National Assembly for Wales / Cynulliad Cenedlaethol Cymru

Health and Social Care Committee / Y Pwyllgor Iechyd a Gofal Cymdeithasol

The Care and Support (Eligibility) (Wales) Regulations 2015 / Rheoliadau Gofal a Chymorth (Cymhwystra) (Cymru) 2015

Evidence from Alzheimer's Society - CSR 02 / Tystiolaeth gan Y Gymdeithas Alzheimer's - CSR 02



## Alzheimer's Society Response

# The Care and Support (Eligibility) (Wales) Regulations

May 2015

**Consultation Response** 



#### 1. Alzheimer's Society

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

By 2016, when these regulations come into force, there will be 46,300 people with dementia living in Wales.

#### 2. Alzheimer's Society response to questions posed

### 1. Do the draft Regulations and Code of Practice achieve the aims of the Act?

- 1.1 Alzheimer's Society believes that the draft regulations and code of practice do not achieve the aims of the Act. The duties set out in the code of practice are now vague to the extent that local authorities could interpret them loosely. Leaving the code of practice open to interpretation could lead to eligibility decisions being made in courts of law. This is the opportunity to ensure that the regulations and code of practice allow access to care and support for people with dementia.
- 1.2 The Act has a strong emphasis on the principle of wellbeing which is supported by Alzheimer's Society. However, we have concerns that with the current drafts of regulations and code of practice, not all people with dementia will be able to meet their personal outcomes in order to achieve wellbeing. In particular, the omission of cognitive impairment in point 3(a) of the regulations could mean the needs of people with dementia are not met. Alzheimer's Society recommends that cognitive impairment is included in point 3(a) in the regulations to ensure that any person with dementia or a learning disability is covered.
- 1.3 As Alzheimer's Society stated in its original response, many people with dementia may be physically able to get washed or dressed, but may need prompting to do so. As such, this can have an impact on maintaining relationships or involvement in the community. Alzheimer's Society strongly recommends including prompting under point 3(c) in the regulations.

- 2. Are the draft Regulations and Code of Practice appropriate to ensure the right access to care and support for people with dementia?
- 2.1 Alzheimer's Society has concerns that the draft eligibility criteria will not ensure the right access to care and support for people with dementia. We recognise that the criteria can be brief in the regulations; however, there are no further explanations in the code of practice. As Alzheimer's Society stated in its original response, many people with dementia may be able to wash or dress, but they may not be able to manage their finances. Point 3(b)(i) in the regulations states that needs could relate to the ability to carry out self-care or domestic routines. This could include the ability to pay utility bills; however, this is not clear if this is the case in the current draft of the code of practice. As stated in the original consultation response, without support with managing finances or paying bills, a person with dementia risks having their electricity or gas supply cut off, which could lead to the need for a higher level of support.
- 2.2 In its original response, Alzheimer's Society expressed concerns over the 'can and can only' test. If a person can only just achieve their outcomes without the need for care and support, they are at risk of their needs worsening and subsequently requiring a higher level of support from local authorities. Alzheimer's Society recommends that the code of practice states what will happen if a person is not eligible for care and support from the local authority in order to emphasise the preventative aspect of the Social Services and Wellbeing (Wales) Act.
- 2.3 Alzheimer's Society believes that the original code of practice was stronger than the current draft and would like to return to this version with the addition of explanations and case studies. Alzheimer's Society strongly recommends that explanations are included in the code of practice to prevent any misinterpretations by local authorities. This must include clarification of the self-care tasks listed under point 1(3) in the regulations, as well as under the eligibility criteria in point 3(b) in the regulations.
- 2.4 The flowchart showing the pathway to personal outcomes is currently illegible and it is impossible to comment on this.
- 2.5 The case studies included in the annex of the code of practice do not demonstrate a variety of circumstances, given that they focus mainly on reablement services. Alzheimer's Society would like to see a case study of an older person who needs preventative services before they are admitted to hospital. Alzheimer's Society would be happy to work with the Welsh Government on a suitable case study.
- 3. Do the draft Regulations and Code of Practice sufficiently address any concerns previously raised?
- 3.1 Alzheimer's Society welcomes some elements of the updated draft regulations and code of practice on eligibility. For example the

inclusion of the 'ability to communicate' as a recognised eligible need for children, adults and carers in the regulations. For people who have conditions that affect their ability to communicate, such as people in the later stages of dementia, taking account of person's communications ability and method of communication is crucial in making sure that they get the care and support at the right time in the right place.

- 3.2 Alzheimer's Society still has major concerns with the regulations and code of practice; in fact, these concerns have been intensified having seen the latest draft versions. Alzheimer's Society recommends that the regulations and code of practice reflect the points sent out below and seeks reassurances from the Welsh Government that this will be the case.
- 3.3 With regards to point 3c, Alzheimer's Society would like to see the addition of the words "or prompting" under (ii). By including these words in the regulations, it would recognise that people with dementia may be physically able to carry out a task but they need prompting to do so (for example, they may be able to have a wash, but they need prompting to do so).
- 3.4 Alzheimer's Society believes that the outcomes in point 1(3) of the regulations are lacking some vital elements. For example, the ability to maintain a home is essential, if it includes paying bills. People with dementia may have the ability to wash, dress or cook a meal, but not be able to look after their finances. Without the right support, this could mean that they lose their electricity or gas supply for non-payment of bills.
- 3.5 Alzheimer's Society also recommends that the outcomes listed under points 2 and 3 in the regulations are expanded and detailed in the code of practice. Doing so would overcome some ambiguities in the regulations and reduce the risk of different interpretations and to provide consistency between local authorities.
- 4. What are the likely consequences of the draft Regulations and Code of Practice for current and future service users and carers?
- 4.1 Alzheimer's Society's main concern is that people with dementia and their carers living in Wales will not be able to access care and support. As the code of practice is so vague, there could be inconsistencies in the interpretation by local authorities. This means that some people with similar needs could receive support whereas others do not. Without support, the needs of people with dementia can worsen; they are more likely to go into hospital in an emergency or move into a care home earlier than expected all of which are more costly interventions than being supported to live in their own home.

4.2 Alzheimer's Society believes that, as a consequence of these regulations and code of practice, eligibility decisions may be made in the courts of law. Alzheimer's Society would like to see vast improvements to the regulations and code of practice in order to prevent lengthy legal battles and eligibility decisions based on case law, rather than correct interpretation.

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For more information, please contact: