



SCC21

Cynghrair Niwrolegol Cymru
Wales Neurological Alliance

Consultation on the Proposed Social Care Charges (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 | ▪ Headway |
| ▪ Association of Spina Bifida and Hydrocephalus | ▪ Huntington's Disease Association |
| ▪ Cerebra | ▪ Motor Neurone Disease Association |
| ▪ College of Occupational Therapists | ▪ Muscular Dystrophy Campaign |
| ▪ Charcot-Marie-Tooth United Kingdom | ▪ Myasthenia Gravis Association |
| ▪ Chartered Society of Physiotherapy | ▪ Myotonic Dystrophy Support Group |
| ▪ Child Brain Injury Trust UK | ▪ Multiple Sclerosis Society Cymru |
| ▪ College of Occupational Therapists | ▪ Parkinson's Disease Society |
| ▪ Dystonia Society | ▪ Progressive Supranuclear Palsy Society |
| ▪ Epilepsy Action | ▪ Stroke Association |
| ▪ Epilepsy Wales | ▪ Tourette's Syndrome Association |
| ▪ Genetic Interest Group | ▪ Tuberous Sclerosis Association |
| ▪ Guillain-Barré Syndrome Support 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, has long been concerned about the charging system in Wales and is pleased to see the Welsh Assembly Government bringing forward a Measure in this area.

The Wales Neurological Alliance believes that no-one living with a neurological condition should have to pay for their social care and that ultimately these costs should either be met by a compulsory insurance scheme or by general taxation. The Welsh Assembly Government has ruled this out in the short term and when Gwenda Thomas AM launched the start of the Paying for Care Consultation, she stated:

“Whilst I would not want to stifle this or any other argument on the options for our future policy on paying for care, it is only honest that I say now that I do not believe that with the significant increase in numbers of older people in Wales over the next 10-15 years that Free Personal Care will be affordable for us.”¹

In the absence of a commitment to abolish social care charges for all, the Wales Neurological Alliance welcomes the proposal to reform charges as an important step in the right direction.

The Wales Neurological Alliance is generally supportive of the specific aims of the Welsh Assembly Government and this is demonstrated in the responses to the seven consultation questions. However, the Alliance is disappointed by the scope of the Measure and concerned by the reliance on Subordinate Legislation to deliver real changes to social care charges. The proposed Measure transfers sweeping powers to a future Minister to set social care charges as high or low as he or she would like, without the need for appropriate scrutiny by the National Assembly for Wales.

1. Is there a need for legislation to be made to ensure that local authorities across Wales adopt a more consistent approach to charging service users for non-residential social care services, and if so, why?

The Wales Neurological Alliance agrees with the Welsh Assembly Government that fundamentally there is a need for legislation to ensure that social care charges across Wales do not differ dramatically in price.

Neurological conditions do not respect county council boundaries. They affect people in all parts of Wales, and therefore someone living with Multiple Sclerosis or Parkinson's Disease is likely to require similar services to someone living the same condition in Cardiff.

The Wales Neurological Alliance believes that people living with neurological conditions should not have to pay social care charges and instead these costs should be paid for by the Welsh Assembly Government or by a compulsory insurance system. However, the Welsh Assembly Government has stated that the main aim of the **Proposed Social Care Charges (Wales) Measure** is to tackle some inequalities of the current social care system, rather than radically overhaul the entire system. The Wales Neurological Alliance accepts that the variation in charges regimes of the 22 local authorities is unfair and therefore in the absence of a commitment to abolish social care charges, welcomes the overarching aim of the Measure to make social care charges uniform.

¹ http://www.payingforcareinwales.net/docs/Deputy_Ministers_launch_speech_11_Nov_English.doc

2. **Are the sections of the proposed Measure appropriate in terms of reforming legislation relating to the social care charging regime? If not, how does the proposed Measure need to change?**

In considering this question, consultees may wish to consider, in particular, the nature of the provisions in the proposed Measure that:

- (a) **when considering what is a reasonable charge for a service, local authorities must comply with regulations to be made by Welsh Ministers which would control or set a maximum charge (Section 2)**

The Wales Neurological Alliance is concerned that the **Proposed Social Care Charges (Wales) Measure** is designed to enable Ministers to reform the social care charges system through Statutory Orders, rather than allowing Assembly Members reform the structure as part of this proposed Measure. This point is expanded upon in answer to consultation questions 6 and 7.

The Wales Neurological Alliance, in common with many other voluntary sector organisations, had expected the long-awaited Measure to set a clear direction for how social care charges would be reformed. As stated in the answer to consultation question 1, the Wales Neurological Alliance had not expected the proposed Measure to abolish social care charges, but the Alliance had expected the proposed legislation to either set a maximum charge or develop a formula that would be used to set charges. This would have given members of Legislative Committee No. 5 and other Assembly Members the ability to contribute to the debate as to what level of charges are reasonable for people wanting to access social care. Instead the proposed Measure conveys greater powers to the Minister.

In Section 2, the proposed Measure states:

- (3) The provision that may be made in the regulations includes (but is not limited to) provisions –
- (a) Specifying an amount which must be considered the maximum reasonable charge for a service, or combination of services, to which this Measure applies;
 - (b) Setting out a formula for determining the amount which must be considered the maximum reasonable charge for a service, or combination of services, to which this Measure applies;²

The Wales Neurological Alliance believes that whilst it is appropriate for the maximum amount charged to be specified in regulations (Section 2-3-a), due the prices rising annually with inflation, the exact formula (Section 2-3-b), should be set out in legislation. The formula could be designed so that it was not linked to a specific amount and therefore would not become dated over time. For example, the formula could be based on “no local authority being able to charge more than 10% higher than the lowest priced authority for the same service.”

² ‘Proposed Social Care Charges (Wales) Measure’, Stage 1 draft, 2009, page 2 (line 28) – page 3 (line 5)

SO02 Whatever formula is developed to ensure that social care charges are either uniform or do not exceed a certain amount, the Wales Neurological Alliance believes that the formula should be clear, transparent and written into the proposed Measure.

(b) the power given to Welsh Ministers to specify in regulations which categories of person, service or combination of services are excluded from charging (section 3);

Section 3 is a very important part of the proposed Measure and yet only accounts for 12 lines of the document. The Wales Neurological Alliance is concerned that section 3 gives a Welsh Minister and the Welsh Assembly Government sweeping powers to include or exclude large groups of people who would be excluded from social care charges.

As it has already been stated in the opening remarks to this consultation response, the Wales Neurological Alliance believes that people living with neurological conditions, as well as other disabled people, should be excluded in this section. However it has also been stated in this response, that the Wales Neurological Alliance is aware that the Welsh Assembly Government can not afford to exclude large groups of people from charges.

The Wales Neurological Alliance is concerned that the proposed Measure as drafted would allow the current Welsh Minister or future Minister to exclude groups of people who the government believe to be special cases without this decision being fully consulted by the National Assembly for Wales.

In Section 3, the proposed Measure states:

- (1) The Welsh Ministers may by regulations specify categories of person, service or combinations of services (or categories of person in respect of a particular service or combination of services) in respect of which a charge must not be imposed under section 1.³

The Wales Neurological Alliance would therefore like the proposed Measure to clearly list the major groups of people who would be exempt from charges and from which charges they would be exempt. If this list was contained within the proposed Measure then the current Section 3-1 could be reworded to give Welsh Ministers the power to add additional groups of people who might be excluded from charges in future.

The Wales Neurological Alliance believes that Section 3 is a key component to reforming social care charges in Wales and therefore Welsh Assembly Members should have the right to state within the Measure which groups should be excluded from paying charges.

³ *Proposed Social Care Charges (Wales) Measure,* Stage 1 draft, 2009, page 3 (line 11 – 15)

(c) the right of service users to have their means assessed and for any charge for the services to be determined in light of that assessment (section 4);

The Wales Neurological Alliance has no objection to section 4 of the proposed Measure. The Alliance accepts that if social care is not free at the point of use, then the services must be means tested so that the most vulnerable are exempt from charges or pay nothing at all.

The Wales Neurological Alliance believes that it is desirable for Welsh Ministers to use regulations to specify how means testing is carried out by local authorities.

(d) the requirement on local authorities to provide information about charges and means testing (section 5);

The Wales Neurological Alliance welcomes the inclusion of section 5 within the proposed Measure ensuring that service users are fully aware of what different charges are and how the means testing assessment is carried out.

In the past service users have been charged for services they have already received without knowing exactly how much they were expected to contribute. This has led them into debt which they can not afford. The **Fairer Charging Guidance (2002)**⁴ states that once a person's care needs have been assessed and a decision has been made about the care to be provided, an assessment on the ability to pay charges should be carried out promptly and written information about any charges assessed as payable, and how they have been calculated should be communicated promptly. In practice this is normally done before sending out the first bill.

The Wales Neurological Alliance would like to see this guidance set in legislation so that service users will not be charged until they have received adequate information from the local authority about the charges and means testing.

Finally, the Wales Neurological Alliance would like the proposed Measure to give service users the right to have the information explained face to face by a member of staff, rather than simply relying on written information. Service users are likely to have many questions and should have the right to query charges and their means testing with an individual.

(e) the right to request a review of charging decisions and the power given to Welsh Ministers to make regulations regarding this process (section 6);

The Wales Neurological Alliance is broadly supportive of the wording of section 6 of the proposed Measure and the Alliance believes that it will empower service users who wish to review a charging decision. It would appear to be appropriate to allow Welsh Ministers the discretion of regulations to review the charging decisions of local authorities.

⁴ *Fairer Charging Policies for Home Care and other non-residential Social Service*, Welsh Assembly Government, 2002, page 18

However, the Wales Neurological Alliance would like to make two comments to this section. Firstly the Alliance would like the rights specified to individuals expanded to include their carers if appropriate.

In Section 6, the proposed Measure states:

- (2) The provision that may be made in the regulations under subsection (1) includes (but is not limited to) provisions –
- (a) Conferring a right upon an **individual** to whom a statement has been provided under section 5(5) to request a review and an obligation upon the local authority that provided the statement to carry out a review and implement its findings;
 - (b) As to the decisions in respect of which the **individual** has the right to request a review;
 - (c) As to the steps that must be taken in order for a **person** to exercise the right to request a review and the time by which such steps are to be taken;
 - (d) As to the procedure to be followed and steps to be taken in connection with, and following, the review;
 - (e) As to the type of officer or groups of officers of the local authority who are to take a decision on the review;
 - (f) Requiring a local authority to provide specified information and assistance to a **person** who has exercised the right to request a review.⁵

The Wales Neurological Alliance would like to see the two references to “a person” and the two references to “an/the individual” in Section 6-2 amended to “an individual or their carer.”

Secondly the Wales Neurological Alliance believes that if a clear formula calculating maximum charges was inserted into section 2, then Welsh Ministers might not need to be reliant on regulations from section 6 to take action against local authorities. The importance of section 6 is dependent on whether the Welsh Assembly Government intends to be prescriptive and instruct local authorities on what to charge for certain services, or whether instead the government intends to solely set a weekly maximum charge for an individual and let local authorities decide what makes up this maximum charge. If the intention is the former, then section 6 is not as important.

- (f) the non-residential care services to which this Measure applies (section 7);**
The Wales Neurological Alliance is disappointed that the proposed Measure specifically excludes residential care charges and the Alliance believes that this is the main weakness of the proposed legislation.

The proposed Measure seeks to set a maximum level for non-residential social care charges, but residential care charges can also vary dramatically between different local authorities and private sector providers. The proposed Measure

⁵ *Proposed Social Care Charges (Wales) Measure,* Stage 1 draft, 2009, page 5 (line 21 – 36)

So it will not tackle the problems of charges and supply of suitable residential accommodation.

The proposed Measure has been frustrated by the decision by the National Assembly for Wales and the UK Parliament to agree to a Legislative Competency Order that excluded residential care. **National Assembly for Wales (Legislative Competence) (Social Welfare) Order 2008** and the subsequent **National Assembly for Wales (Legislative Competence) (Social Welfare and Other Fields) Order 2008** gave the National Assembly the ability to legislate on social care charges but specifically excluded residential charges.

Matter 15.1 in the amended Schedule 5 of the Government of Wales Act 2006 states:

15.1 Charges levied by local authorities for social care services provided or secured by them and payments in respect of individuals with needs relating to their well-being so that they, or persons looking after them, may secure social care services to meet those needs.

This matter does not include charges and payments for residential care⁶.

Even if the Welsh Assembly Members wanted to amend the proposed Measure to include residential care, they would not be able as this is now outside of the competence of the National Assembly for Wales.

For people living with neurological conditions, one of the most expensive charges they might face is paying for respite care, either at home or in a residential facility. The proposed Measure, through future regulation could prevent a local authority from charging above average prices for respite care provided at home by social workers. However the proposed Measure will not offer any assistance to people trying to access respite care at a local authority or privately owned facility.

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 certain voluntary sector organisations are doing, but most of the changes will come from the as yet unpublished regulations that the legislature gives Welsh Ministers the power to introduce.

The Wales Neurological Alliance does not operate any services that would be directly affected by the Measure so it is difficult for the Alliance to comment to this question. However the Wales Neurological Alliance is concerned that local authorities might be forced to reduce services if they have to charge lower prices for them. Local authority budgets are already under pressure and if they have to reduce charges, they may look to withdraw services or change the eligibility criteria so they can reduce costs.

⁶ 'Government of Wales Act 2006', as amended by the 'National Assembly for Wales (Legislative Competence) (Social Welfare) Order 2008' and the subsequent 'National Assembly for Wales (Legislative Competence) (Social Welfare and Other Fields) Order 2008

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?

One of the greatest barriers facing the proposed Measure is the length of time it will take to enact any of the provisions within it. The One Wales Government promised to reform social care charges as part of their programme for 2007 and 2011, but the earliest any changes can be delivered in this Measure is April 2011⁷. The delay in implementing the provisions of this Measure are partly due to the local government calendar, where charges can only be set in April at the start of the new financial year, and it is possible that the legislation may not have been agreed by the National Assembly for Wales or given Royal Assent by April 2010, meaning it is delayed another year. However the real reason for the delay is due to the Welsh Assembly Government's legislative timetable. The proposed Measure was listed as part of the First Minister's Legislative Programme for 2008-09 and therefore should have been passed and received Royal Assent by summer 2009, but instead it was delayed and was only introduced on 29th June 2009, less than one month before the end of the 2008/09. If the Measure had been introduced in autumn 2008, the provisions within it could have been implemented by April 2010.

Another factor for the delay is the reliance on regulations, orders and statutory guidance. This issue has been referred to in answer to question 2, 6 and 7, so will only be touched on briefly here, but the fact remains that once the proposed Measure has received Royal Assent, the Welsh Assembly Government will have to introduce regulations, which will require further consultation with the voluntary sector and will delay the impact to service users still further.

In addition to time, the Wales Neurological Alliance believes that another barrier to implementing the provisions of the proposed Measure might be local authorities changing eligibility criteria. The Alliance is concerned that local authorities might be forced to re-assess service users at a lower category of need or potentially withdraw services from people who do not fall into the Critical or Substantial need category, in order to cut costs and make up for the shortfall in income from lower charges. Whilst a large number of people could benefit from lower charges if a high charging local authority reduces prices, a minority of people might find themselves deprived from any services in order to help the council cut costs.

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.

This question has been answered in response to question 3.

⁷ *Explanatory Memorandum to the Proposed Social Care Charges (Wales) Measure*, Welsh Assembly Government, 2009, p11

6. **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 revised charging arrangements in regulations, orders and statutory guidance? Are the procedures which would apply to these regulations appropriate (negative or affirmative)? (See Part 1, section 5 of the Explanatory Memorandum – “Power to make subordinate legislation”).**

The Wales Neurological Alliance does not believe that an appropriate balance has been struck between the provisions set out within the proposed Measure and the power delegated to Welsh Ministers. Whilst it is appropriate to delegate powers to Welsh Ministers over means testing (section 4), information (section 5) and reviewing charging decisions (section 6) it seems deeply inappropriate to grant such great powers to Welsh Ministers to over the levels of charges (section 2) and the persons who are excluded from charges (section 3).

The National Assembly, as the legislature for Wales, invested 18 months seeking to devolve the power to make laws over social care charges, and yet this proposed Measure will take powers away from the National Assembly and give them to the Welsh Assembly Government. As it has been stated in the Wales Neurological Alliance response to questions 2a and 2b, the Welsh Assembly Government should be allowed some discretion in section 2 and 3 of the proposed Measure, but any formula devised to cap social care charges should be debated, scrutinised and become part of the proposed Measure and not be left solely to future regulations.

The Wales Neurological Alliance is also concerned that the proposed Measure does not guarantee that charges will be reformed and set at a consistent level across Wales.

In Section 2, the Measure states:

- (2) The Welsh Ministers may make provision in regulations for and in connection with controlling and limiting the determinations that a local authority may make under section 1 (2)⁸

Whilst the current Deputy Minister for Social Services, Gwenda Thomas AM, has promised to set a maximum weekly social care charge of £50⁹ there is nothing in the proposed Measure to ensure that this would actually happen. Section 2 would give a future Welsh Minister the ability to set maximum charges, but there would be no compulsion to do so and there would be nothing to stop the Minister from setting a weekly charge of £25 a week or £200 a week.

The Wales Neurological Alliance believes that the proposed Measure should include a clear formula for how maximum weekly charges should be calculated, rather than rely on future regulations.

⁸ ‘Proposed Social Care Charges (Wales) Measure,’ Stage 1 draft, 2009, page 2 (line 25 - 27)

⁹ ‘Proposed Social Care Charges (Wales) Measure: Legislative Statement,’ Gwenda Thomas AM, 30 June 2009

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

The Wales Neurological Alliance is disappointed by the depth and scope of the **Proposed Social Care Charges (Wales) Measure** and the reliance on subordinate legislation and regulations. Voluntary and public sector organisations have been waiting in anticipation for this proposed Measure for over three years and the result is a short 8 page legal document that on its own delivers very little. Charging for social care is a complex topic and it would appear that the proposed Measure does not do the topic justice. The **Proposed Education (Wales) Measure** contained 20 pages, the **Proposed Children and Families Measure (Wales) Measure** contained 43 pages, and yet this proposed Measure is one of the shortest to be introduced by the Welsh Assembly Government. Even the backbench **Healthy Eating in Schools (Wales) Measure 2009** was longer. The reason for this is because of the Welsh Assembly Government's reliance on subordinate legislation, rather than primary legislation to deliver policy objectives. The proposed Measure is an "enabling piece of legislation" rather than a "delivering piece of legislation." If passed unamended by the National Assembly for Wales, the proposed Measure does not change anything, but instead only gives Welsh Ministers power to reform the social care charging system.

In their formal response to the **Proposed NHS Redress (Wales) Measure**, the Law Society in Wales stated:

"Law making powers have been devolved so that the National Assembly can do just that and not itself devolve power to the Executive without robust scrutiny of government policy and stakeholder views." ¹⁰

The Wales Neurological Alliance believes that this quote represents an accurate analysis of the **Proposed Social Care Charges (Wales) Measure**. By relying on regulations and subordinate legislation the Welsh Assembly Government is denying voluntary sector organisations and backbench Assembly Members the right to scrutinise and contribute to the development of a new charging regime. At the moment, the Wales Neurological Alliance has been fully consulted by Legislative Committee No. 5 on the general principles of a short enabling Measure, but when the Welsh Assembly Government brings forward actual details for how the charging regime would work, the voluntary sector would not have the right to contribute to the decision making process.

The Wales Neurological Alliance's final concern is that the proposed Measure offers only a piecemeal reform of the social care system in Wales and fails to take into account wider social care problems and the legal discrepancies developing from legislative powers passing to the National Assembly for Wales.

As referred to in answer to consultation question 2(f), the scope of the proposed Measure has been severely hampered by the limited powers devolved to the National Assembly for Wales through **National Assembly for Wales (Legislative Competence) (Social Welfare) Order 2008** and the subsequent **National Assembly for Wales (Legislative Competence) (Social Welfare and Other Fields) Order 2008**.

¹⁰ Law Society in Wales response to 'Proposed NHS Redress (Wales) Measure': <http://www.assemblywales.org/bus-home/bus-committees/bus-committees-third1/bus-committees-third-nhsr-home/bus-committees-third-nhsr-agendas.htm?act=dis&id=61450&ds=11/2007>

Yet these LCOs were drafted by Welsh Assembly Government civil servants and voted for by the National Assembly. Both the legislative and executive have either inadvertently or deliberately limited the scope of what areas of social care can be reformed. The Wales Neurological Alliance believes that the two LCOs and this proposed Measure have been a missed opportunity and the Alliance is disappointed that neither social services assessments nor residential charges can be considered as part of this proposed Measure.

The Welsh Assembly Government has promised that this proposed Measure is a short term reform and that wider legislation could emerge as part of the Welsh Green Paper for Social Care, expected in autumn 2009. The Wales Neurological Alliance believes that a future Measure must codify in law the Welsh Social Service system to formally separate it from the English Social Services system. Although this proposed Measure applies solely to Wales, it seeks to make amendments to the **Health and Social Services and Social Security Adjudications Act 1983** and the **Local Authority Social Services Act 1970** creating Welsh exceptions to England and Wales laws. The Wales Neurological Alliance believes that there is an urgent need to codify the Welsh social service system even if at the moment approximately 90% of the social service laws apply to both England and Wales. The **National Health Service (Wales) Act 2006** helped to establish the Welsh NHS in law and the Wales Neurological Alliance believes that there is an urgent need to create a future **Social Services (Wales) Measure** to define in law the distinct social services systems.