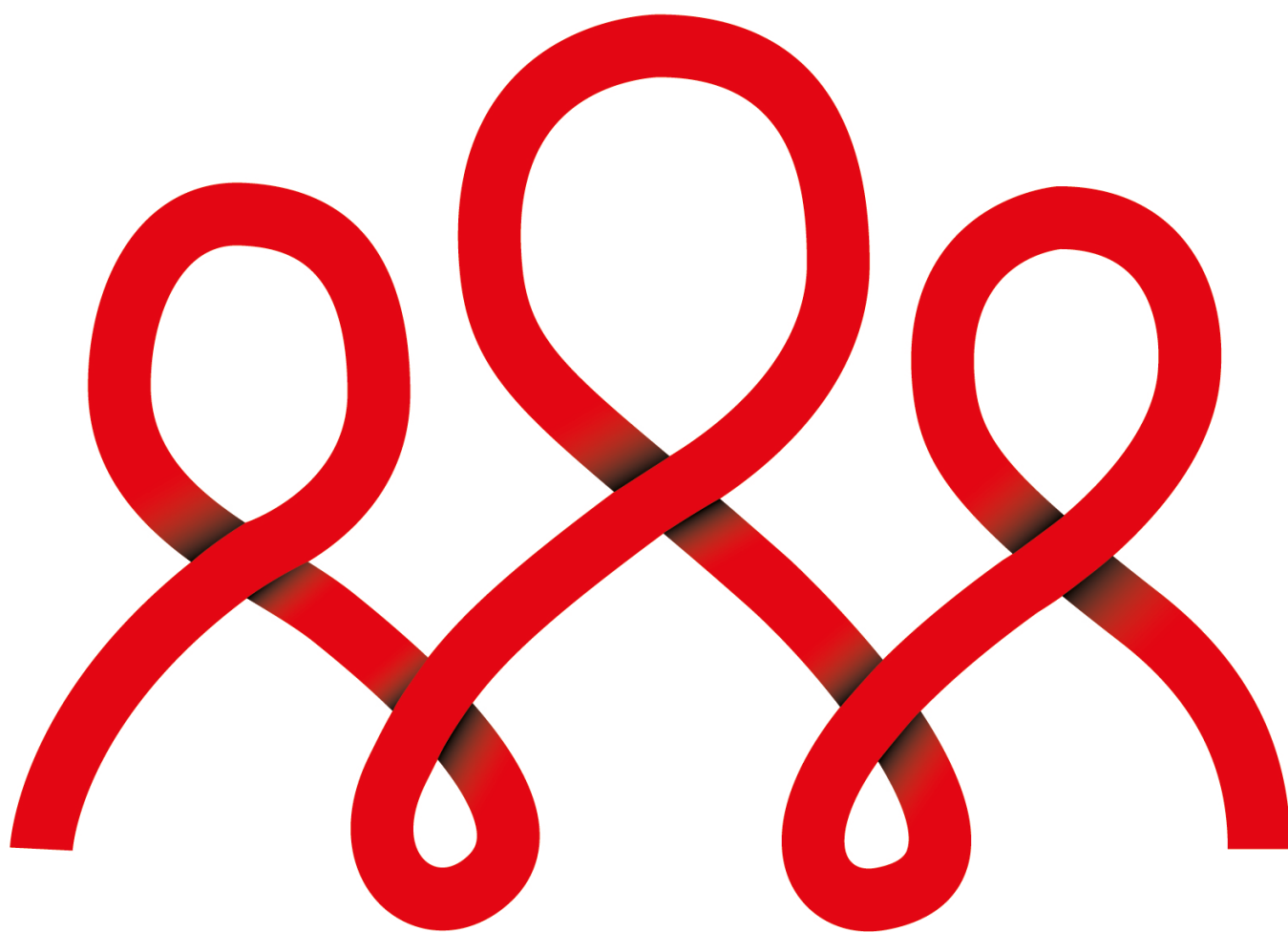


Carers Summit 2021 Report



Introduction

At a time when all sections of society have been under strain due to the COVID-19 pandemic, unpaid carers have faced additional and substantial burdens. Many have been shielding with those they love at the same time as the services, which they would normally rely on for support, were completely withdrawn or reduced as restrictions came into force.

As part of our Welsh Government funded work, Carers Wales hosted an online summit of unpaid carers over two consecutive mornings in March 2021, almost a year to the date of the first lockdown. It focussed on gathering information and feedback on how the pandemic had impacted the lives of carers and the ongoing challenges they face.

The summit also considered what carers want and need and their key priorities for policy makers and service providers in post-covid recovery.

The key themes over the two days were:

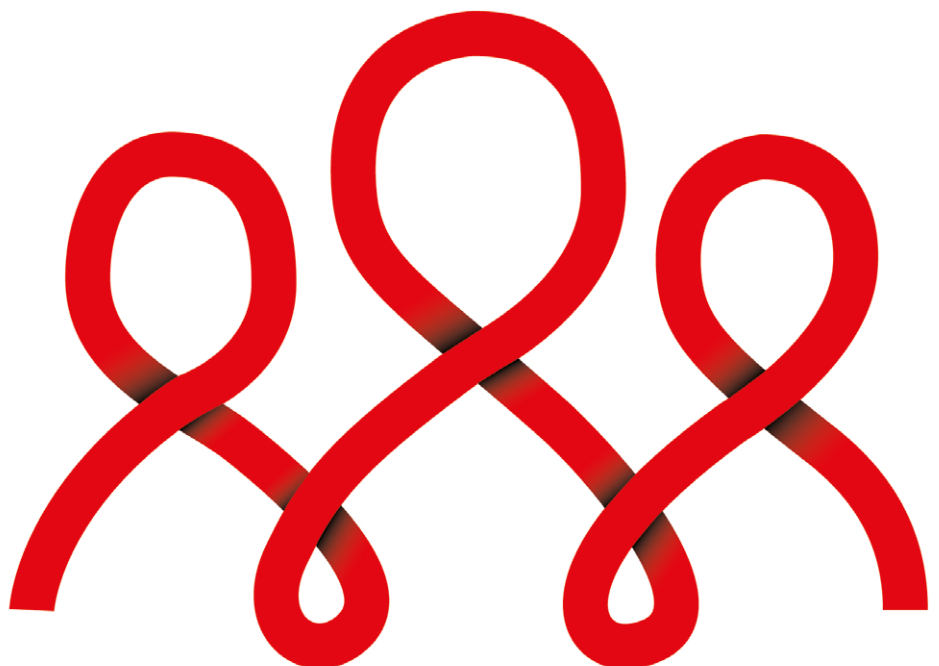
Day 1 - Learning from the pandemic

Day 2 – What next for unpaid carers?

This report contains a summary of the Summit presentations, workshop feedback and powerful testimonials and comments that carers shared through the ‘chat’ function.

A short film was also created summarising the Summit, which can be found on the Carers Wales YouTube Channel.

We would like to sincerely thank all the speakers and carers who took part for their insights and valuable contributions.



Setting the scene

Many carers told us that during the first lockdown they were not able to routinely access support designed to help those such as key workers e.g. PPE, food and medication¹. The number of carers in Wales rose from 487,000 to 683,000² in a matter of weeks, this was at the same time local authority information and support services were cut back as teams were redeployed to other areas of work. Carers found it challenging to speak to anyone about their situation and may have missed out on vital information and advice that could have made their lives easier.

While 91%³ of the Welsh public recognise unpaid carers as having been important during the pandemic, the sad truth is that carers have been struggling for many years. Despite the public's appreciation of the vital contribution that unpaid carers have made, in the same YouGov poll Carers Wales undertook in November 2020 only 7% of the public knew that carers have legal rights.

Carers Wales research during the year and published in November 2020 found that the huge, unpaid contribution carers made throughout the pandemic saved the public purse in Wales £33 million every single day⁴.

Headline findings for Wales⁵ included:

- 80% unpaid carers in Wales providing more care for relatives than before the pandemic
- 76% reported that the needs of the person they care for have increased during the pandemic
- 76% reported they are exhausted and worn out as a result of the pandemic
- 68% worried about further lockdowns
- 60% of carers in Wales have not been able to take any breaks from their caring role during the pandemic
- 29% said they are now struggling to make ends meet and are struggling financially

1 Carers UK (2020): [Caring Behind Closed Doors Forgotten Families in the Coronavirus outbreak](#), p17-18.

2 Carers Week (2020): [Carers Week 2020 Research Report](#), p25.

3 Carers Wales (2020): [Unpaid carers in Wales have saved £33 million every day of the pandemic](#)

4 Carers UK (2020): [Unseen and undervalued: The value of unpaid care provided to date during the COVID-19 pandemic](#), p4.

5 Carers UK (2020): [Caring Behind Closed Doors 6 months on](#)

Summit Day 1 – Learning from the pandemic

Claire Morgan, Director, Carers Wales opened the Summit and set the scene of the challenges facing unpaid carers in Wales, utilising key research findings noted above. She stated that unpaid carers had fulfilled a vital role during the pandemic. Their selfless commitment to provide care for someone who is older, seriously ill or has a disability had been vital to ensure the sustainability of our health and social care system. It has also saved the Welsh NHS and other statutory services tens of millions of pounds a day.

Despite their huge contribution however, they have remained largely unrecognised and undervalued by society. In addition, having to care for longer with less support had come at an extremely high cost to many carers' own personal wellbeing and health.

Emily Holzhausen OBE, Policy Director, Carers UK reflected on the challenges that carers across the UK have faced during the pandemic, the research that has been done and what policy changes need to be made on UK and devolved nation levels as we emerge from the pandemic.

Carers UK and the nation offices saw a huge demand for information. All four nation offices updated their information as government advice was changed almost daily.

The awareness of caring amongst the general public has also increased. However, work now needs to be done to differentiate between paid care workers and unpaid carers as the term carer is being confused.

For those who were juggling work and care, employers who were already 'carer aware' were better equipped to manage the disruption of the pandemic as they were able to activate existing policies to support them.



When did the pandemic start for carers?

- New carers overnight – **4.5 million more**
- The majority are **working** – **2.8 million new working carers**
- Carers are **stressed and exhausted**
- **Awareness of caring higher** than ever before
- **New initiatives introduced** to help carers quickly
- **Carer-friendly employers** were best equipped for change
- Value of care: **£530 million a day UK**
- **Demand for information, huge increase**
- **New digital opportunities for carers**
- **New service developments**

33 million

daily value of unpaid care in Wales

196,000

new carers in Wales

683,000

total carers in Wales at height of pandemic



Luke Clements, Cerebra Professor of Law and Social Justice at the School of Law, Leeds University

then shared his thoughts of what needs to change for carers. He said that actions were needed across multiple areas, but urgent action was needed to remedy the injustices faced by carers in relation to social care, social security and pensions and for carers in employment.

He reflected on the difficulty of getting independent legal information in Wales and the suggested there needed to be greater scope for independent, formal scrutiny of Welsh Government actions regarding unpaid carers.

The pandemic has highlighted the longstanding difficulties and inequalities that carers have faced over the years, but it has also substantially increased the pressures on carers. Luke focussed on three strands in relation to social care, social security and pensions and employment.

There needs to be an adequately funded social care system with care workers, who are properly paid, having decent working conditions so that carers and those they care for are able to access quality care and support. The care should be free at the point of need and paid for by taxation.

Many carers who would normally have had to give up work to care would then remain in employment and continue to pay taxes that would help fund such a system. The social care system needs to change to ensure that support available to carers enables them to get on with their lives and pursue their own aspirations. The system and its inability to provide for carers is often what causes the problems that many carers face.

There also needs to be adequate employment rights for working carers and, through the benefit system, carers must be adequately compensated for their valuable work to society and their pensions must also be protected in the future. Professor Clements argued a reformed social care system should be paid for by taxation and that with more people in work either as care workers or carers able to remain in employment they would be paying tax to help fund the system.

Social care reform

UNIVERSITY OF LEEDS

Straight forward

- Decent, reliable and personalised support for elderly, ill and disabled people;
- Free at the point of need;
- Care workers to be properly paid, with decent terms & conditions, secure employment and genuine career progression opportunities;
- Provided by local authorities and the 'not-for-profit' sectors;
- Paid for by 'taxation'.

Questions to the panel from chat

A parent carer raised the issues they had experienced in having their autistic child assessed and for them to receive a carers assessment, because the child did not have enough points to deem them as having a disability within the social care system. Luke answered that this practice was not acceptable and could be challenged under the Equality Act, he also went on to say that there is information on this on his website as this has also been a problem in England. He also stated that the Social Services and Well-being (Wales) Act differed to the Care Act in England in that there is an expectation that parent carers would need additional support and in some respects the onus would be on local authorities to say why they shouldn't help.

There was some frustration on chat from attendees about how carers were being identified in different parts of Wales for the Covid vaccination. In some areas of Wales GPs have carers registers whilst other don't, leading to confusion among carers as to how they should ensure they would be called to be vaccinated.

Carers Wales had raised this last summer with Welsh Government officials. There had been some push back from GPs regarding their capacity to register carers and Welsh Government was also considering those carers on local authority lists as well as lists of Carers Allowance claimants from GPs. A webform has now been created for carers to self-register and for those who do not use digital platforms, a telephone contact will also be provided.

Other comments in the chat related to various topics and frustrations including the term 'carer' being misused, Direct Payments, problems that carers have faced in relation to shopping during the lockdown, not being included on the shielding list, lack of PPE for carers, lack of services and communication. The general discussion that took place in chat was valuable to help focus on the workshop discussions that followed. Comments have been grouped thematically as follows.

Recognition of Carers:

- It really frustrates me that we still have to talk about 'unpaid carers' years after Welsh Gov defined a 'carer' as unpaid! ☹☹
- We are still not really considered to be carers, the term seems to be applied by government to those who earn a living in caring ☹☹
- I've been a carer for over 6 years, no support at all until the pandemic - it's a shame that it takes a global pandemic to even be noticed ☹☹
- Unpaid carers in Wales were not regarded as 'key workers'... ☹☹
- Don't start - Welsh government on shopping....every briefing, health minister, first minister and chief medical officer don't consider shopping as part of unpaid care ☹☹
- The sad reality is that during covid many didn't receive support when some were at end of life potentially. The risk was deemed more important to protect the paid worker than the unpaid carer ☹☹
- I think we need the status of Carer to be recognised as a human right on its own ☹☹
- 30 yrs unpaid caring at one point for 4...and still governments aren't clear who we are... in wales specifically as 96% of care being unpaid...words are cheap, we need something deeper than that ☹☹

Physical and mental health:

- The stress and impact upon physical health has been frightening ☹☹
- The mental health effects on the people we are caring for have been devastating in many situations and the toll of keeping up a happy face and making light of everything is exhausting ☹☹
- Caring for my mother for 56 years now, and now caring for three people 24/7 and my own substantial health needs seem unimportant to anyone except CREDU staff ☹☹
- I had to contact local GP to find out about getting vaccine. They didn't have on their system that I was a carer... ☹☹
- I've been a carer for over 20 years, 4 people at one point. No training and very little money for being a nurse, advocate, masseuse, advisor, and no respite. No wonder I sometimes look at piles of stuff to be done and just eat a Mars bar instead! ☹☹

- “ I am a care giver, a care worker, a caretaker, a care provider, a guardian, a nurse, a spokesperson for the person I take care of. And that accounts for just 10 hours of the 15 I provide daily ”
- “ I have always said that, at this rate, we will soon become the cared for of tomorrow ”

Services:

- “ Local authorities desperately need training on the 2014 Act ”
- “ What the Health and Wellbeing Act 2014 states and what is actually enacted upon is a major sticking point issue ”
- “ On list for Carers Assessment since 2006. Had a what matters to you chat in 2019, nothing happened ”
- “ Awful, but I had to threaten to drop mum off at social service office unless I got support. It worked and my assessment happened within a week. 10yrs on, I thought things would work ”
- “ We had wonderful spontaneous support from the local community who we had never met but almost none from authorities ”
- “ We lost social work support when the pandemic started and have not got it back ”
- “ Huge sums of money were given to local authorities to support us through covid. Where is that money? and the evidence of its usage..... ”
- “ No provisions at all for shielding food boxes and kidney patients . We ended up giving lots away as he couldn't eat things as on special diet. LA did try and ask for this to be changed but not possible ”
- “ I fear that the increased support we've provided during the pandemic will be expected to continue indefinitely ”
- “ We desperately need an appeal process for social services akin to the special educational needs tribunal where all parties see all evidence ”

Financial strain:

- “ I want to work. My life is on constant hold but I know the support isn't out there ”
- “ In theory family can be paid on direct payments, but the reality is that it's impossible to discuss ”
- “ I wonder how many carers knew about being paid on direct payments, how many have asked to be paid and if any have been paid ”
- “ local authority discussed family and direct payments or paid for caring..... “this is not an excuse for you to get some money” quote from social worker words... to which I replied how dare you..... ”



Workshops

The workshops convened to discuss:

1. What have been the major challenges carers had faced during the pandemic?
2. Had carers been able to access support that helped them?
3. In hindsight what sort of things did they reasonably think could and should have been provided to help them?

What have been the challenges?

Collated feedback is listed below as there was a high degree of commonality about the challenges carers had faced.

- Finding and accessing information had not been easy, information was not generally offered
- Getting food and shopping had been difficult to organise
- Withdrawal of services was keenly felt
- Inability to get responses from the GP and other medical professionals
- Social isolation
- The withdrawal of social services such as day care, coffee mornings, singing groups
- Lack of breaks and respite care
- Inability of carers to get PPE
- People being discharged from hospital with no consultation
- Lack of choice to be a carer
- Not being able to have support from normal family networks
- People not being put on the shielding list when they should have been

Ability to access support

Feedback showed a mixed picture across the Wales. Services were described as “patchy and inconsistent” with some carers finding it easier to access support than others. Some people also felt that offers of support were done reluctantly with one carer being told on a phone call “I’ve been tasked to speak with you”.

Most services moved online, those digitally excluded would have found it a lot more difficult to keep up to date in their local areas and access any support as and when it was provided.

The voluntary sector was found to have been particularly helpful during the pandemic in reaching out and supporting carers. Local shops were also helpful delivering food. Neighbours and local communities were often helpful and supportive which was appreciated. Local authority support was found to be patchy with some local authorities much better than others in contacting and proactively reaching out to disabled people and carers to offer support.

What did carers think could have been reasonably done?

- Help with shopping – slots and recognition
- Easily accessible information
- A dedicated liaison person to contact
- GPs could have made contact
- PPE should have been issued to carers at the beginning of the pandemic
- Local authority workers could have been re-deployed to carers centres to increase capacity
- Dedicated counselling services and sessions for carers
- One stop shop for carers
- Adequate testing of unpaid carers
- A GP carers’ register – some GPs offer a register whilst others do not. There was also some discussion that for those GPs who do offer a register, more than one family member should be recognised and registered.
- Carer recognition and awareness needs improvement

Summit Day 2 – What next for unpaid carers

Building on the first day of the Summit, we began with a re-cap from Claire Morgan, who then introduced the speakers.

Helen Walker, Chief Executive, Carers UK. Helen gave a brief overview of how the charity sector has managed during the pandemic. It became apparent early on, carers needed more support but in different ways and, as we emerge from the pandemic, they will need even more support. Highlighted priorities included the need to resolve financial issues, increased availability of breaks, increased access to ways to manage unresolved grief, and the ability to work more flexibly along with the re-opening of services.

She set out Carers UK's five-year direction of travel that will take us as an organisation to our 60th anniversary. The strategy 'Vision 2025' was developed with carers. The plan is realistic and ambitious and focusses on the areas that carers have told us they want changed. The annual business plan that sits alongside it allows for the organisation to be nimble, flexible and to react to emerging issues so where opportunities arise to make life better for carers, we can take them.

The strategy is split into three main pillars and Helen spoke about each in depth.

Equality – overarching ambition for carers to be the 10th protected characteristic in Equality Law.

Support – consider providing support in different ways to carers, not just through Carers UK but through working collaboratively with other organisations and reforming social care

Recognition – an over-arching ambition that carers, health settings and other statutory services and as well as society as a whole recognise carers so they understand where to seek help before or when they take on a caring role.

She finished with three key aims from the Vision 2025 Strategy. The aim is to:

- Create a society that treats carers equally in all aspects of their lives
- Connect carers so nobody has to care alone
- Halve the time it takes carers to recognise themselves and get the support they need

Julie Morgan, Deputy Minister for Health and Social Services. The Minister opened her address by acknowledging the impact of the pandemic on carers and the vital role they have played. She said that the Summit, funded by Welsh Government, was an opportunity for carers to share experiences and the impact of the pandemic and the feedback would be key to know what carers priorities and needs are.

She reflected that the vital role that carers play in society was spotlighted and it was important not to lose that as we move forward. The public appreciation of health and social care workers shown in the pandemic should also be extended to unpaid carers as the pressure on the health and social care system would have been more acute and could not have been managed.

Much work has been funded and is underway for carers including funding to Carers Wales, Carers Trust Wales, Age Cymru and the All Wales Forum to take carer projects forward. Funding to support carers has also been given to Health Boards and additional funding has been released to help carers during the pandemic including a hardship fund.

In 2020 a consultation was issued on a new national Carers Plan. There were 90 responses including from unpaid carers whose health and well-being suffered badly during the pandemic. On a positive note, many of the responses demonstrated how they had adapted to change and developed new ways of working. In addition to the three national priorities that were published in 2019 a new 4th priority to support carers in education and employment will now be included in the new National Plan. The plan will aim to strengthen strategic priorities and a detailed delivery plan will follow. The Strategy will aim to guide partnership working that recognises, values and supports all unpaid carers to live well and to achieve their well-being outcomes. Finally, the Minister said she was committed to ensuring that carers were top of the Government's agenda and that caring was everyone's business.

Ceri Higgins, Unpaid Carer. Ceri spoke about her caring experiences and how she has shared her views and experiences with policy makers and politicians over the years to effect positive change. She shared the slide below.



Questions to the panel from chat

The chat function was again busy with carers sharing their experiences and observations, and their comments have been grouped thematically below.

Carers Assessments:

- ☞ I think one of the biggest problems for the carers assessment is a lot of authorities don't have a carers assessor, the social worker does the assessment, but the social worker doesn't have the knowledge of what is around for carers and what carers are entitled too. I know Cardiff do not have carers assessors, I live in the Vale of Glamorgan and we have 5 carers assessors in each social service sector and it works really well. I can honestly say the feedback is always positive. This should be in all Councils, social workers are not care assessors and have enough of their own role without having the time to search for services and finances to help carers ☞☞
- ☞ The funding is simply not an issue - if an assessment is undertaken properly as a What Matters Conversation, then the support plan that is coproduced as a result is a legally-enforceable document and must be provided whether the council can afford it or not - it is a legal duty to provide ☞☞
- ☞ The assessment should also take into account mental and physical wellbeing of a carer who may be caring for more than one person and having been a long term carer ☞☞

Legal rights not matched by reality:

- ☞ Why is there not sufficient funding to provide what legislation says should be available and what can be done to address that? ☞☞
- ☞ The Welsh Government legislation has good aims, but these are not consistently being provided by local authorities and LHBs. There is a huge gap between theory; the law; and practice, what people receive. Although there will be a new strategy, until carers have RIGHTS the words from the Welsh Government are ineffective ☞☞
- ☞ Knowing where to go does not help as the reality of care provision bears no resemblance to reality ☞☞
- ☞ We have no choice but to be carers, despite what legislation says ☞☞
- ☞ Our social services is under staffed and lacking in knowledge with a frightening disregard for legislation ☞☞

Dealing with authorities:

- ☞ What needs to be recognised by authorities at all levels is that for most of the time it is not caring that exhausts or depresses Carers it is the constant fight with authorities to get the levels of support that we need just to keep going ☞☞
- ☞ LA personnel should be better educated as to the role and needs of carers. More respect shown ☞☞
- ☞ We would like qualified, professional people to meet us - at least half-way - , or is that asking too much? ☞☞
- ☞ My LA have always, always (for 34yrs +) maintained "no funding" whenever I have asked for an assessment - ?? Where is the funding then? I've asked them when they have been to my home-no answer given, just a lot of paper shuffling and a very uncomfortable look ?! I despair, I really do. ☞☞
- ☞ Social services are closing cases where support is ongoing, failing to carry out reviews and leaving people not just with inadequate support, but some are left with no support ☞☞
- ☞ Getting the Continuing Health Care and Direct Payments fiasco sorted would help ☞☞
- ☞ Not all Regional Partnership Boards take carers or disabled people seriously - we must achieve proper status on these Boards and be listened to ☞☞

Life alongside caring:

- ☞ I don't want support to be a carer, I want those I support to have the support they are entitled to so I can live my own life, without worrying what will happen to them if anything happens to me ☞☞
- ☞ Why is there no support for carers who still have to work? I can't get any support at all why not a tax break like they did for bringing in working from home? ☞☞
- ☞ I can't get respite anymore because the person who I care for refuses to pay for it. Why is respite not free? ☞☞

Recognition:

- ☞ I have saved Wales £563,000 for one parent and £350,000 for the other by unpaid caring. I think I'll send an invoice in ☞☞
- ☞ Carers need to be truly valued ☞☞
- ☞ Even professionals who know about the work unpaid carers carry out are sometimes overburdened and jaded. The whole caring community = paid or otherwise are undervalued. It shouldn't be either or, we all need to support each other ☞☞

Workshops

The workshops convened to discuss what is needed now for carers in the short and long-term. They were tasked with suggesting priorities for Welsh Government, statutory bodies including health boards and local authorities and carer organisations on a local and national level.

Welsh Government

- Carers Assessment – practice varies, and the process needs to be tightened with greater consistency across Wales.
- Practitioners need to be properly trained about the process and have respect for carers and their needs
- A clear achievable vision from Welsh Government and radical changes in the way carers are supported.
- The interface between Welsh Government, Local authorities and Local Health Boards is a maze. Priorities get lost in the middle. Maybe the gap needs to be narrowed to ensure that services are commissioned and filtered through to projects that are available to deliver for carers and the cared for person.
- Transparency of spend to various bodies, greater recognition, one stop shop for information
- Create a National register of carers to ensure carers are identified and offered support
- Develop national minimum service standards for carers
- Ensure that the SSWB Act is properly implemented so carers can access their rights
- Carers recognised in hospital discharge process
- Strategies need to be put into action
- Health and Social Care should be a single funded stream
- New Guidance should not be based on post covid as the same problems have existed previously.
- There should be an appeals process rather than having to go through complaints
- Contingency planning for carers
- Financial recognition for carers
- Ensure that there is a adequate funding for third sector organisations, services get cut and not sustainable year on year.
- There needs to be better recognition of the value of care in society as a whole

Statutory bodies

- Services should be adaptable and people should not be forced to meet criteria before they end up in a crisis.
- If the Social Services Act was properly implemented there would be a lot less issues. The Act needs to be cascaded down from the top and translate into actual services that support people.
- People still do not know where to go for help. There needs to be clearer access and signposting by LAs. WG to ensure LAs are signposting
- LAs need to be more connected to local services.
- Primary and secondary care staff to identify carers
- Carers expertise needs to be recognised by hospital staff and carers recognised in hospital discharge process
- Integrated Wellbeing Networks funded by ICF-could be one stop shop
- Regional Partnership Boards are influential, but carers have regularly and repeatedly said how their needs and input are ignored
- Support should not be a lottery depending on where in Wales you live

Carer Organisations

- There is too much reliance on the 3rd sector and is the sector being used in the right way?
- Should have a knowledge of what support is available and the rights of carers
- Could 3rd sector provide advocacy?
- Carers Services are different across Wales, it can be confusing dealing with different agencies
- Local area co-ordinators were very good in lockdown organising temporary help for people who were shielding

Reflections on the Summit

Even though the Carers Summit was held online it was very interactive with carers freely contributing through the chat function and the workshops. 75% of carers who responded to our evaluation said that they were very satisfied with the Summit and agreed that it was good to hold it online over the two consecutive Fridays. Carers asked that similar events be arranged in future to share their experiences and views.

From the Summit it is apparent that, even though the Social Services and Well-being Act has been in place for five years, carers feel there are still huge inconsistencies in the way the Act is being delivered for carers across Wales.

The pandemic has shone a light on the lack of support available and the recognition of the important contribution that carers have made to prop up the health and social care services.

From what carers have told us much more needs to be done to meet the aspirations of the Act and deliver the real change that carers want.

The summary of the key asks from carers is as follows:

- Improve consistency in the way carers rights to information, advice and assistance are delivered across Wales
- Improve professionals understanding of carers and their rights
- Improve recognition and support of carers in health settings
- Improve financial support for carers
- Create a national register of carers

We would like to thank everyone who gave the time to contribute to the Summit sessions.

Our mission is to make life better for carers



We give expert advice,
information and support



We connect carers so
no-one has to care alone



We campaign together
for lasting change



We innovate to find new ways
to reach and support carers



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