caring for the elderly or people living with dementia taken as seriously as childcare by employers. Staff also commented that they felt there is a need to destigmatise care for those living with dementia, with one comment suggesting that “there is more understanding of caring for a child than of caring for an elderly person.”

6.2 Comments suggested that there should be a push to enshrine carer’s rights in workplaces to attempt to combat the problem outlined above.

6.3 Staff then suggested that the definition of a dependent needed to be expanded to ensure that people living with dementia or other unseen disabilities can fit into the category to allow their carers access to the same right as those who fit into the current definition.

6.4 Evidence from staff also suggested that unpaid carers are effectively taking on a full time job with no training, and that a programme of training in skills such as manual handling, medication, finances and other useful skills should be created and rolled out nationwide.

6.5 Evidence from staff also suggested that there seems to be a system of “crisis management, not crisis prevention” meaning that local authorities and Local Health Boards were willing to let people reach crisis point before intervening rather than fix it in advance.

6.7 Comments suggested that the majority of policy on dementia focuses on the individual with dementia, rather than the team around the person. We believe that this needs to change, and the carers need to be brought more into focus in order to improve the care received by people living with dementia, both in the home, and in more formal settings such as hospitals or care homes.

6.8 Finally, concerns were raised about people with dementia who are also carers in their own right. This group of carers are often overlooked in the wider carer’s policy, and we believe that this needs to be rectified.

Recommendations

- 7.1 Alzheimer's Society recommends the creation of new guidelines to be rolled out nationwide to standardise and futureproof Carers Assessments.
- 7.2 The Welsh Government should consider issuing guidance recognising self -neglect as a form of abuse, as is the case in England.³
- 7.3 The expansion of the definition of dependent to include those living with dementia and other unseen disabilities to allow their carers to access the same help and support in the workplace.
- 7.4 The creation of a training programme for carers to equip them with the skills necessary to provide the best possible care for as long as possible to those they care for.
- 7.5 The implementation of a social care levy as outlined by Professor Holtham in order to boost the ailing finances of the social care sector in Wales.
- 7.6 The inclusion of people living with dementia as carers in all carer's policy and thinking going forward.

Conclusion

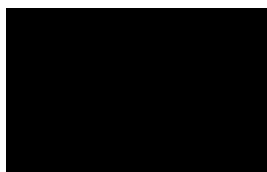
We welcome the Health, Social Care and Sport Committee's interest in the important topic of the impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers. Whilst the evidence outlined above may seem overly negative, we are aware that there is plenty of good practice undertaken by carers; those who work with them; those who provide information, support and advice; and those who offer services to carers.

What we have sought to achieve with this evidential submission is to outline to the committee where there are areas for improvement and to try and offer solutions to these issues. We are acutely aware of the issues that surround the funding of Health and Social Care in Wales and have aimed to provide solutions to these issues that fit into the current funding structures.

We hope that evidence contained in this document is informative and will help the committee accurately examine the impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers.

If you require any other information, please do not hesitate to contact me.

Kind regards



Country Director, Alzheimer's Society Cymru

³ <https://www.scie.org.uk/safeguarding/adults/introduction/types-and-indicators-of-abuse#self-neglect>