

Wales Carers Summit 2023 Report

Introduction

Despite pandemic restrictions being lifted and people's lives getting back to more of a normality, unpaid carers are still struggling against a backdrop of services which haven't been completely restored, a recruitment and retention crisis within the care sector and significant pressures that are facing the NHS. The Carers Summit aimed to identify positive solutions and policy changes that can be made by statutory services, carer support organisations and communities to make life better for carers in Wales.

Hosted by Carers Wales and funded by Welsh Government, the online Summit took place from the end of January 2023 over a period of three weeks. This consisted of 13 different focus group sessions with unpaid carers on a variety of topical subjects. These were often co-hosted with external organisations with expertise in the area. During these sessions, carers shared their personal experiences and expressed how statutory and other organisations could meet their needs now and in the future. The Summit concluded on the 16th February with a Plenary session in the form of questions being put to a panel of experts and decision makers across health and social care.

This report summarises the focus group sessions, including the powerful testimonials and experiences that carers shared with us. We also include the answers from the expert panel in the Plenary session to the questions we put forward on behalf of the carers who took part.

This report will be shared with key policy and decision-makers across Wales. It will also be used in Carers Wales's campaigning and influencing work and act as evidence to put forward arguments for real change in Wales.

A short film has been created summarising the plenary session which can be viewed on the Carers Wales You Tube channel: <https://www.youtube.com/watch?v=I1t06K8kAIA>

We would like to sincerely thank all the organisations who helped us by co-facilitating focus groups along with the expert panel who joined us at the plenary session. Above all, we want to give a huge thank you to all the carers who took part to share their personal experiences and their expertise. It was extremely humbling to hear individuals' testimonials and what needs to be changed and why.

Setting the scene

Since emerging from the pandemic, many services which carers had previously relied on have either been re-configured by local authorities or not been re-opened at all. Against a backdrop of a recruitment and retention crisis across paid care and difficulties within the NHS, many carers are having to pick up the pieces and are left struggling with inadequate information and advice about their rights alongside a lack of care support for their loved ones.

The results of the Carers Wales' State of Caring in Wales survey, launched in late 2022 and based on responses from over 1,000 carers in Wales, sets out the scale of the challenges facing carers.

- 57% of unpaid carers in Wales said they were uncertain about what practical support they might be able to access in the next 12 months.
- 52% of unpaid carers in Wales took over a year to recognise their caring role, with over a third (36%) taking over three years to recognise themselves as a carer.
- 52% of unpaid carers in Wales disagreed that the NHS gave them the information and support they needed to care well and safely.
- Over 7 in 10 (72%) carers said they were extremely worried about managing their monthly costs.
- Only 19% of carers said they had undertaken a Carer's Needs Assessment in the previous year.
- 4 in 10 (43%) carers who had not had an assessment said that a barrier was not knowing what an assessment was.
- Nearly a quarter (24%) of unpaid carers in Wales said their physical health was bad or very bad and over a third (34%) said their mental health was bad or very bad.

Carer Focus Group sessions

The sessions were held over a two-week period in the morning, afternoon and evening to maximise accessibility. They covered a range of topics as outlined below.

Across the sessions, carers shared with us very personal experiences and frustrations across the Health and Social care systems in Wales. Key themes emerged across almost every session including

- Insufficient identification of carers.
- Lack of easily accessible information and advice that would have helped them know their rights and where to go for support and further information.
- Insufficient awareness and knowledge of carers amongst health and social care staff including front-line workers.
- Being unaware about where to go to access information, advice and support in their local area.
- The language used around carer's needs assessments and the feeling that this was a barrier to carers seeking information, advice or support.
- The time it took to have carer's needs assessments, the knowledge of staff undertaking needs assessments and a lack of follow-up or information.

Focus Groups Week 1

What matters to parent carers (in collaboration with the All Wales Forum of Parents and Carers)

This focus group considered what mattered to parent carers. We asked for their views on what information and advice they should receive, by whom and when, and how the health, social care and education systems could meet their needs. Experiences were mixed and were heavily dependent on how well the professionals they were in touch with identified them as carers. Overall, the experience of the education system was extremely poor when helping carers self-identify along with providing them with information and support.

Key points made were

- Information on local authority websites generally did not recognise parent carers. Information tended to be geared towards young carers or other adult carers. For example, those looking after older people. The information often did not include advice for parent carers as a key demographic themselves.
- The vast majority of those who attended the focus group said that they received information from their peers to identify as carers.
- There is a lack of peer-to-peer support groups for parent carers with most local authority services geared towards young and older carers.
- There is a lack of a joined-up approach between the health/social care and education systems.
- It was felt that health including GPs should be doing more to identify parent carers as these are the institutions that are most likely to recognise caring roles earlier.
- They felt that there should be an over-arching duty on health/education and social services to identify carers.

Quotes

“Looked at the carer page on the council website and the only information related to elderly and young carers. Only when I spoke to other parents, I realised I was a carer”

“It would be a good idea for SENCos’ (Special Educational Needs Coordinators’), CAMHS’ (Child and Adolescent Mental Health Services’) and health professionals to get involved with carers.... It is a robotic process, like being on a conveyor belt with no compassion or care, you slide through tick boxes at school, education, health and social services...I was astonished about the whole process and how uncaring and un-supporting it was”

What matters to LGBTQ+ carers (in collaboration with Pride Cymru)

This focus group explored whether there were any key differences in the way that services interacted with people from the LGBTQ+ community. We asked questions in relation to information and advice and how the health and social system can work better for LGBTQ+ carers.

Key points made were

- None of the focus group attendees said that they felt discriminated against in relation to services because of their LGBTQ+ identity, saying that the barriers that they have experienced in receiving information and advice exist for everyone.
- They also stated that there was very little available in terms of services and that services do not work in a joined-up or collaborative approach.
- Much like the information and advice and parent/carer focus groups, they raised very similar points in relation to difficulty finding information and having to set up their own peer-to-peer support groups.

Quotes

“There is no working in a joined-up approach. Not one pathway, it is very complicated. Constant chasing and nagging”

“No services to enable someone to work, [I] had to give up work”

“When under community paediatrics for medication, everything was fine. When transferred to adult NHS services everything just dropped. It’s like falling off a cliff edge”

What matters to carers of those with mental illness (in collaboration with Adferiad)

We asked attendees in this focus group what would have helped to enable them to recognise their caring role earlier, and how they think barriers could be overcome to enable them to be involved in planning care.

Key points made were

- There was a general consensus that primary and secondary care should be doing more to help carers identify as they are often the first point of contact when someone has a mental health concern.
- There were mixed experiences in relation to how well they were involved in care planning. Some were never asked at all, whilst others had good experiences.
- It was mentioned that carers can be in contact with many layers of the health service before someone recognises and identifies them as a carer.
- A number of individuals mentioned the lack of peer-to-peer support and that this would be beneficial in relation to speaking to others with lived experience.
- A carer mentioned the Mental Health (Wales) Measure and that, as a result, she had a good experience that helped her be involved in care planning. Another commented that there is no interconnection between the Social Services and Well-being (Wales) Act and the Mental Health (Wales) Measure. Under the Social Services Act, you can be jointly assessed, yet there is no provision for this within the Mental Health (Wales) Measure.
- The general feeling was that professionals see a duty of care to the person in front of them but not to the carer behind them. It was further felt that there is a lack of joined-up working and information sharing among various agencies and departments.

Quotes

“If services had been planned with me there would have been quicker and better outcomes for the person I care for”

“It was only when I started caring for my elderly parents that I realised I was a carer” – carer had previously been caring for a wife with Bi-polar

“There seems to be an unwillingness by professionals to face how real a toll caring takes on someone”

“Need to be mindful that if we want peer support groups that these need to be facilitated as they can’t be dependent on one person. Almost need a professional organisation to support and facilitate it to ensure it is sustainable”

How can NHS screening appointments meet the needs of carers? (in collaboration with Public Health Wales)

This focus group was held with Public Health Wales as a further information-gathering exercise to contribute to a consultation they were running considering the barriers that carers face when attending screening appointments both for themselves and those they care for.

We considered questions that would feed into the consultation.

Key points made were

- Specifically, and unsurprisingly, there was an overwhelming consensus that it was difficult for some carers to attend appointments without the person they care for as replacement care services were often unavailable to meet need.
- Carers also said that when accompanying a loved one to their appointments, services did not recognise and understand the needs associated with some disabilities such as dementia/autism etc.
- They also said that there needs to be more of an emphasis on the social model of disability and that services should ensure that places are accessible for wheelchair users, those with mobility issues and those who have difficulty hearing. If healthcare staff are wearing masks, visors are more effective so that individuals can lip read.
- There should also not be an assumption that carers are only caring for one person. Getting to screening appointments may mean alternative care arrangements for several people in that care circle.
- Screening should also take place at easily accessible local venues. Appointment times should have the flexibility to meet carers’ needs. It was also felt that staff, including admin staff, should be trained to be carer aware.
- There were also general comments in relation to screening with the feeling that people from some ethnic minorities may be more prone to specific illnesses but that the screening provision did not take this into account.

Quotes

“Went to multiple screenings with Dad who had dementia, it was difficult as the provision didn’t seem to take into account his or my needs”

“Mother had mobility issues and again provision was tricky for those using wheelchairs”

“Social Model of disability should be embedded across the health service”

“Support for carers such as a helpline when they find themselves suddenly being referred for screening due to illness. For example, I was recently referred for bowel screening and all I could think was how would I be able to continue in my caring role had it been cancer, which thankfully it wasn't.”

What matters to minority ethnic carers (in collaboration with Women Connect First)

In this focus group, we wanted to explore what needs to be done by policy and decision makers to encourage carers from the Black and minority ethnic community to identify as carers, to improve provision for carers from ethnic minorities and discuss how language barriers can be broken down in terms of providing information.

Key points made were

- For some of the BME community, caring may be seen as part of the culture which happens automatically within families without recognition that they have taken on a caring role. Many carers from the BME community identified as carers because of peer-to-peer conversations and, even then, it can take a long time to accept the role as a carer and they have rights as a result of this.
- There was a general consensus that statutory services need to be trained to be culturally aware. The language used must also be culturally aware as some carers do not identify with the term and this may be exacerbated by cultural approaches to caring.
- There needs to be more information, advice and advocacy in the language of choice to raise confidence within BME communities to come forward and identify and ask for services.

Quotes

“There needs to be an advocate or someone recognised as the voice of the person. Information needs to be put in its simplest form. There needs to be one document that says the same with the same level of detail”

“Interfacing with statutory bodies – there needs to be an increase in the knowledge of people working on the frontline. There is no blanket understanding. The quality of information of frontline staff needs to be brought up to speed”

“Difficulty in identifying as a carer. The idea of care has got to be put forward in an identifiable way. Brought up in a culture where you automatically become a mother to a cousin. It took five years to get my head around I could ask for help”

“Another black lady at nursery school identified me by asking what help I was getting. It took me another year and a half of her nagging to claim benefits”

The Cost of Living crisis – what support do carers need?

This focus group considered what the main challenges are for carers to manage the increasing cost of living and consider what more can be done by the Welsh Government and others to help them be able to continue to care. We also wanted to explore whether there were schemes or services that could be expanded that would help carers and what the priorities should be.

Key points made were

- There was a general discussion about the price of food and products such as incontinence pads and that food vouchers would be useful to have to offset some of the cost.
- A Carers Register was mentioned to ensure that carers are told of initiatives that they may not be aware of and to ensure that carers are claiming all the correct benefits to which they, or the person they care for, may be entitled.
- Some carers who did not receive the £500 Welsh Government payment because they were not in receipt of Carers Allowance felt unrecognised and undervalued as a result.
- Carers spoke about the importance of services being in place to enable them to work to help meet some of the costs of living.
- They welcomed the warm spaces initiatives but there was also a suggestion that this could be expanded to the hospitality industry with financial incentives to enable them to also provide short breaks to carers.
- Some carers asked whether they could be paid Direct Payments for elements of care they are undertaking. There are a lot of carers across Wales who are also experiencing fuel insecurity, Scotland has a Fuel Insecurity fund and some wondered whether there was potential for this to be replicated in Wales.
- There also needs to be more consistency across Wales in terms of the financial support that is provided to carers via the Welsh Government and statutory services. Health in general should be offering free health checks and appointments over the phone to negate having to travel which costs money.
- It was felt that services are much easier to access if a person lives in a town rather than in a rural part of Wales and this needs to be taken into account when providing services.

Quotes

“Appointments over the phone can avoid the need to travel”

“Carers Trust gave Tesco food vouchers as part of a grant scheme in South East Wales but they go quickly which shows how desperate people are”

“PA is paid £10 per hour to care for my son. I can’t understand why I can’t be paid the same to look after him”

“There needs to be consistency across Local Authorities in Wales in terms of the support they provide to carers”

“Most carers live in fuel insecurity. Scotland has a Fuel Insecurity Fund, could we do the same in Wales?”

How should Llais (the new Citizens Voice Body) work for carers? (in collaboration with Aneurin Bevan Community Health Council)

In this focus group, we wanted to inform carers about Llais and discuss how Llais should be communicating their role to carers and engaging with carers once the new organisation is operational.

Key Points made were

- A lot of participants had never heard of Community Health Councils and were unaware of what their remit was.
- Moving forward the general consensus was that Llais needs to be promoted in the NHS more widely and that literature should be available in primary and secondary care. It was felt that primary care was a key place to advertise as this is the first point of care. Packs should also be available in hospitals.
- The advocacy role of Llais also needs to be promoted widely as many focus group participants were unaware of their rights and where to find advocacy.
- There was some concern that because Llais is effectively a complaints body that Health and Local authorities will not advertise the service.
- It was also felt that the body should be advertising via social media and other channels of communication to ensure that there is constant advertising of their service.

Quotes

“Get into places, GP surgeries, day centres, carer organisations. Never heard of CHC”

“Because it’s a complaints body they won’t want to advertise. People need to make sure they are following the legal requirements and make sure that it is enforced. A report made public to make sure they are accountable”

“Need to be in primary care which is the first point of care. Went through a diagnosis process and wasn’t aware of advocacy. If I was aware I would have challenged things”

Focus Groups Week 2

Views on Carer’s Needs Assessments

We wanted to seek views on carer's needs assessments and what needs to take place to make them more accessible and effective.

Key points made were

- People's experiences of carer's needs assessments were different depending on which local authority area they lived in. It was felt that there needed to be much greater consistency across Wales to ensure carers' rights under the Act are being upheld equally.
- The vast majority felt that the language used and the colloquial term 'carer assessment' puts people off having one. It was also felt that the term 'What matters conversation' was ambiguous.
- Finding information about carers and carer's needs assessments on council websites was also deemed to be difficult. It was also felt that it should be a statutory duty within the NHS to be identifying carers and that there was a need for a Carer Register and a carer ID card.
- Some carers had requested a carer's needs assessment and were turned down or had to wait a number of weeks. There was discussion about timescales involved and issues being raised not being resolved.
- After having a carer's needs assessment, many were not provided with a copy of anything so there was a conversation about how carers are able to challenge any decisions if they have not seen what has been written.
- Generally, most participants had a very negative experience of the assessment process.

Quotes

"The whole language around carer's needs assessments needs to change"

"Every carer should have the same opportunity. What matters conversations need to be adaptable"

"Change the name so it is not intimidating"

"Social workers go to managers after an assessment which is great, but, if things are not being addressed - it is a waste of paper"

"Never been asked about the extent that I am willing and able"

"It feels like they are coming in to assess if we are capable"

Information and Advice for carers – what gaps are there?

This focus group discussed good examples of information and advice for carers, what may be lacking in presently available information or advice for carers and the most effective methods to provide information or advice to carers.

Key Points made were

- Carers found information from other carer charities and carer groups to be particularly useful especially when they could find out about these groups.
- Carers told us it is important that there are clear lists of local services for carers including places where they can take a break.
- Carers also felt it is very important that information is provided on their legal rights as an unpaid carer.
- Carers further said that leaflets and other information need to be kept up to date and appropriately dated.
- Many carers said that a barrier to receiving information is when carers do not identify themselves as carers or they are not identified as such by professionals. Because of this, carers said local authorities and others need to be proactive and imaginative in the way that they provide information to carers so that they reach more people.
- Carers also told us that the quality of information and advice that they received would be improved by appropriate training for the professionals such as local authorities staff who provide carer information.
- The complexity of services and difficulties in navigating the system was further identified as a barrier to receiving information for carers.

Quotes

“Our local carers Facebook page shares all info from our local council, Carers Wales and the Care collective as well as from our local health board, full of great info”

“I would put in the link and a phone number for all carers support groups for the local area”

“The Carer is the expert in their cared for and their conditions”

“I would put in the link and a phone number for all carers support groups for the local area”

“Found some useful information on the Vale website and easy to find their carers page”

“Our council do have a Carer section and since I started bugging them it is kept more up to date”

“Pre covid when I helped to man the Carers Wales stands at events we picked up loads of Carers who had not identified themselves”

“I raised that the Local Authority could put in an information leaflet in annual council tax bills that come through the door”

What matters to parent carers session 2 (in collaboration with All Wales Forum)

In this focus group, we want to explore what information and advice parent carers need, who is best placed to provide information and advice and any barriers experienced by parent carers.

Key Points made were

- Parent carers told us that information on caring can sometimes overlook parent carers as it may primarily focus on people caring for elderly parents or perhaps young carers. It was important to recognise that many parents looking after their own children are carers.
- It was also raised that some activities or events for carers may not be accessible to children with complex needs preventing parent carers from engaging.
- Participants further told us that the language that is used around being a parent carer can be quite negative overlooking the strengths and capabilities of their children.
- Parent carers said that more information on caring needs to be provided by schools, GPs and CAMHS. They also said that it can be exhausting the amount of research they had to do to find out about sources of support.

Quotes

“I’ve only started to identify myself as an unpaid carer when my daughter was nearly 20 years old. She is disabled since birth and she’s now 30”

“I’m someone who learnt to deal with my fears of the future, by talking to other parents in my situation whose children were older. Sometimes you need reassurance and positivity when things are tough”

“Social services are swamped with all the paperwork. They have to do that and they don’t have the time to see the whole picture, i.e supporting parents as well...”

“Carers Wales should be part of the process”

“I’m someone who learnt to deal with my fears of the future, by talking to other parents in my situation whose children were older. Sometimes you need reassurance and positivity when things are tough”

“This is the carers service covering Cardiff & the Vale - <https://carerfriendly.co.uk/> they really should have signposted you at least here”

“Respect for carers”

“I’ve been empowered by meeting other carers”

What matter to working carers? Session with Employers for Carers Wales

This focus group discussed what support is needed in the workplace to balance work and care, carers leave (either paid or unpaid) could and what action is needed from the Welsh Government or employers.

Key Points made were

- Working carers told us that awareness is growing in the workplace about the needs of employees with caring responsibilities but further training of line managers is needed, alongside other steps to embed an understanding of caring and flexible workplace practices.
- Employees should, for example, provide laptops for homeworking to enable employees to work flexibly.
- Existing emergency or dependents leave was felt to be inadequate for planned appointments underscoring the need for dedicated carers leave in the workplace. Participants felt that the Welsh Government has an opportunity to promote and embed greater support for carers in the workplace in Wales but that it should be stronger in requesting changes from employers.
- It was further noted that flexibility in the workplace varies by sector which demonstrates the need for a cross-sectoral role approach.

Quotes

“The biggest thing that would have made a difference for me would have been not having to use my annual leave”

“People take annual leave or go sick to undertake their caring role”

“I’m grateful that I do have that support in my workplace”

“It is very difficult working full-time and being a full-time primary carer”

How can carers be helped to ‘claim what’s yours’ in benefits? (in collaboration with Welsh Government)

This focus group explored whether people were fully aware of their entitlements to claim, the main barriers or obstacles for people seeking to make a claim and what steps are needed to make the process a better experience for claimants.

Key Points made were

- Carers explained that it often takes a significant amount of time and energy to learn about the various benefits.
- Forms were felt to be confusing and sometimes daunting to fill out so it is appreciated when there is help on offer to apply for financial support.
- Carers further reported that it can be difficult to record their caring responsibilities and/or the reality of living with a condition in applications for benefits or other forms of financial assistance.
- It was also raised that people with lifelong conditions should not have to reapply for entitlements.

- Carers felt that the Welsh Government should be more proactive in promoting benefits and other sources of financial support to carers perhaps by writing to them directly among other methods.

Quotes

“I did get the council tax reduction with little fuss, after a quick visit from the local authority (Once I found out about it from my carers group)”

“Mine was "DEFERRED" by 6 years with no notice at all from the Department of Works and Pensions (DWP)”

“I only found out about the council tax reduction from a peer group of carers”

“Turn2Us has a benefits calculator”

“That DWP envelope landing on the doormat causes instant anxiety”

“The first Disability Living Allowance (DLA) claim we did ourselves and put the information on his best day, turned down went via Citizens Advice Bureau (CAB) to appeal who said to do it from the worse day, granted”

“You can only claim one Carer’s Allowance (CA) even if caring for 3 people at 3 addresses as I did for 5 years (when I did not sleep at all)”

“CARERS are not appreciated, despite how much we save the Gov in care costs. I am sure putting hubby in care would cost much more than they give me carers allowance”

“Never seen the adverts, do not read papers (cannot afford them, do not go shopping or transport as still shielding!!!”

“Training in using zoom too. Only just found chat”

Carers views on complaints and assessments (in collaboration with Public Services Ombudsman Wales)

The focus group discussed whether carer’s needs assessments were being delivered in line with the legislation, whether they were being completed in a timely manner and whether any barriers or obstacles had been experienced in arranging an assessment. The session then discussed carer experiences of complaint processes, including whether they had been reviewed and acted upon in appropriate timescales and whether carers faced any obstacles in complaining in the first place.

Key Points made were

- On the topic of assessments, concerningly some carers felt that they were dissuaded by professionals from having a carer’s needs assessment despite wanting one.

- Carers felt that social workers and other relevant professionals need appropriate training so that they can guide carers effectively through the assessment process and explain what will become of it.
- Carers reported that in some cases important aspects of assessments were not covered, for example, the legal rights of carers under the Act were not mentioned.
- Turning to complaints, carers explained that timescales can be very lengthy with one carer mentioning that a stage 2 complaint which commenced in May 2022 was still ongoing as of February 2023. The time involved in complaints means that many carers lose faith in the system.
- Additionally, many carers struggle to find the time to prepare a complaint and then go through the process which represents a barrier to their ability to complain.
- Carers also raised the importance of advocacy services in helping carers to navigate the complaints process.

Quotes

“Again, I’m going through my second formal complaint due to the care/carer assessments being ignored and not allowing us to even view them - refused my complaint twice, the second time they denied we’d had a review. Yet a SAR shows the assessment was updated”

“As a carer who is living through that experience with no choice of their own. It’s an absolutely demeaning process when nothing comes out of it. You feel forgotten about, and completely invisible to society!!”

“With my original complaint to the health board, I sent the royal college of Nursing documentation to support what we were saying about informed consent. They denied any wrong doing but I believe now they have conceded. I am just waiting to hear them say it. The "Putting things Right " is not fit for purpose. over a year from the health board and almost a year for the ombudsman to finally get them to admit they did not have informed consent”

“I’ve worked with advocacy for over a year - it’s still got us nowhere”

“I think it needs to be remembered this is our lives we remember every word ... whereas we are just one of many for the social worker - so they’re not going to have the memory of any situation or meeting that we have. We live it”

“You do not even get the apology they have grudgingly agreed to send”

“Timescales - are so very important cos a lot of us are left in limbo until these complaints are dealt with”

“Totally agree about the energy you have as a carer. Unfortunately, we haven’t got enough of it, to be able to go through the complaint process. I tried most of my life to avoid complaints until it was too much”

“My hand is up for cross-border health complaints”

“Complaining is difficult so what support can be provided to support the person having to complain’s wellbeing?”

“Your annual reports make interesting reading”

“The valid reason being that it took over 12 months to receive a reply from the health board”

Summit Plenary

Following the conclusion of the focus groups, Carers Wales reviewed the points that carers had raised across all of the topics and constructed questions to put to an Expert Panel of senior figures in social care in Wales at the concluding Summit Plenary. The Expert Panel consisted of

- Helen Walker, Chief Executive of Carers UK
- Jemma Morgan, Aneurin Bevan Community Health Council
- Michelle Morris, The Public Services Ombudsman for Wales
- Norma Mackie, Cardiff Council Cabinet Member and WLGA Social Care Spokesperson
- Alwyn Jones, Deputy President of the Association of Directors of Social Services Wales
- Claire Morgan, Director of Carers Wales
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The Plenary began with a video welcome from Julie Morgan MS, Welsh Government Deputy Minister for Social Services. The Minister spoke of her appreciation of unpaid carers in Wales, highlighted the Welsh Government’s Carer’s Strategy and thanked Carers Wales for convening the Summit.

Questions were then put to the Expert Panel members based on themes raised by carers in the Summit focus groups.

Topic 1: Information and Advice.

Question to Alwyn Jones: What should local authorities do to more proactively ensure carers access information and advice relevant to their caring role?

Alwyn said that local authorities need to proactively promote information at a variety of locations, from libraries to post offices, remarking that every contact counts in informing and identifying carers. He said there was a need to ensure staff were well trained to identify carers and that they felt able to follow up with people with caring responsibilities to ensure they have accessed information.

Question to Helen Walker: What needs to happen to ensure that health services can better identify carers at the first point of contact and ensure they have information to care safely and confidently?

Helen said that GP records should be used to identify carers and provide them with information. In hospital settings, she said carers must be consulted during hospital discharge and that the high proportion of NHS employees with caring responsibilities themselves presented opportunities for improved identification.

Topic 2: Carer's Needs Assessments

Question to Norma: How can the Welsh Local Government Association ensure a more consistent approach to carer's needs assessments across Wales, including the content of the assessment, timeframes and providing a final copy of the completed assessment?

Norma responded that the lead councillors for social services in Wales meet regularly through the WLGA. She pledged to use these opportunities to raise the possibility of changing the language around assessments so the language is less off-putting to some, and to discuss how to improve timelines involved in assessments including the role that could be played by early initial assessments before the full carer's needs assessment takes place.

Topic 3: Carer Assessments and Complaints

Question to Michelle: What can the Ombudsman's office do to ensure that complaints are dealt with in a timely manner and ensure that carers received the support needed to take forward complaints?

Michelle explained that the Ombudsman's office can intervene with local authorities when complaints have been ongoing for too long. She explained that the Ombudsman publish data annually on public sector complaints, including on timeliness, helping to hold local authorities and health boards to account. Michelle highlighted the investigation into carer experiences of complaints and assessments that her office has been consulting on.

Topic 4: Llais – Health and Social Care Citizen Voice Body

Question to Jemma: How will the new Citizen Voice Body ensure that the public is aware of its role and how will its performance be scrutinised?

Jemma highlighted that Llais will operate a national advocacy complaints process to assist people looking to complain about a service. Local authorities will have a legal duty to promote Llais. She explained that Llais will have external quality processes and aims to be transparent with documents, publishing reports on their engagement with public services and responses they receive.

Topic 5: Carers from protected characteristic groups

Question to Alwyn: How can Local Authorities and Welsh Government ensure that their communications and information services are effectively reaching out to all carers?

Alwyn said information needs to be targeted in different ways, with non-digital and peer-to-peer approaches having merit for different groups. Alwyn committed to raising the development of peer-to-peer carer support with the Welsh Government and to look into it in his own county.

Question to Norma: Should there be mandatory training for all staff to increase knowledge and understanding of carer needs within these communities?

Norma responded that the WLGA could be used to encourage local authorities to deliver more Carer Awareness training to their staff. Norma suggested it may be possible to include an understanding of carers within already mandatory equalities training.

Topic 6: Carer Impact Assessment

Question to Jemma: It has been suggested that when statutory organisations are undertaking new initiatives or making decisions on services there could be a Carer Impact Assessment along the lines of an Equality Impact assessment. What do you think of this?

Jemma says Community Health Councils currently promote the importance of Equality Impact Assessments, the Socio-economic Duty and similar equality reviews when local health boards are changing services. Llais will continue to do this and believes in the importance of reviewing the impact of changes on key groups.

Plenary conclusion

Question to the Panel: What commitment will you make to make life better for carers?

Michelle: A greater focus on carers this year through their own-initiative investigation into complaints and Assessments.

Alwyn: The Ministerial Advisory Group on carers is recruiting Carer Representative. Look into co-produced approaches to peer-to-peer support.

Norma: Speak to WLGA about the assessment name change and consider how to improve timelines and initial assessments quickly before formal assessments. Carer Awareness training in Cardiff Council.

Jemma: Actively seek out issues, map voices across Wales and identify gaps.

Helen: Continue to push for carers as a protected characteristic and campaign for carers.

Acknowledgements

Carers Wales would like to pay tribute to and acknowledge the contributions of everybody who was involved in the Wales Carers Summit 2023. We believe events like this are vital, to ensure that elected politicians and decision makers in key services are reminded of the challenges that unpaid carers in Wales face every day.

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