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## CONSULTATION ON THE PROPOSED SOCIAL CARE CHARGES (WALES) MEASURE

A response from the National Autistic Society Cymru

### About us

The National Autistic Society Cymru (NAS Cymru) is the charity working throughout Wales for people affected by autism. We are part of the UK's leading charity for autism. We were founded in 1962 by a group of parents who were passionate about ensuring a better future for their children. Today across the UK we have over 18000 members and 80 branches. NAS Cymru has six branches and over 800 members. We also link to a range of independent autism parent support groups. In Wales, we provide:

- Information, advice, advocacy, training and support for individuals and their families
- Information and training for health, education and other professionals working with people with autism and their families
- Specialist residential, supported living, outreach and day services for adults
- Out-of-school services for children and young people
- Support and social programmes for adults with autism

We also provide a Community Care Service which offers advice and information about community care issues, including finding out what help is available from local social services departments, how to access the help, and how to make a complaint to the social services department if there is dissatisfaction with either decisions or the services that they offer.

A local charity with a national presence, we campaign and lobby for lasting positive change for those affected by autism in Wales and across the rest of the UK.

### What is an autism spectrum disorder (ASD)?

Autism is a lifelong developmental disability that affects the way a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition which means that, while all people with autism share three main areas of

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difficulty, their condition will affect them in different ways. The three main areas of difficulty (sometimes known as the ‘triad of impairments’<sup>1</sup>) are:

- Difficulty with social interaction. This includes recognising and understanding other people’s feelings and managing their own. Not understanding how to interact with other people can make it hard to form friendships.
- Difficulty with social communication. This includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice.
- Difficulty with social imagination. This includes the ability to understand and predict other people’s intentions and behaviour, and to imagine situations outside of their own routine. This can be accompanied by a narrow repetitive range of activities.

Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist care. People with autism may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds touch, tastes, smells, light, or colours.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language. People with Asperger syndrome may not necessarily have learning disabilities but often have accompanying learning difficulties, including dyslexia.

We use the term autism here to cover all people on the autism spectrum, including autism, Asperger syndrome and other diagnostic terms used for autism spectrum conditions. One in a hundred people in Wales have autism – that is over 25,000 people. Together with their families they make up over 100,000 people in Wales whose lives are touched by autism every single day. Despite this, autism is still relatively unknown and misunderstood. That means that many of these people get nothing like the level of help, support and understanding they need.

## Our response

NAS Cymru welcomes the opportunity to respond to the consultation on the proposed Social Care Charges (Wales) Measure. The response addresses the questions in the consultation document in the order in which they are raised.

*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?*

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<sup>1</sup>Wing, L. and Gould, J. (1979) Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders*, Vol. 9(1), pp. 11-29

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NAS Cymru believes that there is a need for legislation to ensure that local authorities across Wales adopt a more consistent approach to charging service users for non-residential social care services.

Surveys and research outlined in the Explanatory Memorandum to the Proposed Social Care Charges (Wales) Measure show large inconsistencies in charges across Wales, and concerns on the part of service users, carers and their representatives that charges are often set too high. NAS Cymru is concerned that under the current system some individuals forego services which they need but cannot afford, and that as a result they are disadvantaged in comparison to people with similar care needs in other local authorities where the costs are more affordable.

This lack of equity is unacceptable, and NAS Cymru welcomes moves to address this.

NAS Cymru also notes that in cases where individuals forego services because of they are unaffordable, it is possible that the individual's health needs may escalate, necessitating more costly interventions from the NHS or social services. This may also have other negative impacts on the individual concerned such as greater anxiety or a loss of independence. Furthermore, NAS Cymru believes that the current system is complex and difficult to administer, placing an unnecessarily large administrative burden on local authorities.

*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)*

Although it is acknowledged that local authorities should comply with regulations and guidance issued by the Minister in respect of maximum charges, there is serious concern around how 'reasonable' will be defined. There is no definition or legal precedent regarding what is, or is not, a reasonable charge for social care. Any future regulations made by the Minister in respect of this Measure should be mindful of the fact that what is considered to be a reasonable charge from the perspective of a local authority may be completely unreasonable from the perspective of a service user. The drafting of regulations relating to maximum charges should be done with maximum input from task groups with strong representation from the voluntary sector, and in consultation with service user representatives.



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- 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)*

NAS Cymru welcomes the inclusion of the power for Welsh Ministers to specify by regulations specific categories of persons and services in respect of which charges must not be imposed insofar as this allows for no charging for social care in the future. In theory, we would like to see universally free access to social care but we recognise that, given the current financial situation, this is unlikely to be an option.

NAS Cymru supports calls from the Wales Carers' Alliance that services covered under this Measure should be free of charge to carers. Carers already contribute to health and social services in Wales to the tune of £5.6 billion per annum. As a member of the Wales Carers' Alliance coalition, NAS Cymru supports the call for free services for carers as any charge for services impacts upon the whole household – including the carers. It is important, however, that any groups of persons who are deemed to be exempt from charging should nonetheless retain their rights to reviews, appeals, and advocacy.

- 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)*

NAS Cymru agrees that service users should be able to have their means assessed and for any charges levied for services to be determined in light of that assessment and makes no further observations.

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

The NAS welcomes the acknowledgement that information about charges should be made available in a range of accessible formats. Indeed, this is a requirement under the Disability Discrimination Act 1995, which states that: "It is unlawful for a provider of services to discriminate against a disabled person... in refusing to provide, or deliberately not providing, to the disabled person any service which he provides, or is prepared to provide, to members of the public." Examples of services include "access to and use of information services".

People with autism have difficulties with both verbal and non-verbal language. Many have a very literal understanding of language, and think people always mean exactly what they say or write. Therefore, a reasonable adjustment which should be made in order to allow people with autism to access information in compliance with the disability discrimination legislation would be the provision of easy-read information. Section 5 subsection 3 of the Measure should therefore



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be amended to specifically include the production of easy-read versions. Furthermore, in order to ensure the clearest communication standards, the Measure should provide that all communications follow the guidelines and standards set out by the Plain Language Commission.

There should be no retrospective levying of charges. The Welsh Assembly Government's *Fairer Charging Policies for Home Care and other non-residential Social Services* guidance issued in 2002 under section 7 of the Local Authority Social Services Act 1970 states that service users should not be charged for the period between their care assessment and their financial assessment. This means that service users should not be charged until they have been informed of the charges attached to their care packages, regardless of any care received during that period. However, there are suggestions that it is not being universally enacted. Therefore, a ban on retrospective charging should be made explicitly within the Measure, and section 5 subsection 1a should be amended to include a requirement that a local authority must make arrangements to bring information about the matters in section 5 subsection 2 to the attention of persons who receive a service to which this Measure applies before the charge is levied. Furthermore, there should be no retrospective levying of charges during the period of an appeal.

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 right to a review is welcomed. However, NAS Cymru also argues that it is essential that the right to an appeal is specifically entrenched in the Measure. Reviews and appeals are very different procedures. Indeed, complaints are a different procedure again. Section 6 should therefore be amended accordingly in order to give service users specific rights to a robust complaints procedure, review, and appeal.

Section 6 subsection e also gives cause for concern as it refers only to the participation of officers of the local authority in making decisions on a review. NAS Cymru argues strongly that services users have the right to expect independent representation on any review/appeal panel board.

It is also essential that service users also have the right to independent advocacy at any review/appeal. People with ASD have difficulties with social interaction, social communication and imagination. They therefore need help to express their aspirations, interpret and process information regarding their rights and to request relevant services. People with Asperger syndrome, because of their fluent language, and average or above average IQ level, may not appear to need access to advocacy services. This can be misleading and it is important that advocacy services are available for all people with ASD. Carers often play an important part in supporting people with ASD, but continuing reliance on their families may inhibit their

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independence. This is why access to advocacy can be important in helping adults with ASD to have a greater degree of independence.

Whilst it is acknowledged that section 6 subsection 2 states that the regulations by which Welsh Ministers may make provision for and in connection with the review are not explicitly limited to those items detailed in subsections a to f, independent advocacy is of such high importance that NAS Cymru wishes to see the right to independent advocacy specifically entrenched in the Measure.

*f) the non-residential care services to which this measure applies (section 7)*

As a member of the Wales Carers Alliance, NAS Cymru supports its call for those services provided under the Carers (Equal Opportunities) Act 2004 to be included within the list of care services to which the Measure applies.

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

NAS Cymru provides a Community Care Service which offers advice and information about community care issues, including finding out what help is available from local social services departments, how to access the help, and how to make a complaint to the social services department if there is dissatisfaction with either decisions or the services that they offer. NAS Cymru will continue to provide advice and support to people affected by autism as appropriate insofar as charging for social care is concerned.

*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?*

NAS Cymru believes that a significant barrier to the implementation of the measure is the lack of clarity insofar as the number of services to which the charges apply is concerned (ie. will an individual receiving several services be charged per service or will the whole package of care be cumulatively subject to the one maximum charge?). To that effect, NAS Cymru strongly argues that the maximum charge referred to in the measure should relate to the complete service package, rather than a charge to be levied per service. The Measure should be amended accordingly in order to meet the Measure's objective of ensuring that local authorities across Wales adopt a more consistent approach to charging service users for non-residential social care services.



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Further to this, there is also a lack of clarity regarding whether the maximum charge is per person or per household. NAS Cymru strongly argues that the maximum charge should be per household because it is not uncommon for two or more people in a household to be in a position of needing social care and the financial burden on these families would be unacceptable. Research has shown that about 3% of siblings of a child with autism will also receive a diagnosis of ASD – a rate which is 50 to 100 times greater than the rate in the general population – therefore a number of families affected by autism would face paying for two or more care packages for their children even before other conditions are considered.<sup>2</sup> NAS Cymru notes that this is also the case for parents of children with other conditions, and that these families will also be disproportionately burdened with charges.

In order for the Measure to deliver on its intended effect of reducing inconsistencies in charging and providing a mechanism for establishing a system that is fair to all client groups, it is necessary to have a uniform and uniformly applied list of eligibility criteria across all local authorities. There is concern that local authorities could raise eligibility criteria, thereby disenfranchising individuals from receiving services. NAS Cymru is particularly concerned that individuals with Asperger syndrome may be disenfranchised because this is an unseen condition and individuals with the condition may have average or above average intelligence. However, their social care needs may nonetheless be considerable. NAS Cymru therefore strongly recommends that the Welsh Assembly Government issue a nationally applicable document detailing exactly which services will be covered in order to ensure clarity and compliance.

NAS Cymru is also determined that no current service user should be worse off financially as a result of this Measure, and welcomes the reassurances given by the Minister on this issue. However, this sentiment needs to be made explicit in the Measure.

NAS Cymru has serious concerns that the maximum charge determined by the Minister in any subsequent regulations relating to this Measure will become the 'standard' charge made by local authorities. Given that a number of local authorities currently charge well below the £50 per week which has been suggested may be the maximum charge levied in the first round of regulations attached to the Measure, large numbers of people who are not currently service users could be worse off financially under the new system than they would have been under the previous system.

*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 the implementation of the proposed Measure.*

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<sup>2</sup> Piven J, Folstein S et al (1994), Personality characteristics of the parents of autistic individuals. Psychological medicine 1994;24(3):783-95.

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NAS Cymru does not envisage incurring significant financial costs as a result of the Measure beyond those generated by an increased volume of enquiries from the public relating to the scheme and costs incurred in ensuring that members of staff are informed of the Measure as appropriate.

*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”).*

NAS Cymru acknowledges the requirement to avoid inappropriate detail in the Measure and to allow for flexibility. Nonetheless, NAS Cymru has identified several items in this consultation submission which should be specifically included in the Measure.

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

NAS Cymru highlights the vital role of task groups with a strong voluntary sector and service user representation in advising on the drafting of regulations attached to this Measure. NAS Cymru would be happy to work with the Welsh Assembly Government in the formulation of those regulations.

Rebecca Evans  
Policy and Public Affairs Officer/Swyddog Polisi a Materion Cyhoeddus

National Autistic Society Cymru  
Ground Floor, Units 6 and 7  
Greenmeadow Springs Business Park  
Village Way, Tongwynlais  
Cardiff, CF15 7NE  
Tel: 02920 629316  
Rebecca.Evans@nas.org.uk



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