

National Assembly for Wales / Cynulliad Cenedlaethol Cymru
[Health and Social Care Committee](#) / [Y Pwyllgor Iechyd a Gofal Cymdeithasol](#)

[Regulation and Inspection of Social Care \(Wales\) Bill](#) / [Bil Rheoleiddio ac Arolygu Gofal Cymdeithasol \(Cymru\)](#)

Evidence from Multiple Sclerosis Society Wales – RISC 33 / Tystiolaeth gan Multiple Sclerosis Society Cymru – RISC 33



Multiple Sclerosis Society
Wales

A response from the Multiple Sclerosis Society Cymru

About Multiple Sclerosis and the MS Society

Multiple Sclerosis is the most common disabling neurological disorder affecting young people in the UK with more than 85,000 affected by the condition. We estimate that over 3,800 people are affected in Wales. It is a disease of the central nervous system. MS is unpredictable and can cause a wide variety of symptoms such as loss of mobility, pain, fatigue, vision problems, numbness, loss of balance, depression and cognitive problems. The disease may progress steadily or involve periods of active disease followed by periods of remission.

The MS Society is the UK-wide charity dedicated to supporting people who have MS, as well as providing help to those people's families, friends, carers and colleagues. A significant number of our trustees, staff and volunteers either have MS or a personal connection with MS.

The Society provides care and support through services which include a national information and helpline service, publications, a website that receives more than 40,000 visitors each month, welfare grants, funding research, funding MS specialist nurses and delivering respite care.

We are a democratic organisation with over 44,000 members. Our network of 340 branches delivers local services to people with MS across the UK.

Response

- 1.0 MS Society Cymru is very supportive of the Welsh Government's proposals to regulate the social care workforce in Wales. Hundreds of thousands of people receive some form of social care performed by workers with very little formal training caused by a system where competing care companies seek to undercut rival companies with lower overheads and cheaper staff. This has led to the development of an unmanaged social care market consisting of

social care services which are unsustainable and unable to deliver high quality care.

- 1.1 The current system, where the most vulnerable in society can be cared for by people with little or no training, needs to end. People living with MS who use care agencies often complain of a “conveyor belt” of care staff, where it is rare to see the same person more than once, and where often staff have taken the job, whilst they look for other opportunities. The MS Society conducted a series of focus groups with people with MS, and continuity of care was an issue consistently raised. People with MS told us:

‘I mainly have the same carers but sometimes they introduce new ones – I need more notice of this change. You are letting people into your home.’

‘If you need care then the last thing you want is to be telling people how to care for you every day.’ Many people with MS are not given the opportunity to build any sort of relationship between themselves and the staff commissioned to provide their care.

- 1.2 MS Society Cymru surveyed its members to ask what measures they thought would help to protect adults in care as part of formulating the response to this consultation. 75% of people surveyed thought that better training for social care staff was the number one priority, 32% thought that more social care staff were needed and only 27% thought that new structures and institutions were needed^x. Training and education is therefore a top priority for people living with MS.

As a result we strongly welcome that the Bill states that Social Care Wales may make rules requiring registered persons ('social care workers') to undertake further training and continued professional development.¹ However we would like to add that we would welcome the Bill to include the role that voluntary and community sector organisations can play in continued professional development.

- 1.3 We welcome that Bill aims to reform the regulatory regime for care and support services to include a new service based model of regulation, provisions to monitor the operation of the care market, provisions to improve public engagement, and powers to introduce inspection quality ratings.² The registration and greater professionalisation of this sector would have a positive effect on the standards of care received. For example we would hope that that greater inspection would for example end inappropriately short homecare visit commissioned by services providers. Greater regulation will also ensure that services providers work to develop high quality and sustainable services.

^x Respondents were allowed to vote for multiple options

¹ National Assembly for Wales (2015) *Bill Summary The Regulation and Inspection of Social Care (Wales) Bill*. Available at <http://www.assembly.wales/Research%20Documents/15-014%20Social%20Care%20Bill/15-014.pdf> p.11

² *Ibid.*, p.4

However, it is likely that this will have a negative impact on costs. The process of undercutting solely on price would not be possible if staff had to meet standards and be fully trained, and it would be likely that both administrative costs and wages would rise. In fact the Regulatory Impact Assessment sets out that cost over the first five years of the Bill will be around £9 million, this includes transitional costs of £3.3 million, with a part of this cost failing on service providers.³ We strongly advocate that all is done to ensure that this extra cost is not passed onto the service users. This added cost would be inappropriate and would act as an added barrier to accessing high quality social care services.

- 1.4 We agree that the Bill will bring about significant benefits if working conditions, wages and work satisfaction increase due to professionalisation, then there is a greater chance that people will proactively choose to become personal assistants as a long term career. This would improve the continuity of care that is often lacking and allow personal assistants to build up knowledge and experience of certain conditions and individuals, which would further improve the service user experience.
- 1.5 We would welcome the Bill advocating ways that social care professionals can share skills and knowledge developed. We would also welcome the Bill setting out a commitment to ensure that social care workers are able to benefit from the skills and knowledge of voluntary and community sector organisations. For example, through encouraging voluntary sector organisations and service providers to develop networks in which training and information on common conditions, common care needs, common support needs could be easily shared.
- 1.6 Finally MS Society Cymru hopes that the professionalisation of the social care workforce will have a positive effect on the working conditions of personal assistants and afford them with appropriate protection.

As part of the social care constitution for Wales MS Society Cymru and Leonard Cheshire proposed a series of responsibilities that service users had to their personal assistants as well as responsibilities that social care staff has to the service user.

The responsibilities to social care proposed were:

- You should always treat staff and personal assistants with respect, honesty and dignity. Follow the principle of “Do unto others as you would have them do unto you.”
- You have an obligation to be honest about your care needs when you are being assessed. If you are overly modest and do not explain your requirements, a local authority will not be able to provide support.

³ Ibid., p.15-16

- You should keep anyone involved with your care updated about your needs. If your condition changes or improves, then you should report this honestly.
- You should educate people who are caring for you about your specific condition or needs. It is unlikely that the individual who you are employing or the person assigned by an agency or your local authority will know as much about your condition as you do.
- You and those charged with your support should make sure that any care plan you agree to is designed to help you make sustainable and positive improvements in your life towards the goal of full and active citizenship. You should do your very best to keep to any care plan or package you agree to.
- You should give feedback to your local authority or care agency on staff matters and service provision, especially where you think that things can be improved. This would benefit you and other people receiving a similar service.
- You should keep appointments or cancel with due notice.
- You should seek to make your home a safe working environment for anyone coming into care for you. If you receive support from an agency to clean your home, it is you or your family's responsibility to make sure they leave your home safe.⁴

Whilst the responsibilities of social care staff proposed were:

- Staff will treat you with honesty, dignity and respect throughout your dealings with them.
- Staff have a duty to help you achieve the goals you have identified as important in your life.
- Staff and personal assistants will treat you as an individual with your own personal challenges and aspirations, not as a disability, impairment or condition.
- Staff will recognise that you are the expert on your own life and the support you need, and listen to your thoughts and opinions.
- Staff will be well informed about your needs, and knowledgeable about your condition and what it means for the support you need.
- Staff have a duty to provide you, or your chosen representatives, with simple, clear, and accessible information about the support they are providing you.
- Staff have a duty to inform you in advance of any likely changes in appointments, any changes to personnel, or any other arrangements that

⁴ Leonard Cheshire Disability and MS Society Cymru (2010) '*A social care constitution for Wales*,' p14-15

might affect you.

- Staff have a duty to protect your rights and promote your interests, and those of any unpaid carers.
- Staff have a duty to strive to establish and maintain your trust and confidence and that of unpaid carers.
- Staff have a duty to promote your independence.
- Staff have a duty to assist people in taking control of their lives, but where people need support or representation they also have a duty to make sure that the right system of support is in place.⁵

MS Society Cymru would like the Welsh Government to consider these rights and responsibilities when consulting on regulations under this section.

⁵ Leonard Cheshire Disability and MS Society Cymru (2010) '*A social care constitution for Wales*,' p18-19