

National Assembly for Wales

Cross Party Group on Neurological Conditions

People living with neurological conditions and the Social Services and Well-being (Wales) Act (2014)

Briefing No 1: November 2018

Summary

There are an estimated 100,000 people living with a neurological condition in Wales.

The Social Services and Well-being (Wales) Act (2014) has now been law in Wales since 6 April 2016. This Act sets out duties to promote the well-being of; (a) people who need care and support, and; (b) carers who need support (section 5).

The Act aims to transform the way that social services are delivered and contains important new legal rights for people who use the services.

In order to achieve this, Section 14A of the Act^[1] places a duty on Local Authorities (LAs) and Local Health Boards (LHBs) to gather information on the care and support needs of the population to help service providers to understand more about the lives of people in the area and enable them to make better, more informed decisions about how care and support services are delivered.

The Wales Neurological Alliance (WNA) is a forum of organisations and groups representing people living with and affected by neurological conditions in Wales.

The Cross-Party Group on Neurological Conditions (CPG) asked the WNA to collect information on how the implementation of the Act is having an impact on people with neurological conditions.

The WNA conducted a survey of people living with neurological conditions in Wales, this found;

73% of respondents have not been offered or requested a formal assessment; indicating that people's rights to a formal

assessment are not being promoted, or that people are not aware of their rights.

80% of respondents did not receive any services from a local council as a result of a care plan; indicating that having a care plan does not necessarily lead to social care support.

64% of respondents did not see any information that would help them with a social care or support need; and only 37% were given advice from a professional that would help with a social care need - yet a key provision within the Act is that Local Authorities are required to provide information, advice and assistance on available services and support.

The requirement on Local Authorities to promote non - statutory services such as cooperatives and social enterprises is another key provision within the Act **yet, 79% of respondents have not been referred to other organisations for support.**

46% of respondents have paid out of their own money for additional support.



Conclusion

The Cross Party Group on Neurological Conditions believes that people living with neurological conditions in Wales are being failed by the implementation of the Social Services and Well-being (Wales) Act.

We are deeply concerned that the 'what matters' conversation is not taking place and consequently people living with neurological conditions are missing out on vital support and services.

"How do I ask for help? Speech problem so can't use phone, just come out of hospital and promised Red Cross help, didn't come, too unwell to make a fuss. So fed up!!"

The lack of information, advice and assistance as identified in the survey not only means that people living with neurological conditions are not being sign-posted to services that could increase their wellbeing but it does not afford them a strong voice when deciding what they need to achieve wellbeing either.

The WNA survey findings support existing research carried out by individual neurological charities. For example, the MND Association's recent survey of people with MND and their carers^[2] found that 75% of people with Motor Neurone Disease in Wales do not have a care plan and around two fifths reported that they do not receive a contribution towards their social care from the Local Authority.

Support for practical tasks is vital for people living with neurological conditions to manage living independently and with dignity.

Findings from a MS Society survey^[3] conducted in 2013 and repeated in 2016 gives an understanding of how social care and support has changed for people living with and affected by MS in Wales.

Whilst 61% of respondents in 2016 said that they had access to support with Activities of Daily Living (ADLs) such as washing, dressing and eating, over 35% reported that they had received only some or no support at all and had needed to.

'I seem to get lost in the system because I am not elderly, nor do I have learning difficulties. Because I am 34 and disabled it seems to get missed.'

'I have 3 children and I'm separated from my husband. There doesn't seem to be any social places/groups for me so I end up very alone'.



It is welcoming to note that since 2013 there has been an increase in people living with MS reporting that they had received care however, at the same time there has also been a significant increase in those who are self-funding their care.

The CPG believes that it is unacceptable for people living with neurological conditions to be paying out of their own money for additional support services as they already face significant financial hardship as a result of their conditions.

Research conducted by Parkinson's UK^[4] found that households where someone has Parkinson's in Wales are £17,136 out of pocket each year. This breaks down into:

- higher health costs (£1,861)
- higher social care costs (£3,249)
- loss of income due to early retirement or reduced working hours (£12,026)

People living with more complex and progressed forms of neurological conditions often require significant levels of care and supervision. Consequently those who provide unpaid care can experience very high levels of stress and other mental health issues.

Although LAs now have a duty to promote the well-being of carers who need support, when it comes to unpaid carers of people living with MND in Wales for instance, only 30% of respondents had a carers' needs assessment and only around two fifths of unpaid carers have taken any planned breaks, even for as short as two hours; showing a desperate need for the provision of respite.

'I have a sitter to come in twice a week for a couple of hours to give me a short break but it is almost impossible to secure a place in a nursing home for my husband to receive respite care to allow me to visit my family'.

Recommendations:

'I receive no support what so evernot from the council the NHS nobody and I can't see that changing'.

Local Authorities and Local Health Boards must immediately undertake a robust population needs assessment of people living with neurological conditions and their carers in order to better understand the cohort in their area who may be in need of services.

'More advice available locally. Doc/ consultant, epilepsy nurse listen when available but don't offer good advice'

Local Authorities and Local Health Boards must review their information, advice and assistance to ensure that people living with neurological conditions and their carers who need support are signposted to relevant agencies.

'There is still a big gap between social services and the health board who do not work in partnership very well if at all, neither do cross border partnerships work well'.

Regional Partnership Boards and the Welsh Government must take cognisance of the WNA survey findings and carefully monitor the implementation of the Social Services and Well-being (Wales) Act for people living with neurological conditions.

References:

1. The Welsh Government (2014) The Social Services and Well-being (Wales) Act.
2. MND Association (2018) Improving MND Care Survey
3. MS Society (2016) My MS My Needs Survey
4. Parkinson's UK (2017) The cost of Parkinson's: the financial impact of living with the condition.

About the WNA survey

A total of 415 people representing every Welsh council completed the survey (from January – November 2018).

People living with a range of neurological conditions completed the survey; Multiple Sclerosis (MS) – 25.74%; Parkinson's – 23.28%; Dystonia - 16.19%; Epilepsy - 5.39%; Motor Neurone Disease (MND) – 3.68%; Acquired brain injury 2.94%; Ataxia - 2.94%; Other – 19.85%

22% of respondents were diagnosed for more than 5 years, 49% diagnosed for more than 10 years.

The majority of respondents (56%) were aged 36-64; 30% were aged 65 or older; 9% and 4% were aged 18-35 and 0-17 respectively.

It is the intention of the WNA to repeat this survey in subsequent years to continue to monitor the progress of the Social Services and Well-being (Wales) Act.

With thanks;

The Cross Party Group would like to extend our thanks to everyone living with a neurological condition in Wales who took part in the survey and helped provide the evidence contained in this briefing.

We are extremely grateful to the Wales Neurological Alliance and the Pollen Shop for designing and managing the survey throughout the year.

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