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Agenda - Health, Social Care and Sport Committee

Meeting Venue: For further information contact:

Committee Room 1 - Senedd Claire Morris

Meeting date: 15 November 2018 Committee Clerk

Meeting time: 09.00 0300 200 6355

SeneddHealth@assembly.wales

At its meeting on 7 November, the Committee agreed a Motion under Standing Order 17.42 (vi) to exclude the public from the start of today's meeting

- 1 Scrutiny of Welsh Government Draft Budget 2019-20: Consideration of draft report (09.00 - 09.30)
- Introductions, apologies, substitutions and declarations of 2 interest (09.30)
- 3 Scrutiny of the Welsh Government Draft Budget 2019–20: evidence session with the Minister for Culture, Tourism and Sport (09.30 - 10.15)(Pages 1 - 17)

Dafydd Elis-Thomas, Minister for Culture, Tourism and Sport David Rosser, Director of Sport, Welsh Government Gillian Otlet, Sport Division, Welsh Government

Research Brief

Paper 1 - Welsh Government

Break (10.15-10.30)



4 Impact of the Social Services and Well-being (Wales) Act 2014 in relation to Carers: Evidence session with Carers Wales and Carers Trust Wales

(10.30–11.30) (Pages 18 – 76)

Claire Morgan, Director, Carers Wales

Simon Hatch, Director, Carers Trust Wales

Gareth Howells, Chair, Carers Trust Wales

Research Brief

Paper 2 - Carers Wales

Paper 3 - Carers Trust Wales

Break (11.30-11.35)

Impact of the Social Services and Well-being (Wales) Act 2014 in relation to Carers: Evidence session with the Older People's Commissioner and Age Cymru

(11.35–12.30) (Pages 77 – 120)

Heléna Herklots, Older People's Commissioner for Wales Victoria Lloyd, Chief Executive, Age Cymru

Paper 4 - Older People's Commissioner for Wales

Paper 5 - Age Cymru

Break (12.30-13.05)

6 Impact of the Social Services and Well-being (Wales) Act 2014 in relation to Carers: Evidence session with Hafal

(13.05–13.55) (Pages 121 – 127)

Kay John-Williams, Service User and Carer Participation Officer, Hafal

David Southway, Carer Representative, Hafal Ceri Matthews, Carer Representative, Hafal Tracy Elliott, Carer Representative, Hafal

Paper 6 - Hafal

7 Impact of the Social Services and Well-being (Wales) Act 2014 in relation to Carers: Evidence session with Mencap Cymru

(13.55–14.35) (Pages 128 – 136)

Dr Leanne McCarthy-Cotter, Influencing Manager, Mencap Cymru Wayne Crocker, Director, Mencap Cymru Dot Gallagher, Parent Carer/ Chair of Mencap Mon Jane Young, Parent Carer/Member of Mencap Mon

Paper 7 - Mencap Cymru

8 Paper(s) to note

(14.35-14.45)

(14.35)

8.1 Dentistry in Wales: Additional information from Abertawe Bro Morgannwg
University Health Board regarding prototype practices

(Pages 137 – 143)

8.2 Letter from the Welsh Language Commissioner and Alzheimer's Society Cymru regarding Welsh Speakers' Dementia Care

(Pages 144 – 207)

- 9 Motion under Standing Order 17.42 (vi) to resolve to exclude the public from the remainder of today's meeting and for item 1 of the meeting on 21 November 2018 (14.35)
- 10 Impact of the Social Services and Well-being (Wales) Act 2014 in relation to Carers: Consideration of evidence

By virtue of paragraph(s) vi of Standing Order 17.42

Agenda Item 3

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Pwyllgor Iechyd, Gwasanaethau Cymdeithasol a Chwaraeon Health, Social Care and Sport Committee HSCS(5)-31-18 Papur 1 / Paper 1

<u>Health, Social Care and Sport Committee – Thursday 15 November 2018</u>
<u>Minister for Culture, Tourism & Sport</u>

Memorandum on the Sport and Physical Activity Draft Budget Proposals for 2019-20

1.0 Introduction

This paper provides background financial information to the Committee regarding my spending plans as the Minister for Culture, Tourism and Sport in respect of the Sport and Physical Activity budgets within my portfolio, as set out in the detailed Draft Budget published on 23 October 2018.

In the letter dated 30 July 2018 inviting me to attend the Committee session, the Committee has requested information on specific budgetary matters. The promotion of physical activity requires collaboration across a range of sectors, public bodies and Welsh Government Departments including health, education, transport and environment, as well as sport. This paper responds only in terms of the sport-related budget expenditure lines, and the work which my officials are undertaking in conjunction with officials in other Departments.

2.0 **Summary of Budget Changes**

- a) A breakdown of the 2019—20 Economy and Transport MEG allocations which relate to sport and physical activity (by Spending Programme Area, Action and Budget and Expenditure Line (BEL).
- b) Indicative 2020-21 Economy and Transport MEG allocations which relate to sport and physical activity.
- c) Commentary on each of the Actions relating to sport and physical activity within the Economy and Transport MEG, including an analysis and explanation of changes between the Draft Budget 2019-20 and the First Supplementary Budget (June 2018).

Table 1 presents an over-view of the budget allocations. The Draft Budget 2019-20 provides a one year plan for revenue expenditure and a two year plan for capital investment.

TABLE 1: SUMMARY OF DRAFT BUDGET

Action: Sport and Physical Activity	Budget Expenditure Line (BEL)	2018-19 Supplementary Budget (£000)	2019-20 Draft Budget (£000)	2020-21 Draft Budget (£000)
Revenue				
Sport Wales	5900	22,092	22,092	
Support for Sport	6012	252	252	
Revenue Total		22,344	22,344	
Capital				
Sport Wales	6100	330	329	345
Repayments of Sports Facilities Capital Loan Scheme	6013	0	(320)	(320)
Capital Total		330	9	25

The Revenue Draft Budget figures for Sport Wales for 2019-20 are the same as the original baseline figures for that year.

Capital Draft Budget figures show a reduction of £1,000 between the baseline budget and the draft budget. The 2020-21 indicative budget shows the capital budget returning to the 2017-18 budget figure of £345,000.

Repayments of Sports Facilities Loan Scheme represent repayments made in respect of three loans made to Local Authorities under the scheme. The total loans advanced amounted to £1,964,480. These are fully repayable over a period of seven years (repayments started in 2018-19 and an adjustment will be made in the Second Supplementary Budget for this). These amounts are repayable to Central Finance in the Welsh Government.

3.0 Responses to Specific Information Requested by the Committee

3.1 The funding allocated to Sport Wales, and progress made in monitoring effectiveness of Sport Wales' use of funding.

Total funding allocated to Sport Wales is shown in Table 1.

Monitoring the effectiveness of Sport Wales' use of funding is undertaken at a range of levels: individual discussions of projects, commissioning Sport Wales to review the impact of specific programmes (such as Free Swimming and the Calls for Action programme), quarterly monitoring meetings, and attendance at the Sport Wales Board meetings. My officials also meet regularly with the Sport Wales Chief Executive to monitor progress on key projects and I meet periodically with the Chair and Chief Executive Officer to discuss policy priorities and progress against delivery of the Remit Letter and Business Plan.

We have responded to points made by the sport sector during the independent review of Sport Wales and enhanced our approaches regarding the monitoring and effectiveness of Sport Wales. Sport Wales prepare an annual Business Plan which responds to the remit letter and sets out the key areas of activity for the year ahead, together with respective performance measures. We have introduced a new tracker document to facilitate focussed discussion around projects and spend, and to record progress against the requirements in the remit letter and Business Plan. My officials meet Sport Wales for quarterly monitoring meetings and provide me with regular updates. In addition, officials regularly attend Sport Wales Board meetings as observers in order to build stronger relationships and increase visibility with the members. We have also seconded an official to work with Sport Wales in a policy liaison role, to support policy delivery and to co-ordinate the Healthy and Active Fund development and delivery.

The Insight Team in Sport Wales collects data via its own surveys on levels of physical activity and participation in sport and also provides analysis of data collected through the National Survey of Wales. Sport Wales will be publishing the findings of their School Sport and FE Sport and Active Lifestyle surveys, these are expected towards the end of the year. Analysis from the previous surveys revealed

that the proportion of children participating in sport three or more times a week had increased from 40% in 2013 to 48% in 2015 and 49% of students are hooked on sport and took part in sport and physical activity on three or more occasions per week.

Sport Wales also recently commissioned an evaluation of the social and economic value of sport in Wales. The results will be published over the coming months in themed tranches.

3.2 The Welsh Government's priorities for sport and physical activity for the next three years, and allocations/projected spend for delivery of these.

The priorities for sport and physical activity are presented in the annual remit letter to Sport Wales. This sets out the expectations around priorities for their annual business plan and commitments and objectives for the three-year Corporate Plan.

The priorities are:

- Getting more people active at every stage of their lives: while they are at school, when they leave education, when they get a job, if they have a family of their own, and when they retire.
- Providing children with the best start in life by helping schools to teach them
 the skills and give them the knowledge, motivation and confidence to be, and
 stay, active.
- Investing effort and resources where it is needed most, where there are significant variations in participation and where there is a lack of opportunity or aspiration to be active.
- Helping to support the development of community sport across Wales.
- Helping sport to continue to nurture, develop and support talent to deliver success that inspires people and reinforces our identity as a sporting nation.

Outcomes are also listed in the Sport Wales annual remit letter:

More people meeting the Chief Medical Officers physical activity guidelines.

- More people undertaking sport and physical recreation on three or more occasions per week.
- An increase in sport and physical recreation participation by those most in need or disadvantaged.
- A system that delivers continuous elite sport success while ensuring the safety, well-being and welfare of all sportsmen and sports women.

A key under-pinning theme of this work is the importance of collaboration, working across the many partners and delivery bodies for sport and physical activity across Wales, innovative and regional collaborative approaches and opportunities to scale-up successful programmes and ways of working.

Responding to points made by the independent review of Sport Wales, we have also asked them to undertake a number of operational reviews including:

- Review the vision and produce a new long-term strategy for sport in Wales.
- Give further consideration to the Community Sport and Activity Programme.

Given the overall budget allocation to Sport Wales (broadly £22 million annually in addition to £14.5 million Lottery funding) the Sport Wales Board recommend to me how that funding should best be allocated to meet the priorities. This process is undertaken first through informal discussions then formally through their Business Plan.

3.3 What evidence has driven the Welsh Government's setting of priorities and proposed budget for sport and physical activity.

Evidence has been drawn from the National Survey for Wales, the School Sports Survey, the FE Sport and Active Lifestyle survey and previous surveys such as Active Adults and the Wales Health Survey. Qualitative evidence has been collated from a wide range of consultation discussions, for example, the review of sports facilities in Wales, and results from Sport Wales' "Conversation" with key partners and stakeholders across Wales as part of the development of their new vision and refreshed long-term strategy and the independent review of Sport Wales.

Sport Wales also undertakes a number of programme evaluations (such as the evaluation of Calls for Action that has run concurrently since the programme began in 2012) as well as receiving monitoring reports from key delivery partners (National Governing Bodies and other grant recipients). These results are used as evidence in determining future budget priorities.

The life-course approach highlights clear stages at which individuals are at far greater risk of losing their physical activity levels. It offers a mechanism against which to identify how and where to target interventions and suggests what actions might be the most effective.

3.4 Evidence of how the Well-being of Future Generations Act 2015 and five ways of working have influenced the budget allocations for sport and physical activity.

The well-being outcomes and ways of working are embedded within all aspects of Sport Wales' responsibilities and activities including its strategies and business plans. They have developed four well-being objectives in consultation with stakeholders and these have been published alongside a statement of commitment.

In the review and development of the new vision and long-term strategy for sport in Wales, Sport Wales has successfully sought to involve and collaborate with a wide range of traditional and non-traditional stakeholders (sport sector and individuals). Sport Wales is currently working collaboratively with Public Health Wales and Natural Resources Wales to develop a joint action plan to increase levels of physical activity across Wales. They are also developing the Healthy and Active Fund in partnership with the Welsh Government and Public Health Wales to stimulate collaborative working across communities that will have long-term sustainable benefits.

The new Healthy & Active Fund (HAF) seeks to embed the sustainable development principles of the Well-being of Future Generations Act (Wales) 2015 and five ways of working into its design, delivery, monitoring and evaluation.

3.5 Details of how the budget will support:

Increase levels of physical activity among children and young people in Wales.

Sport Wales administer and invest in a number of dedicated programmes tailored towards children and young people. These include initiatives with StreetGames, BME Cymru Sport Network, the Active Young People programmes, Free Swimming, Young Ambassadors and the Urdd and has involved investment of over £7 million. The impact is being reviewed to determine future year provision.

Sport Wales continue to work with Education to support the implementation of the new curriculum and Well-being Area of Learning and Experience.

Sport Wales will also be publishing its School Sport Survey towards the end of the year which will ensure that schools, colleges and local authorities have valuable insight to be able to better plan their physical activity offerings. This data will also help Sport Wales, national governing bodies and other organisations identify both the latent demand for specific sports and help inform the direction of future investment.

The wider preventative agenda.

The initiatives and interventions funded through the sport and physical activity budget allocations contribute to helping individuals become physically active, or maintain levels of physical activity, with consequent preventative health benefits. The initiatives and interventions are focused both on increasing participation in under-represented groups and on the full range of ages – from the earliest ages to the oldest; and on providing skills and training to individuals to become coaches, volunteers and peer-group champions.

Sport Wales also provide the statutory function of responding to planning applications where green space is threatened by development proposals.

The forthcoming "Healthy Weight: Healthy Wales" plan will focus on long-term, sustainable change for the prevention and reduction of obesity across Wales. A key theme within this plan is encouraging more physical activity. My officials have been working closely with Public Health to contribute to the proposals that will be consulted upon over the coming months.

Joint working between sport, public health and other partners.

Sport Wales has been commissioned to work collaboratively with Public Health Wales and Natural Resources Wales to produce and deliver a joint action plan.

Sport Wales and Public Health Wales are working with Health and Sport Divisions to deliver the new Healthy and Active Fund. Launched in July 2018, thee first phase investment of £5 million over three years will focus on improving physical activity levels. Applicants will be encouraged to develop solutions that take advantage of collaboration, existing community assets such as clubs, schools and workplaces, and new technology. Full details of the Healthy and Active Fund application process were announced on 15th October. A series of roadshows have been held across Wales for interested parties to learn more about how the fund will operate.

My officials in Sport work closely with officials across many Welsh Government Departments, for example, Education (21st Century Schools Programme, Community Hubs); Transport (Active Travel); Health (Healthy and Active Fund, Healthy Weight: Healthy Wales, The Daily Mile, Welsh Network of Healthy Schools, Loneliness and Isolation); and Communities (Community Asset Transfer, Communities Facilities Programme).

By virtue of paragraph(s) vi of Standing Order 17.42

Agenda Item 4

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Pwyllgor lechyd, Gwasanaethau Cymdeithasol a Chwaraeon Health, Social Care and Sport Committee HSCS(5)-31-18 Papur 2 / Paper 2



*Inquiry response*September 2018

Health and Social Care Committee - Inquiry into the impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to carers

1.0 Introduction

Carers Wales is part of Carers UK. Established in 1965, we have led the carers' movement for over 50 years. We are a responsive, expert charity, led by carers, for carers and with carers. As the UK's only national membership charity for carers, we are highly respected in our field – as a support network and as a movement for change. Since our inception, we have been campaigning with carers, transforming understanding and winning critical developments in carers' rights.

We welcome the Committee's inquiry into the impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to unpaid family carers. We were also pleased to host a focus group with carers with your Assembly Communications Outreach and Liaison Officer.

Carers are not a homogenous group and will have different needs depending on their caring situation. In Wales according to the last census in 2011 there were 369,186 carers. Of these carers 87,173 were aged 65+ and 131,120 aged between 50-64.

Caring can take place in the context of relationships which may be positive but it is important to consider that this will not always be the case. Carers are generally linked to people by bonds of love, friendship and duty but they can also be bound by necessity, guilt and family pressure.

103,594 people in Wales according to the last census provide over 50 hours of care each week. People providing high levels of care are twice as likely to be permanently sick or disabled.

96% of annual care in Wales is provided by unpaid carers. The care they provide would cost £8.1 billion pounds a year in Wales if it had to be replaced by statutory services. It is crucial therefore that carers are properly identified, recognised and supported to continue to care.

There are 181,135 carers who are juggling work (including self-employment) whilst providing unpaid care in Wales. 100,260 carers work full-time and 54,480 work part-time. Many of these carers will be "sandwich carers" often with dual responsibility for looking after an elderly parent as well as children. They may also be caring at a distance.

The peak age of caring is between the ages of 45-64 when people have reached the peak of their careers and are valued members of staff.

By 2037 it is estimated that there will be a rise of 40% of carers in Wales meaning that there will be over half a million unpaid carers (518,322).

We welcome Welsh Government's continued commitment to carers and the Minister for Children. Older People and Social Care setting up the Ministerial Advisory group for Carers. We also welcome the Minister allocating specific additional money to the Integrated Care Fund specifically targeted at carers. We will however want to see open and transparent evidence of where the money allocated to carers has been spent and specifically how carers have benefitted as a result.



At implementation of the Social Services and Wellbeing Act, Carers Wales developed the 'Track the Act' programme to monitor delivery for carers. Briefing 1 covered the first six months, Briefing 2 related to the whole first year from April 2016 – April 2017 and Briefing 3 relates to the whole second year April 2017 – April 2018. All briefings can be found here:

https://www.carersuk.org/wales/news-campaigns/track-the-act/track-the-act-survey-briefings

As part of the programme we undertake an annual survey of carers and request information from each Local Authority area in Wales. In briefing 3, for the first time we also asked for information from Local Health Boards. All the information we receive is published on our website.

The third Track the Act briefing can be found here: https://www.carersuk.org/files/section/5763/carers-wales-track-the-act-2018-final-140918.pdf

In general we believe that the vast majority of the general population are unaware that the Social Services and Well-being (Wales) Act exists and what potentially it could mean for them.

2.0 Overview of Enquiry Question Responses

The number of carers' assessments undertaken in Wales and how this has changed as a result of the Social Services and Wellbeing (Wales) Act 2014 and whether there is variation between local authorities;

Our 'Track the Act' research shows that data collection in each local authority area is different and therefore it is difficult to judge how many carers assessments are being undertaken. In addition, in some areas local authorities themselves complete the assessments and in others this service is contracted out e.g. to a third sector provider. We know from our research that in some cases not all completed assessments are being captured in data collection. Furthermore, as a result of some local authorities using a 'What Matters' conversation approach, there is confusion about whether this constitutes an assessment and as a result is captured or not.

The number of carers receiving support following a local authority assessment, including respite care, how this has changed since the Act came into force, and whether there is variation between local authorities;

Again, due to varying data collection, this is difficult to gauge. However, we do know that the vast majority of carers are not receiving an assessment or indeed being supported as a result.

The extent to which local authorities are fulfilling their duties under the Act to provide information, advice and assistance to carers;

Our Track the Act research shows that this is varied and we believe the majority of carers are still not aware of, or are accessing the IAA service.

 Whether local authorities and Local Health Boards have sufficient information on the number and needs of carers in their areas;

The Population Needs Assessments that were produced hold a lot of information on carers at the local level. However, there is an issue of many carers not self-identifying as a carer and therefore data such as that collected in the Census is unlikely to be accurate.



Broader Welsh Government policy on carers and how it should be developed.

We believe the three carer priorities identified by the Minister are appropriate. However they are very high level. The new Ministerial Advisory Group on Carers offers a good opportunity to drive forward carers policy to deliver the priorities.

3.0 Supporting Information

3.1 Provision of Information, Advice and Assistance.

Under the Act local authorities have a duty to secure the provision of a service to provide people with information and advice relating to care and support and information about support.

We are concerned that many carers who may be accessing first point of contact services in local authorities are not being identified and that staff are not adequately trained to recognise carers and give them the information that they need. This seems an opportunity missed and subsequently many carers miss out on appropriate advice and information, with significant consequences to their own health and well-being and their ability to juggle work and care.

As highlighted in our 3rd Track the Act briefing, there are a range of ways that local authorities provide or commission this service and a range of different approaches to provide information.

The provision of information to carers is a key part of the Act and we know from our research that when carers receive information they value it. Information is crucial to prevent carers reaching crisis point. This information should consider all aspects of a carer's life, including rights at work, benefit entitlement, local support and the right to receive a carers support needs assessment which is often key to receiving respite/replacement care services.

The data we have received from local local authorities to our information request for the period April 2017 – April 2018 indicates that each local authority operates differently to collect this data. Several local authorities were unable to provide any data due to the implementation of the Welsh Community Care Information System.

Carers Wales Track the Act research indicates that more and more people are seeing information from local authorities (but generally respondents to our survey had been caring for over a year). We are concerned that information is not reaching new and 'hidden' carers and local authorities along with their key partners should be taking a more proactive approach to reach out to carers and people in need.

From our research 'Missing out – The Identification challenge' (Carers UK 2016)

- Over half of carers (55%) took a year to recognise their caring role
- 24% took over 5 years

Some groups of carers, such as parent carers, mental health carers and distance carers take longer than average to identify their role. By not self-identifying, carers miss out on financial or practical support (or both). 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.

Our research shows that the cost of remaining 'hidden' is significant:



- Half of carers (50%) said that missing out on support had an impact on their physical health
- Three quarters of carers (78%) suffered from stress and anxiety as a result of missing out on support
- For half of carers (52%) missing out on support impacted negatively on their finances
- 42% said missing out on support had caused them to give up work to care.

Almost half (47%) of respondents to Carers Wales State of Caring survey 2017 said that they had given up work completely to care.

Prevention is a key element of the Social Services and Wellbeing Act and local authorities should be doing more to reach out to carers in their communities to signpost them to the IAA service for help, assistance and assessment.

A carer at our Assembly Communications focus group said "People don't understand or recognise the word carer, we need to use language people understand".

There are ways that local authorities could reach hidden carers, such as through issuing local authority tax bills. This could be a relatively cost neutral way of local authorities reaching out to hidden carers and publicising their services. It may also be a way of developing a register of carers and finding out what sorts of services are needed to feed in to local population assessments. Reaching out in this way should not be a one-off process as there is a constant churn of carer turnover.

The Carers Strategies (Wales) Measure was repealed during the legislative process for the Social Services and Wellbeing (Wales) Act 2014 and new strategic planning duties were placed on Local Health Boards and Local Authorities to work together in the Future Generations Act. Two years into the Act we feel that a vital role has been lost within the NHS in identifying carers and signposting them to sources of support, including the local authority IAA services. For 4 out of 5 carers their first point of contact with any statutory agency is generally within a primary care settingⁱ. It is therefore vital that health has a responsibility along with local authorities to identify and signpost hidden carers.

Secondary care services also have an important role to identify and signpost carers in hospital and other secondary care services. In our State of Caring Wales 2017 report, we recommended that a new duty is placed on the NHS in line with the repealed Measure to put in policies to identify and signpost carers, promote their health and well-being. We would also like to see new measures put in place to put a duty on GP practices to identify and supporting carers. In our State of Caring report 2017 73% of respondents said that their GP know they are a carer but that they don't do anything different as a result.

"Hospital service was not connected to the local authority. Had to badger people to get support.

Left to get on with it for 8 months after my husband's stroke having been sent home with meds

and victim support number"

"Don't know what help there is or where to get help from as I'm also disabled so my husband cares for me physically and I care for him as he suffers from mental health".

Track the Act respondents 2018

A carer has also raised a concern about A Healthier Wales – Welsh Government 2018. In this report on page 7 it states "As part of working together to achieve our future vision, we need people to take more responsibility, not only for their own health and wellbeing, but also for their family and



people they care for, perhaps even for their friends and neighbours" the carers stated in her response to me that "This policy explicitly proposes increasing the responsibilities undertaken by carers". Implementation will be critical, as it seems carers will be impacted.

According to Welsh Government statistics released for the period 6 April 2016 to 31 March 2017 only 52759 adults received advice and/or assistance from the IAA Services in relation to their own care and assistance in accessing care and/or support.

From our Track the Act survey not all of the IAA services keep management information data on the number of carers making contact with the service which means that there is no mechanism in place to measure performance. 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.

For those who responded to our Track the Act survey when carers do see information they generally find it useful. Track the Act respondent "The information is out there if you look for it. Carers are often too tired to make that effort".

Where carers do reach the IAA service and are signposted, it is also not clear whether their needs are being met by external organisations. There appears to be no follow-up mechanism to record whether carers or disabled people have had their needs met or not. If needs have not been met and they would meet the eligibility criteria for services and/or support then those carers and disabled people will have fallen through the net.

In the Minister for Children, Older People and Social Care's Written Statement on 24th November 2017, he committed to establishing a Ministerial Advisory Group made of key partners and identified 3 national priorities for 2018/19. These three priorities include:

- Identifying and Recognising carers as being fundamental to the success of delivering improved outcomes is the need to improve carer's recognition of their role and to ensure that they can access necessary support
- Providing information, advice and assistance it is important that carers receive the appropriate information and advice where and when they need it.

This is a positive step welcomed by Carers Wales. However, the rhetoric needs to be turned into reality and we hope that there will be new mechanisms put into place to measure progress against the money allocated to achieve these aims.

It is also worth noting that from our research "In the Know – The importance of Information for carers" that every year in Wales 123,000 people will start caring whilst another 123,000 will stop. Potentially these new carers will not self –identify and may miss out on vital practical as well as financial support which may mean the difference in carers remaining in or giving up work. It is vitally important that all statutory services embed the identification challenge into their work.

Those whose caring role ends can also be a vulnerable group. This is especially so for those carers who have been providing significant care for a number of years who are likely to have given up work, become socially isolated and have possibly developed ill-health conditions of their own because of their caring responsibilities. It is vital that service and information providers also consider this group of carers and ensure that they receive appropriate information and advice about any benefits they may be entitled to, entry back into the labour market, bereavement counsellors and social networks to help carers move forward and alleviate feelings of social



exclusion and isolation. Equally education providers also have an important role to play to help carers to re-skill and prepare for re-entry into the labour market.

3.2 Advice

Most carers who completed our Track the Act survey 2017-2018 61% had not received advice that would help them in their role as a carer. This is disappointing given that the majority of respondents to this year's survey had been caring for over a year with significant caring roles. Where carers did receive advice 62% said they received it from someone working for the third sector and 32% from the local authority. Generally they found the advice helpful. Track the Act respondent. "So glad Carers Wales gave advice about what to claim, prior to this we were not receiving benefits which we were entitled to".

By carers receiving appropriate advice about benefits that they and the person they care for may be able to claim can make a huge difference to their finances and health and well-being. It can make a difference in whether they turn to statutory services for help or buy in services externally themselves to meet their need.

3.3 Assessment of need

According to Welsh Government statistics for the period 6th April 2016 to 31st March 2017 only 6207 assessments for support for carers were undertaken, of these only 1823 carers received a support plan. We have not had sight of Welsh Government statistics for the period 6th April 2017 to 31st March 2018 yet.

We know that not all carers will want or need an assessment. This is largely dependent on the individual and how they are coping with their caring roles. However, we believe at the outset if carers are accessing information, advice and assistance they should be told about this right and what benefits there may be to having an assessment.

Findings from our Track the Act survey 2017-2018 found that 54% of carers said that they had not been offered, requested or had a review of a current carer's needs assessment. For those that were offered or requested an assessment, 37% did not meet the eligibility criteria for services. Given that the vast majority of respondents to this year's survey had been caring for over a year with significant caring responsibilities this is extremely disappointing.

It is also disappointing because often the Carers Needs Assessment is the mechanism that opens up opportunities for respite or replacement care which supports the carer to be able to continue in their caring role, to have a life outside caring and to be able to look after their own health and well-being. The effects of not having a break from caring is shattering and carers are desperate for some time to themselves to be able to sleep, recuperate.

The right to a carers needs assessment is a key element of the Act. Carers have a right to an assessment in their own right and local authorities have a clear duty to promote this. There is an issue with the language used in relation to "Carer Assessment". Often carers will consider this an assessment of their ability to care rather than an assessment of what support needs the carer may have. This language can put many carers off requesting an assessment.

One carer who attended the focus group with Assembly Communications said "Carers Needs Assessment have less value now than before the Act. Local authorities were previously using a Carers Needs Assessment form, now it's a 'What matters' form which is 2 sides of A4. What message does this send to carers?"

Pack Page 41



Another carer at the same focus group said "I didn't know I was being assessed and I felt that a 'what matters' conversation made it easier to not implement support".

A further comment was made that "Social workers are distressed about what they can't do because of austerity/cuts. They feel the most loathed profession"

Many carers may be being assessed as part of the 'whole approach' in the disabled person's needs assessment. If this is the case, then the carer should be informed that their needs have been assessed or are being assessed as part of the disabled person's care plan. As per the Act, the practitioner should ensure the carer's willingness and ability to care and caring responsibilities are properly negotiated. It appears that if carers are being assessed in this way, that this data is often not being captured.

Those carers who are being assessed in the 'whole' approach should be informed that as well as being assessed as part of the disabled person's needs assessment they also have a right to a separate assessment of their support needs should they feel that the practitioner has not adequately taken into account their needs. It is often difficult for carers as part of the 'whole approach' to articulate their needs for fear of upsetting their loved one. An example would be where a daughter is looking after a parent and does not want to undertake personal care.

From our Track the Act survey 2018 it is clear that the way that Carers Needs Assessments are approached by local authorities differs vastly across Wales, along with the time it takes to receive an assessment. Given that the Act is focussed on prevention, it is not acceptable that many carers are waiting for long periods of time or are being declined.

"Assessment took a year - still no result six months later"

"Requested Carers Assessment but was declined"

There still seems to be confusing about whether a 'what matters' conversation is an actual assessment.

A carer has told us "I didn't know I was being assessed and I felt that a 'what matters' conversation made it easier to not implement support"

Another carer said "What value is being placed on carers? 'What matters' is not a lengthy assessment which used to ask us the right questions, it gave up an opportunity to share information"

Some local authorities will offer a pre-assessment 'What matters' conversation, others will send a pre-assessment form in the post, some local authorities commission out the service to third sector organisations whilst others will have dedicated officers in post. We welcome Welsh Government instructing Social Care Wales to identify best practice in relation to this process and we would hope that local authorities will roll out the recommendations in due course.

We are also concerned that the rights afforded to people under the Human Rights Act are not properly being considered at the Information, Advice and Assistance service or in the carers or disabled person's needs assessments. In particular, carer's health and well-being are not being taken into account. Often carers are putting medical procedures on hold with consequences for their health. "I need two knee replacements but get morphine instead to cope". In extreme cases, carers have delayed emergency medical treatment, which could cost them their lives. It is imperative that assessments are therefore done in a timely manner and that the information, Pack Page 42

7



advice and assistance service ask carers whether they have any concerns about their health that required medical intervention so that services can be put in place to meet need.

3.4 Broader Welsh Government Policy on Carers

We have made various recommendations to Welsh Government and local authorities in our Track the Act briefing 3. In particular, that 'there needs to be an honest assessment of the obstacles and barriers currently in the system which is frustrating the successful roll out of the legislative aim of the Act'. Carers need to be supported and have the information and assistance to understand the system and know where they can go to get help.

We also 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.

There needs to be 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.

Welsh Government should fund a national awareness programme to help carers identify and promote their rights to Information, Advice and Assistance and to their rights to receive carers assessments.

Pack Page 43

ⁱ Carers Strategies (Wales) Measure 2010

ii https://gov.wales/docs/statistics/2017/171031-adults-receiving-care-support-2016-17-en.pdf

Pwyllgor Iechyd, Gwasanaethau Cymdeithasol a Chwaraeon Health, Social Care and Sport Committee HSCS(5)-31-18 Papur 3 / Paper 3

Health, Social Care and Sport Committee inquiry into the impact of the Social Services and Wellbeing Act 2014 in relation to carers

Contents

Introduction
Key recommendations
Delivering good services for carers
Impact of the Act on carers
Wider provision of support for carers
Carers services - delivering the preventative agenda
Commissioning to meet carers' needs
Service models
Wider Welsh Government Policy

Appendix 1: The importance of supporting carers

Appendix 2: Background information: Young carers, older carers and carers of people with

mental ill health including dementia

Appendix 3: Summary of Carers Services in Wales

Appendix 4: Evidence of what is working well

Introduction

Carers Trust Wales exists to improve support, services and recognition for unpaid carers in Wales. With our Network Partners – local services that deliver support to carers – we work to ensure that information, advice and practical support is available to carers across the country.

During 2017-2018 the Carers Trust Wales Network reached over 34,000 carers, employed 480 staff and was supported by 475 volunteers.

Carers Trust Wales delivers practical support and information to carers and to those who work with them, including: schools, social workers, nurses, pharmacists and physiotherapists. We also seek to influence decision-makers, the media and the public to promote, protect and recognise the contribution carers make, and the support they deserve.

We welcome the opportunity to contribute to the Health, Social Care and Sport Committee's inquiry into the impact of the Act. We recognise this inquiry as an opportunity to ensure that implementation meets the aspirations of the Act.

Key recommendations

Make carers services sustainable

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.

Make carers needs assessments meaningful

Welsh Government must give clear direction to local authorities that once known to them, carers must be actively offered a Carers Needs Assessment. Welsh Government must also work with carers, professionals and the third sector to understand where this is not happening. Assessments must be delivered in a timely way by an appropriate professional with the intention of delivering a support package that enables carers to live healthy and connected lives in a way that is meaningful to them.

Make service provision equitable throughout Wales

Welsh Government must utilise Population Needs Assessments and ensure a strategic approach to creating sustainable and impactful means of supporting carers through Regional Partnership Boards and other joined-up commissioning processes.

Consistent and transparent monitoring and evaluation of commissioning processes, at a regional and national level, should be facilitated by the development of a national minimum suite of services for carers that should be in place within each local authority. Whilst models for delivery may vary, there are specific services that should always be available to carers.

Make a life alongside caring achievable

Many carers are unable to access appropriate breaks from caring, both to live healthy and fulfilling lives and to reach their potential in terms of education and employment. All carers should be entitled to minimum breaks during which the full cost of replacement or respite care is covered.

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, such as: employment, education or socialising. We believe strongly that Welsh Government should carefully review the barrier eligibility criteria currently present for carers achieving a life alongside their caring role.

Make every contact count

Education, health and social care professionals must all be up-skilled and empowered to identify carers and to refer them on for appropriate support, information and advice. Systems and processes must encourage and enable information sharing and, particularly in the case of young carers, a joined-up approach to understanding and meeting their needs. Building on up-coming Young Carer ID card pilot schemes, Welsh Government should consider encouraging all local authorities to adopt recognition schemes for carers of all ages to act as a facilitator for streamlined information-sharing between organisations and improvements in carer recognition amongst all professionals.

Make evidence-based decisions

At a national level, greater investment needs to be given to developing the evidence base to inform outcome focused commissioning of services. Welsh Government must commit to funding new Wales-based research around unpaid caring and the impact it is having on different groups in society. Additionally, Welsh Government should ensure that research priorities are aligned with more robust and transparent monitoring and evaluation processes to ensure that commissioning processes result in the most impactful services.

Make investment proportionate

Welsh Government must invest in developing appropriate capacity within the third sector and within Welsh Government to develop, scrutinise and utilise an appropriate evidence-base Pack Page 45

regarding the needs of carers and how they can best be met, to inform decision making at a national level.

It is essential that national third sector organisations are funded in a transparent and sustainable way to engage with professionals, carers and carers services to deliver practical solutions to overcoming the barriers to the successful implementation of the Act.

Delivering good services for carers

Carers Trust Wales has identified 6 common factors that contribute to the development and delivery of good services for carers, in keeping with obligations under the Act and the Ministerial priorities for carers:

- 1. Involvement of carers in the design and development of provision to meet their needs - Carers are experts in their own lives and they are key to identifying what will make the most difference to them and those they care for. It is vital that their involvement is meaningful and that they are fully supported to engage effectively.
- 2. A diverse and sustainable funding base for carers services This model of funding ensures consistency and continuity of service provision for carers. It will also support the provision of a diverse range of services which are key to meeting the varied and often complex needs of carers.
- 3. A clear focal point from which carers and professionals can access up to date information, advice and support Carers consistently state that, despite clear rights under the Social Services and Wellbeing (Wales) Act 2014, it can be difficult to access information and support. 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. Additionally, these services help to facilitate access to the views of the carers they support helping to improve engagement, planning and service development.
- 4. A proactive approach to identifying and supporting all carers and raising the profile of caring amongst professionals and communities The term carer is not a description with which all those with caring responsibilities identify. Many carers are harder to reach and therefore it is key that a proactive approach is adopted to reach out to carers and those that work with them to raise the profile of caring, improve identification and to ensure easy access to assessment and support.
- 5. Parity of provision across geographical area served 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.
- 6. Working collaboratively and in partnership Services must actively identify and develop partnerships and collaborative working with relevant organisations and existing services to promote a joined-up approach, reducing duplication and promoting choice. Clear pathways must be developed to ensure that the needs of carers are met by the most appropriate service in a streamlined manner.

Impact of the Act on carers Pack Page 46 Strong legal rights delivered through the Social Services and Wellbeing (Wales) Act 2014 have yet to be consistently delivered to the spirit and letter of the law at the point of implementation.

Assessment of need

Carers Trust Wales and our local Network Partners, have been made aware of waiting lists for carers needs assessments, low levels of awareness amongst carers of their entitlement to an assessment or a clear understanding of when an assessment has been undertaken. Where carers are aware of their rights under the Act they often identify that this knowledge has been gained through peer-to-peer support rather than through formal engagement with statutory services.

The inconsistent interpretation of rights delivered by the Act and the processes that need to be developed and embedded to deliver against them, have negatively impacted on the quality and consistency of support available to carers. Some of our Network Partners report that even within a local authority, social workers can be using different forms and approaches to either delivering a Carers Needs Assessment or deciding upon whether an assessment is necessary.

We are particularly concerned that where councils are using "What Matters" conversations as an assessment process they may not be meeting their statutory duty to offer and undertake a Carer's Needs Assessment'. The Act encourages relevant proportionate assessments, but councils may be acting unlawfully if carers do not know the legal basis of the conversations or assessments they are having.

Carers and carers services often report that when assessing need, social workers can reference limits to the amount of support available. For example, suggesting to carers that the nature of their caring role would only make them eligible for a specific amount of support. This approach is contrary to the intention of the Act in terms of enabling an approach that recognises the very individual nature of support each carer may require.

Some of our Network Partners, who are involved with the delivery of assessments, have strongly illustrated the value of involving third sector organisations in the process of assessments. Carers may be more comfortable speaking with a third sector professional about their needs and often third sector workers have a better knowledge of existing support services and groups. Whilst Carers Trust Wales does not recommend a specific approach to understanding and meeting carers needs, we would recommend that more needs to be done to ensure that the process is transparent, delivered in a way that empowers carers and undertaken by a professional that has adequate knowledge of carers rights and the services that may be most appropriate to meet carers' needs.

Additionally, some carers have identified that the process of having needs assessed through a formal process, often involving a social worker who is involved with the person they care for, is a barrier to them accessing their rights. Many, particularly in the case of parent carers, will be reticent to discuss struggling with their caring role; fearing negative repercussions if they admit to needing additional support.

Whilst we recognise the relevance and importance of assessments as defined by the Act it is important to recognise that not all carers want an assessment – there are still concerns with the name 'assessment' and fears around getting involved with statutory services. If uptake of assessments is to be improved this needs to be addressed.

Additionally, not all carers will need an assessment, particularly if they access support via a local service as their needs have already been met. Therefore, it is important that the breadth of local carers services is fully understood as a mitigating factor for the creation of needs as defined under the Act. Reducing funding for preventative services will inevitably and unnecessarily create more needs that will have to be met more formally via assessment at the point of crisis. It is essential that investment and commissioning processes truly recognise the preventative value of carers Pack Page 47

services and avoid necessitating more formal approaches to identifying and meeting carers' needs.

Whilst some carer support workers report that the Act has helped to challenge and influence statutory decisions about the availability of support, many reflect that there remains a fundamental lack of support services. As a result of this we are aware that some social work teams are reticent to undertake assessments for carers when they know that there simply aren't services in their area to signpost them to. Carers Trust Wales is concerned that levels of unmet need may be significant and that current processes do not capture the number of carers discouraged or unable to access an assessment of their need.

The Care and Support (Eligibility) (Wales) Regulations 2015¹ sets out eligibility criteria and the requirement for a National Assessment and Eligibility Tool to ensure a consistent approach to assessments and recording information. Determination of eligibility flows from assessment. However, regulations make clear that in making a determination of eligibility there should not be an over-reliance on any voluntary caring arrangements. Local authorities must ensure that the ability of the carer to provide care is sustainable and that they comply with their general duty to promote the wellbeing of the carer and the person cared for.

In some parts of Wales, parent carers have found themselves ineligible for a carers needs assessment because their child is awaiting diagnosis or not currently in receipt of services. In these cases, parents are having to wait more than a year without being eligible to have a needs assessment. In some areas, once these carers become eligible, the waiting times for an assessment can be upwards of a year. We are aware of cases where some carers have been advised that the local authority has no suitable route for them to access a carers needs assessment unless their child is eligible for a specific type of local authority led support. Copies of correspondence to this effect can be provided confidentially to the committee.

This year we have seen examples from across Wales of eligibility criteria for services being set at critical and high-level need. This 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.

We have also identified examples where criteria for services have changed with local authorities reducing the availability of specific services. For example, this includes no longer commissioning calls just to support the taking of medication. This type of call can be particularly useful for those in early stages of dementia and of course their carer.

Particular challenges for assessing the needs of young carers

There is a lack of clarity as to the extent to which assessments include consideration of whether the level of care provided by a young carer is appropriate.

The legislation is very clear in England² and Scotland³ in stating that young carers should not be providing "inappropriate" levels of care. The Scottish statutory guidance provides more detail on how to identify whether the level of care provided by the young carer is inappropriate, and that care provided by statutory agencies on a more permanent basis to relieve the young carer of inappropriate caring responsibilities and ensure that the cared-for person's needs are being met would not be considered "replacement care".

In Wales this assessment of whether the young carer is providing inappropriate care is only provided for in the Code of Practice (part 3, Section 15): "the assessment must have regard to his

¹ http://www.legislation.gov.uk/wsi/2015/1578/pdfs/wsi_20151578_mi.pdf

² Children and Families Act 2014, Section 96 (7)

³ The Carers (Scotland) Act 2016, Section 15 Rack Page 48

or her developmental needs and t the extent to which it is appropriate for the child to provide the care".

However, it is unclear what is deemed appropriate or what action should be taken to remove the responsibility for providing inappropriate care from young carers. There could be potential benefit from revising the Code of Practice to provide more clear guidance for Local Authorities in this regard.

It may be possible to remove inappropriate levels of care from young carers through joint assessments. Although the current statutory guidance allows for joint assessments, it is not clear to what extent these are combined for young carers and those they care for.

Professional awareness, information sharing and signposting

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. 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.

This is particularly apparent in the case of young carers. Our Young Carers in Schools pilot clearly demonstrates some excellent practice within school environments in Wales in identifying and supporting young carers to be successful and happy at school. However, even some of the most carer aware schools in Wales still do not have links with local carers services or mechanisms to signpost carers to preventative services or for a formal assessment of their wider support needs beyond an education setting.

Where carers services have engaged with schools, colleges, universities or in primary and secondary care environments, professionals' ability to identify and appropriately support carers are significantly improved. In particular, having specialist support workers for carers within hospitals is an efficient way to support clinical staff and carers alike. There is a need for funding to be given to support the roll out of resources available to support professionals to work with carers more effectively, such as:

- The Triangle of Care, Carers Included: A Guide to Best Practice in Dementia Care,
 Wales Edition
- Supporting Young Carers in Schools: A Step-by-step Guide for Leaders, Teachers and Non-teaching Staff
- Supporting Students with Caring Responsibilities: A Resource for Further Education Providers to Help Young Adult Carers Succeed in Further Education in Wales
- Training resources for social care teams

Additionally, the introduction of the Act has had some unintended consequences in terms of the level of responsibility various public-sector organisations consider themselves to have in relation to carers. Whilst Regional Partnership Boards potentially facilitate a step forward in joint-working it remains clear that in practice the Act has served to dilute what the Carers Measure had set out in terms of Health Board's responsibility for carers.

There is a genuine concern that highly-valued, carer-lead roles will not be prioritised within Health Boards once transitional monies come to an end.

Meeting carers' needs following assessment

Carers and some carers services report that where needs have been identified through an assessment, there are often not adequate resources to meet those needs. It is felt that in some cases inordinate pressure is put on carers to identify ways of meeting their own needs, such as through accessing paid for services or asking family participals for support. In particular, carers

identify that there can be a lack of joined-up thinking in terms of how needs are met. For example, where respite or replacement care is given to enable a carer to maintain employment they may find themselves unable to access additional respite or replacement care to facilitate rest and relaxation. In effect, carers are being asked to choose between their needs rather than have them all met.

Carers services report that when signposting carers for assessments they feel the need to manage carer's expectations. It can be challenging for services to encourage carers to have their needs formally assessed when they are aware that the types of support they may need are not available.

It is important to recognise that when considering how best to support carers the intrinsic link between the carer and cared for is fully recognised. Often, if the needs of the cared for are appropriately met, many of the challenges faced by carers will be significantly mitigated. It is important that the needs of carers are not considered in isolation of the individual that they care for. Often it is the lack of appropriate services for the cared for that increases the pressure on carers. For example, a lack of facilities for children with disabilities during weekends and school holidays will impact greatly on parent carers.

Linked to this is the fact that in many cases the cared for must agree to have a service (in order for the carer to have a break) and not all do. More frequently the cared for must agree to pay where charges have been implemented, which creates another barrier for carers.

Additionally, it is important that carer accreditation (as referenced in Prosperity for All) is delivered in a way that is ambitious for carers, recognising skills and opening up opportunities – guarding against pigeon-holing carers skills within a social care context. Whilst we recognise the importance of providing carers with opportunities to develop their skills and have them recognised, it is essential that no carer feels obliged to under-take training or to deliver types of care they are uncomfortable delivering.

Carers Wales' Track the Act briefing provides clear evidence to support our concerns regarding the extent to which the Social Services and Wellbeing (Wales) Act 2014 is ensuring that Carers' needs are being identified and met in all Local Authorities across Wales.⁴

7

⁴ https://www.carersuk.org/files/section/5763/rache-aga:50g-2-final-draft-year-1.pdf

Wider provision of support for carers

Carers' own health and wellbeing needs are often exacerbated or caused because of their caring role.⁵ If a carers' health continues to deteriorate it will have a negative impact on their own wellbeing, and also the wellbeing of the person or people they care for. It may also have an impact on health and social care services as they may be required to provide unplanned, emergency care to the people with care and support needs.

Despite the Act setting out clear responsibilities in terms of preventative services:

"Part 2, Section 15 places a duty on local authorities to provide or arrange for the provision of a range of preventative services to prevent or delay people's needs for care and support.

"A relevant partner, such as an LHB, must comply with a request to cooperate in relation to the delivery of preventative services, unless to do so is incompatible with their own duties."

There remains a lack of join-up in the commissioning of specialist and generic carers services and an expectation that the third sector will be able to innovate and sustain preventative services, upon which the statutory sector relies, without appropriate public-sector investment.

There are limited funding options for third sector organisations seeking to support carers, which consist of charitable trusts and foundations, European funding, lottery funding, and fundraising. All of these approaches require investing in appropriate resources and management to facilitate these funding approaches.

In terms of charitable trusts, there are very few that have a remit for carers. Outside of other, larger scale funders, i.e. Big Lottery Fund, Lloyds Bank Foundation and Triangle Trust, The Waterloo Foundation is one of the only funding foundations in Wales that has the remit specifically for carers and availability of funding for large scale projects.

Funding is highly competitive and can be a long process, taking months for a decision. This is an issue for any long-term planning within charities, where many do not have the time or capacity to complete the applications.

WCVA offers some of the information about the remits of funders, however it is usually up to the individual organisation to do this time-consuming research. There is no straight-forward list of trust and foundations identifying their remit for funding. Some local authorities have these available however, in most cases it will be up to the organisation to do this research.

Carers Trust Wales strongly recommends that Welsh Government has an accessible list of funding sources available for charitable organisations which identifies the funding opportunities along with funding remit.

The challenges facing unpaid carers in Wales are significant and have growing potential to impact on our public services if they are not robustly addressed. The demand on health and social care services is growing and is projected to grow further still. If just a small percentage of carers stopped caring, health and social care services could easily become unsustainable. Supporting our unpaid carers is the definition of a preventative integrated health and social care service.

We recognise the potential of Regional Partnership Boards (addressed below) however it is important to recognise the scale of support services provided for carers that are developed and funded solely by the third sector.

⁵ http://static.carers.org/files/in-poor-health-carers-uk-repack 67age 51

Carers Services – delivering the preventative agenda

We are proud of the services provided across the Carers Trust Wales Network and their impact on carers and those that work with them. However, in order for carers services to have the most impact they need to be funded in sustainable ways that fully appreciate both the importance of innovation and the importance of funding long-term mainstream services. There is a clear and growing need for additional investment in social care across Wales with local authorities having felt the pressure of reducing budgets over many years.

Within our Network, we have recent examples of closures, mergers and the cessation of services as a result of the increasing local financial pressures. The particular challenges that have been faced are often as a result of commissioning processes that don't sufficiently prioritise achieving the wellbeing outcomes of those they are designed to support.

As employers, all of our Network Partners have seen rising salary costs in line with rises to the National Living Wage. Whilst fair and appropriate remuneration is, of course, important, this increase alongside the costs associated with training and developing the workforce has made the cost of delivering services substantially higher. This increase in cost has not been recognised by all commissioners, with many service providers themselves often facing real-term cuts year on year.

As providers, Network Partners have experienced a range of challenges to being commissioned in a way that enables them to continue to deliver a high-quality service for carers and those they care for in a way that is sustainable.

To develop appropriate and impactful services, it is important that when service specifications are developed the third sector are engaged as equal partners in determining what support is needed and how this can best be delivered to the individual. Many of the additional benefits that can be gained as a result of providing care within the home, such as signposting to other services, providing assurance and support to the family and delivering appropriate and compassionate care are often curtailed by seemingly arbitrary limits on call times.

Within our Network we have had examples where Partners have been commissioned by Local Authorities to deliver domiciliary care at a rate that is below what it costs to deliver the service. This has resulted in some Network Partners handing contracts back, with others facing significant financial difficulty as a result.

Other examples, in terms of financial disincentives to providing domiciliary care, include the cost of travel between calls in rural areas. This cost is both the pay for the care worker and the actual cost of travel, which can be prohibitive in some rural areas. We have numerous examples from within our Network where Partners have had to cease providing care to those in rural or remote areas because it is not financial viable to do so under the current system.

Local authorities can and have changed their method and timing of payments, sometimes moving from in advance to in arrears. One of our Network Partners reports that if they had not had sufficient reserves to withstand a short-term shortfall because of a change in payment methods and process they would have risked closure.

As more people with increasingly complex needs are choosing to live at home, the skills required to deliver this type of care are growing. Upskilling the workforce presents challenges, both the time and cost implications of doing so, and the challenge of retaining them within the social care sector once they have been trained. Training and recruitment costs can be significant for care providers and are often not accounted for in commissioning processes.

The regulations under the Regulation and Inspection of Social Care (Wales) Act 2016 are a welcome move towards the creation of a recognised and highly-skilled registered workforce. While our Network supports the professionalisation of the workforce, we are concerned by the potential to add pressure to the ability to recruit and retain the workforce on current terms and conditions. These measures will undoubtedly create additional costs for the sector in terms of training, administration and registration fees.

To deliver against legislative and policy obligations, and to ensure high-quality services for carers, commissioners must ensure that carers services are accessible, responsive and relevant. Developing and implementing integrated service delivery models that work with and across public, statutory and third sector organisations is essential to achieving these aims.

In England, commissioning of Integrated Carers Hubs has become **recognised** as good practice in enabling carers to access support through a single point of access, enabling councils to meet their statutory obligations under **section 4 of Care Act 2014**.

In Wales, the model of carer service delivery is still largely disaggregated, relying on goodwill within and between the main service providers. Many local authorities use the Single Point of Access (SPoA) to help meet obligations under the Act.

Consideration needs to be given to the cost benefit of properly mapping, commissioning and resourcing appropriate services throughout Wales.

Rural challenges

Meeting the needs of carers in rural Wales is particularly challenging. Those challenges were summarised in a recent **report** from the Welsh NHS Confederation that provided an insight into providing health and care services in rural parts of Wales and included:

- Achieving seamless access to services
- Overcoming challenges linked to small population bases
- Delivering services sustainably
- Addressing loneliness and isolation
- Recruiting and training the required workforce
- Ensuring provision of service in a person's preferred language, can all relate equally to service provision for carers

There are increased costs when providing any services for a large, sparsely populated area, as it is more difficult to achieve economies of scale. Given that many carers tell us that they prefer face to face interaction, the need for a greater number of staff per head of the population in rural areas is clear.

The report by the Welsh NHS Confederation recommends the creation of generalist workers; frontline professionals with the skills and capabilities to take care of a persons' health and social care needs. This has the benefit of reducing the number of professionals from separate agencies making repeat visits to a person's home (or local community centre) for the same outcome. This needs forethought, training and closer working relationships between health and social care services to achieve, but it is an approach to meeting a growing carer need that is worth further consideration. It has the potential to reduce duplication and to offer a more seamless service delivery.

Respite care

As outlined above, we know that carers value a range of services provided by statutory and third sector organisations. However, it is apparent that carers particularly value flexible breaks and

respite care. Breaks can help to ensure that the carer remains well and is able to continue to provide care.

Despite this, services across Wales that provide quality breaks and respite for carers have been squeezed, and commissioning has focused increasingly on price rather than quality. We have also seen a significant decrease in individuals accessing day services or respite care since 2012⁶.

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. Carers Trust Wales has been funded by Welsh Government to undertake a Wales-wide study to investigate the ways in which flexible support (including emergency support and short breaks) could best be provided longer term. It is important that these report findings are used to deliver a step-change in the funding and commissioning of appropriate respite services for carers across Wales.

In Scotland the local authority, when determining which support to provide to a carer, must consider in particular whether the support should take the form of, or include, a break from caring⁷. A local authority must also have regard to the desirability of breaks from caring being provided on a planned basis. There is also a specific requirement that the "Young Carer Statement" should contain information about whether support should be provided in the form of a break from caring. Each local authority is required to publish a 'Short Breaks Services Statement'.

There is also a requirement for local authorities in Scotland to waive charges for services provided to carers under Section 24 of the Act⁸. This includes support in the form of a break from caring and "the charge to be waived covers the cost of all the element of the break the local authority has decided to provide to meet the carer's identified needs (having considered its local eligibility criteria)"⁹. The statutory guidance sets out some complex considerations in terms of whether providing care so the carer can take a break constitutes chargeable "replacement care" or not chargeable, as it is integral to allowing the carer to take a break. There are also provisions for the carer and cared-for person to have a break together with additional support for the cared-for person and in such cases charges would only be waived for cost of the break for the carer.

In Wales there is no specific requirement for respite to be provided. There does not appear to be any specific provision for respite to be considered in the legislation or the associated guidance. The introduction of the Social Services and Wellbeing (Wales) Act 2014 resulted in the revocation of the only legislation specifically providing for breaks (for carers of disabled children)¹⁰.

Commissioning to meet carers' needs

Regional Partnership Boards and regional funding of services

Whilst Regional Partnership Boards and the Social Value For that sit alongside them are, in theory, well placed to ensure that support needs are identified and met in innovative and creative ways – there is still significant work to be done to make this aspiration a reality.

There are 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.

⁶ https://carers.org/sites/files/carerstrust/related_documents/carerstrustwalesmanifesto.pdf

⁷ The Carers (Scotland) Act 2016, Section 25, Section 15, Section 35

⁸ The Carers (Waiving of Charges for Support) (Scotland) Amendment Regulations 2018

⁹ Carers (Scotland) Act 2016 Statutory Guidance, Section 3.3

¹⁰ The Breaks for Carers of Disabled Children Regulations 2011 were revoked under the 2014 Act by the Consequential Amendments) (Secondary Legislation Regulations 2016

The fact the third sector are not budget holders in the same way as statutory services results in them not being treated as equal partners when it comes to commissioning and planning of services.

Whilst carers services are struggling to maintain services because of a lack of funding it remains that statutory services continue to rely on them as a main referral source to support carers.

Having met with a number of Regional Partnership Board carer representatives across Wales, Carers Trust Wales and Carers Wales identified a number of concerns including:

- there remains a very mixed level of support and engagement across Wales
- contributions by carer representatives are often hindered by regular use of jargon and acronyms
- meetings can be very formal, intimidating, high level and fast-paced
- the size and complexity of the Board papers can often be overwhelmingly with little preparation time
- It is difficult for one carer representative to be truly representative of different areas within a region

Delivering Transformation in Wales: Social Services and Wellbeing (Wales) Act (SSWBA) 2014 and the role of the Third Sector outlines experiences, issues and concerns from a third sector RPB representatives and County Voluntary Councils perspective with regard to how the Act is being implemented across Wales. Carers Trust Wales supports the key findings of this report.

Additionally, we are concerned that Regional Partnership Boards are failing to take an appropriately evidenced-based approach to planning carers services relying too greatly on national third sector organisations to provide the scrutiny needed to ensure the right decisions are made. An example of this occurred in Autumn 2017: Carers Trust Wales were given the opportunity, alongside other stakeholders, to provide feedback on a carers service mapping report that had been undertaken by the North Wales Collaborative on behalf of the Regional Partnership Board. The mapping exercise represented an important opportunity to understand current service provision, demand and options for the future.

Whilst we welcomed the opportunity to provide feedback following the initial draft report, we had significant concerns, which were shared by others within the third sector, about the accuracy, representativeness and scope of the mapping exercise.

The purpose of carers service mapping report was to facilitate discussions between partners organisations to ensure robust service arrangements were in place to meet the requirements and aspirations of the Act.

It was anticipated that significant weight would be placed on this report by the Regional Partnership Board and ultimately commissioning of future carers services. It was widely felt that had the mapping exercise involved the third sector in the design and planning process the data collected and presented would have been considerably more accurate.

The main concerns outlined were:

- The significant lack of insight reflected within the report regarding the range, breadth and depth of the generic carer service model, including regulated care, specialised tasks and information, advice and support services; the report provided no context or summary of the funding environment for carers and carers services across north Wales
- the findings set out in the North Wales Population Assessment (PNA), upon which this report was meant to build, had either been diluted or ignored
- Detailed information within the PNA on what services carers wanted was underutilised

- Contrary to the findings of the mapping report, the review of services outlined in the PNA
 concluded that there is provision in north Wales to meet many of the needs of carers
 although this is not consistent across the region
- Funding for carers services from local councils and health boards varies significantly from county to county resulting in varying levels of support for carers across the region, an issue the report fails to recognise

The report recommended one respite service contract across North Wales without sufficient evidence that this would deliver the best support to carers and the people that they care for. This went against the evidence provided within the PNA advocated an increase in range, availability and flexibility of respite and short breaks for carers.

Ultimately the report exposed a lack of depth, insight and knowledge from a statutory lead perspective when it came to accurately reporting the needs of carers and support services, emphasising the need for third sector inclusion at all stages of planning. As a result of our feedback the report was dismissed and a more collaborative method of engagement was adopted.

We would recommend that RPBs ought to issue a clear mandate as to how the third sector (specifically, local carer strategy or partnership boards) must be involved in the planning process. We would also suggest that consideration should be given as to whether the third sector could be directly delegated a budget, in the same way as statutory partners.

ICF and other carer-focused allocations

We remain concerned that the planning of ICF spending is rarely agreed with the third sector. Carers services are often the last to receive allocations and at best are provided only with limited opportunities to apply and draw down monies.

The variation in timing and distribution of allocated monies from Local Authorities and Local Health Boards varies widely and, as such, not all third sector organisations receive the same opportunities. As well as late funding confirmation, late guidance is also a cause for concern.

Given that the majority of preventative services are delivered by third sector and often developed in response to identified need, it is disappointing that planning for such services does not have sufficient third sector input.

There are no general functions directed at the third sector within Part 9 responsibilities and, as a result, they can often be overlooked as equal partners in the early strategic planning discussions which are critical to the long-term sustainability of preventative services.

Correspondence and notification of funding to the third sector, either directly or via CVCs, in many instances is very short, leaving just a few weeks for bid submissions and a limited window for service delivery.

According to the ICF guidance (point 23) "ICF capital and revenue funding is available for the financial year in which it is allocated by Welsh Government". However, this only works effectively when allocations are timely - if there is a delay in the funding release date then this should be reflected in the date by which the monies need to be spent and extensions granted. In 2016/17 the second tranche of ICF funding wasn't confirmed until September 2016 yet the spend deadline remained March 2017, leaving just 6 months for delivery. In some areas, to allow for expressions of interest and assessment panels to be established, service delivery was reduced to a period of just 4 months.

Whilst this has, in some instances, improved over the last year, there are ongoing issues. As a recent example of poor practice, in one region, ICF monies allocated under the Dementia Action Plan gave just 3 weeks for bid submissions and a 6 month window for service delivery. This is not

an efficient method of ensuring that ICF monies are spent in the most coordinated and impactful way possible.

Another example of how the process of deciding on ICF funding can be unfair for the third sector is as follows (from a Network Partner of ours, edited to preserve anonymity at their request):

"We have just been awarded some of the money for xxx in xxx, with hopefully more to follow, but this has been an amazingly long, difficult battle to have the bid heard. 1 hour before the meeting I was phoned to say that I was not allowed to attend the meeting, despite it being our bid, our evidence, our expertise, that wrote the bid. Their reason, because the CVC were there.

The disproportionate nature comes in to play when a local authority or health board send the most appropriate team member to present their case, but the third sector are not able to."

There are a number of areas that could be strengthened within the existing ICF guidance to help promote and improve third sector and carer involvement. For instance, the guidance suggests that Regional Partnership Boards should involve primary care clusters in developing and agreeing spending plans where appropriate to avoid duplication and to ensure investment from the ICF and the primary care fund is complementary. Carers Trust Wales would recommend that equally Regional Partnership Boards should also develop clear mechanisms to enable a similar process with carers services and carer strategy groups.

There is a need to strengthen and clarify regional forums and to give a clear mandate to facilitate meaningful partnership working. The Carers Officers Learning and Information Network (COLIN) is one such National mechanism that could be better utilised. Whilst currently open to Health Boards it remains largely a local authority-lead forum.

In our view, the carer focus at Regional Partnership Board level is at risk of being diluted due to the level, complexity and breadth of issues it needs to govern. Local Strategic Carers Partnership arrangements are working well but the impact of that is losing focus at Regional Partnership level.

Welsh Government need make full use of regional governance processes, i.e. The Regional Partnership Boards' main function is to be a conduit for integrated working and pooled budgets for all carer services. It is unfortunate that the recent respite grant bypassed this process and was issued directly to local authorities.

Further clarity is urgently needed around the future of respite funding and how it will be managed. Our Network Partners have voiced concern that once taken into Revenue Support Grant this money will no longer be protected for carers.

There is a lack of clarity as to whether the formal Integrated Care Fund (ICF) agreements submitted by each region are made public. It is essential that there is a Wales-wide clear and transparent process relating to the publication of information regarding ICF spends.

Service models

Regardless of the service model used, it is important that the services commissioned to support carers:

- Meet obligations under the Social Services and Wellbeing (Wales) Act 2014
- Deliver the Wellbeing Objectives under the Wellbeing of Future Generations (Wales) Act 2015
- Deliver against the Ministerial priorities for carers

It is also important that services adequately reflect carers' views, experiences and preferences.

Pack Page 57

We would advocate using the guidelines **outlined above** to assess the appropriateness of service design as they reflect legislative obligations, good and emerging practice and the views of carers.

The development of services within each region ought to be based on the needs identified through population needs assessments, reflecting on the thematic findings of the national needs assessments. However, commissioners and service providers must be mindful of the low levels of self-identification amongst carers and potential levels of unmet need that has yet to be identified.

When developing new service models, it is important that carers, the third sector and the public sector work together through Regional Partnership Boards to fully assess existing provision and to understand its effectiveness, including the sustainability challenges facing carers services themselves.

Building upon a clear understanding of existing provision and the extent to which it meets current and anticipated future need, services should be commissioned in a way that reflects the importance and value of:

- Investing in ensuring the appropriate support mechanisms are in place to enable carers to engage effectively with approaches to co-production
- Integrating new services with existing provisions and pathways
- Evolving a whole-system approach which is designed to ensure increased identification of carers at the earliest possible opportunity in their caring journey
- Developing support services that reflect the needs of carers
- Identifying clear and appropriate mechanisms for information sharing, both with the carer and the organisations and professionals that are best placed to support them
- Supporting a plurality of providers to have the skills to engage with tendering processes.
- Developing measurable targets and outcomes focused on providing high-quality and appropriate support to a significant proportion of carers and families, recognising the importance of adapting service provision to meet the needs of the most vulnerable carers
- Ensuring accountability by building in clear monitoring processes to assess whether the services and initiatives are effective in supporting carers and families

The importance of co-production and regional collaboration in service development

For services to be effective it is essential that they are co-produced with carers. It is important that carers are supported as key contributors to the development of service specifications and involved in commissioning processes.

The National Population Needs Assessment identifies that improvements must be made to the involvement of carers in service development. Our Network Partners strongly identify that involving carers in service design and development is essential. However, current processes for engagement are often tokenistic and repetitive.

To join-up carer engagement it is important that stronger relationships are built within each region between:

- Carers Services
- Carers representatives on Regional Partnership Boards, and relevant associated groups that sit under them
- Carers Leads within local authorities and local health boards
- Community Safety Partnerships
- Public Service Boards
- Local and national third sector erganisations that support carers

Developing High-Quality Models of Service

It is important that commissioners better understand the breadth of carers needs and the skills and insight of carers services in identifying, understanding and meeting carer's needs.

It is important that the diversity of carers, both in terms of their needs and the barriers they face, is recognised and reflected in the types of services made available. It is essential that a range of services are commissioned which include links to both specialist and generic services. They must be delivered through flexible service models that are able to be proactive in meeting the needs of carers. It is essential that regardless of the service model used, support is integrated, coordinated and easy to navigate for carers.

Additionally, it is important that effort is made to understand which professionals are most likely to meet families and carers before they have been formally identified. To improve identification before points of crisis it is essential that support and training is given to appropriate staff to ensure that they can provide an active offer of support and signpost effectively.

Whilst teachers and medical professionals are likely to meet families and carers, it is unlikely that identifying and supporting carers is central to their role. Therefore, it is important that they receive clear training and guidance to enable them to refer to appropriate services easily and efficiently, regardless of which service model is used.

Additionally, it is essential that all services consistently monitor, evaluate and refine their service provision to ensure that they achieve successful outcomes for carers.

A variety of methods are currently used across carers services to monitor and evaluate their effectiveness, including:

- Recording "distance travelled" following a "what matters conversation" or "reflective listening"
- Capturing anecdotal feedback including quotes
- Evaluation forms, surveys and questionnaires
- Analysis of staff reports and assessment against intended outputs
- The Carers Star
- · Pen pictures and case studies
- Social Return on Investment (SROI)

It is essential that services are designed and commissioned with a focus on utilising approaches that can be shown to demonstrate maximum impact for carers.

Wider Welsh Government Policy

In terms of wider Welsh Government policy, we remain concerned that there has been significant underinvestment in developing the evidence-base to inform decision-making at a national level. There remains a considerable lack of data in relation to carers and limited academic study of the experiences and outcomes of carers in Wales.

To ensure that carers' needs and experiences are understood and that carers are supported in the most impactful ways, more investment is needed in the collection and analysis of appropriate data at a national level. In particular, we would consider that there is insufficient investment in applied research to test new approaches and to enable fuller understanding of the approaches that are most likely to improve carers experiences, wellbeing and life outcomes.

Whilst Welsh Government has developed funding streams focused on facilitating locally determined solutions, insufficient investment Page to Page 1990 wider-scale analysis and

information sharing. There are insufficient platforms to identify, explore and share emerging practice creating inefficiencies in the development of recognised good practice.

More widely, national organisations, that are best placed to act both as a critical friend and as a facilitator of policy into practice, struggle to achieve funding for these much-needed areas of work. The sustainable social services grant is central to enabling organisations to support the implementation of the Act. However, in the last funding round organisations were unable to access funding for policy and development work. Currently, with less than 6 months to run on the current funding programme, organisations funded through this grant, including Carers Trust Wales, have had no notification regarding its continuation.

The Welsh Government team with responsibility for carers remains disproportionately small and this lack of capacity both for scrutiny and innovation will undoubtedly have an impact on the extent to which the Act is implemented effectively. Too often the expertise of the third sector is heavily relied upon without adequate funding to ensure the sustainability of policy, research and engagement expertise within the sector.

In order to embed the Act efficiently, in a way that maximises impact for carers, it is essential that national third sector organisations are funded in a transparent and sustainable way to engage with professionals, carers and carers services to deliver practical solutions to barriers to the successful implementation of the Act and the development of Welsh Government policy on carers more broadly.

Appendix 1: The importance of supporting carers

Supporting carers appropriately delivers benefits for carers and the people they care for. For example:

- supporting carers by providing breaks and emotional support helps to prevent burnout and keep carers caring for longer
- working to encourage carers into or to continue in education improves their emotional wellbeing and personal fulfilment as well as widening their options for future employment, education or training
- involving carers in hospital treatment and clinical decisions improves communication and planning which results in better outcomes for both patient and carer

However, too often carers are not supported in any of these ways.

The specific support individual carers need to thrive will be as diverse as their circumstances. In our experience, this can range from requiring better information on managing medicines to having access to reliable services to provide a much-needed break from caring¹¹. However, the first step in delivering appropriate support will always stem from ensuring that more individuals and professionals are equipped with the information and tools they need to identify carers and to understand the barriers they face.

In order to deliver appropriate support for carers more investment is needed to:

- make local carers services sustainable
- support professional to identify carers, put in place appropriate support and information sharing systems and to signpost for more direct support (such as through an ID card or other recognition scheme)
- work with the third sector to identify, share and mainstream good practice and to support the commissioning of the most impactful services

Experts calculate that Welsh carers contributed the equivalent of £8.1bn of care during 2015¹², far exceeding the £1.7bn spent across Wales on social care during 2016-17¹³. 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. The detrimental effect on carers' health, wellbeing and financial circumstances has been well documented, with older carers at higher risk than younger carers¹⁴. Around 65 percent of older carers - those aged 60 to 94 - have a long-term health problem or disability themselves and 68 per cent of carers say that being a carer has had an adverse effect on their mental health, with a third reporting that they have cancelled treatment or an operation for themselves because of their caring responsibilities¹⁵.

In England, the Royal College of General Practitioners has worked with Baker Tilly to identify the social return on investment which can be made when CCGs invest in services which support carers. The study shows that this could equate to a saving of almost £4 for every £1 invested 16.

Additionally, an Impact Assessment published by the Department of Health in England in October 2014 makes an estimate of the "monetised health benefits" of additional support for carers. This estimates that an anticipated extra spend on carers for England of £293 million would save

¹¹ https://carers.org/sites/files/carerstrust/related_documents/carerstrustwalesmanifesto.pdf

¹² https://www.sheffield.ac.uk/polopoly_fs/1.546409!/file/Valuing-Carers-2015.pdf

¹³ https://statswales.gov.wales/Catalogue/Local-Government/Finance/Revenue/Social-Services/socialservicesrevenueexpendituresubjectiveanalysis-by-authority

¹⁴ Mansell and Wilson 2009; Mullan et al 2011; O'Brien et al. 2012; Chapman 2014; Greenwood et al. 2017; Smith et al 2017

¹⁵ http://record.assembly.wales/Committee/4621

¹⁶ http://www.rcgp.org.uk/clinical-and-research/clinical-

councils £429 million in replacement care costs and result in "monetised health benefits" of £2.3 bn. This suggests, as a ratio, that each pound spent on supporting carers could save councils £1.47 on replacement care costs and benefit the wider health system by £7.88¹⁷.

The services carers receive and require are diverse and include a wide range of local and national services. Services include:

- information, advice and support
- short breaks
- · replacement care
- palliative care

- employment support
- training
- benefit support.

The preventative value of these services, both in securing the well-being of individuals, and in avoiding additional costs to local authorities and local health boards, is well-established. For example:

A longitudinal study of 100 people with dementia found a 20-fold protective effect of having a coresident carer when it comes to preventing or delaying residential care admissions¹⁸.

One study found that problems associated with the carer contributed to readmission in 62% of cases¹⁹.

Appendix 2: Background information: Young Carers, older carers and carers of people with mental ill health including dementia

3 in 5 of us will become a carer at some point in our lives. There are millions of unpaid carers providing support across the UK with the last census showing that there are at least 370,000 in Wales²⁰.

In almost every category, Wales has the highest proportion of carers in the UK – including the highest proportion of older carers and the highest proportion of carers providing over 50 hours of care a week.

- According to the 2011 census, in almost every category, Wales has the highest proportion
 of carers in the UK including the highest proportion of older carers, young carers and of
 carers providing over 50 hours of care a week²¹
- 65% of older carers (aged 60–94) have long-term health problems or a disability themselves²²
- 68.8% of older carers say that being a carer has an adverse effect on their mental health²³
- One third of older carers say they have cancelled treatment or an operation for themselves because of their caring responsibilities²⁴

http://www.legislation.gov.uk/ukia/2014/407/pdfs/ukia_20140407_en.pdf

¹⁷ Department of Health (2014) Impact Assessment (Carers)

¹⁸ Banerjee, S, Murray, J, Foley, B, Atkins, L, Schneider, J, Mann, A (2003) Predictors of institutionalisation in people with dementia, *Journal of Neurology, Neurosurgery & Psychiatry 2003*, 74,1315–1316.

¹⁹ Williams, E, Fitton, F (1991) Survey of Carers of elderly patients discharged from hospital, *British Journal of General Practice*, 41, 105 –108.

²⁰ https://carers.org/key-facts-about-carers-and-people-they-care

²¹ https://www.ons.gov.uk/census/2011census

²² https://carers.org/key-facts-about-carers-and-people-they-care

²³ https://carers.org/article/mental-health

²⁴ https://carers.org/key-facts-about-carers-andkoeoaqqt62-care

- 27% of young carers (aged 11–15) miss school or experience educational difficulties (this rises to 40% where children care for a relative with drug or alcohol problems)²⁵
- Young carers on average cut short or miss 48 days of school a year²⁶
- Young adult carers are more likely than the national average not to be in education, employment or training (NEET) between 16 and 19²⁷
- A quarter of young carers say they are bullied at school because of their caring role²⁸
- Carers provide 96% of care in the communities of Wales²⁹
- Unpaid carers contribute £8.1 billion to the Welsh economy each year³⁰

Young and Young Adult Carers

In Wales there are an estimated **370,000** unpaid carers, including **21,611** young adult carers (aged 16-24) and **7,544** young carers (aged under 16). Wales has the highest percentage of young carers in the UK.

Young carers are a vulnerable and disadvantaged group specifically mentioned in Estyn's School Inspection Guidance. Official figures show that there is at least one young carer in every class and research suggests that the real figure is closer to 4 in every class.

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.

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.

Welsh Government has acknowledged³¹ that robust arrangements have to be in place locally so that professionals and organisations collaborate effectively in considering support and commissioning services, both within school and outside. It is evident that in many parts of Wales the support available to young and young adult carers is disjointed and inconsistent.

We know from young carers, schools, support workers and academic research that the current system is not delivering adequately or equitably for all young carers. For many young carers, the aspiration set out in Our National Mission of being "well-educated, safe and happy, to be treated fairly and benefit from high-levels of wellbeing" is one that is very far from being achieved.

Carers Trust Wales welcomes Welsh Government's focus on the importance of co-constructing policy and doing so based on evidence and research. However, to ensure evidence-based policy making and practice development, research regarding young carers must be improved upon significantly for this aspiration to be realised.

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.

²⁵ https://carers.org/young-carers-schools

²⁶ https://www.bbc.co.uk/news/uk-wales-44306700

²⁷ Young adult carers are more likely than the national average not to be in education, employment or training (NEET) between 16 and 19

²⁸ https://carers.org/content/anti-bullying-week-quarter-young-carers-are-bullied-school-because-their-caring-role

²⁹ https://carers.org/sites/files/carerstrust/related_documents/carerstrustwalesmanifesto.pdf

³⁰ https://www.carersuk.org/news-and-campaigns/news/vale-of-unpaid-care-in-wales

³¹ https://carers.org/welsh-government-supports-young-carers-schools

Being tired or distracted when in school can adversely affect their educational attainment and young carers have significantly lower educational attainment at GCSE level³². There is a one in three chance that a young carer in year 9 will become NEET (not in education, employment or training) between the ages of 16 and 19, compared to a one in four risk for those without caring responsibilities. This often results in unemployment, reduced earnings, poor health and depression³³.

Caring responsibilities can be difficult and stressful at any age. Taking on the physical and emotional demands of supporting a family member or friend with a long-term sickness, disability, mental ill health or addiction is a lot for young minds to deal with.

For many young people, particularly those who go unidentified, caring can lead to a significant and long term negative impact on their physical and mental health and wellbeing.

Young carers often talk about feeling tired and under pressure. Many experience traumatic life changes such as bereavement, family break-up, losing income or housing, and seeing the effects of an illness or addiction on the person they care for³⁴. All these things alongside the pressures of school or college and the social isolation experienced by many, can lead to stress, anxiety and depression.

Research by Carers Trust and the University of Nottingham³⁵ found that almost a third of young carers surveyed (29%), reported that their own physical health was 'just OK', and 38% reported having a mental health problem.

Young carers' physical health may also suffer. Financial pressures, time pressures, exhaustion as a result of interrupted sleep, physical injuries from repeatedly having to support or move someone with poor mobility.

The health of young carers may be affected for a variety of reasons and might not be addressed if their health appointments are missed, not prioritised or there is a distrust of health services.

Issues related to health and wellbeing can be broken down into several categories, including difficulty balancing young carers' responsibilities, the physical demands of caring, feelings of a lack of control and anger. Where young carers have shared their biggest worries and fears relating to their role, school has frequently emerged as a source of anxiety³⁶.

- Young carers are 1.5 times more likely than their peers to have a special educational need or a disability³⁷
- "65% of those responding to the Nottingham University survey said they had one or more disability or health difficulty and 45% of those responding to the survey reported having a mental health problem, including anxiety, depression and eating disorders"
- Young adult carers are developing health problems, including high levels of mental ill health, at a much higher rate than other young people"38

³² Children's Society 2013, https://www.childrenssociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf

³³ http://www.education.gov.uk/childrenandyoungpeople/youngpeople/participation/neet

³⁴ https://professionals.carers.org/protecting-health-and-wellbeing-young-carers

³⁵ https://professionals.carers.org/sites/default/files/young_adult_carers_at_school-8_11_13-1 proof 4 final.pdf

³⁶ Cascade report: "Young Carers Speak Out!" 2016. Dr. Jen Lyttleton-Smith, Children's Social Care Research and Development Centre. **Available online** [Accessed 8 February 2018].

 ³⁷ See reference 9.
 ³⁸ Time to be heard report (Wales) 2015, Carers Trust. Available online [Accessed 8 February 2018]

- 19% of young carers reported "Getting stressed"; 22% reported "Worrying about the person you care for" and 13% "Being depressed"³⁹
- The 2011 Census shows that for young carers doing more than 50 hours of care a week they are five times more likely to report that their health is 'not good'
- The 2011 census also shows that young carers providing between 20 and 49 hours
 of care per week are over three times more likely to report their health as not good
 compared to other children without caring responsibilities.

Transport, or affordable transport, is an issue for many young carers whose families may rely on state funded financial support. 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.

Young carers have said that public transport is expensive and not all operatives, such as bus drivers, are understanding. Problems accessing suitable transport means that young carers can be isolated or excluded from social activities⁴⁰. Young carers need to be identified when accompanying someone they care for on buses, trains or at airports/on flights in case of a medical or other incident⁴¹.

An inability to access affordable public transport limits young carers ability to access education, leisure and other opportunities which are integral to maintaining good physical and mental health.

There are some key barriers which limit young and young adult carers ability to access opportunities for leisure and, in particular, physical activity.

Whilst there is a distinct lack of robust evidence regarding physical activity rates amongst young carers, anecdotal reports gained through our Young Adult Carers Council, suggest that young carers are less likely than their peers to undertake regular physical activity. This can be because of time pressures, access to replacement care or financial barriers.

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 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.

We believe 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. Whilst caring cannot be considered an Adverse Childhood Experience, we know that young carers are more likely than their peers to experience mental ill health⁴². Physical exercise has been clearly identified as a resilience factor in terms of young people's mental health and therefore it should be a priority for Welsh Government to remove barriers to young carers accessing opportunities for regular physical activity.

Our Young Adult Carer Council, has identified 5 main barriers young carers face to accessing regular physical activity⁴³:

 Time away from caring. This can be broken down into two different barriers: the first being that it is too difficult to have any time away from the person that they care for and the second being that having regular time away to attend a specific class or to

⁴⁰ Caerphilly County Council. 2016. Available online [Accessed 8 February 2018].

³⁹ Caerphilly County Council. 2016. Available online [Accessed 8 February 2018].

⁴¹ Barnardo's report (2017). Greater Gwent Carers Programme Board: scoping a proposal to establish an ID Card Scheme for young carers and young adult carers Barnardo's. 2017

⁴² www.wales.nhs.uk/sitesplus/documents/888/PHW%20ACEs%20Resilience%20infographic%20(Eng).pdf

⁴³ http://senedd.assembly.wales/documents/s67283/PACYP%2019%20Carers%20Trust%20Wales.pdf

join a team is impossible to accommodate, even if respite / replacement care is in place

- The needs of the person they care for come first. Many young carers recognise the importance of regular exercise and leisure activities. However, they do not view its importance as being greater than undertaking their caring role
- Financial constraints. Many young and young adult carers report that they do not have the money for either appropriate sports equipment (including clothes) or to join a gym or team. This includes school-based teams where money is needed to go to away games
- A lack of appropriate / interesting activities available at convenient times in accessible locations
- Confidence. Evidence shows that a quarter of young carers report being bullied at school because of their caring roles. Many lack the confidence to participate in physical activities

Young carers' responsibilities can prevent them socialising with other children or young people. They may also experience poverty and social isolation or exclusion due to their family's financial circumstances.

- "77% of the young carers surveyed would like to do more exercise" and "79% of the young carers surveyed visited a sport's centre every week, every month or now and again"44
- 10% of students reported being unable to go to after school clubs due to their caring responsibilities⁴⁵

Older Carers

The number of older carers is increasing with the number of those aged 85 and over growing by 128% in the last decade (Carers UK and Age UK, 2015).

Older carers have their own specific needs and have tended to be a forgotten group, often going unidentified because they do not recognise themselves as a carer or are not adequately recognised by professionals and services.

With an aging population and the increase in the life expectancy of people with learning disabilities; people are caring for longer and later in their lives⁴⁶.

Key issues for older carers include:

- Lack of recognition of their own health needs and the impact of caring on their own health and wellbeing
- Isolation and loneliness, especially in relation to unavailable, inappropriate or inaccessible transport
- Complex management and navigation models of health and social care systems with no support
- Lack of preparation including a lack of awareness of the likelihood for caring in later life, especially so for carers who have been caring for children with long term conditions

⁴⁴ Full of Care report. "All Right Gov?". 2009. Children in Wales. Available online [Accessed 8 February 2018],

⁴⁵ Caerphilly County Council. 2016. Available online [Accessed 8 February 2018].and Barnardo's report (2017).

⁴⁶ Marks. L, Retirement on Hold, Carers Trust, 2016 (due to be published January 2017)

- whose life expectancy meant they were previously unlikely to reach old age where increasing numbers now are
- Older carers have a strong sense of "duty to care", this can be reinforced by health and social care professionals which means they may feel they have no choice or continue to do so longer than they are able
- Lack of information on financial planning, including information on lasting powers of attorney are not provided at an early enough point

Carers Trust has produced a number of reports looking in more detail at the challenges facing older carers across the UK^{47&48}.

Carers aged 60–69 often juggle caring with the demands of work and financial pressures while those aged over 70 may be more likely to find it difficult to cope with the physical demands of caring.

Over 16% of older carers in research in 2011⁴⁹ were caring for more than one person. This is more common for those aged 60–75 where significant numbers care for a parent as well as an adult son or daughter, grandchild or someone else with a disability or long-term health condition.

Additionally, this research found that:

- Two thirds of older carers have long-term health problems. Commonly reported conditions are arthritis and joint problems, back problems, heart disease, cancer and depression
- One third of older carers report having cancelled treatment or an operation they needed due to their caring responsibilities
- 50% reported that their physical health had got worse in the last year, and 70% said specifically that their caring responsibilities had a negative impact on their physical health
- Across all of the older age groups, more than 40% said their mental health had deteriorated over the last year, with 75% of the 60–69 age-group saying that caring had a negative impact on their mental health
- Less than 50% of carers over 70 who had to lift the person they care for, think that they do
 this confidently or safely

Many older carers caring for a partner find themselves having to provide personal care alongside having to do all the household jobs that once were shared, resulting in high levels of stress and physical fatigue.

Tiredness is also a significant issue when a carer is on call for 24 hours a day and may be awake often in the night to attend to the needs of the person they care for. Dealing with challenging or unpredictable behaviour also causes particular stress and emotional strain, for example when then person being cared for has dementia.

Carers' health deteriorates incrementally with increased hours of caring⁵⁰. This is a concern as data shows that the oldest carers are more likely to spend more hours caring than those who are younger, particularly as this is compounded by the fact that age-related illness will be more likely.

There is a considerable body of evidence⁵¹, to show that carer wellbeing is a key factor in hospital admissions, readmission and delays in the transfer of care. For example, a whole systems study

⁴⁷ Fraser. M, Always on Call, Always Concerned, Carers Trust, 2011

⁴⁸ Caring about Older Carers: Providing Support for People Caring in Later Life, Carers Trust, 2015

⁴⁹ https://professionals.carers.org/sites/default/files/caring_about_older_carers-finallo.pdf

⁵⁰ https://www.gov.uk/government/policies/carers-health

⁵¹ http://static.carers.org/files/supporting-carers-the-case-for-change-5728.pdf, (Conochie, G, 2011)

tracking a sample of people over 75 years old who had entered the health and social care system found that 20% of those needing care were admitted to hospital because of the breakdown of a single carer on whom the person was mainly dependent.

Supporting Carers: The Case for Change⁵² also highlights that carer-related reasons for admission to nursing or residential care are common, with carer stress the reason for admission in 38% of cases⁵³. This suggests that giving carers extra support to manage their caring role more effectively and maintain good health could reduce unwanted residential care admissions.

Deterioration in carer health and wellbeing therefore is likely to increase demand on health and social care services for both the carer and the person with care needs. Preventative interventions to support the carer may therefore reduce the likelihood of increased future health, social care or residential care needs of both parties.

To support older carers it is important that:

- Primary and secondary care services identify older carers as early as possible and ensure they are referred for a carers need assessment
- Planning for caring in later life should be considered as a public health priority and the
 public supported to plan for their own care needs and the potential for becoming a carer in
 later life
- Health and social care systems must be aligned and integrated to ensure older carers are not required to navigate the complex systems for both their own and the person they care for's health needs. This presents particular challenges when discharging an unpaid carer from hospital.

Carers of people with mental ill health including dementia

Carers Trust's research into the experiences and needs of carers of people with dementia, demonstrates clearly what the issues faced by this group of carers experience. A Road Less Rocky⁵⁴, sets ten key crisis points when carers of people with dementia need specific, information, advice and support in their own right to prepare for and cope with their caring journey. These are:

- When dementia is diagnosed
- When the carer takes on an "active" caring role
- When the capacity of the person with dementia declines
- When the carer needs emotional support and/or a break from caring
- When the person with dementia loses their mobility
- When the person with dementia has other health problems
- When the carer has to cope with behavioural problems
- When the carer's own circumstances change
- When the person with dementia becomes incontinent
- When decisions about residential care and end of life care have to be made

Carers are still going unidentified at an early enough point, meaning they reach crisis point at one of the later positions which has long term implications for their own health and wellbeing and often leads to the person they care for being admitted to residential care.

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⁵² http://static.carers.org/files/supporting-carers-the-case-for-change-5728.pdf, (Conochie, G, 2011)

⁵³ Bebbington, A et al, 2001

⁵⁴ Newbronner. L, Chamberlain. R et al, A Road Less Rocky – Supporting Carers of People with Dementia, Carers Trust, 2013

Carers of people with dementia experience particular challenges that are in addition to the wider issues experienced by all carers. Often due to their age, the nature and complexity of dementia and their own health needs they are a particularly vulnerable group who need attention in their own right.

It is important that all hospitals in Wales develop their carer awareness to ensure that carers are included throughout the care pathway which would reduce poor discharge practices.

Additionally, Commissioners must ensure carers of people with dementia are included in commissioning decisions including ensuring their own needs (as identified in the Road Less Rocky) are taken into account when commissioning services.

The Triangle of Care - The Triangle of Care was originally developed by staff and carers to improve carer engagement in acute inpatient and home treatment services. Created in partnership with the National Mental Health Development Unit it aims to improve communication between those caring for people with a mental health problem and mental health professionals. Since its launch in 2010, the programme has been adapted for use across all mental health services, not only inpatient, and includes a universal self-assessment tool as well as guidance notes.

The Triangle of Care best practice guides and audit tools aim to build upon existing good practice to recognise and include carers as partners in care. It offers key standards and resources to support mental health service providers if incorporated in their everyday practice, policies and procedures. In Wales, 50% of health boards have shown an active interest in implementing a Triangle of Care model and support is growing within other health boards throughout Wales.

Betsi Cadwaladr Health Board is the most advanced in terms of actioning a Triangle of Care pilot and last year set up a steering group to take the work forward, with an initial pilot receiving positive feedback from staff and carers.

In 2018, with support from the RCN Foundation, Carers Trust Wales published **The Triangle of Care, Carers Included: A Guide to Best Practice in Dementia Care, Wales Edition** which sets out to ensure consistent carer involvement and support across all health and social care services irrespective of where and when a person is being treated.

Appendix 3: Summary of Carers Services in Wales

The majority of services for carers are delivered by third sector organisations commissioned by local authorities⁵⁵. The tables below summarise the organisations that deliver these services across Wales as well as the regional approaches being taken to service delivery and commissioning. Whilst many more services for carers exist, this report focuses on the main adult carer service providers for advice, information assistance and respite, in each local authority area.

It is worth noting that since the introduction of the Social Services and Wellbeing (Wales) Act 2014 many local authorities and local health boards are developing a more integrated and collaborative approach to addressing the needs of carers. However, this is an ongoing process with varying levels of collaboration achieved within each region.

⁵⁵ Carers services do receive funding from Local Health Boards and non-statutory funders, but this has traditionally been for specific or time-limited carer focused projects.

Local Authority: Bridgend

Bridgend carers service (advice, information and support)
Bridgend Crossroads Care (adult respite)

Local Authority: Neath Port Talbot

NPT Carers Service (advice, information and support for adult carers)

Local Authority: Swansea

Swansea Carers Service (advice, information, respite and support for adult carers and young adult carers)

Regional approach

Western Bay Carers Partnership Board has recently commissioned a carers mapping exercise to inform the development of more consistent approaches and services.

The Board is developing a new plan for 2018 - 2019 to address carers priorities highlighted in the **Area Plan** as well as the Ministerial priorities for carers.

Strategic Direction:

New Carers Partnership Action Plan 2018/19 (to be published) **Valuing Carers Transition Plan 2017-18**

Local Authority: Torfaen

Carers Trust South East Wales (respite)
Torfaen CBC (adult carers)

Local Authority: Newport

Carers Trust South East Wales (advice, information, respite and support)

Age Cymru Gwent (respite carer service)

Local Authority: Blaenau Gwent

Carers Trust South East Wales (respite)

Age Cymru Gwent (advice, information and support for adult carers)

Local Authority: Monmouthshire

Carers Trust South East Wales (respite)
Age Cymru Gwent (respite care service)

Local Authority: Caerphilly

Carers Trust South East Wales (respite)
Caerphilly CBC (adult carers)

Regional approach

As part of their draft **Wellbeing Area Plan** in relation to carers, Greater Gwent Regional Partnership Board sets out the following actions:

- Coordination of consistent community based services such as community connectors / social prescribers to identify and support carers
- Accurate Information, Advice and Assistance through DEWIS and Five Ways to Wellbeing
- Consistent commissioning across health and social care to ensure equitable, region wide and effective models of carer support including flexible respite
- Ensure that the implementation of the Care Closer to Home Strategy increases the community level support for carers across Aneurin Bevan University Health Board (ABUHB)

Success will be measured by:

- Increase in number of befrienders providing flexible respite for carers
- Increase in the number of schools involved in the Young Carers awards scheme
- Increase in number of GP surgeries that are 'Carers aware'

Local Authority: Anglesey

Carers Outreach Service (advice, information and support for adult carers)
Carers Trust North Wales Crossroads Care Service (respite)

Local Authority: Wrexham

Wrexham Carers Service (advice, information and support for adult carers)
Carers Trust North Wales Crossroads Care Service

Local Authority: Flintshire

NEWCIS (advice, information, respite and support for adult carers and young adult carers) **Carers Trust North Wales Crossroads Care Service** (respite for all ages)

Local Authority: Conwy

Carers Outreach Service (advice, information and support for adult carers)
Carers Trust North Wales Crossroads Care Service (respite for all ages)

Local Authority: Denbigshire

NEWCIS (advice, information and support for adult carers) **Carers Trust North Wales Crossroads Care Service** (respite for all ages)

Local Authority: Gwynedd

Carers Outreach Service (advice, information and support for adult carers)
Carers Trust North Wales Crossroads Care Service (respite for all ages)

Regional approach

As part of the **regional plan**, the **North Wales Regional Partnership Board** have set out a number of actions in relation to carers to support the integration of health and social care. The actions outlined are as follows:

- Map current provision and services and assess these against the requirements in the Social Services and Wellbeing (Wales) Act 2014
- Explore and develop approaches for integrated Carer's services and consider whether a pooled budget can be created to support these services

In response to this, the North Wales Social Care and Wellbeing Improvement Collaborative, which is advised by several groups (North Wales Strategic Carers Leads Group, North Wales Operational Carers Group and the North Wales Young Carer) are now in the process of developing a regional offer for carers:

- Understanding where they are at and what success looks like
- What the priorities should be
- Being clear on funding and the sustainability of services for the future

Current activities include resource mapping giving an overview of the services available for carers in North Wales and an estimate of the investment in those services, a mapping of carers journeys and workshops with multi-stakeholder engagement to help shape the regional carer offer.

Local Authority: Cardiff

N/A

Local Authority: Vale of Glamorgan

Crossroads Care in the Vale EMI (dementia respite for adults)

Regional approach

As part of the **Area Action Plan**, **Cardiff and Vale Regional Partnership Board** has committed to identify and implement a carer engagement model based on best practice. Work undertaken to date includes:

- Delivering Phase 1 of the Carers Engagement Project which considered potential carer forum models and barriers to engagement.
- Commissioning a Carer's Support services report to help shape a future offer to carers in Cardiff. This report will include a local carers voice and an analysis of best and emerging practice across Wales.

Local Authority: Merthyr Tydfil

Merthyr CBC

Carers Trust South East Wales (respite)

Local Authority: Rhondda Cynon Taff

Carers Support Project RCT (advice, information and support for adult carers)
Carers Trust South East Wales (respite)

Regional approach

As part of their Area Plan, Cwm Taf Social Services and Wellbeing Partnership Board commissioned the Welsh Institute of Health and Social Care to review current service model for carers and consider how more effective integrated services across the region could be provided.

As a result of this work an integrated service model for carers has been developed which will see the creation of an integrated, dedicated team (initially in-house) to provide a coordinated response to carers issues across the region. The team will operate from multiple places, implementing relevant elements of a 'blueprint' offer whilst scoping detailed implementation of more innovative model.

- Tier 1 Universal and preventive services. Single point of entry providing advice, information and support on all aspect of caring
- Tier 2 Early intervention and re-ablement (training, peer support, carer network etc.)
- Tier 3 Specialist Services (respite, complex care needs, palliative care etc.)

Local Authority: Carmarthenshire

Carers Trust Carmarthenshire Crossroads Care (carers information service for adult carers)
Carers Trust Carmarthenshire Crossroads Care (respite for all ages)

Local Authority: Ceredigion

British Red Cross (adult carers)
Action for Children (young carers)
Hafal Crossroads (respite)

Local Authority: Pembrokeshire

Hafal Crossroads (carers information and support service for adult carers)
Hafal Crossroads (Respite)

Regional approach

West Wales Area Plan 2018-2023 - Delivering Change Together

The West Wales Carer Development Group has developed a Carers Delivery Plan, to address both the Welsh Government priorities as well as the gaps highlighted within the Population Needs Assessment. The following key workstreams have been established for adult carers:

- Investors in Carers (IiC) to include evaluation of current schemes and development of proposals for long term sustainability across health, social care and community settings.
- Joint Commissioning of Carers Services (Outreach, Respite and Information Services) including review of current provision
- Information, Advice and Assistance (specific to the needs of Carers) including the production of a Carers Communication Plan in line with the regional IAA framework
- Service improvement & integration (including Hospital Discharge and Transfers of Care, improving the wellbeing of Carers) – to include an audit of carer assessments, promotion of carer resilience models, review workforce carer policies and establishing a regional carers quality group
- Training & Development (including formal/informal training for Carers) to audit and assess the Learning & Development opportunities for Carers and carer awareness training for staff.

Local Authority: Powys

Credu (adult carers, young carers and young adult carers)
Hafal Crossroads (respite)

Regional approach

Delivering the Vision – Joint Area Plan

Priorities identified within the plan include:

- Reviewing and updating the Powys Carers Joint Commissioning Strategy including Implement The "Everybody's Business" Model for Carers
- Focus on accelerating the integration of Health and Social Care Services work ongoing with integration of care teams for older people.

Appendix 4: Evidence of what is working well

In 2017 the Social Care Institute for Excellence (SCiE), on behalf of Social Care Wales, undertook a rapid review of carers services in Wales. The report **Preventative support for adult carers in Wales: a rapid review**⁵⁶ identifies some emerging good practice and new models in adult carers support, with a particular focus on prevention. However, the review doesn't go far enough to realise its intended aim of capturing emerging good practice in preventative services. Instead, it offers a snapshot of existing practice and carer issues.

It is pleasing that the report echoes the feedback we have received from our Network Partners which clearly demonstrates the importance of ensuring that carers services focus on the important impacts that can be achieved by improving identification and recognition, information, advice and advocacy, mechanisms to achieve a life alongside caring and appropriate and flexible respite.

From our experience, it is clear there are many emerging practices can be identified in Wales, particularly relating to: primary care, respite, hospital liaison, advocacy, mental health and palliative care. These examples provide a much richer and deeper narrative and help to provide a platform for some promising areas of work.

Similarly, **research** carried out by Care and Social Services Inspectorate Wales (2017) into carer engagement, identified many areas that support the **views of carers in Cardiff and the Vale of Glamorgan**, reaffirming that:

- carers want to have their stories heard and hold meaningful 'what matters' conversations with social workers
- carers value carer group meetings which offer peer support as well as an opportunity to receive good sources of information
- that multiple sources and entry points of information and support be simplified

Areas of good practice noted include:

- providing a diverse range of flexible and creative provision, including courses
- counselling and direct payments to enable carers to make their own arrangements
- statutory services adopting carer-friendly policies to support carers they employ and developing partnerships with job centres to support carers into employment

Many local authorities have developed successful initiatives with health boards and, notably, GP practices, which are often the first point of contact for carers. Others have extended this to hospital wards. This area of development has often been driven by NHS involvement, delivered in partnership with local third sector carer organisations.

A common thread throughout the report was the requirement of specialist support groups, such as those for mental health, substance misuse and learning disabilities (particularly parent carers for children with complex needs), which are less universally available for carers than those for older people for instance. It is important that service models and commissioners recognised the importance of ensuring access to appropriate specialist services within an integrated and easy-to-navigate care and support pathway.

This report also further emphasises the views of carers regarding the need for significant forward planning to enable effective use of short-break care. It noted that little help was available when

short breaks were ur as a priority.	gently needed,	something	that many of our	Network Partne	ers have identified
			70		



Response from the Older People's Commissioner for Wales

to

National Assembly for Wales, Health, Social Care and Sport Committee: Inquiry on the Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to carers

September 2018

For more information regarding this response please contact:

Older People's Commissioner for Wales



About the Commissioner

The Older People's Commissioner for Wales is an independent voice and champion for older people across Wales, standing up and speaking out on their behalf. She works to ensure that those who are vulnerable and at risk are kept safe and ensures that all older people have a voice that is heard, that they have choice and control, that they don't feel isolated or discriminated against and that they receive the support and services they need.

The Commissioner's work is driven by what older people say matters most to them and their voices are at the heart of all that she does. The Commissioner works to make Wales a good place to grow older - not just for some but for everyone.

The Older People's Commissioner for Wales:

- Promotes awareness of the rights and interests of older people in Wales.
- Challenges discrimination against older people in Wales.
- Encourages best practice in the treatment of older people in Wales.
- Reviews the law affecting the interests of older people in Wales.

National Assembly for Wales, Health, Social Care and Sport Committee: Inquiry on the Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to carers

Response by the Older People's Commissioner for Wales ('the Commissioner')

Contents

- Summary
- Introduction
 - Older carers in Wales
 - Legal duties
 - Carers Ministerial Advisory Group
- Carers' assessments
 - Legal duty to an assessment
 - What matters approach
 - Access to assessments
 - Identification of carers
 - Assessments and support plans
- Support for carers and respite
 - Information, advice and assistance
 - Respite services
 - Respite and Dementia Action Plan for Wales
 - Continuing Health Care
 - Direct Payments
 - Access to advocacy
 - Making Voices Heard
 - Current & future need for advocacy
- Broader Welsh Government policy
 - Health
 - Health & Carers Strategies (Wales) Measure 2010
 - GP services
 - Dementia Action Plan for Wales
 - Caring and domestic abuse
 - Caring and finances
 - Caring and housing
 - Caring and technology

Summary

- The Social Services and Well-being (Wales) Act 2014 provides carers with an equal right to an assessment – but there is concern that too few are accessing assessments, too few assessments are turning into support and it is unknown why assessments are being refused. There is a lack of intelligent data which prohibits meaningful evaluation of these statistics. The Welsh Government, Local Authorities and Health Boards need to collect more detailed information about assessments, including the reasons behind refusal and the type of support offered.
- Support for carers is often viewed only in relation to a narrow interpretation of respite. Perspectives of respite and the availability of alternative options are preventing carers from experiencing flexible and appropriate respite that contributes towards their wellbeing outcomes.
- 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 support is in place for carers, and promote flexible, meaningful use of direct payments for equipment and respite.
- Following the repeal of the Carers Strategies (Wales) Measure, health services must continue to focus on identifying and delivering for the needs of carers. Far more carers deal with health services than with social care as part of their caring role. 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.
- More needs to be done to ensure that carers' needs for independent advocacy are being appropriately considered and met under the Act. Targeted awareness initiatives, such as information in GP surgeries and libraries, would ensure that those who are most vulnerable are made aware of independent advocacy,

regardless of whether they are in contact with statutory services or identify as carers.

 The support needs and well-being outcomes of carers as individuals must be recognised in their own right, as well as recognising their caring role and the significant contribution this makes to health and social care services.

Introduction

Older carers in Wales

Across Wales, an estimated 370,000 carers are providing unpaid care and support to a loved one¹. More than half of carers are aged 40 to 64 and a quarter of carers are aged 65 or over². Carers provide the vast majority of care to people in communities across Wales, with 96% of care in communities being given by family and friends³.

It is likely that the proportion of older carers is higher than these estimates and is likely to grow further, as is the number of older people receiving unpaid care and support from a loved one. For example, the data on the number of carers is from the 2011 Census. In those seven years, the demography of Wales has evolved, and the proportion of older people to younger people in Wales is now higher than the rest of the UK. The prevalence of dementia has also grown and is now one of the main causes of mortality in older people⁴.

Furthermore, many older people will not recognise themselves as carers and will not declare themselves as such. For example, 55% of carers took over a year to recognise their caring role, and 24% took over five years to identify as a carer⁵.

Whilst stating the estimated number of older people who may be carers across Wales is a starting point to understand the level and scale of unpaid support that is provided to loved ones – statistics alone do not delve into who these older carers are.

¹ ONS, Census 2011

² Social Market Foundation, Caring for Carers, 2018

³ Statement, Huw Irranca-Davies AM, Minister for Children, Older People and Social Care, 14 June 2018

⁴ONS, Deaths registered in England and Wales, 2017

⁵ Carers UK, Missing Out: the identification challenge, 2016

It is important to remember that carers are not a homogenous group. Caring relationships are varied, diverse and not necessarily limited to a two-person relationship. Carers may be fulfilling one or multiple caring roles across and between generations, and they may be part of a wider caring network.

Older people are not simply always the recipients of care. Many older people are carers themselves, providing support to siblings, spouses, partners (and ex-partners), their children, parents and friends. Older carers may also provide support to more than one loved one. For example, the Commissioner's office has provided support to a woman who was a carer for both her disabled son and her husband.

In addition to the diversity of caring relationships and networks, there is diversity amongst carers. People with one or more protected characteristics may encounter a variation in their experience of caring. For example, familial responsibility for older people is expected in some cultures, and myths about BAME cultures may shape the outlook of a professional working within health and social care^{6,7}. Furthermore, heteronormative assumptions can force LGBTQ older people and carers 'back into the closet' when interacting with health and social care professionals⁸.

Section 6 (2) of the Social Services and Well-being (Wales) Act 2014 (the Act) outlines how a person exercising functions under the Act must have regard to an individual's views, wishes and feelings, their characteristics, culture and beliefs. The Act also includes a duty to have due regard to the United Nations Principles for Older Persons. A depth of understanding of who carers are is therefore critical to the achievement of these overarching duties in the Act.

The contribution of carers to our economy and our society is significant. The economic contribution of all carers in the UK is estimated to save £91 billion every year in potential care costs, with an economic value of £139 billion per year. In Wales, unpaid older carers save the Welsh economy an estimated £1.88 billion in care costs, predicted to rise to £2.44 billion by 2030. Other estimates indicate that the value of total

⁶ Health and Social Care in the Community, Barriers to access and minority ethnic carers' satisfaction with social care services in the community: a systematic review of qualitative and quantitative literature, Greenwood, Habibi, Smith & Manthorpe, 2015

⁷ IRISS, Improving Support for Black and Minority Ethnic Carers, 2010

⁸ Marie Curie, Hiding who I am – The reality of end of life care for LGBT people, 2016

carers' contributions in Wales could in fact be estimated at £8.15 billion per year⁹. The risks to the wider system, and society as a whole, cannot be underestimated if the well-being of carers is not supported.

Fundamentally, however, older carers want and need support to enable them to continue caring and to support their wishes to achieve their own outcomes and well-being goals in their own right as citizens under the Act.

Legal duties

It is positive that the Act has placed carers on an equal footing with their loved ones. For example, carers have a legal right to an assessment and a legal right for support for eligible needs from a Local Authority following an assessment. The definition of a carer has also been broadened and Local Authorities must ensure that they have information, advice and assistance services in place, which are clearly signposted, so carers can get the right information at the right time¹⁰.

There are duties within the legislation that make direct reference to carers, but there are also many other duties that impact on and protect carers as an individual in their own right. For example, the overarching principles of the Act should influence all interactions with a carer regarding their support needs. A Local Authority must have regard to an individual's views wishes and feelings, provide appropriate support to enable an individual to participate, and begin with the presumption that an individual is the best person to judge what is best for them¹¹. As highlighted above, a person exercising duties under the Act must also have due regard to the United Nations Principles for Older Persons¹².

However, the Carers Strategies (Wales) Measure 2010 and other preexisting carers legislation was repealed by the introduction of the Act. Although some of the provisions within the Measure have been passported across to the Act, this action was strongly opposed by carers organisations, as some of the provisions have been weakened. This is explored further below.

⁹ Bangor University, Living well for longer: The economic argument for investing in the health and wellbeing of older people in Wales, 2018

¹⁰ Carers Wales, Track to Act, Briefing 2, 2017

¹¹ Section 6 Social Services and Wellbeing (Wales) Act 2014

¹² Section 7(1) Social Services and Wellbeing (Wales) Act 2014

Over two years on from the implementation of the Act, focus needs to shift from its content and onto its impact. It is not yet clear whether the Act is delivering upon its wide-reaching intent and whether the impact on carers has been positive. On the whole, 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.

Welsh Government, Carers Ministerial Advisory Group & National Priorities

In 2017, the Welsh Government established three national priorities to guide work to enhance the lives of carers and announced an attached £1 million funding to support this¹³. A Ministerial Advisory Group (MAG) has also been established, and £95,000 has been allocated in 2018/19 to fund projects to drive forward a national approach to delivering against the priorities. Prior to this, the Carers Strategy 2013-2016 was being followed.

National priorities are not as substantial as a national strategy and these priorities do not include specific actions. It is therefore unclear whether the priorities in themselves constitute a strong enough commitment to ensure the needs of carers are met. For example, the priorities are all linked to duties already provided under the Act and it is currently difficult to see how they further progress the rights of carers and carer awareness across Wales.

Furthermore, the success of the national priorities in improving support and recognition for carers will depend on the effectiveness of the MAG to form the basis of a clear action plan for Wales.

It was disappointing to note that the funding linked to support for carers had already been allocated and objectives set before the MAG had met, with specific funds allocated to young carers support, an employment hub and respite¹⁴. Funding to meet the quality of life and outcomes of older carers was not explicitly named but is implicit in the £1m budget to raise carer awareness across GP practices in Wales and improve support for carers in relation to hospital discharge. It is vital that this funding is used prudently to benefit older carers in Wales. For example,

¹³ Welsh Government, Written Statement, A Carer Friendly Wales, 24 November 2017

¹⁴ Welsh Government, Carers Ministerial Advisory Group, Terms of Reference

the consistent development and use of GP registers or more expedient discharge processes would contribute to ensuring that the needs and wishes of carers are recognised and responded to.

Carers' Assessments

Legal duty to an assessment

The Act places a number of duties on Local Authorities relating to the assessment of a carer's need for support. These include the right to an assessment, the ability to combine or separate assessments and care and support plans, a duty to assess a carer's willingness and ability to provide care, and a duty to consider how the needs of a person with care and support needs would be met in the absence of a carer¹⁵.

A carer can refuse to have a needs assessment under the Act if they so wish, but prior refusal does not prevent a carer from requesting an assessment again in future. Furthermore, a duty on the Local Authority to assess does not diminish if this is refused. For example, the Local Authority can assess a carer if they are satisfied that the carer lacks the relevant capacity, and an authorised person can make a decision on the carer's behalf. If there is no authorised person, a Local Authority can assess if it would be in the carer's best interest¹⁶.

What matters conversations

When older people contact a Local Authority for help, information, advice or assistance, a 'what matters' approach should lead the discussion. The focus 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-being¹⁷.

Once an individual has made contact with social services, this conversation should set the tone and direction for the whole of an individual's access to support and the realisation of their rights. This approach is key to ensuring that older people are recognised as carers

¹⁵ Section 24, 28, 29 Social Services and Well-being (Wales) Act 2014

¹⁶ Section 25 Social Services and Well-being (Wales) Act 2014

¹⁷ Section 6(3)(a) Social Services and Well-being (Wales) Act 2014

(both by themselves and public services), and that their own needs are recognised and provided for through an assessment and an appropriate resultant plan.

Access to assessments

As set out above, carers should have access to a needs assessment under the Act, undertaken through a 'what matters' approach. Access to an assessment, and the quality of its undertaking, are both critical to the recognition of a carer's outcomes, well-being and support needs in their own right.

However, carers assessment rates are significantly lower than would be expected, given that there are an estimated 370,000 carers in Wales:

- In 2016/17, 6,207 carers' assessments were carried out during the year.
- Out of these assessments, 1,823 led to a support plan
- 6,864 carers refused an assessment¹⁸.

Carers receiving or refusing an assessment accounted for less than 4% of the estimated number of carers in Wales and only 29% of those assessed received a support plan.

According to Carers Wales' State of Caring report, , it is concerning that over half (66%) of the 370,000 people in Wales providing unpaid care said they had not been offered or requested an assessment¹⁹.

Serious questions therefore need to be asked regarding why so few carers are accessing assessments, why so few assessments are resulting in support plans and whether other forms of support are in place, to enable these figures to be interpreted in a meaningful way.

The Commissioner's office has provided support to an older carer who expressed her feelings that older carers were not given the same considerations as other carers, and were waiting longer for access to an assessment.

¹⁸ Stats Wales, Adults assessed by local authority and measure, 2016/17

¹⁹ Carers Wales, State of Caring 2017, 2017

There are local and regional variations across Wales in the access that carers have to assessments. For example, Carers Wales' Track the Act report highlights that there is currently 'a 'postcode lottery' where carers in some areas will receive an assessment, whereas others won't'. ²⁰ Furthermore, feedback from carers to the Commissioner shows that there is even variation in practice within Local Authorities and between social workers on the same team.

There are a number of possible reasons that sit behind the statistics for carers assessments: carers may be signposted to community or preventative services that are not recorded through a formal support plan, an individual may choose to refuse an assessment because of the perception that their ability to care is being assessed, or an individual may not recognise themselves as a carer or be recognised by health and social services as a carer to be able to access an assessment.

The data released by Stats Wales in relation to carers assessments is experimental, and there is some recording variation between Local Authorities. It is of concern that the data currently being recorded is not accurately reflecting the carer experience in relation to accessing assessments. For example, data recording does not include:

- Community/preventative support not included within a support plan
- Reason for refusing an assessment
- Whether the carer's outcomes are being met through support plans
- Feedback from carers on the assessment process

Identification of carers – relevance to assessments

In broad terms, Carers Wales Track the Act highlights a variance across Wales in strategic approach and delivery of services to identify and meet the needs of carers²¹.

An individual identifying themselves as a carer, or the identification of a carer by social services [or through referral from health services] is critical to the access that a carer has to an assessment. There are many older people in Wales who may not recognise themselves as carers or who may care for a long time before recognising their role; in Wales,

²⁰ Carers Wales, Track the Act, Briefing 2, 2017

²¹ Carers Wales, Track the Act, Briefing 2, 2017

55% of carers took over a year to recognise their caring role, and 24% took over 5 years to identify as a carer²².

The duties for carers' assessments under Section 24 of the Act are triggered 'where it appears to a Local Authority that a carer may have needs for support'. There is not a proactive duty on a social worker to seek out and identify individuals who may or may not be carers, and who may or may not have needs for support (as identified through an assessment).

Older people may therefore not be contacting their Local Authority to ask for support as a carer, as they do not recognise themselves as such. If individuals do not self-identify, the role of social services staff in recognising carers and communicating this relationship between being identified as a carer and accessing support to an individual becomes more important. For example, the Commissioner's office has provided support to an older man who was not considered as a carer for his wife and therefore could not access his right to an assessment because his wife had not yet been discharged from hospital and was under inpatient care.

Staff training of health and social care staff is therefore important to ensure the approach to individuals is consistent with the Act. Social Care Wales is developing a series of learning materials for social care workers and connected staff in relation to supporting carers and carers assessments. These resources are in development, but how they are rolled out and implemented 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.

Population Assessments, as set out in Section 14 of the Act are a crucial part in a Local Authority's ability to understand the care and support needs of the people who live within their area, including carers, and the services needed to meet those needs²³. This is one step towards improving carer awareness and recognition and, in turn, increasing assessments and support.

However, if the findings of the Population Assessments are going to move beyond an academic exercise, Local Authorities will need to undertake critical analyses of their findings against the reality of carers

²² Carers UK, Missing Out: the identification challenge, 2016

²³ s14 Social Services and Well-being (Wales) Act 2014

assessments and consider whether the carers assessments completed within their area are consistent and expected with the number of carers identified through their Population Assessment?

Assessments and support plans

Across Wales in 2016/17, 1,823 support plans were provided following 6,207 carers' assessments²⁴; only 29% of those assessed received a support plan.

The number of support plans following an assessment may be low because support is sometimes merged with the needs assessment and plan of the person with care and support needs, support by informal community support or preventative services that do no feature in a plan, or eligibility criteria may not be clear enough and applied differently across Wales²⁵.

The Care and Support (Assessment) Wales Regulations 2015 state that a Local Authority must produce a written record of an assessment²⁶ and a copy of the written record of assessment must be given to the person²⁷.

However, older people have contacted the Commissioner describing how paperwork explaining support plans and other decision making are not always accurate, given in a timely manner, or not provided to carers. For example, the Commissioner's office provided support to an individual who was assessed as having no needs as a carer, but was not given a copy of the assessment for five months once requested. Once a copy was received, inaccuracies in the assessment were spotted and a new assessment took place which subsequently identified support needs.

Support for carers and respite

Carers Wales' State of Caring report, published in 2017, states that 1 in 5 carers caring for 50 hours or more a week receive or buy no practical

²⁴ Stats Wales, Adults assessed by local authority and measure, 2016/17

²⁵ Carers Wales, Track the Act, Briefing 1, 2016

²⁶ Regulation 5(1) Care and Support (Assessment) (Wales) Regulations 2015

²⁷ Regulation 6 Care and Support (Assessment) (Wales) Regulations 2015

support at all to help them²⁸. However, appropriate recognition and support is essential to maintaining and improving a carer's well-being, helping them to continue their caring role and supporting their life outside of a caring role.

There is a duty within the Act to provide preventative services, and this includes support services for carers²⁹. Appropriate support and preventative services are essential to the achievement of the outcomes of carers, and preventative and support services for carers and people living with dementia have been proven to have a positive return on investment³⁰.

However, Social Care Wales found that the identification and recognition of carers by themselves and professionals, and the information, advice and assistance about rights, entitlements and services available to carers were key themes affecting access to preventative services³¹. Furthermore, services and support are not always designed or provided in a way that is most appropriate for those in need. For example, the Commissioner's 'Rethinking Respite' report found that a fundamental rethink in the design and delivery of respite services for carers is needed and that carers and people living with dementia need to be more involved and should be instrumental in the design of respite support services³².

Information, advice and assistance

The Act places a duty on Local Authorities to provide information, advice and assistance (IAA) to citizens, including carers³³. The provision of information advice and assistance is critical to the knowledge of, and access to support and preventative services that carers have. However, Local Authority IAA services across Wales will vary in structure and approach and could range from a telephone line, to a community hub.

Regardless of the type of IAA provision, when contacting an IAA service in Wales there is no duty within the Act to collect data about how carers are using the service. Carers Wales Track the Act report found that in the first six months of the Act's implementation, only 16% of carers had

²⁸ Carers Wales, State of Caring 2017, 2017

²⁹ s15 Social Services and Well-being (Wales) Act 2014

³⁰ Bangor University, Living well for longer: The economic argument for investing in the health and wellbeing of older people in Wales, 2018

³¹ Social Care Wales, Preventative support for adult carers in Wales: rapid review, 2018

³² Older People's Commissioner for Wales, Rethinking Respite for people affected by dementia, 2018

³³ s17 Social Services and Well-being (Wales) Act 2014

received information from their Local Authority to support them in their caring role. This increased to 46% in the following six months. 78% of carers said that the information they had received was either useful or very useful³⁴.

However, whilst an indication, these figures are not national, official data. 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.

It is not currently possible to define the current success of IAA services in effectively signposting or referring carers to support services. Notwithstanding this, concerns have been raised with the Commissioner by third sector organisations that individuals using IAA services have been signposted back into the community where a further assessment may have been more appropriate.

Respite services

Respite is often seen as one of the most common forms of support for carers. However, it is often only thought of as an overnight stay or day visit to a care home for the individual with care and support needs.

The Commissioner's 'Rethinking Respite' report³⁵ found that respite should not be limited to this narrow choice, which does not always meet the needs of carers or those living with dementia. Whilst the report focused specifically on people living with dementia and their carers, many of the key messages are equally applicable to other people who need respite.

People need opportunities to have breaks together and apart, within the home and away from home, in line with their views, wishes and feelings. There is a clear need for more creative forms of respite, in partnership with a range of sectors, covering hospitality, the environment, sports, arts and leisure – such as the respitality scheme in Scotland.

³⁴ Carers Wales, Track the Act, Briefing 2, 2017

³⁵ Older People's Commissioner for Wales, Rethinking Respite for people affected by dementia, 2018

However, current systems for monitoring, measuring and evaluating levels of 'respite' are not fit for purpose, as they relate to a narrow and one-sided definition of respite (e.g. the Welsh Government respite performance indicator only relates to overnight stays). Furthermore, information about respite options is not sufficiently accessible, delivered at the right time and in the right format, and there is insufficient support to make sense of the options available. Social services staff may not be fully aware of the options themselves.

The report also found that health and social care systems are not sufficiently responsive to people with multiple caring roles. For example, the Commissioner's office has provided support to a woman who is a carer for both her husband and son. Whilst she receives infrequent respite support from social care workers who take her son out, she does not have any time for herself as she is still caring for her husband.

The Commissioner proposed a new respite outcomes map within the report, based on the outcomes that carers and people living with dementia stated that they wanted to achieve. This correlates to the National Outcomes Framework and has the potential to be a useful tool – for practitioners, regulators, policy makers, providers and people who use services – to promote the development of more meaningful respite alternatives and measure their impact.

The outcomes map has also been welcomed by the Carers Officers Learning and Information Network, carers organisations and professionals who have described it as a useful discussion point for making the National Outcomes Framework both meaningful and achievable in terms of personal outcomes.

Respite and the Dementia Action Plan

The Welsh Government's Dementia Action Plan for Wales 2018-2022³⁶ (the Plan) was published in February 2018. An additional £10m a year will support the delivery of key actions within the Plan and progress against delivery of the plan will be overseen by a Dementia Delivery

³⁶ Welsh Government, Dementia Action Plan for Wales, 2018

Assurance and Implementation Group³⁷, the minutes of which will be published for transparency³⁸.

The Plan recognises that there needs to be different options for respite care relevant to different age groups, includes a commitment to ensure that the new 'teams around the individual' approach enables families and carers to access respite care that meets the needs of the carer as well as those of the person living with dementia, and commits to learn from the 'Rethinking Respite' report. Progress against this plan will be 'a key vehicle for demonstrating achievements and areas for improvement outlined within the Health and Care Standards for Wales'³⁹.

Carers and Continuing Health Care

Continuing Heath Care funding may be provided by a Health Board if an individual's needs are assessed as being primarily health needs. However, once this funding and package of care is in place, there may still be a carer present who should be recognised and supported.

Local Authorities are responsible for assessing the support needs of carers, which includes carers of individuals receiving CHC funding⁴⁰. However, when carers are involved in supporting an individual in receipt of CHC funding, the Commissioner is aware that in practice there can be a lack of clarity or action as to which public body is responsible for supporting the carer.

The Commissioner's office provided support to an older man when a best interests decision was made to move his wife into a care home. The man expressed his desire to care for her in their own home, but to do so the Health Board advised him that he needed to provide a care plan to demonstrate how he intended to care for his wife. No support to develop such a plan was offered or accessible, and a further best interests meeting decided that he did not provide sufficient assurance that he was able to meet his wife's needs, despite the fact that he had been a vital member of his wife's care team when she was receiving treatment in hospital.

17

³⁷ This group has now been renamed the Dementia Oversight, Implementation and Impact Group. Membership of this group will include people living with dementia and their carers and families.

³⁸ Welsh Government, Dementia, 2018

³⁹ Older People's Commissioner for Wales, Rethinking Respite for people affected by dementia, 2018

⁴⁰ s24 (1)(a) Social Services and Wellbeing (Wales) Act 2014

Additionally, the Commissioner's office supported an individual when they disputed the removal of one-to-one support for their family member who received CHC funding. Following the Commissioner's intervention, the Health Board invited the carer to comment on new patient literature to prevent similar disputes from occurring. The carer expressed that they felt they had contributed to making a difference for other carers and that the Health Board had taken her feedback seriously.

In relation to respite, funding can be obtained for this where CHC funding is involved but older people have reported that it was difficult to obtain, and that they had to question or complain to the Health Board in order to access this.⁴¹

Direct payments

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.

'Rethinking Respite'⁴² found that direct payments can be an important vehicle to enable flexibility, choice and control in relation to supporting older carers. For example, a small number of 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 (either in a care home or within the hospitality sector), or paying for a 'buddy' for a few hours or days a week, to help support the person living with dementia with what they wanted to do, in or outside of the home.

However, there is very limited uptake of this option, particularly amongst older people and carers⁴³. As demonstrated by the quotes below, the 'Rethinking Respite' report found that the majority of older people living with dementia and carers were unfamiliar with this route to support and

18

⁴¹ Older People's Commissioner for Wales, Rethinking Respite for people affected by dementia, 2018

⁴² Older People's Commissioner for Wales, Rethinking Respite for people affected by dementia, 2018

⁴³ <u>Social Care Institute for Excellence, Keeping personal budgets personal: learning from the experiences of older people, people with mental health problems and their carers, Newbronner, L., Chamberlain, R., Bosanquet, K., Bartlett, C., Sass, B. & Glendinning, C. 2011</u>

said they had not been informed about direct payments by their social worker.

"Direct payments - here you have to fight for it." Carer

"I have heard the Council now say that they will not pay carers direct payments now and that's illegal." Carer

Some carers who tried to use direct payments for respite did not have a positive experience, either because they did not feel adequately supported to manage them, the amount of money provided by Social Services did not cover the costs or because they could not find anyone to provide the service.

Carers are also entitled to seek support for themselves in the form of a direct payment. For example, a carer had used the payment for someone to mow the lawn, which was something he found difficult due to health reasons. It met the outcomes of having a break and sustaining him in his caring role:

"Helping with some of the difficult things I was finding to do – things that might alleviate that." Carer

Carers access to advocacy

"[Advocacy] helped me know my rights." - Carer and Advocacy User44

Upholding the rights of carers to access advocacy, where appropriate, is necessary to ensure they can access the services and support they need to continue in their role and is also a vital part of successful implementation of the Act.

However, the Commissioner's report, 'Making Voices Heard: Older People's Access to Independent Advocacy in Wales⁴⁵' found that a

⁴⁴ Older People's Commissioner for Wales, Making Voices Heard: Older People's Access to Independent Advocacy, 2018

⁴⁵ Older People's Commissioner for Wales, Making Voices Heard: Older People's Access to Independent Advocacy, 2018

significant number of older people are unable to access independent advocacy, both more generally and in relation to legislative duties.

"You don't know what you don't know." – Older person living with dementia⁴⁶

It suggests that more needs to be done to ensure that carers' needs for independent advocacy are being appropriately considered and met under the Act. Targeted awareness initiatives, such as information in GP surgeries and libraries, would ensure that those people who are most vulnerable are made aware of independent advocacy, regardless of whether they are in contact with statutory services or identify as carers.

For many carers, a family member, friend or the person they provide care and support to may be able to provide informal advocacy to allow them to participate and have their views and wishes heard in the decision-making process. However, the number of carers who have received support from an informal advocate to assist them in their contact with social services is currently unclear. Similarly, it is not clear how many carers have received an offer of statutory Independent Professional Advocacy (IPA) in line with the Act or how many carers have accepted the offer of IPA.

National data⁴⁷ shows that 762 people received an 'advocacy' service during 2016-17 as part of their care and support, but no further data is available to confirm the type of advocacy that was provided or the percentage of carers accessing advocacy support. In addition, whilst the Annual Report on the National Outcomes Framework shows that 71% of carers receiving support agreed that they had been involved in any decisions made about how their care or support was provided⁴⁸, it does not contain any further detail on the reasons why almost 30% of carers

⁴⁶ Older People's Commissioner for Wales, Making Voices Heard: Older People's Access to Independent Advocacy, 2018

⁴⁷ Welsh Government, Adults receiving care and support in Wales, 2016-17 (Experimental statistics); Stats Wales, Children receiving care and support by local authority and age group, 2016-17 (Experimental statistics)

⁴⁸ Welsh Government, Measuring national well-being: A report on the national outcomes framework for people who need care and support, and carers who need support, 2016–17, 2017

did not feel involved in decisions made about them and whether their need for advocacy, statutory or otherwise, was a factor in this.

The lack of data to demonstrate whether a carer's need for advocacy has been considered is a concern. Carers were unanimous in their desire for specialist independent advocacy services to be available to them to ensure that they are aware of their rights, and the rights of the person they care for, so they can feel better informed and better able to continue to provide care and support.

The current lack of data collected in relation to the offer of advocacy during assessment process makes it unclear as to whether independent advocacy, or the lack of the carer having an effective voice during the process and not knowing their rights, may be a factor in the low number of Support Plans resulting from carers' assessments.

The report also found potential shortcomings in the level of training for staff working in statutory services on the legal requirements in relation to advocacy, resulting in a lack of understanding amongst professionals on people's rights to independent advocacy, which may act as a barrier to carer's access to advocacy.

Under the Mental Capacity Act 2005, those acting as informal advocates for the person lacking capacity, such as an unpaid carer, family member or friend, can receive support from an IMCA⁴⁹ to help support them perform the role of informal advocate. The extent to which this right is offered to informal advocates, and the use of IMCA at a national level is largely unknown. This is a concern as denying informal advocates the support of an IMCA to be effective in their role potentially undermines the voice of the person for whom they are advocating.

For example, the Commissioner's office has provided support to a family who disagreed with a best interests decision made about their family member. An IMCA referral was not considered as the individual already had family involvement. However, it is in situations like these where an IMCA could have been used to ensure the older person's best interests were protected.

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⁴⁹ The Mental Capacity Act 2005 states that where a person has an unpaid representative, a 39D IMCA must be instructed if a request is made by the person or their unpaid representative or the supervisory body believes that the person or their representative would benefit from the support of a 39D IMCA

The low level of uptake of support from a 39D IMCA by family or friends who are acting as an informal advocate for a person who lacks capacity is a concern. It calls into question the extent to which professionals are appropriately informing those undertaking the informal advocate role, many of whom will be carers, of this right. Whilst the latest monitoring report for Deprivation of Liberty Safeguards⁵⁰ shows that a higher proportion of challenges to DoLS authorisations were made when an IMCA was present, it states that use of IMCA in the DoLS process has remained relatively steady since 2015/16. The report shows that, of the 363 cases where an IMCA was appointed (out of a total of 13,627 DoLS applications made in 2016/17⁵¹), only 94 of these were a 39D IMCA. Given the important role played by an IMCA (including 39D IMCAs) in ensuring that the person's voice is heard when decisions about best interest are made, it is vital to ensure that people's rights to an IMCA (including informal advocates right to a 39D IMCA) are promoted more consistently.

Current and future need for independent advocacy

It is concerning that the current Population Assessments under the Act do not feature independent advocacy in any great detail, despite the requirement to do so. Whilst the Population Assessments identify several different groups within the reports – including people with a learning disability, people with a mental health condition, older people and carers, who potentially require independent advocates with different skills – there is no indication as to what different types of independent advocacy services may be required to meet this need.

It should be quite possible to analyse data on specific groups of people to estimate demand for independent advocacy; an increase in the number of people living with dementia, for example, will indicate a need for a proportionate increase in the number of independent advocates who are able to work in this area. It is concerning that this link has not been made in any of the Population Assessment reports.

⁵⁰ CSSIW & HIW, Deprivation of Liberty Safeguards: Annual Monitoring Report for Health and Social Care 2016-17

⁵¹ CSSIW & HIW, Deprivation of Liberty Safeguards: Annual Monitoring Report for Health and Social Care 2016-17

This is a significant missed opportunity and raises concerns about the effectiveness of the PAs as a tool to 'ensure services are planned and developed in an efficient and effective way by public sector partners to promote the well-being of people with care and support needs'52.

Broader Welsh Government policy

Health

Caring can have a negative impact on carer's physical and mental health. Carers Wales' State of Caring report showed that:

- Carers can find it a challenge to find time to take care of their own well-being whilst caring:
 - Over half of carers in Wales (53%) reported that they have reduced the amount of exercise they take because of caring and 47% reported that they have found it difficult to maintain a balanced diet.
- Carers are more likely to have physical or mental health conditions and often neglect those conditions:
 - 6 in 10 carers (59%) said their physical health was worse as a result of caring, whilst 70% of carers in Wales said they suffered from mental health problems.
- Carers are more likely to experience stress, anxiety and worse mental health:
 - Half (50%) of carers in Wales said their mental health has got worse as a result of caring, 8 out of 10 people (78%) said they feel more stressed because of their caring role, and 7 out of 10 (67%) said caring has made them feel more anxious⁵³.

In addition to their own health needs, far more carers deal with health services than with social care as part of their caring role⁵⁴. Awareness, identification and responsiveness to carers from health services is therefore absolutely critical in

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⁵² Paragraph 79, Part 2 Code of Practice (General Functions), Social Services and Well-being (Wales) Act 2014

⁵³ Carers Wales, State of Caring 2017, 2017

⁵⁴ Wales Carers Alliance, Assembly Member Briefing for the Stage 3 Debate of the Wellbeing of Future Generations (Wales) Bill, 2015

supporting carers to continue in their caring role and to maintain their own wellbeing.

Health & Carers Strategies (Wales) Measure 2010

The Carers Strategies (Wales) Measure 2010 (the Measure) and other pre-existing carers legislation was repealed by the introduction of the Act, on the basis that its provisions were intended to be passported across to the Act, an action that was strongly opposed by carers organisations at the time.

The Wales Carers Alliance raised concerns that the repeal of the Measure, and introduction of the Well-being of Future Generations (Wales) Act 2015 have diluted the role of Health Boards when jointly planning services for carers, and detailed guidance that sat under the Measure has been lost⁵⁵.

Under the Measure, Health Boards were designated as the lead agencies when developing local carers' strategies, the purpose of which was to deliver systematic carer identification and provision of information to carers⁵⁶. This is now included within a more general requirement for Public Services Boards to complete assessments of well-being and publish a local well-being plan⁵⁷.

Whilst the impact of these legislative changes is currently unknown, the legal framework for recognising and providing information to carers that previously existed through the Measure has been dismantled, a change that has also been reflected in the dismantling of accompanying strategic roles⁵⁸.

Notwithstanding this, there are examples of good practice in relation to carers across Health Boards, such as schemes that aim to encourage and motivate practices to aspire to higher levels of information and support for carers, such as the 'Investors in Carers' scheme for GP practices across Hywel Dda University Health Board⁵⁹. Furthermore, the role of a Carers Champion within GP services has been well

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⁵⁵ Wales Carers Alliance, Assembly Member Briefing for the Stage 3 Debate of the Wellbeing of Future Generations (Wales) Bill, 2015

⁵⁶ Carers Strategies (Wales) Measure 2010; Carers Strategies (Wales) Measure 2010 Guidance issues to Local Health Boards and Local Authorities, December 2011

⁵⁷ s37 Wellbeing of Future Generations (Wales) Act 2015

⁵⁸ Evidence gathered from Carers Officers Learning and Information Network for OPCW Rethinking Respite

⁵⁹ Hywel Dda University Health Board, Investors in Carers

implemented in some practices, but there has been a variation in the success and impact of this role⁶⁰. However, the future of these schemes and action across each Health Board is now dependent on the will of each organisation opposed to requirements set out within the Measure.

GP services

The Commissioner published a report into GP services in 2017⁶¹, in which almost 17% of questionnaire respondents identified as carers, and a number of issues were raised in relation to carers.

The report found that health systems can be inflexible and unresponsive to people's individual needs – for example when booking an appointment and a lack of recognition of the difficulty carers may face in attending last minute appointments. Carers talked about the challenges in getting a home visit, and the frustrations in having to explain their situation multiple times when requesting this.

"Difficult for carers to attend same day appointments as cannot get cover or help that quick - even volunteer car service may not be available at such short notice." – Carer at GP services engagement event

"The biggest problem is getting past the receptionist. We need home visits as my wife is housebound and I am her carer. It's like an interrogation every time - a minefield of questions demanding answers. There should be a flag on your file if you need home visits. Instead it's a battle every single time." – Carer at GP services engagement event

Overall, the feedback from older people appeared to show a positive shift in welcoming and recognising the presence and role of carers, and there were examples of good practice such as effective use of system flagging (with consent) to identify individuals who are carers, living with dementia, or specific communication needs.

"There is no problem bringing a carer. They talk to both of us. We are accepted as a couple - neither is excluded." – Carer at GP services engagement event

⁶⁰ Older People's Commissioner for Wales, GP Services in Wales, 2017

⁶¹ Older People's Commissioner for Wales, GP Services in Wales, 2017

However, a small number of older people felt that health professionals spoke to a carer or support worker instead of directly to them, and were not sufficiently responsive when keeping a record of an individual's status as a carer.

"I believe that the needs of (unpaid) Carers needs to be better addressed by my surgery. I handed in a Carer registration form but it is hard to see if anything has been actioned. I asked for a referral to my local Social Services (to receive Carer related information) but nothing has been received. I have not had any Carer related communication from my Surgery (e.g. invitation to flu clinic)." – Response to online questionnaire on GP services

Dementia Action Plan for Wales 2018-2022

The Welsh Government's Dementia Action Plan recognises the crucial role that carers play in supporting people living with dementia. It also recognises the right to a carers assessment, the need for flexible respite provision and introduces the principles of John's Campaign for carers to stay with the people they support in hospitals⁶².

Carer involvement in in-patient care planning for people living with dementia is key to enable better outcomes following admission, whereas current hospital processes can mean carers are excluded from meaningful participation in supporting a loved one with dementia. The implementation of the strategy will therefore need to include carers, not only as an individual accompanying someone whilst in hospital, but as a key partner in the planning and delivery of care.

It is currently unknown how the Welsh Government will require Health Boards to report on the implementation of John's Campaign across Wales. However, any regional approach must ensure that carers rights to stay with their loved one are not diluted or left to chance.

Domestic abuse and caring

There is an increased risk⁶³ of people living with dementia experiencing abuse from a family carer. Similarly, carers are also at risk of being

⁶³National Centre for the Protection of Older people, Abuse of Older People with Dementia, 2013; Journal of Interpersonal Violence, Coercive control and physical violence in older adults, 2015

⁶² Welsh Government, Dementia Action Plan for Wales, 2018

abused by the person they are caring for. Findings indicate a significant correlation between experiencing trauma, poor health, low levels of social support and living alone, with experiencing emotional coercive control by an intimate partner during one's lifetime, which are risk factors associated with an increased risk of physical abuse after the age of 60⁶⁴. It is therefore essential that health and social care professionals are able to recognise the risks to a carer and the person they are caring for in a potentially abusive situation.

However, staff capacity issues may limit the opportunities that social workers have for developing positive, trusting relationships with older people. There is evidence in Wales that statutory agencies resort to case management by telephone⁶⁵, a practice that can inhibit the development of a 'person-centred' ethos within adult safeguarding and hinder the promotion of personalisation of adult care in general⁶⁶.

Local Authorities and Health Boards need to actively promote awareness of the hidden problem of domestic abuse experienced by older people, and recognise and implement a co-ordinated community response as the most appropriate strategy for tackling the complexity of domestic abuse⁶⁷.

Caring and finances

Being a carer can have a negative impact on personal finances. Carers may experience higher household costs, increased transport costs (especially for those in rural areas) and may not have access to flexible working, or be less able to work, due to their caring role⁶⁸. An older carer may still wish to participate in work, but find this challenging due to their caring role, or may not be accessing the financial support to which they are entitled.

Carers Trust state that UK-wide:

 The employment rate for carers is at 67%; over half of those who are not working say that they want to do so. One in five carers gives up employment to care.

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⁶⁴ Journal of Interpersonal Violence, Coercive control and physical violence in older adults, 2015

⁶⁵ Older Peoples Commissioner for Wales, Access to support and justice, 2015

⁶⁶ British Journal of Social Work, Social work in the context of adult social care in England, 2010

⁶⁷ <u>Journal of Gender Studies, Inching forward on domestic violence: The 'co-ordinated community response' and putting it in practice in Cheshire, Hague and Bridge, 2008,</u>

⁶⁸ Carers UK, The Cost of Caring, 2013

- In a survey, 53% of carers have borrowed money as a result of their caring role.
- 60% have used all of their savings to cover the costs of caring.
- 35% of carers had missed out on state benefits because they didn't realise they could claim them. 9% had missed out on Carer's Allowance for 3–5 years, 10% for 5–10 years and 14% for over 10 years, because they did not realise they were entitled to it⁶⁹.

Attendance Allowance is a benefit available to people aged 65 and over who have a disability which means that they require care or supervision on a daily basis. It is claimed by 100,000 people in Wales, equating to 17% of people over 65 the age of 65 (at a cost of £400m). There are concerns that Attendance Allowance is not reaching all those who need it, and older people may not see themselves being entitled to claim benefits. For example, there is no correlation with the proportion of older people receiving Attendance Allowance and older people receiving non-residential care across Wales' Local Authority areas⁷⁰. Raising awareness of benefits such as Attendance Allowance could be one step towards improving the financial situation of carers.

Caring and housing

It is well known that the quality and appropriateness of housing is a key factor in an individual's health and well-being. Warm, energy efficient homes can keep costs down and prevent problems related to cold and damp living conditions. Furthermore, accessibility and appropriate adaptation can greatly improve the quality of life of an individual with care and support needs and also their carer.

Housing issues experienced by carers include not being prioritised for housing, not being recognised as needing a separate bedroom, inheritance or tenancy rights not being recognised if a carer is not on the deeds/tenancy, and ongoing challenges in securing adaptations or an adapted home⁷¹.

In taking forward the recommendations of the Expert Group on Housing an Ageing Population⁷² and further housing policy, the Welsh

⁶⁹ Carers Trust, Key facts about carers, accessed September 2018

⁷⁰ Bevan Foundation, Future of Attendance Allowance in Wales, 2016

⁷¹ The Princess Royal Trust for Carers, Carers and Housing: Addressing their needs, 2010

⁷² Welsh Government, Expert Group on Housing an Ageing Population, 2017

Government needs to be aware and responsive to the specific issues faced by carers.

Caring and technology

If desired, assistive technology could support both a carer and an individual with care and support needs to live more independent lives at home and when out in their community. There has been a rise in the types of technology available in recent years, which extend further than traditional community alarm systems. Today we use more electronic equipment than ever before, from remote control lighting to voice activated technologies such as Alexa or Google Home. These offer an opportunity to manage independence and can be linked to a variety of devices around the home, supporting things such as appointment management.

The Parliamentary Review into Health and Social Care also makes a recommendation to the Welsh Government and health and social care services to 'Harness innovation and accelerate technology and infrastructure developments"⁷³.

Older carers need good quality information, advice and guidance about what assistive technology is available and how it can help maintain independence. This is frequently provided by Occupational Therapists and Physiotherapists, but more general advice through Social Workers and Information and Advice Services should be available to support the preventative aims of the Act.

However, digital inclusion, and the quality of broadband services across Wales are a barrier to the adoption of such technologies for many. Furthermore, technologies should always be seen as a support mechanism rather than a replacement for the human interaction and connectedness that is essential to our well-being.

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⁷³ Parliamentary Review of Health and Social Care, A Revolution from Within: Transforming Health and Care in Wales, 2018



Consultation response

Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to carers

Welsh Assembly

August 2018

Introduction

- 1. Age Cymru is the leading charity working to improve the lives of all older people in Wales. We believe older people should be able to lead healthy and fulfilled lives, have adequate income, access to high quality services and the opportunity to shape their own future. We seek to provide a strong voice for all older people in Wales and to raise awareness of the issues of importance to them.
- 2. We welcome the opportunity to respond to the Health, Social Care and Sport Committee's consultation on the impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to carers.

Background

- 3. In Wales, healthy life expectancies are increasing, but the number of years spent living with poor health is also increasing. Public Health Wales states¹ that men and women are likely to spend on average 17 and 20 years respectively living in poor health. Worryingly, differences in both life expectancy and healthy life expectancy between different areas in Wales are not reducing. In fact, men and women in the most deprived areas of Wales spend approximately 19 and 18 years less in good health respectively, and die on average 9 and 7 years earlier respectively, than those living in the least deprived areas.
- 4. The instance of diseases people in Wales are living with is changing. Although the number of disability adjusted life years (DALYs) due to cardiovascular disease has fallen by 42% over the last 26 years, there has been a rise of 25% in DALYs associated with neurological conditions including dementia. 45% of adults aged over 75 in Wales report having two or more long term illnesses.

¹ Public Health Wales Observatory (2018) Health and its determinants in Wales



- 5. In the UK 75% of 75 year olds have more than one long-term condition, rising to 82% of 85 year olds.
- 6. Many people in their sixties and seventies enjoy good health and do not need any additional support with daily living, but as we move into our ninth decade and beyond this becomes less common and more of us will need help. Increasing numbers of **those providing care** are themselves older people. The peak age for caring in the UK is estimated to be between 50 and 59 and the number of those aged 65 or over providing care is increasing more rapidly than the increase among the general population.
- 7. Good quality, properly funded support for carers enables older people to live independently for longer in their own homes and communities whilst enabling carers to receive respite and maintain their own health and independence as they age. Carers play a vital role in service provision that the health and social care systems are unable to cover. A small shortfall in the care provided by informal carers would have a large impact on formal care services.
- 8. Family and friends are increasingly being expected to provide care for their loved ones, but there are limits to what they can do. Changing family structures, greater geographical dispersal, demands of the workplace (likely to increase with rising State Pension age) and a reliance on older carers, often experiencing poor health themselves, all impact on the capacity of people to care for loved ones. There are likely to be many cases where families are providing significant levels of support but are simply unable to provide enough. Together with unmet need and a rapidly ageing population, this points towards families and communities reaching the limits of the care they are able to provide
- 9. For older people living with frailty or complex needs, their health and their quality of life is vulnerable to sudden change. A 'trigger event' such as the loss of a carer, can mean an older person experiences a rapid deterioration in their health and or a significant loss of their independence. This becomes all the more likely where carers are stretched to their limits.
- 10. Forecasts highlight the importance of ensuring that health and social care services adapt so that they can adequately respond to the needs of an increasing older population with complex care needs.² The rise in care needs contrasts with other trends that suggest that relying on families and other unpaid carers more than done so currently does not appear to be a sustainable solution. The supply

² A Kingston, Forecasting the care needs of the older population in England over the next 20 years, The Lancet, 30 August 2018



of unpaid care to older people by their adult children (in England) is unlikely to keep pace with demand, whereas care provision by spouses is growing and is projected to continue to increase in importance. Older spouse carers are increasingly likely to be living with disabilities themselves, resulting in mutual care relationships that are not yet well recognised by existing care policy and practices. Extending the retirement age of the UK population is likely to further reduce the informal and unpaid carer pool, who have traditionally provided for older family members, and so shift this responsibility to the state. These forces will unite to add further stress to social care budgets that help people to maintain independence within the community or fund long-term care needs.

- 11. It has been estimated that at least two-thirds of older carers already have long-term **health problems** or a disability themselves3. Carers often suffer from higher levels of arthritis, high blood pressure, long-term back problems or mobility problems, all of which can create difficulties in and be aggravated by the demands of caring. Caring can be exhausting as carers engage in a whole range of activities from boosting morale through to lifting the person being cared for. Large numbers of carers receive no training in how to lift safely. Paid care workers would carry out lifting only in tandem, due to health and safety concerns.
- 12. Physical exhaustion may be further compounded by a lack of sleep, due to the person cared for having trouble sleeping, getting up at night, or engaging in challenging behaviour, or to worry and anxiety. Caring can cause isolation from family, friends and colleagues, and can lead to carers feeling as though they have lost their identity. According to a survey carried out by Carers Wales, 87% of respondents felt more stressed as a result of their caring roles and 79% of respondents also reported feeling more anxious4. In a survey of older carers across the UK, more than 75% of carers aged between 60 and 69 reported that caring had had a negative impact upon their mental health5.
- 13. Reaching crisis point can result in short-term decisions being made that can place future **financial security** at risk, for example leaving a job or selling a house. The peak age for caring, 50-64, is often when workers are at their most skilled and experienced. In a Carers Wales survey, 51% of adult respondents (of all ages) had given up work to care and 18% had reduced their working hours. 23% of working carers were worried about their ability to remain in work. Older women are more likely to have given up work or reduced their hours as a result of

³ The Princess Royal Trust for Carers (2011): Always on Call, Always Concerned

⁴ Carers Wales (2015): <u>State of Caring 2015</u>. NB, both of these figures have increased from the 2014 survey.

⁵ The Princess Royal Trust for Carers, 2011.



caring responsibilities. The situation is particularly acute for older women who are or were in receipt of a lower income.

- 14. A lack of flexible working arrangements is most commonly cited as the biggest barrier to carers remaining in **work**. Carers who do remain in work have to make compromises, for example using annual leave to provide care. Carers find it more difficult to pursue professional training and advancement. A lack of suitable and/or affordable care services also creates a barrier to remaining in work. Juggling multiple commitments can have implications for physical and mental health.
- 15.36% of respondents to a survey of carers who had left work reported that they would no longer be able to **save for a pension** and 49% that they would be unable to save to meet their own future care needs6. Many carers rely on social security and state-funded care in later life. Once an individual claims their State Pension, they can no longer receive the full amount of Carer's Allowance, even though they continue to face the additional costs of providing care. This can create a sense of injustice. Many carers do not take up their entitlements, either because they are not aware that these are available to them, because of the complex application process, or because of knock-on implications for the finances of the person for whom they care.
- 16. A survey carried out by Carers Wales reported that 53% of respondents were struggling to **make ends meet**, with 36% of those respondents having cut back on essentials such as food and heating. Utility bills often become more expensive as heating and appliances may be used more often. 32% of respondents were using up their savings in order to get by7. For adult children who have moved away, fuel or transport costs often increase significantly.
- 17. Older people tell us that **what matters most** to them is a lot more tangible support for carers, especially for those caring for an older person with dementia, alongside a reliable service, committed staff with enough time, and some progress towards meeting unmet needs.

Assessments of needs

18. There is a disparity in the numbers of assessments carried out by local authorities, which appears to bear no relation to population, demography, health profile or disadvantage in communities.

⁶ Carers UK, September 2014

⁷ Carers Wales, 2016.



- 19. This may be because carers often **do not identify themselves as carers**, as they view care as a normal part of their relationship with the individual they are helping. This means they may lose out on the support that is available to them.
- 20. It may also be due to the nature of the initial contact systems. Although a single point of access to social services has been welcomed in some areas, it has been indicated to us that people contacting local authorities, by telephone or in person, are being referred to third sector agencies without appropriate consideration of their circumstances. We have been told that some local authorities allocate a fixed number of call-backs to residents at the beginning of each day, referring the unsuccessful callers to other agencies.
- 21. Older carers we have spoken to also raise concerns about: waiting times for assessments; being signposted inaccurately and referred inappropriately; difficulty in finding out what is available, and the use of jargon and duplication in the assessment process.
- 22. In April 2018 Age Cymru and Age Alliance Wales conducted a series of four focus group events with people aged 50 and over, in Wrexham, Bangor, Swansea and Newport, looking at issues including social care. We asked participants about their attempts to obtain the assistance of social services departments, from first point of contact onwards.
- 23. Many people gave positive feedback, finding access easy and contact centre and social services staff helpful and cooperative, and reporting very good outcomes, although staff were sometimes busy and under pressure. In one location, the social service department holds fortnightly surgeries in a local health centre. Users of this service told us that they found it very accessible, and the service was well liked. However, a sizable number of others at each of the four venues reported not receiving the same level of service.
- 24. Participants generally contacted their local authority by phone or in person at a single point of access. One older carer found information online beforehand, but felt that many others would not be able to access information online without help, and the person they cared for would not have been able to do so.
- 25. One individual found the telephone number online but received no response when calling, suggesting the information was out of date or the line not monitored. Another stated that advertised numbers were not accessible and messages did not result in returned calls.



- 26. A number of people with hearing loss told us their authority's telephone system lacked provision for their needs, despite the technology being readily available.
- 27. Some individuals told us that rather than approach social services directly, a third sector organisation's "gateway" scheme would contact the local authority on their behalf. However, one man told us that, when phoning on behalf of a friend who lacked to confidence to make a call, it was very difficult to get the person dealing with the enquiry to accept he had been given permission to act on his friend's behalf, despite that person briefly speaking on the phone to confirm he had.
- 28. Others told us they found it complicated to obtain **specific help** and remained unsure about the department or individuals with whom they needed to speak.
- 29. One man's attempts to contact an older friend's named social worker on his behalf failed entirely. Staff were out of the office for extended periods, making them uncontactable (other than to leave messages which in this man's experience were fruitless) or unavailable for meetings. One person, attempting to seek assistance with care for an older relative with dementia, said social services failed to signpost him to alternative sources of assistance, leaving him feeling "isolated". Another told us that a neighbour with glaucoma, who sought help around the home, waited over 12 months for an appointment, and that the meeting had been cancelled four times.
- 30. Others reported having to "chase for updates", having not received expected contact from social workers. One person was not informed their social worker had taken sick leave, and was not available, leaving them feeling "left out of the loop".
- 31. We also encountered a number of older people who would simply **avoid contacting social services**. One person felt they were making themselves a nuisance. She stated "Perhaps that's because I am older. I should not have felt that way, but I did". Another said it had been so difficult to obtain social services in the past that they would not attempt it in the future, stating "I can't face it". Another person simply stated: "Never contact Social Services. Trouble!"
- 32. The Social Services and Well-being (Wales) Act states that people are only **eligible for care and support** if their needs 'can and can only' be met by social services. We have heard from older carers that assessors have made unreasonable assumptions about their ability to cope without formal support.
- 33. We are also hearing through our helpline of people being told they cannot have an assessment prior to leaving hospital as a social worker is not available, but that they can put in support until an assessment takes place. In other cases,



people are being told that they are not eligible for support through social services as they are managing by buying support.

- 34. For example, Mrs G's husband was discharged from hospital with advanced dementia. No care assessment was carried out. Unable to cope without night time support, Mrs G arranged for a private care service to assist her husband for several nights per week, costing over £2000 a month. When Mr G was finally assessed, the care plan noted the need for night time care, but did not treat this as a responsibility of the local authority as it was judged that the family had managed to cover these requirements themselves. The expense of this privately arranged care meant that Mrs G tried to carry out as much of the care as she could manage herself, a situation she found very difficult.
- 35. Mrs G's lack of formal support and respite had a very negative impact on her health and well-being and she confessed to feeling lonely and desperate. Our concern, illustrated by this case, is that unreasonable assessments made by local authorities about the level of support needed, are pushing more and more individuals and carers to crisis point, ultimately costing the NHS more. 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.
- 36. Age Cymru made a Freedom of Information request to Local Authorities on 17 October 2017, as follows: How many adult* individuals in your authority have received assessments regarding needs for care and support since April 2016, when the Care and Support (Charging) (Wales) Regulations 2015 came into force? (*If possible those aged 65 years and older.); of those, how many resulting Care and Support Plans stipulated a need for night-time domiciliary care?; Of those individuals assessed as requiring night time domiciliary care, how many have received that night time care at a maximum weekly charge of £60 (or £70 per week as from 10 April 2017 following the implementation of The Care and Support (Choice of Accommodation, Charging and Financial Assessment) (Miscellaneous Amendments) (Wales) Regulations 2017?)
- 37. Only 8 of the 22 authorities were able to tell us how many people aged 65+ received night time domiciliary care during this period. From these responses, an average of just 1.92% assessments led to night time domiciliary care provision. Although there are no Welsh Government regulations or policies differentiating the entitlement to night time care from day time care entitlement, responses to our FOI requests indicated substantial differences in its provision from local authority to local authority.



- 38. At a focus group, an older man told us his daughter had had a serious road accident, and had to stay with him whilst she recovered. Despite his age and own physical limitations he received no assistance with her care until he demanded she be placed in respite care until social services could fully provide for her needs at home. It was only at this point that she underwent a care needs assessment, and he a carer assessment. This resulted in the provision of a wheelchair, among other things. Previously, he had to hire a chair at his own expense, as his daughter would otherwise have been unable to attend medical appointments.
- 39. Welsh Government must ensure that no assumptions are made that a person does not have needs to be met because a carer is available. The contribution that the carer is willing and able to make should be shown in the care plan, as should contingency plans if the carer is not able to continue to provide care. A carer should not feel under pressure to meet needs where they do not feel willing or able to do so.
- 40. A lack of **person-centred assessment** was not uncommon among focus group participants. One older carer of an older person said, that social services did not listen or respond to the concerns of the family of the person requiring care, or that person's carers. They believed that "more concern was given to benefits and who was going to pay for extra care". Whilst some were ultimately happy they believed it took staff too long to properly assess and respond to the situation.
- 41. Older carers' complex health and social care needs mean that the assessment process to determine the support needs of an older carer often needs to be multidisciplinary. For this to be effective, a number of institutional barriers need to be overcome, including some fairly fundamental issues such as data-sharing underpinned by ICT.
- 42. A small number of focus group participants had made a **complaint** about the responses they had received from social services, one through their local councillor. Several had not made a complaint, despite their dissatisfaction, because they did not feel it worthwhile, because the person cared for "did not want to make a fuss", or because "I thought they had enough on their plate".

Provision of support, including respite care

43. The Welsh Government's *Assessments and Social Services for Adults in Wales,* 2015-16 8 showed that:

⁸ Assessments and social services for adults in Wales, 2015-16, available at http://gov.wales/statistics-and-research/assessments-social-services-adults/?lang=en



- a. the provision of adult community-based care services is falling year on year
- b. the provision of home care is falling year on year
- c. the provision of respite care is also falling.
- 44. Evidence suggests that provision is at the higher end of the spectrum for people with the most complex needs. 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.
- 45. We are worried that it is becoming increasingly unlikely that older people will benefit from the support of social services, and that the knock-on effect on carers is likely to increase.
- 46. From what we hear from the older people with whom we are in contact, from calls to our advice line, from our local partners and from colleagues in Age Alliance Wales, we believe that there is significant **unmet need** for support for carers in our community. However, due to gaps in data, it is difficult to estimate the scale.
- 47. We welcome the acknowledgement in "A Healthier Wales" of the key role that carers play. Carers want to feel like a partner in decision-making and receive an acknowledgement not just of the contribution that they make in providing care, but also their knowledge of the person for whom they care. Key parts of the document address delivering services in the community and tailoring preventative services, both of which are potentially helpful to carers. However, we await the evidence of how the policy is being implemented in practice.
- 48. We asked focus group participants about their experiences of obtaining social care after hospital discharge. Whilst many had not required it, those who had told us they had generally received very good care. We were told of people receiving help from contracted third sector agencies, positive support from reablement teams, timely adaptations being made to homes, and a range of other positive experiences.
- 49. There were a smaller number who had not had such positive experiences, however. We were told of people having to remain in hospital unnecessarily whilst awaiting the organisation of social care, and social workers having difficulty seeing patients in good time to make arrangements. One person told us of a relative with dementia who remained in hospital, unnecessarily, for six months, waiting for the local authority to find a suitable care home, before contracting Norovirus, which led to his death.



- 50. A health crisis for a carer can rapidly develop into a crisis for both the carer and the individual cared for. In order to prevent the need for a crisis intervention, for example a double hospital admission, contingency plans must be in place if the carer is unavailable to provide care.
- 51. We welcome the £1 million allocation to Local Health Boards to encourage carer awareness in GPs across Wales and for hospitals to improve support for carers on hospital discharge. Again, we await the evidence of the impact of the funding. We are concerned about the sustainability of the funding, and about how successful initiatives may be mainstreamed as normal practice within the NHS.
- 52. **Respite care**, especially the cost and quality, is a particularly significant issue. Older carers need to have more regular breaks as a number of them will tire more easily and/or suffer from their own health and mobility issues in comparison with younger carers. Dealing with challenging behaviour is particularly tiring and frustrating because of the need for constant vigilance.
- 53. Respite is viewed by many as an extremely valuable service, but there is a need for greater flexibility in the type of respite offered, to suit individual circumstances. Many carers are reluctant to use support or respite services as they do not trust the quality of the care provided. Worrying about care standards can lead to refusal of care to the detriment of the carer's own wellbeing.

Provision of information, advice and assistance

- 54. Some local authorities, responding to the definition of 'adults' in the Social Services and Well-being (Wales) Act 2014 are arranging generic 'all-adults' IAA services which are unable to meet the needs of older people and may amount to indirect discrimination under the Equality Act 2010. Older people need specialist **information** on, for example, retirement, changing or declining physical or mental health, sensory or cognitive impairment, bereavement, changes in housing or living arrangements and ageism. 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.
- 55. One focus group participant said the information their authority provided on dementia services was out of date, whilst another person was given details of services which were no longer available. Many people stated they were aware of friends or relatives who had difficulty getting help from social services, or having to wait too long. One stated that when attempting to seek assistance "The



response wasn't good. [I was] asked for information I didn't have. Then [they] told me to sort it out myself".

- 56. Generic IAA services often refer older people to local older people's organisations, including Local Age Cymru Partners, who provide valuable services and expertise. However, many of these organisations have lost their service contracts, and do not receive any funding from the IAA service referring to them. Older people's organisations which receive referrals from contracted IAA services must be properly funded for the work they do.
- 57. The Social Services and Well-being (Wales) Act requires local authorities to consider whether an individual may need Independent Professional **Advocacy** (IPA) at every step of their journey through the social services system, including at their first point of contact. However, advocacy is often the last resort after other channels have already been tried.
- 58. Some older carers may struggle with complex formal processes, which they are expected to negotiate without any formal training or knowledge. An IPA has that training and knowledge. Carers may also find it difficult to disentangle their own concerns and interests from those of the person that they are seeking to represent, and may therefore need the support of an advocate to ensure that their own rights are upheld and that they are supported to challenge social services to obtain the right services.
- 59. Examples of issues dealt with by advocates in Wales include: arranging care and paying for care; dealing with finances or financial issues; neglect/ abuse/ scams/ financial abuse; change of accommodation; and dealing with utility companies9.
- 60. Staff working in IAA services therefore may need to refer some carers to an IPA service. Local authorities are required by the Part 2 Code of Practice (General Functions) to "ensure that staff within the service are suitably skilled to identify individuals who need an advocate, and that the service takes action to ensure those individuals are supported." We suspect that many carers are not receiving the advocacy support they need but it is difficult to quantify the scale of the problem in the absence of data.

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⁹ Age Cymru (March 2011): Advocacy Counts 3: p20



Information collected by local authorities and Local Health Boards on carers and their needs

- 61. We welcome Social Care Wales and Data Cymru's work to develop a social care "one stop shop" data set. However, current data gathered about unpaid carers is weak and should be more comprehensive and accurate.
- 62. The English Longitudinal Survey on Ageing (ELSA), Healthy Ageing in Scotland (HAGIS), the Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA) and The Irish Longitudinal Study on Ageing (TILDA), provide the data to estimate unmet need in the rest of the UK and in the Republic of Ireland. Wales is now the only UK nation without an equivalent data set on which to base our evidence.
- 63. Identification of carers is a key obstacle, both self-identification and identification by health and care professionals. Carers UK's "Missing Out" report noted that in Wales 55% of carers took more than a year to recognise their caring role, while 24% took more than five years to identify as a carer. This is particularly true in relation to older carers (aged 80 years old or above) looking after a spouse or partner, and carers of people with dementia, where there may be perceived to be an element of stigma and a wish to keep things private.
- 64. Carers Wales' "Track the Act" programme found that most Welsh Local Authorities do not capture any data on carers' needs assessments for carers of people under the age of 18. This may include the needs of grandparents caring for grandchildren, sometimes in addition to caring for their adult children and others.

Broader Welsh Government policy on carers

- 65. Task and time based **commissioning** makes it increasingly difficult for staff to delivery good quality support and preserve the health and independence of the carer being supported. Commissioning needs to shift to an outcomes-based approach, reflecting the intention of the Social Services and Well-being Act.
- 66. Commissioning practices, lack of sustainable funding and the price paid to domiciliary care and support service providers by the local authority can impact upon recruitment, retention and staff morale. Zero hours contracts and the minimum wage are widespread, undermining the ability to provide good quality support.



- 67. A high turnover within the workforce militates against continuity of support and exacerbates threats to older people's human rights, especially for carers of people living with dementia, as unfamiliar faces can lead to confusion, fear and more difficult behaviour.
- **68.** Domiciliary care is fundamental to an older person living a more independent life and maintaining their dignity. The relationship between quality and dignity is critical it is not just about what support is provided, but about the way in which it is provided. Commissioning, funding and terms and conditions must be improved to make the domiciliary carer role more attractive.
- 69. We are keen to see decisions about paying for care and support separated from decisions about getting it, in order to alleviate the stress the current decision making process causes older people and their families. Age Cymru's longstanding view is that a far more equitable system would be to ensure that care and support services should be provided free at the point of use in the same way as NHS services, instead of the cost simply falling on those people unfortunate enough to develop care needs, including their needs for support as carers.
- 70. The maximum weekly charge for non-residential care in Wales represented a clear step forward in seeking to make services affordable and eliminating inconsistency in charging levels and practices. We are supportive of the aims of the intermediate care fund, however, we are not necessarily seeing our local partners being able to access the fund in the same way that health and local authorities are to develop the innovative services that were intended.
- 71. It is important that older people have access to good quality **housing** that meets their needs and minimises their need for formal or informal care. Older people generally wish to remain in their own homes.¹⁰ It is vital that they have access to services that help them to adapt and improve their homes to help them to live independently for as long as possible.
- 72. Further investment is also needed in specialist housing, for example co-housing, Intentional Communities, home sharing models, retirement villages, park homes and intergenerational living,11,12 as it reduces demand on informal carers as well as on residential care homes and hospitals, and benefits both the carer and the

¹⁰ Welsh Government (2012) Consultation document. The Strategy for Older People in Wales. Number: WG16742. 25 October 2012.

¹¹ Welsh Government (2017) Our Housing AGEnda: meeting the aspirations of older people in Wales. A report by the Expert Group on Housing an Ageing Population in Wales. January 2017.

¹² Age Cymru (2016) EnvisAGE Towards an age friendly Wales. Article by C. Boswell and J. Beauchamp: Housing options for older people in Wales.



cared-for person. The presence of a warden is a key factor in reducing demand on the health services. Retirement housing should be built within age friendly communities, to ensure residents can access local services and facilities that support independence and wellbeing.

73. Carers should be able to build up adequate retirement **income**. State pension changes aimed at ensuring that carers who have missed National Insurance Contributions are able to obtain a full state pension should apply to people who reached state pension age before 2010. The UK Government should simplify the application process for Carer's Allowance and ensure that working for 16 hours a week on the National Living Wage never exceeds the eligibility threshold for Carer's Allowance. The benefits system should be reformed to ensure all carers have adequate incomes. This should include financial support for older carers who often receive no financial recognition of their role.

Agenda Item 6



Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers

Evidence from Hafal

1. About us

Hafal is Wales' principal organisation run by people with serious mental illness and their carers. In the last two years Hafal has extended its services to a broader range of clients with other disabilities but this evidence is based primarily on discussion with carers of people with a mental illness.

All Hafal's services stem from our unique Recovery Programme which empowers clients to make a step-by-step recovery plan, to look at all aspects of their life and set goals, and to take control of their lives: carers are of course key supporters of the people they care for as they work towards recovery.

Hafal provides a range of services and support specifically for carers. These include:

- **Family support:** working closely with carers and family members to provide the best support for clients
- Advocacy: supporting carers by representing their interests
- **Breaks for carers:** engaging a person being cared for in an activity so that carers can take a break
- Accessible information and advice: providing carers with the latest news and information relevant to them
- Mutual support: enabling carers to support each other through carers' groups
- Giving carers a voice: especially in the planning of local services
- Awareness raising: highlighting carers' rights, such as the right to an assessment

2. Who we represent

This response is based on our experience as a mass membership, client-led organisation representing many carers as well as service users. In addition during August and September 2018 we talked to informal groups of carers in Conwy, Gwynedd, Swansea, and Pembrokeshire about the specific issues under scrutiny by the Health, Social Care and Sport Committee.

3. Our conversations with carers

Wider context

It is impossible to separate carers' experience of the Act from the wider issue of their experience of mental health services since 2016. Although we specifically asked about the Act the wider issues were far more important to carers:

One group said their local authority was doing its best despite a 40% reduction in budget.

Individuals told us:

There are no staff to give support

There is no social worker since 2016 for the person I care for or for me

Less is being offered at the moment

Assessment achieves nothing – all support services have been discontinued

Attitudes to carers

One group commented that carers are not kept informed of events (e.g. when patients have been transferred from one unit to another); and their concerns about a lack of activities/recovery programmes on wards are ignored.

Some carers feel that they are *perceived as a "problem" rather than part of the solution*.

Others felt that [one inpatient unit] would prefer carers not to come to the ward.

Access to information

One group said: **professionals frequently feel unable to provide information that may be beneficial to the carer or the cared-for.**

This lack of easily-accessed information means that: carers and service users need insider knowledge to access services/resources to which they have a right or entitlement.

Other points:

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.

Not supported well enough, especially from a communicative point of view when dealing with families and relatives

Respite support

A typical comment was: I used to get respite support but it has not been offered or discussed at all in the last year

And: no respite support at all!

General comments

We are all at the back of the queue

People don't listen to us enough

Carers are left to support each other

We are lonely and need the help and support

Crisis support at [one inpatient unit] was superb

The Local Mental Health Team offered me no support and lacked all understanding of the mentally ill person and myself as carer

Not included in the care and treatment of my daughter

Shocking turnover of staff

Support was zero

Not enough staff

<u>Ideas for improvement</u>

Reduce the amount of jargon and social care "corporate speak" so that information/advice given to carers is succinct and practical

Carers need more respite to be made available

Services that would improve carers' well-being include a befriending service, carer training (e.g. resilience, etc), carer advocacy, talking therapies, rural transport service, home help (maintenance and gardening service)

Carers should be provided with a "carers pack" which provides information about generic services/resources with an element tailored to the specific condition of the "cared for"

Carers should be kept informed about decisions made about the cared-for (some carers feel that professionals hide behind confidentiality rules).

More staff and reinstating support workers

More funding

A lot more understanding is needed

Offer more advice and help

Listen carefully, please, to carers' concerns

Free bus pass for carers

Help with ways to give more help to the person with the problem

Better information on facilities available

Helpful to have a point of contact when we are concerned

4. Our Response

Most carers have not noticed any improvement since the introduction of the Act because:

- The legal right to assessment predates the Act and the strengthening of that legal right is relatively marginal compared with other factors affecting carers' experience
- Reduced resources have affected the capacity of services to undertake good quality assessments and to deliver on needs identified in assessments, including respite care
- Reduced resources have also impoverished services for the people whom the carers support a far greater concern for carers than carer-specific rights and services
- Services have not built on the Act to create a new culture of respect for and cooperation with carers

But in our view this does not reflect badly on either the wider intention or the detail of the Act as it affects carers: it is rather 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.

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: 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.

Unfortunately this is not an untypical situation: many carers of adults with a serious mental illness have no access to any carer-specific services including respite care; further, the

person they care for may receive no service beyond prescription of medication and access to inpatient care when a major crisis occurs. In these circumstances a carer could be forgiven for questioning the point of doing an assessment although we would always encourage them to do so.

So the wider issue of resources cannot be avoided in responding to this enquiry and it will remain the highest priority for carers, for those they care for, and therefore for Hafal.

But there are other issues, perhaps more tractable because they are not so dependent on resources - and might indeed lead to better use of those resources...

The Act provides a useful platform on which a new relationship could be developed between services and carers but this has not happened. There are examples of course of excellent practitioners who engage well with carers to everybody's advantage but this is exceptional and not the prevailing culture within services. Why is this?

Services routinely perceive carers as:

- Making unreasonable demands on services both for themselves and those who they care for
- "Part of the problem" causing or exacerbating the problems of those they care for.
 In the case of mental illness this can take the form of professional prejudice concerning the alleged role of families in causing some illnesses

This can result in:

- Contact with carers being avoided or made difficult
- Ignoring carers' suggestions about provision of care
- Justifying exclusion of carers from planning or delivering support because of their alleged anti-therapeutic behaviour
- Hiding behind confidentiality considerations to exclude carers
- Grudging carer-specific services including respite care

In practice:

- Many carers do indeed advocate vigorously for those they care for, not least because many people with a serious mental illness (and many other vulnerable people) have low self-esteem and therefore low expectations for services. Without such advocacy by carers many vulnerable people would live miserable lives without complaint – hardly a satisfactory outcome
- Carers typically have the best insights into what is needed and what works in terms of support for those they care for and therefore how resources can best be used
- A very few carers may cause problems but if they do then this should be raised candidly with them: avoiding or excluding them will only make matters worse
- Carers understand the principles of confidentiality and, where exceptionally the
 person they care for wishes to keep matters confidential from them, then services
 should explain this clearly to carers

But the key to improvement and making best use of the Act is not just to change the response of services to these specific issues but to encourage them to see carers in a wholly new light, namely as equal partners in making the best of shared resources.

Those who plan and provide services should have regard to three key resources: what the person can do for themselves; what the carer/family can do; and what services can do.

To do this effectively they need to start their dialogue and cooperation with both the client and their carer before concluding what they need to provide themselves.

Services need to be candid with clients and carers about what resources they bring to the table: better to be clear about the constraints they are operating under than let clients and carers find out the hard way that services are limited. If this leads to the client or carer complaining then that complaint will be directed at those who decide on and deploy resources rather than at front-line practitioners — which is how things should be in order to sustain cooperation and good relationships where it matters.

Carers' assessments are also a good place for candour about what services can be provided to carers: carers want to know what is possible and they can then operate on that basis. Of course services should deliver what they promise but if they promise realistically and then deliver they will benefit from a cooperative relationship in everybody's interest.

Of course front-line practitioners cannot deliver such a change of culture without the support of their agencies and managers.

In addition we make four specific recommendations:

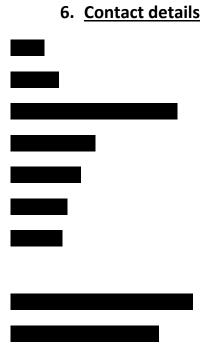
- Welsh Government should provide guidance to Local Authorities on meeting the specialist information, advice, and support needs of mental health carers, for example in relation to Nearest Relative rights under the Mental Health Act. "Onesize-fits-all" generic carer services are not able to cover these specialist areas adequately and specialist services should be recruited or commissioned.
- In Conwy Hafal provides (mental health) carer assessments with funding from the local authority and Health Board. Carers report a good experience of this approach, receiving good quality assessments from a specialist agency separate from the main service providers. The cost of this approach is demonstrably less than in-house provision of assessments.
- There would be great advantage in services linking closely development of individual Care and Treatment Plans for people with a mental illness (required under the Mental Health Measure) with their carers' Assessments (under the Social Services and Wellbeing Act): in most cases this would be welcomed by carers and cared-for and would effectively create a complete and linked package setting out what each party will do to support the recovery of the cared-for and the well-being of the carer.
- 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. In practice Direct Payments for people with a serious

mental illness are usually dependent on carer involvement and this represents a key means of extending choice.

5. Conclusion

The provisions for carers in the Social Services and Wellbeing (Wales) Act 2014 provide a platform on which a new relationship could be established with carers to the benefit of carers, cared-for, and service-providers. But this will not happen until resources for social care are sufficient and services change their view of carers to one of respect and cooperation.

Meanwhile carers are vastly more worried about the current pressure on services for those they care for than on the impact of the Act on carers.



Pwyllgor lechyd, Gwasanaethau Cymdeithasol a Chwaraeon Health, Social Care and Sport Committee

Agenda Item 7 / Paper 7

Mencap Cymru Response to the Health, Social Care and Sport Committee Consultation on The Impact of the Social Services and Wellbeing Act (Wales) 2014 on Carers

September 2018

1. About Us

Mencap Cymru is the voice of learning disability in Wales. Our vision is a world where people with a learning disability are valued equally, listened to and included. We want everyone to have the opportunity to achieve the things they want out of life. Everything we do is about making sure people with a learning disability are valued equally, listened to and included.

We welcome the opportunity to submit evidence to the Health, Social Care and Sport Committee Consultation on the impact of the Social Services and Wellbeing Act (Wales) 2014 on carers.

This response has been informed by speaking directly to carers across Wales through focus groups, seeking their views and experience. It has also been informed by our Wales' Independent Support and Empowerment (WISE) project, an advice and support service we offer across Wales, from the data we collect and the case work that we undertake.

2. Key Recommendations

- 1. Welsh Government should run a national awareness programme to promote the rights of carers.
- 2. Local Authorities should increase its work with third sector organisations to raise the awareness of the information, advice and assistance available to carers across Wales.
- 3. Local Authorities should publish if, and how, they are using 'What Matters Conversations' during Carers Needs Assessment.
- 4. Local authority staff awareness of the Social Services and Wellbeing Act (Wales) 2014 is often poor. Therefore, more needs to be done to inform social workers and social work teams of the Act, and their obligations to carers.
- 5. There should be a standard sheet of information that social workers provide that directs people towards other sources of information. The social worker should be required to work through this sheet, ensuring that the carer knows that they can refer back to the checklist of topics to request further information. This will ensure consistency of experience for all carers.
- 6. Social Workers should provide surgery like sessions. They would either talk around a specific theme, or provide the opportunity for groups of careers to come and ask the questions they need an answer to.
- 7. Whilst the Act represents a progressive attempt to change the general environment surrounding [] Carers' experiences are still either negative, or perceived as being negative. There needs to be significant cultural/institutional change in practice to change both the actual experience, and perceived experience, of carers so that the intentions of the Act become a reality.
- 8. To fully improve the wellbeing of carers the Government needs to address what will happen to the Cared for Person when the Carer is no longer alive to provide care, with particular focus on housing and support.
- 9. There is a need for clear and accessible information and guidance around direct payments. The information also needs to be readable and relatable. There is a

need for clear and accessible information and guidance around direct payments. The information also needs to be readable and relatable.

3. Detailed Response

Assessments of Needs

3.1 Access to a Carers Needs Assessment

The right to a Carers Needs Assessment remains a key element of the Act. Carers have a right to an assessment in their own right, and local authorities have a clear duty to promote this right. Whilst the Act states that carers in Wales have equivalent legal rights to support as those that they care for. However, from what we have seen, carers are not routinely being offered assessment.

Access to a Carers Needs Assessment is varied – some carers confirmed they had received an assessment and knew who to contact for support; others commented that they were not aware that they were entitled to a Carer Needs Assessment. Moreover, some carers with significant caring responsibilities stated that they had to chase for an assessment, or had been refused an assessment. This is not acceptable.

The lack of knowledge around where to find out further information suggests that Carer's Needs Assessments need to be promoted more widely, both to carers and Social Workers, so that people are aware of their rights and what extra support they can expect from the assessment. Immediate action needs to be taken. A national awareness programme should be launched to promote the rights of carers.

Some carers we spoke to stated that they were unaware they were entitled to an assessment, others stated that they were denied an assessment. For example:

"I heard that others were getting them, I asked but was told I wasn't entitled, I'm not entirely sure why".

"I've asked to have my needs re-assessed and the person I care for re-assessed but they won't."

"I didn't know that I could have an assessment."

Others highlighted the need to fight for a Carers Needs Assessment:

"It's basically if you don't ask, and keep asking, then you won't get."

"It comes down to how good your social worker is. We had a trainee social worker and she was fantastic, she went through it all with us explaining what I could access and helping us access it, but the one before was awful everything was no. She was so good that she helped others families where the social worker they had was rubbish. It shouldn't be in the hands of an individual, the luck of if we get a good one."

3.2 Issues with the Process

Of those that we spoke to who had received a Carers Needs Assessment a strong theme emerged, that the assessment was a negative or difficult experience. A number of carers reported feeling that the assessment was being used to judge their ability to care, rather

than what support they need. Many stated that they felt judged and intimidated by the process, often feeling unable to be honest about their needs out of fear. The process is seen as inherently negative by many carers and as such it colours their engagement with the assessment. Therefore, we feel that a cultural change is needed. There needs to be more consideration around the assessment process itself, and a movement towards proactively offering support.

The statements put forward by some of the carers we spoke to highlights the urgent need to modify the culture and language used in assessments.

"It is just all so negative, so demeaning."

"Sometimes you lie because the truth hurts. You always have to say what you can't do or they can't do, to get the support you need. You come away feeling dreadful, it really hurts. You feel like you are insulting them [the person they care for], doing them a disservice, like they are a burden, what about all the good they can do? Or you feel like you are a terrible parent failing them, it's not fair."

"I feel judged, the tone is always so negative, I feel like a can't be honest because if I am then maybe they will decide I'm not capable of caring for my son and he will be removed. I'd rather struggle than see him go into a home".

"Sometimes I just feel ashamed or embarrassed, like I am failing as a parent, so I lie. I say something isn't an issue, I don't want people looking down on my daughter, I don't want to focus on what she can't do. I'm proud of her, I want others to be too. They don't realise how difficult it is to be honest. It's the whole approach, it's so negative and cold, it needs to change".

3.3 Use of 'What Matters Conversations'

There is ambiguity around how 'What Matters Conversations' are being used. We are aware that some local authorities are utilising pre-assessment 'What Matters' conversations and/or 'What Matters' documents. Whilst other local authorities are using a 'What Matters' conversation as the formal assessment. We are aware that in Anglesey those wishing to refer a client to the Social Services are being asked to complete a 'What Matters' referral form, which asks for information around what support an individual can access from the community. This is inappropriate.

Our concern regarding 'What Matters Conversations' is twofold. Firstly, each local authority is utilising 'What Matters' conversations in a different format, we feel that this is creating confusion for carers. Secondly, we are concerned with how some Local Authorities are using 'What Matters Conversations'. In theory 'What Matters Conversations' could be greatly beneficial to the carer, we can see that they can be used a create a 'person centred approach' where care is tailored around the person's wants and wishes. However, we fear that these are being used inappropriately and, in some cases, used to justify a reduction in support.

We feel that whilst the Act encourages fair assessments, councils may be using them inappropriately, especially if carers do not know the legal basis of the conversations or assessment they are having. We fear that some local authorities assess carers in terms of the support they could receive, considering personal circumstances of the family and extended family, and makes a claim of what support they think is available from the family.

Therefore, we ask for clarity on how 'What Matters Conversations are being used across Wales. Local authorities should publish whether, and how, they are using 'What Matters Conversations' during Carers Needs Assessment.

Provision of Information and Advice

3.4 Poor Dissemination

Providing information and advice to carers is a core component of the Act. However, information and advice is not being effectively disseminated to carers. A proactive and focused approach to disseminating information and advice is urgently needed. The carers that we spoke to stated that local authorities were not a source of information and advice. Instead they view charities and word of mouth as their main source of information and advice. For example:

"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".

"Sometimes it's hard for people to communicate what they want or what support they need because they don't know what types of support they can receive"

Many carers do not know about their rights and entitlements. When a carer phones the WISE Helpline with a concern, they will have little (if any) awareness of their entitlements as a carer. We support nearly 1,000 via our helpline each year. Carers are often unaware that they are entitled to a Carers Assessment. This should not be the case.

A key theme that emerged amongst the carers that we spoke to was frustration around accessing information. Many reported that accessing information required considerable time and energy. For instance:

"We just don't know what support or help is available, nobody has told us, and where do we look? I don't know where to start, it's a puzzle".

"I know that information is out there if you look hard enough for it. But the reality is that I don't have time to look for it. And if I do find something it is often completely illegible to me, I don't know what it really means, it's as if it is another language".

"Everything is just by chance or luck. The luck of speaking to someone or coming across something, then the luck of speaking to the right person who wants to help".

"There is a feeling of being passed from pillar to post, it's so demoralising knowing that you don't matter, so much so that it's easier not to try."

When we asked carers how they would like to see information disseminated, three key themes emerged.

First, a number stated that they prefer to get information and advice from the third sector. From those that stated this, it was felt that when information was disseminated by the third sector it was more accessible and felt "less daunting, like I could ask what something means and not get judged".

Therefore, as the third sector is often the preferred source of information, we feel that local authorities should increase their work with third sector organisations to disseminate information and advice to carers across Wales.

Second, a number of carers commented on how local authorities and social workers were often unreachable or impenetrable. For instance:

"Social services office is not accessible on the phone or physically, you can't get into the office".

"Council receptionists act as a barrier, they either just won't let you see someone, or they ask you why you are here and what you want, there is no privacy... I feel like they are doing this on purpose to dissuade people. It's either shame or not getting the help, sometimes not getting the help is the easier option"

"As an individual parent access to care managers is so difficult, but if you say that you are a support worker then you will get access. I phone for my son and can't get through, nobody speaks to me, I phone as a support worker during my day job and I get through or the person phones me back, it's horrible. Basically it is stating that my role doesn't matter, I don't matter. As a parent people just don't get back to me. I keep asking and phoning but nothing."

Carers stated that a less formal and more personal approach was needed, where social workers and local authorities go into the community to pro-actively disseminate information and answer questions. One option put forward by a carer was for local authorities to hold surgery like drop in sessions where somebody would be available at a set time to answer questions. Other suggestions include social workers delivering talks around a theme followed by a 'Q&A' session.

Third, a number of carers stated information needed to be standardised and condensed into a manageable resource. One carer stated that they wanted a directory of information with where they could seek further advice and guidance.

There should be a standard sheet of information that social workers provide that directs people towards other sources of information. The social worker should be required to work through this sheet, ensuring that the carer knows that they can refer back to the checklist of topics to request further information. This will ensure consistency of experience for all carers.

3.5 Local Authority Staff Awareness

A major area of concern is around the level of understanding and awareness that staff in Local Authorities possess. We have directly encountered staff that lack a solid understanding of the Act, that are unsure of their own roles, or how services are supposed to meet individuals' needs. This needs to be address urgently. The Act places a duty on Local Authorities to ensure that a wide range of community services and activities are not only provided but also signposted, we are finding that in some areas this is not happening sufficiently. Often carers are not aware of community services and activities. Carers are also reporting a lack of understanding and awareness amongst local authority staff. For example:

"They often don't know themselves, so how on earth are we supposed to know? There's been times that I've had to tell them what they are supposed to know, I am the one giving them the information".

"If a social worker doesn't know about something then how can they inform you that it's an option?".

Local authority staff awareness of the Social Services and Wellbeing Act (Wales) 2014 is often poor. Therefore, more needs to be done to inform social workers and social work teams of the Act, and their obligations to carers.

Provision of Support

3.6 Access to Services

We have encountered cases where inflexible care plans meant that they could not access services they needed. Several carers stated that care plans were too rigid and when they requested for them to be updated they were met with resistance. For instance:

"it's hard to modify it, but in reality things change, and things change a lot. How it is at the moment means that there is a need to get it right at the beginning because if they don't it's near to impossible to change. Life changes, but changing the document is so difficult. The document needs to be more flexible."

"You might find out about something and want it but you can't because it's not in the care plan, and it's so hard to change the document."

"Assistant social workers often act as gatekeepers, they say that the care plan cannot be updated, you can't access this service, you can't speak to the social worker. They shouldn't do this, it's not their responsibility, they shouldn't make this decision. I understand that this is often because they don't know enough and it's easier to say no."

Several carers also highlighted that some social workers are unreasonably refusing access to services. For instance:

"When I asked for more support they just said no. The only way I could get support is to put the person into emergency respite, I don't want that."

"They always say, 'no that can't be done, we don't do that' then we always have to say 'but I know a person that'..."

"They seem to view only certain things as acceptable, swimming is constantly encouraged, but she doesn't like swimming, when I suggest something else it's frowned upon, they shouldn't be allowed to decided what a person does."

3.7 Lack of respite services

For the carers that we spoke to the lack of respite services is a common concern. Several emphasized the need for respite, as one carer stated: "I cannot emphasise enough the value of respite services to carers of children with disabilities, they are our lifeline." However, carers also stated that access to respite services was often very difficult.

"No, most don't get it. Does it really exist? Has anyone ever used it?"

"I asked about respite, I was offered it four years later."

Some carers also stated that when they had used respite services it was often problematic and/or inappropriate. One carer stated that she had to refuse the respite that she was

offered for her 19-year son as it was to be in a care home for the elderly with dementia. Others also stated that respite services were often problematic. For example:

"Respite is more trouble that it's worth, it's so time consuming to arrange and then they just sit around and get distressed, and it means more work when they come home."

Another theme that arose was fear to request respite services. For instance:

"I'm too scared to ask for respite even though we need it desperately. I worry that if I ask for respite then they will think I can't cope and the person I care for will be removed, or I will lose my direct payments. It's not either or but it's made to feel like it is."

"Asking for respite or emergency support is like asking for forgiveness for failing, or begging for forgiveness, so much shame."

This feeds in to our earlier call more to be done around the culture of care and support. It is not acceptable that many carers feel this way.

3.8 Wellbeing of Carers

The Act states that local authorities are required to promote the wellbeing of both people in need *and* carers. However, we feel that this is not fully integrated into the approach of local authorities. The main theme that emerged when speaking to carers was the fear of what will happen to the individual that they care for then they are no longer able to care for them. As one carer astutely states:

"There's a focus on the small stuff, but it's the big things that hang over us, what is going to happen when I die, this is the biggest strain on my wellbeing. It haunts us everyday.

The not knowing is just awful. Where will they go when they can't live with me?"

"It's the worse feeling in the world wanting your child to die before you because that's better than what might happen to them if you die first."

"Life after us is the biggest stress for us, what will happen to our children. It's the thing that takes the biggest toil on us".

One elderly carer spoke of how whilst she was ill with cancer she considered how she could end her and her sons lives together. She felt that it was the only option available to her. It was kinder than the alternative, as she did not know where he would go and who would care for him.

If the Government are committed to improving the well-being of carers they need to ensure that this overwhelming burden is removed. Considerable work needs to be done to provide support for carers to prepare for their loved one's life after the carer, with a focus around housing and support.

3.9 Direct Payments

When we spoke to carers issues and frustration around direct payments quickly emerged. Several carers highlighted that they had received little, or no information, around direct

payments. Several stated that they did not know how to use their direct payments, for instance:

"There is no information disseminated regarding direct payments. It's a complete enigma, a puzzle, it's a joke".

"We don't know what we can use it for, we look to other families and see how they use it, and most of them are making it up".

"I want to use my direct payments but I don't know how."

"I want to use mine but I struggle to understand how it works".

Some carers stated that the were not using their direct payments, but instead sending them back because they were worried about getting it wrong. For instance:

"I don't use my direct payments because I'm worried that I will do it wrong and have to pay it back".

Other carers highlighted that whilst they like being able to tailor how they spend the money and organise the support, they often feel overwhelmed by how much time and work is involved. One carer highlighted that he was unaware that he could get a direct payments account manager, whilst another spoke of their negative experience of using an account manager. For instance:

"It's too much work, I can't do it on top of everything else."

"Direct payments are OK in principle, but we have to become employers, accountants, it became another full time job, I don't have the time or energy, or the skills. I manage the account; I didn't know someone could manage it for me. I didn't know I could have an account manager. This is exactly the problem, another thing I didn't know about, nobody told me."

"When our account was managed there were errors that we then needed to pick up on. We needed to audit it. We had to go through the accounts and there were mistakes, this isn't encouraging others to take up and use their direct payments."

There is a need for clear and accessible information and guidance around direct payments. The information also needs to be readable and relatable. One method would be the use scenarios, e.g. this is how family X uses direct payments, this is how person Y uses direct payments.

4. Summary

- Carers are not routinely being offered a Carers Needs Assessment.
- Some Carers have been denied a Carers Needs Assessment.
- Many Carers are unaware that they are entitled to a Carers Needs Assessment.
- Many Carers report that the Carers Needs Assessment was a negative process. Several Carers stated that they felt judged and intimated by the process, often feeling unable to be honest about their needs out of fear.
- We are concerned with how some local authorities are using 'What Matters Conversation'. We feel that clarity is needed around where and how they are being used.

- Information and advice is not being effectively disseminated to carers. Many carers do not know their rights and entitlements.
- Carers reported frustration around access to information. Many highlighted that there were often barriers to accessing information.
- The understanding and awareness that staff in Local Authorities possess is often poor. We have directly experience staff that lack a solid understanding of the Act, and are unsure of how services are supposed to meet individuals' needed. Carers also recognised and voiced this concern.
- Care plans are often inflexible, and some social workers are unreasonably refusing access to services.
- There is a lack of appropriate respite services.
- If the wellbeing of carers is to be fully considered the Government and Local Authorities needs to provide support for carers to prepare for their loved ones' life after the carer, with a focus around housing and support.
- There was frustration around direct payments, several carers highlighted that they received little, or no information, around direct payments. Others emphasized the considerable time and work that is involved. Some carers stated that they were not using their direct payments due to a fear of getting it wrong.

5. Further information

We are happy to discuss any aspect of this response in further detail, please do not hesitate to contact us for more information if required.

Agenda Item 8.1

Purpose of paper

Following the presentation on Dental Contract Reform to the Health Social Care Committee [the Committee] members on 27 September, Abertawe Bro Morgannwg University Health Board [ABMU] was asked to provide a briefing on the Prototype practices. The two Prototype practices in ABMU preceded the roll out of the current contract reform programme that was introduced from September 2017 and remain in place. This paper sets out the background to the Prototype approach and its current status within the dental contract reform programme. Attached, for ease of reference, is the section on Dental Contract Reform extracted from ABMU's submission to the Committee for its review.

Background- Welsh Dental Pilots Programme

In November 2007 the Minister for Health and Social Services requested that a Task and Finish Group be convened to review the dental contract that had been introduced the previous year and look at a range of issues to improve the way in which the contract worked, several problems having already been identified. For example, it had already been highlighted that the contract, being based on dentists' delivery of a set number of Units of Dental Activity [UDAs] was not incentivising the provision of oral health advice. It was tending to drive increased intervention but also made it challenging for dentists to treat patients with high need as they received the same payment for a patient whose course of treatment might take six sessions as for one who could be treated in one visit.

The group's report to the Minister highlighted many of the complexities in NHS dentistry and, particularly given the recent experience with the new contract, recommended that any proposed changes to the dental contract be pilotted thoroughly, carefully evaluating any changes to the patient pathway.

Introduction of Pilot programmes, April 2011

The Pilot Programme sought to move away from the existing system of payment for dentists through Units of Dental Activity and quantified service delivery, and towards a system that focussed on care tailored to the individual patient, based upon risk assessment. Two different pilots were developed and 8 practices across Wales were selected to adopt them.

The **Quality and Outcome Pilot** was designed to test a new way of working addressing issues of access, quality and prevention by removing the UDA target from the whole of a practice's contract and instead based payment on a Capitation and Quality Payment that focussed on patient numbers and promoting prevention. Through the removal of UDAs it was hoped to give clinicians more freedom to make their own decisions, using their own clinical judgement about what was in the best interests of their patients. Under this pilot model practices received the same contract sum as they had previously.

The **Children and Young Peoples Pilot for 0-17 year olds** aimed to incentivise prevention in the care of 0-17 year olds, complementing the *Designed to Smile* programme and test the introduction of Quality and Access indicators. All children in the pilot practices were taken out of the UDA-based system, with payment to dental providers based on a formula linked to a deprivation based capitation plus access, quality assurance, *Designed to Smile* and prevention. Practices were also allocated additional monies to increase access.

Between 2013 and 2015 the number of Pilot sites was reduced and a core group selected to continue the Quality outcome pilot only as the learning from the Children's Pilot was complete. Within ABMU, Belgrave Dental Centre had been testing the Children's Pilot; Eastside Dental had tested the Quality and Outcome model.

PROTOTYPE CONTRACTS 2016

By 2016 **ABMU** was the only Health board in Wales that wished to continue to support its two Pilot sites, namely Eastside Dental and Belgrave Dental Centre to pursue a new model which built upon the learning from their pilot experience.

ABMU was confident it could do so based on the effective communication it had established with the two Practices from 2011 and the learning gained. The positive experience and maintenance of activity and access within the pilots was also complemented by continuation of the less positive experience of the 2006 (Wales) Dental Contracts. These continued to fail to demonstrate effective outcomes, and an increasing number of performers and providers were being performance managed. By 2014 over thirty dentists within ABMU were under professional scrutiny, including Reference Panels, usually as a consequence of having misinterpreted the contract regulations sometimes resulting in inappropriate claims for treatment.

The Prototypes continued to run the pilot systems of a Dental Care Assessment, Increased prevention focus, patient recall intervals based on NICE guidance, providing more access to new patients in a prudent healthcare environment, where a Red/Amber/Green scoring gave clear indicators to the patients' journey. The Prototype practices trailed a new 'Banding' arrangement, where five Stages were trialled as opposed to the 3 bands applicable under the UDA contract.

The introduction of five Stages of treatment following assessment and planning comprised Urgent care, Risk Reduction, Stabilisation, Restoration of Function, and Advanced Care. This supported the Dental care Assessment and patient's journey along Prudent Healthcare principles, allowing the Practice teams to review the patient's progress before committing to Advanced care. It also tested a more equitable system for patient charge revenue.

Summary

By supporting the Prototypes and, previously, the pilots, ABMU benefitted and demonstrated:

- Enhanced methodology and implementation of Co-production in Dental Practice
- Increased use of Skill mix allowed advancement in Prudent Healthcare Principles by engaging the Patients at the onset of their Journey in Prevention Based Care.
- That Dental Care Plans and Toolkits can evidence patients health improvement
- Increased Prevention
- Increased recall intervals
- Reduced courses of treatment, with a reduction in repeated courses within one year
- Increased access for patients
- Courses of treatment tailored to the Patients needs and wishes.
- Reduced pressure on the Dental workforce to hit UDA targets and practice within their competencies.
- Increased team motivation where Dental Care professionals can work to the upper limit of their competencies.

CURRENT STATUS

As is implied by their name, in 2016 it was thought that the Prototypes would provide the model for dental contracts for the future. However, as conveyed to the Health Social Care and Sports Committee, not all Health Boards had had the same positive experience of the pilots and in some areas there had been a significant loss of patient income which had not offset expenditure on dental services to the level

PAGE 3 OF 7

required. In ABMU, although there had initially been problems in one practice, once the new approach had been established and both practices were in a position to attract more new patients, patient income rose to its former levels.

In the intervening period, the new Chief Dental Officer, who had overseen the test of several 'compromise' or 'blended' contracts in England, shared her view that greater progress could be made at less risk to both practices and Health Boards if UDA targets were merely reduced rather than eliminated. This would release practice time to complete a new, comprehensive Assessment of Clinical Oral Risk and Need [ACORN] . The ACORN data has, to date, provided a robust source of information for practices and Health Boards on whether the practices are responding appropriately to different categories of patients, eg to reduce or extend recall intervals, introduce more or less dental clinical professionals and create more capacity. The Prototype practices have participated in this exercise and noted where they too can make greater progress in these areas.

Although some disappointment may have been expressed initially that the prototype approach was not being adopted adopted at scale, the current Welsh Government approach is supported. The Contract reform programme is developing a new primary dental care framework that uses Prototype learning but not the historical Terms of Reference, and the timescale of its roll out is determined by the learning being gleaned Wales wide as well as local circumstances. It is providing a much bigger, Wales wide, test than the Pilots/Prototypes ultimately could and the prospect of a 'zero' UDA contract such as the Prototypes work to has not been excluded from consideration.

For example, Cardiff and the Vale and ABMU Health Boards are currently in discussion with the Public Health Wales project leads with a view to introducing the Prototype approach in two brand new practices which are opening in their respective Health Boards. It is considered that, in what comprises a 'green field' site, this would appear to offer a more appropriate basis on which to start a new contract than set a UDA contract then gradually reduce it. It is still anticipated that, ultimately, UDAs will be phased out of primary care dental practice, but in a phased, managed basis with the support of the ACORN data and pump-priming being made available through the WG Innovation Fund (announced September) to broaden practice teams.

Lindsay Davies, Head of Primary Care

PAGE 4 OF 7

HEALTH SOCIAL CARE AND SPORTS COMMITTEE INQUIRY INTO DENTISTRY IN WALES – EXTRACT FROM ABMU'S SUBMISSION

1. Welsh Government's Dental Contract Reform

- 1.1 In 2017 four of 95 general dental contractors in the Abertawe Bro Morgannwg University Health Board [ABMU] area volunteered and met the locally developed criteria to test out a Wales-revised version of the 2005 General Dental contract which aims to reduce the disincentives to providing holistic. preventive care that are inherent in the original. The problems associated with the 2005 contract are described in other Health Board submissions and were so significant that three alternative models were being piloted across Wales within three years of its inception. By 2011 only ABMU was content to pursue a more effective alternative and continued to support two practices operating without an 'activity' target with very positive results in terms of treatment and access. These two 'Prototype' practices are now providing a helpful foundation and in-built control test for the dental contract reform programme introduced from September 2017. The six practices (four Contract Reform and the two Prototypes) have, for the past year, formed a ABMU Contract Reform group, supported by the Health Board, Public Health Wales and the Chief Dental Officer to share learning, and views on the proposed programme, its benefits, potential pitfalls and how it can be taken forward. ABMU is also represented on the Chief Dental Officer's [CDO's] national contract reform group through the Dental Director and Primary Care Manager who has driven and supported much of this work locally.
- 1.2 The ABMU pre-2017 legacy is that, from 2011 onwards the two Prototype practices had their standard Unit of Dental Activity [UDA] target removed from their contract and were instead paid on a Capitation and Quality Payment which focused on patient numbers and promoting prevention. The UDA activity is still recorded as a background check. They introduced a new Dental Care Assessment service, increased the focus on prevention, recalled patients based on NICE clinical guidance (rather than fixed 6 month periods) and scored patients' oral health cards as Red/Amber/Green to give clear indicators of the patients' journey and facilitate a genuinely co-produced plan. Following assessment and planning, five stages of treatment were identified: Urgent care, Risk Reduction, Stabilisation, Restoration of Function and Advanced Care. This allowed Practice teams to review the patient's progress with them before committing to providing advanced care, e.g.crowns, implants. The Prototypes also tested a more equitable system for patient charge revenue and allayed fears associated with that aspect of the pilot. By 2017 it had been demonstrated successfully that removing the UDA as a driver from these practices gave clinicians more freedom to make decisions, using their own clinical judgement about what was in the best interests of their patients. Once established, it became evident that more individual patients

PAGE 5 OF 7

- were being seen and the proportion of patients provided with advanced treatment had reduced.
- 1.3 The national dental contract reform programme launched by the Chief Dental Officer in 2017 built upon the Prototypes as well as experience introduced from elsewhere in the UK. They were joined by four other practices in ABMU (14 across Wales) to test a 'blended' contract methodology which comprises a compromise between the GDS contract and the prototype described above. Phase 1 of the contract reform programme (September 2017 March 2018) reduced rather than eliminated the UDA target by 10%, easing the time/financial pressures on practices to enable them to complete and submit clinical profiles on all patients assessed and treated.
- 1.4The six, very different, practices who comprise the Phase 1 Contract Reform group hold a total contract value of approximately £2.2 million to deliver 86,833 UDAs or equivalent. The UDA rates per practice varied from £23.13 £38 (average £26) for contracts ranging from 5,800 to 34,500 UDAs. Between them, they can provide a true test of what can be delivered with contract restrictions lifted to varying degrees.
- 1.5 In June 2018 Public Health Wales colleagues produced and shared the initial draft of the practice-based patient and practice profiles drawn from the data collected by the practices the 'ACORN' reports). Further, more detailed profile information which would support decision making (factoring in practice size, contract value etc.) is awaited from year-end returns. However that available to date indicates that Health Boards and Practices can be confident in reducing further UDA targets in return for specific quality initiatives to secure greater, more appropriate, patient access to General Dental Services with improved health outcomes.
- 1.6 The Wales contract reform programme has, as an aim, that 10% of Wales' practices will be testing the reformed contract by 31 March 2019. The current thinking within ABMU is that the next phase of the reform project, from October 2018, will seek to reduce the contract targets by 10% in at least two more practices* and drop further the UDA target in the phase 1 practices in return for specific quality initiatives, some of which are already being explored. Some examples discussed within the Primary Care team and/or contract reform group to date include initiatives that could:
- improve practice sustainability and retain Dental Foundation trainees in struggling practices
- improve patient access to general dental services with demonstrable increases in unique patient numbers (in contrast to current high levels of repeat attenders) and/or
- support enhanced skills training of General Dentists to help reduce what are currently secondary care waiting times for treatment which could be delivered out of hospital.

PAGE 6 OF 7

- *NB 10% of contractors in Swansea and Neath Port Talbot = 8. There are currently no contract reforming practices in Bridgend county.
- 1.7 ABMU is aware that not all practices are in a position to embrace the multidisciplinary approach upon which a holistic model of service depends. This is particularly the case in those who are single-handed and/or operating in small premises that cannot accommodate additional staff, e.g. hygienists, therapists, dental nurses. As an integral part of its service planning and development in 2018/19 ABMU will undertake a survey, jointly with the Local Dental Committee, of practice staffing and facilities to help gauge the extent to which practices are in a position to remodel the services they provide.

ABMU's view, based on its experiences to date with the Prototype Practices and the wider contract reform is that the changes have resulted in improved access, especially for the most vulnerable, and care provided driven by the need of the individual rather than a contract target. However, as the programme is rolled out it is important that it is underpinned by robust governance and that changes for individual practices are based on the needs of the local population and not simply an 'all-Wales' framework. Experience from the Prototype practices should be shared nationally and these practices should continue to drive and test innovation. Local management teams will need to ensure they have the resources and the capabilities to support the changes and provide reassurance to Health Boards and Welsh Government.

Pwyllgor lechyd, Gwasanaethau Cymdeithasol a Chwaraeon Health, Social Care and Sport Committee HSCS(5)-31-18 Papur 9 / Paper 9







Dai Lloyd AM Chair Health, Social Care and Sport Committee National Assembly for Wales

<u>Dai.Lloyd@cynulliad.cymru</u> Seneddlechyd@cynulliad.cymru

05/11/18

Dear Dai Lloyd AM

Welsh Speakers' Dementia Care

Over the last year the Welsh Language Commissioner and Alzheimer's Society Cymru have been working on a project looking at the experiences of Welsh speakers of dementia care, information and support services. The report will be launched on 7 November in the Assembly and we thank you as an Assembly Member for sponsoring the event. I attach a copy for your attention. It will also be available on the websites of the Welsh Language Commissioner and Alzheimer's Society Cymru from 7 November onwards.

There is a general recognition that offering services in Welsh is a clinical need for Welsh speakers with dementia. Although there are examples of good practise the report highlights failures in the care that Welsh speakers receive that can be detrimental to them. At an all Wales level, therefore, it appears that dementia care for Welsh speakers is inadequate. This is unacceptable. There are doubts as to the extent to which the active offer has developed from being a policy concept in strategies such as *More than just words...* to a reality which reflects a genuine understanding of the practical meaning of the concept. In the same way the findings of the report suggest that requirements made in relevant legislation such as the Social Services and Well-being (Wales) Act 2014 are not being fully implemented in relation to the Welsh language.

The report also highlights inconsistencies in the range of tools, diagnostic tests and assessment resources available and used with Welsh speakers that can affect the care that they receive. The need to collect data in order to plan services and train the workforce to offer care in Welsh

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Pack Page 144

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was also apparent. The report makes several recommendations to the Welsh Government and other relevant bodies that include:

- That the Welsh Government should audit the extent to which understanding of the active offer; people's right to receive services in Welsh and the clinical need to do so, has filtered down and is being applied by workers involved in the care packages of people with dementia and of leaders in the field.
- That the Welsh Government, in implementing the Dementia Action Plan for Wales considers the extent to which the relevant targets set for health and social care services in More than just words have been met and the extent to which they facilitate efforts to offer Welsh language dementia provision.
- The need for the Welsh Government to integrate the Welsh language more closely into the Dementia Action Plan for Wales such as by ensuring that the Dementia Allied Health Practitioner post includes responsibility for providing advice and support on considerations relating to the Welsh language and dementia; setting up a similar post or responsibility with regards to the clinical needs of Welsh speakers; that workers' Welsh language skills are a key consideration when reviewing and standardising the role of dementia support workers and developing teams around the individual; and that a specific action plan is developed to plan, develop and train Welsh medium care teams when developing the care pathway and multidisciplinary teams
- That the Welsh Government should set up a Welsh medium dementia care pathway and cooperate to develop a national platform to share tests, resources, expertise and information about dementia and the Welsh language.

The report also asks the Health, Social Care and Sport Committee to conduct a review of the extent to which the requirements of the Social Services and Well-being (Wales) Act 2014 are being implemented in relation to providing dementia care through the medium of Welsh and the extent to which the statement regarding the national well-being outcome 'I get care and support through the Welsh language if I need it' is being met in relation to dementia care, and specifically, the consideration given to the Welsh language in assessments; commissioning and delivering care; individual care plans, and how local authorities and Local Health Boards jointly assess the range and level of services required to meet the care and support needs of people in the local authority area.

We would be very grateful if you could consider the findings and recommendations of this report especially the recommendation that is made to the Health, Social Care and Sport Committee. You are welcome to contact Huw Owen, Huw.Owen@alzheimers.org.uk to arrange a meeting if you wish to discuss the report further. We will also be setting up an implementation group which will include members from the Royal College of Nursing, Royal College of Practitioners, Royal College of Psychiatrists and other relevant organisations from the fields of health and social care to support the work of implementing the recommendations.





We look forward to discussing the report with you further,

Meri Huws

Welsh Language Commissioner

Sue Phelps

Sisdelp

Wales Director, Alzheimer's Society Wales

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Pack Page 146

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Pack Page 147

Yn unedig yn erbyn dementia

United against dementia



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Contents

Foreword	
Main findings	
Introduction	
Part 1 Setting the context	
Part 2 The research and its findings	
Part 3 Policy recommendations	

Foreword

If care is not available in Welsh, there is a shortcoming in that care. Welsh language provision is an important part of people's health and care package, whatever their age or need. It is even more important for children, vulnerable individuals and people living with dementia.

I have heard the stories, experiences and evidence of dozens of people affected by dementia who have been unable to receive care through the medium of Welsh. Hearing these stories, it became clear to me that each individual case is not an exception, and that there are examples of inadequate provision across the country. With an ageing population and forecasts that the number of people living with dementia will increase significantly over the next decades, robust and urgent action must be taken to ensure that Welsh-medium provision is available to meet the need. That was the impetus of this partnership with Alzheimer's Society Cymru.

From the initial diagnosis to the dealings with various professionals, not offering a service in the language most natural to an individual can lead to delays and shortcomings in the planning and delivery of appropriate care. As dementia is a condition which affects linguistic ability, people are at risk of losing grasp of their second language, and not providing care in the Welsh language can lead to frustration and to losing dignity and respect.

Today, there are more laws, policies and strategies than ever before which recognise the importance of providing services and care through the medium of Welsh. The recommendations in this report concentrate on putting the principles into action and ensuring that care in Welsh is offered proactively, without the added stress of having to fight for it, at a time which is already challenging and difficult.

Meri HuwsWelsh Language Commissioner



Foreword

We estimate that there are currently 45,000 people living with dementia in Wales. Every single person in Wales living with dementia, regardless of a formal diagnosis, has the right to live well with dementia. What living well means varies from person to person, but what is not in doubt is that for a large amount of people across Wales, that means being able to access services, receive care, and deal with medical professionals in their first language, Welsh.

As the *Dementia Action Plan* states "For Welsh speakers living with dementia, receiving care and support in their first or preferred language is a matter of clinical need." The Welsh Government also committed to strengthening the active offer with the Welsh language standards coming in for the sector in 2019.

Whilst these commitments by the Welsh Government are to be welcomed as a step in the right direction, we need to ensure that we turn them into action to deliver on the principles and rights stated in the *Dementia Action Plan* to ensure that we can provide the highest quality service, and ensure that everyone can live well with dementia.

We hope that this report, and the recommendations contained within will not only provide impetus to the Government to drive forward their changes to Welsh language care, but to practitioners across all medical fields, and the social care sector, to ensure that the people they work with on a daily basis are supported to live well in the language they choose.

The time to act on this is now. Together, we can make Wales a dementia friendly nation.

Sue PhelpsDirector, Alzheimer's Society Cymru



1. Introduction

- 1.1 One of the strategic aims of the Welsh Language Commissioner is to influence the consideration given to the Welsh language in policy development. From the outset, the Commissioner has identified health and social care as a key area in relation to the Welsh language and the needs of Welsh speakers. The Welsh language in primary healthcare services was the subject of the Welsh Language Commissioner's first inquiry, *My Language*, *My Health*, published in 2014.² This report builds on that work.
- 1.2 Alzheimer's Society is the UK's leading dementia charity. It provides information and support to people with dementia and their carers and funds research in order to create permanent change for people affected by dementia.³ Alzheimer's Society Cymru strongly believes that a Welsh language service should be delivered to those who need it for clinical reasons as it affects their health and well-being outcomes.
- In light of this, the Welsh Language Commissioner and 1.3 Alzheimer's Society Cymru have collaborated on a project focussing on the Welsh language and dementia. The research company Wavehill was commissioned to undertake a study of the care and support services delivered to Welsh speakers with dementia. This qualitative research involved consultation with senior officers from local authorities and health boards; academics in the field; care and support providers; and people living with dementia. The purpose of the study was to investigate the main factors and themes influencing the provision, or lack of provision, of Welsh medium dementia health and support services, and learn about the experience of Welsh speakers with dementia of that provision. A round-table event was held with experts in the field to discuss the findings of the research and offer possible policy solutions in response to the difficulties identified.
- 1.4 This document summarises the findings of the project. Firstly, it outlines the nature of dementia and highlights the relevant language considerations. It then discusses the policy and legislative developments that are relevant to the field. We then present the findings of our research and the experiences of those living with dementia of the Welsh medium care available to them. Finally, it highlights the difficulties identified and the policy solutions which could, if adopted, make a positive difference to the provision for Welsh speakers.

Welsh Language Commissioner, My Language, My Health: The Welsh Language Commissioner's Inquiry into the Welsh language in Primary Care http://www.comisiynyddygymraeg.cymru/English/ Publications%20List/Health%20inquiry%20full%20report.pdf [accessed 6 September 2018]

^{3.} This may include a person with dementia, unpaid carers, family, friends and the wider support network.

Recommendations

Recommendation 1

We ask the Assembly's Health, Social Care and Sport Committee to conduct a review of the extent to which the requirements of the Social Services and Well-being (Wales) Act 2014 are being implemented in relation to providing dementia care through the medium of Welsh and the extent to which the statement regarding the national well-being outcome 'I get care and support through the Welsh language if I need it' is being met in relation to dementia care. Specifically, the consideration given to the Welsh language in the following areas should be examined:

- Assessments
- Commissioning and delivering care
- Individual care plans
- How local authorities and local health boards jointly assess the range and level of services required to meet the care and support needs of people in the local authority area.

Recommendation 2

We recommend that Care Inspectorate Wales and the Healthcare Inspectorate Wales recognise that a lack of care in the Welsh language for those who require it constitutes poor care which may have a harmful effect on people. The ability of providers to offer care in Welsh to people with dementia should constitute good practice and be a measure of the quality and safety of services. This should form part of their inspection work.

Recommendation 3

We ask the Welsh Government, in implementing the *Dementia Action Plan for Wales*, to consider the extent to which the relevant targets set for health and social care services in *More than just words* have been met and the extent to which they facilitate efforts to offer Welsh language dementia provision. If they have not been met, steps should be taken to rectify this in order to facilitate implementation of the Action Plan and other recommendations made in this report.

Recommendation 4

We ask local authorities, health boards and the Welsh Government to work together to develop a Welsh language care pathway. This is a golden opportunity to ensure that the Welsh language is central to individuals' care pathways and that staff working with them and their families can respond to their language needs.

Recommendation 5

We ask the Welsh Government to produce a specific action plan to plan, develop and train Welsh medium care teams when developing the care pathway and multidisciplinary teams which form part of the Action Plan, in order to ensure that the care commitments made in the Social Services and Well-being (Wales) Act 2014 are fulfilled.

Recommendation 6

As part of the commitment above to undertake further work on dementia assessment tools we ask the Welsh Government to work with local authorities and health boards in Wales to develop a national platform to share Welsh language tests as well as resources, expertise and information about dementia and the Welsh language. This will ensure that they are recognised by the different professions working with people with dementia and raise awareness of them amongst health and social care workers.

Recommendation 7

We ask the Welsh Government along with health boards and local authorities to develop national and local forums to share experiences of delivering care and volunteering in Welsh which would contribute experiences and information to the national platform mentioned above.

Recommendation 8

We ask the Welsh Government to put technology in place to ensure that information about patients' language choice and needs is recorded and that this information is transferred effectively between health and social care services.

Recommendation 9

We ask the Welsh Government to ensure that the new Dementia Allied Health Practitioner post includes responsibility for providing advice and support on considerations relating to the Welsh language and dementia. This can include raising awareness of the importance of the active offer, in order to drive service improvement and raise awareness of the importance of the language of provision when delivering dementia care.

Recommendation 10

We ask the Welsh Government to ensure that the equivalent responsibility or post to the All Wales Dementia Allied Health Practitioner is created in the clinical field in order to provide clinical advice and leadership and support in relation to dementia and the Welsh language to health boards, local authorities, health professions and others, and to raise awareness of the importance of the language of provision and the active offer when delivering dementia care. This national leader could be responsible for developing the platform and national forums in recommendations 6 and 7 also.

Recommendation 11

We ask that the commitments made in *More than just words* relating to collecting data about the linguistic needs of the public and the language skills of the workforce be implemented fully and promptly in relation to delivering dementia services. Based on this information Health Education and Improvement Wales should cooperate and strategically plan with higher and further education establishments, the Coleg Cymraeg Cenedlaethol and health boards to commission places for Welsh speakers on relevant training courses and ensure that Welsh speakers are aware of the need for Welsh speaking health and social care workers and the opportunities open to them.

Recommendation 12

We recommend that Health Education and Improvement Wales should ensure that language awareness, an understanding of the impact of dementia on bilingual people; the fact that offering health and social care provision in Welsh is a clinical need for a number of Welsh speakers; the rights of Welsh speakers to receive services in Welsh, and the importance of the active offer are an integral part of the education and training of all health service professionals across Wales. This should be part of the initial training of health workers and part of their continuing professional development, and especially part of the training of leaders in these fields.

Recommendation 13

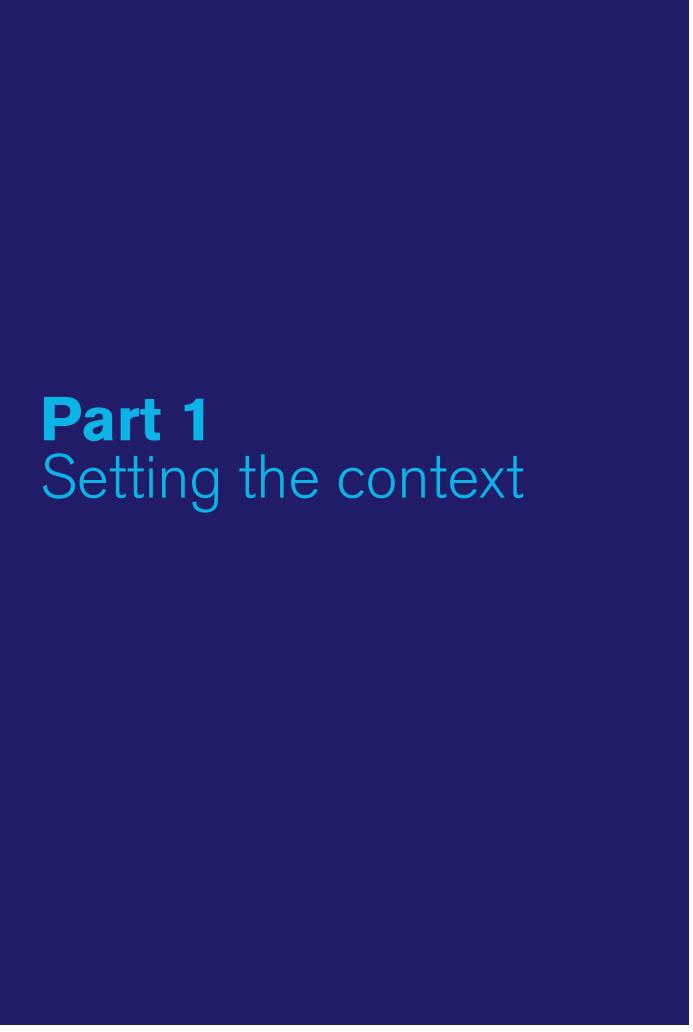
We recommend that workers' Welsh language skills are a key consideration when reviewing and standardising the role of dementia support workers and developing teams around the individual as part of the *Dementia Action Plan*.

Recommendation 14

We recommend that the Welsh Government should audit the extent to which understanding of the active offer; people's right to receive services in Welsh and the clinical need to do so, has filtered down and is being applied by workers involved in the care package of people with dementia and of leaders in the field. Based on this audit, plans should be made to raise awareness of these matters amongst these workers, e.g. by undertaking a specific campaign to raise awareness of dementia and the active offer.

Recommendation 15

As part of the *Dementia Action Plan for Wales* and in light of the requirements that are and will be applicable to them in accordance with the Welsh language standards, health boards and local authorities should ensure that specialist Welsh learning provision is available for workers involved in the care package for people living with dementia, using the plans offered by the National Centre for Learning Welsh for example. Also, where possible, relevant health and social care workers from all professions should be released for extended periods to develop language skills that will enable them to provide care through the medium of Welsh.



Overview of this section

- The effects of dementia are progressive and people experience different stages.
- People living with dementia deal with a number of different professionals and therefore the Welsh language provision offered by all services needs to be considered.
- Dementia is a condition which affects people's linguistic ability and there is evidence, from Wales and beyond, which shows that bilingual people are at risk of losing grasp of their second language.
- Failure to deliver services in the most appropriate language can lead to delay in diagnosing dementia and shortcomings in the planning and delivery of care to Welsh speakers with dementia.
- Delivering services in the language which feels natural to people living with dementia is a basic clinical need and this is recognised in Welsh Government policy.
- Legislation places a duty on authorities to consider the Welsh language in assessing, commissioning and delivering care to individuals in order to ensure that they experience the best possible outcomes.

1. Dementia and the dementia care pathway

- 1.1 Dementia can include several different conditions including Alzheimer's, vascular dementia and dementia with Lewy bodies. People with dementia can develop a number of different symptoms including memory loss; difficulty in solving problems and language difficulties. Dementia is a progressive condition and is often described as a series of steps on a journey which reveals new symptoms.
- 1.2 People living with dementia will come into contact with many different professionals and services on their journey. A detailed explanation can be found on Alzheimer's Society's website. The first point of contact will often be the GP. Sometimes, the GP or a specialist nurse may be able to make the diagnosis themselves, depending on their expertise and training. More often, people are referred to a memory clinic or another specialist service for assessment and diagnosis. Professionals delivering this service can include psychiatrists, clinical psychologists, specialist clinical nurses, geriatricians or neurologists and assessments range from discussing the individual's history (how their symptoms have developed), physical tests (e.g. blood tests), cognitive tests and a brain scan.
- 1.3 After diagnosis, the next step is to undertake an assessment of care needs. Local authority social services departments have a duty to undertake this assessment.⁵ See section 2 for more information about this. The assessment includes a number of questions, often in the form of a discussion, to determine the individual's needs and the type of support that they require. The assessment will normally involve a face to face discussion in the individual's home undertaken by a social worker from the local authority.
- 1.4 Then, the local authority will decide whether the individual is eligible to receive funding for their care needs. Subsequently, the individual can receive advice and support from a dementia support worker and the opportunity to discuss their diagnosis with a health or social care professional. This may include a psychiatrist or a mental health nurse, a clinical psychologist, an occupational therapist or a GP.

https://www.alzheimers.org.uk/info/20007/types_of_dementia/1/what_is_dementia/6 [accessed 4 September 2018]

https://www.alzheimers.org.uk/info/20032/legal_and_financial/35/assessment_for_care_and_support_in_wales/3 [accessed 4 September 2018]

- 1.5 The next step, after the needs assessment, is to develop a Care and Support Plan for the individual setting out how their needs should be met.⁶ The plan may state that the individual is independent enough to live at home but requires regular visits from a social worker, for example, to assist with eating, washing and so on. The plan may note that a day care centre would be the most suitable support provider and, once the condition progresses to a specific stage, it is possible that the individual may need continuous support and live in a care home. Support will either be delivered directly by the local authority; or the authority will arrange for another organisation (e.g. from the private sector) to deliver the service; or the authority may make a payment to the individual or their carer to arrange their own care and support.
- 1.6 Around 60% of people receiving domiciliary care in Britain are living with dementia, and around 70% of people living in care homes have dementia.⁷ According to a report by Alzheimer's Society in 2007, a third of people with dementia live in care homes and therefore, the vast majority live in the community.8 As mentioned above, people living in the community can receive a range of different services including respite care, visits to day care centres, participation in a wide range of activities etc. In terms of care homes, there are two main types - nursing and residential care. There are also more specialist forms of care such as specialist dementia care, palliative care and recovery care. The type of support required depends on the individual's needs. Residential care homes provide personal care, such as washing, dressing and eating and in some of these homes, a few of the workers will have received specialist training in dementia support. Nursing homes provide personal care, as described above, but they also have a qualified nurse on duty 24 hours a day.9

https://www.alzheimers.org.uk/info/20032/legal_and_financial/35/assessment_for_care_and_support_ in_wales/5 [accessed 4 September 2018]

^{7.} Alzheimer's Society (2007), Home from Home: A report highlighting opportunities for improving standards of dementia care in care homes, London: Alzheimer's Society. [accessed 4 September 2018]

^{8.} Alzheimer's Society (2007). Dementia UK. London: Alzheimer's Society.

^{9.} https://www.alzheimers.org.uk/info/20046/help_with_dementia_care/384/finding_a_care_home/2 [accessed 6 September 2018]

2. Dementia and language

- 2.1 The nature of dementia means that it can impair people's linguistic ability as it affects those parts of the brain which control language. It has long been understood that the condition leads to a general language decline amongst people with dementia and monoglot people, but much research has been published recently on the more specific effects on bilingual people.
- 2.2 There is a substantial body of international research and evidence which demonstrates the harmful effects of dementia on people's linguistic ability including, in some cases, a complete decline in the ability of bilingual people to speak one of those languages. There is also significant evidence in Wales, particularly through qualitative research, of the importance of the language of provision in delivering support to people with dementia.
- 2.3 When discussing the importance of the language of provision in delivering support to people with dementia as part of this project, Dr Catrin Hedd Jones, a Lecturer and Researcher in Dementia in the Dementia Services Development Centre Wales at Bangor University, said:
 - We must remember that receiving a service in the language that feels natural to people living with dementia is not a matter of choice but a clinical need, especially as the ability to communicate in their second language becomes more challenging for some.

If you question someone in the language with which they are most comfortable, you will glean more information about their situation. Some will be able to describe their feelings and emotions much more naturally if they're given the opportunity to do so in their first language, especially if they don't have the ability to express themselves as well in their second language. Help must be in place to support them in Welsh if that is most appropriate.

Dr Catrin Hedd Jones (Translation)

- 2.4 The importance of ensuring that people with dementia receive services in Welsh was highlighted in the report Welsh Speakers' Experiences of Health and Social Care Services prepared by IAITH (for the Welsh Government's Department for Health, Social Services and Children, and Care Council Wales) in 2012¹⁰. In producing the report, evidence was received from 51 respondents including four who had received a dementia diagnosis. For a number of respondents, using their language of choice was powerful in terms of creating affinity and forming closer professional relationships.
- 2.5 This supports the findings of the Welsh Language Commissioner's inquiry My Language, My Health. Although the work focuses on Welsh medium primary care, some elements are particularly relevant to people with dementia. The evidence received by the Commissioner from stakeholders and members of the public emphasised that the primary care sector must recognise that, for a number of patients, receiving a service in Welsh is a matter of need and not a matter of choice. The report explains that Welsh language services are needed by some patients who would otherwise face a real risk to their safety and welfare. To many, using English to discuss their inner, emotional life is difficult as there is no connection between the words in English and the experiences and emotions being discussed. Dr Catrin Hedd Jones underlined this when discussing the impact of not being able to receive a service in the most appropriate language:
 - Lack of effective communication can be dangerous when the needs of a Welsh speaker are misunderstood. On a wider level, the care and support delivered to people depends on developing a relationship and language is obviously a crucial element of that.'

Dr Catrin Hedd Jones (Translation)

IAITH, Welsh Speakers' Experiences of Health and Social Care Services, 2012, p.48. http://www.wales. nhs.uk/sites3/documents/415/120208welshresearchreporten[1].pdf [accessed 6 September 2018]

3. The policy context

Relevant policies

Taking Wales Forward – Programme for Government 2016-21¹¹ and Prosperity for All: the national strategy¹²

- 3.1 The Welsh Government's programme for government for 2016-21 outlines the Government's commitments to a healthy and active Wales. In the context of care and older people the Government states that it will do the following, which applies directly to dementia care provisions:
 - ensure our ground-breaking social services legislation is fully implemented and all the benefits are realised.
 - take further action to make Wales a dementia friendly country through developing and implementing a new national dementia plan.
- 3.2 Prosperity for All takes those key commitments made in Taking Wales Forward and places them in a long-term context, and sets out how they fit with the work of the wider Welsh public service to lay the foundations for achieving prosperity for all. 'Better Mental Health' is one of the five cross-cutting priorities for this current Welsh Government term and in relation to dementia the commitment is made to help people with dementia and their families and carers to access information, advice and support to maintain their independence by a joint health service/local authority 'team around the family approach.'

^{11.} Welsh Government, *Taking Wales Forward – Programme for Government 2016-21* https://llyw.cymru/docs/strategies/160920-taking-wales-forward-en.pdf [accessed 19 July 2018]

Welsh Government, Prosperity for All: the national strategy https://gov.wales/docs/strategies/170919prosperity-for-all-en.pdf [accessed 19 July 2018]

A Healthier Wales¹³ and the Dementia Action Plan for Wales 2018-22¹⁴

- 3.3 In February 2018, the Welsh Government published the *Dementia Action Plan for Wales 2018-2022* which highlights its commitment to promoting the rights, dignity and autonomy of people living with dementia. The plan focuses on statements of rights for people living with dementia and their carers developed by people affected by dementia. These include an important statement in the context of care through the medium of Welsh and, indeed, in the context of the findings of this report in its entirety:
 - We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live. ■¹⁶

^{13.} Welsh Government, A Healthier Wales https://gov.wales/docs/dhss/publications/180608healthier-wales-mainen.pdf [accessed 17 August 2018]

Welsh Government, Dementia Action Plan for Wales 2018-22 https://gov.wales/docs/dhss/ publications/180214dementiaen.pdf [accessed 19 July 2018]

^{15.} https://www.dementiaaction.org.uk/ [accessed 30 August 2018]

^{16.} Ibid., p. 4.

- 3.4 The action plan recognises the importance of delivering services in individuals' first language stating 'our service and community response needs to be equitable...and it needs to meet diverse needs...people who may be able to understand only their first language as their condition progresses'. The action plan is structured around outcomes which follow a pathway approach to dementia care. The Welsh language is crucial to all of the outcomes which form part of the dementia care pathway. 18 The action plan explains the importance of actively offering services through the medium of the Welsh language. It is also stated that the active offer commitment will be strengthened when the Welsh Language Standards for the health sector are introduced. The plan also emphasises that receiving care and support in Welsh is a clinical need for Welsh speakers with dementia and that as their condition progresses, people with dementia may understand or be able to communicate in their first language only. It makes the following specific commitment to dementia care in Welsh:
 - We will...work with stakeholders to identify and utilise the most robust clinically validated dementia assessment tool(s) for use in the Welsh language and commission research as necessary.

More than just words: Follow-on Strategic Framework for Welsh Language Services in Health, Social Services and Social Care 2016-2019¹⁹

- 3.5 This strategic framework builds on the previous strategic framework for Welsh language services in health, social services and social care published in 2012. The framework sets out actions relating to seven objectives and assigns lead responsibility for completing them and by when. The seven objectives relate to the following matters:
 - National and local leadership, and national policy
 - Mapping, auditing, data collection and research
 - Service planning, commissioning, contracting and workforce planning
 - Promotion and engagement
 - Professional education
 - Welsh in the workplace
 - Regulation and inspection
- 3.6 More than just words 2016-19 specifically states that the Welsh language should be viewed as a fundamental element of dementia services.²⁰ It is stated that it is important to recognise the concept of language need as part of people's quality of care and as a clinical necessity. In addition, it is stated that health and social care and support services should be available in Welsh in order to maintain professional standards and meet the language needs of people as well as comply with legal and statutory requirements. Reference is also made to the European Charter for Regional or Minority Languages which establishes the principal that 'the right to use a regional or minority language in private and public life is an inalienable right'. Reference is then made to article 13 of the Charter relating to Economic and Social Life which is binding upon the UK Government and, therefore, the Welsh Government to ensure that social care facilities such as hospitals, retirement homes and hostels offer the possibility of receiving and treating in their own language persons using a regional or minority language which are in need of care on grounds of ill-health, old age or for other reasons.²¹

Welsh Government, More than just words: Follow-on Strategic Framework for Welsh Language Services in Health, Social Services and Social Care 2016-2019 https://gov.wales/docs/dhss/ publications/160317morethanjustwordsen.pdf [accessed 19 July 2018]

^{20.} Ibid, p. 10.

^{21.} Ibid. p.13.

Cymraeg 2050 Strategy²²

3.7 The Cymraeg 2050 Strategy outlines the Welsh Government's intention to reach a million Welsh speakers by 2050, and for the percentage of the population that speak Welsh on a daily basis, and can speak more than just a few words of Welsh, to increase from 10 per cent (in 2013-15) to 20 per cent. One objective is to increase the use of the Welsh language in the workplace across all sectors. It is noted that increasing the use of Welsh in health and social care sector workplaces is extremely important in this regard. The relevance of the active offer principle is also highlighted when considering services in the health and social care sector in particular.

Relevant legislation

Social Services and Well-being (Wales) Act 2014²³

3.8 The Social Services and Well-being (Wales) Act 2014 contains specific requirements relating to the Welsh language including the language of assessment, considering the Welsh language when commissioning and delivering care and in individual care plans prepared in accordance with the Act. Section 14(1) states that local authorities and each local health board must jointly assess the range and level of services required to meet the care and support needs of people in the local authority area, as well as the range and level of preventative services required. They must also jointly assess the actions required to provide the range and level of services identified through the medium of Welsh. The Act and Regulations and the Part 2 Code of Practice include details on preparing care and support plans and specifically the rights and responsibilities of people who need care and support to achieve their personal outcomes. The Code states that when people use social services and their partners to implement their care and support plan, people can expect to achieve personal outcomes which reflect the national well-being outcome statement 'I get care and support through the Welsh language if I need it'.24

^{22.} Welsh Government, *Cymraeg 2050 Strategy* https://gov.wales/docs/dcells/publications/170711-welsh-language-strategy-eng.pdf [accessed 19 July 2018]

^{23.} Social Services and Well-being (Wales) Act 2014https://www.legislation.gov.uk/anaw/2014/4/pdfs/anaw_20140004_en.pdf [accessed 18 July 2018]

^{24.} Welsh Government, Social Services and Well-being (Wales) Act 2014 Part 2 Code of Practice (General Functions) https://gov.wales/docs/dhss/publications/151218part2en.pdf [accessed 18 July 2018]

Regulation and Inspection of Social Care (Wales) Act 2016 25

3.9 The aim of the Regulation and Inspection of Social Care (Wales) Act 2016 is to put quality and service improvement at the heart of regulation. It ensures that services deliver high quality care and support in accordance with the objectives of the Social Services and Well-being (Wales) Act 2014. Part 7, section 24 of the Regulated Services (Service Providers and Responsible Individuals) (Wales) Regulations 2017, which arise from this Act, places requirements on service providers in relation to the standard of care and support that they deliver. The aim of Part 7 is to ensure that individuals receive care and support that enable them to achieve the best possible outcomes. The service will be planned in consultation with the individual and will consider their personal wishes, aspirations and outcomes and any risks and specialist needs which inform the care and support delivered. In terms of the Welsh language, it is stated in regulation 23 that 'the service provider must take reasonable steps to meet the language needs of individuals and the service provider must ensure that individuals are provided with access to such aids and equipment as may be necessary to facilitate the individual's communication with others.' The Statutory Guidance²⁶ resulting from these regulations outlines methods that could be adopted by service providers to help people with language and communication needs:

^{25.} Regulation and Inspection of Social Care (Wales) Act 2016, https://gov.wales/docs/dhss/publications/151218part2en.pdf [accessed 18 July 2018]

Welsh Government, Statutory guidance for service providers and responsible individuals on meeting service Standard regulations, p.36. https://beta.llyw.cymru/sites/default/files/consultations/2018-02/170502statutoryguidanceen.pdf [accessed 9 October 2018]

3.10 Care Inspectorate Wales inspects and drives improvement in regulated services and local authority social services. Care Inspectorate Wales' code of practice for inspection outlines the Inspectorate's intentions in fulfilling its duties in accordance with the Regulation and Inspection of Social Care (Wales) Act 2016. It is stated that the focus of its inspections is the quality and safety of services and the outcomes for people using these services.

Well-being of Future Generations (Wales) Act 2015²⁷

- 3.11 The Well-being of Future Generations Act requires public bodies in Wales, including Government Ministers, Local Authorities and Local Health Boards, to think about the long-term impact of their decisions; to work better with people; communities and each other; and to prevent persistent problems such as poverty, health inequality and climate change. The seven well-being goals to which these bodies are expected to contribute include the following:
 - A more equal Wales
 - A healthier Wales
 - A Wales of vibrant culture and thriving Welsh language

^{27.} Well-being of Future Generations (Wales) Act 2015 https://www.legislation.gov.uk/anaw/2015/2/contents/enacted

Welsh Language (Wales) Measure 2011²⁸ and the Welsh Language Standards

- The Welsh Language (Wales) Measure 2011 gives the Welsh language official status in Wales. The Measure also sets a legal framework which places a duty on some organisations to comply with standards. The standards explain how organisations are expected to use the Welsh language in different situations. The duties resulting from the standards mean that organisations must not treat the Welsh language less favourably than the English language, and that they should promote and facilitate the use of the Welsh language making it easier for people to use the Welsh language in their everyday lives. The purpose of the standards is to set out clearly for organisations their duties in relation to the Welsh language and to set out clearly for the public which services they can expect to receive in Welsh. Their aim is to ensure greater consistency in terms of the Welsh language services on offer and improve their quality. There are standards in the following areas:
 - service delivery
 - policy making
 - operational
 - promotion
 - record keeping
- 3.13 The Welsh Government and local authorities have been under a duty to comply with the Welsh language standards since 2016. It is anticipated that health boards and other health bodies will be under a duty to do so from 2019. It should be noted that the duties on health bodies will not extend to primary care provision, but that the Welsh Government will agree non-statutory duties for primary care bodies instead.

3.14 This section demonstrates that legislation and policies already in place create favourable conditions for delivering care through the medium of Welsh to people living with dementia. The Social Services and Well-being (Wales) Act 2014 means that the Welsh language is a consideration when preparing care and support plans and the Regulation and Inspection of Social Care (Wales) Act 2016 requires service providers to consult with individuals when planning their services and to take reasonable steps to meet individuals' language needs. More than just words 2016-19 and the Dementia Action Plan for Wales 2018-2022 also recognise that receiving care and support in Welsh is a clinical need for Welsh speakers with dementia. Both policy documents also highlight the importance of the active offer. There are clearly-defined actions in More than just words 2016-19 that would, if fully implemented, greatly complement and support the legislative requirements.



Overview of this section

- Dementia affects bilingual people in a different way to monoglot people and their care should reflect this.
- Providing care and services through the medium of Welsh is a basic clinical need for many Welsh speakers and people have a right to receive such care.
- Although there is good practice at a local level and the awareness of the Welsh language and the active offer at a strategic level has improved, the research suggests that there are many gaps in the care and very few examples where the needs of Welsh-speaking service users are being fully met.
- The research highlights inconsistency in the range of tools, diagnostic tests and assessment resources available for use in Welsh. The language of the provision offered can depend on the linguistic ability of the practitioners offering the provision.
- Although national policies emphasise that receiving care in Welsh is a matter of clinical need and not a matter of choice, this awareness and understanding has not filtered down into practice.

Service planning

- The research demonstrates that failure to collect and use sufficient data on the language skills of staff and service users and share this data between agencies is a barrier to service planning.
- There are doubts as to the extent to which the active offer has developed from being a policy concept to a reality which reflects a genuine understanding of the practical meaning of the concept.
- All professions involved in an individual's care plan need to take ownership of efforts to improve care and services for Welsh speakers.
- Positive examples were seen of requirements in relation to the Welsh language being included when commissioning services and monitoring them.
- There was very little evidence of multi-agency collaboration on a wide scale to ensure that people receive the Welsh language service they need. However, examples of good practice were seen, such as joint working with local groups and the third sector to fill gaps in staff skills and deliver a Welsh language experience.

Education, training and recruitment

- Recruiting people to work in the field is a problem in general and recruiting Welsh speakers is an additional challenge.
- The lack of training and awareness of the effects of dementia on Welsh speakers is also a challenge.
- The need for more language awareness training, to improve Welsh language skills as well as training through the medium of Welsh more generally, including online courses, was highlighted.
- The lack of confidence amongst staff in their Welsh language skills is a significant challenge.

1. Introduction to the research

- 1.1 This section demonstrates the main difficulties affecting the dementia care received by Welsh speakers. To do this, we have drawn together the findings of qualitative research that we commissioned and research that has been undertaken by others in the field. As part of the qualitative research that was commissioned visits were undertaken to eight locations across Wales where dementia care is provided. These included a wide variety of areas and settings, including public, private and third sector settings; day care centres, residential and nursing homes; and traditional Welsh-speaking areas and areas where the language is traditionally less spoken, as well as rural and urban areas. During these visits interviews were conducted with 14 practitioners and 18 individuals who lived with dementia and were at different stages of the condition. Five further interviews were conducted with senior officers from local authorities and health boards including those who have lead responsibility for dementia services in their areas and those who have lead responsibility for Welsh language services. In addition, two interviews were conducted with academics from the fields of dementia and health and social care. A round-table event was convened of people from different organisations with expertise in the field. The report also includes a summary of the answers received in response to freedom of information requests made by Alzheimer's Society Cymru in 2017. The aim of the information requests was to establish a baseline for the current Welsh language provision and the policy commitments which have been made to Welsh speakers with dementia.
- 1.2 As the research that was commissioned is based on consultation with a limited number of stakeholders an effort was made to make this sample as representative as possible. It should be emphasised that the report does not include a quantitative analysis of all the dementia services delivered across Wales. However, the research that we commissioned does include the opinions, experiences and testimony of people living with dementia and practitioners in the field. Together with research conducted by others it provides a representative picture of dementia care available to Welsh speakers.

The research

- visits were undertaken to eight locations across Wales where dementia care is provided.
- o interviews were conducted with 14 practitioners and 18 individuals who lived with dementia and were at different stages of the condition.
- five interviews were conducted with senior officers from local authorities and health boards
- two interviews were conducted with academics from the fields of dementia and health and social care
- a round-table event was convened of people from different organisations with expertise in the field
- a public event was held in the National Eisteddfod in Cardiff in 2018.

2. Dementia assessments

2.1 Evidence shows that the language of provision is extremely important when assessing and diagnosing dementia. Failure to deliver services in the most appropriate language can lead to delay in diagnosing dementia. It was also stated in our interviews with practitioners and experts in the field that the language of provision is essential when conducting diagnostic tests that are part of diagnosing dementia and it can impact people's performance in them. This is supported by international evidence and research studies undertaken in Wales. For example, according to research published in the Journal of Neuropsychology, 29 Welsh speakers receive a dementia diagnosis three years later on average than those who only speak English, and their cognitive condition will be a great deal worse by the time they receive that diagnosis. Dr Catrin Hedd Jones says that this may be due to a lack of bilingual services as well as cultural factors within Welshspeaking communities.³⁰ This is echoed in a research briefing³¹ prepared by Dr Catrin Hedd Jones for the National Assembly for Wales' research service. The briefing highlights the response to the research of a focus group with a team of community psychiatric nurses specialising in dementia. The research briefing states that three main themes arise from the focus group's discussions the influence of culture, mental health stigma and the importance of cultural sensitivity.

^{29.} Linda Clare, et al,' Bilingualism, executive control, and age at diagnosis among people with early-stage Alzheimer's disease in Wales', Journal of Neuropsychology, September 2016. https://onlinelibrary.wiley.com/doi/full/10.1111/jnp.12061 [accessed 16 August 2018)

^{30.} Golwg 360, 'Canfod dementia yn hwyrach mewn Cymry Cymraeg', 19 May 2017. https://golwg360. cymru/newyddion/cymru/264166-canfod-dementia-yn-hwyrach-mewn-cymry-cymraeg (Welsh only) [accessed 17 August 2018]

Catrin Hedd Jones, Research Briefing Access to dementia services for bilingual (Welsh and English) residents, National Assembly for Wales, 2018. http://www.assembly.wales/research%20documents/18-017/18-017-web-english.pdf [accessed 20 August 2018]

- 2.2 As part of her work with LLAIS (Language Awareness Infrastructure Support),³² Gwerfyl Roberts from Bangor University who currently works as an Independent Adviser translated and linguistically validated Welsh language dementia cognitive assessments.³³ Following this experience, she said that an individual's chances of obtaining a high score in the assessment depended on their proficiency in the languages being used. This supports international evidence which demonstrates that language is one of the main factors that affect cognitive screening tools:³⁴
 - Previous studies have demonstrated that while age and education are the most important determinants of normal variation in performance on cognitive testing, ethnicity and language may also affect selected items of standard cognitive screening instruments. This may be particularly important when assessing bilingual patients who may vary in comprehension and performance on cognitive tests depending on the language used to administer the tests.
- 2.3 Alzheimer's Society Cymru also drew attention to these challenges during the development of the Dementia Action Plan for Wales 2018-22. Specifically, it emphasised the difficulties experienced by Welsh speakers in the process of obtaining a dementia diagnosis. Reference was made to Public Health Wales' audit of memory clinics in 2014³⁵ which stated that 'Welsh language assessment was available in all clinics, but usually by involving a Welsh-speaking colleague from another service'. The report did not identify this as a weakness in the service however. Alzheimer's Society Cymru hoped to see further details in the Action Plan on how the Welsh Government would ensure that Welsh speakers can access dementia services. It was recommended that only qualified assessors should be involved in diagnosing dementia and where there are no Welsh-speaking assessors, clinics should take action to train Welsh speakers to diagnose dementia.

^{32.} http://nworth-ctu.bangor.ac.uk/llais/staff.php.en

Bangor University, LLAIS (2014) Cognitive Assessment Toolkit http://nworth-ctu.bangor.ac.uk/ documents/25714CognitiveAssessmentToolkitCYMRAEG.pdf.

^{34.} Aaron McMurtray, MD, Erin Saito, MSc, and Beau Nakamoto, MD. 'Language Preference and Development of Dementia Among Bilingual Individuals', Hawaii Med J. 2009.

^{35.} Public Health Wales, Wales National Audit Memory Clinic and Memory Assessment Services, 2014. https://www.rcpsych.ac.uk/pdf/Wales%20National%20Audit%20-%20Memory%20Clinics%20Aug%202014.pdf [accessed 17 August 2018]

- We know that a number of dementia diagnostic tests are available 2.4 in Welsh (e.g. MOCA, ACE III) and information about these is available on the Mi-Cym website.³⁶ However, in general, the evidence highlights inconsistencies in the range of tools, diagnostic tests and resources used with Welsh speakers. The freedom of information requests from Alzheimer's Society Cymru revealed some inconsistency in the dementia diagnostic tests available for Welsh speakers living with dementia. One health board stated that they were aware of one Welsh language dementia diagnostic test which had been validated and that they ensure that it is available to doctors. However, the responses to the request for information about whether tests were used in Welsh were inconsistent. In the round-table discussion, it was noted that not all of the professionals in the field recognise and take ownership of the Welsh language tests that are available due to doubts about their quality and validity. It was noted, however, that the same could be said for English language tests used with Welsh speakers too because they have not been moderated to consider Welsh speakers or bilingual people.
- 2.5 Research from 2003 conducted by Morgan and Crowder³⁷ studied the response of bilingual people with Welsh as a first language to the MMSE (Mini Mental State Examination) cognitive test.³⁸ It showed that the same people achieved a different score when completing the test in Welsh and in English. This, according to the researchers, was a cause for concern as the result of the test affects the care subsequently received by these people. As noted in the research:
 - It is felt that misleading results are being achieved for Welsh speaking patients. In the context that decisions about the allocation of health and social care services are increasingly made on the basis of people's scores on a screening instrument this may have potentially significant consequences, both for those concerned whose ability to live independently may be questioned and also for the health and social care services where resources may be inappropriately targeted.

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^{36.} http://www.micym.org/llais/measure/index http://www.micym.org/llais/static/index.html [accessed 12 September 2018]

^{37.} Tracey Morgan, Ruth Crowder. 'Mini Mental State Examinations in English: are they suitable for people with dementia who are Welsh speaking?', 2003. http://journals.sagepub.com/doi/abs/10.1177/14713 01203002002009

^{38.} This test has now been superseded by more recent tests.

^{39.} Ibid. p. 271.

- 2.6 The research undertaken in care settings showed once again that the language of tests depended on the language of those conducting them. Evidence suggested that some Welsh speakers undertake cognitive tests in English relying on others to translate them into Welsh. These were sometimes members of staff who were not trained to conduct the tests nor were they qualified translators. We also heard of carers or family members having to translate. As one manager of a care location said:
 - I sat in on two tests some weeks ago and the psychiatrists didn't speak Welsh. I was there to translate but I found it difficult to understand them and I felt quite uncomfortable. It wasn't fair on the individual because this is important, the tests are hard enough as it is but not being able to do them in your first language is even harder. I have never seen a psychiatrist conducting the test in Welsh.

Care location manager (Translation)

- 2.7 The research by Morgan and Crowder also stated that it is crucial that assessments are undertaken by bilingual workers in order to ensure that individuals receive the best care, as follows:
 - Each public body must have its own procedures to accommodate Welsh speakers. It is essential that clients are treated individually using bilingual staff as it is believed this is the only way to ensure that Welsh speaking clients with dementia receive the client-centred and holisitic assessment they require. 40

- 2.8 It also became clear that there was uncertainty regarding which cognitive tests are available, the language of provision and the support delivered to Welsh speakers taking these tests.
 - We must understand whether the tests which have been translated are being offered by memory clinics. Is it dependent on having bilingual staff? If receiving a Welsh language service led to delay, there's a risk that Welsh speakers would make do with the English language test and this could mean that they wouldn't perform to best of their ability. Staff need to be there to ensure that bilingual individuals don't feel that they're causing trouble if they wish to receive the service and, importantly, their tests through the medium of Welsh.

Dr. Catrin Hedd Jones (Translation)

2.9 In the IAITH study of Welsh Speakers' Experiences of Health and Social Care Services one respondent referred to the difference they saw when they took a relative to a memory clinic where the assessment was not available through the medium of Welsh and then took them to see a Welsh-speaking psychologist. In the first case, the relative was described as being agitated and she had to be forced to stay there. In the second case, the respondent said that the psychologist explained that she uses every day Welsh ... The diagnosis is the same but we feel different.' The report explains that 'the essential difference, is that having a shared language and an associated understanding of culture has helped create a clinical relationship'.⁴¹

3. The demand for Welsh language services

I'm happier speaking Welsh to people but there are very few Welsh language services here. No one asks us [about our language choice for services].

Person with dementia (Translation)

- 3.1 Alzheimer's Society Cymru's freedom of information request revealed a lack of data amongst health boards and local authorities alike about the number of Welsh speakers accessing dementia support services and their language choice. The case studies gave examples of organisations which deliver care and support to people with dementia and the availability of those services through the medium of Welsh. The research sample was insufficient to provide definitive findings about the nature of services but, put together, the case studies provided useful evidence to create a general picture of the linguistic nature of dementia services in Wales.
- 3.2 According to Alzheimer's Society, 42 1 in 14 individuals over 65 years old in the UK are living with dementia. Therefore, even in those areas with fewer Welsh-speaking inhabitants, there will be several cases of Welsh speakers with dementia. In counties with higher percentages of Welsh speakers, it is likely that several hundred or indeed thousands of Welsh speakers have dementia. Therefore, even though the demand for Welsh language services is currently much higher in the more Welsh-speaking areas in north, mid and south-west Wales, the research revealed several cases of demand for Welsh language services in areas with lower percentages of Welsh speakers, such as the south-east. The demand for Welsh language services, therefore, varied between settings and areas but there is a need for Welsh language services in all of the settings and areas covered by this study. The long term consequences of the recent increase in the number of Welsh speakers in those areas with traditionally fewer Welsh speakers must also be borne in mind. This population will of course age with time.
- 3.3 Most of the settings visited assessed service users' language needs before they arrived at the home/centre and/or asked their family to complete an information pack which included a section on the language of the individual with dementia. Three practitioners said that they receive this information from social services and all but one of the settings said that they have a systematic approach to identifying service users' language needs.

3.4 The research suggested, therefore, that these services assess the language needs of residents/service users on the whole. However, during one interview, it was said that there is a reliance on the family to disclose information about individuals' language needs. The round-table discussions revealed that information about individuals' language needs was not always shared effectively between various agencies. In addition, the freedom of information request to local authorities found a lack of clarity regarding the way in which information about the language needs of Welsh speakers with dementia was disseminated between services.

4. Delivering a Welsh language service and the active offer

There are hardly any Welsh language services available now.
 Hardly anyone can speak Welsh here but there are some Welsh language activities. I would be far happier if there were more Welsh language services. It isn't always easy expressing yourself in English. If I ask, I do sometimes get things in Welsh, but I don't normally ask.
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Person with dementia (Translation)

- 4.1 One of the basic principles when considering the extent to which an adequate Welsh language service is being offered is whether an active offer is made or whether the patient is expected to ask for the service, or whether there are any barriers to receiving a Welsh language service. In the paper Welsh Speakers' Experiences of Health and Social Care Service⁴³, a number of service users and carers said that Welsh language services were delivered on the basis of demand rather than need. The paper concludes that the onus should be placed on the provider to ask the question rather than on the service user to identify the need, and that this is particularly pertinent for vulnerable service users.
- 4.2 My Language, My Health comes to a similar conclusion. The responses to the Inquiry demonstrated that a number of Welsh speakers make do with primary care service in English even though they would prefer to speak Welsh. It is noted that several factors contribute to a patient's reluctance to ask for a Welsh language service, including the perception that there is no language choice available in most cases and that it is only available in other areas by chance. The unequal balance of power between the service provider and the patient makes it very difficult for a patient to change the situation by asking for a Welsh language service.

4.3 This is supported by the research undertaken in care settings. Even though they had information about the language needs of people with dementia, they did not always actively offer a language choice. It was clear from some of the interviews conducted with people with dementia that they avoided asking for a Welsh language service. Some of the interviews with service providers demonstrated ignorance regarding the importance of the active offer, with some assuming that people are equally comfortable in Welsh and English if they do not ask for a Welsh language service. However, this varied between settings and others said that they actively offered a language choice. The general shortage of dementia services can also mean that people who need support are reluctant to demand a Welsh language service due to concerns that they will not receive any support at all. This in turn makes it difficult to demonstrate the need for Welsh language services.

I do [speak Welsh], but they don't understand.

Person with dementia (Translation)

Alzheimer's Society Cymru's freedom of information request demonstrated that the majority of local authorities confirmed that they have a high level policy commitment to delivering bilingual services to people with dementia, with several references to the active offer. As such, requirements in relation to the Welsh language were also included in a significant number of service commissioning specifications. However, the freedom of information requests revealed several cases where local authorities relied on translators to deliver services. In addition, in some health board areas, there was evidence of difficulty in delivering a full care pathway through the medium of Welsh to Welsh speakers with dementia, although efforts are being made in this direction.

- 4.4 Not all care settings had considered workforce planning in such a way as to deliver a Welsh language service across the service (e.g. general care, nursing etc.). There was also inconsistency in the way in which the settings visited planned their services purposefully to ensure that Welsh language services were available to those who required them. Two settings stated that they ensure that Welsh speaking carers are on duty on every shift. Another stated that they did not have enough Welsh-speaking staff to ensure that there were Welsh speakers on the rota at all times, but that they tried to pair Welsh-speaking staff and residents where possible. Staff caring for one of the Welsh-speaking residents in one home had learnt some simple phrases, but there were no fluent Welsh speakers available to be able to plan a more comprehensive Welsh language service.
- 4.5 In the areas where less Welsh was spoken, there were very few Welsh-speaking staff and therefore it was not possible to deliver full care and support through the medium of Welsh. As a result, some of these settings relied on other ways of delivering some kind of Welsh language service. One setting had established close links with local Welsh language organisations, including Mudiad Meithrin, in order to hold events and activities through the medium of Welsh for residents. One setting had translated many of its resources into Welsh and two homes offered televisions and radios to enable residents to hear the Welsh language through those media. Many of the practitioners stated that the focus placed on the Welsh language has increased significantly over recent years and that it is becoming far more of a live issue. This mixed picture was supported by comments from people with dementia and a number of residents said that they do not believe that there are enough Welsh language services available to them.

- 4.6 It became clear also that difficulties arise when people living with dementia come into contact with services outside the care settings. This highlights weaknesses in terms of collecting, recording and sharing information about people's language needs and ensuring that this information informs wider workforce and service planning. In general, it was seen that support providers give priority to delivering the service rather than waiting for Welsh speakers when moving from one service to another. A number of settings said that they ask for a Welsh speaking professional when a service user requires an external service, but that this depends on the service's ability to meet the request.
 - We do everything in Welsh. The only service which may be delivered in English is the medical side when doctors are treating them and so on. With locums, it's impossible to get the same GP every time and so some of the ones that visit don't speak Welsh... Perhaps the main challenge is a lack of Welsh-speaking psychiatrists.

Care location manager (Translation)

There is a general awareness at a policy level of the clinical need to offer care through the medium of Welsh to people with dementia and, indeed, policy commitments have been made in response to this need. However, it does not appear that this awareness and action to fulfil these policy commitments have filtered down to grass roots level so that professionals in the field understand that receiving care in Welsh is a matter of clinical need rather than choice.

I think that multi-agency support [is the main gap] where there aren't many Welsh-speaking professionals, in terms of the medical profession as well as local social groups.

Care location manager

5. The workforce

✓ Very few of the staff speak Welsh, most of them are English speakers... I've been to see the doctor but they're English too... I have to speak English with them.

Person with dementia (Translation)

- 5.1 It is essential to ensure that there is an adequate number of people in the health and social care workforce that can provide services through the medium of Welsh and that people are aware of the active offer and the care needs of Welsh speakers. It is essential therefore that there are steps in place to collect data about Welsh speakers and that the workforce is planned and trained on the basis of data. Despite this, from the research undertaken in care settings, it was seen that the ability of the workforce to deliver a service in Welsh, and the efforts made to ensure that people have sufficient ability and the means to develop that ability, vary widely from setting to setting and from area to area. In one setting, all of the staff spoke Welsh and in another two settings, more than 50% of the staff were Welsh speakers. In two settings, there was a big gap between the percentage of staff who could speak Welsh and the percentage of residents who could speak Welsh (8% to 42% and 17% to 50%). In another setting, even though there were two residents who required Welsh language services, there were not enough Welsh speakers to deliver a regular Welsh language service. An inconsistent approach to recruiting Welsh speakers was seen across Wales, with some job descriptions stating that the Welsh language is essential and others stating that it is desirable. The ability to speak Welsh was not considered part of the quality of care that an individual could offer to residents.
 - Our job descriptions don't currently state that the Welsh language is essential because that would make it difficult to recruit anyone, but it would be nice to have more Welsh-speaking members of staff. It would also be good to have more Welsh-speaking professionals in the field, including doctors, nurses and external agencies.

Care location manager

- 5.2 In general, evidence from these case studies suggests that few care locations, assess workers' language skills and record that information in a formal and systematic way. Several said that they get an insight into the Welsh language skills of staff during the interview process and a few relied on the fact that they know the staff or come to know them. One manager said that they could only estimate the number and that they would guess that some members of staff may have Welsh language skills of which the manager is unaware. Examples were also seen of a lack of confidence amongst people with Welsh language skills to use the language.
- 5.3 From the evidence of members of the round-table and comments from two events held by the Welsh Language Commissioner, Alzheimer's Society Cymru and Theatr Genedlaethol Cymru, and the other by Social Care Wales in the National Eisteddfod in Cardiff in 2018 to discuss dementia care, it was emphasised that one of the main challenges in the field was a lack of confidence within the workforce in their language skills. It was noted that a number of people felt that they should not use Welsh at all if they could not deliver a full Welsh language service. Several emphasised the need to encourage workers delivering services to people with dementia to use the Welsh skills that they have, whatever their level. It was also noted that cultural awareness is crucial in order to be able to discuss with people with dementia in Welsh.
- 5.4 The importance of providing Welsh lessons for health board staff was also discussed. Reference was made to requirement in Sweden that clinical health professionals are required to possess sufficient language skills in order to obtain a licence to practise.44 The individual in question was released from work on full pay in order to learn the language. Currently, authorities and organisations managed by local authorities have a specific duty to assess and develop the Welsh language skills of their staff due to the Welsh language standards. In 2019, the same requirements will apply to health boards. These standards will require health bodies to assess the language skills of their workforce and provide training for staff to learn Welsh and develop their Welsh language skills, as well as raise awareness of the language and improve understanding of the way in which Welsh can be used in the workplace.

- 5.5 The research found significant evidence that most settings try to improve the Welsh language skills of their workforce. Many care homes and day centres said that they encourage staff to attend Welsh courses and that many of them do so. Only two of the eight said that they do not have any specific structures in place to improve the workforce's ability to deliver Welsh language services. The need for more language awareness training, Welsh language improvement training as well as training through the medium of Welsh more generally, including online courses, was highlighted.
- 5.6 In general, there is lack awareness of the needs of patients living with dementia. Successful initiatives such as This is me⁴⁵ and the Butterfly Scheme⁴⁶ have helped to raise awareness amongst professionals in care settings. Similar initiatives should be developed to ensure that health professionals are aware that patients need care and support in Welsh, especially people with dementia. To achieve this, strong leadership in relation to the Welsh language and an understanding of the active offer is required from health professions involved in dementia care as well as senior officers within local authorities and health boards. However, the freedom of information request to health boards revealed a difference of opinion in several areas between clinical leaders responsible for dementia care and corporate leaders responsible for the Welsh language. It was noted that clinical leaders did not always recognise the clinical importance of delivering Welsh language services to people with dementia. It was seen that further collaboration is needed to overcome this. In this regard, the round-table discussions revealed the need for all professions involved in the care package of people with dementia to recognise the importance of the Welsh language as a clinical need when delivering care. It was noted that all professions need to take ownership of efforts to change and improve the care delivered in order to create change and improvement.

^{45.} https://www.alzheimers.org.uk/about-us/wales [accessed 12 September 2018] https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/this_is_me_bilingual_welsh.pdf

^{46.} https://www.pembrokeshire.gov.uk/hospital-care-admission/butterfly-scheme [accessed 6 September 2018]

6. Impact on service users

As their dementia develops, we've noticed that some of the residents feel more comfortable discussing their personal needs in Welsh. This is something which happens often.

Care location manager (Translation)

- 6.1 Unfortunately, the research revealed examples where a lack of Welsh language services has had a harmful effect on people. In one case, an individual had started to lose her grasp of English and spoke Welsh to staff even though they did not understand her. This caused great frustration to the individual:
 - I think that she gets very frustrated when we don't understand what she's trying to tell us, especially if she's in pain or upset about something. As staff, we've discussed not asking her to repeat everything in English because that makes her feel very frustrated. The staff who have been here since she moved in understand her needs well, but maybe some of the new staff can make her feel frustrated... When she came to us initially, she had lived in the area for a long time and she spoke English with us easily. But, lately and after her dementia progressed, she has started to speak a lot more Welsh with us.

Care location manager

- 6.2 In another case, a resident did not speak at all and staff were unaware that he was a Welsh speaker. Therefore, for a period, he did not talk to anyone until staff found out, by chance, that he was a Welsh speaker. It is difficult to imagine the experience of this individual and the pain of not being able to communicate with those around him even though he had a language of communication.
 - One of our residents, who is no longer with us, refused to talk to anyone so we thought he couldn't talk. Subsequently, one of the managers here, whose first language is Welsh, happened to say a few words of Welsh to the resident and he started talking to him straight away not in broken Welsh but fluent Welsh. He had dementia and he would only speak in Welsh. It was only by chance that we found out. Learning about this completely changed the way I think about the service and the opportunity to speak Welsh had a big impact on him.

Care location manager

- 6.3 In the IAITH study of Welsh Speakers' Experiences of Health and Social Care Services several respondents refer to the way in which language use can either agitate or placate an individual with dementia. One respondent, discussing the experience of his father who had been admitted to hospital and who had lost grasp of English completely, said that 'there were two people who spoke Welsh on the ward and when one of these happened to be on duty, he'd be quieter... It makes the condition a lot worse if you can't communicate in your first language. If there weren't any Welsh speakers on the shift, he used to be wild. He'd stare. His arms used to flay around... It's the last thing you learn which is the first to go with dementia.' 47
- 6.4 These examples and other sections of this report underline the fact that offering care in Welsh is a clinical need for Welsh speakers with dementia and that they have a right to receive such care. If care is not available to individuals in Welsh, it constitutes a weakness in the care delivered, which is harmful and impacts their care. More than just words states that 'ensuring the safety, dignity and respect of Welsh speakers is at the heart of providing health and social services in Welsh...it is also about improving the quality of care and meeting the language need of people and providing good public services that focus on the individual'.48 These examples do not focus on the needs of the individual nor do they ensure their dignity and respect. It can be interpreted, therefore, that these services which affect individuals' clinical care - be they public, private or voluntary - are not good services. At an all Wales level, therefore, it appears that dementia care for Welsh speakers is inadequate. This is unacceptable.



1. Full implementation of legislation and policies

1.1 Part 1 of this report demonstrates that legislation and policies already in place create favourable conditions for delivering care through the medium of Welsh to people living with dementia. Taken together, legislation and policies in favour of the Welsh language in care are relatively powerful. However, the findings in Part 2 of this report reveal gaps in the implementation of these policies and legislation leading to gaps in the care currently delivered to individuals living with dementia. These gaps represent a failure in care. We therefore conclude that these policies and legislation need to be implemented, reviewed and inspected more effectively and action taken in response to the findings. We also conclude that there is a need to promote the understanding of the clinical need of people with dementia to receive services in Welsh and that this right needs to be upheld through service planning, collaboration between agencies, and recruitment, education and training processes for professionals involved in the care package of people with dementia.

Recommendation 1

We ask the Assembly's Health, Social Care and Sport Committee to conduct a review of the extent to which the requirements of the Social Services and Well-being (Wales) Act 2014 are being implemented in relation to providing dementia care through the medium of Welsh and the extent to which the statement regarding the national well-being outcome 'I get care and support through the Welsh language if I need it'49 is being met in relation to dementia care. Specifically, the consideration given to the Welsh language in the following areas should be examined:

- assessments
- commissioning and delivering care
- individual care plans
- how local authorities and local health boards jointly assess the range and level of services required to meet the care and support needs of people in the local authority area.

Recommendation 2

We recommend that Care Inspectorate Wales and the Healthcare Inspectorate Wales recognise that a lack of Welsh language care for those who require it constitutes poor care which may have a harmful effect on people. The ability of providers to offer care in Welsh to people with dementia should constitute good practice and be a measure of the quality and safety of services. This should form part of their inspection work.

2. Develop a Welsh language dementia care pathway

2.1 The Welsh language, understanding of the impact of dementia on Welsh speakers and a recognition of the rights of Welsh speakers with dementia should be central to the vision of the Dementia Action Plan for Wales. Despite the commitments in current legislation, the research demonstrated that the Welsh language is often an 'additional' consideration in terms of dementia care. The Action Plan states that people living with dementia and their families and carers have said that a support system needs to be developed which is 'flexible – with services able to respond to an individual's needs rather than expect people to adapt to what exists already... and able to respond to the language and cultural needs of their population. 150 lt states the Welsh Government's commitment to 'develop a consistent clearly understood diagnosis, care and support pathway which incorporates standards of care and outcome measures'. The Plan also states the intention to 'develop multidisciplinary 'teams around the individual' which provide person-centred and coordinated care, support and treatment as needed.'51

Recommendation 3

We ask the Welsh Government, in implementing the *Dementia Action Plan for Wales*, to consider the extent to which the relevant targets set for health and social care services in *More than just words* have been met and the extent to which they facilitate efforts to offer Welsh language dementia provision. If they have not been met, steps should be taken to rectify this in order to facilitate implementation of the Action Plan and other recommendations made in this report.

Recommendation 4

We ask local authorities, health boards and the Welsh Government to work together to develop a Welsh language care pathway. This is a golden opportunity to ensure that the Welsh language is central to individuals' care pathways and that staff working with them and their families can respond to their language needs.

Recommendation 5

We ask the Welsh Government to produce a specific action plan to plan, develop and train Welsh medium care teams when developing the care pathway and multidisciplinary teams which form part of the Action Plan, in order to ensure that the care commitments made in the Social Services and Well-being (Wales) Act 2014 are fulfilled.

3. Collaborate to share resources and information

- 3.1 The *Dementia Action Plan for Wales* states that 'diagnostic tools must be available in a variety of languages, which are culturally appropriate, and in various formats to ensure that health boards can meet the needs of their population.'⁵² Specifically, in the context of the Welsh language, the commitment is made. We will work with stakeholders to identify and utilise the most robust clinically validated dementia assessment tool(s) for use in the Welsh language and commission research as necessary.'⁵³
- 3.2 This commitment is to be welcomed, of course, but it needs to go further and develop and maintain a national online platform providing quality Welsh language resources for dementia workers and carers. We know that a number of resources are available on the Mi-CYM⁵⁴ website and that some health boards refer to these resources, but there is inconsistency across Wales. Further work needs to be undertaken to ensure that standardised translations are available and that further assessments in the field of dementia care are validated. This is in addition to developing guidelines and training to conduct tests and assessments with Welsh speakers and collecting anonymized data to set the norms for Welsh speakers undertaking test. The Welsh Government needs to raise awareness of these resources and ensure that they are recognised by the different professions working with people with dementia, including psychiatrists and clinical psychologists. It must also be ensured that these tests are administered by people who can do so through the medium of Welsh.

Recommendation 6

As part of the commitment above to undertake further work on dementia assessment tools we ask the Welsh Government to work with local authorities and health boards in Wales to develop a national platform to share Welsh language tests as well as resources, expertise and information about dementia and the Welsh language. This will ensure that they are recognised by the different professions working with people with dementia and raise awareness of them amongst health and social care workers.

^{52.} Ibid., p. 16

^{53.} Ibid., p. 16.

^{54.} http://www.micym.org/llais/static/index.html

3.3 Participants in the round-table discussions also suggested that a national forum should be developed to enable dementia workers delivering care in Welsh to share information and support each other. Regional forums could contribute information to this national forum. It should be ensured that people living with dementia and their carers are prominent in these forums.

Recommendation 7

We ask the Welsh Government along with health boards and local authorities to develop national and local forums to share experiences of delivering care and volunteering in Welsh which would contribute experiences and information to the national platform mentioned above.

3.4 Even when language needs and choices are recorded by a specific service, difficulties were seen to arise when transferring this information between services. The Welsh Government should ensure that there are systems in place to record and transfer this information between agencies effectively. The Welsh Community Care Information System (WCCIS) and GP records are examples of such systems.⁵⁵

Recommendation 8

We ask the Welsh Government to put technology in place to ensure that information about patients' language choice and needs is recorded and that this information is transferred effectively between health and social care services.

3.5 Leadership is essential in this field and leaders in health and social care fields need to take professional responsibility for ensuring that awareness and understanding of the needs of people with dementia is disseminated and is fully considered when planning and providing services. The *Dementia Action Plan for Wales* refers to the Government's intention to create a new All Wales Dementia Allied Health Practitioner post. They will provide advice and support to health boards and local authorities to drive service improvement.

Recommendation 9

We ask the Welsh Government to ensure that the new Dementia Allied Health Practitioner post includes responsibility for providing advice and support on considerations relating to the Welsh language and dementia. This can include raising awareness of the importance of the active offer, in order to drive service improvement and raise awareness of the importance of the language of provision when delivering dementia care.

Recommendation 10

We ask the Welsh Government to ensure that the equivalent responsibility or post to the All Wales Dementia Allied Health Practitioner is created in the clinical field in order to provide clinical advice and leadership and support in relation to dementia and the Welsh language to health boards, local authorities, health professions and others, and to raise awareness of the importance of the language of provision and the active offer when delivering dementia care. This national leader could be responsible for developing the platform and national forums in recommendations 6 and 7 also.

4. Develop and raise the awareness of the workforce

4.1 The findings of the research demonstrate clearly that a lack of Welsh-speaking staff is the main barrier to offering Welsh services to people living with dementia. More than just words highlights that a lack of data on Welsh speakers within the workforce impedes not just workforce planning but also restricts the process of providing appropriate training and support to enable the workforce to develop their Welsh language skills. There are specific actions for NHS Wales Chief Executives and Directors of Social Services relating to collecting data and establishing language profiles of communities and the workforce⁵⁶ in order to plan Welsh language service provision and provide the active offer to individuals. Obtaining such data is crucial for workforce planning. In autumn 2018 Health Education and Improvement Wales will come into being and this body will have an important role in training and developing the Welsh health workforce.

Recommendation 11

We ask that the commitments made in *More than just words* relating to collecting data about the linguistic needs of the public and the language skills of the workforce be implemented fully and promptly in relation to delivering dementia services by local authorities and health boards. Based on this information Health Education and Improvement Wales, should cooperate and strategically plan with higher and further education establishments, the Coleg Cymraeg Cenedlaethol and health boards to commission places for Welsh speakers on relevant training courses and ensure that Welsh speakers are aware of the need for Welsh speaking health and social care workers and the opportunities open to them.

Recommendation 12

We recommend that Health Education and Improvement Wales should ensure that language awareness, an understanding of the impact of dementia on bilingual people; the fact that offering health and social care provision in Welsh is a clinical need for a number of Welsh speakers; the rights of Welsh speakers to receive services in Welsh, and the importance of the active offer are an integral part of the education and training of all health service professionals across Wales. This should be part of the initial training of health workers and part of their continuing professional development, and especially part of the training of leaders in these fields.

4.2 The Dementia Action Plan includes a commitment to 'reviewing and standardising the role of dementia support workers – increasing their numbers as required' and to develop 'teams around the individual'. Reviewing and standardising the role of dementia support workers and developing new teams offer an important opportunity to include Welsh language skills as a requirement for new posts in the field of dementia and to ensure that Welsh speakers enter the dementia care professions.

Recommendation 13

We recommend that workers' Welsh language skills are a key consideration when reviewing and standardising the role of dementia support workers and developing teams around the individual as part of the Dementia Action Plan.

Recommendation 14

We recommend that the Welsh Government should audit the extent to which understanding of the active offer; people's right to receive services in Welsh and the clinical need to do so, has filtered down and is being applied by workers involved in the care package of people with dementia and of leaders in the field. Based on this audit, plans should be made to raise awareness of these matters amongst these workers, e.g. by undertaking a specific campaign to raise awareness of dementia and the active offer.

4.3 Work is already underway to develop new Health and Social Care and Child Care qualifications for Wales and it is hoped that these new qualification will raise awareness of the importance of offering care in Welsh and the active offer as well as other cultural considerations. It should be ensured that it is possible for Welsh speakers to undertake these courses in full and that an adequate number of Welsh speakers do so. There is a joint project underway between the National Centre for Learning Welsh and Social Care Wales to develop the Welsh language skills of the current workforce. It must be ensured that these courses are available to all workers involved in the care package for people living with dementia.

Recommendation 15

As part of the Welsh Government's *Dementia Action Plan for Wales* and in light of the requirements that are and will be applicable to them in accordance with the Welsh language standards, health boards and local authorities should ensure that specialist Welsh learning provision is available for workers involved in the care package for people living with dementia, using the plans offered by the National Centre for Learning Welsh for example. Where possible, relevant health and social care workers from all professions should be released for extended periods to develop linguistic skills that will enable them to provide dementia care through the medium of Welsh.

4.4 As well as these recommendations made jointly by Alzheimer's Society Cymru and the Welsh Language Commissioner, we believe that full consideration should be given to implementing the recommendations made in the research briefing prepared by Dr Catrin Hedd Jones for the National Assembly for Wales' Research Service.⁵⁷ Many of these recommendations complement the recommendations made in this report.

Catrin Hedd Jones, Research Briefing Access to dementia services for bilingual (Welsh and English)
residents, National Assembly for Wales.
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Appendix 1

Round-table members

Beti George, person affected by dementia and broadcaster
Sue Phelps, Alzheimer's Society Cymru
Meri Huws, Welsh Language Commissioner
Conor Martin, Betsi Cadwaladr Health Board
Catrin Hedd Jones, Bangor University
Gwerfyl Roberts, Independent Consultant
Rachel Rahman, Aberystwyth University
Emma Harris-Jones, Dementia Support Worker, Alzheimer's Society
Cymru
Eirlys Rowlands, person affected by dementia
Marc Roberts, Care Inspectorate Wales
Meilyr Emrys, Betsi Cadwaladr Health Board
Anke Cupok, Royal College of Psychiatrists
Julia Rose Kramer, Royal College of Psychiatrists
Sandie Grieve, Social Care Wales

Officers

Morgan Griffith-David, Alzheimer's Society Cymru Sophie Douglas, Alzheimer's Society Cymru Steffan Bryn, Welsh Language Commissioner Dyfan Sion, Welsh Language Commissioner Lowri Williams, Welsh Language Commissioner

Notes	





Comisiynydd y Gymraeg Welsh Language Commissioner

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