

Caring for our future

An inquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation to carers

November 2019



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November 2019



About the Committee

The Committee was established on 28 June 2016. Its remit can be found at: www.assembly.wales/SeneddHealth

Committee Chair:



Dai Lloyd AM
Plaid Cymru
South Wales West

Current Committee membership:



Jayne Bryant AM
Welsh Labour
Newport West



Angela Burns AM
Welsh Conservatives
Carmarthen West and South
Pembrokeshire



Helen Mary Jones AM
Plaid Cymru
Mid and West Wales



Lynne Neagle AM
Welsh Labour
Torfaen



David Rees AM
Welsh Labour
Aberavon

The following Members were also members of the Committee during this inquiry:



Dawn Bowden AM
Welsh Labour
Merthyr Tydfil and Rhymney



Neil Hamilton AM
UKIP
Mid and West Wales



Julie Morgan AM
Welsh Labour
Cardiff North



Rhianon Passmore AM
Welsh Labour
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Chair's foreword

Unpaid carers are the cornerstone of community care. They are responsible for delivering the vast majority of care in Wales, under informal arrangements, estimated by the Sector as being equivalent to £8.1 billion a year.

Without them, the social care system would face collapse. Yet many feel desperate, undervalued and that they are treated with little respect.

In addition to the day-to-day demands of caring, being an unpaid carer brings with it so many related issues for the carer themselves – exhaustion, physical and mental health problems, anxiety, isolation from friends and family, and a feeling of lost identity. Lack of proper support can also lead to financial problems, with many carers cutting their working hours or giving up work altogether in order to manage their caring responsibilities, placing their own financial future in jeopardy.

Looking ahead, the role of the carer will become even more important given the demands of an ageing population with increasingly complex health needs.

It is, therefore, crucial that unpaid carers of all ages are properly recognised, valued and supported to continue to care. As part of this, the significant contribution of the third sector in supporting carers must also be recognised, both in terms of more sustainable funding arrangements, and in their meaningful involvement in planning and decision-making about that funding.

This is something that requires strong national focus and leadership. The Welsh Government has already taken some of the steps needed in enacting the legislation. It must now follow this up with prompt and decisive action that ensures the rights and support promised by the Act are delivered.



Dr Dai Lloyd AM
Chair

Recommendations

Recommendation 1. The Welsh Government must, as a matter of priority, demonstrate stronger national leadership in the delivery of rights and services for carers under the Act. As a starting point, it must prepare, within 6 months, a clear action plan for addressing the failings of implementation highlighted in the evidence we received. In doing this, it must consult key stakeholders and carers. It must also set out a clear timetable for delivery of the actions identified in its plan.
..... Page 19

Recommendation 2. The Welsh Government must plan now for the anticipated rise in the number of unpaid carers. It must take a long term view of what the needs of carers will be in the future and how, along with local authorities, local health boards and the third sector, it will meet those needs. The Welsh Government must clearly set out how it will achieve this and report back to us on progress in 6 months. Page 19

Recommendation 3. The Welsh Government must ensure that the Ministerial Advisory Group is supported and resourced to be an effective forum. It must be of sufficient status within the Welsh Government to raise the profile of caring and carers' needs across government policy areas, including local government, health, housing and transport. As such, it should be chaired by a member of the Welsh Government. It should be transparent, and should publish agendas and minutes of its meetings. The Deputy Minister must report back to this Committee within 6 months on the actions that have been taken to address these issues. Page 19

Recommendation 4. The Welsh Government must, as a matter of priority, give effect to its commitment to undertake a major publicity drive to raise awareness of the Act and carers' rights under it. This should raise the profile of caring, improve identification of carers, promote the benefits of needs assessments under the Act, and encourage take-up. It should also signpost people to appropriate information, advice and assistance about caring. The Deputy Minister must report back to this Committee within 6 months on progress. Page 41

Recommendation 5. The Welsh Government must ensure that those health and social care professionals most likely to come into contact with carers, including GPs, are able to identify carers and signpost them to appropriate services. The Welsh Government must ensure that specific training is provided for this.
..... Page 42

Recommendation 6. The Welsh Government must ensure that the formal needs assessment process for carers is clarified and standardised across local authorities. It must be able to demonstrate how it has achieved this and should report back to this Committee within 6 months on progress. Page 42

Recommendation 7. The Welsh Government must ensure that those social care professionals responsible for delivering needs assessments are trained to provide an improved user-experience for carers. Training should include an emphasis on appropriate language to be used around assessments, breaking down barriers to engagement with social services and ensuring that carers are able to access the support they are entitled to under the Act. The Welsh Government must evaluate the impact of this training..... Page 42

Recommendation 8. The Welsh Government must require an evaluation of the effectiveness of the needs assessment process. The method of this evaluation is a matter for the Welsh Government, but it should be done on an annual basis and the results should be published..... Page 42

Recommendation 9. The Welsh Government must set out the maximum time that it believes a carer should wait to receive a needs assessment. Page 43

Recommendation 10. The Welsh Government must require local authorities to report back on waiting lists for needs assessments. The Ministerial Advisory Group may provide an appropriate forum for reviewing these reports. Page 43

Recommendation 11. The Welsh Government must ensure that refusal rates of needs assessments are kept under review. The Ministerial Advisory Group may provide an appropriate forum for this work. Page 43

Recommendation 12. The Welsh Government should ensure that emergency planning is a core component of all needs assessments to ensure that specific arrangements are in place for a time when the carer is unable to continue to care. Page 44

Recommendation 13. The Welsh Government must ensure equitable provision of services for carers across Wales, including respite services. As a starting point, it must ensure that a baseline range of support services for carers, based on eligibility criteria, is provided by all Local Authorities. The Welsh Government must introduce a mechanism to monitor delivery of this support. It should report back on progress within 6 months..... Page 56

Recommendation 14. The Welsh Government must publish information on expenditure by local authorities on respite services. This should cover each

financial year since the government's investment of £3 million of recurring funding began in 2017-18.....Page 56

Recommendation 15. The Welsh Government must ensure that the impact of its £3 million recurring investment for respite services is evaluated. This work must identify the quality and quantity of the services provided, as well as capturing information about gaps in provision.....Page 56

Recommendation 16. The Welsh Government should ensure that a minimum standard of advice and support is provided across Wales to those carers wishing to make use of Direct Payments. This should form part of a baseline range of support services on offer to carers..... Page 57

Recommendation 17. The Welsh Government must ensure that all young and young adult carers are able to access the support and services they need. In doing so, it must address the specific concerns raised by young carers in evidence to this committee. It must ensure that the support and services for young and young adult carers are person-centred, age-appropriate and flexible to meet their specific needs. There must also be a strong connection between schools and carers' services. The Welsh Government must clearly set out how it will achieve this, and must report back on progress within 6 months..... Page 72

Recommendation 18. The Welsh Government should strengthen the existing Code of Practice for Local Authorities about what is considered to be an "appropriate" level of care for a young carer to ensure that the position in Wales is at least equal to that in England and Scotland. Page 72

Recommendation 19. The Welsh Government must update and strengthen existing guidance for schools about identifying and supporting young carers, to ensure awareness throughout all schools of the demands on young carers. It should encourage and create opportunities for the sharing of best practice of support services for young carers within schools..... Page 73

Recommendation 20. We believe that the young and young adult carers' ID card scheme should be a national scheme, delivered by all local authorities with appropriate support from the Welsh Government and accessible to all young and young adult carers. The Welsh Government should ensure this is achieved as a matter of priority. It should report back on progress within 6 months..... Page 73

Recommendation 21. The Welsh Government needs to ensure the standardisation of information, advice and assistance for carers across local authorities and local health boards. This must include bilingual provision of these services. As part of this, the Welsh Government should convene representatives

from local government, health boards and the third sector with the aim of developing an approach that will secure these improvements for the service user. We ask the Deputy Minister to report back to us on progress within 6 months.

.....Page 82

Recommendation 22. The Welsh Government needs to work with local authorities to better promote the availability of information, advice and assistance for carers, including clear details of how to access it. This should be done as part of the publicity campaign referred to in Recommendation 4.....Page 82

Recommendation 23. The Welsh Government needs to ensure that staff providing information, advice and assistance as part of each local authority's central advice and information point have up-to-date information about rights and services for carers under the Act, and that refresher training will be provided where necessary. We note the work being undertaken by Social Care Wales, the Welsh Government and local authorities to develop a competency framework to support the development of information, advice and assistance workers. We ask that the Deputy Minister updates us on progress with this project.....Page 82

Recommendation 24. The Welsh Government must ensure that the independent evaluation of the Act considers whether the funding for carers' services has been sufficient to deliver the policy intentions of the Act. It must also consider the funding that will be necessary in the longer term to deliver the rights and services promised by the Act.....Page 89

Recommendation 25. The statutory sector is heavily dependent on the third sector for delivery of vital services to carers. That dependency needs to be reflected in both the provision of adequate funding for the third sector, and the meaningful involvement of the sector in planning and decision-making around that funding. We believe this matter should be explored by the Ministerial Advisory Group. We ask the Deputy Minister to provide us with an update on this work within 6 months.....Page 90

Recommendation 26. There is a need for a long-term, sustainable and streamlined funding arrangement for third sector organisations delivering essential services to carers under the Act. We believe that funding should be provided on a three-yearly basis as a minimum. The Welsh Government must move towards this as a matter of priority.Page 90

Recommendation 27. The Welsh Government should provide a comprehensive and accessible list of available funding sources for support for carers to be

delivered by the third sector. This should be done as soon as practicable.
..... Page 90

Recommendation 28. The Welsh Government should consider making available a single funding stream for carers services. This should replace the current system of individual grants. It should be accompanied by a monitoring and reporting mechanism to ensure it is delivering value for money..... Page 90

Recommendation 29. The Welsh Government must take a stronger lead on a national approach to data collection on carers to ensure that appropriate and meaningful data is collected across all sectors in a coordinated and consistent way. We believe this should be a function of the Ministerial Advisory Group, which should develop national guidelines to determine what data needs to be collected, how it should be collected and how it will be used following collection. The data should be published, and should be used to inform future service and financial planning. We believe that the Performance and Improvement Framework is an important part of this work, and we ask that the Deputy Minister provides us with an update on progress..... Page 97

Recommendation 30. We endorse the recommendation from Estyn in its report of May 2019 that the Welsh Government should produce reliable, nationally-collected data to help identify young carers. Page 97

Recommendation 31. The Welsh Government must provide an update on progress of implementation of the Welsh Community Care Information System within 6 months. Page 97

1. Background and purpose of our inquiry

Background

- 1.** The Social Services and Well-being (Wales) Act 2014 (the Act) came into force in April 2016. Amongst other things, it strengthened social services support for carers, providing them with rights to a needs assessment and to support for any “eligible needs”. It also placed duties on local authorities to provide “information, advice and assistance” to carers regardless of whether such an assessment is undertaken. The Act aimed to improve service planning by requiring local authorities and health boards to assess the care and support needs of their populations, including carers who need support.
- 2.** The Act defines a carer as “a person who provides, or intends to provide care for an adult or disabled child”. This definition is broader than that in earlier legislation, which was limited to carers who provided “a substantial amount of care on a regular basis”.
- 3.** Although the Act intended to provide strengthened rights and better services for carers, by 2018, evidence had emerged to suggest that it was not having the desired impact. Reports by Carers Wales (2018)¹ and Care Inspectorate Wales (2017)² raised concerns that local authorities were not prioritising carers’ needs. The former Older People’s Commissioner, Sarah Rochira, also highlighted the low number of carers having their needs assessed by local authorities, and even lower numbers receiving support services.³
- 4.** In addition, significant provisions within the Carers Strategies (Wales) Measure 2010, which required local health boards and local authorities to produce carers strategies, with local health boards to take the lead on these, were not replicated in the Act (the Act also repealed the Measure).

Our inquiry

- 5.** It was within this context, and as part of our commitment to follow-up on legislation within our remit⁴, that the Committee agreed to undertake an inquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation

¹ Carers Wales - Track the Act Briefings

² Care Inspectorate Wales - In support of carers – carers engagement overview report

³ Record of Proceedings (RoP), 9 May 2018, paragraph 84

⁴ The Health, Social Care and Sport Committee’s strategic objectives for the Fifth Assembly

to carers of all ages in Wales, and to consider broader Welsh Government policy on carers. This post-legislative inquiry focused particularly on:

- assessments of need;
- provision of support, including respite care;
- provision of information, advice and assistance; and
- information collected by local authorities and health boards on carers and their needs.

6. From 13 July to 20 September 2018, we ran a public consultation. We received **31 written responses**, representing the views of a range of health and social care organisations, professional groups and individuals.

7. Alongside this, we held 14 informal **focus group sessions** in a number of locations across Wales, where we heard the views of 136 carers and support staff with a wide range of experiences, including caring for people with dementia, mental ill health, cancer and stroke, about their awareness of the Act and the current services and support available to them. These findings helped inform discussions with representatives from these groups at a formal **roundtable event** with Committee Members in Cardiff in October 2018.

8. In addition, we heard **oral evidence** from a number of witnesses. This included a session with young carers, as part of a workshop held on 31 January 2019 marking Young Carers Awareness Day, in partnership with Carers Trust Wales. We also heard from the Deputy Minister for Health and Social Services.

9. We would like to thank everyone who has taken the time to contribute to our work. We particularly appreciate the involvement of all the carers who took time out to come and share their experiences with us.

2. Effectiveness of the Act

Key themes in this Chapter

Broadly, the evidence we received supported the legislation, but expressed disappointment both in the way that the Act has been implemented and the way it has been resourced. We heard that “the system is seriously underfunded”.

We heard from support workers and carers across Wales who told us that they felt that the Act had diluted what the Carers Measure had put in place, and that initial optimism about the difference the Act would make had faded.

We heard that there have been some improvements since the introduction of the Act but that this was “patchy”.

The report of the service-user experience commissioned by the Welsh Government – “Measuring the Mountain” – found that 75% of the carers who shared their stories rated them as negative or very negative.

The Welsh Government has commissioned an evaluation of the implementation of the Act. This is being conducted by the University of South Wales. The final report and recommendations will be published in 2021.

10. Broadly, the evidence we received as part of our inquiry supported the legislation itself. According to the Chair of Ein Llais North:

“The Social Services and Well-Being Act (SSWBA) recognised the pressures caring puts on individuals and families and has hopefully begun a societal change to both recognise the vital economic contribution of family carers and puts pressure on local authorities to consider and meet their needs, not as an afterthought but as a right.”⁵

11. However, many respondents expressed disappointment in both the way that the Act has been implemented and the way it has been resourced. Age Cymru suggested “the system as it stands is seriously underfunded”, while Hafal told us that resources, especially for adult social care, had been under intense pressure since the introduction of the Act.⁶

⁵ Written evidence, C08

⁶ Written evidence, C10

12. In correspondence, Damien McCann, Association of Directors of Social Services Cymru (ADSS), said:

“...the Social Services and Well-Being Act (Wales) 2014 was developed essentially because we could not afford to continue to deliver services as we had been. Therefore, any new Act which was to be ‘cost neutral’ would be based on maintaining or reducing costs and not increasing costs, this was to be done by focussing on prevention and early intervention.”

“It was also a change of culture for those staff delivering services from an approach based on ‘what’s your problem’ and ‘here’s the solution or service’ we can provide. To a conversation now based on ‘what matters to you?’ and a more strengths based, collaborative, co-productive and individualised approach.”

“More importantly and sadly this cultural change was poorly promoted to the public and their expectations of what Social Services could deliver under this Act was not diminished and in fact was being promoted as delivering more.”⁷

13. We heard from support workers and carers across Wales who told us that they felt that the Act had diluted what the Carers Measure had put in place⁸, and that initial optimism about the difference the Act would make had faded.⁹

14. Hafal told us that “most carers have not noticed any improvement since the introduction of the Act”. It suggested this was due to a number of factors, including reduced resources “which have affected the capacity of services to undertake good quality assessments and to deliver on needs identified in assessments”.

15. Hafal further stated that “services have not built on the Act to create a new culture of respect for and cooperation with carers”.¹⁰ However, it did not believe this was a reflection on the Act, rather:

“it is (...) a reminder that legislation has a limited role and provides little unless it is combined with both resources and also a matching policy and delivery response by service providers.”¹¹

⁷ Letter from Association of Directors of Social Services - 18 January 2019

⁸ Focus Group Summary

⁹ Roundtable event – Summary of discussion

¹⁰ Written evidence, C10

¹¹ Written evidence, C10

16. This view was shared by participants in our Focus Groups, who reported not having seen any impact as a result of the Act:

“The Act promises a lot to carers but resources are not there to provide them.” Participant from Carers Trust frontline staff group

“The Act is not working. We are all at the brink. We are not coping.” Participant from Hafal West Wales Carers Group¹²

17. The Older People’s Commissioner told us that while it was positive that the Act had placed carers on an equal footing with their loved ones, it was not yet clear whether the Act was delivering upon its wide-reaching intent and whether the impact on carers had been positive. She urged that:

“Over two years on from the implementation of the Act, focus needs to shift from its content and onto its impact.”¹³

Evidence from the Deputy Minister

18. We heard from the Deputy Minister that the Social Services and Well-being (Wales) Act provides the same right for carers to access eligible support as those they care for. The Welsh Government is also undertaking a major exercise to improve the quality of data on the impact of the Act, to drive continuous improvement in the delivery of the rights set out in the Act.

19. The Deputy Minister advised that, in the meantime, the Welsh Government is taking practical steps through national priorities, direct support for carers and the establishment of a Ministerial Advisory Group (MAG) to continuously improve understanding of the needs of carers.

20. The Ministerial Advisory Group will provide a national forum to steer the delivery of improvements for carers and provide a cross-sector response to the challenges all carers face. In addition, an Engagement and Accountability Group will be established to support the MAG. This group will provide a voice for a more diverse range of carers and carers representatives than is possible on the MAG, and will help the group to focus on the issues that matter in the day to day lives of carers.

21. In terms of evaluating the Act, the Deputy Minister confirmed that the Welsh Government has committed to an evaluation “to explore the implementation of the Act and the impact on people who receive care and support and carers who

¹² Focus Group Summary

¹³ Written evidence, C24

receive support. It will provide robust information as to how the Act has been implemented at a national, regional and local level”.

22. The evaluation is being conducted by the University of South Wales. It commenced in November 2018 and will run for a minimum of three years. The final report and recommendations will be published in 2021.¹⁴

23. Separately, the final report of “*Measuring the Mountain*”, a community-based evaluation of the effectiveness of the Act, was published in 2019. The report, commissioned by the Welsh Government as part of its overall evaluation commitment, contained 17 recommendations for improving the experiences of carers.

Our view

24. Over the past 25 years, since the introduction of the Carers (Recognition and Services) Act 1995, there have been incremental improvements in the legal rights of carers. The experiences of carers during this time, however, did not improve along with these rights.

25. The Social Services and Well-being (Wales) Act 2014 represented the next step. Its intention was to deliver strengthened rights and better services for carers. Under that Act, carers have the same rights to an assessment and support as those they care for, and local authorities are under a statutory duty to assess the needs of carers and provide support for any eligible needs.

26. Unfortunately, this further improvement in rights has, once again, not been accompanied by a better experience for carers. This is very disappointing.

27. For so many that we heard from, the Act has failed to have any meaningful impact on their lives. Problems with assessments, inappropriate services and inconsistent information and advice have resulted in carers telling us that they feel forgotten about, undervalued and desperate.

28. Perhaps more worrying was the view that things had worsened in the last few years, primarily because financial constraints for local authorities (and the health service) meant that support services were not being delivered.

29. Five years on from the passing of legislation that was meant to be transformative for the lives of carers, the results are, at best, underwhelming.

¹⁴ Written evidence, Deputy Minister for Health and Social Services

30. Currently, around 96 per cent of annual care in Wales is provided by unpaid carers. Estimates indicate that, by 2037, more than half a million people will be providing some form of informal care.

31. Given the lack of impact of the legislation to date and the scale of the future challenge, we believe that the Welsh Government needs to demonstrate stronger national leadership in support for carers. It needs to provide stronger direction to local authorities and regional partnership boards in the planning and delivery of services to carers, and needs to be more actively involved in the oversight of this.

32. The establishment of a Ministerial Advisory Group is a positive step by the government in providing a forum for this work, but it seems to have lacked momentum to date.

33. The Act is a significant piece of Welsh Government legislation, promising much to carers. It has not made good on those promises so far, and the Welsh Government now needs to take greater ownership of its delivery.

Recommendation 1. The Welsh Government must, as a matter of priority, demonstrate stronger national leadership in the delivery of rights and services for carers under the Act. As a starting point, it must prepare, within 6 months, a clear action plan for addressing the failings of implementation highlighted in the evidence we received. In doing this, it must consult key stakeholders and carers. It must also set out a clear timetable for delivery of the actions identified in its plan.

Recommendation 2. The Welsh Government must plan now for the anticipated rise in the number of unpaid carers. It must take a long term view of what the needs of carers will be in the future and how, along with local authorities, local health boards and the third sector, it will meet those needs. The Welsh Government must clearly set out how it will achieve this and report back to us on progress in 6 months.

Recommendation 3. The Welsh Government must ensure that the Ministerial Advisory Group is supported and resourced to be an effective forum. It must be of sufficient status within the Welsh Government to raise the profile of caring and carers' needs across government policy areas, including local government, health, housing and transport. As such, it should be chaired by a member of the Welsh Government. It should be transparent, and should publish agendas and minutes of its meetings. The Deputy Minister must report back to this Committee within 6 months on the actions that have been taken to address these issues.

34. We welcome the independent evaluation of the implementation of the Act commissioned by the Welsh Government. The report and recommendations, to be published in 2021, will surely be a matter of great interest to our successor committee in the next Assembly. This work should not, however, be a reason to delay the actions we are recommending in this report.

35. Inevitably, and based on the evidence we heard, the biggest stumbling block to the successful delivery of the Act as regards carers is funding. It is clear that there are real challenges facing the Welsh Government, health and social care providers, and the third sector in supporting the ever-growing and increasingly complex needs of an ageing population. Much work is already underway by all of the above agencies, both in terms of prioritising and maximising existing resources, and planning for future provision.

36. We have, however, identified a number of areas where meaningful improvements could be made and these are set out in the Chapters that follow. These include awareness raising of rights amongst carers and professionals; better signposting of carers to existing services; better training for those staff most likely to deal with carers; and standardised levels of information, advice and assistance across local authorities.

37. In all of this, it is imperative to remember that, for so many individuals, the day-to-day responsibilities of caring for their loved ones continue. Their work must be recognised and valued, and their ability to continue caring, and to have a life alongside caring, fully supported.

3. Assessments of need

Key themes in this chapter

It can be difficult to identify carers, particularly because not all carers identify themselves as such. Health care professionals are ideally placed to identify carers for assessment, but need better support and training to do this.

Most carers are not aware of the Social Services and Well-being (Wales) Act 2014 or their rights under it, particularly regarding the right to a carer's needs assessment. There is also a lack of awareness of the Act and carers' rights amongst professionals, including social services staff.

Many carers find it hard to get a carers assessment; assessments are not routinely offered. When offered, there is a high number of refusals of assessments.

Carers say that it is not always clear when an assessment is taking place. The assessment process needs clarifying and standardising, both for adult and young carers.

Knowledge and attitudes of social services staff have a significant bearing on assessment access and process – some can be discouraging or unaware of carers' rights to an assessment.

Carers are often reluctant to contact social services due to perceived stigma, or the language used in assessments which can create the impression that ability to care is being judged. Seeking help from social services may be seen as an admission of failure.

There are important issues for carers around what will happen to the cared for person when they are no longer able to care for them. This needs consideration.

38. The Social Services and Well-being (Wales) Act 2014 strengthened social services support for carers, including providing rights to assessment and support for eligible needs. The Act broadened the definition of carer in earlier legislation to “a person who provides, or intends to provide care for an adult or disabled child” so that it is no longer limited to those who provide “a substantial amount of care on a regular basis”.

39. Local authorities have a duty to provide information, advice and assistance. In addition, the Act requires local authorities and Local Health Boards to undertake

assessments of the care and support needs of their populations, including carers who need support. This assessment should consider the outcomes the carer wants to achieve.

Numbers of assessments

40. We heard that the numbers of carers in receipt of a formal needs assessment are low. According to Welsh Government statistics for the period April 2017 to March 2018¹⁵, 6,178 assessments for support for carers were undertaken. Of these, only 2,027 carers received a support plan.

41. As part of a survey undertaken by Carers Wales in 2017-18, 54 per cent of carers said that they had not requested or been offered an assessment or had their current assessment reviewed. Of those that had requested or been offered an assessment, 37 per cent did not meet the eligibility criteria for help or support as a result of that assessment. Carers Wales described this as “extremely disappointing” given that the vast majority of respondents had been caring for over a year with significant caring responsibilities.¹⁶

42. This was supported by evidence from our focus group sessions, held across Wales, where around half of the participants reported having received a carers’ assessment.

43. However, it is important to recognise that carers will have different needs depending on their caring situation, and not all carers want or need support all of the time. Carers Wales Trust told us they hear from a lot of carers who say:

“We don’t need an assessment, we just need a little bit of help.”¹⁷

44. According to evidence submitted by Ceredigion County Council, it is generally accepted that there is a turnover of approximately 30% of carers who start caring and cease caring during the course of the year. A percentage of these will not want to engage with services because they are managing with the caring role or have sought and accessed support outside of statutory services.¹⁸

¹⁵ Experimental statistics:- [Adults receiving care and support in Wales, 2017-18](#)

¹⁶ Written evidence, C27

¹⁷ RoP, 15 November 2018, paragraph 217

¹⁸ Written evidence, C25

Reasons for not having an assessment

45. In addition to carers who have chosen not to have an assessment, there are a number of other reasons why a carer may not have received an assessment of need.

Not identifying as a carer

46. Before a carer's needs can be assessed, that person must first be identified as a "carer". This can be challenging, particularly because not all carers identify themselves as such and therefore do not recognise that they have rights. As the chair of Ein Llais North told us,

"Most people at some time in their lives will become a carer for a family member, it is not something we plan for or a role we actively seek, but we become a carer because we love the person and want to help them as much as we can."¹⁹

47. In its 2016 report²⁰, Carers UK found that, in Wales, 55 per cent of carers took over a year to recognise their caring role, and 24 per cent took over five years to identify as a "carer".

48. Evidence from the WLGA/ADSS Cymru suggests that this is often because carers "see the support they provide as a natural part of their relationship with the cared-for person".²¹

49. Many of the carers who took part in our focus group sessions across Wales talked of having "fallen into the role" and not having identified with being a carer straight away. Many felt this had made it difficult to recognise they needed support until they were desperate.²²

"No one ever expects to become a carer and we are often thrust into this with no preparation, no role description, no agreement, no pay, no breaks and a loss of control over your future."²³

50. However, according to Carers Wales, by not self-identifying, carers miss out on financial or practical support (or both):

¹⁹ Written evidence, C08

²⁰ Carers UK report 2016 "~~Missing out: the identification challenge~~"

²¹ Written evidence, C28

²² Focus Group Summary

²³ Written evidence, C03

“These carers would probably say ‘I’m just being a husband, a wife, a mum, a dad, a son, a daughter, a friend or a neighbour’ and it is imperative that there should be a national awareness raising campaign by Welsh Government to reach out to these ‘hidden’ carers to ensure that they know that there is information and support available to them.”²⁴

Awareness of own needs

51. Carers themselves are not always aware of what they need. Evidence from Hafal stated:

“A major problem is that carers often don’t know what to ask for i.e. unless you know that a service or resource exists, professionals don’t provide signposting.”²⁵

52. This was supported by Jayne Goodrick, a carer of a person living with dementia, who told us:

“If we don’t know what our needs are, how do we know that we need? So, it’s just a waste of time, unless we know. [...] Ceri and I have been carers for years now, we actually know a little bit more—the new carers don’t.”²⁶

53. A carer representative with Hafal told us that, in many instances, particularly for carers caring for people with mental ill health, it would be helpful to have somebody advise what they think is needed as part of the assessment process and outline what support is available, as many carers in this situation prioritise the cared-for person’s needs and find it difficult to identify their own.²⁷

54. Kay John-Williams, Service User and Carer Participation Officer, Hafal, suggested that training for carers should be provided prior to, or alongside, receiving a needs assessment so that there is a full understanding of the process.²⁸

Awareness of the Act amongst carers

55. We heard that there is little awareness of the Act, and rights under it, amongst carers. In particular, many carers do not know that the definition of a

²⁴ Written evidence, C27

²⁵ Written evidence, C10

²⁶ RoP, 21 November 2018, paragraph 172

²⁷ RoP, 15 November 2018, paragraph 548

²⁸ RoP, 15 November 2019, paragraph 484

“carer” has been broadened under this legislation, so are not aware that they may have become eligible for an assessment.

56. Mencap Cymru told us:

“If we look at the carers assessment, the majority of those who we spoke to had no awareness that it was something that they were entitled to. They didn’t know what it was.”²⁹

57. This was echoed by the participants in our focus group sessions, the majority of whom said they were unaware of the Act. Where there was an awareness, this tended to come either from an advocate or through their own research.

“Nobody has ever told me about my rights under the Act.” *Participant from Caerphilly Mental Health Carers Group*

“Out of sheer desperation, I went online and found Carers Wales. Only then did I find out about my rights.” *Participant from Carers Wales Committee*³⁰

58. However, having heard of the Act from friends and family or another carer, many individuals would not then know how to access a carers assessment or where to go for that information.³¹

Awareness of the Act amongst professionals

59. In addition to limited awareness of the Act amongst carers, we heard of a similar lack of awareness amongst professionals, including health and social services staff. According to Carers Trust Wales, a key issue identified by carers and carers services is the continued lack of knowledge amongst a range of professionals, including social workers, those who work in schools and healthcare professionals, about carers’ rights. It states:

“Beyond a lack of ability to appropriately signpost for support, there is ongoing concern that too many professionals fail to identify carers or to have appropriate information-sharing mechanisms to ensure holistic packages of support are delivered for carers.”³²

²⁹ RoP, 15 November 2018, paragraph 560

³⁰ Focus Group Summary

³¹ RoP, 15 November 2018, paragraph 560

³² Written evidence, C23

60. This can lead to problems such as not identifying carers properly, not signposting them to appropriate supporting services, and not making them aware of their rights under the Act.

61. Ceri Higgins, a carer for a person living with dementia, told us:

“I printed off a lot of paperwork representing the Act and actually gave it to the social worker, and he said, ‘Oh, I’ve never heard of that before.’”³³

Interaction with social services

62. Under section 24 of the Social Services and Wellbeing (Wales) Act 2014, local authorities have a duty to assess the needs of carers where it appears to them that a carer may have needs for support.

63. In 2017-18, there were 6,178 assessments of need for support for carers undertaken in Wales, which led to the provision of 2,027 support plans for carers³⁴.

Variations in approach

64. We heard evidence that the way carers’ needs assessments are approached by local authorities varies considerably across Wales. The Royal College of Nursing (RCN) Wales described these variations in practices as a post code lottery of how and when a needs assessment is received, if at all, and the services subsequently provided.³⁵ Evidence from the Older People’s Commissioner suggested that there was even variation in practice within local authorities and between social workers on the same team.

65. Carers Wales told us that some local authorities offer a pre-assessment “What matters” conversation,³⁶ others send a pre-assessment form in the post, some local authorities outsource the service to third sector organisations, whilst others have dedicated officers in post.³⁷

66. Care Inspectorate Wales (CIW) reported that carers were clear that they want to have their stories heard and hold meaningful “what matters” conversations with

³³ RoP, 21 November 2018, paragraph 209

³⁴ Welsh Government statistics [Adults receiving care and support 2017-18](#), 30 October 2018

³⁵ Written evidence, C11

³⁶ A focussed conversation with an individual to establish their current situation and what support might help to improve it and promote their well-being and resilience.

³⁷ Written evidence, C27

social workers, which are then responded to. However, this was inconsistent across Wales.³⁸

67. The Older People’s Commissioner also highlighted the importance of the “what matters” approach, saying the focus of the discussion should be on “what matters” to that individual and learning about that person, their strengths and support needs, with the presumption that they are the best person to judge what is best for them in relation to their well-being.³⁹

68. The Alzheimer’s Society agreed that experiences varied amongst its service users, saying that some carers viewed assessments as inconsistent and tokenistic.⁴⁰ It said there was “evidence [that] suggested that assessments were being done over the telephone as opposed to face to face, meaning that the assessor was not getting the full picture and situation of the carer being assessed”.⁴¹

69. We were told by Carers Wales and Carers Trust Wales that they had examples of local authorities sending a letter and form out for a carer to complete as an offer of assessment. This raised concerns that those carers who did not complete the form may be considered to have refused an assessment.⁴²

70. We also heard reports that the assessment process itself was unclear, and that many carers did not realise that they were being assessed. On this point, Carers Wales suggested that there could be a lack of understanding when conversations took place between carers and those providing support about the status of that conversation.⁴³

71. This corresponded with the experiences of participants at our focus groups, some of whom reported that they were unaware that they were being assessed and had no understanding of what would happen next, while others reported being assessed in front of the person they were caring for and, as such, felt unable to be as honest as they would have liked.

“If people don’t know they’re having an assessment, they don’t know what to ask for, or what they’re entitled to.” *Participant from Stroke Association Carers Group*⁴⁴

³⁸ Written evidence, C08

³⁹ Written evidence, C24

⁴⁰ Written evidence, C18

⁴¹ Written evidence, C18

⁴² Additional information, Carers Trust Wales – 23 November 2018

⁴³ RoP, 15 November 2018, paragraph 181

⁴⁴ Focus group summary

72. Many said that the quality of the assessment received was dependent on the individual social worker and their understanding of the Act and carers' rights.⁴⁵

Quality of initial contact

73. We heard that knowledge and attitudes of some social services staff can have a significant bearing on access to assessments and the process for this, and that some staff can be discouraging or unaware of carers' rights to an assessment.

74. There was a view amongst participants at our focus group, who felt that public services, including social services, were driven by processes and targets and did not put the user at the centre. There was also a suggestion that services only responded where they had a duty to do so.⁴⁶

75. Age Cymru reported that the initial contact between a carer and social services was hugely important. It reported that, in some areas, people contacting local authorities by telephone or in person were being referred to third sector agencies without appropriate consideration of their circumstances. Further, it had been told that some local authorities allocated a fixed number of call-backs to residents at the beginning of each day, referring unsuccessful callers to other agencies.⁴⁷

76. Carers at our roundtable event reported discouraging experiences when requesting an assessment, saying that some social services staff had questioned why the assessment was needed, or that they had needed to make more than one attempt to obtain an assessment.⁴⁸

77. Within our focus groups, we heard from parent carers who felt they could not be honest about how they were coping with their responsibilities for fear of repercussions. Similarly, young carers said they associated social services with negative experiences and were fearful of saying they were struggling to cope.⁴⁹

78. It was suggested that, in some cases, social work staff were attempting to manage expectations around assessments because services are limited due to resources. Carers Wales told us:

“The critical issue is funding, because the reality is that a lot of social workers, or people undertaking the carers needs assessments, will be

⁴⁵ Focus group summary

⁴⁶ Focus group summary

⁴⁷ Written evidence, C19

⁴⁸ Roundtable event – Summary of discussion

⁴⁹ Focus group summary

concerned about raising expectations about what support is available, because in many cases that support isn't available."⁵⁰

79. Some participants at our focus groups said they had been told the cost of the assessments in an attempt to dissuade them from formally requesting an assessment. Similarly, Carers Wales and Carers Trust Wales suggested that some local authorities were actively discouraging carers from taking up the offer of an assessment, stating:

“we have examples of some local authorities discouraging carers from taking up the offer of an assessment on the grounds that the menu of services they can offer does not meet that individual carer's needs. Clearly, this is contrary to obligations set out under the Social Services and Wellbeing (Wales) Act.”⁵¹

80. We also heard that the “churn of social workers” was a concern.⁵² YMCA told us that social worker turnover can be quite high, so “you can identify an issue within the family and then two months later someone else is coming in, another three months, someone else is coming in”.⁵³

81. Ceri Higgins, a carer for a person living with dementia, told us she was on her “fifth social worker for her parents”.⁵⁴

82. Age Cymru highlighted particular concerns for carers of people living with dementia, as a high turnover within the workforce can affect continuity of support, and unfamiliar faces can lead to confusion, fear and more difficult behaviour.⁵⁵

83. Monmouthshire County Council also highlighted concerns around social services resources:

“...the people on the ground are shrinking. And when you do a carer's needs assessment, [] we spend a lot of time talking to somebody because a carer's needs assessment is not just a tick-box exercise. So, to

⁵⁰ RoP, 15 November 2018, paragraph 176

⁵¹ Letter from Carers Trust Wales and Carers Wales regarding carers needs assessments - 27 February 2019

⁵² RoP, 15 November 2018, paragraph 623

⁵³ RoP, 21 November 2018, paragraph 109

⁵⁴ RoP, 21 November 2018, paragraph 182

⁵⁵ Written evidence, C19

do a carer's needs assessment, you need to do it properly, and manpower is time."⁵⁶

Staff training

84. We heard that better training for staff about the Act was needed. Carers Wales suggested that many carers accessing first point of contact services in local authorities were not being identified, as staff were not adequately trained to recognise carers and give them the information that they needed.⁵⁷

85. Carers Trust Wales believed that it was important to understand which professionals were most likely to meet families and carers and give them the appropriate support and training to ensure they could provide an active offer of support and signpost effectively.⁵⁸

86. This was acknowledged by Social Care Wales, which stated:

"We know we have much more to do and we continue to work with partners to identify workforce needs in relation to the Act and carers. This work will contribute directly to improving the experiences for people using care and support services and their carers."⁵⁹

87. It went on to say that it was shortly publishing a free e-learning module to raise awareness of carers' circumstances, which it hoped would help with the identification of carers when they made contact with services.

Social Care Wales Toolkit

88. Social Care Wales told us that it intended to publish a new toolkit for working with carers aimed at improving the consistency of the assessment process. The toolkit would include guidance for working with carers to help them prepare for their assessment and get the most out of it, skills in conducting the assessment with a particular emphasis on communication and listening skills and good support planning.

89. The toolkit⁶⁰ was subsequently published in May 2019, although it is not yet known what the level of take up has been.

⁵⁶ RoP, 21 November 2018, paragraph 372

⁵⁷ Written evidence, C27

⁵⁸ Written evidence, C23

⁵⁹ Written evidence, C09

⁶⁰ [Social Care Wales resources to support carers' assessments](#)

90. A number of witnesses highlighted the need for a standardised approach to assessments. Glamorgan Voluntary Services told us:

“Both the Vale of Glamorgan Council and Cardiff Council have taken steps to raise awareness of the right to a carers’ assessment and this is to be welcomed. However, it is clear that there is much more to do in terms of raising awareness of carers rights and this could be further improved via a more focussed and co-ordinated approach to information and advice.”⁶¹

91. Alzheimer’s Society Cymru said that the overwhelming experience of their staff was that “third sector organisations and Local Health Boards & local authority services are speaking different languages”. It went on to say:

“this includes different policies and different structures [] there is a need for some form of standardisation.”⁶²

92. The WLGA suggested that the introduction of the toolkit could provide the standardised approach people were calling for.⁶³

93. The Older People’s Commissioner said its roll out and implementation could be critical in improving the awareness and identification of carers amongst social care staff and increasing the access that older carers have to assessments.⁶⁴

Refusals of offers of an assessment

94. In addition to the small proportion of carers who have received a formal needs assessment under the Act, there appears to be a relatively high number of refusals. According to Welsh Government statistics⁶⁵, 6,891 carers refused an assessment in 2017-18.

95. We heard there are many reasons why carers may refuse an assessment, which are set out in the following sections. These can include fear of becoming involved with social services, the timing of the offer, or the way in which the offer is presented and the language used.

⁶¹ Written evidence, C14

⁶² Written evidence, C18

⁶³ RoP, 21 November 2018, paragraph 380

⁶⁴ Written evidence, C24

⁶⁵ Experimental statistics: [Adults receiving care and support in Wales, 2017-18](#)

Stigma

96. We heard that, for some carers, a general reluctance to engage with social services meant they were refusing offers of needs assessments. Some carers felt there was a stigma associated with seeking help from social services, and that doing so may be seen as an admission of failure to cope.

97. Alzheimer’s Society Cymru told us many carers fear that social services will remove the person being cared for if the carer cannot cope. Often, social services are seen as an extension of a figure of authority and carers are afraid to question or fight for something they need.⁶⁶

98. It went on to highlight other reasons why a carer might refuse an assessment, including: fear of financial assessment and loss of assistance; loss of control of personal and home life; lack of advocacy support for carers and cared for, and feeling a duty to provide.⁶⁷

99. Age Cymru told us this was particularly true of older carers (aged 80 years old or above) looking after a spouse or partner, and carers of people with dementia, where there is a wish to keep things private.⁶⁸

100. A participant at our focus group session from the Carers Trust frontline staff group told us that the third sector was very important in supporting carers and helping them understand that the stigma surrounding social services is outdated.⁶⁹

101. We did, however, hear from the carer of a person living with dementia that, when support is provided by social services, it can be very beneficial. She told us that she had initially been fearful to engage with social services but that:

“the social worker was one of the best people that came into our lives to unlock doors for me.”⁷⁰

Waiting times

102. Carers who are offered an assessment under the Act often face long waits. The Alzheimer’s Society told us that anecdotal evidence from frontline staff had

⁶⁶ Written evidence, C18

⁶⁷ Written evidence, C18

⁶⁸ Written evidence, C19

⁶⁹ Focus Group Summary

⁷⁰ RoP, 21 November 2018, paragraph 173

revealed that most local authorities have long waiting lists, and it is often a case of “take a ticket and wait for your number to be called”.⁷¹

103. Participants in our focus groups reported being told that waiting times for assessments in their areas were three to six months.

104. Age Cymru and the Older People’s Commissioner both reported that older carers had raised concerns about waiting times for assessments; suggesting that older carers were not given the same considerations as other carers, and were waiting longer for access to an assessment.⁷² This is particularly concerning given the importance of early access to appropriate services to prevent carers reaching crisis point. On this, Age Cymru told us:

“A health crisis for a carer can rapidly develop into a crisis for both the carer and the individual cared for.”⁷³

105. We also heard about the importance of timely assessments for those living with life-limiting conditions. Together for Short Lives told us:

“Our voluntary sector members (...)feel that they are reaching children and their families too late in the course of their illness, because assessments that would allow for these lifeline services to be accessed sooner are being carried out too late.”⁷⁴

106. Evidence from the Motor Neurone Disease Association cited recent research by Carers UK that 39% of people caring for someone at the end of life waited six months or more for their assessment. It stated that “timely access to an assessment is critical for carers of those with a rapidly progressing condition like MND” and called for carers of people with progressive and terminal illnesses like MND to be fast-tracked for assessments.⁷⁵

Language used around assessments

107. We heard evidence that the language surrounding needs assessments can be negative and off-putting. The Older People’s Commissioner for Wales suggested that some carers believed the assessment to be an assessment of how well the carer is performing, rather than being an assessment of what they need.

⁷¹ Written evidence, C18

⁷² Written evidence, C19 and C24

⁷³ Written evidence, C19

⁷⁴ Written evidence, C29

⁷⁵ Written evidence, C26

This, she said, highlighted the importance of using language that people can understand.⁷⁶

108. Jayne Goodrick, a carer of a person living with dementia, said the term “carers’ needs assessment” sounded judgemental.⁷⁷ She added:

“It’s just sometimes the language that is used. You know, ‘We’d like to come along and see if there’s anything we can to help you’ is a much better way of saying, ‘We’re doing an assessment of needs.’ Sometimes, it’s as simple as changing the language.”⁷⁸

109. Evidence from Hafal highlighted the need to “reduce the amount of jargon and social care ‘corporate speak’ so that information/advice given to carers is succinct and practical”.⁷⁹

110. However, the WLGA told us that much consideration was given to the language used around carers’ needs assessments and that:

“...if you can emphasise the word ‘needs’, it concentrates people’s thoughts that this is around the carer—about what their needs are.”⁸⁰

Planning for the future as part of the assessment process

111. Alzheimer’s Society Cymru raised concerns that the carers’ assessment only focused on the immediate position of the carer and not any potential needs in the future.⁸¹

112. This is an extremely important issue for older and parent carers, who are concerned about what will happen to the cared for person when they (the carer) are no longer able to care for them.

113. Mencap Cymru stated that there needed to be an emphasis on the well-being of carers within the assessment process as the quality of life for the cared-for following the death of a carer (particularly when a parent is caring for a child with learning disabilities) is a cause of anxiety for many.⁸²

“A few years ago, I had cancer. I have a son with quite complex learning difficulties—he was born with part of his brain not formed and he’s on

⁷⁶ RoP, 15 November 2018, paragraph 334

⁷⁷ RoP, 21 November 2018, paragraph 172

⁷⁸ RoP, 21 November 2018, paragraph 181

⁷⁹ Written evidence, C10

⁸⁰ RoP, 21 November 2018, paragraph 341

⁸¹ Written evidence, C18

⁸² RoP, 15 November 2018, paragraph 596

the autistic spectrum. (...) I couldn't bear to think of William on this earth without me, because I have to do everything for him really in essence (...) and I thought, 'Well, the only way out is to make sure that he's gone, that I kill him, and that I then die myself,' because, at the beginning, I thought it was terminal, that the disease was going to kill me. When I found out it was curable, then I thought, 'What do I do if it's not?'" *Jane Young, parent care and Member of Mencap Cymru*⁸³

"We've got a 90-year-old that comes in...Ninety-three—she's got a 60-odd-year-old son with Down's syndrome. On a daily basis, she says, 'I'm only here until he goes. As soon as he goes, I can go'. (...) You don't know where they'll live, who'll support them, who'll look after them." *Dot Gallagher, Chair of Mencap Cymru and parent carer*⁸⁴

Follow-ups, reviews and reassessments

114. We heard the importance of reviewing assessments. Alzheimer's Society Cymru told us that, following the initial assessment, carers are too often left to fend for themselves or required to call again for another assessment, which could involve waiting for long periods of time.⁸⁵

115. Alzheimer's Society Cymru called for reassessments to be placed on a statutory footing:

"... once an assessment has been made, social services go back, even if it's to pick up the phone in six months and say, 'How are you? How are things? Do you need us to come out again?'"⁸⁶

116. This was an issue raised at the roundtable discussion, where carers felt it was important to follow up on assessments periodically. Several carers suggested that an annual review for carers was needed to take account of changing circumstances. It was proposed that this could be done through a GP and should include both physical and emotional needs.⁸⁷

⁸³ RoP, 15 November 2018, paragraph 577

⁸⁴ RoP, 15 November 2018, paragraph 583

⁸⁵ RoP, 21 November 2018, paragraph 178

⁸⁶ RoP, 21 November 2018, paragraph 184

⁸⁷ Roundtable event – Summary of discussion

Role of the NHS

117. Since the introduction of the Act and its specific focus on local authorities' responsibilities, there was a view amongst carers that the health service had "taken its foot off the pedal".⁸⁸ On this point, Carers Wales, told us:

"I think there's been a step back from the health sector since the social services and well-being Act came into being. It seems to me that because it says 'social services' in the title of the legislation, there is an expectation that that's a social services responsibility."⁸⁹

118. Carers Trust Wales agreed, saying

"there's no strategic direction now –that's the difference. There's no requirement for health to do anything other than work in collaboration under Part 9 of the Act. So, that's all gone with the end of the carers Measure."⁹⁰

119. Carers Wales argued that, given that for four out of five carers their first point of contact with any statutory agency is generally within a primary care setting, it is vitally important that health has a responsibility along with local authorities to identify and signpost hidden carers.⁹¹

120. RCN Wales said that healthcare professionals working alongside carers should be fully cognisant of the rights of carers under the Act, and be supported to signpost carers towards the information and services they need.⁹² Social Care Wales made a similar point, saying:

"It is essential, in particular, that colleagues in health services are able to recognise and respond appropriately to individual carers. Health services have clear responsibilities under the Act. Health partners should be required to contribute to the local authority assessment and support plan, where appropriate."⁹³

121. The Older People's Commissioner told us that health services must continue to focus on identifying and delivering for the needs of carers, as more carers dealt with health services than social care as part of their caring role:

⁸⁸ Focus Group Summary

⁸⁹ RoP, 15 November 2018, paragraph 162

⁹⁰ RoP, 15 November 2018, paragraph 163

⁹¹ Written evidence, C27

⁹² Written evidence, C11

⁹³ Written evidence, C09

“However, health services, such as GP services, can be inflexible to the specific needs of carers. Awareness, identification and responsiveness to carers from health services is critical in supporting carers to continue caring and to maintain their own well-being.”⁹⁴

Role of the third sector

122. The evidence we received was clear that much of the work of supporting carers takes place outside statutory services, by the third sector. This was reflected in our focus group work, where many participants said they could not have coped without this support.

“The third sector is keeping us alive” *Participant from Hafal West Wales Carers group*

“The Welsh Government needs to recognise the work of the third sector. This is the only way some carers know anything about support services.”
*Participant from Carers Wales Committee*⁹⁵

123. We heard that a key role of the third sector was its preventative work, which could mean that a formal assessment was not needed in some cases. We heard that this preventative work was especially important as waiting times can be long and carers may reach crisis point by the time an assessment is completed.⁹⁶

124. Carers Trust Wales described how support plans were in place for many carers across Wales, supported by third sector organisations, which were meeting the immediate need for many carers and may be reducing the requirement for a statutory carer’s assessment.⁹⁷ They told us:

“...if our service is meeting that need, we wouldn’t then need to make a referral for a carers assessment. If we feel that there are needs that we cannot meet, we’ll then refer to the local authority for a wider carers assessment.”⁹⁸

125. We heard some evidence that statutory needs assessments do not necessarily need to be delivered by local authority staff. Carers Trust Wales said

⁹⁴ Written evidence, C24

⁹⁵ Focus Group Summary

⁹⁶ RoP, 15 November 2018, paragraph 221

⁹⁷ RoP, 15 November 2018, paragraph 185

⁹⁸ RoP, 15 November 2018, paragraph 192

that, in practice, more could be delivered for carers through the support of the third sector.

126. It was suggested by some participants at our focus group that assessments could be delivered by a third party, as this could prevent the carer worrying that they are being judged on their ability to care, especially in the case of parent carers, who are often reluctant to have an assessment in case of repercussions.

127. In Conwy, Hafal provides mental health carer assessments with local authority and LHB funding. Hafal stated that carers report a good experience of this approach, and that the cost of this approach is “demonstrably less than in-house provision of assessments”.⁹⁹

128. However, concerns were raised by others in the focus groups that third sector assessments did not always lead to the right support being offered. Support staff at these sessions confirmed that they were not always kept informed on the progress of recommendations made as part of the assessment process.¹⁰⁰

129. Alzheimer’s Society Cymru also cautioned that the consistency of assessments would need to be carefully considered to ensure that the services being offered to people are the same across Wales:

“If these assessments were to be contracted out, we would need to ensure that that [consistency] was offered, so that if people moved to care for relatives living with dementia or the person with dementia themselves moved, there is the same service wherever they go, and that there’s also communication between the bodies as well.”¹⁰¹

Evidence from the Deputy Minister

130. The Deputy Minister told us that she believed the best way to raise the awareness of carers about their rights was through the third sector, as they worked so closely with carers:

“... we have funded a number of third sector organisations in order to promote rights. From 2016 to 2020, funding of over £1.7 million has been awarded from our third sector sustainable social services grant scheme to Carers Wales and to the Carers Trust Wales.”¹⁰²

⁹⁹ Written evidence, C10

¹⁰⁰ Focus Group Summary

¹⁰¹ RoP, 21 November 2018, paragraph 198

¹⁰² RoP, 14 February 2019, paragraph 8

131. However, she agreed there was still a lot more work to be done to make people aware of their rights.

132. In relation to the number of assessments undertaken, the Deputy Minister's official acknowledged that fewer assessments were taking place than should be, but he said it was hard to identify what the actual number was. He went on to say:

“the evaluation that’s in train to look at the impact of the Social Services and Well-being (Wales) Act 2014 and the ‘Measuring the Mountain’ report, which is qualitative, citizens’-jury-style information, will start to shed some more light on that [...] to help us understand the extent of the number of assessments that we need, which would not necessarily be the whole population, but it’s probably more than we have currently.”¹⁰³

133. In relation to refusals of assessments, the Deputy Minister's officials confirmed that the data showed that more people who were offered an assessment refused the offer than took it up. The Deputy Minister told us she believed that many people refused an assessment because they felt they did not need it:

“But that’s why I think if we make people more aware of what possible help they can get that they might be more willing to identify—. Because a lot of people don’t identify themselves as carers.”¹⁰⁴

134. She also thought that some people might refuse because they are nervous about officials thinking that they cannot cope:

“So, I think there’s a multitude of reasons [for refusing an assessment], but the more awareness that we can get of the fact that we do recognise the hugely valuable job that people are doing, the more willing people will be to say that they are carers and will be prepared—or want an assessment.”¹⁰⁵

135. In relation to the variation of approach to assessments by local authorities, the Deputy Minister drew attention to the Carers Wales “Track the Act 3” briefing published in October 2018¹⁰⁶, which highlighted a lack of consistency in the approach that local authorities take to how and when carers are assessed, and some confusion amongst carers about assessments. She said that these concerns

¹⁰³ RoP, 14 February 2019, paragraph 53

¹⁰⁴ RoP, 14 February 2019, paragraph 64

¹⁰⁵ RoP, 14 February 2019, paragraph 65

¹⁰⁶ [Track the Act 4](#) was published in October 2019.

are likely to be significantly helped by forthcoming practitioner guidance from Social Care Wales, who have commissioned the Institute of Public Care (IPC) to develop a suite of engaging, bilingual tools to support practice for social workers and other professionals.¹⁰⁷

136. The Deputy Minister's official told us:

“The new carers assessment toolkit that Social Care Wales are producing [] will help very much in terms of undertaking those assessments, whatever age the carer. It's work very much with the individual, the carer and the family—the young carer—to look at the capacity resources and the outcomes that they want to achieve.”¹⁰⁸

137. The Deputy Minister said that a lot of training had taken place when the Act was introduced, but since then there had been a high level of staff turnover, so it was important to keep professionals up to date in their training. She went on to say that there were a number of support groups for professionals who worked with carers and her officials were in regular contact with them via the Carers Officers Learning and Improvement Network.

138. The Deputy Minister confirmed that, in her view, all the bodies identified in the Act, whether that was social services or the NHS, had a responsibility for helping to identify and support carers. The Deputy Minister's official said:

“The health boards, local authorities and the third sector are joint partners in those regional partnership boards, and together they should be assessing and agreeing the needs of people in their areas, and commissioning plans to meet those needs.”¹⁰⁹

139. He went on to say:

“Carers is one of the four priority areas in the integrated care fund, and the additional £15 million that was put into the integrated care fund for 2019-20 is purposed for adults with care needs, and carers specifically.”¹¹⁰

¹⁰⁷ Written evidence, Deputy Minister for Health and Social Services

¹⁰⁸ RoP, 14 February 2019, paragraph 72

¹⁰⁹ RoP, 14 February 2019, paragraph 29

¹¹⁰ RoP, 14 February 2019, paragraph 31

Our view

140. Carers are not an homogenous group. They have very different needs, dependant on a great variety of factors including the particular needs of the person they care for, their own financial position, their age, education needs, employment status, health and other caring responsibilities. As such, their needs assessment must be designed around them, be holistic, sensitive and responsive to changes in their needs, as well as offering meaningful opportunities for rest and respite, and a life alongside caring.

141. Not all carers will need a formal needs assessment. For many, access to appropriate information, advice and assistance will be sufficient for them at that point in their lives. They should, however, be made aware that the option of a formal assessment remains available should they require it later on.

Awareness of the Act

142. Much work is needed to address the lack of awareness of the Act, and carers rights under it, amongst the general public. This work should be aimed at helping people to identify as carers, promote the benefits of needs assessments, and encourage take-up where appropriate.

143. In addition to greater public awareness, there is a specific need for greater awareness of the Act amongst health and social care professionals and refresher training for relevant staff to ensure they are confident in identifying carers and signposting them to the appropriate services. This is particularly important for healthcare professionals, who will be the first point of contact for many carers.

144. We welcome the Deputy Minister's commitment to the Finance Committee that the Welsh Government intends to undertake a major publicity drive to raise awareness of the Act, and that a specific strand of this work will be targeting unpaid carers. We are disappointed by the lack of progress. That commitment was given last year and, to date, no such campaign has been launched.

Recommendation 4. The Welsh Government must, as a matter of priority, give effect to its commitment to undertake a major publicity drive to raise awareness of the Act and carers' rights under it. This should raise the profile of caring, improve identification of carers, promote the benefits of needs assessments under the Act, and encourage take-up. It should also signpost people to appropriate information, advice and assistance about caring. The Deputy Minister must report back to this Committee within 6 months on progress.

Recommendation 5. The Welsh Government must ensure that those health and social care professionals most likely to come into contact with carers, including GPs, are able to identify carers and signpost them to appropriate services. The Welsh Government must ensure that specific training is provided for this.

145. It goes without saying that any increase in demand for services as a result of greater awareness of the Act must be accompanied by sufficient resources to deliver those services. Our detailed views on funding and resources are outlined in Chapter 7.

Inconsistency in delivery of needs assessments

146. There is considerable inconsistency across local authorities in the way that needs assessments are delivered, and this must be addressed. Carers should be entitled to expect a minimum consistent service, regardless of where they live.

147. Further, they should be able to have confidence that their assessment will be a positive experience that can deliver real improvements for them and those they care for. It is unacceptable that carers can be discouraged from seeking an assessment, either by the way the offer is presented or a feeling that it is not worth their while, or that they are unclear about whether they have been formally assessed.

148. We, therefore, welcome the work undertaken by Social Care Wales to provide a toolkit for working with carers aimed at improving the consistency of the assessment process.

Recommendation 6. The Welsh Government must ensure that the formal needs assessment process for carers is clarified and standardised across local authorities. It must be able to demonstrate how it has achieved this and should report back to this Committee within 6 months on progress.

Recommendation 7. The Welsh Government must ensure that those social care professionals responsible for delivering needs assessments are trained to provide an improved user-experience for carers. Training should include an emphasis on appropriate language to be used around assessments, breaking down barriers to engagement with social services and ensuring that carers are able to access the support they are entitled to under the Act. The Welsh Government must evaluate the impact of this training.

Recommendation 8. The Welsh Government must require an evaluation of the effectiveness of the needs assessment process. The method of this evaluation is a

matter for the Welsh Government, but it should be done on an annual basis and the results should be published.

Waiting times

149. Assessments need to be timely and take account of the variety of circumstances facing carers and those they care for. We have heard evidence of long waiting lists for assessments. These delays can have a devastating effect on the carer and the person for whom they are caring.

150. More specifically, for those caring for people living with life-limiting, progressive and terminal illnesses, timely access to a needs assessment is critical. We draw the Deputy Minister's attention to the evidence from Together for Short Lives and the Motor Neurone Disease Association on this point, particularly in relation to fast-tracking assessments for carers of people with these types of illnesses.

Recommendation 9. The Welsh Government must set out the maximum time that it believes a carer should wait to receive a needs assessment.

Recommendation 10. The Welsh Government must require local authorities to report back on waiting lists for needs assessments. The Ministerial Advisory Group may provide an appropriate forum for reviewing these reports.

Refusals of offers of needs assessments

151. We are concerned about the relatively high rate of refusals of needs assessment offers. In many cases, refusals appear to be the result of the way the offer is presented - the language used and the waiting times for an assessment. The means by which an assessment is offered also influences take-up. For carers already exhausted by their responsibilities, receiving an assessment form through the post is off-putting.

Recommendation 11. The Welsh Government must ensure that refusal rates of needs assessments are kept under review. The Ministerial Advisory Group may provide an appropriate forum for this work.

Contingency/emergency planning

152. A particular concern for carers is what will happen to the person they care for if they (the carer) are no longer able to provide care. More needs to be done both by local authorities and local health boards to support carers in

contingency/emergency planning, and the Welsh Government needs to satisfy itself on this matter.

Recommendation 12. The Welsh Government should ensure that emergency planning is a core component of all needs assessments to ensure that specific arrangements are in place for a time when the carer is unable to continue to care.

4. Support for carers

Key themes in this chapter

Support provided to carers is preventative; it can help to maintain carers' ability to continue caring. It is also cost effective – carers' ill health and crises cost more in the long run.

Carers' services need to be flexible and person centred. But carers have told us that they have to “fight” for services – this shouldn't be necessary.

Respite care is an essential service for carers but in many cases it is difficult to access, there can be a lack of suitable provision, and it lacks flexibility.

Direct Payments for respite care can offer greater flexibility and control but not everyone wants the additional responsibilities they can bring. There may be less need for Direct Payments if conventional services had greater choice, control and flexibility.

153. In Wales it is estimated that there are currently 370,000 carers, with over 100,000 people providing over 50 hours of unpaid care per week. Whilst providing unpaid care saves the Welsh economy around four times the amount spent on all forms of social care, this comes at a cost to the carers.

154. We spoke to a large number of carers and support staff as part of our focus group work. The majority felt strongly that they were supporting the care system and saving local authorities money, yet most felt undervalued.

“I strongly believe family carers are undervalued and that without them NHS Wales and Social services would be in an even bigger crisis.”¹¹¹

Care and support planning

155. The Social Services and Well-being (Wales) Act 2014 requires local authorities and local health boards to undertake assessments of the care and support needs of their populations, including carers who need support

156. The Act also put onto a statutory footing seven Regional Partnership Boards (RPBs), bringing together Health Boards, Local Authorities and third sector partners. Under the Act, all regions are required to develop and publish Regional

¹¹¹ Written evidence, C01

Population Needs Assessments, which provide an assessment of the care and support needs of their area.

157. In their evidence to us, WLGA and ADSS Cymru reported that the assessments have been completed and Population Area plans published. All regions identified the important and vital role that unpaid carers undertake and were committed to improving access to suitable breaks and respite that meet the varied, often complex needs of the people they care for.

158. However, it also stated that, while regions recognised it was vital that all carers need to have a break from their caring role, with a need for suitable and flexible respite opportunities, some regions also highlighted concerns over the sustainability of carers services, which in many cases were provided through third sector support which was often reliant on short term grant funding.

159. It also drew attention to the impact that funding cuts had placed on local authorities and their capacity to be able to continue to offer such services.

Rural areas

160. We heard that support for carers is more difficult and costly in rural areas. Ceredigion County Council said that many carers live in rural and remote communities where lack of transport and challenges with transport services, together with financial hardship and long travel times, can make it difficult to access support services.¹¹²

161. On this point, Carers Trust Wales called for parity of provision across geographical areas-

“It can be more difficult for carers in remote or rural areas to access support. Parity of provision is key to ensure that all carers are able to access the support they need. Services must adapt their model to meet need and commissioners must factor in additional costs for service delivery in rural areas such as additional travel costs for domiciliary or respite care.”¹¹³

Eligibility for support

162. A formal local authority assessment should identify whether a carer has any need for support and, if so, whether any of those needs meet the eligibility criteria

¹¹² Written evidence, C25

¹¹³ Written evidence, C23

set out in regulations¹¹⁴ made under the Social Services and Wellbeing (Wales) Act 2014. A carer with needs that meet the eligibility criteria has a right to support from the local authority.

163. According to the Carers Wales, of those carers that were offered or requested a needs assessment in 2017-18, 37 per cent did not meet the eligibility criteria for services.¹¹⁵

164. According to the Older People's Commissioner:

“the eligibility criteria are quite tough in the sense of the level of need that you need to demonstrate before you get any services, that has an impact on the services that somebody gets who needs that care directly. So, it means that, if you're caring for someone, say, with moderate need, you may not get that additional support for the person you're caring for.”

165. Carers Trust Wales said it had “seen examples from across Wales of eligibility criteria for services being set at critical and high-level need”. This, they argued, “sets a high bar for when people with care needs can access services, which has a knock-on effect on the whole family, including carers”.¹¹⁶ It also said it had identified examples where criteria for services have changed with local authorities reducing the availability of specific services.

166. Age Cymru also told us of its concerns about local authorities making “unreasonable assessments about the level of support needed” which was “pushing carers to crisis point and costing the NHS more”. It said:

“The aim of the eligibility criteria is to increase access to and use of locally based preventative services, but we fear that it is actually being used as a means to deny much needed formal support.”¹¹⁷

167. It argued that evidence from Welsh Government statistics showed that the number of people receiving social care services is falling, with provision concentrated on people with the most complex needs:

¹¹⁴ [The Care and Support \(Eligibility\) \(Wales\) Regulations 2015](#)

¹¹⁵ Written evidence, C23

¹¹⁶ Written evidence, C23

¹¹⁷ Written evidence, C19

“Our sense is that people who would previously have received help are no longer being supported, and that this is increasing demands on informal carers.”¹¹⁸

168. In its report “The cost of caring for an ageing population”, the Assembly’s Finance Committee commented on the eligibility criteria in the Act, saying that these criteria “must be implemented in a way to ensure the correct balance is met between meeting the needs of those who require care and making the best use of alternative approaches”. The Committee believed that the Welsh Government should ensure that the impact of the criteria under the Act is thoroughly examined as part of the evaluation work commissioned by the Welsh Government.¹¹⁹

169. However, ADSS Cymru told us that, as a result of the Act, the way support was provided had changed and rather than always looking to statutory support services, it could involve the use of community based solutions that better enabled individuals and carers to achieve “what matters to them”.

170. ADSS said that this move towards more innovative approaches to support had blurred the line between what was formerly considered “social services support” and support in the wider community. Therefore, even though a Social Worker might put in place support to meet the needs of the carer, to the carer it appeared as though “social services” had not offered any support and that they were receiving support from a charity or third sector organisation instead, unaware that the Council in part funded these organisations.¹²⁰

Respite care

171. According to the last census, 103, 594 people in Wales provide over 50 hours of care each week, with those providing high levels of care being twice as likely to become permanently sick or disabled.¹²¹

172. Respondents told us that, without regular and appropriate respite, many carers felt they couldn’t cope with their caring responsibilities and that their own health was suffering as a result.^{122 123}

¹¹⁸ Written evidence, C19

¹¹⁹ The cost of caring for an ageing population: -October 2018

¹²⁰ Letter from Association of Directors of Social Services – 18 January 2019

¹²¹ Written evidence, C27

¹²² Focus Group Summary

¹²³ RoP, 15 November 2018, paragraph 288

“A short break re energises you and is good for both the carer and the person who is being cared for.”¹²⁴

173. In addition to providing an essential service for carers, we were told that respite care also provides opportunities for the cared-for person to have new experiences. Dot Gallagher, a parent carer and Chair of Mencap Môn told us:

“For me, respite for my sons is more about them having a better time than a weekend with their mum. I don’t want him to go to sit in a house with other people doing nothing for the weekend so that I can lie on the bed...”¹²⁵

174. Carers Trust Wales called for “all carers to be entitled to minimum breaks during which the full cost of replacement or respite care is covered”. It went on:

“We would recommend that carers be entitled to a minimum amount of respite for rest and relaxation on top of any replacement care they may need to enable them to do the things that matter to them on a weekly basis.”

Availability and appropriateness of respite care

175. A number of witnesses highlighted concerns about funding for respite care. RCN Wales told us:

“... financial pressures on Local Authorities has meant the availability of services which can provide valuable and meaningful respite have reduced, and carers’ access to respite is becoming increasingly difficult.”¹²⁶

176. Carers Trust Wales also told us that services across Wales that provide quality breaks and respite for carers have been squeezed, and commissioning has focused increasingly on price rather than quality. It stated:

“It is clear that further funding is needed for respite and short breaks. This must be ring-fenced to Local Authorities, and part of a long-term funding stream.”¹²⁷

177. It was suggested to us that there had been cuts in the provision of respite services. Alzheimer’s Society Cymru cited an example of Denbighshire cutting

¹²⁴ Written evidence, C01

¹²⁵ RoP, 15 November 2018, paragraph 636

¹²⁶ Written evidence, C11

¹²⁷ Written evidence, C23

their respite care provision to half, with the Council outlining that the full eight weeks were only available in exceptional circumstances. This, it said, had led to a situation where volunteer-led services were attempting to fill the gaps in the care, with befriending services asked to go in and provide respite care.¹²⁸

178. The WLGA and ADSS Cymru, however, were clear that, from a local authority perspective, “there has not been a reduction in respite provision, in a number of local authority areas they have indicated there has been an increase”. It is possible that a perception of a reduction in the provision of respite services could be a result of the changing way in which respite services are being provided.

179. ADSS told us that traditional respite in residential or nursing care is becoming less utilised because this model of care is no longer seen as positive by the cared-for person and local authorities are moving towards more individualised and flexible respite. It stated:

“Although there has been no reduction in services, demand is increasing and people’s expectations are difficult to manage at times.”¹²⁹

180. Another key concern for carers was the appropriateness of respite services. A participant in one of our focus groups told us that she had been forced to cancel her holiday because the respite services for her mother were not appropriate.¹³⁰

181. Other respondents talked about the need for respite care to be “age - appropriate”, Age Cymru and Alzheimer’s Society Cymru told us that “older carers need more regular breaks because they tire more easily or have own health problems”¹³¹ and “what is considered appropriate for older people living with dementia is not always appropriate for those living with early onset dementia”.¹³²

182. Age Cymru said it was aware of examples where respite was provided but where the carer is required to go with the person they are caring for or drive them to and from their care. This, it said, was not quality respite care:

“it’s respite of a form, but it’s not giving you the break or the opportunity to have some space for your own life.”¹³³

¹²⁸ Written evidence, C18

¹²⁹ Letter from Association of Directors of Social Services – 18 January 2019

¹³⁰ Focus Group Summary

¹³¹ Written evidence, C19

¹³² Written evidence, C18

¹³³ RoP, 15 November 2018, paragraph 312

183. We heard about the importance of flexible arrangements which meet the different needs of carers, including providing opportunities for the carer and person they care for to attend activities together. Alzheimer’s Society Cymru told us:

“... often, carers and the people they care for would like to have a holiday or break together, but are unable to do so due to a lack of options or availability of help whilst on the break.”¹³⁴

184. This was acknowledged by Swansea Council which said that, currently, the majority of its respite services were directed at the cared-for person, providing an opportunity for the carer to receive a break. However, they had received feedback that this assumed the carer needed a break from the people they cared for when actually there were carers who would like support to attend events or activities with the person they care for:

“Thus it has been identified there may be gaps within the service to support the carer directly in alternative ways.”¹³⁵

Quality of provision

185. We heard evidence of the need for respite services to be of an appropriate standard to enable the carer and the cared-for to feel confident and safe. Alzheimer’s Society Cymru told us that issues had been raised with them about:

“the state of respite facilities available to carers and people they care for, with staff giving examples of carers refusing to take up respite due to negative experiences in respite homes.”¹³⁶

186. Age Cymru also told us that many carers were reluctant to use support or respite services as they did not trust the quality of the care provided. As such, concerns about care standards can lead to refusal of care to the detriment of the carer’s own wellbeing.¹³⁷

187. We heard that some people chose to pay privately for respite care, either because they were happier with the standard of service provided or because they were deemed not to require respite care in the social services assessment.¹³⁸

¹³⁴ Written evidence, C18

¹³⁵ Written evidence, C17

¹³⁶ Written evidence, C18

¹³⁷ RoP, 15 November 2018, paragraphs 289-292

¹³⁸ RoP, 15 November 2018, paragraph 311

Direct Payments

188. Direct Payments are provided by local authorities to enable individuals to manage their own support as an alternative to services arranged or provided by the local authority.

189. We heard evidence that these payments can offer greater flexibility and control for some carers, as well as a means of extending the choice of services. Evidence from the Older People's Commissioner highlighted examples where people had used direct payments to organise respite support with positive results. These included paying for overnight respite in a place of choice, either on their own or as a family, or paying for a "buddy" for a few hours or days a week, to help support a person living with dementia.¹³⁹

190. However, this approach may not be suitable for all, particularly because not everyone wants the additional responsibilities that come with Direct Payments.¹⁴⁰ On this point, Hafal, spoke of some of the challenges in using Direct Payments to fund respite care:

"... you have to have an audit trail for the moneys coming in. You have to keep bang-on records, you may have to interview staff, depending on the situation, and that may mean a CRB check. Also, you've got financial responsibilities in training staff because, if you are paying staff, there's a health and safety aspect of regulatory support. So, it becomes a minefield."¹⁴¹

191. We were told that information and access to Direct Payments across local authorities varied, with relatively low take-up. According to the Older People's Commissioner, this was because the majority of older people living with dementia and their carers were unfamiliar with this route to support and had not been informed about Direct Payments by their social worker. She went on to say:

"Direct Payments should be widely offered as a route to respite that people are encouraged to explore and empowered to use. Local Authorities must increase their understanding and use of direct payments, ensure necessary support is in place for carers to use direct payments, and promote their use for equipment and respite."¹⁴²

¹³⁹ Written evidence, C24

¹⁴⁰ RoP, 15 November 2018, paragraph 318

¹⁴¹ RoP, 15 November 2018, paragraph 498

¹⁴² Written evidence, C24

192. Similarly, Hafal told us:

“More advice and help should be given to enable carers to obtain Direct Payments for their own needs and to support their cared-for to take control of their own care through Direct Payments.”¹⁴³

193. The Older People’s Commissioner also reported that she was aware that some carers who had tried to use Direct Payments for respite had not had a positive experience, either because they did not feel adequately supported to manage them, because the amount of money provided by Social Services did not cover the costs or because they could not find anyone to provide the service.¹⁴⁴

Innovative approaches

194. We heard that more innovative approaches to respite are needed. The Older People’s Commissioner referred to the “Respitivity” scheme in Scotland which makes use of spare hospitality industry capacity in the off-season to provide carers with respite opportunities, such as access to a hotel gym.¹⁴⁵

195. She also highlighted an initiative at Pontypridd rugby club where they are offering walking rugby, which is geared to older men in particular, to help them either have a break from caring or combat isolation. She reported that the Welsh Rugby Union were considering ways in which this could be supported and rolled out across Wales.¹⁴⁶

Evidence from the Deputy Minister

196. In her evidence, the Deputy Minister stated that £3m has been allocated to local authorities for the provision of additional respite care. First funded in 2017-18, she reported that this recurring funding is now provided via the local government Revenue Support Grant, and reports submitted to Welsh Government showed that the additional funding had enabled the provision of a range of traditional and new and innovative models for providing breaks for carers (with or without the person they care for).¹⁴⁷

197. The Deputy Minister told us that there was a need to look at respite in a much more flexible, person-centred way, moving away from the idea that respite

¹⁴³ Written evidence, C10

¹⁴⁴ Written evidence, C24

¹⁴⁵ RoP, 15 November 2018, paragraph 296

¹⁴⁶ RoP, 15 November 2018, paragraph 307

¹⁴⁷ HSCS Committee, 14 February 2019, Paper 1

is about the person being cared for going away for a couple of nights to give their carer a break.¹⁴⁸

198. The Deputy Minister's official said that, while there is still a demand for traditional forms of respite care and overnight stays:

“it's very much on looking at new forms and innovative ways, and people helping themselves, perhaps using direct payments as well, in terms of pooling funds and being able to purchase different mechanisms that actually give them a break rather than it being a form of care.”¹⁴⁹

199. She also said that officials were aware of the Respitality scheme in Scotland and were looking at ways to work with the Welsh hospitality sector to develop short breaks in a similar way.¹⁵⁰

200. In response to questions about whether the additional £3 million funding for respite care would result in additional respite provision, as it was being provided through the local government revenue support grant and not ring-fenced, the Deputy Minister told us:

“it is a duty on all local authorities under the Act to ensure that a carer receives assessment of their needs and that eligible needs are identified and a care and support plan is drawn up. [] we have written a clear letter to local government saying what we do expect of them. [] The expectation is there that they should do it.”¹⁵¹

201. When asked if the Welsh Government had any plans to develop a more strategic approach to supporting the growing number of carers in Wales, the Deputy Minister told us:

“I think there's a balance between what you do from the centre and what you allow to happen locally, and I don't think it would be appropriate for the Welsh Government to dictate what the regional partnership boards do.”¹⁵²

202. In relation to the involvement of carers on regional partnership boards, the Deputy Minister said:

¹⁴⁸ RoP, 14 February 2019, paragraph 91

¹⁴⁹ RoP, 14 February 2019, paragraph 92

¹⁵⁰ RoP, 14 February 2019, paragraph 94

¹⁵¹ RoP, 14 February 2019, paragraph 92

¹⁵² RoP, 14 February 2019, paragraph 137

“I know carers have said that they feel a bit out on a limb in those boards; that they don’t feel that they’re there with equal status with some of the bigger organisations. So, I think that’s the area where we’ve got to ensure that carers and the third sector feel that they are equal partners.”¹⁵³

Our view

203. The Act is ambitious in terms of the entitlements it promises to carers. With this, comes a reasonable expectation that services will be provided to those considered to be in need. Yet, we have heard very concerning evidence about the difficulties facing carers both in terms of accessing services (because of problems with eligibility criteria, long waiting times and a lack of resources) and in terms of the appropriateness of the services on offer.

204. Across the board, access to appropriate respite services was cited as one of the most important resources for carers. As well as providing opportunities for rest and relaxation, respite should enable carers to pursue a life alongside caring, whether through employment, education or socialising.

205. As such, respite arrangements must be regular, appropriate (including age-appropriate) and flexible. They must be of a sufficient standard to give confidence to both the carer and cared-for. They must recognise the variety of circumstances in which carers and the cared-for live, including rural location, and be flexible enough to meet these different needs. This should include meeting any additional costs.

206. Most importantly, carers should be involved meaningfully in the design and development of services that meet their needs. They should be partners in this process and supported to enable this to happen.

207. Of course, having a break from caring may not necessarily mean having a break from the person being cared for. It is, therefore, important that services are flexible enough to enable and support joint respite opportunities for both the carer and the cared for.

208. Unfortunately, so many of the carers we have heard from have had bad experiences. Whilst there have been some examples of good initiatives in different local authorities, these are far from standard and many carers are left with little or no respite provision, or an offer that is unsuitable for them and the person they

¹⁵³ RoP, 14 February 2019, paragraph 20

care for. Others are paying privately for help and this is putting strain on their personal finances as well as their health and well-being.

209. We believe there is a need for a more equitable provision of services for carers across Wales. Whilst the delivery of these services does not have to be the same in all local authorities, carers should be able to access a baseline of appropriate services, set to a minimum standard.

Recommendation 13. The Welsh Government must ensure equitable provision of services for carers across Wales, including respite services. As a starting point, it must ensure that a baseline range of support services for carers, based on eligibility criteria, is provided by all Local Authorities. The Welsh Government must introduce a mechanism to monitor delivery of this support. It should report back on progress within 6 months.

210. One of the main barriers to the provision of services for carers, including respite, is a lack of resources; our views on this are set out in Chapter 7. However, we believe there are a number of other matters that need addressing.

211. Since 2017-18, the Welsh Government has provided £3 million of recurring funding for respite to local government through the Revenue Support Grant. We welcome this, but recognise that this funding is part of a general allocation for local authorities and is not ring-fenced.

212. It is important that the use of this funding is transparent so that its impact can be evaluated. As such, the Welsh Government must publish information on expenditure on respite by local authorities on an annual basis. Further, we believe that the independent evaluation of the Act should consider the effectiveness of this investment, if it is not already doing so.

Recommendation 14. The Welsh Government must publish information on expenditure by local authorities on respite services. This should cover each financial year since the government's investment of £3 million of recurring funding began in 2017-18.

Recommendation 15. The Welsh Government must ensure that the impact of its £3 million recurring investment for respite services is evaluated. This work must identify the quality and quantity of the services provided, as well as capturing information about gaps in provision.

Direct Payments

213. Direct Payments have the potential to provide real choice and tailored support for carers and the people they care for, but they are not widely known about and not properly supported. We believe there is merit in the Welsh Government working with local authorities to provide greater advice and support for carers about Direct Payments. It is, however, important to recognise that this service will not necessarily be suitable for everyone, nor will every carer wish to make use of it. As such, it should be part of a suite of options available to carers.

Recommendation 16. The Welsh Government should ensure that a minimum standard of advice and support is provided across Wales to those carers wishing to make use of Direct Payments. This should form part of a baseline range of support services on offer to carers.

5. Young and young adult carers

Key themes in this chapter

There is a lack of recognition by public services of young carers. In particular, better school involvement is needed in terms of identifying and supporting young carers.

There is an inconsistent approach to assessing and supporting young carers across local authorities. Information advice and assistance (IAA) services have had some positive impact but it's very mixed.

It's important that a holistic approach is taken to assessing and supporting young carers and their families; a team around the family is needed.

There is a lack of respite care for young carers and it is of variable quality.

The Welsh Government has provided funding for Carers Trust Wales to develop the guidance and tools for a national roll-out of ID cards for young carers to enable them to access the support they need from schools, surgeries, pharmacies and other professionals

There was evidence that the Welsh Code of Practice should be revised to ensure young carers assessments take account of the burden of caring, as they do in England and Scotland.

214. Carers Trust Wales reports there are an estimated 21,611 young adult carers (aged 16-24) and 7,544 young carers (aged under 16) in Wales. Wales has the highest percentage of young carers in the UK.¹⁵⁴

215. Evidence from third sector bodies suggests that the prioritisation of young carers has declined in the last five years and is worse since the introduction of the Social Services and Well-being (Wales) Act 2014.¹⁵⁵

216. We were therefore particularly keen to hear directly from young and young adult carers about the unique challenges they face. On 31 January 2019, as part of Young Carers' Awareness Day, we held a workshop with 19 young and young adult carers, in partnership with Carers Trust Wales. This was followed by a formal

¹⁵⁴ Written evidence, C23

¹⁵⁵ RoP, 21 November 2018, paragraph 122

evidence session with representatives of the Carers Trust Wales' Youth Council, who are young carers themselves, to hear about their day-to-day experiences.

217. Young carers told us that, in their opinion, there are four clear things that most young carers think need to improve:

- Awareness of young carers at school;
- Opportunities to socialise with other young carers both at school and outside of school;
- Chances to be active and to go on holiday with and without the people they care for; and
- Guaranteed funding for young carers services so that they don't have to worry about losing the support they rely on.¹⁵⁶

Identifying as carers

218. The issues outlined earlier in this report about identifying as a carer also apply to young and young adult carers. Many young people themselves do not recognise the pressures of being a carer as it is just their "norm":

"I couldn't tell you when I started to call myself a young carer, because it was just something that I grew up with and I didn't know anything else."¹⁵⁷

"I just thought I was a daughter. I still don't use the term very much. Only recently I've started using the term – that I'm a young carer."¹⁵⁸

219. ADSS told us that it had been a challenge within local authorities to identify young carers, because the needs of young carers were unique and quite often complex when intertwined with those of the cared for and other adults carers in the household. It went on to say that children and young people quite often did not identify as carers, particularly when there was another adult carer in the house.¹⁵⁹

220. Additionally, young carers can be very protective and try to play down their role to avoid involvement with official agencies. Children in Wales told us:

¹⁵⁶ Letter from Carers Trust Wales' Youth Council - 26 February 2019

¹⁵⁷ RoP, 31 January 2019, paragraph 103

¹⁵⁸ RoP, 31 January 2019, paragraph 111

¹⁵⁹ Letter from Association of Directors of Social Services -18 January 2019

“I think one of the things is they [young carers] often underestimate or underreport the responsibilities that they have, and the work that they do, for fear that somebody will intervene and take them away.”¹⁶⁰

221. Further, support staff working with young carers raised concerns that there was a lack of recognition from schools and GPs about how much care is actually being provided by young carers.¹⁶¹

Assessing the needs of young carers

Numbers of assessments

222. Under the Act, all carers regardless of their age, have the right to an assessment where it appears that they may need support. However, talking to a number of young carers, we found that in a group of seven children, four had received an assessment and two did not know they existed.¹⁶² No participants in our focus groups could identify an assessment being carried out.¹⁶³

223. YMCA told us that young carers’ assessments were not taking place routinely across Wales. It reported that, in Swansea alone, YMCA was working with about 150 young carers, and not one of them had a young carers’ assessment as a statutory service.¹⁶⁴

Social services assessment process – inconsistencies/variation in approach

224. According to children’s charities, local authorities across Wales have different methods for assessing the needs of young carers. Some local authorities complete their own assessment then share this information with organisations that can support young people and their families. Others commission third sector organisations to develop and implement assessments of need and create action plans to work with families to reduce the impact of caring on a young carer. Unfortunately, we also heard that there are some that do not provide or complete any at all.¹⁶⁵

¹⁶⁰ RoP, 21 November 2018, paragraph 49

¹⁶¹ Focus Group Summary

¹⁶² Note of informal session with young carers

¹⁶³ Focus Group Summary

¹⁶⁴ RoP, 21 November 2018, paragraph 9

¹⁶⁵ HSCS Committee, 21 November 2018, Paper 3

225. Children in Wales told us that it was only aware of one local authority in Wales (Torfaen) that provided young carers' assessments in accordance with the Act.¹⁶⁶

226. Torfaen County Borough Council confirmed that it has "a dedicated Young Carers team who have always had a very proactive role in identifying young carers and carrying out young carer assessments".¹⁶⁷

227. YMCA believed that local authorities should be held accountable for completing assessments or commissioning services that undertake this role for them. It called for a national standard for a young carers assessment, that linked into the Social Services and Well-being Act and Future Generations Act, and highlighted the importance of a holistic approach to assessing and supporting young carers and their families:

"... our assessment asks five questions to identify the level of care that the young carer is providing. And if we aren't the best person to support that young carer, we will refer to either [] social services, or to the voluntary services, or to who that family needs. So, it's not just about the young carer, it's about the family as a whole, so there's a holistic approach."¹⁶⁸

228. Carers Trust Wales also raised concerns that too many professionals fail to identify carers or to have appropriate information-sharing mechanisms to ensure holistic packages of support are delivered for carers, and this was particularly apparent in the case of young carers.¹⁶⁹

Appropriate levels of care

229. In Wales, the assessment of the extent to which it is appropriate for a young carer to provide care is set out in a Code of Practice that accompanies the Act¹⁷⁰.

230. According to Carers Trust Wales, the Code is not clear in terms of what is deemed appropriate or what action should be taken to remove the responsibility for providing inappropriate care from young carers. It said that, in England and Scotland, the legislation is very clear in stating that young carers should not be providing "inappropriate" levels of care. Further, it stated that the Scottish

¹⁶⁶ RoP, 21 November 2018, paragraphs 10-12

¹⁶⁷ Written evidence, C13

¹⁶⁸ RoP, 21 November 2018, paragraph 47

¹⁶⁹ Written evidence, C23

¹⁷⁰ Social Services and Well-being (Wales) Act 2014: [Part 3 Code of Practice](#) (assessing the needs of individuals)

statutory guidance provided more detail on how to identify whether the level of care provided by the young carer is inappropriate.¹⁷¹

231. Carers Trust Wales said that there could be potential benefit in revising the Code of Practice to provide more clear guidance for local authorities in this regard.¹⁷²

232. We heard from ADSS that improvements were needed in how young carers are identified and supported, particularly young children who are eight years and under, that need protecting from inappropriate caring roles.¹⁷³

233. Social Care Wales told us that the Welsh Government should consider carefully its policy in relation to young carers:

“Whilst realistically it may be necessary and appropriate to support young carers in their caring role, it is important to understand and put policies in place that support people needing care and support to access that from available services, and significantly reduce a reliance on children to provide significant amounts of care and support to their families. This may well require more investment in paid care and support.”¹⁷⁴

The impact of caring on children and young people

234. The impact of caring on children and young people is clearly substantial and the range of support they are providing is significant.

235. During our workshop with young carers, they discussed their experiences of caring, i.e. what they do on a day to day basis. They identified the following tasks:

- Domestic chores (cooking, cleaning, laundry etc.);
- Giving treatment, including injections, pumps/tablets/drinks;
- Taking responsibility for and looking after other children (siblings), including preparing meals, personal care, help with homework, getting ready for and accompanying to school and attending school parents' evening;
- Shopping;
- Personal care for cared for person, including feeding. Cared for person may be a child (sibling) or adult (e.g. parent);

¹⁷¹ Written evidence, C23

¹⁷² Written evidence, C23

¹⁷³ Letter from Association of Directors of Social Services - 18 January 2019

¹⁷⁴ Written evidence, C09

- Caring for, supporting and “being there” for the family. Making people happy when they feel down;
- Handling seizures;
- Operating equipment, including wheelchair;
- Accompanying cared for person to hospital, meetings and appointments;
- Watching/supervising/spending the night with the cared for person;
- Help with organising the household/cared for person, including scheduling/ timekeeping;
- Providing company for the cared for person;
- Collecting and organising medication;
- Looking after pets;
- Sacrificing social life/emotional support;
- Involvement with clubs/voluntary organisations connected with cared for person; and
- Love.

236. According to Carers Trust Wales, more needs to be done to ensure that systems and structures are developed in a way that supports and empowers carers both to deliver good care and to prioritise their life alongside caring. This is particularly important for young and young adult carers who experience a range of barriers which can have a lasting detrimental impact on their life outcomes:

“Despite pockets of good practice, our Young Adult Carers Council report that for many young carers, a lack of support and understanding at school had a detrimental impact not just on their ability to achieve academically, but also on their wider health and wellbeing.”¹⁷⁵

Mental health and well-being

237. Young adult carers are developing health problems, including high levels of mental ill health, at a much higher rate than other young people. Research by Carers Trust Wales found that 38 per cent of young carers surveyed reported having a mental health problem:

- 19 per cent of young carers reported “getting stressed”;
- 22 per cent reported “worrying about the person you care for”; and
- 13 per cent reported “being depressed”.¹⁷⁶

238. Oliver Davies, Carers Trust Wales Youth Council representative, told us:

¹⁷⁵ Written evidence, C23

¹⁷⁶ Written evidence, C23

“It has a massive effect on your mental health. It can tend to get you get you quite low, and bring you quite down. There aren’t many people who you can turn to to talk to who have a full understanding of what a young carer’s role is and why this has made you so upset or brought down.”¹⁷⁷

239. CIW told us:

“Young carers generally are well supported, however, there are an increasing number with complex emotional needs and the lack of child mental health services means that workers supporting young carers are dealing with some challenging and complex issues. Some local authorities have safety plans in place for young carers on who they can contact for support if needed.”¹⁷⁸

240. Having someone to talk to about their experiences can be particularly beneficial for young carers. The majority of young carers told us that they want to be able to talk to somebody who they can relate to, and spoke positively about young carers groups as a helpful forum to enable them to share their experiences.¹⁷⁹

241. Young carers’ responsibilities can often prevent them socialising with other children and young people; and young carers groups can help fill this gap. One young carer, Bethan Evans, described how important young carers’ groups can be:

“Once you walk into that room, you get your childhood back.”¹⁸⁰

Opportunities for physical activity

242. Anecdotal evidence suggests that young carers are less likely to undertake regular physical activity than their peers. Reported barriers that limit access to leisure, and in particular physical activity, include time pressures, access to replacement care, and financial barriers.¹⁸¹

243. Carers Trust Wales told us:

“Young and young adult carers are a marginalised group with numerous restrictions on their ability to engage in exercise and we believe that more research needs to be undertaken to fully understand

¹⁷⁷ RoP, 31 January 2019, paragraph 12

¹⁷⁸ Written evidence, C08

¹⁷⁹ RoP, 31 January 2019, paragraph 56

¹⁸⁰ RoP, 31 January 2019, paragraph 64

¹⁸¹ Written evidence, C23

these barriers and how best they might be overcome, including the potential use of Young Carers ID Cards to offer free access to local authority run leisure facilities.”¹⁸²

244. It went on to say that young carers and young adult carers have an even greater need to be able to access regular activity than their peers to ensure their physical health and wellbeing, and called on the Welsh Government to make it a priority to remove barriers to young carers accessing opportunities for regular physical activity.

Transport

245. Transport, or affordable transport, is an issue for many young carers. Discounted travel and travel to young carers support groups was highlighted during our informal workshop with young and young adult carers.¹⁸³

246. Carers Trust Wales reported how most young carers cannot drive, and this impacts on their ability to travel when the person who normally drives them is ill or not available. Problems accessing suitable transport mean that young carers can be isolated or excluded from social activities.¹⁸⁴

Young carers and school

247. 27 per cent of young carers (aged 11-15) miss school or experience educational difficulties and young carers on average cut short or miss 48 days of school a year. Young adult carers are more likely than the national average not to be in education, employment or training (NEET) between 16 and 19.¹⁸⁵

248. Carers Trust Wales stated that official figures show that there is at least one young carer in every class and research suggests that the real figure is closer to four in every class.¹⁸⁶

249. Problems with school attendance or attainment can impact on the future of young carers. It can be difficult for young carers to think about the future when their focus is on more immediate concerns. One young carer reported missing school “when Mum is suicidal”.¹⁸⁷

¹⁸² Written evidence, C23

¹⁸³ Note of informal session with young carers

¹⁸⁴ Written evidence, C23

¹⁸⁵ Written evidence, C23

¹⁸⁶ Written evidence, C23

¹⁸⁷ Note of informal session with young carers

250. Additionally, young carers are more likely to be bullied, with a quarter of young carers reporting they have been bullied at school because of their caring role.¹⁸⁸

Support in schools

251. Carers Trust Wales' Young Adult Carers Council reported that, for many young carers, a lack of support and understanding at school had a detrimental impact not just on their ability to achieve academically, but also on their wider health and wellbeing.¹⁸⁹

252. Grace Barton, 17, a young carer from Mid Wales, told us that being a young carer had definitely impacted on her educational experience. She suggested that this was the case for most young carers and was largely down to a lack of support at school.¹⁹⁰

253. We heard from many young carers that support at school is variable, and that the support available will depend on individual staff members, and is not provided by the school as a whole.

254. Oliver Davies, 13, a young carer from Bridgend said:

“There are definitely a few teachers in my school, personally, that have been an amazing help to me and my family, but there are still other members of staff and teachers in school who don't have that understanding.”¹⁹¹

255. Many young carers told us that some teachers are sympathetic and helpful, but others are “not on the same page” and do not understand the impact of being a young carer. Refusing extensions to deadlines for work was cited as an example.¹⁹²

256. Bethan Evans, 17, a young carer from Swansea told us:

“...we can deal with homework, and we can deal with the stress of school, it's having that understanding that we may need a bit more

¹⁸⁸ Written evidence, C23

¹⁸⁹ Written evidence, C23

¹⁹⁰ RoP, 31 January 2019, paragraph 8

¹⁹¹ RoP, 31 January 2019, paragraph 20

¹⁹² Note of informal session with young carers

time, and, if we do ask for that time and say we have had a problem at home, it's the recognition that it's what is needed..."¹⁹³

Awareness of young carers by their peers

257. We have already heard that young carers do not feel supported by teachers and staff at school, but many also reported a lack of understanding by friends and peers about what it means to be a young carer.

258. Oliver Davies told us:

"A few of my friends know [that I'm a carer], but still lack that understanding. And some recent research went out, and almost a quarter—23 per cent—of young carers came back telling us that they find that their caring role makes it harder for them to make friends."¹⁹⁴

259. We heard that a greater understanding of the role and needs of young carers was needed at a whole school level.¹⁹⁵

Guidance for schools

260. A number of young carers indicated that guidance for schools on how to support young carers would be a useful tool.¹⁹⁶

261. Carers Trust Wales has developed guidance for schools¹⁹⁷, with the aim to make the identification and support of young carers in primary and secondary schools in Wales as easy as possible. Further, we heard that some schools have initiatives in place to raise awareness of young carers and to provide support where it is needed. For example, Gwent has a Young Carers in Schools programme in which a named teacher acts as a young carers' champion. This is a voluntary scheme.

262. However, we heard that the picture was mixed, with some schools providing this type of support and other young carers reporting that their school either did not have a carers' champion or that they were not aware that they had one.¹⁹⁸

263. Carers Trust Wales stated that even some of the most "carer-aware" schools in Wales still did not have links with local carers services or mechanisms to signpost

¹⁹³ RoP, 31 January 2019, paragraph 22

¹⁹⁴ RoP, 31 January 2019, paragraph 16

¹⁹⁵ RoP, 31 January 2019, paragraph 29

¹⁹⁶ RoP, 31 January 2019, paragraphs 45-47

¹⁹⁷ [Young Carers in Schools Step-by-step Guide tools \(Wales\) \(2017\)](#)

¹⁹⁸ RoP, 31 January 2019, paragraphs 31-33

carers to preventative services or for a formal assessment of their wider support needs beyond an education setting.¹⁹⁹

264. ADSS Cymru also highlighted the work being done in Gwent through the Young Carers in Schools programme but said:

“The issue [] I have is that that is a voluntary scheme—it’s up to the schools whether they decide to take that on or not. What I’d like to see is all of the schools taking it on and introducing it. [] the difficulty is, that we can’t make it compulsory.”²⁰⁰

265. At the launch of the pilot programme in 2017, the then Cabinet Secretary for Education and Minister for Children and Social Care issued a joint statement highlighting the importance of supporting schools to identify young carers and to provide appropriate support to meet their needs in terms of educational attainment, emotional health and learner well-being. It was also announced that to help develop a stronger evidence base, Estyn would undertake a thematic review into how young carers are identified and supported at school and in Further Education colleges to take place in 2018-19.²⁰¹

266. The findings of Estyn’s thematic review were published in May 2019²⁰². The report stated that many secondary schools, colleges and pupil referral units did not know which learners had a caring role at home, and as a result, the support young carers received varied widely across Wales. The inspectorate highlighted that providers who identify and support young carers can help make a real difference to academic success and wellbeing for these learners.

267. The report recommended that schools, colleges and pupil referral units identify which learners have a caring role and have a dedicated member of staff to lead on championing young carers’ needs.

Young carers identification (ID) cards

268. We heard that young carer ID cards have the potential to identify young carers in a variety of settings, such as schools, healthcare and leisure. Some local authorities have been operating these schemes for a number of years, but general recognition of the card by professionals is “really low”.

¹⁹⁹ Written evidence, C23

²⁰⁰ RoP, 21 November 2018, paragraph 389

²⁰¹ [Joint statement](#), December 2017

²⁰² Estyn thematic report, [Provision for young carers in secondary schools, further education colleges and pupil referral units across Wales](#), May 2019

269. Carers Trust Wales told us that the lack of recognition of the cards was something that “our youth council speaks about that a lot, particularly in terms of [recognition of the card in] the pharmacy”. It went on:

“Some can have trouble picking up medications for their parent and the use of an ID card potentially has helped for some. But recognition levels are really low. [...] I think that’s something that was described really strongly when we met in October as a whole council.

There was an experience where someone had shown a card and somebody didn’t know what it meant and it was embarrassing, so they’re not going to use it anymore. So, I think, for us, it is the consistency of the professionals knowing that they need to recognise the card and adapt what they’re doing to meet the needs of that young carer.”²⁰³

270. We also heard from young carers that there is a need for more recognition and awareness of the scheme:

“I do have one [a young carers ID card] and it has been really helpful. But there are still teachers who are like, ‘Oh, it’s just an excuse; it’s not good enough.’ I think that they need to be more recognised.”²⁰⁴

271. In 2018-19, the Welsh Government provided funding to Carers Trust Wales to develop guidance and tools for a national roll-out of ID cards for young carers to enable them to access the support they need from schools, surgeries, pharmacies and other professionals. It is reported that this funding will continue in 2019-20.²⁰⁵

272. Barnardo’s Cymru told us:

“We would really advocate for a Wales-wide card. We’d also advocate for it not only being used in schools, but also being used to access leisure services at a discounted rate, but also to access health and health requirements, so health services—for example, being able to collect medication from a pharmacy.”²⁰⁶

²⁰³ RoP, 31 January 2019, paragraph 131

²⁰⁴ RoP, 31 January 2019, paragraph 129

²⁰⁵ Written evidence, Deputy Minister for Health and Social Services

²⁰⁶ RoP 21 November 2018, paragraph 41

Evidence from the Deputy Minister

273. In terms of the appropriate levels of care that should be provided by young carers, the Deputy Minister's official told us that the statutory codes of practice were very clear in terms of the role of the assessment, in that it must consider the extent to which the carer is able and willing to provide the care and to continue to provide the care.²⁰⁷

274. She said that the new carers assessment toolkit being produced by Social Care Wales would help in terms of undertaking those assessments, whatever age the carer:

“It's work very much with the individual, the carer and the family—the young carer—to look at the capacity resources and the outcomes that they want to achieve. It's very much outcome-focused on what does the young carer want to achieve.”

275. She stated that it was important to consider young carers' needs holistically and without making any judgements.²⁰⁸

276. In relation to the role of schools, the Deputy Minister told us that they are “crucial in helping young carers, recognising young carers and making their pathway a bit easier”. She said that the development of the new curriculum, with its emphasis on well-being, should provide an opportunity for there to be more empathy and understanding in schools.²⁰⁹

277. She highlighted the work that has been undertaken by Carers Trust Wales to produce two guides for schools, the “Supporting Young Carers in School” guide and toolkit, and “Supporting Young Carers in Schools: A Step-by-step Guide for Leaders, Teachers and Non-teaching Staff”, which were written in association with teachers and school staff, to make the identification of carers as easy as possible.²¹⁰

278. The Deputy Minister also drew attention to a toolkit developed by Carers Trust Wales aimed at supporting students with caring responsibilities who are in further education.

²⁰⁷ RoP 14 February 2019, paragraph 72

²⁰⁸ RoP, 14 February 2019, paragraph 72

²⁰⁹ RoP, 14 February 2019, paragraph 39

²¹⁰ RoP, 14 February 2019, paragraph 40

279. She went on to say that while these resources were available for schools to access, she believed there was a need for awareness training in order for schools to know that they need to access them.²¹¹

280. In relation to ID cards, the Deputy Minister confirmed that the programme for implementation was being finalised and she would be writing to local authorities, providing details of the scheme and their role in implementing it. She confirmed it would be a national scheme, specifically designed to meet the needs of young carers.

281. She also said that it would be important that professionals understood the issues relating to young carers, to ensure the benefits of the scheme were fully realised.²¹²

Our view

282. Children and young people who are carers face significant challenges. We heard directly from young carers about the sorts of tasks they have to undertake on a daily basis. These included collecting, organising and administering medicines to the person they care for; managing the household, including shopping and cooking; and taking responsibility for their siblings, which could mean helping with homework and even attending parents' evenings.

283. In addition to the practical burdens of caring, we should not underestimate the considerable emotional pressure on young carers. The young carers we spoke to told us they felt a responsibility to "be there" for their families and to "make people happy when they feel down".

284. As a result of these challenges, young carers face worse prospects than their peers in many respects, including in terms of employment and access to higher education. In addition, approximately 10% of young carers are on the child protection register, mainly due to concerns around neglect.

285. It is deeply troubling, therefore, to hear evidence from third sector bodies that prioritisation of young carers has declined in the last five years, and that matters are worse since the introduction of the Act.

286. As we state earlier in this report, assessing and supporting carers and their families demands an holistic approach, and young carers are no different in this

²¹¹ RoP, 14 February 2019, paragraph 41

²¹² RoP 14 February 2019, paragraph 47

respect. Services for young carers should be person-centred, age-appropriate and flexible to meet their specific needs.

287. Unfortunately, there are inconsistencies in the approach to assessing and supporting young carers across local authorities, and the experiences of advice, information and assistance provided to young carers has been mixed. This is unacceptable.

288. We believe that the Welsh Government needs to be more ambitious about the services and support that all young and young adult carers can expect to receive, both in terms of their caring role and in their life alongside caring. The support and services for these young carers must be consistent, long-term and ensure a strong connection between schools and carers services.

Recommendation 17. The Welsh Government must ensure that all young and young adult carers are able to access the support and services they need. In doing so, it must address the specific concerns raised by young carers in evidence to this committee. It must ensure that the support and services for young and young adult carers are person-centred, age-appropriate and flexible to meet their specific needs. There must also be a strong connection between schools and carers' services. The Welsh Government must clearly set out how it will achieve this, and must report back on progress within 6 months.

Appropriate levels of care

289. It is unclear the extent to which needs assessments for young carers include consideration of whether the level of care provided by a young carer is "appropriate". The position appears to be more straightforward in England and Scotland, where the statutory guidance accompanying the relevant legislation provides examples of the types of tasks that may be considered inappropriate for a child carer to undertake, including "personal care such as bathing and toileting, carrying out strenuous physical tasks such as lifting, and administering medication".

290. The Code of Practice that deals with this matter in Wales should be strengthened to bring it in line with England and Scotland, as a minimum.

Recommendation 18. The Welsh Government should strengthen the existing Code of Practice for Local Authorities about what is considered to be an "appropriate" level of care for a young carer to ensure that the position in Wales is at least equal to that in England and Scotland.

Schools

291. There appears to be a lack of recognition of young carers by public services generally. We believe there are significant benefits to all involved in improving the understanding of health, social and education services of the role and responsibilities of young and young adult carers.

292. In particular, we feel there is a need for better, more consistent involvement by schools in terms of identifying and supporting young carers. There are dedicated teachers who are doing excellent work, but the system cannot depend on the actions of individuals.

293. We heard of a number of good initiatives in some schools, such as carers' champions and peer groups, and we welcome these. Where they exist, they seem to provide much needed support structures for those young people, but unfortunately they are far from standard. There are also a small number of freely available toolkits to support schools in meeting the needs of young carers, but their use is also not standard.

294. The significant demands placed on young carers should be recognised by, and throughout, all schools, and there is a need for stronger guidance and better sharing of best practice to underpin this. There is also a need for strong links to the Welsh Government's "Whole School" approach to mental health and wellbeing support in schools.

Recommendation 19. The Welsh Government must update and strengthen existing guidance for schools about identifying and supporting young carers, to ensure awareness throughout all schools of the demands on young carers. It should encourage and create opportunities for the sharing of best practice of support services for young carers within schools.

Young carers' ID cards

295. We strongly support the young carers' ID cards scheme. We believe it is an important tool in identifying young carers and recognising their unique status.

296. However, the benefits of the ID cards scheme will only be fully realised if it is a national scheme, delivered by all local authorities with appropriate support from the Welsh Government and accessible to all young and young adult carers across Wales. To date, we feel that insufficient progress has been made in this area.

Recommendation 20. We believe that the young and young adult carers' ID card scheme should be a national scheme, delivered by all local authorities with

appropriate support from the Welsh Government and accessible to all young and young adult carers. The Welsh Government should ensure this is achieved as a matter of priority. It should report back on progress within 6 months.

297. Beyond this, and in the future, there could be opportunities via the scheme to enrich the lives of young carers in other ways, for example through a concessionary public transport and leisure scheme for cardholders.

6. Provision of information, advice and assistance

Key themes in this chapter

There were mixed views from carers about the quality of information advice and assistance provided by local authorities – some have found it helpful, others were unaware of it or found it unsuited to their needs, especially young carers.

Poor experiences of some seeking information, advice and assistance from local authorities. Many don't know where to go to access information, and their main sources are often friends and family, other carers or the third sector.

Reports of inconsistent information being provided by local authorities. There is a need for standardisation of information, advice and assistance across all local authorities and local health boards.

Important that people are able to access appropriate information at the right time, before they reach crisis point.

WLGA stated that all local authorities now have a central advice and information point, and provision for Welsh speakers. Dewis Cymru provides an online information service about improving well-being.

298. Section 17 of the Social Services and Wellbeing (Wales) Act 2014 requires local authorities to secure the provision of information, advice and assistance about care and support. The service must include information about the care and support available and how to access it. The information, advice and assistance must be provided “in a manner which is accessible to that person”.

Availability of information

299. The provision of information, advice and assistance is critical to the knowledge of, and access to, support and preventative services for carers.

300. Care Inspectorate Wales told us that there is a wide range of information available but carers sometimes have to go to several places to obtain this and it is not always easily accessible, especially at times of crisis.²¹³

²¹³ Written evidence, C08

301. This corresponded with reports we received from carers that they felt frustrated in their attempts to access information, as this required considerable time and energy.

“We need more information, where do we go for information on the support available?” *Participant from Credu Carers Llandinam*

“I only know about support through word of mouth.” *Participant from Stroke Association Carers group*²¹⁴

302. Carers who took part in our focus groups told us that there were inconsistencies in the information and support offered to them, with some members of the group even having received different levels of information from the same authority. There was also a view that the help offered depended heavily on individual social workers.²¹⁵

303. Torfaen CBC told us that the message they were hearing from carers was that they needed to know that help was available from the local authority if it was needed:

“Too often we only hear a cry for help when a carer reaches crisis point and feels that they can’t go on with their caring role.”²¹⁶

304. Carers Wales told us that their Track The Act survey showed that, when carers were able to access information from their local authority, they found it useful, but:

“the issue is that not enough carers are seeing that information. We need to increase the reach of that information out.”²¹⁷

Accessibility of information

305. Care Inspectorate Wales highlighted the need to recognise that some carers had no internet access and therefore felt disempowered by the increased focus on web-based information. It also advised that improvements were needed to ensure that carers information was available in a wider range of formats, including for those with visual impairments, especially via the local authorities web pages.²¹⁸

²¹⁴ Focus Group Summary

²¹⁵ Focus group summary

²¹⁶ Written evidence, C13

²¹⁷ RoP, 15 November 2018, paragraph 153

²¹⁸ Written evidence, C08

306. We also heard of the importance of providing information, advice and support in an age appropriate way. Age Cymru told us:

“Many older people are unwilling or unable to use the Internet, or may not trust the accuracy and reliability of an Internet source. Many older people have trouble speaking and/or hearing on the telephone and this needs to be handled appropriately and respectfully.”²¹⁹

307. YMCA Swansea drew attention to the specific needs of young carers. It said that local health boards had created and adopted Carers Strategies that included the provision of information, advice and assistance, and while this was a positive start, far too often young people’s views and experiences were not thought about:

“Many of the events that are hosted by local authorities or voluntary services are hosted during the day time on weekdays to cater for adult carers. This is then not accessible for young carers as the aim of the services supporting young carers is to ensure they are attending school. YMCA Swansea.”²²⁰

Single point of access

308. According to the NHS Confederation, “the provision of information and advice is an overcrowded market with many duplicating and competing with other”. It believed that carers need a single hub or contact that addresses all of their needs:

“This needs to range from advice on benefits and financial matters, accessing respite services, medical advice and advice on legal matters. Particularly for carers who find themselves having to care for someone living with dementia where there is no lasting power of attorney, there are often challenges in accessing the right support.”

309. Glamorgan Voluntary Services told us that carers would “value a one-stop-shop where they could get information on support and services for them from one phone number” and this would “do much to alleviate stress of the carer”.²²¹

310. Carers Trust Wales also called for “a clear focal point from which carers and professionals can access up to date information, advice and support”. It stated:

²¹⁹ Written evidence, C19

²²⁰ HSCS Committee, 21 November 2018, Paper 3

²²¹ Written evidence, C14

“Our evidence shows that having an easily identifiable point of contact, whether that be a physical building, a main telephone line, an outreach worker or combination of these things, is key in ensuring carers are able to access the support they need.”²²²

311. WLGA told us all local authorities now have a central advice and information point. In addition, WLGA told us Dewis Cymru is a key information hub for carers looking for information about their wellbeing.²²³

312. However, we did hear some concerns in relation to the use of single access points. Firstly in relation to people’s ability to navigate through those single points of access and secondly where people were referred once they were through. Age Cymru highlighted the importance of training for staff delivering the single points of access to recognise a carer’s needs and be able to point them in the right direction.²²⁴

313. We heard from Social Care Wales that it had been working with Welsh Government and local authorities to develop a competency framework to support the development of a wide range of Information, Advice and Assistance workers. It stated that the needs and experiences of carers is specifically referenced in this emerging framework.²²⁵

314. We heard from the NHS Confederation that health boards were also supporting specific projects and groups on a local level to increase awareness of the needs of carers and improve the quality of information and support services that are available to them.²²⁶

Dissemination of information

315. We heard that, although there were many different ways that information was being disseminated to carers, this was not being done effectively. On this point, Mencap Cymru stated that the carers they had spoken to did not view local authorities as a source of information and advice but instead relied on charities and word of mouth as their main source of information:

²²² Written evidence, C23

²²³ RoP, 21 November 2018, paragraph 365

²²⁴ RoP, 15 November 2018, paragraph 322

²²⁵ Written evidence, C09

²²⁶ Written evidence, C31

“Getting information is a matter of luck, whether you get a decent social worker, or you know a family that have a good social worker, or a family that have experience of something you are looking for information on.”

316. A number of carers indicated that they would prefer to get information and advice from the third sector, as it was felt to be more accessible and “less daunting, like I could ask what something means and not get judged”.²²⁷

317. Carers who took part in our roundtable event generally felt there was a lack of information on carers’ service in the places where it would be most useful and accessible, such as GP surgeries, libraries, hospitals, post office, food banks, community boards in supermarkets and social media.

318. Carers felt that a less formal and more personal approach was needed, perhaps with social workers and local authorities going into the community to pro-actively disseminate information and answer questions.

319. We also heard that information needed to be standardised and condensed into a manageable resource, for example a directory of information with details of how to obtain further advice and guidance.

320. According to Care Inspectorate Wales, carer group meetings were valued and felt to be a good source of information and support providing good company, a place to meet people and share concerns and positive experiences. It said that some counties had regular carer information days and they had been told by carers about the warm human response they had received, along with information leaflets and contact details of support groups and services available to them.²²⁸

321. We also heard examples of training courses for carers being provided by local authorities. In Torfaen, for example, a six-week carers induction course aimed primarily at new carers had been introduced which would cover all carers issues and information”.²²⁹

Performance of IAA services

322. A number of witnesses raised concerns that there was currently no way of measuring the performance of IAA services. Evidence from Care Inspectorate Wales stated:

²²⁷ Written evidence, C30

²²⁸ Written evidence, C08

²²⁹ Written evidence, C13

“It was apparent that local authorities do not have robust monitoring arrangements in place to determine the quality of the services they commission to provide information and support to carers.”²³⁰

323. Both the Older People’s Commissioner and Carers Wales told us that, because management information data on the number of carers making contact with the service is not collected by all of the IAA services, there was no mechanism in place to measure their performance.

324. Carers Wales told us:

“From our information request responses from local authorities, it is apparent that there is clearly good practice in many areas but this is not translated across every local authority in Wales.”²³¹

Welsh language

325. Carers Trust Wales²³² and the Older People’s Commissioner highlighted the importance of being able to access information through the medium of Welsh. The Commissioner told us:

“... when you’re in a caring situation, and it can be really difficult and you might be at a point of crisis, it’s so important, then, that you’re able to access services in the Welsh language if that’s what you want to do.”²³³

Evidence from the Deputy Minister

326. We heard from the Deputy Minister that “IAA services, provided by local authorities in accordance with the Act, provide a proportionate response to an enquiry to empower the individual to access early intervention and preventative services”.²³⁴

“For carers, this may include;

- information on support, without the need for an assessment (which for many people is not needed and would be disproportionate);

²³⁰ Written evidence, C08

²³¹ Written evidence, C27

²³² Written evidence, C23

²³³ RoP, 15 November 2018, paragraph 328

²³⁴ HSCS Committee, 14 February 2019, Paper 1

- advice on support, that is comprehensive, impartial and appropriate to the individual, following an assessment that is proportionate to the information provided by an individual;
- assistance which enables the individual to access the appropriate care; and
- support services, including early intervention and preventative services.”²³⁵

327. In relation to being able to access information and services through the medium of Welsh, the Deputy Minister told us that health bodies and local authorities had a duty under the Welsh Language Act to ensure people were able to receive services in the language of their choice.²³⁶

Our view

328. Being able to access appropriate information at the right time is crucial for carers to avoid them reaching crisis point. It can mean greatly improved outcomes for them in terms of their physical and mental health, and their financial situation. It can also reduce the likelihood of needing a formal assessment.

329. It was very disappointing, therefore, to hear that carers are still not routinely being provided with information, advice or assistance. They told us that, often, they do not know where their first point of contact is, who to approach, or who to believe when information sources conflict. We also heard reports of inconsistent information being provided not just by different local authorities, but in some cases, within the same authority.

330. We heard that, although there is a wide range of information out there, carers have to seek it out themselves as it is not readily available. They also have to go to multiple sources to gather it, and it is not always easily accessible particularly at times of crisis. For many carers, their main source of information continues to be friends and family, other carers, or the third sector.

331. It is important that there is a central point of information for carers and professionals that is good quality, comprehensive and fully accessible. It should meet the specific needs of different groups of carers, including young and older carers, disabled carers and Welsh speakers.

²³⁵ HSCS Committee, 14 February 2019, Paper 1

²³⁶ RoP, 14 February 2019, paragraphs 15-16

332. It is clear that efforts have been made by local authorities to improve the information they provide to carers and the way that they provide it, and we have heard of some really good initiatives operating in several local authority areas. Further, we understand that all local authorities now have a central information point, and that an online information service for carers, Dewis Cymru, is available. However, based on the evidence we heard, there is a need to better publicise the availability of these services.

333. There is also work to be done on standardising information, advice and assistance across, and within, all local authorities and local health boards. This should not mean that all local authorities and health boards will have to provide the same services, but it should ensure a minimum standard is provided to all service users whilst giving flexibility to tailor services and trial new initiatives.

Recommendation 21. The Welsh Government needs to ensure the standardisation of information, advice and assistance for carers across local authorities and local health boards. This must include bilingual provision of these services. As part of this, the Welsh Government should convene representatives from local government, health boards and the third sector with the aim of developing an approach that will secure these improvements for the service user. We ask the Deputy Minister to report back to us on progress within 6 months.

Recommendation 22. The Welsh Government needs to work with local authorities to better promote the availability of information, advice and assistance for carers, including clear details of how to access it. This should be done as part of the publicity campaign referred to in Recommendation 4.

Recommendation 23. The Welsh Government needs to ensure that staff providing information, advice and assistance as part of each local authority's central advice and information point have up-to-date information about rights and services for carers under the Act, and that refresher training will be provided where necessary. We note the work being undertaken by Social Care Wales, the Welsh Government and local authorities to develop a competency framework to support the development of information, advice and assistance workers. We ask that the Deputy Minister updates us on progress with this project.

7. Funding and resources

Key themes in this chapter

We heard strong evidence about a lack of funding and resources to support carers' services.

The third sector is a major provider of services to carers but its funding is insecure and unsustainable.

Short-term grant funding arrangements make it difficult for the sector to plan service delivery.

Resources to implement the Act

334. One of the main messages that came through in the evidence we received was about funding; that statutory service providers were under pressure because of reducing budgets and that the third sector was struggling with short-term, unsustainable funding arrangements.

335. Hafal told us that “resources, especially for adult social care, have been under intense pressure since the Act to the point where for some carers the right to assessment has little meaning”. It went on:

“if there are no carer-specific services available, including respite care, then a major part of the point of the assessment is removed; if in addition there is little or no service being delivered to the person they care for, then much of the rest of the purpose of an assessment (namely to agree cooperation between the carer and services in providing care) is also lost.”²³⁷

336. This evidence was supported by other third sector organisations, as well as a number of carers in our focus groups, who told us that they had “lost faith in the system” and did not want to go through the process if little or no help or support could be offered by social services as a result of that assessment.²³⁸ Similarly, a number of support workers in our focus groups told us that assessments raised

²³⁷ Written evidence, C10

²³⁸ Focus group summary

expectations when, because of a lack of resource, very little support could then be offered.^{239 240}

“Nothing happens after an assessment now – but how could it without the money?” *Participant from Carers Wales Committee*²⁴¹

337. The WLGA and ADSS Cymru outlined the problems facing local authorities in delivering services to carers during times of austerity:

“(…) over the last 8 years Councils’ core grant funding has reduced by 22% after adjusting for inflation. If you take schools funding out, core funding has fallen by 35%.”²⁴²

338. From a local government perspective, the WLGA and ADSS Cymru told us that it was “clear that the local government funding position has serious consequences for wellbeing. It constrains social care which, in turn, constrains the voluntary sector and care providers. This all points to the need to urgently reform our current arrangements and take on the complex task of developing a long term sustainable funding framework for social care”.²⁴³

339. This was reflected to a degree in the views of participants in our focus groups, who told us that they felt that social services staff “know how much they have to work with and will offer support accordingly, rather than based on the need of the carer”²⁴⁴. The Alzheimer’s Society felt, however, that “statutory service staff and unpaid carers are doing the best job possible in the current climate”.²⁴⁵

340. We heard from the Deputy Minister about specific financial support from the Welsh Government for carers services. This is covered in more detail later in this Chapter. However, in relation to the £3 million for local authorities for the provision of additional respite care, the Motor Neurone Disease Association (MNDA) recommended that the Welsh Government should seek an evaluation of the impact of this funding on respite provision in Wales, and specifically identify the quality and quantity of respite provision and support for carers of people with complex conditions like Motor Neurone Disease.

²³⁹ Focus Group Summary

²⁴⁰ Roundtable event – Summary of discussion

²⁴¹ Focus Group Summary

²⁴² Written evidence, C28

²⁴³ Written evidence, C28

²⁴⁴ Focus group summary

²⁴⁵ Written evidence, C18

Funding for the third sector

341. The third sector is a major provider of services to carers on behalf of local authorities. It also provides support to carers who are not receiving services as a result of a carers' needs assessment. We heard strong evidence that funding for the third sector is insecure and unsustainable. On this point, Carers Trust Wales told us that sustainability of funding for the third sector "is the biggest risk" to delivery of services for carers.²⁴⁶ It said that third sector carers' services are "struggling financially across the piece", and that carers' services have reduced in recent years at a time when unmet need is increasing.²⁴⁷

342. Carers Trust Wales told us that, in order to make carers' services sustainable, the Welsh Government must ensure a "sustainable and proportionate funding base for generic carers services. This will ensure that more carers are able to access preventative support, rather than having to access their right to formal support under the Act once at crisis point".

343. Similar points were made by a number of other organisations, including third sector and local authority representatives, highlighting the challenges of short-term grant funding arrangements for the third sector, and the need for longer term arrangements to enable good planning and delivery of services. On this point, Carers Wales stated:

"We (...) recommend that Welsh Government change its approach from annual funding allocations to longer term grants to enable longer term planning and sustainability of carers services."²⁴⁸

344. ADSS Cymru expressed similar views, stating:

"There is universal agreement that short term funding is not viable for providing consistent and quality services for carers. It makes it difficult for all sectors to plan and provide services, and leads to staff turnover and the loss of experienced staff, especially in the third sector."

"There appears to be universal agreement that a single grant for carers services either through a pooled budget and/or delivered through the Regional Partnership Board would be widely supported."²⁴⁹

²⁴⁶ RoP, 15 November 2018, paragraph 215

²⁴⁷ RoP, 15 November 2018, paragraph 212

²⁴⁸ Written evidence, C27

²⁴⁹ Letter from Association of Directors of Social Services - 18 January 2019

345. It went on:

“If Welsh Government persists with giving grants specifically for carers we would require flexible criteria for its use to allow creativity and the ability to pilot new initiatives.”²⁵⁰

346. Similar points were also made by Swansea Council, which called on the Welsh Government to recognise the challenges that come with short term funding at very short notice and consider a three to five year funding model, which would enable more effective planning of services resulting in sustained and consistently delivered services.²⁵¹

347. Separately, we heard that the process of applying for funding within the third sector is highly competitive and can be a long process, taking months for a decision. This is an issue for long-term planning within charities, many of whom lack the time and capacity to devote to the application process.²⁵² To assist with this, Carers Trust Wales called for a list of funding sources available for charitable organisations.²⁵³

Involvement of third sector in service planning and funding decisions

348. We heard concerns from witnesses that third sector organisations are not sufficiently involved in planning and funding decisions at a regional level.

349. Carers Trust Wales told us that, given that the majority of preventative services are delivered by the third sector, “it is disappointing that planning for such services does not have sufficient third sector input”. It went on to describe:

“growing concerns relating to the lack of meaningful representation of the third sector and carers at regional partnership board level. Lack of support, limited financial autonomy and opportunity to strategically plan are all factors that contribute to a power imbalance that ultimately impacts on the quality and appropriateness of services commissioned.”²⁵⁴

350. Carers Wales supported this view, stating that carers’ representatives on the regional partnership boards say their ability to influence is limited.²⁵⁵

²⁵⁰ Letter from Association of Directors of Social Services - 18 January 2019

²⁵¹ Written evidence, C17

²⁵² Written evidence, C23

²⁵³ Written evidence, C23

²⁵⁴ Written evidence, C23

²⁵⁵ RoP, 15 November 2018, paragraph 247

351. Carers Trust Wales believed that regional partnership boards should issue a clear mandate as to how the third sector must be involved in the planning process.²⁵⁶

Evidence from the Deputy Minister

Resources to implement the Act

352. In her evidence to us, the Deputy Minister outlined the financial support for carers that had been agreed prior to the establishment of the Ministerial Advisory Group. This included £3m to local authorities for the provision of additional respite care (recurring funding provided via the local government Revenue Support Grant); and £50m in revenue to regional partnership boards (in 2018-19) to support the development of innovative services in various priority areas on integration, including specifically for carers.²⁵⁷

353. In November 2018, the Minister for Children, Older People and Carers announced that additional funding to support carers would be included as part of a larger investment of an extra £15m in 2019-20 for older people and carers in the Integrated Care Fund (ICF).

354. At the time of taking evidence, the Welsh Government's Ministerial Advisory Group had met on two occasions. The Welsh Government told us that its focus at that time was on respite, and that a sub-group had been established to constructively challenge and develop ideas to take forward.²⁵⁸

355. We asked the Deputy Minister whether she was confident that funding transferred to the revenue support grant would result in additional services for carers. She told us that all local authorities were under a duty to ensure that carers were assessed and a care plan drawn up based on their eligibility. She confirmed that the Welsh Government had written to local authorities setting out what it expected of them.

Funding for the third sector

356. We discussed with the Deputy Minister the challenges facing the third sector in terms of sustainability of funding, and specifically the merits of a single carers' fund. Responding to this, the Deputy Minister told us that a single fund could be achieved now, as "regional partnership boards are required to consider whether to

²⁵⁶ Written evidence, C23

²⁵⁷ Welsh Government evidence paper

²⁵⁸ RoP, 14 February 2019, paragraph 140

establish a pooled fund whenever they do anything jointly, and so this could include pooling budgets in relation to the delivery of services for carers”.²⁵⁹

357. We also discussed the problems identified by witnesses of the short-term nature of grant funding for the third sector. The Deputy Minister told us:

“(…) you understand why they [the third sector] want the core funding, because it does give stability. But, basically, I suppose the purpose of having the third sector is that it is more of an independent body, and they do have their own funds as well (…).”²⁶⁰

358. The Deputy Minister’s official went on to say that the Welsh Government had “set a goal” for all regions that 20 per cent of integrated care fund resources should be used for third sector projects, and that progress towards this was monitored on a quarterly basis. At the time of taking evidence, only one of the seven regions was meeting that test.²⁶¹

359. In terms of monitoring the services being delivered as a result of Welsh Government funding, the Minister’s official told us that “health boards, local authorities and the third sector are joint partners in (…) regional partnership boards, and together they should be assessing and agreeing the needs of people in their areas, and commissioning plans to meet those needs”.²⁶²

360. We asked how the Welsh Government monitored this, and the Minister’s official said this was done “through monitoring of the integrated care fund”.²⁶³ He went on to say:

“Government isn’t always in the best position to determine what the nature of provision should be on the ground. Regional partnerships boards are those mechanisms that are there to assess needs and commission plans. It’s Government resources that we are accountable for, so we take that role very seriously and we do scrutinise.”²⁶⁴

Our view

361. As we have already stated, unpaid carers are estimated by the Sector to deliver the equivalent of £8.1 billion of care per year. The work undertaken by unpaid carers represents huge cost savings to the state, and as such, providing

²⁵⁹ RoP, 14 February 2019, paragraph 131

²⁶⁰ RoP, 14 February 2019, paragraph 115

²⁶¹ RoP, 14 February 2019, paragraph 116-128

²⁶² RoP 14 February 2019, paragraph 29

²⁶³ RoP 14 February 2019, paragraph 31

²⁶⁴ RoP, 14 February 2019, paragraph 33

appropriate support to unpaid carers is a significant area of preventative spend. The less support there is for unpaid carers, the greater the demand for state-funded services.

362. The legislation promised improved rights and services for carers but it is clear from the evidence we received that there are questions about whether sufficient funding is available to enable these rights and services to be delivered in practice.

363. We were deeply concerned to hear that, for many carers, the right to an assessment has little meaning because of a lack of resources to provide the necessary services arising out of that assessment. Equally, it is concerning to hear of social services staff trying to manage down carers' expectations because services are either not available or have long waiting lists.

364. Whilst the Welsh Government has made additional money available for carers services, including respite, over the last few years, questions remain as to whether overall funding is sufficient to meet current and projected need.

365. The Welsh Government needs to be clearer about what support services can reasonably be offered and delivered to unpaid carers with the money available, remembering that providing the right support at the right time can save money in the longer term by reducing crises and the collapse of informal care arrangements.

Recommendation 24. The Welsh Government must ensure that the independent evaluation of the Act considers whether the funding for carers' services has been sufficient to deliver the policy intentions of the Act. It must also consider the funding that will be necessary in the longer term to deliver the rights and services promised by the Act.

Funding arrangements for the third sector

366. Current short-term, grant-funding arrangements present real challenges for the third sector, making it difficult for them to plan ahead for service delivery with any real certainty. Further, the process of applying for funding is resource-intensive and can be lengthy.

367. The additional money provided by the Welsh Government over the last few years has been mostly via 1-2 year government-financed grant funding. Where longer-term funding commitments have been given, this money has been transferred to the Revenue Support Grant. (We note that the Welsh Government has written to all local authorities setting out its expectations of service delivery.)

368. Given the crucial role of certain third sector organisations in supporting unpaid carers, these funding arrangements potentially expose carers to an unnecessary level of risk.

Recommendation 25. The statutory sector is heavily dependent on the third sector for delivery of vital services to carers. That dependency needs to be reflected in both the provision of adequate funding for the third sector, and the meaningful involvement of the sector in planning and decision-making around that funding. We believe this matter should be explored by the Ministerial Advisory Group. We ask the Deputy Minister to provide us with an update on this work within 6 months.

Recommendation 26. There is a need for a long-term, sustainable and streamlined funding arrangement for third sector organisations delivering essential services to carers under the Act. We believe that funding should be provided on a three-yearly basis as a minimum. The Welsh Government must move towards this as a matter of priority.

369. In the meantime, there are several steps that could be taken by the Welsh Government to mitigate some of the challenges of the current arrangements.

370. Firstly, we believe the Welsh Government should make available a single list of all funding sources for third sector organisations. This would make it easier for third sector organisations to identify available funding opportunities.

371. Second, we believe there is merit in making available a single funding stream for carers services. This would have the advantage of being easier to administer and monitor than the current arrangements.

Recommendation 27. The Welsh Government should provide a comprehensive and accessible list of available funding sources for support for carers to be delivered by the third sector. This should be done as soon as practicable.

Recommendation 28. The Welsh Government should consider making available a single funding stream for carers services. This should replace the current system of individual grants. It should be accompanied by a monitoring and reporting mechanism to ensure it is delivering value for money.

8. Data collection

Key themes in this chapter

Data on carers is being collected by various organisations but it needs coordinating and collating.

Better data is needed on the number of carers (including young carers) in each local authority. In its report in May 2019, Estyn recommended that the Welsh Government should produce reliable, nationally-collected data to help identify young carers.

Data is also needed on reasons for refusal of assessments, outcomes of assessments, hospital admissions as a consequence of a breakdown in the ability of a carer to continue caring.

Welsh Community Care Information System (WCCIS) is the community infrastructure around care information. The Welsh Government has committed to introducing WCCIS across health and social services in Wales. It is being delivered through a phased roll-out. As of April 2019, 13 organisations had adopted it.

Insufficient data

372. We heard from a number of respondents that information and data collected in relation to carers was insufficient. In particular, the Older People’s Commissioner told us that “there appears to be a concerning lack of robust information and data that can support us to conclude whether the duties within the Act are being met”.²⁶⁵

373. This view was shared by Carers Wales, who said it was difficult to determine how well the Act was being implemented, given the lack of a universal mechanism to collect basic management information on the numbers of carers contacting local authorities for information, advice and assistance or accessing support services²⁶⁶. Carers Wales told that “really poor data collection about carers across Wales” was:

²⁶⁵ Written evidence, C24

²⁶⁶ Carers Wales, [Track the Act Briefing 3](#)

“(…) due to different systems being used, different ways of capturing information and also systems not identifying carers when they go to local authorities.”²⁶⁷

374. A similar point was made by the Older People’s Commissioner. She told us that “improved data would mean a greater understanding about carers’ needs and would help to identify gaps in support and IAA services, such as whether an individual is self-identifying as a carer or has been identified by IAA staff, the type of support requested, whether an individual is referred for an assessment, or the reasons behind a refusal for a carers assessment”.²⁶⁸

375. In addition, she felt it was important that data was collected on hospital admissions as a consequence of a breakdown in the ability of a carer to continue caring.²⁶⁹

376. Similarly, Age Cymru identified significant shortcomings in the data collected on carers, particularly about carers’ assessments and their outcomes, saying that current data about unpaid carers is “weak and should be more comprehensive and accurate”. Age Cymru said it believed that there was significant unmet need for support for carers, but that gaps in the data meant it was difficult to estimate the scale of the problem.²⁷⁰

377. We heard from local government that there needed to be a balance between the information that local authorities needed to record and what carers were comfortable with providing.²⁷¹

378. ADSS cited a number of challenges facing local authorities in collecting data on carers, including the difficulties in identifying carers and the lack of a definition of a “carer” within the Act which does not allow consistency of responses from each local authority to Welsh Government.

379. It also referred to difficulties with the roll-out of WCCIS (covered in a later section of this Chapter), and told us that “the issue around the collection of more data during this era of austerity and the capacity within local authorities is going to be a challenge moving forward”.²⁷²

²⁶⁷ RoP, 15 November 2018, paragraph 138

²⁶⁸ Written evidence, C24

²⁶⁹ RoP, 15 November 2018, paragraphs 334-335

²⁷⁰ Written evidence, C19

²⁷¹ Letter from Association of Directors of Social Services - 18 January 2019

²⁷² Letter from Association of Directors of Social Services - 18 January 2019

380. Finally, ADSS said that the focus should not be purely on quantitative information but more qualitative data to match the outcomes approach within the Act. It suggested that “case study examples of cases may be more appropriate to evidence how we have worked on an outcomes basis, collaboratively and co-productively than the number of assessments completed”.²⁷³

381. Carers Wales called for robust data collection as part of Social Services Performance Measure requirements from local authorities and this should be done in collaboration with others, including members of the Ministerial Advisory Group for Carers to set out a clear mandate and unambiguous approach to ensure that effective data is collected”.²⁷⁴

382. Swansea University Centre for Innovative Ageing commented on the UK position, saying that there are significant data gaps in relation to carers and an absence of accessible, comprehensive data more broadly. It referred to a lack of coordination and large data gaps identified across the four nations of the UK, and called for the establishment of a UK coordinating body for adult social care to coordinate and summarise data trends for policy and research use.²⁷⁵

Estyn

383. In May 2019, Estyn issued a report, “*Provision for young carers in secondary schools, further education colleges and pupil referral units across Wales*”. In that report, it recommended that the Welsh Government should produce reliable, nationally-collected data to help identify young carers.

Welsh Community Care Information System (WCCIS)

384. We were told that, once fully rolled out, the Welsh Community Care Information System (WCCIS) will greatly improve and enhance the consistency of data collection across health and social services²⁷⁶. Progress on implementing the new system, however, appears to be slow.

385. ADSS told us that it was difficult for local authorities to provide accurate information when not all local authorities had migrated to the new system.²⁷⁷

²⁷³ Letter from Association of Directors of Social Services - 18 January 2019

²⁷⁴ Written evidence, C27

²⁷⁵ Written evidence, C22

²⁷⁶ Written evidence, C27

²⁷⁷ Letter from Association of Directors of Social Services - 18 January 2019

Longer term data

386. Both Age Cymru and the Older People’s Commissioner referred to the need for a longitudinal study on ageing for Wales, noting that Wales is “now the only UK nation without an equivalent data set on which to base our evidence”²⁷⁸. It was felt that such a study would necessarily capture data about carers.²⁷⁹

387. This is a matter that the Assembly’s Finance Committee has previously considered. That Committee recommended that “the Welsh Government continues scoping more targeted research building on the health and cognitive study carried out by Bangor and Swansea universities. This would ensure the most accurate data is available for projecting the total demand for social care services for older people”.²⁸⁰

388. Carers Trust Wales were similarly concerned about the lack of an evidence base to inform decision-making at a national level. It called for the Welsh Government to commit to funding new Wales-based research around unpaid caring and the impact it is having on different groups in society.²⁸¹

Co-ordination across services and sectors

389. Third sector organisations told us that, in addition to data collected by statutory agencies, a considerable amount of data is being collected by third sector and other organisations. The challenge, according to Carers Trust Wales, is to coordinate such efforts and collate the data:

“In terms of data that is collected on carers, there is an awful lot of data that is actually there before the local authority line, before the statutory services are there. (...) There needs to be a mechanism for how that information is used. It shouldn’t just be about what is contained within the local authority remit or the health board remit. It’s about what’s there already. There is a wealth of knowledge across Wales in terms of the information and the support and the IA that is being provided outside of that statutory concern.”²⁸²

²⁷⁸ Written evidence, C19

²⁷⁹ RoP, 15 November 2018, paragraphs 338-341

²⁸⁰ “The cost of caring for an ageing population” October 2018

²⁸¹ Written evidence, C23

²⁸² RoP, 15 November 2018, paragraph 144

390. We heard that some local authorities are working with their associations of voluntary organisations to encourage more collaboration between the third sector and local authority.

Evidence from the Deputy Minister

391. The Deputy Minister told us current data about carers is “imperfect but work is underway to ensure that data will be more reliable and more usable in the future”.²⁸³

392. She said that the Welsh Government was developing a new Performance and Improvement Framework which will “improve the way that data is collected in relation to the Social Services and Wellbeing (Wales) Act 2014 and thus our understanding of the impact of the Act, including its impact on carers”.²⁸⁴

393. She confirmed that the framework was being developed “in partnership with local authority heads of service and data leads, and would be in place in April 2020 with the first data returns due for submission in March 2021. A full consultation will be taking place in Spring 2019”.²⁸⁵

394. Under the framework, “local authorities will be required to collect additional data on carers, including an increased emphasis on qualitative data, so that carers’ opinions and experiences of the Act are collected, as well as quantitative information”.²⁸⁶

WCCIS

395. In relation to the Welsh Community Care Information System, the Deputy Minister told us:

“WCCIS will provide for the seamless service envisaged in our shared plan. As a national programme of scale, it is being delivered through a phased roll-out and 13 organisations have already adopted it with over 11,000 users.”²⁸⁷

²⁸³ Written evidence, Deputy Minister for Health and Social Services

²⁸⁴ Written evidence, Deputy Minister for Health and Social Services

²⁸⁵ Written evidence, Deputy Minister for Health and Social Services

²⁸⁶ Written evidence, Deputy Minister for Health and Social Services

²⁸⁷ Letter from the Deputy Minister for Health and Social Services, 4 April 2019

396. She said that, for those organisations that have signed deployment orders, “the latest go-live date is January 2021. We will continue to progress the sign-up and deployment orders for outstanding organisations”.²⁸⁸

397. She confirmed that, while the NHS will be required to use the system, “local authorities will need to make their own individual decisions”, although the Welsh Government has “been very clear that this is the expected system for use across Wales through the national procurement”.²⁸⁹

Longer term data

398. In her response to the Finance Committee’s recommendation about studies of future caring needs, the Deputy Minister stated that there are “a range of data sources which already exist in Wales which allow individuals to be tracked over time in a similar way to a longitudinal study”.²⁹⁰

399. She went on to state that “sources such as Secure Anonymised Information Linkage (SAIL) can be used to monitor individuals’ interactions with the health service over time, whilst Health Wise Wales would allow a series of questions to be asked to the same participants over time”.²⁹¹

400. She confirmed that “officials are currently examining what such a study in Wales would achieve which is not available through existing sources”.²⁹²

Our view

401. Good quality data collection is crucial both in terms of understanding the current position and planning future services for a growing number of carers in Wales. As acknowledged by the Welsh Government and local authorities, there is scope for considerable improvement in the current arrangements, which are inconsistent and disparate.

402. It is clear that a considerable amount of data about carers is being collected by various organisations, including the third sector, but this needs coordinating and collating in order to be effective.

403. Better quality data is needed in many areas, including the number of carers (including young carers) in each local authority; the reasons for refusals of

²⁸⁸ Letter from the Deputy Minister for Health and Social Services, 4 April 2019

²⁸⁹ Letter from the Deputy Minister for Health and Social Services, 4 April 2019

²⁹⁰ ~~Welsh Government response~~ to “the cost of caring for an ageing population” – 2 January 2019

²⁹¹ ~~Welsh Government response~~ to “the cost of caring for an ageing population” – 2 January 2019

²⁹² ~~Welsh Government response~~ to “the cost of caring for an ageing population” – 2 January 2019

assessments; the outcomes of assessments; and hospital admissions as a consequence of breakdown in caring.

404. There are some good examples of cross-working with the voluntary sector but, overall, there needs to be better sharing of good practice.

405. Welsh Government needs to take a stronger lead on data collection about carers to ensure that appropriate, meaningful data is collected in a coordinated and consistent way to inform future service and financial planning.

406. To this end, we welcome the evidence from the Deputy Minister about the Performance and Improvement Framework being developed by the Welsh Government in partnership with local authorities. We note that this will be in place by April 2020, and will require local authorities to collect additional data on carers, including an increased emphasis on qualitative data. As far as we are aware, this work will not include data collected by the third sector.

Recommendation 29. The Welsh Government must take a stronger lead on a national approach to data collection on carers to ensure that appropriate and meaningful data is collected across all sectors in a coordinated and consistent way. We believe this should be a function of the Ministerial Advisory Group, which should develop national guidelines to determine what data needs to be collected, how it should be collected and how it will be used following collection. The data should be published, and should be used to inform future service and financial planning. We believe that the Performance and Improvement Framework is an important part of this work, and we ask that the Deputy Minister provides us with an update on progress.

Recommendation 30. We endorse the recommendation from Estyn in its report of May 2019 that the Welsh Government should produce reliable, nationally-collected data to help identify young carers.

WCCIS

407. We were disappointed by the progress to date in implementing the Welsh Community Care Information System (WCCIS), and also disappointed that the Welsh Government was unable to give a clear timeframe for completion of the rollout. We believe there is a need for a more urgent approach to the roll-out of WCCIS.

Recommendation 31. The Welsh Government must provide an update on progress of implementation of the Welsh Community Care Information System within 6 months.

Longer term data

408. In relation to arrangements for collection of longer-term data on ageing, we note the Welsh Government's commitment to examine what might be achieved via a specific longitudinal study for Wales that would not be available through existing sources. We would be interested to see the results of that work, and we ask the Deputy Minister to update us accordingly.