

Improving access to support for unpaid carers: Engagement Findings

November 2025



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1. Engagement Summary

The following engagement summary offers an overview of the engagement programme design, delivery, and key findings.

Background

1. The Health and Social Care Committee is conducting an inquiry into improving access to support for unpaid carers.
2. The Committee wished to hear directly from unpaid carers. The Citizen Engagement Team facilitated interviews and focus groups with people with this lived experience.
3. This report summarises the perspectives shared by this target audience.

Objectives

4. The objective of the engagement sessions was to deepen the Committee's understanding of the issues faced by unpaid carers when accessing support.
5. Views were gathered to ensure that those with diverse and relevant lived experience contributed to the evidence-gathering programme, with specific focus on the following inquiry terms of reference:
 - the main barriers faced by unpaid carers in accessing the support they need; including any specific challenges for carers based on factors such as age, ethnicity or where they live;
 - the current availability of respite care across Wales, including levels of variation across regions.

Methodology

6. The research was qualitative and data was collected via one-to-one interviews and focus groups. Sessions were designed to ensure they suited an audience who are generally time poor. To enable this, participants were able to



select their preference on taking part in-person, in a location that suited them, or online.

7. The engagement comprised of the following:

- 6 online interviews
- 3 in-person interviews
- 1 telephone interview
- 3 in-person focus groups
- 1 online focus group

8. Notes of each session are available to Members upon request.

9. At engagement sessions, a semi-structured question approach was used. Questions used to structure the sessions were shared with participants before the sessions. These can be found in Annex 2 (interview questions) and 3 (focus group questions).

10. Interviews were conducted to ensure people could talk openly about their experiences in private, encouraging honesty and removing bias. Furthermore, focus groups were structured around the preliminary data gathering from interviews. This supported consolidating key themes and supported participants to move to solution-based conversations at the focus group sessions. Suggested solutions from unpaid carers can be found within the body of the report and in Annex 1.

11. In addition to the main engagement findings, one participant generously contributed a poem reflecting their lived experience. This creative account helps to illustrate key themes and provides valuable context to the challenges and realities faced by unpaid carers in Wales. This can be found in Annex 4.

Participants

12. Unpaid carers were approached via gatekeeper organisation / charity working with unpaid carers. A list of organisations that supported this work can be found in Annex 5.

13. To foster diversity within the sample, a short “expression of interest” survey was set up for anyone wishing to take part, this was available online or over the phone. The survey identified eligibility and requirements for those interested in taking part.

14. Of the 10 participants selected for interviews, the sample contained the following characteristics:

- 4 are from Mid and West Wales (Carmarthen West and South Pembrokeshire, Ceredigion, and Llanelli), 1 is from North Wales (Arfon), 2 are from South Wales Central (Cardiff North and Vale of Glamorgan), 2 are from South Wales West (Bridgend and Ogmore) and 1 is from South Wales East (Islwyn).
- 6 identified as older unpaid carers (+50)
- 3 said they are caring for a partner, 3 said they are caring for their disabled child, 2 said they are caring for their disabled child who is an adult, 2 said they are caring for older relatives, in these cases, a parent.
- 1 carer is a multiple carer, for two adults
- 7 are solo carers, caring for someone else on their own, 3 shared caring responsibilities with a partner
- 5 said they had received respite care in the last two years, 5 said they had not
- Participant identified themselves as conducting anywhere from 90 – 168 hours of unpaid care a week to another person.

Ethical considerations

15. All methods used in this engagement programme adhered to the standards set out in the Market Research Society Code of Conduct and complied with relevant data protection and safeguarding legislation to ensure the ethical treatment and privacy of all participants.

16. The approach to this audience was mindful of the ethical considerations involved in engaging unpaid carers. Sensitivity was conducted to preserve emotional wellbeing and support. Participant-led strategies encouraged the opportunity for participation and inclusiveness.

Summary of the Key Findings

"Care for the unpaid carer is non-existent... as long as you aren't too much trouble, you won't get too much help."- quote from an interview participant

Term of Reference 1: Barriers to Support

Theme 1: Limited awareness of available support for unpaid carers

17. Many unpaid carers were unaware of the support and entitlements available to them. Most hadn't received a Carers Assessment, with some not knowing what it was - despite experiencing stress, loneliness, and exhaustion. Time for self-care was rare, as their own wellbeing was often deprioritised.

Theme 2: One-size-fits-all approaches undermine effective support for diverse carers

18. Support was often described as generic and unresponsive to individual needs. Whether solo, disabled, or working carers, many felt services failed to reflect their needs. Support for carers and those they care for was described as inextricably linked, therefore when care services don't join up, it creates more work and stress for both.

Theme 3: Negative public and professional perception, poor financial support and lack of a voice for carers

"Get rid of the 'unpaid' part of being a carer."

19. Carers felt undervalued, exacerbated by the public's misunderstanding of Carer's Allowance, which they said was insufficient and undignified. Many weren't recognised in healthcare settings, missing early support opportunities.

Theme 4: Inaccessibility of carers assessments and support

20. Awareness of Carers Assessments was low. Some carers had never been offered one, while others were turned away when they asked. Those who had assessments often described them as superficial "tick-box" exercises. A reactive

approach from social care meant some carers only received help after reaching crisis point.

Theme 5: Breakdown of trust in support and difficulty getting a true break

21. Respite experiences were mixed, with some reporting neglect or worsened health outcomes for the person they care for. One carer only accessed respite to undergo surgery. Many carers delayed their own health needs due to lack of cover and the assumption they'd always be available. Even during respite, carers struggled to relax, worrying about unmet needs.

Theme 6: Challenges within systems designed to help

22. Carers with hearing loss, learning disabilities, or limited English faced barriers accessing primary care. Forms required to access support were described as overwhelming.

Term of Reference 2: Availability of Respite Care

23. Across all five Senedd regions, carers consistently said: "There is nothing."

24. Suitable venues for those with complex needs were rare. While some had good access, most issues stemmed from underfunding and stretched services.

25. Respite was seen as a postcode lottery, with regional disparities and a lack of emergency care.

26. A shortage of Personal Assistants (PAs) meant even eligible carers could not access respite.

Thank you to everyone who contributed to the programme of engagement, particularly the unpaid carers who made time to be involved.

2. Engagement Findings

Term of Reference 1: this section outlines the main perceived **barriers to support** identified by unpaid carers.

27. At the end of the themes below, we present solutions suggested by participants during the engagement sessions. All solutions can be found in Annex 1.

“There have been more negatives than positives when trying to access support as an unpaid carer.”

Theme 1: Limited awareness of available support for unpaid carers

28. Many unpaid carers demonstrated being unaware of the support systems and entitlements available to them.

29. Some put this down to it being an audience that are extremely time poor, a lack of signposting, or even not initially identifying as an unpaid carer themselves or by health professionals.

“When you’re in, or leaving the hospital, someone should flag you’ve become an unpaid carer.”

30. Most of the unpaid carers within this study had not had a Carer’s Assessment and a number of them were not even aware of what a Carer’s Assessment was, despite sharing feelings of stress, loneliness, exhaustion and being overwhelmed;

“The amount of people who don’t know that they need a carers assessment is incredible. People just don’t know it’s there.” – Participant who has supported others as a volunteer to access respite

"I feel lost a lot of the time, that's my base feeling, I just feel totally lost...I don't really have a wider support system, so everything we get is what is given, which is not a lot."

"I feel like I'm in the middle of an ocean and I can't get out."- Participant describing the overwhelming nature of constant caregiving.

31. A lack of time was expressed by most, demonstrating that there was little time to think about themselves or their wellbeing after they had completed their caregiving role:

"There's so much to think about. You have to manage everything. You have to manage your job, you home life, you have to think of your other children...everywhere they're supposed to be, what day is it today, and what appointment is it?"

32. One participant expressed how they had not received any formal training, while being responsible for complex medical care,

"Nobody teaches you how to administer morphine... I'm literally piecing it all together from ChatGPT."

Solutions

- Carer Advocates: Appoint named contacts to guide carers through available services and options.
- Basic Medical Training: Equip carers with essential skills like first aid and medication management to boost confidence.

Theme 2: One-size-fits-all approaches undermine effective support for diverse carers

33. The approach to support was described as not responsive to carers' specific needs, even when carers do know where to find it.

“Help isn’t there...when you get there, the help isn’t responsive to your needs. It’s not individualised.”

“Unpaid carers are so different.”

34. Multiple carers explained that if they were offered respite, it would have to come at a time where both people they care for could be left with another carer. They did not feel adequately recognised and this meant any support that was offered often was not viable.

“If you are a multiple carer then things are so much harder.”

35. Solo carers described feeling emotionally isolated and unsupported highlighting, the inaccessibility of carer-focused events due to lack of alternative care:

“If you can’t leave the one you care for then you can’t go on these trips – it’s a catch 22 situation.”

“We want that community...but who is going to have our kids? It’s not the same online. We want that support group.”

36. Support groups were described as often being scheduled in ways that unintentionally exclude working unpaid carers.

“The groups set up generally offer activities that suit people who aren’t working.”

37. Support for carers and those they care for are inextricably linked. Therefore, when services do not work in a joined-up way, it impacts them both.

38. For example, transportation services for children with disabilities were highlighted as a critical issue in the North Wales focus group, with reports of unreliable taxi services, inappropriate groupings of children, and safety risks.

39. Some carers have had to personally accompany their children on trips due to mistrust in the provided services. These logistical challenges further limit access to community activities and respite opportunities for the carer.

“Transport is a huge problem. Every three years they put it out to tender and they take the cheapest option... it is causing a lot of problems for families.”

40. Participants gave a number of other examples of where there was a lack of joined-up services across health, education, and transport. Explaining that because they do not communicate effectively it creates extra work for carers.

“None of the services really speak to each other... this lack of communication makes more work for unpaid carers.”

“As a carer, it really impacts on your time when you are constantly having to chase up this rubbish.”

Solutions

- Carer Buddy System: Foster peer support networks to reduce isolation and share experiences.
- Flexible Respite Options: Provide real breaks, like day trips or overnight stays - to support carer wellbeing.
- Amplify Carer Voices: Ensure carers can shape local services through regular feedback opportunities.

Theme 3: Negative public and professional perception, poor financial support and lack of a voice for carers

“Get rid of the “unpaid” part of being a carer. Recognise that the services that the unpaid carer provide is invaluable to the individual sufferer, the local authority and national government. And as such, that we deserve to be remunerated...We [unpaid carers] offer the best possible service to our family, with the love and kindness that they deserve.”

41. Participants felt there was a lack of public compassion and understanding for unpaid carers, partly due to the misconception that receiving Carer's Allowance equates to being paid. They emphasised that the allowance is insufficient to live on and does not reflect the significant value of the care they provide, which would otherwise place a far greater financial burden on society.

"I think there's a stigma with being a carer. Carer's allowance is like a pittance. It's not a living wage."

"I don't think the general public understand what a large proportion of the population are carers and the millions it saves the government in care fees and everything else."

42. Several unpaid carers said they were not routinely identified or acknowledged in healthcare environments, which could prevent early access to support.

"I have never been asked in a health setting 'are you their unpaid carer?'" – Participant who has been caring for more than three years with frequent interaction within healthcare settings

43. Some felt the amount they received via Carer's Allowance was undignified given the return the government gained from unpaid carers:

"I wonder if these people that make the rules, could they live on £151 per week?"

"It's degrading the amount carers are expected to live on."

44. In relation to the fact that many unpaid carers access suitable respite or support from charitable organisations, one participant said, *"You shouldn't have to rely on charity funding to have a good quality of life."*

45. Most participants said more financial support would make the biggest difference to them.

46. They suggested that unpaid carers could get a tax break rather than additional payment if this made it easier to administer.

"If you were to pay a family member, like myself, to do the care that I do, then you [Welsh Government] would not need to pay for a second rate service from social care...that would also be better value for money."

47. Carers felt their input and feedback to services was selectively valued. One participant said when they described dealing with social services over many years for the adult child:

"Social services want your opinion when it suits and then other times they don't want to acknowledge you as a carer."

48. One participant felt decisions about the respite they could access were made without a true understanding of their lived experience, and that the process lacked transparency and empathy.

"You would think that given they (social care services) don't have to do this (provide respite care) for 51 weeks of the year, one week isn't too much to ask."

Solutions

- Public Awareness Campaigns: Promote understanding of unpaid carers' roles and the challenges they face.
- Tax Relief Over Benefits: Offer tax breaks instead of benefits to reduce stigma and provide meaningful support.

Theme 4: Inaccessibility of Carer's Assessments and support

49. Understanding of the purpose and eligibility of a Carer's Assessment was relatively low with the majority of participants in both interviews and focus groups.

50. One participant who had been caring for over three years for their autistic daughter did not even know what it was.

- 51.** Many said they had not been offered an assessment or they had been turned away when they had asked for support or access to an assessment.
- 52.** A number of them explained that they had received one but it lacked meaningfulness, or it had been conducted but they have never received a copy.
- 53.** There was confusion and inconsistency around those eligible for a Carer's Assessment, particularly for carers not living with the person they care for.
- 54.** Some participants felt judged by social workers based on appearances, rather than being supported for their emotional and mental strain.

"They [social workers] didn't look at us, and the fact I was bursting into tears in front her."

- 55.** One participant was told they were not eligible for support due to being financially stable:

"Because I'm well paid and middle class, I was told it 'wasn't for me.'"

- 56.** Participants who had an assessment questioned how meaningful they were, describing them as "a tick-box" exercise.
- 57.** There was a perception from some participants of a reactive approach by social care to assessments, as well as other support for unpaid carers;

"A lot of social workers don't do them. Lots of people don't know they're entitled to them. Social workers aren't proactive at telling people they're entitled to them."

- 58.** There were further examples of where there is a lack of proactiveness, including not forward planning for respite where the carer knew they would require it months in advance.

"It was left to me to sort out... four care sessions a day would not have been enough to keep my wife safe, I approached the social worker 4-5 months ago with a request to go away and I think allowing my wife to go into 24 hour care could have been explored more."

59. There were even examples of people going past crisis point due to a lack of intervention of support at earlier stages:

“It has to be preventative because we're constantly firefighting and even then we're not putting out those fires. We've still got parents and kids with disabilities that are jumping off cliffs or doing horrendous things because their needs are not being met because the services aren't there to help them when they're drowning.”

Solutions

- Clear Eligibility Criteria: Make assessment processes transparent and easy to understand for all carers.
- Early Intervention by Social Services: Shift from reactive responses to proactive outreach and support.

Theme 5: Breakdown of trust in support and difficulty getting a true break

60. Please note that more detailed information about respite is covered in the following section separate to these themes.

61. Five participants indicated that they had received respite care in the last two years. Of these, three indicated this respite had been overnight. Two described their first occasion as poor; in one case, this included reports of neglect and abuse by the temporary carer.

62. Following a five-day paid respite arrangement for one carer, it was reported their husband was found “in bed, soaking wet and the house smelled of urine.” In the days after the carer returned from this respite, they found blisters on her husband’s back as a result of rough handling.

63. Another participant described how a negative respite experience led to a decline in the health of the person they care for, compounding their existing concerns of their health.

"She lost 6kg in four days in the care home."

64. In one case, a carer had only accessed respite to have a medical procedure and recover.

"In the 13 years of my wife having this disease (Motor Neuron Disease), I have had two weeks of respite care. I took these breaks to enable me to get surgery and focus on my health."

65. It appeared many of the unpaid carers put their own health needs after the person that they care for. Some carers explained this is because of a lack of time to focus upon health issues, limited availability to attend appointments for themselves compounded by a lack of cover for their caring role. Also, some carers felt it is assumed they will care for their family regardless and therefore naturally their health becomes secondary.

"No body ever asks how we are; you are the first person who has asked that."

66. One participant missed cataract surgery because no care was provided to cover her role.

"I was given a date for eye surgery, but I couldn't make that appointment because the local authority wouldn't offer care to cover my role as an unpaid carer...You could be dead by the time the care is in place."

67. Participants generally had concerns about getting a true break when away from the person they care for as they are preoccupied with the thought the person they care for is not getting their needs met:

"You struggle with the uncertainty of knowing the phone could go any minute...Even with respite in place, it's still really stressful. You never can relax."

"I've refused my son go somewhere before because I haven't trusted the person taking him....We're just expected to accept anyone who comes to our door and vulnerably pass him over. It's scary."

Solutions

- Annual Carer Health Checks: Help carers prioritise their own wellbeing, which often takes a back seat.
- Health & Social Care Communication: Trigger a Carer's Assessment from social care when a carer seeks medical treatment within health care.
- Respite in Care Plans: Include dedicated respite support in care plans, especially for carers aged 50+ and / or disabled carers.

Theme 6: Challenges within systems designed to help

68. The most significant barrier for one unpaid carer is the lack of accessible communication methods in healthcare settings, especially for carers and those they care for who have hearing loss.

"One day a nurse turned up out of the blue and started asking loads and loads of questions and there was no interpretation or anything, although that should have been on mum's file to say she needed communication. So I ended up being mum's interpreter."

69. In addition, the lack of accessible communication channels impacted on them being able to access health care for the person they care for, and themselves:

"So I have to find somebody to phone the GP for me, and you're only allowed to phone at a certain time in the morning and then all those slots are gone, tough, you have to phone the next day. So if we manage to get through for mum, you don't bother for yourself. Why would you try? You just don't do it."

70. Participants in one focus group discussed the lack of access to easy read or plain English documentation from official channels and how this was a barrier to them as unpaid carers with learning difficulties. It would cause anxiety or stress when confronted with written material which they could not easily access.

71. One participant required a Bengali translator at all appointments with their child, which was offered by the health service. However, in reality, the service was described as intermittent as often translators would turn up late or not at all.

72. The forms participants are asked to complete to access support were described as overwhelming and a hinderance.

73. One participant was required to complete a 50-page form and conduct interviews to gain a Personal Assistant (PA), which they described as daunting.

"I would like someone to talk through the processes and work with me on this [form to apply for a personal assistant]."

74. Another explained the process of applying for Disability Living Allowance (DLA), which was described as emotionally draining and dehumanising.

"The DLA form takes six weeks to complete – the devil wrote those forms. You have to write a worst case scenario and it's like you are throwing your child under the bus."

Solutions

- Accessible Services: Set guidance for primary care services to offer improved accessible access to health services, especially GPs
- Accessible Information: Provide clear, easy-read materials to support all carers, not just those with learning needs.
- Rethinking forms and assessments: design forms or the approach to assessment in a way that offers more dignity and support those in need
- Create a passport system communicated across health and social care which avoids carers having to repeat their circumstances.

Term of Reference 2: this section outlines the perceived availability of respite care to unpaid carers.

75. We spoke to people from all five Senedd regions, and when asked about the current availability of respite care in their experience as unpaid carers, the response was consistently that there is none:

“None... simple answer. There’s nothing there for you.”

76. Participants identified very few suitable venues available to meet an individual’s medical needs, particularly for those with high or complex needs;

“When my wife was in the care home, she couldn’t get the wheelchair into the bathroom. She had to be taken on a sling, down two sets of corridors, into a sluice room, amongst the wee bottles and everything else, to go to the toilet. Once she was left on the toilet for 40 minutes, because they told her “when you are ready, pull the cord.” And she couldn’t physically do it, and she couldn’t communicate to them that she couldn’t do it.”

77. Some reported good access to respite opportunities and generally it was recognised that a lot of the issues around availability stem from a lack of funding:

“The respite set up is really good and attentive to all ages. But it’s so underfunded by our local authority.”

78. Often carers reported they must accept substandard services because there are no alternatives.

79. Some carers reported being denied emergency respite even when at crisis point.

“When you reach out to the services and say ‘I’m having a mental breakdown’ and they say ‘there is nothing we can do’ and you’re stuck there thinking ‘I’m drowning and you’re telling me there’s nothing available’. It needs to change.”

“We had an awful summer...I phoned begging for emergency respite and was just told “no”.”

80. Those in rural locations generally identified it could be because of their rurality that they cannot get carers to cover while they take an opportunity for a break.

81. Those participants who were multiple carers, caring for more than one person, were also restricted with what was offered given they may get a chance to take a break from one person they care for but that just gave them the breathing space to focus on the other individual they were caring for; therefore the time was not spent focusing on themselves.

“When she’s in school it is not a break, it’s a chance for me to catch up.” – Participant caring for a disabled child and partner.

82. Those with a disability explained that even after the offer of respite it may still be unviable. For example, one participant received information from the social worker, none of the options were practical or accessible, such as a coffee morning in the town centre that lacked accessible parking.

83. Respite care was described as a postcode lottery, with significant regional disparities:

“If you were living to the east of Swansea, then I suspect that there would be more options available. If you are living to the west then getting, not just respite care, but any care and support is virtually impossible.”

84. There are geographical challenges for some, with one participant content to travel a 2.5 hour round trip to access respite care. They explained it was a good setting, their son was happy to go there and they would tend to stay for a long weekend. However, this might not be as feasible for some given the travel time.

85. For some, there were transport barriers, either from being a non-driver, only having public transport available to them, being from a rural location or due to a disability. For example, as a non-driver with sight loss, accessing respite locations is difficult for one participant who said:

“Respite is not local to me...There’s no time to travel either because I’m a non-driver.”

86. Participants talked about a lack of emergency care as well as respite care. Where participants were or will need to have surgery or focus on their health needs, social care was not forthcoming with support or planning for managing their caring responsibilities during recovery. Also participants referenced there is no logical system in place for short-notice cover if they become ill unexpectedly.

“I need respite to just be ill.”

87. There was a general perception that when disabled children were at school, the parent “takes a break”. However, participants highlighted that school does not provide adequate respite, since cover during school holidays is often lacking.

88. What cover was available was not conducive to a full-time working parent. Summer activities that are suitable for disabled children are limited and quickly booked up, leaving working parents at a disadvantage.

“We are penalised for working – it’s grossly unfair.” – Sub-urban Vale of Glamorgan based participant

“We will be offered a day or maybe two days a week for those four weeks... there is no respite care available over the other school holidays.” – Rural Ceredigion based participant

89. There was also a mention of a lack of after-school care, especially for disabled teenagers, which limits working carers’ flexibility.

90. Carers explained that there was a shortage of trained and reliable Personal Assistants (PAs).

“We were signposted to potential PAs in a list given to us by the social worker. However the list was very out of date.”

“Something needs to change within the sector, it can’t just be given to minimum wage workers. It’s got to be a focused training programme

and upskilling. It can be an amazing job. It's seen as a really low-value job."

91. The lack of PA staff was reported across Wales, and the reality of this is that where many people are eligible for respite they could not access it due to recruitment and / or retention issues.

"We have been given personal assistant hours but we can't use them. Finding people is hard."

92. Carers themselves felt the roles were not attractive to the workforce as they were poorly paid and short hours with a high level of responsibility.

"Trying to find a PA who can drive is like hens' teeth!" – Participant in a rural location

93. Where participants had received meaningful respite, generally, this was through charities providing opportunities for breaks and reflection.

94. Carers appreciated the support they found among other carers. They valued the opportunity to share experiences and support each other. Carers want to build community but face barriers due to a lack of accessible venues and / or lack of respite or in-house carers while they go and take respite. Online support was not seen as a sufficient substitute for in-person connection.

95. One carer described their respite as non-traditional, explaining that they cannot leave the person they care for overnight, so they tend to access respite through day trips and they see funding pots as a route to respite. They described accessing:

- Pottery sessions funded by a charity (Amser Fund):

"Pottery sessions were the best thing for me – it really was time out for me."

- Attending musicals, bouldering/climbing trips, and applying for garden centre vouchers: These were used creatively to create moments of rest, such as buying a garden bench to relax.

- Support from local authority schemes: The participant praised a specific scheme by Cardiff Council that helped them learn how to navigate respite opportunities and even assist others:

"I learnt a lot from the staff on this scheme about respite – I helped a friend who wouldn't have done it without my help... a lot of people don't find out about grants because they are not in the know."

- Monthly support groups run by Adferiad (a charity focused on carers of people with mental health diagnoses):

"That charity is amazing, and with more funding they could do so much more."

96. There was a shared view that charities providing support are good at getting it right – but finding them and taking the step to reach out and make contact is sometimes daunting to unpaid carers.

"I have been very lucky with the respite support we've had. And as a result of that, our family unit has benefited. So from a mental health perspective, I can say that we have felt supported."

Solutions

- Increase funding and bespoke facilities: Improve current services to increase opportunities with suitable spaces for all.
- Professionalise Care Work: Invest in training, fair pay, and career paths to attract and retain skilled care workers.
- Community Hubs: Develop inclusive spaces for people with complex needs and their families to connect, learn, and recharge.
- Leverage Local Resources: Partner with universities and schools for training, volunteering, and holiday support.

Annex 1: Solutions from unpaid carers

In this section, we present ideas suggested by participants during the engagement sessions.

97. These ideas represent diverse perspectives aimed at improving the current situation. The following solutions were proposed by participants during discussions as potential pathways for positive change and are shared here to inspire further dialogue and consideration.

Theme 1: Limited awareness of available support for unpaid carers

- Carer Advocates: Appoint named contacts to guide carers through available services and options.
- Basic Medical Training: Equip carers with essential skills like first aid and medication management to boost confidence.

Theme 2: One-size-fits-all approaches undermine effective support for diverse carers

- Carer Buddy System: Foster peer support networks to reduce isolation and share experiences.
- Flexible Respite Options: Provide real breaks, like day trips or overnight stays - to support carer wellbeing.
- Amplify Carer Voices: Ensure carers can shape local services through regular feedback opportunities.

Theme 3: Negative public and professional perception, poor financial support and lack of a voice for carers

- Public Awareness Campaigns: Promote understanding of unpaid carers' roles and the challenges they face.

- Tax Relief Over Benefits: Offer tax breaks instead of benefits to reduce stigma and provide meaningful support.

Theme 4: Inaccessibility of carers assessments and support

- Clear Eligibility Criteria: Make assessment processes transparent and easy to understand for all carers.

- Early Intervention by Social Services: Shift from reactive responses to proactive outreach and support.

Theme 5: Breakdown of trust in support and difficulty getting a true break

- Annual Carer Health Checks: Help carers prioritise their own wellbeing, which often takes a back seat.

- Health & Social Care Communication: Trigger a Carer's Assessment from social care when a carer seeks medical treatment within health care.

- Respite in Care Plans: Include dedicated respite support in care plans, especially for carers aged 50+ and / or disabled carers.

Theme 6: Challenges within systems designed to help

- Accessible Services: Set guidance for primary care services to offer improved accessible access to health services, especially GPs.

- Accessible Information: Provide clear, easy-read materials to support all carers, not just those with learning needs.

- Rethinking forms and assessments: design forms or the approach to assessment in a way that offers more dignity and support those in need.

- Create a passport system communicated across health and social care which avoids carers having to repeat their circumstances.

Solutions in reference to availability of respite

- Increase funding and bespoke facilities: Improve current services to increase opportunities with suitable spaces for all.
- Professionalise Care Work: Invest in training, fair pay, and career paths to attract and retain skilled care workers.
- Community Hubs: Develop inclusive spaces for people with complex needs and their families to connect, learn, and recharge.
- Leverage Local Resources: Partner with universities and schools for training, volunteering, and holiday support.

Annex 2: Interview Questions

The following interview questions served as a flexible guide for the interviewer.

98. The interviews were participant-led, allowing for an organic conversation flow; questions were not presented in a specific order or exact wording but were used to facilitate discussion based on the participants' responses and needs.

Questions:

1. What are the positives and/or negatives you've experienced when trying to access support as an unpaid carer?
2. What are the main barriers faced by unpaid carers in accessing the support they need?
3. Have you faced any specific challenges in accessing support as an unpaid carer? (For example, related to your age, ethnicity or where you live)
4. What is the current availability of respite care in your experience as an unpaid carer?
5. How can unpaid carers be better supported?
6. Can you give examples of ways to improve access to support for unpaid carers?
7. What would make the biggest difference/improvement to your experience as an unpaid carer?

Annex 3: Focus Group Questions

The following questions served as a flexible guide for the interviewer at focus groups.

99. The sessions were participant-led, allowing for an organic conversation flow; questions were not presented in a specific order or exact wording but were used to facilitate discussion based on the participants' responses and needs

Questions:

1. Being an unpaid carer:

There will be a selection of pictures on the table. Choose from the pictures something that describes how you feel about being an unpaid carer. Tell the group

2. The Positives:

We know that caring can be incredibly demanding, but many carers have also shared positive moments. Here are a few examples...

- They find joy and fulfilment in caring for their loved ones at home.
- They've built strong friendships and a sense of community with other unpaid carers.
- They've had the opportunity to take a meaningful break from their caring responsibilities.
- They've received a Carers Assessment, where a social worker explores what support they might need.
- Charities have provided financial support, helping them purchase items that make it easier to take a break or improve their wellbeing.

Have you experienced these positives?

Do you have different positive experiences?

3. The Challenges:

Here are some common challenges unpaid carers have told us about. Do any of these feel familiar to you? Are there others you've experienced?

- Not being able to take a proper break, leading to exhaustion.
- A negative impact on their own health and wellbeing.
- Difficulty accessing a Carers Assessment.
- Feeling misunderstood or unsupported by their community.
- Receiving help that doesn't meet their specific needs.
- Struggling to find services due to lack of time and clear information.
- Support not being accessible for disabled people.

4. Solutions:

Some carers have suggested the following ideas to improve support:

- Raising public awareness of the vital role unpaid carers play in our communities.
- Ensuring all unpaid carers are offered a Carers Assessment.
- Providing annual health checks through their GP.
- Creating dedicated roles to help carers navigate services and complete forms more easily.
- Supporting employers to develop workplace policies for unpaid carers.

What do you think of these? Would they work for you?

Are there other ideas - big or small - that you think could make a real difference?

5. Thank you for taking part, before we go,

Is there anything else you'd like to share that could help improve access to support for unpaid carers?

Your experiences and ideas are invaluable - even small insights can lead to meaningful change.

Annex 4: Participant Input: Poem

100. In addition to the main engagement findings, one participant generously contributed a poem reflecting their lived experience. This creative account helps to illustrate key themes and provides valuable context to the challenges and realities faced by unpaid carers in Wales.

101. The participant cares for her husband full time at home. Her husband had a stroke in 2018 and, despite making some progress in recovery, remains totally dependent throughout the day and night, for all aspects of his life.

102. The participant described how he struggles with showing any empathy and with emotional regulation, a relatively common symptom after a stroke. This can result in her husband becoming very angry, despite the participant's constant support.

In the experience of the participant, as an unpaid carer she is:
the most lonely she has ever felt.
the most alone she has ever felt.
the most exhausted she has ever felt.
the most unhappy she has ever felt.

In no particular order:

I have lost trust.

If anyone ever asks how things are, I say, 'fine' and see the relief on people's faces.

I have lost count of the number of cups of coffee I make each day and never manage to drink.

The person who used to tell me he loves me, now treats me with disdain and never asks if I am alright. An occasional thank you would help!

I can go days without having a conversation with another person.

Life has become immeasurably complicated.

Life has to be taken a minute at a time.

No body hears when I cry. He hears but doesn't care.

I want to be able to go to bed and sleep.

This is not multitasking. It is being faced with layer upon layer upon layer of relentless demands.

This is not what we worked and planned for in retirement.

Dare I think ahead? The future seems a very bleak place.

But:

I have improved the quality of life of a person.

I have given a person the opportunity to defy all expectations.

I keep a person alive.

On my own.

Annex 5: Partner Organisations

103. Thank you to the following for their support in sourcing participants for the focus groups and interviews. A particular thanks to those that hosted focus groups (marked in bold):

- **Adferiad**
- Carers Outreach Service
- Carers Trust Wales
- Carers Wales
- CWVYS Council for Wales Voluntary Youth Service
- **Dal Dwylo**
- Family Fund
- **KidsCare4U**
- Older People's Commissioner
- **Pembrokeshire People First**