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Welsh Government

Consultation – summary of responses

Consultation on a Carers' National Plan for Wales

Date of issue: 23 March 2021

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.
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Introduction

The Social Services and Well-being (Wales) Act 2014, defines a carer as someone who provides unpaid care to an adult or disabled child.

1. The cared for person may be a family member or a friend, who due to illness, disability, a mental health problem or an addiction cannot cope without their support. A carer could be a husband caring for his wife, a parent caring for their child who has care and support needs or a child caring for their parent.
2. This consultation set out our proposed direction for a new strategy for unpaid carers. We want carers to continue their own lives alongside their caring role regardless of their age, circumstance or background and as stated in the consultation, we intend to use the finalised plan to set out how we will work with a range of partners to strengthen our existing national priorities for carers, to better reflect every aspect of a carer's life.
3. Having prepared the consultation document shortly before the Covid-19 pandemic, it was consequently revised to include feedback from carers, their representatives, local government, health boards and others.
4. The core theme running throughout the final plan is prevention and early intervention, with our vision for everyone in Wales to have longer, healthier and happier lives and remain active, independent and in their own homes for as long as possible. This is a whole-system approach to health and social care, focusing on keeping people well by anticipating health needs, preventing illness, and reducing the impacts of poor health. This approach has become more important in light of the impact of Covid-19 on individuals and communities in Wales.

Methodology

5. We have engaged with a wide range of stakeholders, including individual carers, to inform the development of our cross-government strategic plan and the refresh of our national priorities for carers. We worked closely with the Ministerial Advisory Group on Carers to draft the consultation document and engaged with carers of all ages via the Carers Engagement Group. Funded by Welsh Government and facilitated by Carers Trust Wales, this group ensures the voice of the carer is well placed to inform the work of the Ministerial Advisory Group on Carers and subsequent policy development and practice.
6. The launch of the consultation document was delayed due to the start of the global pandemic. As a consequence of this, several questions were added asking respondents to comment on the impact of the pandemic on their daily lives.
7. The consultation was published on the Welsh Government website at: Welsh Government website carers national plan. Information on how to respond was widely distributed and shared via social media and via e-mail. A young people's version of the consultation was produced by Children in Wales. An Easy Read version of the consultation was also produced.

Overview of responses

8. In total, 91 responses were received in a combination of either online responses submitted via the website, or email. A small number e-mailed a letter with specific points rather than using the form. None were received in paper copy. 2 replies were received in both English and Welsh.

9. 50 responses were from organisations and representative groups, whilst 41 were from individuals. Figure 1 provides a breakdown of the consultation respondents by type. 35 respondents wished to remain anonymous. For the full list of respondents see Annex 1.

10. Due to the pandemic and the necessary restrictions in place to protect health and prevent the spread of the Covid 19 virus, face to face consultation events across Wales could not be arranged, however, officials communicated with, and encouraged external stakeholders and networks to engage with, carers and others.

Figure 1 – consultation responses by type

NHS, local health boards and health organisations	8
Local government	7
Carer representative groups - including public and third sector organisations	4
Public sector including Commissioners, academics, education and training bodies	6
Third sector or community organisations	21
Representative / professional umbrella bodies	3
Individuals	41
Regional Partnership Boards	1

Summary of responses to specific questions

11. Several of the questions asked respondents to clearly indicate if they agreed or disagreed, with a proposed action or idea in the consultation. Other questions sought narrative information and evidence. Each section below provides a brief summary of the comments provided.

Question 1 - How has Covid-19 impacted on your life as a carer, or as an organisation supporting carers?

12. There were 78 responses to this question with many of the individual carers providing personal examples of how different issues, including problems accessing shopping slots and restrictions on movement during periods of lockdown. Others included examples of the care and support needs of those they are caring for, as well as their own experiences.

13. For the majority, the impact of the pandemic has been negative. Issues which affect many carers day to day have been exacerbated alongside new challenges. In many cases, individual carers are experiencing an increase in their caring hours and carrying out more or different caring tasks. The risk of catching Covid 19 and the potential effect on the person being cared for, or the carer, was an overarching concern.

14. Several individuals and organisations working with and / or representing carers, such as charities and local authorities, identified carers as taking on more caring responsibilities. Some individuals requested their care worker cease visits to their household because of the fear of infection and concerns about insufficient supplies of Personal Protective Equipment (PPE). However, a small number of responses commented that people being put on furlough by their employers led to them having the opportunity and time to care for someone.

15. Practical challenges for unpaid carers included lack of access to priority shopping slots online, adjusting to using the internet for the first time to order shopping or being unable to enter supermarkets alongside key workers at set hours, because they weren’t recognised by staff as a carer. However, of more concern to many was access to health and social care services, many of which had to move towards a predominantly online or telephone form of access, rather than face to face appointments. Problems accessing GP appointments for the person they care for, or themselves, were mentioned, as well as delays in obtaining dental treatment. However, not everyone had a negative experience, saying that NHS staff were kind and supportive.

16. Carers of individuals with specific health conditions and illnesses including dementia, a stroke, Motor Neurone Disease (MND), or those requiring palliative care, were mentioned as facing particularly severe caring pressures, with some carers providing the equivalent of nursing care.

17. Being unable to accompany and visit the person they care for when in hospital was identified as a major concern and cause of distress for individuals who are caring, as well as wider family and friends. This distress increased for carers who were bereaved as they felt they did not have time to grieve. This affected young carers and young adult carers, as well as adults. The responses highlighted the increased pressure experienced by carers and families of adults and children with learning disabilities who became increasingly frustrated because they could not leave the house, maintain normal routines or understand the reasons for lockdown.

18. A common theme in individual replies was a sense of increased isolation and loneliness, often because wider family contact and help, or formal support from paid care workers, was reduced or ceased completely. This, combined with a lack of access to respite, such as meeting with friends or use making use of day centres and local community groups, meant those with care needs and their carers, were unable to have a break. Closure of face to face support in the public sector, but also third sector negatively affected many. However, many service providers in both the public and third sectors adapted swiftly from the start of the pandemic and moved to offering opportunities for online forms of respite.

19. Both individual responses and those from organisations mentioned the problem of deteriorating mental health, with many carers experiencing anxiety, stress and depression, and potentially a deterioration in their own physical health. The inability of carers to access psychological support and mental health services, either for the person they care for, or their own mental health needs, was a problem identified in a large number of the replies. A small number of replies stated that individuals had been left feeling suicidal.

20. For other carers, including those who might not have contacted any services or support before, they were pro-actively seeking out information, advice and assistance. Several organisations including local authorities and local health boards, reported an increase in carers contacting them. These organisations and their partners, including commissioned service providers, adapted their provision swiftly, for example, by using keep in touch phone calls to carers; offering carers' support meetings online; providing 7 day a week support lines for carers and using volunteers to call individual carers just to chat.

21. Public sector bodies and stakeholder partnerships sought to ensure they maintained a clear flow of information to local communities, checking official government guidance and considering the impact of changes in legislation.

22. Local health boards and local authorities also took action to support their employees who have caring responsibilities by using social media and forming working groups to see how they could help their employees maintain a balance between work and caring, and therefore continue to deliver key public services.

23. Several responses from carers illustrated their frustration and confusion about using Direct Payments. Some of the comments included were: a lack of clear guidance for families and carers; long delays waiting for contact with social workers; being informed that their care packages were being reviewed but in a manner that wasn't perceived as being helpful for the person or their carer and being given contradictory information about how they could adapt use of their Direct Payments.

24. A large number of the responses raised significant concerns about an increase in the financial pressures being experienced by families and individuals with caring responsibilities. This included carers worrying about being able to pay bills. Spending has risen for many people on items such as food and heating, because of the increased time spent at home due to government-imposed restrictions on movement and the need to work from home where possible. This has increased levels of stress and anxiety for carers. It has particularly affected households already on low incomes, but many more households are now facing difficulties because of being furloughed by their employers, or made redundant.

25. Several responses highlighted that not all carers can claim Carers' Allowance. Where carers are eligible, they want the level of the Carers' Allowance payment increased. Others are struggling to get by on Universal Credit and organisations mentioned that too often, carers are not claiming the full range of benefits they are entitled to.

26. The different and increased costs facing carers have also been illustrated by the "digital divide". Replies from individual carers, statutory bodies and third sector organisations state that many carers are failing to access services and get the necessary help and support they need, because they do not possess a smartphone or laptop. Where they do have a device, they cannot afford suitable data packages. Others lack confidence in using IT and require training to help them get online.

27. Transport was identified as important for many - local community transport services adapted their services to carry out regular food shopping for those unable to leave home; deliver food parcels and work with local pharmacies to arrange prescription collections and deliveries.

Question 2. What do you think Welsh Government should prioritise to better support unpaid carers affected by Covid-19, both now and in the instance of further waves of infection?

28. There were 75 responses to this question. As with question 1, this question prompted a wide range of replies from all types of respondent, including individual carers. Key amongst the calls for prioritising support was a rapid re-opening of face to face support and services.

29. The importance of carers and their families having access to increased levels of financial help and support was clearly identified, particularly amongst the replies from individual carers. Suggested mechanisms for achieving this included increasing the level of the UK welfare benefit, Carers Allowance. However, other carers stated that they do not qualify for this allowance.

30. Older carers identified increased pressure because they were dependent on their pensions but faced increased costs for food and household bills, plus the care and support needs of the person they are caring for. It was suggested that other forms of financial support for eligible individuals, such as Personal Independence Payments (PIP) and Disability Living Allowance (DLA) should be increased. Making it easier for carers to claim benefits was called for, because many do not have the time or energy to complete lots of paperwork, which can frequently be confusing.

31. The need for government and others to raise the profile of, and highlight the importance of unpaid carers and their role, was mentioned by many. Individual carers expressed the view that whilst the NHS staff and paid care workers had been recognised and thanked for their role in the pandemic, unpaid carers were forgotten.

32. Helping carers to understand their rights and what help and support they can get, at the same time as ensuring communities and organisations understand the needs of carers, was identified as most important. Some respondents were concerned that services had defaulted to focusing on the needs of those cared for, and were therefore excluding the needs of carers. Others called for a national form of identification for carers, and for government and organisations to ensure individuals are not excluded from important updates and communications or guidance because of an over-reliance on websites.

33. Whilst reference was made to the importance of the Covid 19 vaccination and calls for all carers to be amongst the priority groups, few comments were made on this topic. More views were provided about the importance of carers being able to access forms of respite. Mental pressures were increasing because individuals and families have been unable to leave the house except for exercise, or take short breaks away from home. This is particularly acute during the highest level of national lockdown – Level 4.

34. Ongoing supply and access to free Personal Protective Equipment (PPE) for carers was mentioned several times, as well as the need for more and better access to psychological support and mental health services. Calls were also made to prioritise and fund digital devices, free broadband and phone lines. Young carers need support with their learning now, but also additional support on return to school or college. They should also be aware of their right to a carers’ needs assessment.

35. Organisations stated the importance of tackling and prioritising system issues and planning for recovery by ensuring front line social services employees have appropriate training to recognise carers, and ensure they have a voice. Several respondents called for carers to be treated as equal to professional care staff.

36. Financial investment in both public and third sector services was raised, with comments including the need to invest in the paid social care sector to help alleviate pressure on carers, and to invest in infrastructure and services for older people and children. The importance of strategic leadership and planning across stakeholders was stated by a small number of respondents.

Protected characteristics

37. Section 3 of the consultation document asked questions about “Carers with protected characteristics under the Equality Act 2010”, the Public Sector Equality Duty (PSED) contained within the Equality Act 2010 and Welsh specific equality duties, which require us to identify what we can do to remove barriers and improve participation and outcomes for people who are under-represented or who suffer disproportionate disadvantage.

Question 3. What are the key areas of inequality experienced by carers with protected characteristics that should be addressed by the new Strategy for unpaid carers?

38. There were 68 responses to this question - a view that was expressed and reinforced with examples from individual and organisations, was a need to recognise that carers can have their own physical and mental health support needs and therefore support needs to be tailored to reflect this. Support should be adaptable to meet the diverse needs of all carers, reflect the community in which they live and be sensitive to cultural needs and age. There should not be a one size fits all approach. Overall there was a call for a greater effort across all health, social care and other services used by carers, to identify, understand and ensure the needs of carers with protected characteristics are met.

39. Covid-19 has highlighted pre-existing difficulties but has also generated new and additional difficulties. For example, digital exclusion can be related to language, disability or age. Wider awareness raising and training for staff interacting with carers with protected characteristics was seen as beneficial.

40. Other barriers identified for Black, Asian and Minority Ethnic communities included health and social care organisations failing to recognise and cater for specific cultural, dietary and language needs in hospital, care homes and in people’s own homes and information and support being unavailable in different languages. Health, social care and third sector organisations may also presume that families from a specific cultural background will automatically care for their family members and that they are not in need of support. Often this is not the case.

41. Partnership working was seen as key to help resolve these issues by working with organisations who can engage more effectively with ethnic minority communities, as well as more targeted communications for carers from ethnic minority communities. To do this effectively, different cultural circumstances and attitudes or beliefs should be directly addressed, rather than using a generic communication approach targeting all carers.

42. Services can fail to be culturally aware of differing needs relating to an individual’s faith and belief. Carers may not be widely recognised in some ethnic minority or faith communities - there can be cultural barriers preventing some communities from accessing services in general.

43. For disabled carers, their own disabilities can be overlooked or the care they are providing not always recognised, therefore support is needed for carers who are themselves disabled, have learning difficulties or Autism Spectrum Conditions, for example.

44. Several responses submitted information about the inequalities very often experienced by women and girls who experience barriers to accessing services, or a lack of the right services in the right places to support them. There are links between caring and a lack of opportunities for employment, with many women facing poverty or living on a low income. This is a common problem globally because societies often fail to value caring roles. Women are more likely to be carers which affects their earning potential and their confidence levels. Comments included there being too little support that is specifically tailored for male or female carers.

45. Examples were provided of the considerable mental and physical strains experienced by individuals caring for adults or children with physical disabilities or learning difficulties. Carers with disabilities or health problems may need physical adaptations as well as access to information and advice. There were also calls for access to more respite, and a need on the part of social care organisations and others to consider the health needs of the carer, not just the individual with care and support needs. The fears of parent carers, who may be ageing and looking after an adult son or daughter with a learning disability, often related to what will happen if and when they can no longer care for their family member.

46. Those in the LGBTQ+ community were identified as experiencing inequality due to fears of stigma or discrimination within health and social care, often feeling that services are unsuitable for their needs and therefore they may not access them. Carers told us that services often make assumptions about the relationship of a carer to the person they care for, which can cause unnecessary distress or anxiety. They may feel more comfortable staying in their home due to this fear, inevitably increasing pressure on a carer to provide more care for longer.

47. For LGBTQ+ individuals with care needs, and carers, one particular aspect of inequality related to their experiences of end of life care. It was highlighted that partners often feel isolated or unsupported during the bereavement process because of their sexuality. Their relationships may not be open and known about meaning grief may not be recognised or acknowledged in a supportive way. As a result carers of the LGBTQ+ community may be missing out on the physical, emotional or financial aid that they are eligible for.

48. Evidence provided of the experiences of transgender carers indicate services can be unfamiliar with treating trans patients and that staff can ask inappropriate questions or display a lack of confidence when supporting a trans person. Training to prepare and equip staff to work with carers who present in a way that is different from them, or outside their frame of reference, was suggested as one way of addressing this.

49. Carers with sensory loss were identified as needing additional support to ensure they are included in conversations and decisions regarding the person they care for. For deaf individuals and those with hearing loss, access to BSL interpretation at medical appointments (for the carer and not just the patient) would provide real benefits, with poor and too few services catering for people who use British Sign Language. They also need medical and other information in accessible formats. One example offered was a need to raise awareness of dementia in the deaf community. For those with sensory loss living in rural communities and where English is not their first language, a mixture of IT and helpline support could assist them in accessing appropriate resources online, to engage, talk and connect with others.

50. Older people were identified as being less likely to recognise and act upon symptoms of common mental health problems for a number of reasons including practical barriers, the language of mental health, GP assumptions about preferences, and acceptance of low mood as normal aspects of ageing. Action was called for to explain mental health support, make it more relevant and understandable to older carers. This could be achieved by working with trusted community organisations to ensure the right support is accessible. The importance of helping those who care for people with dementia was also referenced, because many carers, including older carers, experience mental health issues, such as depression.

51. For young people and young carers, replies mentioned different barriers. Many young carers and young adult carers will require additional support or information due to their gender, disability, religion, race or sexual orientation. More generally barriers mentioned by respondents included difficulty communicating with professionals because they are young and their caring role is not recognised. Many young carers therefore need help to identify as carers and seek timely support. Others included a lack of general and professional training for employees in health and other sectors to raise awareness of young carers and the issues they face. Services for young carers may set a minimum age in order to access local authority or commissioned services. Also young carers are not routinely involved in consultations or decision making that involves the person they care for. They can also disproportionately experience additional barriers, inequalities and poorer wellbeing outcomes due to their age.

52. Carers come from all walks of life, across all demographics. Many carers will have one or more protected characteristic. It was therefore argued that carers should be a group with a protected characteristic in their own right. There were also calls for carers' needs assessments to be used to help tackle inequality. Social care practitioners undertaking carers' needs assessments should have training about the Equality Act 2010, and how it relates to the Social Services and Well-being (Wales) Act 2014. The carers' assessment paperwork should also include a mechanism for monitoring and ensuring that any equality aspects have been properly considered in the process.

Young Carers and Young Adult Carers

Question 4 - What are the key challenges experienced by you as a young carer or young adult carer; or as an organisation supporting young carers?

53. There were 48 responses to this question. The majority of replies highlighted a range of challenges, many of them influenced by or worsening because of the pandemic, including:

- being unable to leave home and see their friends or wider family networks;
- managing an increase in the number of hours they are caring;
- problems accessing services including online shopping slots;
- their needs as a young carer failing to be adequately considered when collecting medication for those they care for;
- little or no access to forms of respite especially face to face support;
- closure of social activities such as clubs and community groups so they are unable to pursue interests and hobbies; and
- trying to balance online learning with their caring responsibilities with schools and colleges closed.

54. A key theme across all responses to this question was the large rise in anxiety and stress experienced by the young carers, including fears about taking the virus home to vulnerable family members. These concerns were often combined with other

factors such as a lack of breaks from the caring role, being unable to see friends and worries about school exams. Many of these have led to a deterioration in young carers' own mental health and wellbeing.

55. A critical issue affecting many young carers and reported in a number of responses, was insufficient access to digital devices. Young carers need help to access online learning and support from their teachers.

56. Many of the respondents referenced long held concerns and barriers experienced by young carers, for example, a lack of sufficient age appropriate support for young carers, with services too often focused on adults. Others highlighted concerns that schools fail to provide sufficient help and advice for young adult carers who need support as they move from school into further or higher education, or are looking for employment. Most however stated that an overall lack of recognition by schools of the issues affecting young carers remains a major barrier to improving support for them.

Challenges for organisations

57. Local authorities which either directly provide services for young carers, or via third sector commissioned providers, highlighted their difficulties in supporting young carers. The pandemic has prevented them from offering face to face services, provide group work, or offer trips out and fun activities. Supporting young carers who are experiencing increased mental health problems has also presented challenges for organisations when a young carer cannot access face to face support. Their needs for support can become more complex as different factors interact, such as increased anxiety or depression.

58. Fear and stigma around being identified as a family with care needs is often mentioned in relation to young carers who do not want school to know that they have caring responsibilities. Other services have been unable to access schools and talk with young carers leading to concerns that they will have more difficulty in re-engaging the young carer in the future. A multi –agency approach to supporting the young carer and their family, with different services in contact with the family sharing information and considering how different problems interact, was recommended by one respondent.

59. Third sector organisations commented that a major challenge for their delivery of young carers' services is a lack of strategic and long term investment by government or statutory bodies, including local authorities. In the views of some, this has led to fragmented service provision, uncertainty and an inability to plan for the longer term.

Question 5. What additional support would help? (For young and young adult carers)

60. There were 47 responses to this question although around half of the replies were general points about issues affecting all ages of carer. However, several different themes clearly emerged focusing on the issues identified in previous responses to questions 1 – 4. These were the importance of educational help and support; addressing health and mental health and well-being needs; improving understanding and knowledge of carers' rights; plus the importance of respite and having a break from their caring role.

61. Improved support in schools and education settings was referenced by most with a need to ensure education professionals, schools and colleges help young carers

and young adult carers at key transition points, particularly at age 16 and age 18. It was stated that school staff and other people should not have low expectations of what a young carer can achieve. Young carers should have career ambitions and not be caught in a trap of low expectations, lower attainment and feel their only choice is to continue in a caring role after school or college. Reference was also made to the provision of targeted careers information, advice and guidance, which could include helping young carers recognise the skills they acquire from their caring role.

62. It was suggested that the recommendations in Estyn's Thematic report published in May 2019, "Provision for young carers in secondary schools, further education colleges and pupil referral units across Wales", should be considered and addressed by all schools and colleges. https://www.estyn.gov.wales/system/files/2020-07/Young%2520carers%2520thematic%2520report%2520-%2520en.pdf There was also a call for a specific legal duty to be placed on education providers to identify young carers and young adult carers.

63. A number of other suggestions to improve support were made and included the importance of undertaking formal carers' needs assessments for young carers, with more training to local authority staff to carry these out, as well as ensuring they are carried out in an age appropriate way.

64. The introduction and use of a national Young Carers ID card was supported, particularly if a card offered benefits such as free transport and access to leisure facilities or discounts in shops. Others mentioned increased financial support for young carers and young adult carers in the form of grants. The Scottish Government's young carer grant for 16-18 year olds was given as an example.

65. The critical importance of ensuring more young carers can access respite and have a break from caring was highlighted, plus the importance of respite being timely and appropriate with a choice of different forms of respite.

Question 6. How has Covid-19 impacted on your daily life? (To young / young adult carers)

66. There were 55 responses to this question. Many of the responses included comments which had been raised in previous replies to question 1 and question 4, and have therefore been included in the summaries for those questions.

67. Sibling carers were mentioned in more than one response as experiencing an increase in physical harm because of their sibling displaying behavioural issues. Several commented on an increase in sibling carers' time spent caring and missing support from family and friends. These carers may also experience a lack of understanding from teachers and other people. This can make a young carers' experience of caring for a family member with learning disabilities, physical disabilities, or a mixture of complex health and support needs, more difficult.

Three National Priorities for Carers

Priority 1 – Identifying and recognising unpaid carers - all carers deserve to be recognised and supported to continue to care.

Question 7 - Do you agree with the suggested actions?

68. Of the 60 responses to this question with a majority of replies agreeing with the suggested actions stated in the consultation document.

69. Replies included a need for more effective communications with and for carers, but also amongst services in all sectors, to ensure unpaid carers are identified early so they can receive appropriate help and support. Carers need to know which services are available for them, and that they can access good quality information and advice.

70. A small number of third sector bodies commented that whilst they agree with the actions identified, action needs to be delivered with relevant partners and in more collaborative ways. There should also be suitable means to hold people or organisations accountable for what they do. Activity also needs to be supported with suitable funding.

71. The terminology, language, purpose and outcomes identified when an unpaid carer is having a carers' needs assessment was raised as being very important. The use of different words or phrases by local authority social care staff was seen to cause confusion amongst carers. A softer, less formal approach when carrying out an assessment could be easier for a carer to have that important conversation about their support needs. Simple and easy to understand language was therefore needed.

72. Across a range of public and third sector replies they stated confusion was generated amongst carers because of national media and government communications using the term carer, when referring to a paid care worker. The weekly National Clap for Carers during 2020 was seen by some as a major cause of confusion. Some disagreed with the term carer being used by other groups, because they were not unpaid carers.

73. There was considerable support and calls for the Welsh Government to deliver a national communications campaign to raise awareness amongst individuals that they are carers, that carers' have rights, and to inform them of the options available for unpaid carers.

74. To aid the discussions and actions at a national, regional and local level about identification of unpaid carers, there were recommendations that carers should be considered by government and others as partners. Carers should be members of working groups, planning forums and advisory boards, to ensure their voice is heard. The carers engaged in this way should also reflect the diversity of carers themselves, who can have a wide range of caring responsibilities and circumstances.

75. A particular concern was raised that some parent carers might not be recognised as a carer because they are the parent of the child with care and support needs. The use of personal carer stories were seen as way of improving training for public sector and other staff, as well as the creation of parent carer forums in all areas of Wales.

76. Whilst most comments focused on raising awareness of carers' rights and communications, a small number of respondents commented on the use of data. The importance of establishing the number of carers in Wales was mentioned with references to the 2021 National Census. Some called for more "metrics", ways of measuring or assessing activity, to be added to the existing Social Services Performance and Improvement Framework. These should include counting the numbers of unpaid carers who refuse a carers' needs assessment.

77. More generally it was recommended that awareness raising work is undertaken with organisations and businesses across the Welsh economy, not just those working in the social care sector. This would help ensure everyone has an understanding of carers and build this into their ways of working. This could be recognising the support employers can provide to their own employees with caring responsibilities, to making sure products and services better meet the needs of unpaid carers.

Question 8. Is there anything more public bodies and their partners should do to identify and recognise carers?

78. 68 replied to this question and a wide range of suggestions were made by all types of respondent. A large number of the suggestions echoed replies for question 7, such as improved support for employed carers.

79. Individual carers focused most comments on practical things which could directly improve their situation. Others commented on what they saw as the role of public and statutory bodies, including local authorities and the NHS. The interaction and partnership work across health settings and the third sector was consistently raised as being important.

80. Health settings featured in many replies with some respondents recommending the creation of a central register or list of unpaid carers which could be accessed by different agencies. Also, ensuring all NHS Trusts and organisations have clear organisational policies to help both their own staff who are carers, as well as unpaid carers in the population, was suggested.

81. Other ways of improving recognition and support were to promote IT based forms such as the use of the national DEWIS website. It was recommended that the information in this is kept up to date, also NHS 111 services could align their information with such resources.

82. Other respondents took examples from other strategic initiatives or looked at good practice in their own communities. One suggestion was for a “wrap around the carer” model which would help ensure communication between different agencies and help avoid duplication. There was also a suggestion, that because of the frequent link between caring and low incomes, the carers’ needs assessment should include a right to be referred for a benefits check.

Question 9. Should the existing wording of Priority One be changed? If yes, how?

83. Of the 55 responses to this question a majority wanted the wording of Priority One to be adjusted but not completely revised.

84. For many, the use of the word ‘deserve’ was troubling with some going so far as to say it was inappropriate. Suggestions of a stronger alternative word that could be used in its place included ‘should’ or ‘must’.

85. A number of responses mentioned that they would like to see the wording of this priority expanded to recognise that not all carers want to continue providing care. Comments referred to an assumption in the way the priority is currently worded that all carers want to continue to care, but that this wasn’t always the case. With this in mind, a number of alternative suggestions were provided that would expand the scope of this priority to emphasise that carers should have a choice about whether to provide care or not, as well as the kinds of care they are able or willing to carry out.

86. Others said that the wording of this priority should be strengthened with reference to carers’ rights under the Social Services and Well-being (Wales) Act 2014, and that valuing and respecting carers needed to be better reflected in the wording.

87. For those who did not think the wording needed to be changed, there was a general acceptance that the wording was understandable to most people, clear, succinct and sufficiently broad to encompass all ages and characteristics.

Priority two - Supporting life alongside caring - all carers must have reasonable breaks from their caring role to enable them to maintain their capacity to care and have a life beyond caring.

Question 10. Do you agree with the suggested actions above?

88. Of the 52 responses to this question the majority said they agree with the suggestions made in the consultation document.

89. Many responses expressed the view that the word respite can be viewed negatively by carers. Suggestions for other words that could be used instead of respite were short break, sitting service, replacement care, and alternative care. The traditional term “respite” was seen as failing to cover the wide range of respite opportunities available. This can include provision within local communities. However, some were concerned that ending use of the term respite in some settings might leave the forms of respite provided, open to interpretation by local authorities and this would have a negative impact on carers. Any change in terminology would also require a clear understanding amongst carers, providers and more widely. A change in emphasis was suggested, so that respite is seen as a positive and preventative activity, not just something offered at a point of crisis for the carer.

90. Several replies stated that carers usually regard it as their responsibility to look after their loved one, which can lead to a reluctance to take up respite opportunities. In conditions like dementia, those with dementia frequently become anxious after being away from their carer or experiencing a change in routine, making the carer reluctant to use respite. Whilst it might help the carer to have a break away, the respite provision has a disrupting and negative effect on the person being cared for.

91. It was commented on that respite is not always the responsibility of local authority social care, but that other services and sectors should be helped to recognise where they can provide the form of break that a carer needs. Considerable support was expressed for carers and families to take breaks together. The different ways of providing short breaks, and the “Respitality” scheme operating in Scotland, were mentioned as examples for Welsh organisations to develop more innovative approaches to design and delivery of respite for carers, as well as those they care for.

92. Some carers were identified as needing regular, longer breaks not just as a necessity for their own wellbeing, but a chance to develop their resilience and continue in their caring role. Ensuring a one size fits all approach is avoided was seen as important, with carers and their families at the heart of decisions. Local authorities should therefore be expected to work with carers and families to identify suitable solutions and not expect people to simply accept existing services if they are unsuitable for them.

93. Whilst most focus is on adult carers, respite and short breaks were identified as being a key part of the care and support young carers require. There was a call for assessments and support plans to ensure respite and short breaks are included in these, that everyone is clear who is responsible for delivery and funding of the respite. Most

importantly that the young carer or young adult carer is fully involved in decisions about their needs and respite.

94. Direct Payments (DP) were addressed by several replies, with support for more creative uses of these to ensure they have an impact on improving the resilience and wellbeing of carers. There were a number of comments from individual carers that local authorities do not understand Direct Payments and more innovative use of DPs should be encouraged. However, there should be clarity between the users of DPs, with a comment made that these are awarded as the result of a needs assessment for a cared for person, not the carer.

Question 11. Is there anything more we should do to support life alongside caring?

95. There were 57 people and organisations that replied to this question offering a number of different ideas and proposals that could help all carers have their own life alongside their caring responsibilities.

96. Suggestions about respite and breaks from caring included learning for personal interest and leisure purposes, with education providers offering carers discounts on their course fees. A carers' gym card could provide discounts at national fitness chains or council owned leisure facilities or enable carers to purchase a bicycle at a reduced price, to help with fitness. Having free access to leisure facilities and local discounts, free public transport, and information about local community groups offering classes e.g. yoga, were examples where carers could gain a positive benefit for their own health and wellbeing, as well as giving them a break.

97. Several suggested encouraging more carers to take up and use Direct Payments would bring benefits. Making Direct Payments more flexible in terms of what they can be used for, reducing bureaucracy, plus clearer guidance for local authorities around their use could mean local authorities and others are able to provide more flexible and creative solutions.

98. The idea of flexible, sessions of 'respite' was seen as helpful, with carers able to quickly access breaks from their caring role and do so more regularly. This could help many carers attend ad hoc appointments, or have an impromptu break quickly arranged at the point in time when they need it.

99. A large number of organisations raised the issue of carers' needs assessments with surveys of carers showing many carers had not had a Carer's assessment, or review of their assessment within the last 12-months. It was recognised that not all carers need or want a statutory carers' needs assessment, but all carers should know how to access the support they need as their circumstances change.

100. Other points raised in replies to this question, which were seen to help were: legislation to enable carers to have time off to attend medical appointments; and improving legal rights for unpaid carers in the workplace.

Question 12. How can we improve the provision of psychological support to carers?

101. There were 63 responses to this question and it generated a large number of detailed replies, with a range of suggestions for how psychological support could be improved. A first step was improving how carers are identified.

102. Improvements to preventative support were considered essential to avoid carers reaching a crisis point with their own mental health and wellbeing. Suggested options

for improvement included regular check-ins or welfare calls, mindfulness sessions, and regular meetings of peer support groups.

103. Increased funding to both the primary health care and third sectors was suggested as a way to meet increasing demand for mental health and wellbeing services. There were calls for more investment and sustainable support packages for local options, for example local carer centres which often provide counselling and befriending services.

104. One key improvement mentioned often in the replies was to ensure that the services on offer were more varied and tailored to the individual needs and circumstances of the carer. This was especially important for young carers, parent carers and those caring for people with specific conditions such as dementia or mental health issues. Suggestions for how this could be achieved included ensuring that psychological support needs were identified during the carers' needs assessments, and more focus on agreeing with the carer how their needs can be met.

105. Finally, some believed that there was an opportunity to learn from the alternative ways of delivering support that local services had adopted in response to the pandemic, such as online opportunities for counselling. Exploring new good practice examples could lead to improvements in the delivery of psychological services now and in the future.

Question 13. What types of respite do you normally use or deliver? How has Covid-19 impacted on your respite services?

106. There were 52 responses to this question and a key theme amongst the replies from individual carers was an inability to access respite, or having their support withdrawn as a result of Covid. The majority of answers all indicated that the pandemic is having a significant detrimental effect on all ages of carer, with face to face support and activities halted because of the need to protect everyone's health, and being in various levels of local restrictions or national lockdown.

107. In more normal circumstances a range of different types of respite and breaks are used by individuals. These range from using day centres to befriending services, local community activity groups, classes such as art or taking part in sport. Participation in local activities and events in village halls and community centres were seen as a positive way to take a break from caring. For parent carers of children with life limiting conditions, or adults receiving end of life care, the hospice network was mentioned as providing important day care for individuals, as well as offering their carers some respite.

108. In some local authority or health board areas provision of an unpaid carers' fund has enabled carers to do different things to improve their wellbeing for example, weekend trips away, or carers have used these funds to take up hobbies and new interests, for example gardening or painting, which provide forms of respite.

109. Respite for those with care and support needs was also being accessed via care homes, although overnight stays in care homes have been very limited during the pandemic, unless there is a crisis situation for the person or their carer. Other offers from organisations including the third sector were short day time visits to people's homes. Some carers had made more requests for day time respite for those they care for, as people sought to avoid hospital admission.

Question 14. Should the existing wording of Priority Two be changed? If yes, how?

110. Of the 45 responses to this question most of the responses received indicated a preference for the wording of Priority Two to be changed. In many cases the replies agreed with the spirit of this priority but felt that it was too vague as currently worded. It was felt that clearer definitions of the terms used were needed. This could lead to improved understanding of the purpose, and therefore implementation of the priority. For example lots of replies commented on the term ‘reasonable breaks’ and suggested that should be defined more explicitly to avoid differences in interpretation.

111. Similarly, some replies questioned the term ‘beyond caring’ and raised potential confusion if this was interpreted as being a life after the caring role had ended. A life ‘alongside caring’ was suggested as an alternative. However, others suggested that a life after caring should be seen as part of the caring journey.

112. Related to this was the theme of quality of life and wellbeing. There were many comments pointing out that a life beyond or alongside caring should also be fulfilling and promote wellbeing, and that the wording of this priority should reflect that aspiration.

113. A small number of responses pointed out that the word ‘must’ may not be appropriate as it didn’t take into account that all carers might not accept or want a break. It was suggested that this be expanded to ‘must be offered’.

114. For those who did not think the wording needed to be changed, there was a general acceptance that the wording was clear, succinct and sufficiently broad to encompass all ages and characteristics.

Priority three - Providing information, advice and assistance - it is important that all carers receive the right information and advice when needed and in an appropriate format

Question 15. Do you agree with the suggested actions?

115. Of the 48 responses to this question a majority agreed with the suggested actions. There is continuing support for Priority 3 and the important of ensuring all carers can access the right information, advice and assistance (IAA) at the right time.

116. A number of replies called for better awareness raising amongst health, social care and other professionals, so that they can inform and advise carers and explain what these IAA services can offer. This training should also take place in third sector organisations, government and other organisations to ensure all carers are aware of their legal rights and the support available if needed.

117. Practical suggestions included ensuring that IAA provided by GP’s, or in health and care settings, are improved. Whilst there may be local variations in services the information provided by statutory bodies should be consistent throughout Wales. Carers should not feel as if there is a ‘postcode lottery’.

118. One point raised by a small number of public sector organisations was the need to improve wider understanding amongst the public and organisations, of the role of IAA services in supporting carers, as well as the legal duties on local authorities under the Social Services and Well-being Wales Act 2014 relating to IAA. They commented that many carers will not require formal support services, or a carers’ needs assessment, nor do carers need to have such an assessment to access and receive help from IAA provision. This means there will be many carers receiving support from local

authorities, third sector organisations, health services and others, who do not require and will not have a carers' needs assessment.

119. A small number of respondents referenced access to advocacy services, commenting that it is important in many situations both for older carers and young carers and can help carers access information, help those who find it hard to access services, or find it difficult to talk about their problems.

Question 16. Is there anything more we should do to improve Information, Advice and Assistance (IAA) services in Wales?

120. There were 52 responses to this question and a number repeated their replies to previous questions, for example, calls to improve use of the DEWIS database, improve its content and ensure the site is linked to other online platforms.

121. For many carers there can be confusion as to where to start if they want to find out more and get help with their caring responsibilities. It was raised that there is no Wales wide universal IAA service, therefore the names used for such services vary by local authority. Some may not be referred to as an IAA service and some authorities do not use a Single Point of Access such as a telephone call centre. Once a carer has made contact however, the importance of staff listening to the carer was highlighted and such services should do more than sign post carers to organisations, they should also make referrals of carers to relevant services and support.

122. Assumptions that IAA is only provided by local authority social services should be addressed as the recommendation in one reply. This was seen as important when organisations who are signposting carers to the local authority may be better placed to give information to the carer. If the need does not relate to social care, and for many carers they do not need formal social services support, other bodies may be able to directly provide suitable information and advice. The range of IAA covered should also be more comprehensive, for example, advice on what happens of a carer becomes ill or dies, a topic which for many people is upsetting and worrying to consider and discuss. Access to more user friendly Advanced Care Planning information was therefore suggested.

123. There was a call for more third sector support working in partnership alongside the public sector IAA teams, and there should be induction training for employees about advocacy services so that frontline workers recognise when an advocate could support someone.

124. Given the importance of IAA services for carers, a small number of replies expressly referenced the need to ensure all information is available in formats and languages that people can understand and use. This includes duties on public organisations, including health bodies, to meet different legislative requirements such as compliance with Welsh language standards.

Question 17. What have we learnt from Covid-19 and the need to get accessible information to carers in a short space of time?

125. There were 53 responses to this question. The replies provided, particularly from organisations, indicate the pressures and need for fresh thinking and swift reactions to changing circumstances generated by the pandemic. Examples were provided such as the important of getting information to carers and the public quickly, which helped carers' access community support to get food parcels, assistance with shopping and collecting prescriptions.

126. Using different ways to communicate was highlighted as being of great importance, but also taking into account those people who are digitally excluded and need support to get online, or helped via traditional methods such as by post and by telephone. There was a suggestion that local authorities having a supply of IT equipment to loan to carers and people with care needs, would be helpful.

127. For too many carers however, there was confusion caused by national press and TV coverage, with many carers feeling alone and left to manage on their own, given the high profile focus on NHS services. For Welsh language speakers and speakers whose first language is not English, there was dissatisfaction that information was apparently being provided only in English and updated via television or social media, not using more local and targeted methods.

128. The rapid roll out of new telephone support services, or expansion of existing helplines by public and third sector bodies did make a positive impact on carers, and their ability to obtain good quality and relevant information, advice and help. Third sector organisations reviewed official guidance from Welsh Government, Public Health Wales and others, turning it into shorter and easily understood information for carers and service users. In this way they ensured the most essential information was shared.

129. More critical comments made by about communications during the pandemic included information from Welsh Government to local authorities taking too long which caused delays for other organisations in providing information to carers. Information needs to be in a language that is understandable and in places which are accessible, and for carers from ethnic minority communities and their families they were having to wait for information to be translated.

130. Two final points summarised here are calls for all communications to take into account of and made available quickly to young carers and young adult carers, because they also need fast access to rapidly changing information and official guidance.

Question 18. Do you have examples of good practice during the pandemic that could be replicated or inform development of services?

131. There were 55 responses to this question. Amongst replies from individual carers there was a mixture of views, but a number of them briefly described how a social worker, care workers, health staff, GPs or others had provided positive support and help. For the majority, their positive experience arose from someone making the effort to contact the carer, ask how they were, did they need help, for example, with shopping, or being there on the phone and listening. Feedback from those working with young carers found that regular telephone calls made a difference, enabling the carer to feel connected and for professionals to respond and address any issues quickly.

132. For many carers, being unable to access more usual forms of day to day respite and breaks from caring has had a significant negative effect on their mental health and wellbeing. Amongst the public sector organisation replies there were examples illustrating how their employees had provided different online opportunities such as cooking classes. There were benefits for carers where staff had been given the opportunity to plan and organise activity which could help boost a carer’s mental health and wellbeing.

133. Public sector organisations reported establishing closer working relationships with a wide range of different organisations, including their commissioned carers’ service providers, has brought benefits during the pandemic for both parties in delivering services for carers.

134. A key benefit observed in large organisations was ensuring their employees had more and better knowledge of the range of support available for carers. In one local health board region they ensured both paper copy and online versions of the health board’s carer contacts directory of information was circulated. Another local health board set up systems for carers to obtain PPE and to access Covid tests. They also arranged for their Volunteer Services and Dietician teams to put together and provide food parcels for carers living in poverty.

135. A number of organisations referenced their provision of welfare packs to carers and young carers which included updated carers handbooks and guides, links for accurate Covid 19 advice and tips on maintaining mental wellbeing. In one example, a local authority created a database of all shops and food banks operating alternative services and food deliveries within a city. Co-ordination with voluntary sector led response services and third sector partner was highlighted as an example of improving support for carers, by linking statutory services with organisations delivering different forms of support in the community.

Question 19. Should the existing wording of priority three be changed? If yes, how?

136. Of the 42 responses to this question most of the responses received indicated a preference for the wording of Priority Three to be changed, with a number of replies proposing that ‘receive’ be replaced with ‘access to’, to reflect that carers should have a choice about whether to obtain information or not. Others suggested that there should be more emphasis on ‘all’ carers, and also that ‘it is important’ should be changed to ‘it is vital’.

137. For those who thought the existing wording should be expanded suggestions included adding ‘the right help at the right time’ or ‘in a timely manner’, to emphasise the need to ensure that carers receive the information they need when they need it.

138. For some, ensuring that the information and advice was accessible, both in format and the ways in which it was issued, clear and proportionate were points that should be specifically reflected in the wording of this priority.

139. Other replies suggested updating the wording to highlight the importance of this priority in empowering carers to access their rights under the Social Services and Well-being (Wales) Act. Linked to this were calls for stronger references to advocacy and coproduction.

140. For those who did not think the wording needed to be changed, there was a general acceptance that the wording was appropriate, clear, succinct and understandable.

Priority four - Supporting carers in education and the workplace: employers and educational / training settings should be supported to adapt their policies and practices, enabling carers to work and learn alongside their caring role

Question 20. Do you agree with the suggested wording above?

141. Of the 41 responses to this question, a majority agreed with the suggestion for the addition of a new fourth priority, and the actions already suggested in the consultation document. Given the similarity of the responses to questions 20 and 21 (which received 51 replies) they have been combined into a single summary below.

142. A new priority which emphasises the links between education, training and employment, and the benefits of this impacting on carers of all ages, was seen as having the potential to help deliver positive benefits for both carers and employers.

Employed carers

143. Amongst the replies a number of them linked the proposed new priority with wider social and economic concerns about gender equality, low income and poverty. Too often carers give up paid employment in order to provide care. During the pandemic many people have had the opportunity to provide more care, but some found it stressful to explain to their employer that they needed time off, for example to shield alongside the person they care for. Others have faced difficulties balancing working from home with their caring responsibilities.

144. There were several comments that the new priority aligns with the fair work principles set by the Fair Work Commission for Wales, with commitments to encourage inclusive working environments. This included a call for the Welsh Government to establish a fair work forum for employed carers, and to encourage public, private and third sector employers to work with their employees who have caring responsibilities, or with workplace carer representatives to produce organisational carer friendly policies.

145. The impact of a new priority and action to improve rights in the workplace for carers, such as the proposed UK government legislation to introduce a new legal right to unpaid carers' leave, did raise a concern that in the current pandemic some employers such as small, independent businesses, might struggle to implement changes if there were cost implications.

146. Replies also focused on the needs of carers for improved and appropriate support in the workplace. Carers are regularly having to take unpaid leave or use their annual leave allocation in order to take the person they care for to hospital or other appointments. However, some replies did suggest employers are willing to give a small amount of additional unpaid leave to carers, but this means a loss of income for the employee. It was suggested employers look at holiday leave entitlements of their employees, and allow these to be split up and taken as hours rather than whole days. This was seen as more flexible and helpful.

147. Improving awareness of the needs and issues affecting carers amongst employers in all sectors, as well as providing them with information and advice on how to be more carer friendly was described. The needs of carers who are self-employed and require accessible information should not be forgotten however. The existing Employers for Carers Wales scheme was mentioned but in the respondent's view, membership is too costly, particularly for smaller organisations. An alternative mechanism for calculating charges for employers should be considered. Others however see this scheme as playing an important role in driving forward awareness raising amongst employers, giving them the support they need to be more supportive of their own employees.

148. The ability to claim Carers Allowance was raised as an issue for many carers because of the eligibility criteria. Carers cannot receive Carers Allowance if they are on a course of full-time education, or even if a course part-time but attendance is required for 21 hours or more each week. This not only affects young adult carers but adults who wish to return to education. Exploring how this welfare benefit could align with the ability to train part-time to improve employment prospects was suggested, which could also be beneficial for small organisations. These could be encouraged to put in place carer friendly policies in their workplace, which would enable their employees to learn new skills or improving their existing skills.

149. Other actions which were suggested and which were seen as having the potential to improve the situation for employed carers were:

- Encouraging employers to train their managerial staff in carer awareness;
- the Welsh Government encouraging Wales based employers to introduce their own policies with entitlements for employees to take paid carers’ leave;
- not to adopt a ‘one size fits all approach’ for solutions in the workplace;
- awareness-raising work with private businesses, which may not understand the business case for retaining carers amongst their workforce;
- providing support for carers returning to paid employment having been out of the workforce in order to provide care, with many requiring help in building confidence, refreshing their skills, and recognising transferable skills;
- recognise that education and employment are important in keeping carers well and giving them an identity outside of their role as a carer;
- provision of more affordable and flexible provision which can support carers to remain in employment and balance their caring responsibilities;
- Welsh Government funds to enable carers who wish to retrain or re-skill alongside or after their caring role has finished;
- carers’ needs assessments taking into account the carer’s wishes whether to remain in employment or not, and have opportunities for education, training and leisure;
- a Welsh Government policy that businesses accessing government funds to expand their business or create new start-ups, should be required to implement carer friendly policies and monitor equality in their workplace to ensure carers are not disadvantaged or discriminated against.

Young Carers and Young Adult Carers

150. Key transition points in a young carer and young adult carer’s life were mentioned, for example, moving into post 16 education. Processes need to be in place to enable the smooth delivery of support during the young carer’s transition into becoming a young adult carer, whether they remain in education or are seeking employment. Young adult carers may struggle when looking for, and gaining employment, therefore responses flagged the importance of information and support. This needs to be improved, particularly when young carers are considering their options after school and may feel these are limited by their caring role. Support should also be improved for those wishing to continue to higher education so they can maintain their caring role whilst studying.

151. Local authorities are seen to play a key role in encouraging schools to identify and support young carers and young adult carers across Wales. There is too much inconsistency, with some schools and education settings taking more action to help young carers, than others. Identification of a lead employee with responsibility for young carers was seen as ensuring the profile of the young carer agenda within schools. Also support from a network of Young Carers’ development workers to ensure school leads have access to information and training resources.

152. Whilst great emphasis was placed on the importance of the school role in supporting young carers, with school teachers and other school staff able to deliver positive support and interventions, there remains a risk that a young carer will not achieve their

potential. A whole family approach was recommended, with more support for families to engage with services and access carers' needs assessments. A "team around the carer" approach was suggested to ensure professionals working with the young carer can appropriately share information and the young carer is supported holistically.

153. Other recommendations in the replies to this question were: to embed carer awareness as part of the national curriculum; and encourage schools, colleges, young carers' services, public sector and third sector organisations to work together and adopt the Investors in Carers scheme to support young carers

154. The importance of enabling all carers to access and use services through their first language was referenced. Support for young carers should and needs to be available through the medium of Welsh. Many young people receiving Welsh-medium education should have a reasonable expectation that support and resources would be available to them through the medium of Welsh, regardless of their location.

Question 21. Is there anything more we and others should do to support carers of all ages in education and employment? Do you have examples of good practice?

155. There were 51 responses to this question and within these were calls for this aspect of the new carers' plan, and a new fourth priority, to align with social and economic Covid recovery plans. Recommendations around education extended beyond the school setting to cover all ages of carer, including employed carers, who wish to progress their careers or undertake higher education.

156. For young carers good practice examples focused on the use and recommended expansion of existing carer recognition and accreditation schemes, with schools working towards achieving different levels of accreditation and demonstrating to others evidence of improving support. Whilst work is frequently undertaken with secondary school age children, there was a recommendation that more is done to support young carers in primary schools.

157. Apart from school focused schemes, other public sector organisations illustrated their work in partnership with third sector carers' organisations to develop existing support mechanisms for carers, for example, by participating in carer friendly accreditation schemes. These also extend to businesses but an emphasis was placed on ensuring employers can participate at low, or no cost in such schemes. A small number of public sector bodies referenced the benefits to their staff of introducing a Carers' Passport, the ability for carers to apply for "carers' leave", and resilience and wellbeing training.

158. Individuals and carers' organisations offered examples where employers are already seeking to improve support via reasonable adjustments, for example, to daily working hours, permitting time off for the carer to attend appointments, sick leave and temporarily reduced working hours.

159. Enabling employed carers to access different forms of education, learning and training was mentioned, but also for carers seeking employment, or to generally improve their skills. The Carers UK "Learning for Living" accredited online learning programme was mentioned as a starting point.

160. Comments from the education sector called for alignment with other Welsh Government policies, with a call for the national carers' plan to detail how government will work with and support higher education providers. Carers should benefit from the ability to transfer credits and have recognition of prior learning, if they need to interrupt their studies and return to them at a later date, or possibly on a part-time basis. A

national offer of distance learning was suggested as offering benefits to student carers to help them balance their studies with their caring responsibilities. Post-16 education and training was also flagged. This was seen as potentially offering wider benefits beyond learning new skills and knowledge. It can also build confidence, resilience, and personal wellbeing.

161. When considering the legislation around support for carers there were calls for a new duty on education providers, for all schools to identify the young carers on “roll” and schools to adopt recommendations from Estyn to engage with Investors in Carers and other carer accreditation schemes. The needs of young carers should continue to be considered alongside those of other vulnerable learners.

162. Other comments included funding for one to one support for childcare and increasing direct payments for parent carers to be able to take up employment or training. Another key means of enabling carers to remain in employment or take up work was improving flexibility of provision and support for the person being cared for. Having more flexible support could help carers think about and engage with employment or education, where previously they may have seen it as impossible.

Question 22. How can we better support carers who are struggling financially?

163. There were 65 responses to this question and it generated a number of themes where respondents felt action by government, the NHS, social care, local authorities and more, could improve the financial situation of many carers.

164. There was seen to be a pressing need for longer term issues and barriers to be considered and addressed. This would see a multi-agency approach to supporting carers and their families, as well as discussions between the Welsh Government and UK central government about welfare benefits and allowances.

165. UK Government welfare benefits and allowances were mentioned repeatedly, with particular focus on Carers Allowance. Changing the eligibility criteria and enabling more people to claim this allowance was called for, as well as increasing the amount of money it pays per week to at least to the same level as Employment and Support Allowance. Where flexibility had been introduced to the qualifying criteria because of the pandemic, there were calls to keep this. The impact of the cared for person dying and the ending of payment of Carers Allowance after 8 weeks was seen as too short a time period for a carer to grieve, adjust and find a new job. It was argued that the ability to claim should be extended up to six months. For younger carers support for their circumstances could be improved by allowing those in education for more than 16 hours per week to claim. There was also a suggestion that Welsh Government might provide some form of top-up to the allowance.

166. The complexities of the current situation facing many carers who need financial help and support was clear from the responses, given the range of different welfare payments, allowances, benefits and discounts which a carer might claim. There was also an impact in relation to the age of carers, with older carers often struggling to manage with just their pensions as income.

167. Suggestions as to what could improve the situation for many, included the following:

- improving the benefits system to make it less complex and easier for people to apply and complete applications – the forms are seen as being too long and complicated;
- provision of specific financial and benefits advice for carers;

- stopping a claim of Carers Allowances affecting a carers' Universal Credit payments and how indirect or direct costs faced by a carer could be taken into account;
- improved access to attendance allowance;
- reduction of council tax bills;
- looking at working age benefits and tax limits;
- disability allowances;
- extension of winter fuel allowances;
- support with paying utility bills;
- emergency grant schemes to help carers in a crisis situation or facing severe financial pressures;
- more non-means tested grants and trialling a Universal Basic Income payment;
- communication campaigns and awareness raising so that carers know what benefits and support they are entitled to claim.

168. Individuals living with a terminal illnesses often rely on benefits as their main source of income. As control of welfare benefits is not devolved to the Welsh Government, there was a call for them to work with UK central government and make the case for quicker and easier access to financial support for terminally ill people.

169. Amongst the responses there were also calls for all carers to be paid a "living wage". The interaction between financial support such as scholarships and bursaries and welfare payments, which can negatively affect the financial situation of a student with caring responsibilities, was raised. There were also calls to review Education Maintenance Allowance in Wales so that it could better support young adult carers.

170. Overall there was a clear push from a number of the respondents including public sector bodies, for Welsh Government to consider or follow the actions of the Scottish Government, reviewing and increasing carer allowances, provision of top up payments and one off grants to carers during the pandemic, as well as provision of grants to young carers aged 16-18.

Question 23. Do you agree with the addition of the fourth national priority for carers based on education and employment?

171. Of the 52 responses the majority agreed with the addition of this new fourth national carers' priority.

Question 24. Do you think the list of national priorities for carers, and proposed fourth priority, require further amendment? If so, what?

172. Of the 37 responses a majority of the replies did want to change the list of the existing three national carers' priorities, beyond adding the proposed fourth priority.

173. The journey of the carer was seen as having a start and end therefore the addition of a reference to life after caring was proposed because many carers need emotional, practical and targeted support when their caring role ends, but also when someone has to place the person they care for, into residential or nursing care. This was described as an aspect of caring thrown into focus during the current pandemic. This has left many carers feeling isolated and alone.

174. Some organisations wished to change the wording of all three national priorities to provide more detailed focus on the emotional and practical aspects experienced by many carers. Others provided more details of the types of action they would like to see taken forward in tackling many of the challenges and barriers carers can face and wanted these included in the wording of the priorities.

175. A suggestion was made that Welsh Government follow the national carers' plan with development and publication of a specific action plan. This was because many of the actions to support delivery of the four national priorities were described as being fairly general in nature and are not outcome focused and lack monitoring arrangements. A new rolling action plan with milestones and detail of the specific actions in each priority, as well as describing reporting arrangements, was suggested as a way to ensure the national priorities are met.

176. Feedback from organisations and those working with young carers and young adult carers indicated agreement with all four carers' priorities, but stated that better reporting measures should be introduced. These should hold local and central government to account, when measures are not met or achieved. More emphasis should be placed on the role of political office holders, and those holding senior leadership positions with corporate duties and responsibilities, who have a duty of care for the lives of young carers.

A Charter for Carers

Question 25. Do you agree with our intention to develop and publish a Charter for Carers?

177. Of the 68 responses to this question a majority of the replies agreed with our proposal to work with carers, stakeholders and partners to develop a national charter. A number of respondents whilst generally supportive mentioned concerns about being able to engage stakeholders in the process, getting organisations to sign up to the principles within a charter, the impact for carers themselves, and how implementation would be guaranteed.

178. Feedback from carers received by respondents and referenced in their replies to this consultation indicated a mixed reaction. Any such document would need to be developed with carers, carer led and carer focused. There was a perceived risk that a charter could become a box ticking exercise and then forgotten about once published. Also it should apply to all ages of carer, including young carers, with the status of the document clearly explained. Questions asked included whether the charter produced would have any review dates or clear timelines, would it include specific standards, or ensure carers are involved as equal partners and having a voice in policy development, planning, research and training.

179. A small number of third sector bodies want to see a charter being supported with funding to enable implementation, provision of complaints mechanisms and measures for holding organisations accountable. Another reply raised an example of a carers charter in Scotland, seeing a new charter in Wales as a means to enshrine the rights of carers, place additional duties on local authorities and help carers self-identify as unpaid carers and know their rights.

180. Where replies disagreed, they did not see a charter making any practical difference to carers or the people they support, rather they thought there would be greater impact from scrutinising via performance reporting, and challenging local authorities and health boards to ensure carers' rights under the Social Services and Wellbeing

(Wales) Act 2014 were being met. This should be accompanied by clarification of the consequences for poor performance and non-compliance of organisations delivering the requirements of the 2014 Act.

Question 26. Should the charter describe national expectations of organisations supporting carers?

181. Of the 58 responses to this question a majority of replies agreed with the statement. A specific reference was made to the importance of a new charter setting out the services that carers should receive through the medium of Welsh, in accordance with the Welsh language standards and the Social Services and Well-being (Wales) Act 2014.

182. Several NHS organisations supported the proposal indicating that as service planners and system leaders they wish to see a move towards clearly defining the roles of the Welsh Government, local authorities, local health boards, carers and partner organisations in such a way that carers feel supported to maintain their own health and wellbeing, alongside their caring responsibilities.

183. Comments from public sector bodies emphasised the importance of getting all key stakeholders signed up, with the charter setting out what carers can expect from different agencies, in the form of standards and outcomes, with separate standards and outcomes identified for young carers. However, there were also calls for a balance between national and local requirements and expectations, with every local authority and health board area having different demographics, for example, adapting services to support carers in ethnic minority communities, or addressing the needs of carers living in rural areas. A general charter providing oversight of what can be expected by carers in terms of services in each region would be seen as a step forward. A charter should not be so prescriptive it fails to recognise a need for flexibility, but ensures everyone works towards certain common standards.

184. A number of replies see the charter as an opportunity to show carers that they are valued and respected, the type of support that they are eligible for, and should be able to access.

Question 27. Do you think a Charter would help to improve the services you deliver or access?

185. Of the 56 responses to this question there were a mixture of replies, with some clearly stating that yes, they did believe a charter would make a difference, however others did not agree. Expectations of what the charter could achieve in terms of service delivery improvements were mixed but the level of expectation amongst carers and organisations in all sectors was seen to be very important.

186. Throughout the responses the importance of equity in obtaining help and support and access to services was clear, with the creation of a level playing field for carers, ensuring they have equality of access and standards of support regardless of where they live or their needs due to age, disability, or ethnicity. A role was identified for Welsh Government in securing commitments from each local health board and local authority to deliver improvement in services, but also to ensure these bodies have the capacity and the finances to offer the necessary services.

Question 28. Do you agree a Charter could help to reduce apparent geographic variation in services to carers?

187. Of the 59 responses to this question a majority agreed that the Charter could help reduce the apparent geographic variation in services for carers. Once again, views expressed ranged from strongly supportive, to sceptical and negative.

188. One key feature of many of the replies was that they identified the differences which already exist in terms of services delivery not just between local authorities, but many other deliverers including health boards. Local authorities in Wales offer different services in line with findings from their population and well-being plans but the view was expressed that a charter might help focus the planning process in future. This planning process is required by the Social Services and Well-being Wales Act 2014, and the Well-being of Future Generations Act 2015.

189. The use of a charter to promote collaborative working was seen as important. Such as document could promote the avoidance of duplication and ensure collective resources could be used more effectively. Co-operative efforts to identify specific inequalities facing different groups of carers, or within geographical areas, could lead to these being reduced over time through targeted action, and a redistribution of resources (people, services and money) where necessary. Pooling of funding was given as one example, but also the idea of collective agreement so that funding already provided to one charity or organisation could be reallocated if there was greater need in a different area. In this way funding would move in a targeted manner to meet the needs of the carer population.

190. A charter was seen as a means to identify variations in support and services for carers across Wales. It should also be a vision of best practice to ensure service providers don’t just aspire to deliver a minimum set of requirements. There should also be more alignment between local, regional and national organisations in terms of the vision, model and service delivery.

191. One local authority described how it had recently launched a Carers Charter and has seen benefits in terms of encouraging organisations to adopt carer-friendly practices, and with charter status, organisations showcasing their commitment to supporting carers within their businesses, schools, colleges and communities.

Measuring success: data and research

Question 29. What other ways can we work with partners to measure the success of the national plan for unpaid carers?

192. There were 50 replies to this question. As with any proposal to measure success the twin aspects of the source of information and data and the nature of the data i.e. qualitative and quantitative, was raised. Most of the respondents to this question emphasised the importance of acquiring qualitative information from unpaid carers. Several mentioned the use of annual surveys and asking carers to assess their outcomes and whether they felt their own situation had improved compared with the previous year.

193. Caution was expressed about over-reliance on any one source of information and data. A breadth of sources in different sectors, including the third sector, with suitable checks on quality and accuracy was mentioned. To support this there should be common terminology amongst collectors and users of the information and data, including national and local government, as well as other public bodies and the third sector. A small number of third sector bodies recommended the creation by Welsh Government of a suite of standardised measurement tools, for example, the approach used in the Common Assessment Framework for Safeguarding.

194. Alongside the use of performance measures and indicators several respondents emphasised the use of evaluation studies, including an evaluation of the national carers' plan. These shouldn't always be new evaluations however if existing evaluation projects could identify gaps in knowledge and be adapted.

195. Accountability for measuring the success of the national plan was raised, with respondents frequently suggesting the Carers' Ministerial Advisory Group as a mechanism for reviewing progress. This group was seen as playing a key role in monitoring the success of the new national plan, regularly reviewing reports. There was also a call for the Welsh Government to publish a dedicated carers' action plan by the end of 2021.

196. The use of existing IT systems was raised, with calls for any new developments for management information systems providing data, which would help local authority social care staff deliver timely and effective carers' needs assessments. Other suggestions as to what should be routinely measured included: the level of investment in specialist carers services, the number of carers in receipt of carers allowance, how many young carers are being supported and what form this takes (both through statutory commissioned services and directly through the third sector), plus the number of carers able to access respite breaks.

197. Understanding and measuring delivery of services in the Welsh language was an important aspect identified in the replies to this question. Specific comments flagged that the current Performance and Improvement Framework for Social Services includes measurements to record evidence that the Welsh language "active offer" has been made to carers and those with care and support needs, when carrying out assessments, and that it has been received. However, an active offer can only be provided if the provider is able to speak Welsh.

198. It was recommended that future population needs assessments should examine how many local authorities possess information about the need and demand for Welsh language service provision. It was also suggested that the current Social Services Performance Framework includes more detailed measures to identify which services are available, once a person's language choice has been identified. More detailed data

should also examine the extent to which the needs of Welsh speakers have been met, when in contact with social care provision.

Question 30 - We would like to know your views on the effects that the national plan for unpaid carers would have on the Welsh language, specifically on opportunities for people to use Welsh and on treating the Welsh language no less favourably than English.

What effects do you think there would be? How could positive effects be increased, or negative effects be mitigated?

199. There were 41 responses to this question. Overall, views of the respondents were that Wales is a bilingual nation and people should and need to be able to communicate in the language of their choice, therefore the new national plan for carers provides an opportunity to reflect these important social, cultural, health and legal aspects. There was also a suggestion that the wording of priority one should be modified to reflect the need to support carers who are Welsh speakers.

200. Delivery of services through a carer’s language of choice was raised as an issue with regard to provision and access to information and services. It was mentioned that young people can experience difficulties in communicating their thoughts and emotions if not using their language of choice. Also, the provision of care through the Welsh language was seen as very important where the person being cared for has dementia. Services must be designed to meet the needs of the person, and for them to receive treatment and care through the medium of Welsh.

201. A number of replies emphasised the “active offer”, so that Welsh speakers can use the language when in contact with a wide range of services and providers. However it was also suggested that more people and employees need to understand the “active offer” and why it is so important. It should be promoted in all settings, with both the carer and the person with care and support needs, given choice. Greater benefits for carers could potentially be realised with the third sector, as well as the public sector, ensuring provision of information, advice and services in both languages.

202. The need for compliance with legislation was a key feature in a number of replies. The Welsh language must not be treated less favourably than the English language when providing services to the public. However, it was recognised in some of the comments that more help and support is needed to enable organisations to recruit Welsh speaking staff, as well as train more employees to speak Welsh. The costs of Welsh translation services were seen to be a barrier for smaller organisations.

203. For many the plan could be used to promote investment in services, the importance of workforce language policies, and improved recruitment of Welsh speaking staff which would improve services and the ability of individuals to have language choice and delivery of help, care and support through their preferred language.

Question 31 - Please also explain how you believe the proposed policy Strategy for unpaid carers could be formulated or changed so as to have positive effects or increased positive effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language, and no adverse effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language.

204. There were 25 responses to this question many of which repeated what had been provided in replies to question 30. Additional comments however suggested professionals need to better understand how they can achieve more effective outcomes for individuals, and services, when language is taken into account. The language of preference for both carer and the person cared for should be noted as a matter of course, with carers and those they care for being given the choice to have information, either verbally or in writing, in their preferred language.

205. Recommendations for changing strategic carers' policy to ensure implementation will have a positive impact on opportunities to use the Welsh language included for example:

- Providing guidance and support in relation to Welsh language services to local authorities and other providers in order to fully implement the national carers' priorities;
- consider what the Welsh Government and its partners can do to support the provision of Welsh language services for carers, e.g. information on practitioners' linguistic skills gaps in order to contribute to the implementation of the Health and Social Care Workforce Strategy:
- guidance for each national priority regarding the expectations on providers to achieve them in accordance with Welsh language standards and the requirements of the Social Care and Well-being (Wales) Act 2014.

206. The role of Regional Partnership Boards (RPBs) was raised given the requirement for RPBs to undertake population needs assessments to assess the range and level of services required to meet the care and support needs of individuals, and carers, in the relevant local authority areas. The needs of Welsh speakers should be carefully considered within these assessments, including the needs of Welsh speaking carers. Also, the Welsh Government should work with local authorities, local health boards and other providers to understand how they will meet the care and support needs of Welsh speaking carers. Wherever a carer lives in Wales the requirements to provide and deliver services in Welsh should be the same.

Next steps

The finalised national plan for carers will be produced and published, with a future action plan being developed in consultation with stakeholders and carers, during 2021.

Annex 1: List of respondents

List of respondents
ADSS Cymru
Age Cymru
All-Wales Directors of Planning Executive Group for NHS Wales Organisations
All Wales Forum of Parents and Carers of People with Learning Disabilities
Alzheimer’s Society Cymru & TIDE **(joint response)**
Aneurin Bevan University Health Board
Board of Community Health Councils in Wales
British Association for Counselling and Psychotherapy
Cardiff and Vale University Health Board
Cardiff and Vale University Health Board - School Nurse Service
Cardiff Social Services & Vale of Glamorgan Social Services **(joint response)**
Carers Officers Learning and Improvement Network
Carers Trust South East Wales
Carers Trust Wales
Carers Wales
Ceredigion County Council
Children in Wales
Children’s Legal Centre Wales
Community Transport Association (Wales)
Contact Cymru
Cwm Taf Morgannwg Carers Steering Group
Hafal
Hourglass Cymru
Hywel Dda University Health Board
J Ashley
J Killick
K Wyke
L Jones
Marie Curie
M Evans
MENCAP Cymru
M Clarke

List of respondents
Monmouthshire Young Carers & Carers Strategy Group
Motor Neurone Disease Association
Newport County Council + Barnardo's (joint response)
North Wales – Local authorities, Betsi Cadwaladr University Health Board, and Third Sector Partners **(joint response)**
Nursing and Midwifery Council
Older People's Commissioner for Wales
Open University Wales
Oxfam Cymru
P Stephens
Public Services Ombudsman for Wales
R Roberts
Royal College of Paediatrics and Child Health
S Barr
Social Care Wales
Stroke Association
S Hurrell
Swansea Parent Carer Forum
Torfaen Local Authority Social Services Department
Velindre NHS Trust
Wednesday Dementia Group
Welsh Ambulance Services NHS Trust (WAST)
Welsh Language Commissioner
West Glamorgan Regional Partnership Board
West Wales Carers Development Group