

P-06-1241 Welsh government to meet with a wider audience of unpaid carers, Correspondence – Petitioner to Committee, 31.01.22

To whom it may concern,

Whilst I appreciate Julie Morgan has asked her officials to put me in touch with Carers Trust Wales re the Carers Engagement Group I feel I need to inform you that as of yet I have not heard anything from either her officials or Carers Trust Wales in respect of this. However, this is not what I was aiming to achieve with the petition. My hope is that something along the lines of what we had with Joel James and Heledd Fychan last year (but on a larger scale) could be set up on a regular basis where carers are invited to meet with Ministers or their officials to discuss carer related issues without the need to be a member of a group or carers organisation. I'd like to thank both Joel and Heledd for agreeing to such a meeting and for taking the time to hear our concerns and this is something I'd like to repeat with members of the Welsh government, Julie Morgan or their officials.

I understand the need for the Ministerial Advisory group and their roles in advising Ministers and as such would also be happy if unpaid carers were given the opportunity to talk with them without the need for a carers organisation to be present at the time.

From past consultations we've seen that these fail to reach as wide a group of unpaid carers as possible and for many it can be difficult to find the time to complete the consultation. However, given a date in advance for the opportunity to discuss such consultations or other issues would provide a greater opportunity to make alternative care arrangements and take part in such a meeting.

We are all aware that social care right across the UK is at a crisis point due to the pandemic, Brexit and staff shortages, so now it's more important than ever that the Welsh Government listen to and engage with unpaid carers as we're being asked to take on even more and even give up careers to relieve the pressure on social care. Health boards are also stating that people entering into unpaid care roles will be entitled to claim Carers Allowance. This may well be true, but only a small percentage can actually claim. For example, a person who has reached pension age and is claiming State Pension or a full time student would not be eligible. Health boards are also not making people aware of the financial, physical and mental impacts of entering into a full time caring role

At press briefings during the pandemic minister's repeatedly stated that the Social Services and Wellbeing Act for Wales was working and it was also stated by ministers that there hadn't been any evidence of the suspension or closure of services at any time during the pandemic and multiple lockdowns. Had they engaged with unpaid carers they would have known that this simply wasn't true and that services had been suspended. For example, parents of disabled children often rely on the child's school to provide additional support and services which was impossible while schools were closed. Respite services were also closed during the pandemic meaning that many carers haven't had any breaks from their caring roles for at least the past two years. Many carers also feel that the SSWB simply isn't working as intended and that ministers are only hearing part of the story or being told what others think they want to hear rather than being shown the bigger picture or told the whole story.

Disabled children were also meant to be given priority places at school along with the children of key workers during the lockdowns. However, for many disabled children this simply didn't happen and meant that they missed out on education, support and therapy they would have normally received at school. For many of these children home schooling simply wasn't an option and they needed to be in an education setting in order to continue with their learning and various therapies. This simply can't be allowed to happen again and had the Welsh Government engaged with the parent carers of disabled children they would have known what was really happening.

Unpaid carers are much more than just somebody to do the shopping, make cups of tea and provide emotional support. Many provide nursing level care and much more with little to know support and we have a great deal of lived experience and knowledge of what is needed. It's this lived experience and knowledge that need to be heard by the Welsh government in greater numbers rather than just from the select few.

The following is comments from another unpaid carer and my comments above also include comments from others. No names are provided as all wish to remain anonymous.

Although the Carer's Trust claims to speak for carers in Wales, I feel that they are an added layer of bureaucracy acting as a gatekeeper between the authentic voices of those currently engaged in full-time caring.

Many of the activities and social events are dominated by those who are not currently in a direct caring role, such as those whose cared for are in residential accommodation. Whilst it is difficult to argue that they have no needs, they are not dealing with day-to-day procedures.

Letters that are sent to the Senedd go unanswered or are answered in such a peremptory fashion that it is clear that they are not viewed as important.

We wish to have a better voice, one that is unmediated by professional bodies and request that you consider alternative methods of speaking to those with access to power - even an online open letter system would be preferable to the current situation.

Much information offered is irrelevant or uninformed, so that Health Boards are requesting that people take on increasing responsibility for family members who are well but require support. This is being done without an understanding that caring is a massive financial as well as a social burden and the current care system is at the point of collapse.

We have experienced a 50% cut in care hours and are also providing additional cover for staff absences. Whilst unavoidable, it is also not acceptable. It is having a marked effect on our physical and mental health.

We are not prioritised by other services such as health services and dental care, so access to essential medications has proved difficult. Many GP receptionists are unaware of the significance of having a carer's representative. In our own surgery, when we asked to speak to the Carer Rep, their response was one of confusion and irritation at us.

Other services have been cut so that ministers have shown themselves to be complacent - possibly because the larger carer organisations are unwilling to criticise their paymasters.

There is little recognition of the highly skilled nature of care work - many care workers are exceptional, but respite requires additional training because many needy and vulnerable people can present with challenging behaviours.

We have witnessed a very marked decline in our son's confidence and skills as essential services such as access to leisure centres, outdoor

activities, social opportunities and activities have all been subject to Covid restrictions.

Money that is being allocated to the needs of carers appears to be spent on computer access and technicians as it is cheaper to do that than provide services. Websites are no better for all of the money that is spent.

Carers are at breaking point and it's only the knowledge that local service provision is generally unreliable, inappropriate and incompetent that is keeping many carers going.

We need a more authentic voice because carer's organisations are not representative of all carers.