



Consultation on the Proposed Carers Strategies (Wales) Measure

A response from the Wales Neurological Alliance

About the Wales Neurological Alliance

The Wales Neurological Alliance (WNA) was established in 2002 to meet the challenges of a changing institutional and political structure in Wales post devolution. Membership has grown to include 26 voluntary organisations representing over 100,000 people and their families affected by a neurological condition living in Wales. The charities are:

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| ▪ Alzheimer's Society | ▪ Guillain-Barré Syndrome Support Group |
| ▪ Association of Spina Bifida and Hydrocephalus | ▪ Headway |
| ▪ Ataxia South Wales | ▪ Huntington's Disease Association |
| ▪ Brain & Spine Foundation | ▪ Motor Neurone Disease Association |
| ▪ Cerebra | ▪ Multiple Sclerosis Society Cymru |
| ▪ Charcot-Marie-Tooth United Kingdom | ▪ Muscular Dystrophy Campaign |
| ▪ Chartered Society of Physiotherapy | ▪ Myotonic Dystrophy Support Group |
| ▪ College of Occupational Therapists | ▪ National Tremor Foundation |
| ▪ Different Strokes | ▪ Parkinson's Disease Society |
| ▪ Dystonia Society | ▪ Progressive Supranuclear Palsy Society |
| ▪ Epilepsy Action | ▪ Stroke Association |
| ▪ Epilepsy Wales | ▪ Tuberos Sclerosis Association |
| ▪ Genetic Interest Group | ▪ Welsh Association of ME & Chronic Fatigue Syndrome |

The aims of the Wales Neurological Alliance are to:

- Raise awareness of neurological conditions and their impact on individuals and alliance
- Inform and influence policy makers in Wales about the needs of people with neurological conditions
- Secure improved services and care for people with a neurological condition living in Wales
- Promote the dissemination of information about neurological conditions
- Support and promote appropriate research

Summary of key points

The Wales Neurological Alliance is grateful for the opportunity to submit written evidence to assist the scrutiny of the proposed Measure by Legislative Committee No. 5. The Alliance, like many voluntary sector organisations, watched the progress of the **National Assembly for Wales (Legislative Competence) (Social Welfare) Order 2009** with great interest and now that the National Assembly for Wales has acquired the powers to legislate in the area of carers, the Alliance is keen to see new laws in this area.

The Wales Neurological Alliance fully supports aims of the **Proposed Carers Strategies (Wales) Measure** to improve the lives of Wales' 341,000 carers. Family member carers are the unpaid workforce that hold together the current Welsh social care model. They often provide around the clock care, which would otherwise cost Local Authorities tens of thousands of pound to commission. However despite this important service they are providing to Wales and the fact that to be a "carer" holds a legal status, they are often brushed aside by medical professionals and social service staff as an "interfering family member", rather than given the respect that they deserve.

Many new carers do not understand that they are carers, seeing their work instead as part of the wider role of being a husband, wife, son, daughter, mother or father. When the person they care for is discharged from hospital, the carer is given little or no information about what services and support are available to them. The Alliance believes that the proposed Measure will ensure that carers receive the advice and information they need.

Despite this support the Wales Neurological Alliance has some concerns about the lead organisation always being the Local Health Board regardless of an individual's condition and about how the proposed Measure related to other carers legislation.

1. Is there a need for legislation (by means of an Assembly Measure) to be made to introduce a new requirement on the NHS and Local Authorities in Wales ("the relevant authorities") to work in partnership to prepare, publish and implement a joint strategy in relation to carers and if so why? If not, what alternatives do you propose?

The Wales Neurological Alliance agrees with the Welsh Government that fundamentally there is a need for legislation to ensure that the NHS and Local Authorities work in partnership to develop Carers Strategies.

As explained in the Deputy Minister's Explanatory Memorandum, Welsh Ministers do not currently have the power to require Local Authorities or health organisations to develop Carers Strategies¹. Information does exist and different Local Authorities vary in how proactively they inform carers about information and services, but there is no uniformity to the type of information that is provided. For example Cardiff Council currently provides a 36 page carers handbook, whilst Isle of Anglesey Council provide a 5 page publication.

The Alliance believes that a big problem with the current system is the lack of carers' information when someone is at hospital. For the husband or wife of someone who has just suffered a serious head trauma, or of someone who has just been diagnosed with Multiple Sclerosis or Parkinson's Disease, their primary concern is to understand the problems facing their loved one, not to immediately think of themselves. However it is at this early stage where a medical professional or a social worker brought into the hospital needs to explain the person's new status as a carer, and ensure that they get all of the help and information they need.

Instead too often a carer only realises they have become a carer, once they have unknowingly taken on more and more responsibility for a loved ones' wellbeing and are suddenly unable to cope. At this point, they often find support and information from the

¹ Proposed Carers Strategies (Wales) Measure, Stage 1 Explanatory Memorandum, page 7, paragraph 3.7

charities associated with the loved ones condition or specific carers' charities, rather than the statutory bodies that should have provided the information at the start.

2. Are the sections of the proposed Measure appropriate in terms of reforming legislation relating to the provision of information and advice to carers? If not, how does the proposed Measure need to change?

As stated in response to question one, the majority of the proposed Measure is appropriate in reforming legislation relating to the provision of information and advice to carers. However the Wales Neurological Alliance believes that there are areas where the proposed Measure could be improved further or be clarified.

Consultation of Carers

The Wales Neurological Alliance welcomes the decision by the Welsh Government to fully consult carers in deciding what services they provide in Section 2 of the proposed Measure, but the Alliance believes the reference could have been stronger rather than relying on future regulations.

In Section 2, the proposed Measure states:

- (1) The Welsh Ministers may by regulations require two or more relevant authorities to prepare and publish a strategy setting out how they will work together –
 - (a) To provide appropriate information and advice to carers
 - (b) To ensure that, where it falls to any of those authorities to decide what services (if any) are to be provided to or for a carer or the person cared for, the carer is consulted before the decision is made, and
 - (c) To ensure that the authorities consult carers before they make decisions of a general nature regarding the provision of services to or for carers and the persons they care for.²

The Wales Neurological Alliance believes that this section could have been stronger and instead have been specified within the proposed Measure. By using the wording “this consultation includes (but it is not limited to)”, the proposed Measure could guarantee a minimum standard of consultation but without limiting the standard.

Another concern with this section is the absence of a role for carers within the development of the strategy. The legislation would guarantee carers the right to be consulted on any provisions coming out of the strategy, such as what services will be provided, but they are not given a role within the development of the strategy.

² ‘Proposed Carers Strategies (Wales) Measure’, Stage 1 draft, 2010, page 2 (line 18 – 26)

The Alliance would therefore suggest amending this section to:

- (1) The Welsh Ministers may by regulations require two or more relevant authorities *to work with local Voluntary Action groups* to prepare and publish a strategy setting out how they will work together –
 - (a) To provide appropriate information and advice to carers
 - (b) To ensure that, where it falls to any of those authorities to decide what services (if any) are to be provided to or for a carer or the person cared for, the carer is consulted before the decision is made, and
 - (c) To ensure that the authorities consult carers before they make decisions of a general nature regarding the provision of services to or for carers and the persons they care for. *The consultation may include (but is not limited to) stakeholder meetings, a survey of all carers and service users, and a 28 day consultation period.*

Designation of an NHS organisation as lead authority

The Wales Neurological Alliance is concerned that the proposed Measure seeks to always designate the lead authority as an NHS organisation, regardless of the circumstances.

The Alliance would accept that there is a need to educate staff at hospitals about the important role of carers, and as this is often the place where following preparations for the discharge of a relative, a family member realises that they now have a carer role. However this does not mean that the lead authority should always be the health organisation. The proposed Measure as currently drafted would mean that examples of good practice in Local Authorities that have functioning carers strategies, could be lost as the role of lead authority would pass to a possibly less experienced Local Health Board.

The current wording also limits the scope of future regulations. The current wording in Section 5(3) is as follows:

- (3) The Welsh Ministers may, for each strategy, designate an NHS organisation as the lead authority for the purposes of co-ordinating and overseeing the preparation and publication (and any subsequent review) of the strategy.³

The Alliance would suggest amending Section 5(3) to the below paragraph. This would still allow the Welsh Government to make health organisations the lead authority in the first set of regulations if it saw fit, but still retain the flexibility to allow one of the other “relevant authorities” to be the lead organisation in future regulations.

- (3) The Welsh Ministers may, for each strategy, designate a *lead authority from any of the “relevant authorities” contained in section 2(3)* for the purposes of co-ordinating and overseeing the preparation and publication (and any subsequent review) of the strategy.

³ ‘Proposed Carers Strategies (Wales) Measure’, Stage 1 draft, 2010, page 3 (line 36 – 38)

3. How will the proposed Measure change what organisations do currently and what impact will such changes have, if any?

The Wales Neurological Alliance believes that the proposed Measure will have a profound effect on what Local Authorities and health organisations are doing, but most of the changes will come from the as yet unpublished regulations that the legislation gives Welsh Ministers the power to introduce.

Depending on the regulations developed by Welsh Ministers, both Local Authorities and health organisations may have to review their protocol and decision making processes so that carers can be involved.

The Wales Neurological Alliance believes that these potential changes should have a positive impact of the type of services developed.

4. What are the potential barriers to implementing the provisions of the proposed Measure (if any) and does the proposed Measure take account of them?

The Wales Neurological Alliance believes that greatest barriers to delivering the provisions of the proposed Measure are Local Authorities and Local Health Boards.

Although the proposed Measure gives Welsh Minister substantial power to force Local Authorities and Local Health Boards to develop Carers Strategies, Ministers will be reliant on these organisations to prioritise the development of these strategies and execute them effectively.

The rationale for the proposed Measure is that Welsh Ministers have not got the authority to compel organisations to develop Carers Strategies, so legislation is needed to give Welsh Ministers this power. However Local Authorities and Local Health Boards have many competing priorities and demands on their time, most of which originate in legislation and regulation. Regulations coming from the proposed Measure will legally compel the organisations to work together on these strategies, but with the time of senior staff and resources being finite, the development of Carers Strategies will have to compete with other priorities.

The proposed Measure relies on regulations for much of the detail of the Carers Strategies, so it is possible that these may overcome this barrier. However without seeing the draft regulations it is difficult to comment further at this time.

5. What are the financial implications of the proposed Measure for organisations, if any? In answering this question you may wish to consider Section 2 of the Explanatory Memorandum (the Regulatory Impact Assessment), which estimates the costs and benefits of implementation of the proposed Measure.

The financial implications of the proposed Measure are stated within the Explanatory Memorandum. The Wales Neurological Alliance is not in a position to query these figures so for the purposes of our response we have assumed that they are an accurate estimation.

6. Are there any other comments you wish to make about specific sections of the proposed Measure?

The Wales Neurological Alliance is disappointed by the narrow extent of the ***Proposed Carers Strategies (Wales) Measure***. Under the ***National Assembly for Wales***

(Legislative Competence) (Social Welfare) Order 2009 the National Assembly for Wales has gained a broad legislative competence within the area of carers, which contrasts with the very restrictive competences in social care, where competency has only been granted around non-residential charged.

The proposed Measure's primary aim is to give the Welsh Government the power to make Local Authorities and Local Health Boards develop strategies, but the legislation could have covered other aspects of carers' rights.

The proposed Measure offered the opportunity to repeal the **Carers (Equal Opportunities) Act 2004** and the **Carers (Recognition and Services) Act 1995** for Wales, and consolidate the 2 Acts' provisions into a single source of Welsh legislation for Carers. The provisions of the proposed Measure would fit very well into Section 2 of the 2004 Act, "Co-operation between authorities", extending the Act but also establishing a single body of Welsh legislation for Carers. Instead the proposed Measure makes no mention of either Act, and it is unclear how the three laws work together. For an individual or organisation seeking to understand the rights of carers, they will now have to consult 3 different pieces of legislation, whilst the proposed Measure offered the opportunity to consolidate carers' legislation into a Measure that could be built on over time.

The Wales Neurological Alliance is also unclear how the proposed Measure sits with the **Local Authority Social Services Act 1970**. Both the **Carers (Equal Opportunities) Act 2004** and the **Carers (Recognition and Services) Act 1995** amended the schedule 1 of the 1970 Act (which sets out enactments conferring functions referred to each Local Authority's social services department). The Alliance believes that the proposed Measure should be amended to take into account the additional responsibilities placed on Local Authorities.

After section 7 of the proposed Measure, the Wales Neurological Alliance would recommend inserting:

8 Amendment to the Local Authority Social Services Act 1970

- (1) The Local Authority Social Services Act 1970 (c. 42) is amended as follows.
- (2) At the end of the table in Schedule 1 to the Act insert—

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| Carers Strategies (Wales) Measure 2010 | Co-operating with other authorities to develop prepare and publish Carers Strategies |
| Section 2, 3, 4, 5, 6 and 7 | |

If accepted this amendment would renumber section 8 (Orders and regulations) to section 9, section 9 (Commencement) would become section 10, and section 10 (Short title) would become section 11.

7. What are your views on powers in section 8 for Welsh Ministers to make subordinate legislation?

The Wales Neurological Alliance is broadly supportive of the powers given to Welsh Ministers to make regulations regarding the finer details of what a Carers Strategy would look like.

However the Wales Neurological Alliance would like to see the first set of regulations subject to the affirmative procedure rather than the negative procedure. The reason for this is that the proposed Measure is largely a non-contentious framework law that is difficult for any party or individual to oppose. However the regulations could be very different depending on whom the Welsh Minister was or which parties were in government after the 2011 Assembly elections.

The regulations could bring substantial changes to how carers are treated by Local Authorities and Local Health Boards, particularly those using Section 2(1) (b) and (c):

- (a) To provide appropriate information and advice to carers
- (b) To ensure that, where it falls to any of those authorities to decide what services (if any) are to be provided to or for a carer or the person cared for, the carer is consulted before the decision is made, and
- (c) To ensure that the authorities consult carers before they make decisions of a general nature regarding the provision of services to or for carers and the persons they care for.⁴

The Alliance would also like to note the observations of the Subordinate Legislation Committee when they scrutinise the ***Social Care Charges (Wales) Measure 2010***. The report stated:

“The Committee is increasingly concerned by the framework of Measures being proposed by the Welsh Assembly Government. The Committee questions whether due to the framework nature of this Measure whether the first set of regulations made under the Measure should be subject to the affirmative procedure.”⁵

The Wales Neurological Alliance believes this observation is as equally relevant in the ***Proposed Carers Strategies (Wales) Measure*** and would therefore like to see the first set of regulations subject to the affirmative procedure.

- 8. Question 2 sets out the powers to make regulations (subordinate legislation) that the proposed Measure would give to Welsh Ministers. It is proposed that all of these powers would be exercised by the ‘negative procedure.’**

Has the appropriate balance been struck between the provisions set out in the Measure and the power delegated to Welsh Ministers, to set out the detail of the requirements to be placed on the relevant authorities in Wales through subordinate legislation? Is the use of the negative procedure appropriate in each case or are any of the powers sufficiently significant for the affirmative procedure to apply?

This has been addressed in response to question 7.

⁴ ‘*Proposed Carers Strategies (Wales) Measure*’, Stage 1 draft, 2010, page 2 (line 21 – 26)

⁵ ‘*The appropriateness of the subordinate legislation provisions in the Proposed Social Care Charges (Wales) Measure*’, Subordinate Legislation Committee, 2009, page 5, paragraph 5.6