Cynulliad Cenedlaethol Cymru
Y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
National Assembly for Wales
Health, Social Care and Sport Committee

Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr

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

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C01

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr

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

Ymateb gan Unigolyn

Response from an individual

To whom it may concern.

My name is [redacted], I live in [redacted].
I noticed a short section in Thursday's South Wales Argus regarding an inquiry into support for carers in Wales.
I myself was a carer for both my parents (who had Alzheimer's and vascular Dementia) for five years up until March of this year.
I took voluntary redundancy in June 2015 to care for my Mother full time as I did not want her to go into a home.
I am a member of the Alzheimers Society and the carers group Wales.
I strongly believe family carers are undervalued and that without them NHS Wales and Social services would be in an even bigger crisis.
I had carers to help my parents through the day, but no help from Social Services in the nights. Any breaks I had was paid for privately or was reliant on my brother travelling from London to give me a short break.
I am in my fifties and fairly fit but some days and nights I felt totally drained and frustrated. I do not know how older people cope.
I believe the carers allowance should at least be equal to those claiming unemployment benefit.
I also believe there should be more help provided for night care for those in most need.
I know that if I had not had these breaks and a good family to support me I would not have been able to care for my parents in their home environment.
Although I am no longer caring for my parents who have both passed on, I still feel strongly that family carers are undervalued and need more support financially and physically.
A short break re energises you and is good for both the carer and the person who is being cared for!
I would be willing for this e mail to be used in the Senedd during the enquiring.

Regards

[redacted]

C02

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr

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

Ymateb gan Unigolyn

Response from an individual

I like to think that I am a pretty strong person and I cope with pressure reasonably well. I do a lot of Voluntary Work with my three Therapy Dogs visiting School, Hospital and ironically Care Homes.

I am very, very fortunate to live in a beautiful part of the world and I don't have to venture far to get to a beautiful place to spend time with my dogs on my own.

[redacted]. *She is probably the only one who would ever see the emotional impact that all this has on me.*

I have lovely neighbours who are very supportive.

However I find that the time I can leave mum is getting shorter and shorter. There is no way that you could ask neighbours or even friends to deal with some of the personal issues for my mum that I have had to deal with over the last few months. I would never have believed that I could deal with them but I HAVE to, I have no choice.

The sad thing is that whilst one tries not to let it, inevitably it affects the Mother/Daughter relationship. Some people can be Carers unfortunately I am not one of those I do it because I have no choice.

BUT I WANT TO BE A DAUGHTER TO MY MUM NOT HER CARER. We have always been very close and I sincerely hope we will remain that way but all of this does have an impact.

At the moment I do feel very constrained.

I take the dogs out and am care free for all of about an hour and then the worry kicks in.

I can no longer take a job as I fear I may be called home. It is not fair on employers. I like to do seasonal work it means I can fund my volunteering in school term and have a bit extra.

I have had to cash in some of my savings to supplement my pension.

My last holiday was in 2010 for my [redacted] birthday. Even then there was the constant fear that something might happen at home.

I am now contemplating selling Mums home (which as previously stated I own) to fund her going into a Care Home. This is a major decision as that house is a security blanket in different ways for both me and my Mum.

I have been told that Respite Care is no longer an option offered by Social Services but the Crossroads Organisation seem to think that is not the case. I wish someone had told me about the provision that Social Services had made after Mums hospitalisation in 2014!!!

I was in receipt of carers allowance but am no longer. In 2016 Mum went from paying no Council Tax to Full Council tax (minus 25% reduction for Single Occupancy) we found out that was due to the fact that owing to her long stay in hospital the balance of her Bank Account went over the threshold where she was eligible receive free Council Tax. On seeking advice from CAB we found that if I gave up my Carers Allowance Mum could get Pension Credit (savings) and therefore would qualify for the Council Tax reduction. I was lucky to be able to do this for my Mum and more than willing to do so, however that Carers Allowance was a big help whilst I had it.

I do not feel that either my Mum or myself has had the best of services from the relevant Care Providers. I hope that my experience helps give you an insight from our prospective. I would like to think that we have been unfortunate and slipped through the “gaps” as it were but I suspect that there are many more like us. I also fear that there are many elderly people who are totally on their own with no one able to speak or fight for them and that is a very scary and sad thought. If this goes someway to help others in the future it was worth sending. If anyone would like to discuss things further with me I am more than willing to help. Thank you for taking the time to read this.

Annexe 1: SS Letter

[redacted]

[redacted] [redacted]

Subject – Provision of Care for Elderly

Dear Sir,

I am Carer for my elderly mother who is 90 years of age, she will be 91 [redacted]. My mum lives independently across the road from me and has done for the past 16 years since she moved here when my father passed away. The move was made so that Mum would be close to me in her old age should she need help. This would not have been so easy had she [redacted] where she lived for over 30 years. Over the first 12 years we have been a support for each other and have managed without any help apart from two periods of 6-Week Reablement Care Packages following lengthy hospital stays, detailed below. Even though Mum became much more frail following both of those hospital stays we were able to manage without Carers once the package of care ceased.

In essence **we have never asked for any help**.

We hoped therefore that when we needed it we would be able to access it.

Apparently, that is not the case!

On [redacted] [redacted] [redacted] Mum was admitted to [redacted] having passed out whilst washing herself in the bathroom of her home and hitting her head on the radiator valve causing a nasty gash to her head. Mum remained in hospital for two weeks. To date no cause of her collapse has been identified and the head injury after scans and observations was not deemed to be serious. This incident had been preceded by several weeks of general ill health, feeling unwell with a dizzy head, blurred vision and feeling nauseous. The Dr had attended the house on several occasions, but no cause was identified. It is true to say that this has been an ongoing problem for some 5 years now. At times, as on this occasion, the situation was worse than usual.

On [redacted] [redacted] [redacted] Mum was discharged from hospital. She was assessed by Occupational Health and because she had demonstrated her ability to wash herself in the presence of staff, even though on their admission it took rather a long time, she was released without any support whatsoever. Despite my efforts to find out when she was going to be assessed by Social Services following **a referral** [redacted] it never happened.

Whilst in hospital my Mum, very bravely came to the decision that she felt it was time that she went into a home, it is still her wish to do that. We now know it is not that simple!

<u>In summary: -</u>

- My mother is 90 soon to be 91.
- She has had an operation for a Melanoma Tumour which has left her with eye problems and bad heads, due to nerve damage following her operation to stabilise the Tumour.
- She often suffers with Nausea.
- She has had High Blood Pressure for many years.
- She has bad heads which make her feel very dizzy and unwell to varying degrees.
- She has Diverticulitis and Irritable Bowel – resulting NOW in uncontrollable diarrhoea for which she has no warning and is unable to cope with her own.
- The above bouts leave her feeling weak and sometimes near collapse.
- She has had two long periods in hospital – in 2014/15 she spent 6 months in [redacted]. In 2016 she spent 5 weeks [redacted].
- She is short of breath because of her age and very easily gets exhausted.
- She is unable to shower confidently without a supervisory presence.
- She has now had a fall resulting in a head injury.
- She has fallen on previous occasions when an ambulance has been called.
- She is unable to walk unaided and uses a Trolley indoors and a walker outdoors. However even outdoors with the aid she needs a supporting arm. She cannot walk far at all.
- She has started to get quite forgetful of late but no more (until her accident) than you would expect of a 90-year-old.
- NOW her memory since her fall seems to have deteriorated to a noticeable degree to me and indeed to her.
- The Doctors have been called regularly over the last few months but seem unable to give any help and therefore we have to carry on as best we can.
- Mum is Socially isolated. She is afraid to go out because of her bouts of incontinence which come with no warning or control.
- Mum suffers from extreme anxiety and worries over every little thing. This does not help all the above.
- Her confidence is rock bottom.

On [redacted] I spoke to one of your Social Workers [redacted] it was not a very productive conversation as I was extremely anxious, emotional and frustrated following a meeting with the discharge team at the hospital who informed me that my Mum would be coming home without any Support OR indeed even a Social Service Assessment. My frustrations turned to anger, for which I have apologised to the gentleman concerned, however it did not help when he told me that Mum wasn't entitled to an assessment or any help: -

- **Because we did not have Carers prior to her hospital admission.**

We haven't had any help because we thought we were doing the right thing by managing by ourselves. We did so in the mistaken belief that when we needed help we would be able to access it!
Again, apparently not the case.

In addition to which I was informed, [redacted] that after her previous stay in hospital a provision for Emergency Respite Care had been put in place should either of us need it.
NOBODY EVER TOLD US THAT!
About 20 minutes after I spoke to [redacted] [redacted] rang me back to say that my Mum could have an assessment, but it would take at least 6 weeks for this to happen.

Carers are wonderful BUT:-

- What are the chances they will be with Mum when she has a dizzy turn?
- What are the chances they will be with Mum falls?
- What are the chances they will be with Mum when she has a bout of Diarrhoea?
- The chances of me being around when Mum has any of these episodes are more likely BUT I have to attend to things in my life and do all the practical stuff for Mum like shopping etc and chances are I won't be around.

I am not the issue here, my Mothers safety is utmost in my concern, but my circumstances are:-

1. I am a [redacted], I have been since [redacted]
2. I worked [redacted] after my retirement [redacted] [redacted] when due to my Mums health I finished completely. I didn't feel it fair to be called away from work as happened on several occasions.
3. I have taken on Casual and Seasonal Work which I love but that has not happened for the last 2 years for reasons as at 2.
4. [redacted].
5. [redacted].
6. [redacted].
7. My support comes from close friends and neighbours but there is a limit to what you can ask of them.

8. I remain very busy Volunteering [redacted], [redacted] [redacted]. As a Volunteer cancelling meetings and appointments doesn't matter quite so much but nevertheless is not ideal.
9. Most importantly of all **_*I WANT TO BE A DAUGHTER TO MY MUM I DON'T WANT TO BE HER CARER.*_**
10. I find it very difficult doing her personal care, I don't want to do it and she doesn't want me to have to do it.
11. I have Lasting Power of Attorney for Mum in relation to both Health and Finance.
12. Because of my commitment to Mum I don't go away on holidays any more, fortunately I am happy in [redacted] which offers the Walks and Beaches that I love.
13. I last went on holiday [redacted] for my [redacted] birthday at my Mums insistence however as nice as it was there being always the fear that something will happen whilst I am away.

Please can you advise me what we do from here?
We have tried our utmost to cope without any help up until now. We are very close and always have been which helps tremendously but I say again I WANT TO BE A DAUGHTER TO MY MUM NOT HER CARER AND IT WORKS THE OTHER WAY TOO.
I feel at the very least my Mum deserves Carers to help her in the mornings for which we are now paying privately. Assessing her whilst in hospital in a controlled environment when she was well was assessing her at her **BEST, surely the need is to look at her at her WORST**. Someone needs to speak to ME in relation to the whole picture not just what she was like in hospital. Mum is of a generation if someone in "authority" asks her to do something she will do her utmost to do it even at her age which is what happened on the day she was asked to wash herself. She told me she was exhausted afterwards. Also, she will never complain or moan and say she can't do something.

[redacted]

Not until the afternoon of the day before she was discharged from hospital did anyone speak to me or responded to my requests to speak to someone who I could give some history to! That discharge meeting had a lot of awkward silences in it when I outlined the whole scenario.

CURRENT SITUATION

- My Mum after [redacted], spent all of [redacted] [redacted] [redacted] in bed as she was feeling unwell. She was adamant she didn't wish me to call a doctor or stay the night.
- On [redacted] [redacted] [redacted] I receive a call from my Mum she had had a very bad diarrhoea attack and needed help to clean up the house and herself. This left her exhausted.
- We have now taken on a Private Care Agency to help mum wash and shower 5 days a week.

- I am cooking meals and taking them over to her, as well as doing all the practical things I have always done.

I now have the same situation we were in before her fall just three weeks ago which was an accident waiting to happen. Whilst I understand Social Services advocate it is better for people to remain in their own home as long as possible, we have kept ourselves out of the system until now, we have done our best to manage without help and now when we need help I am having to fight for it.
My Mum and I, NOW feel she needs to be somewhere she is taken care of 24/7 for her physical, emotional wellbeing and most important of all for HER SAFETY.
She does not have the finances to pay for this privately. She does not own the property in which she now lives and although she has savings they are nowhere near the threshold that would necessitate her paying for her care.

IF it is deemed that she in not suitable/able to go into a home THE VERY LEAST she deserves an assessment AND carers in the morning to help her wash/shower. We know that has to be paid for in part, but it will not be the [redacted] a day we are paying now. My Mum and Dad worked hard all their lives and paid into a system in the belief that they would be looked after in their old age, both worked well passed their retirement age.
My Mum NOW deserves help and she NEEDS, not in 6 weeks and however long after that we have to wait for a decision. She needs it as soon as is possible and SHOULD have had it from her discharge from hospital.
I will have to manage the rest as best I can whilst still carrying on with my life. IF the worst comes to the worse at least I will know that **I tried my best for her.**
Thank you for taking the time to read this letter. I look forward to receiving a reply within the next 7 days.

Your Sincerely

[redacted]

C03

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr

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

Ymateb gan Unigolyn

Response from an individual

Good Morning,

I am unsure if my views are relevant to this consultation.

My 4 year old son was diagnosed with Autism in [redacted] 2018, and overnight I was defined as his mother and carer.

It was a term that didn't really affect me one way or the other. As his mother it is my main priority to make sure he accesses the best possible services, education etc that he possibly can. It is also imperative to me that we lead a happy and 'normal' life as much as possible.

Being a mother to two young sons is demanding as it is for many parents. This is my normality I don't have experience of motherhood without autism so I have nothing to compare my experience against.

What I wanted to share today was the demands and affects that being a parent and carer can have. All carers are defined as 'carers' yet we all varying responsibilities and we all have different emotional attachments to those we care for.

I don't mind sharing with you that having a son with autism has been tough. Although it is my normality, life is still difficult. I would not change him for the world and he is an incredible little boy, but his condition has take a toll on my mental health, my marriage, my family and my work. But despite this I still have to care for him and his brother, who is also showing significant signs of autism, I have to work 28 hours a week, and look for extra employment to support the home, and attend the weekly appointments , and deal with my severe anxiety.

I don't know if parent carers are overlooked slightly. Because it is expected for me to care for my son as a mother, the caring element is overlooked. But I have more demands placed on me as a parent than perhaps other parents do.

The endless battles to get the right services provided for my son, the constant appointments, the form filling etc. Then there is the home life to contend with. My son is non verbal at 4 years old. I have to accept the fact that he may never talk and I will need to be his voice. I have to deal with meltdowns that can last all day. My sons sensory needs are incredibly demanding and normal life is thrown out of the window. A 4 hour meltdown because he can't tolerate sun cream on his face. The sleepless nights, the smearing of faeces, running into the road, the list is endless.

I work for a charity and I know there is considerable support out there for carers. But you have to look and search for it. The Carers Project [redacted] have been great and given me access to discounted leisure facilities. I can't access support groups because my time is so stretched and respite is not an option for my son.

Although I have been in touch with social services - I was deemed to be 'managing' and wasn't offered a carers assessment - although I'm not sure I would be entitled to one.

Many areas of my life and my family's life is dictated to by autism. My mental health has suffered to such an extent that I am now needing to take medication to control my anxiety so that I can continue to care for my son and potentially my younger son if he also gets diagnosed with autism.

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

My suggestions would be:
-A specific carers assessment for parents.
-An acknowledgment that parent carers have significant additional responsibilities.
-Carers Allowance should be offered to all parent carers - currently parents can only apply for this benefit if they earn under £150 a week. This is an incredibly low threshold when most families need to earn more than this to survive. I provide daily care for my son well over 35 hours a week, but because I earn more I'm not entitled to it. This benefit would prevent me from having to work additional hours and be there for my sons who both have demanding needs.

I hope my above ' ramblings' make sense, please contact me if you need me to clarify anything.

Many Thanks
[redacted]

C04

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr

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

Ymateb gan Unigolyn

Response from an individual

I was diagnosed with Parkinson's 20 years ago and about the same time my Wife was diagnosed with depression . From which she suffered on and off until her death in January 201 8 from multiple organ failure, resulting from chronic alcoholism. I feel that she was badly served by the mental health services who failed to address her problems of coping with my PD. Part of the problem was that people Would offer me sympathy but leave her to' get on with it'. Not realising that things were in fact worse for her. Having to look after both of us

Since 2004, I have been involved with Parkinson U.K, being PARKINSONS champion from 2010-5 and a member of Ceredigion Carers Alliance and the Red Cross Carers support Group. I feel that these experiences Give me a unique insight into the problems experienced by unpaid Carers and their families .

Yours sincerely

[redacted]

C05
Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Unigolyn
Response from an individual

Hello,

I received an email via the North Wales Cancer Forum containing the information leaflet regarding How much support is there for carers in Wales?

I thought I would send a short example of my own experience as a carer for an autistic adult as I believe that support for autistic young adults has been non-existent for many years. I am aware that work is being done to rectify this, with a self-referral centre based in [redacted]. I have only recently received information via my GP about this service so I'm not sure of the extent of their support.

During the many years that I lived i[redacted] and two years that I lived[redacted] , I repeatedly asked for help with my 18-21 year autistic son who was experiencing severe mental health problems. I received two separate letters telling me that 'there is no support for autistic adults in North Wales'. Every time I asked for help I found none. Thankfully I have now moved to a house that has the right environment for my son and most of the time we are coping well. We were near to break[redacted]oint while in and I feared for my son's life. My G.P. was supportive and caring, but there was only so much he could do.

I hope my information might urge your committee to assess the support for young autistic adults in North Wales.

Regards
[redacted]

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Y Gymdeithas Genedlaethol i Blant Byddar
Response from The National Deaf Children's Society

Dear Sir/Madam,

I am responding from the National Deaf Children's Society Cymru to the consultation on the Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers.

If you are able to send me confirmation of receipt of this response, that will be appreciated.

Our Response

Parents/ Carers of deaf children and young people in Wales should be provided access to a broad range of freely available and readily accessible British Sign Language (BSL) learning opportunities to allow them to communicate with, and fully support their deaf child's social, emotional and mental health and development.

Courses are hard to find and learning BSL can be expensive. Furthermore, the Children's Commissioner for Wales' highlights the difficulties parents have accessing BSL which include "prohibitive costs, a lack of childcare, and a lack of support or suitable informal BSL learning opportunities such as support groups as key barriers to access to BSL." (2017, p20) and continues to make recommendations for "accessible and affordable BSL learning opportunities at a range of levels" (2017, p20).

Reference List:

The Children's Commissioner for Wales (2017) A Year of Change 2016-17: Annual Report & Accounts. Available at: https://www.childcomwales.org.uk/wp-content/uploads/2017/10/A-Year-of-Change-CCFW-Annual-Report.pdf (Accessed: 6th August 2018).

About us

The National Deaf Children's Society Cymru is the national charity dedicated to creating a world without barriers for deaf children and young people. We represent the interests and campaign for the rights of all deaf children and young people from birth until they reach independence. In referring to deaf, we refer to all levels of hearing loss including mild to profound, unilateral and temporary.

Thank you/ Diolch yn fawr

Regards/ Cofion

[redacted]

[redacted]

[redacted]

The National Deaf Children's Society/ Y Gymdeithas Genedlaethol i Blant Byddar

C07
Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan unigolyn
Response from an individual

Hello

I would like to convey my experience in relation to the sswb act and social care.

An unpaid carer of 20 plus years of experience in caring and dementia. I am an activist and a constant mature student in developing my knowledge in relation to dementia and the legislation that is supposed to support us. I have contributed to many focus groups offering real life experience of caring and dementia. I have previously emailed the committee and got no reply.

I am a trained trainer assessor..and volunteer with hundreds of persons living with and affected by dementia. I contributed to the consultation on the dementia action plan.

And attend the cross party on dementia.

I have been caring for my dad for the last 9 yrs..

What is obvious to me is that there s a huge lack of understanding about the act.

During the carers assembly at th hywel attended by carers like myself there was an overwhelming feeling that carers rights and their relatives or friends rights in relation to sswb act in social care. The director admitted that he has recommended a second phase of learning.

In the name of the act we have been refused help to learn to use my dad's hoist. Leaving him in danger...I was refused support to study to enable me to care for my dad's complex needs.

I have had 10 days off in 9yrs...and as my dad requires two carers only one can receive carers allowance..I've requested support to have an overdue holiday in the UK..

Which absolutely will increase my wellbeing..and been told "we ve never heard of that..direct payments is only for care" my manager has never heard of this.

In the name of the act we ve been refused help to toilet my dad..when one of us needs to attend an appointment or go to pay bills etc do food shopping.

Told that within [redacted] that people are being told to stay in their chairs and wait or make them wear pads and wee..until a carer or visitor comes.

This a breach of their human rights 70/169? Relating to access to physically use sanitation..they acknowledge they are breaching their human rights but that's what they ve been told to do.

I showed the social worker nhs guidelines on sswb act for unpaid carers. He said we ve never seen that or told that.

After 10 yrs .everything I've requested that the sswb act can do for me..as identified in a carers assessment..has been refused saying..

I didn't know the act was for that. That's not what we ve been told and we can't help with that. Speak to my manager and she s never heard of that.

I am thoroughly ashamed having already informed the the committee of such appauling lack of understanding of the sswb act that is being upheld by senior management .and directors that are part of their partnership board.

I ask kindly that on this occasion that you listen..

And should you require more information please contact me.

I 'll gladly address you health wellbeing and sports committee. Real life experience.

It's the people that have no support to offer their opinion and voice that concerns me.

I am appalled that the land of my father's.. that aims to be the first dementia friendly nation..

Allows raf veterans to be treated in such a way that s due to a lack of understanding of an act that should be helping us.

A thorough investigation should be conducted..as it's no less than neglect and institutional abuse..

In the hope that this will be acknowledged.

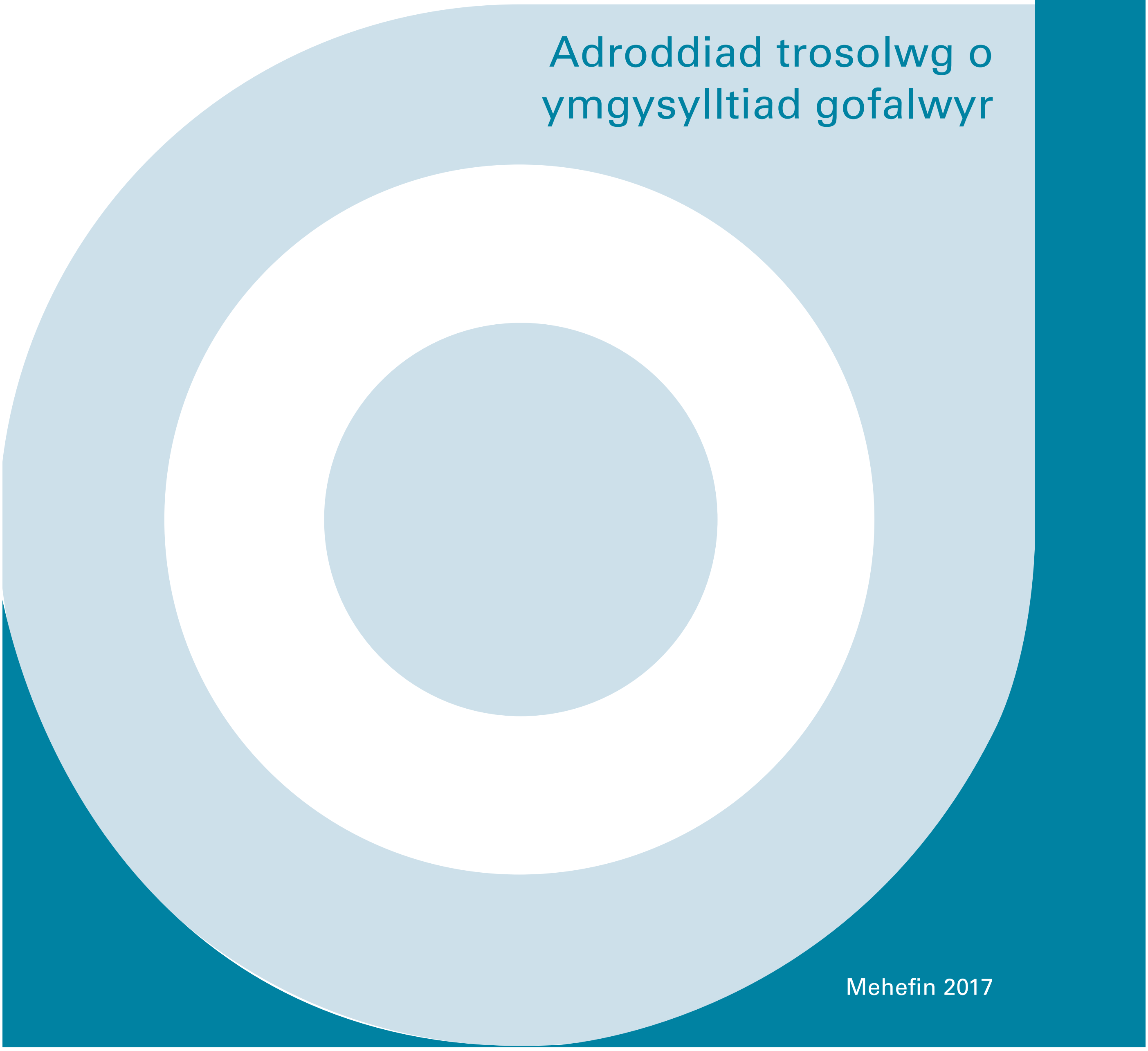
[redacted]

C 8
Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Arolygiaeth Gofal Cymru
Response from Care Inspectorate Wales

AGGCC
CSSIW
Arolygiaeth Gofal a Gwasanaethau Cymdeithasol Cymru
Care and Social Services Inspectorate Wales

Wrth gefnogi *gofalwyr*

Adroddiad trosolwg o ymgysylltiad gofalwyr



Mehefin 2017

Rhagair

Gan [redacted], aelod o Fwrdd Cynghori Cenedlaethol AGGCC a Chadeirydd Ein Llais Gogledd

Bydd y rhan fwyaf o bobl rywbryd yn eu bywydau yn dod yn ofalwr i aelod o'r teulu, nid yw'n rhywbeth y byddwn ni'n cynllunio ar ei gyfer neu'n rôl rydyn ni ei heisiau'n weithredol, ond rydyn ni'n dod yn ofalwr oherwydd ein bod yn caru'r person ac eisiau eu helpu cymaint ag y gallwn. Yn ystod fy oes mae cymdeithas wedi newid yn aruthrol ac mae teuluoedd yn aml yn llai a mwy gwasgaredig, mae'r boblogaeth yn heneiddio a gyda'r rhan fwyaf o fenywod yn cymryd y swydd ofalu, pan ddaw, gall achosi brwydr go iawn i nifer o deuluoedd.

Mae'r Ddeddf Gwasanaethau Cymdeithasol a Llesiant (SSWBA) yn cydnabod y pwysau mae gofalu'n ei roi ar unigolion a theuluoedd a gobeithio ei fod wedi dechrau newid cymdeithasol i gydnabod cyfraniad economaidd hollbwysig gofalwyr teuluol a rhoi pwysau ar Awdurdodau Lleol i ystyried a diwallu eu hanghenion, nid fel ôl-ystyriaeth ond fel hawl. Mae'n bwysig iawn bod yr aelodau etholedig mewn awdurdodau lleol yn cyflawni eu rôl o ran cynnal ysbryd y ddeddf hon, gan drin gofalwyr fel partneriaid cyfartal yn y rôl maen nhw'n ymgymryd â hi a sicrhau bod gwybodaeth a chymorth ar gael iddynt fel hawl, nid yn unig pan fydd teulu mewn argyfwng sydd yn draddodiadol wedi bod yn wir.

Fel rhiant i fab anabl iawn rwyf wedi bod yn ofalwr am nifer o flynyddoedd a byddaf yn parhau i ofalu am weddill fy mywyd. Rwyf wedi gofalu am rieni oedrannus, ac aelodau eraill oedrannus o'r teulu tan eu marwolaeth. Nid wyf yn sant, cymerais y rôl fel mae'n digwydd, ond wrth i mi gyrraedd oedran ymddeol, cefais fy ngorfodi i chwilio am gefnogaeth ar gyfer fy mab sydd angen mwy o symbyliad a gofal na'r hyn roeddwn i'n gallu eu cynnig am nad oedd gen i ddigon o egni. Ond pam, ddeng mlynedd wedyn, mod i'n dal i deimlo'n euog am orfod cymryd y cam hwnnw, gorfod cyfaddef nad oeddwn i'n ymdopi bellach fel ag yr oeddwn cyn hynny.

Gobeithio bydd y SSWBA yn cefnogi gofalwyr yn gynharach, yn gwneud beth sy'n iawn i bobl sydd angen mwy o ofal a chymorth nag y gall aelod o'r teulu eu rhoi. Mae angen i ofalwyr deimlo'n ddiogel wrth rannu gofal aelod o'u teulu, mae angen dull partneriaeth sy'n sicrhau fod y canlyniad gorau posibl mewn bywyd yn cael ei gyflawni ar gyfer y rhai sy'n derbyn gofal, a thrwy hynny, rhoi'r cyfle i mi a nifer fel fi i fod yn Fam neu'n Nain neu'n ferch wirioneddol.

Yn fy rôl fel Cadeirydd grŵp Gogledd Cymru Ein Llais, byddaf yn codi'r cwestiwn lawer gwaith "Ydy gofalwyr yn cael y cymorth maen nhw'n ei haeddu? Os na, pam felly?" Rhaid i arolygwyr AGGCC, drwy eu harolygiadau sicrhau nid yn unig bod y gwasanaethau mae pobl yn eu derbyn o ansawdd uchel, ond bod ethos SSWBA fel mae'n ymwneud â gofalwyr yn cael ei gynnal. Bydd angen i AGGCC weithio'n agos gyda Chyfarwyddwyr Gwasanaethau Cymdeithasol a phrif swyddogion cyngor i godi proffil hawliau gofalwyr, i sicrhau eu bod yn deall y rôl hynod anodd a gwerthfawr mae gofalwyr yn ei darparu yn y byd heddiw ac yn eu cefnogi yn unol â'u hawl pan fyddant angen y cymorth hwnnw.

Crynodeb

- Wrth drawsnewid gwasanaethau yn unol â'r Ddeddf Gwasanaethau Cymdeithasol a Llesiant, nid yw cefnogaeth i ofalwyr wedi bod yn cael blaenoriaeth o ran cynllunio a chyflawni ar gyfer awdurdodau lleol a'u partneriaid.
- Mae gan y rhan fwyaf o awdurdodau lleol strategaethau ar gyfer gofalwyr ar waith ond nid yw'r rhain wedi cael eu hadolygu i adlewyrchu newidiadau o dan y SSWBA.
- Ceir enghreifftiau o arfer cadarnhaol ac arloesol ledled Cymru a fyddai'n elwa o'i ledaenu yn fwy eang.
- Mae cyllid ar gyfer gwasanaethau i ofalwyr yn parhau i fod yn gyllid tymor byr i raddau helaeth.
- Nid yw gofalwyr yn cael cynnig asesiad o'u hanghenion fel mater o drefn nac yn cael gwybodaeth, cyngor neu gymorth .
- Mae ystod eang o wybodaeth ar gael ond weithiau mae angen i ofalwyr fynd i sawl man i gael hyn ac nid yw hyn bob amser yn hygyrch, yn enwedig ar adegau o argyfwng.
- Rydym wedi nodi dau fath o ofalwyr lle mae'r diffyg mwyaf o ran cymorth. Y rhain oedd gofalwyr sy'n rhieni i blant gydag anghenion cymhleth a gofalwyr i oedolion gydag anghenion iechyd meddwl.

Cefndir

Yn 2016 newidiodd Arolygiaeth Gofal a Gwasanaethau Cymdeithasol Cymru (AGGCC) ei ddull o werthuso perfformiad awdurdodau lleol yng ngoleuni Deddf Gwasanaethau Cymdeithasol a Llesiant 2014 (SSWBA). Roedd y newid hwn yn cynnwys mwy o ymgysylltu gyda phobl sydd ag anghenion gofal cymdeithasol a gyda'u gofalwyr. Ar gyfer 2016/17 cytunwyd y byddai gweithgarwch ymgysylltu'r AGGCC ar draws y 22 awdurdod lleol yng Nghymru yn canolbwyntio ar brofiad y gofalwyr. Arweiniwyd y gwaith hwn gan Reolwyr Ardal AGGCC.

Pam gofalwyr?

Yn 2015, cynhaliwyd y Cynulliad Gofalwyr cyntaf yng Nghymru[1] a bu i hyn nodi nifer o themâu gan gynnwys:

- Hawliau ac asesu.
- Darparu gwybodaethn.
- Gofal seibiant a thoriadau.
- Gwaith ac arian.

Hefyd, nododd AGGCC fod llawer o'r adroddiadau blynyddol a gynhyrchir gan gyfarwyddwyr Gwasanaethau Cymdeithasol ledled Cymru yn dweud ychydig yn unig ynghylch y cymorth ar gyfer gofalwyr. Arweiniodd hyn yr AGGCC i nodi'r angen i ddeall mwy am brofiad gofalwyr ledled Cymru.

Y Ddeddf Gwasanaethau Cymdeithasol a Llesiant fel y mae'n berthnasol i ofalwyr

Mae'r SSWBA yn ehangu'r diffiniad o ofalwyr drwy ddileu'r cyfeiriad at lefelau gofalu 'rheolaidd a sylweddol' a chynyddu'r pwyslais ar atal a llesiant fel pethau pwysig i ofalwyr. Mae'r Ddeddf yn cynnwys dyletswydd i ymgynghori â gofalwyr cyn belled ag sy'n ymarferol yn asesiad yr unigolyn sy'n derbyn gofal ac yn rhoi cyfle i gynnal asesiad gofalwr a'r person sy'n derbyn gofal ar y cyd.

Mewn perthynas â'r asesiad o anghenion gofalwyr, nid oes rhaid i ofalwyr 'wneud cais' am asesiad bellach; mae'n rhaid cynnig hwn a chynnwys p'un a yw'r gofalwr yn gallu neu'n fodlon parhau yn eu rôl gofalu. Dylai'r asesiad hefyd gytuno ar y canlyniadau mae'r gofalwr yn dymuno eu cyflawni mewn bywyd o ddydd i ddydd, p'un a yw'r gofalwr yn gweithio neu'n dymuno (a/neu) gymryd rhan mewn addysg, hyfforddiant neu hamdden.

Bellach, mae dyletswydd ar awdurdodau lleol i ddarparu cymorth i ofalwyr ac mae'n rhaid iddo hefyd ystyried p'un a fyddai'r gofalwr yn elwa o wasanaeth ataliol neu wybodaeth, cyngor a chymorth. Pan asesir fod gan ofalwr anghenion cymwys, rhaid i'r cyngor roi cynllun cymorth ar waith sy'n canolbwyntio ar y canlyniadau mae'r gofalwr yn dymuno eu cyflawni.

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[1] https://gofalcymdeithasol.cymru/hub/hub-resource-sub-categories/gofalwyr-ar-ddeddf

Beth wnaethom ni

Mynychodd Rheolwyr Ardal AGGCC fforymau a digwyddiadau a drefnwyd yn lleol i gefnogi gofalwyr a chynnal cyfweliadau ffôn gyda gofalwyr fel y gallem glywed am eu profiad. Edrychom ar strategaethau gofalwyr a chyfweld swyddogion allweddol ac Aelodau'r Cyngor oedd yn hyrwyddwyr i ofalwyr, a hefyd fe wnaethom gyfarfod â phartneriaid allweddol ac ystyried dogfennau ganddynt gan gynnwys darparwyr gwasanaethau sy'n cefnogi gofalwyr, arweinwyr y bwrdd iechyd ar ofalwyr a phennaeth cydweithio rhanbarthol ar gyfer gofalwyr.

Roedd tua 400 o ofalwyr yn rhan o'r gwaith hwn, ac roedd hyn yn cynnwys gofalwyr ifanc, gofalwyr sy'n rhieni a gofalwyr i oedolion ag anghenion gofal cymdeithasol.

Yn ogystal â hyn, bu i ni gwrdd â Gofalwyr Cymru a thrafod y canfyddiadau oedd yn dod i'r amlwg o'u gwaith ar 'Olrhain y Ddeddf' ac adborth ac roedden nhw wedi'i dderbyn gan ofalwyr a sefydliadau gofalwyr.[2]

Cytunwyd ar bedwar prif lwybr ymholi oedd yn gysylltiedig â'r fframwaith canlyniadau cenedlaethol a'r safonau ansawdd ar gyfer awdurdodau lleol. Y canlyniadau y bu i AGGCC ganolbwyntio arnyn nhw oedd:

- Bod gofalwyr yn derbyn y gefnogaeth maen nhw ei angen .
- Bod gofalwyr yn gwybod beth yw eu hawliau ac yn deall y cymorth sydd ar gael iddynt .
- Bod gofalwyr yn bartneriaid cyfartal ac yn teimlo eu bod yn cael eu cefnogi a'u gwerthfawrogi am y gofal a roddant.
- Bod y weledigaeth ar gyfer cefnogaeth i ofalwyr yn cydnabod eu cyfraniad economaidd a'i bod yn glir ynghylch y canlyniadau a fwriedir.

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[2] www.carersuk.org/wales/news-campaigns/track-the-act/track-the-act-survey-findings

Ein canfyddiadau

Canlyniad: Bod gofalwyr yn derbyn y gefnogaeth maen nhw ei angen.

Y cwestiwn a ofynnwyd: Pa mor dda mae'r awdurdod yn deall anghenion gofalwyr?

Mae gan y rhan fwyaf o awdurdodau lleol strategaethau ar gyfer gofalwyr ar waith ond nid yw'r rhain wedi cael eu hadolygu i adlewyrchu newidiadau o dan y SSWBA. Yn fwy diweddar mae rhai awdurdodau lleol wedi datblygu strategaeth gofalwyr newydd mewn ymateb i SSWBA yn seiliedig ar yr egwyddor o 'gyd-gynhyrchu' a chydnabod yr angen am newid sylweddol i feddwl am sut y gall adnoddau mewn cymunedau gael eu datblygu'n well; mae strategaethau gofalwyr o'r fath yn mabwysiadu dull partneriaeth gref gyda gofalwyr a'r sector gwirfoddol. Mae'n rhy gynnar i ddweud p'un a fydd cynhyrchu strategaeth yn arwain at ganlyniadau gwell i ofalwyr ond maen nhw'n rhoi trosolwg o'r cyfeiriad teithio a fwriedir.

Dros y 18 mis diwethaf, bu cryn dipyn o weithgarwch o ran casglu a dadansoddi data ar sail ranbarthol ar draws Cymru i gefnogi datblygu Asesiadau Anghenion Poblogaeth sy'n cynnwys pennod ar ofalwyr. Mae gofalwyr wedi cyfrannu at y gwaith hwn mewn gwahanol ffyrdd, gan gynnwys drwy eu cynrychiolaeth ar Baneli Dinasyddion rhanbarthol a Byrddau Partneriaeth rhanbarthol. Fodd bynnag, dywedodd gofalwyr wrthym fod dal angen i'r rhan fwyaf o awdurdodau lleol wneud mwy i wrando, a gweithredu, ar leisiau a safbwyntiau gofalwyr.

Datblygwyd amrywiaeth eang o wasanaethau lleol i gefnogi gofalwyr ar draws Cymru, gan gynnwys rhai mentrau arloesol. Daeth y rhain i'r amlwg dros nifer o flynyddoedd yn ystod cyfnod y Strategaeth Gofalwyr blaenorol ac fel ymateb i'r angen a nodwyd yn lleol. Y canlyniad yw clytwaith o wasanaethau, rhai sydd wedi cael eu comisiynu'n effeithiol ac yn aml yn cynnwys monitro trefniadau cymhleth am symiau bach o arian, sydd i raddau helaeth o ganlyniad i orddibyniaeth ar arian grant tymor byr. O bosibl o ganlyniad i ariannu yn y modd hwn, mae llawer o wasanaethau sy'n cefnogi gofalwyr yn parhau i fodoli gydag ansicrwydd contractau tymor byr. Roedd ychydig o adroddiadau blynyddol cyfarwyddwyr gwasanaethau cymdeithasol yn 2015/16 yn tynnu sylw at yr angen i adolygu eu cymorth i ofalwyr, a'r asesiadau a'r cymorth sydd ar gael iddynt yng ngoleuni'r SSWBA.

Nid oes tystiolaeth glir i awgrymu pa fodel cymorth yw'r mwyaf effeithiol ac o gofio'r gwahaniaeth mewn gwasanaethau a daearyddiaeth, nid yw'n glir y byddai cymhariaeth uniongyrchol yn bosibl nac yn ddymunol hyd yn oed. Er enghraifft, mae rhai awdurdodau lleol yn comisiynu sefydliadau trydydd sector i gynnal asesiadau anghenion gofalwyr a darparu cymorth; mae eraill yn cyflogi swyddogion gofalwyr uniongyrchol. Lle mae awdurdodau lleol yn ymgynghori, ymgysylltu a chomisiynu'n uniongyrchol gyda sefydliadau o'r trydydd sector i ddarparu cymorth i ofalwyr, mae'r cydgysylltu digwyddiadau, y wybodaeth a'r broses o gyflawni diweddariadau'n cynnwys mwy o ffocws ac wedi'u targedu, ac mae tystiolaeth fod canlyniadau ar gyfer gofalwyr yn well yn glir. Mae cymorth ychwanegol drwy ddatblygu gwefan ac adnoddau ar-lein ar gyfer darparwyr statudol a darparwyr o'r trydydd sector, ynghyd â gofalwyr yn hollbwysig.

Fodd bynnag, yn gyffredinol mae tystiolaeth o leihad o ran ffocws strategol a gweithredu mewn perthynas â chefnogi gofalwyr oedd eisoes yn cael ei ysgogi gan ddisgwyliad y Strategaeth Gofalwyr. Mae barn na fu i'r broses o symud y prif gyfrifoldeb o'r awdurdodau lleol i'r Byrddau Iechyd Lleol (LHB) o dan y Mesur Gofalwyr blaenorol gael yr effaith a fwriadwyd. Yn aml, er bod prif swyddogion gofalwyr sydd wedi'u cyflogi gan awdurdodau lleol a Byrddau Iechyd Lleol wedi ymrwymo'n unigol i wella cymorth i ofalwyr, nid ydynt wedi bod yn ddigon uchel i ddylanwadu ar wneud penderfyniadau a chyflawni camau gweithredu strategol. Hefyd, mae risg amlwg nad yw cefnogi gofalwyr yn 'fusnes pawb' ar draws timau iechyd a gofal cymdeithasol ac ar draws y cyngor a'r GIG.

Canlyniad: Bod gofalwyr yn gwybod beth yw eu hawliau ac yn deall y cymorth sydd ar gael iddynt.

Y cwestiwn a ofynnwyd: Pa mor effeithiol yw'r Cyngor wrth ddarparu cyngor gwybodaeth, cymorth ac asesiad a chefnogi cynllunio i ofalwyr?

Mae lefel dda o wybodaeth ar gael ar draws Cymru drwy awdurdodau lleol a'r trydydd sector gyda chysylltiadau da rhwng grwpiau gofalwyr a chynghreiriau mewn awdurdodau lleol ac yn y trydydd sector gyda nifer yn cynhyrchu gwybodaeth a chylchlythyrau rheolaidd. Mae hyn yn amrywio, ac mewn rhai ardaloedd mae cyhoeddiadau gofalwyr traddodiadol yn llai poblogaidd, gyda gofalwyr bellach yn cael gafael ar wybodaeth drwy amrywiaeth o ffynonellau cyfryngau cymdeithasol. Yn anochel bydd ehangu cynnwys cyfryngau cymdeithasol a mynediad yn datblygu i fod y dull a ffefrir o ran cymorth a chyngor, a bydd angen i awdurdodau lleol gydnabod a chefnogi'r newid hwn. Mae'r system wybodaeth DEWIS ar y we nawr wedi'i chyflwyno mewn rhai siroedd a nododd gofalwyr bod mynediad yn hawdd i'r wybodaeth hon ar y dudalen we. Lle mae partneriaethau rhanbarthol yn gryf yna mae tystiolaeth o fwy o gydlynu'n glir.

Mae'n peri pryder penodol bod gofalwyr yn nodi eu bod weithiau yn ei chael hi'n anodd dod o hyd i wybodaeth, yn enwedig ar adegau o straen. Mae hefyd yn bwysig nodi bod rhai gofalwyr wedi nodi nad oes ganddynt unrhyw fynediad i'r rhyngrwyd a'u bod yn teimlo'n ddi-rym oherwydd y ffocws cynyddol ar wybodaeth ar y we. Mae hefyd angen gwelliannau i sicrhau bod gwybodaeth i ofalwyr ar gael mewn amrywiaeth ehangach o fformatau gan gynnwys tudalennau gwe ar gyfer y rhai â nam ar eu golwg, yn enwedig drwy dudalennu gwe'r awdurdodau lleol.

Roedd cyfarfodydd grŵp gofalwyr yn cael eu gwerthfawrogi a theimlir eu bod yn ffynhonnell dda o wybodaeth a chymorth gan ddarparu cwmni da, yn lle i gwrdd â phobl a rhannu pryderon a phrofiadau cadarnhaol. Mae rhai siroedd yn cynnal diwrnodau gwybodaeth i ofalwyr yn rheolaidd a dywedodd gofalwyr wrthym am yr ymateb dynol cynnes maen nhw'n ei gael ynghyd â thaflenni gwybodaeth a manylion cyswllt grwpiau cefnogi a gwasanaethau ar gael i ofalwyr.

Mae gofalwyr yn sicr eu bod eisiau i bobl glywed eu straeon a'u bod am gynnal sgyrsiau ystyrlon gyda gweithwyr cymdeithasol o ran 'beth sy'n bwysig', a bod y rhain yn cael ymateb. Mae hyn yn parhau i fod yn anghyson ledled Cymru ac awgrymodd gofalwyr bod angen symleiddio'r ffynonellau a'r pwyntiau mynediad niferus at wybodaeth a chymorth o wahanol fathau a lefelau a ddarperir gan wahanol sectorau ac asiantaethau. Mae angen i awdurdodau lleol wella ymwybyddiaeth gweithwyr cymdeithasol o ehangder y wybodaeth a'r gwasanaethau cymorth i ofalwyr.

Er bod tystiolaeth bod rhai awdurdodau lleol wedi datblygu mewn ymateb i SSWBA o ran cefnogi gofalwyr, mae gan eraill gryn ffordd i fynd o hyd. Dangosodd trafodaeth gyda rhai aelodau o staff nad yw'r angen am ddull newydd o sgwrsio am 'beth sy'n bwysig' yn cael ei gyflawni ar gyfer gofalwyr ac mae angen gwaith pellach i sefydlu diwylliant newydd i fodloni gofynion y SSWBA.

Mae mynediad i asesiad o anghenion gofalwyr yn amrywio -cadarnhaodd rhai gofalwyr eu bod wedi cael asesiad a'u bod yn gwybod gyda phwy i gysylltu am gymorth; dywedodd eraill bod y meddyg teulu yn cefnogi eu mynediad i asesiad o anghenion gofalwyr tra bod gofalwyr eraill yn dweud fod hyn yn cael ei wneud fel rhan o'r cymorth a ddarperir i'r person maen nhw'n gofalu amdanynt. Nododd gofalwyr fod dyblygu'n digwydd a bod rhaid iddynt ddweud eu stori nifer o weithiau ac mewn rhai awdurdodau lleol mai'r 'pwynt unigol o fynediad' yw anfon gofalwyr am asesiad heb gychwyn asesiad drwy sgyrsiau 'beth sy'n bwysig'. Siaradwyd hefyd â gofalwyr nad oedd mor glir p'un a oeddent wedi cael asesiad o anghenion gofalwyr nac yn deall perthnasedd y sgyrsiau maen nhw wedi'u cael.

Cymysg yw'r farn o ran ansawdd ac addasrwydd at ddiben yr asesiad o anghenion gofalwyr. Cadarnhaodd rhai gofalwyr bod pobl yn gwrando ar eu barn yn gyffredinol lle mae asesiadau wedi'u cynnig a'u cynnal. Dywedodd gofalwyr bod diffyg ymgysylltu wyneb yn wyneb a bod hynny'n aml yn arwain at ddiffyg cadarnhad ysgrifenedig o'r hyn oedd wedi cael ei drafod dros y ffôn neu o'r canlyniadau y cytunwyd arnynt. Mae hefyd yn bryder mewn rhai siroedd fod gofalwyr yn mynegi pryder am fod ar restr aros am asesiad o anghenion gofalwyr. Nodwyd materion penodol ynghylch pwy sy'n gwneud yr asesiadau ar gyfer gofalwyr plant anabl sydd wedi achosi straen sylweddol ar gyfer rhieni.

Cawsom adborth cadarnhaol gan ofalwyr a phartneriaid allweddol lle'r oedd strwythurau clir i gefnogi gofalwyr yn bodoli ynghyd â dealltwriaeth glir o ddefnyddio sgyrsiau 'beth sy'n bwysig' yn seiliedig ar gysylltiadau ehangach ar draws y cyngor a'i bartneriaid. Nodwyd bod cydlynwyr lles cymunedol newydd yn gam cadarnhaol i rai awdurdodau lleol. Gall presenoldeb hyrwyddwr gofalwyr mewn timau gwaith cymdeithasol, addysg ac iechyd fod yn effeithiol o ran codi ymwybyddiaeth, ond mae hyn yn anghyson. Mae'r angen i awdurdodau lleol a gwasanaethau gofalwyr a gomisiynwyd ddangos hyblygrwydd ac arloesi wrth ymateb i'r hyn sydd o bwys i ofalwyr yn hollbwysig.

Canlyniad: Bod gofalwyr yn bartneriaid cyfartal ac yn teimlo eu bod yn cael eu cefnogi a'u gwerthfawrogi am y gofal a roddant.

Y cwestiwn a ofynnwyd: Beth mae gofalwyr yn ei ddweud ynghylch: pa mor dda mae eu hanghenion yn cael eu diwallu?

Roedd darlun cymysg ledled Cymru o ran gofalwyr yn dweud eu bod yn teimlo fel partneriaid cyfartal. Dywedodd rhai gofalwyr eu bod yn ymgysylltu ac yn cael eu clywed yn weithredol fel partner yng ngofal person sy'n derbyn gofal tra bod eraill yn dweud fod asesiadau'n ymarfer ticio blychau yn unig. Dywedodd rhai gofalwyr wrthym eu bod yn cymryd rhan yn weithredol mewn grwpiau lleol a dysgu gan ofalwyr eraill am sut i gael mynediad at wybodaeth a chymorth, mae eraill yn teimlo fod pobl a grwpiau yn ymgynghori gyda nhw fel dewis olaf. Nododd rhai eu bod yn teimlo nad oedd unrhyw beth wedi newid yn dilyn eu hasesiad ac felly herio ei werth.

Fel y nodwyd eisoes, mae'r cymorth sydd ar gael ar gyfer gofalwyr yn amrywiol iawn. Dywedodd yr awdurdodau lleol sy'n perfformio orau wrthym am amrywiaeth eang o ddarpariaeth hyblyg a chreadigol gan gynnwys cyrsiau, cwnsela a thaliadau uniongyrchol i alluogi gofalwyr i wneud eu trefniadau eu hunain. Roedd llawer o awdurdodau lleol wedi datblygu polisïau i gefnogi gofalwyr oedd yn cael eu cyflogi gan y cyngor ac roedd rhai siroedd wedi datblygu cysylltiadau gyda chyflogwyr eraill, yn bennaf drwy sefydliadau gofalwyr yn y trydydd sector. Roedd ychydig o siroedd hefyd wedi datblygu partneriaethau gyda chanolfannau gwaith i gefnogi gofalwyr i mewn i gyflogaeth.

Mae nifer o siroedd hefyd wedi datblygu mentrau llwyddiannus gyda byrddau iechyd a phractisau meddygon teulu yn arbennig sydd yn aml yn brif bwynt cyswllt i ofalwyr; mae eraill wedi ymestyn hyn i wardiau ysbyty ac roedd y maes datblygu hwn yn aml wedi'i lywio gan gyfranogiad y GIG yn dilyn cyflwyno'r Mesur Gofalwyr.

Fodd bynnag, dywedodd gofalwyr eraill, lle mae cymorth yn cael ei ddarparu, ei fod yn gyfyngedig o ran darpariaeth cymhorthion ac addasiadau neu seibiannau byr. Yn yr awdurdodau lleol hyn roedd yn anodd dangos beth oedd yn cael ei ddarparu i'r gofalwr o ran eu cymorth eu hunain yn hytrach na chymorth i'r person maen nhw'n gofalu amdanynt.

Yn gyffredinol mae gofalwyr ifanc yn derbyn cymorth da, fodd bynnag, mae nifer gynyddol gydag anghenion emosiynol cymhleth ac mae diffyg gwasanaethau iechyd meddwl i blant yn golygu fod gweithwyr sy'n cefnogi gofalwyr ifanc yn delio gyda rhai materion heriol a chymhleth. Mae gan rhai awdurdodau lleol gynlluniau diogelwch ar waith ar gyfer gofalwyr ifanc a gallant gysylltu gyda'r rhain am gymorth os oes angen. Mae'r broblem o ganfod gofalwyr ifanc yn parhau i fod yn bryder ac mae gan rai gwasanaethau gofalwyr ifanc restr aros ar gyfer cymorth lle mae'n aneglur sut mae'r gofalwyr ifanc yna cael cefnogaeth wrth aros i gael mynediad at y gwasanaeth. Yn amlwg, mae rôl addysg a gwasanaethau ysgolion yn hollbwysig, ac unwaith eto mae hyn yn gymysg ar draws Cymru. Unwaith y bydd gofalwyr ifanc yn cael eu nodi mae'r cymorth a ddarperir yn ymddangos yn gryf.

Mae datblygu cynlluniau marchnata a hyrwyddo, gwefannau, ymgysylltu ag ysgolion a'r gwasanaeth ieuenctid, cyfrifon ar Twitter a Facebook ac ymgysylltu â chanolfannau gwaith i gyd yn dystiolaeth o'r gwaith datblygu parhaus.

Dywedodd llawer o ofalwyr am y fantais o gael mynediad at wasanaeth seibiant byr. Mae gwahaniaethau o ran argaeledd gwasanaethau o'r fath rhwng awdurdodau lleol a rhwng grwpiau o ddefnyddwyr gwasanaeth. Roedd sylwadau yn cyfeirio at yr angen i gynllunio ymlaen llaw yn sylweddol er mwyn galluogi gofalwyr i ddefnyddio gofal seibiant byr sy'n golygu mai ychydig o help sydd ar gael pan fydd angen seibiant byr ar frys. Mae llawer o awdurdodau lleol wedi lleihau gwasanaethau gofal dydd a gwasanaethau seibiant byr oherwydd toriadau ariannol ond nid yw'r AGGCC wedi gallu profi p'un a yw hyn wedi cael effaith uniongyrchol ar ofalwyr.

Dywedodd gofalwyr y byddent yn croesawu mwy o wybodaeth am Daliadau Uniongyrchol yn enwedig ar y gallu i ddefnyddio taliadau o'r fath mewn ffordd fwy hyblyg. Mae rhaid awdurdodau lleol yn cael problemau wrth fynd i'r afael â'r mater hwn gyda chreadigrwydd a gwrando ar yr hyn sy'n bwysig i ofalwyr.

Mae'n ymddangos fod grwpiau cefnogi ar gyfer pobl hŷn ar gael i bawb ond lle mae angen grwpiau cymorth arbenigol fel iechyd meddwl ac anableddau dysgu nid yw hyn bob amser ar gael ym mhob sir.

Mae ymgysylltiad AGGCC wedi nodi dau fath o ofalwyr lle mae'r diffyg mwyaf o ran cymorth. Y rhain oedd gofalwyr sy'n rhieni i blant gydag anghenion cymhleth a gofalwyr i oedolion gydag anghenion iechyd meddwl.

Dywedodd rhieni sy'n ofalwyr i blant ag anghenion cymhleth, awtistiaeth neu ymddygiad heriol fod cymorth yn gyfyngedig. Gwelwyd diagnosis weithiau fel porth i wasanaethau ar gyfer plant ag anghenion cymhleth, ond dywedodd rhai rhieni eu bod yn siomedig nad oedd cynnig am gefnogaeth neu wasanaeth yn dilyn diagnosis. Nid oedd plant oedd yn derbyn gwasanaethau CAMHS yn gymwys am yr un ystod o wasanaethau â phlant anabl, a nodwyd hyn fel mater sy'n effeithio ar lefel y cymorth ar gyfer y teulu cyfan.

Nododd gofalwyr i bobl gydag anghenion iechyd meddwl neu broblemau camddefnyddio sylweddau mai anaml y byddai asesiad gofalwyr yn cael ei ddiweddaru neu ei adolygu, hyd yn oed pan fyddant yn cael un, a bod diffyg cymorth arbenigol ar gael oedd yn hygyrch yn lleol. Dywedodd rhai gofalwyr pan oeddent yng nghanol 'anhrefn argyfwng' mai ychydig o gefnogaeth oedd a bod rhaid iddynt ymdopi ar eu pen eu hunain. Credwyd bod mynediad at gymorth yn haws lle'r oedd cydgysylltydd gofal wedi'i neilltuo'n barod i berson ag anghenion iechyd meddwl. Roedd gofalwyr hefyd yn disgrifio cyfnodau o amser pan roeddent yn pryderu am ddiogelwch a lles y rhai maen nhw'n gofalu amdanynt ac am yr anawsterau o ran cael gafael ar gymorth meddygol ac nad oeddent yn cael eu hysbysu am faterion oherwydd dyletswyddau cyfrinachedd. Dywedwyd y byddai'r person sy'n derbyn gofal yn dewis peidio gwneud defnydd o'r gwasanaethau sydd ar gael iddynt ac roedd hyn yn cael effaith enfawr ar y pwysau ar ofalwyr, roedden nhw'n teimlo nad oedd y straen mae hyn yn ei roi arnynt yn cael ei gydnabod. Gwelwyd bod llawer o'r gofalwyr hyn mewn cyflwr pryderus ac agored i niwed.

Canlyniad: Bod y weledigaeth ar gyfer cefnogaeth i ofalwyr yn cydnabod eu cyfraniad economaidd a'i bod yn glir ynghylch y canlyniad a fwriedir.

Y cwestiwn a ofynnwyd: I ba raddau mae arweinwyr y cyngor wedi darparu gweledigaeth glir ar gyfer cefnogi gofalwyr ac wedi cynnwys ei bartneriaid yn hyn gan gynnwys y gofalwyr eu hunain?

Mae angen i awdurdodau lleol sicrhau ansawdd ac archwilio gwaith ei wasanaethau a gomisiynir yn fwy effeithiol, gan ganolbwyntio mwy ar ganlyniadau i ofalwyr, ac ar leisiau gofalwyr. Roedd yn amlwg nad oedd gan awdurdodau lleol drefniadau monitro cadarn ar waith i bennu ansawdd y gwasanaethau y maen nhw'n eu comisiynu i ddarparu gwybodaeth a chymorth i ofalwyr. Er bod rhai awdurdodau lleol wedi symud i ganolbwyntio ar ganlyniadau i ofalwyr yn hytrach nag allbynnau yn eu trefniadau monitro, mae eraill yn parhau i ddefnyddio dull ticio blychau i fonitro contractau sy'n canolbwyntio ar bolisïau a gweithdrefnau, a mwy o ffocws ar gyflawni canlyniadau i bobl. Cefnogir gwaith gyda gofalwyr trwy amrywiaeth o fodelau gan un swyddog gofalwyr, un swyddog monitro cysylltiadau neu dimau llai o swyddogion gofalwyr a chymorth busnes wedi'u halinio. Mae rhai awdurdodau lleol yn archwilio'r broses o gynnal ac adolygu asesiadau gofalwyr, mewn awdurdodau lleol eraill, tynnwyd sylw at ansawdd asesiadau, prydlondeb annigonol yr ymateb ac adolygu parhaus. Fel y cyfryw mae anghysondeb o ran goruchwylio, monitro canlyniadau a sicrhau ansawdd. Mae hwn yn faes pwysig i'w ddatblygu.

Mae gallu a chapasiti'r gwasanaethau a gomisiynir i gyflawni agenda eang gofalwyr yn her ac nid yw'n un a gydnabyddir gan gomisiynwyr bob amser. Mae p'un a gall y gwasanaethau hyn aros yn sefydlog ac yn gynaliadwy o fewn y trefniadau ariannu grant presennol, a lle mae cytundebau lefel gwasanaeth hanesyddol yn cyfyngu ar arloesi yn fater allweddol. Roedd pwysigrwydd tyfu a chydlynu'r sector hwn i sicrhau llwyfan cadarn a chynaliadwy i ddarparu gwasanaethau yn cael ei amlygu drwy waith AGGCC yn ystod y flwyddyn.

Gan fod gymaint o'r cymorth ar gyfer gofalwyr yn cael ei ddarparu drwy gomisiynu sefydliadau gwirfoddol mae wedi arwain at ddarlun cymysg ynghylch ymgysylltiad awdurdodau lleol â gofalwyr trwy ddigwyddiadau, fforymau a diwrnodau gwybodaeth a bu i ofalwyr wneud sylwadau am y diffyg hwn. Fodd bynnag, gwelsom dystiolaeth o gefnogaeth wleidyddol gref gyda nifer o awdurdodau lleol yn dynodi aelod etholedig fel hyrwyddwr gofalwyr ac a oedd yn rhagweithiol yn y rôl hon. Eto mae angen datblygu cydnabyddiaeth gorfforaethol ehangach eu rôl hanfodol wrth yrru, cydlynu a darparu cymorth ymhellach. Mae angen i'r pwyslais ar ddiogelu'n 'fusnes i bawb' nawr angen canolbwyntio ar gefnogi gofalwyr 'yn fusnes i bawb'.

Casgliad a’r camau nesaf

Mae sylfaen dystiolaeth gref sy’n tynnu sylw at y cyfraniad economaidd hanfodol a wneir gan ofalwyr a phwysigrwydd nodi a chefnogi gofalwyr yn y rôl hon yn bodoli.

Bu i ymgysylltiad blwyddyn o hyd AGGCC gyda gofalwyr ganfod rhai arferion cryf iawn o ran cefnogi gofalwyr, ond nid yw hyn yn gyson ledled Cymru.

Yn yr ymdrech i drawsnewid gwasanaethau yn unol â’r SSWBA, roedd cymorth ar gyfer gofalwyr wedi llithro i lawr yr agenda ac mae angen i awdurdodau lleol, gyda’u partneriaid, sicrhau bod hawl gofalwyr i gael asesiad a chefnogaeth dda yn cael ei ddeall a’i roi ar waith gan staff rheng flaen.

Roedd pwysigrwydd hanfodol mynediad amserol at wybodaeth, cyngor a chymorth yn thema allweddol a ailadroddwyd gan ofalwyr ac mae angen i awdurdodau lleol weithio gyda phartneriaid i sicrhau darpariaeth hygyrch ac effeithiol.

Mae’n bwysig hefyd bod strategaethau gofalwyr yn cael eu diweddaru a bod cynlluniau comisiynu cydlynol ar waith sy’n adlewyrchu cyfrifoldebau a nodir yn y SSWBA.
Mae angen hyn yn seiliedig ar egwyddorion cyd-gynhyrchu a beth sy’n bwysig i ofalwyr a gall ddangos sut y gellir cyflawni canlyniadau cadarnhaol ar gyfer gofalwyr.

Bydd AGGCC yn parhau i ymgysylltu â gofalwyr fel rhan graidd o’i raglen arolygu ac adolygu perfformiad gydag awdurdodau lleol a bydd yn parhau’r ddeialog gyda Gofalwyr Cymru i lywio’r gwaith hwn.

C08
Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Arolygiaeth Gofal Cymru
Response from Care Inspectorate Wales

AGGCC
CSSIW
Arolygiaeth Gofal a Gwasanaethau Cymdeithasol Cymru
Care and Social Services Inspectorate Wales

In support of *carers*

Carers engagement overview report

June 2017

Foreword

By [redacted], member of CSSIW National Advisory Board and chair of Ein Llais North

Most people at some time in their lives will become a carer for a family member, it is not something we plan for or a role we actively seek, but we become a carer because we love the person and want to help them as much as we can. In my lifetime society has changed hugely and families are more scattered and often smaller, the population is getting older and with most women working the caring role, when it comes, can pose a real struggle for many families.

The Social Services and Well-Being Act (SSWBA) recognised the pressures caring puts on individuals and families and has hopefully begun a societal change to both recognise the vital economic contribution of family carers and puts pressure on local authorities to consider and meet their needs, not as an afterthought but as a right. It is really important that elected members of local authorities fulfil their role in upholding the spirit of this Act, treating carers as equal partners in the role they undertake and make information and support available to them as a right, not just when a family is in crisis which has traditionally been the case.

As a parent of a severely disabled son I have been a carer for many years and will continue to care for the rest of my life. I have cared for elderly parents, and other elderly family members till their death. I am no saint, it just happened that I took on the role but as I reached retirement age, I was forced to look for support for my son who needed more stimulation and care than I had the energy to offer on a daily basis. But why, 10 years on, do I still feel guilty about having to take that step, having to admit that I was no longer coping as I had before.

The SSWBA hopefully will support carers earlier, will do what is right for people who need greater care and support than a family member can give. Carers need to feel secure in sharing the care of their family member, there needs to be a partnership approach ensuring the best outcome in life possible for those being cared for is achieved, thus giving me and many like me, the chance to be a proper Mum or Gran or daughter.

In my role as Chair of the Ein Llais, North Wales group I will raise the question many times “Are Carers receiving the support they deserve? If not why not?” CSSIW inspectors, through their inspections must ensure that not only are the services people receive of high quality, but that the ethos of the SSWBA as it relates to carers is upheld. CSSIW will need to work closely with Directors of Social Services and lead council officers to raise the profile of carers rights, to ensure they understand the hugely demanding and valuable role carers provide in today’s world and support them as is their right when they need that support.

Summary

- In transforming services in line with the Social Services and Well-being Act, support for carers has not been at the forefront of planning and delivery for local authorities and their partners.
- Most local authorities have carers strategies in place but some of these have not been reviewed to reflect changes under the SSWBA.
- There are examples of positive and innovative practice across Wales which would benefit from spreading more widely.
- Funding for carer support services remains largely short term.
- Carers are not routinely being offered an assessment of their needs nor provided with information, advice or support.
- There is a wide range of information available but carers sometimes have to go to several places to obtain this and it not always easily accessible, especially at times of crisis.
- We identified two types of carers where support was most limited. These were parent carers for children with complex needs and carers of adults with mental health needs.

Background

In 2016 the Care and Social Services Inspectorate Wales (CSSIW) changed its approach to evaluating the performance of local authorities in the light of the Social Services and Well-being Act 2014 (SSWBA). This change included greater engagement with people who have social care needs and their carers. For 2016/17 it was agreed that CSSIW engagement activity across the 22 local authorities in Wales would focus on the experience of carers. This work was led by CSSIW Area Managers.

Why carers?

In 2015, the first Carers Assembly was held in Wales[1] and this identified a number of themes including:

- Rights and assessment.
- Provision of information.
- Respite care and cuts.
- Work and finances.

In addition, CSSIW noted that many of the annual reports produced by directors of Social Services across Wales said little about support for carers. This led CSSIW to identify the need to understand more about the experience of carers across Wales.

The Social Services and Well-being Act as it applies to carers

The SSWBA broadens the definition of carers by removing reference to 'regular and substantial' levels of caring and increases the emphasis on well-being and prevention as important to carers. The Act includes a duty to consult carers so far as is feasible in the assessment of the cared for person and provides for possible combined assessment of carer and cared for person.

In relation to the carers needs assessment, carers no longer have to 'request' an assessment; this must be offered and include whether the carer is able or willing to continue in their caring role. The assessment should also agree the outcomes the carer wishes to achieve in day to day life, whether the carer works or wishes to (and/or) participate in education, training or recreation.

Local authorities now have duty to provide support to carers and it must also consider whether the carer would benefit from a preventative service or information, advice and assistance. Where a carer is assessed as having eligible needs, the council must put in place a support plan which focuses on the outcomes the carer wishes to achieve.

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[1] www.ccwales.org.uk/learning-resources-1/carers-and-the-act/

What we did

CSSIW Area Managers attended forums and events that had been organized locally to support carers and held telephone interviews with carers so that we could hear about their experience. We looked at carers strategies and interviewed key officers and Council Members who were carers champions, and also met with and considered documentation from key partners including providers of services that supported carers, the health board lead on carers and the head of regional collaboration for carers.

Approximately 400 carers were involved in this work and this included young carers, parent carers and carers of adults with social care needs.

In addition we met with Carers Wales and discussed the emerging findings from their work on 'Track the Act' and feedback they have received from carers and carers organisations.[2]

We agreed four key lines of enquiry linked to the national outcomes framework and quality standards for local authorities. The outcomes CSSIW focused on were:

- Carers receive the support they need.
- Carers know their rights and understand the support that is available to them.
- Carers are equal partners and feel supported and valued for the care they give.
- The vision for support for carers recognises their economic contribution and is clear about the intended outcomes.

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[2] www.carersuk.org/wales/news-campaigns/track-the-act/track-the-act-survey-findings

Our findings

Outcome: Carers receive the support they need.

Question posed: How well does the authority understand the needs of carers?

Most local authorities have carers strategies in place but some of these have not been reviewed to reflect changes under the SSWBA. More recently some local authorities have developed a new carers strategy in response to the SSWBA underpinned by the principle of 'co-production' and recognition of the need for a significant shift in thinking about how resources in communities can be better developed; such carers strategies strongly adopt a partnership approach with carers and the voluntary sector. It is too early to say whether the production of a strategy will result in improved outcomes for carers but they do provide an overview of the intended direction of travel.

Over the past 18 months, there has been significant activity in collecting and analysing data on a regional basis across Wales to support the development of Population Needs Assessments which include a chapter on carers. Carers have contributed to this work in different ways including through their representation on regional Citizens Panels and regional Partnership Boards. However, carers told us that most local authorities still need to do more to listen to, and act upon, the voices and views of carers.

A wide range of local services to support carers has developed across Wales including some innovative initiatives. These emerged over a number of years during the period of the previous Carers Strategy and as a response to locally identified need. The result is a patchwork of services, some of which have been ineffectively commissioned and often involving complex monitoring arrangements for small amounts of money, largely as a result of over reliance on short term grant funding. Possibly as a result of funding in this way, many services that support carers continue to exist with the uncertainty of short term contracts. A few annual reports of directors of social services in 2015/16 highlighted the need to review their support for carers, and the assessments and support available to them in the light of the SSWBA.

There is no clear evidence to suggest which model of support is most effective and given the difference in services and geography it is not clear that direct comparison would be possible or even desirable. For example, some local authorities commission third sector organisations to carry out carers needs assessments and provide support; others directly employ carers officers. Where local authorities directly consult, engage and commission with a number of third sector organisations to deliver support to carers, the coordination of events, information and the delivery of updates is more focused and targeted, and evidence that outcomes for carers are improved is clear. Additional support through website development and on-line resources for statutory and third sector providers, together with carers is vital.

However, overall there is evidence of a diminished strategic focus and action in relation to supporting carers previously driven by the expectation of the Carers Strategy. There is a view that moving lead responsibility from local authorities to Local Health Boards (LHBs) under the former Carers Measure did not have the impact intended. Often the carers lead officers employed by local authorities and LHBs, whilst individually committed to improving support for carers, have not been sufficiently senior to influence strategic decision making and action. There is also an evident risk that supporting carers is not owned as 'everybody's business' across social care and health teams and across the council and NHS.

Outcome: Carers know their rights and understand the support that is available to them.

Question posed: How effective is the council in providing information advice, assistance and assessment and support planning to carers?

There is a good level of information available across Wales via local authorities and the third sector with good links between local authorities and third sector carers groups and alliances with many producing information and regular newsletters. This does vary and in some areas traditional carers publications are less popular, with carers now accessing information through a range of social media sources. The expansion of social media content and access will inevitably become the preferred method of support and advice, and local authorities will need to recognise and support this change. The DEWIS web based information system has been rolled out in some counties and carers reported easy access to this webpage information. Where regional partnerships are strong then evidence of greater coordination is clear.

It is of particular concern that carers report that they sometimes struggle to find information, especially in times of stress. It is also important to note that some carers reported having no internet access and feel disempowered by the increased focus on web based information. Improvements are also needed in ensuring that carers information is available in a wider range of formats including for those with visual impairments, especially via the local authorities web pages.

Carer group meetings were valued and felt to be a good source of information and support providing good company, a place to meet people and share concerns and positive experiences. Some counties have regular carer information days and carers told us about the warm human response they receive along with information leaflets and contact details of support groups and services available to carers.

Carers are clear that they want to have their stories heard and hold meaningful 'what matters' conversations with social workers, which are then responded to. This remains inconsistent across Wales and carers suggested the need to simplify the multiple sources and entry points for information and support of different types and levels provided by different sectors and agencies. Local authorities need to enhance social worker awareness of the breadth of information and support services for carers.

Whilst there is evidence that some local authorities have progressed in responding to the SSWBA in relation to supporting carers, others still have some way to go. Discussion with some staff demonstrated that the need for a new style 'what matters' conversation is not yet being applied to carers and further work is required to embed the new culture to meet the requirements of the SSWBA.

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 the GP supported their access to a carers needs assessment while yet other carers said this was undertaken as part of the support provided to the person they care for. Carers reported duplication with them having to tell their story a number of times and in some local authorities the 'single point of access' is passing carers on for assessment without commencing an assessment through 'what matters' conversations. We also spoke to carers who were not clear whether they have had a carers needs assessment nor understand the relevance of conversations they have had.

The view of the quality and fitness for purpose of the carers needs assessment is mixed. Some Carers confirmed that where assessments have been offered and carried out generally their views are listened to. Carers reported a lack of face to face engagement which often led to no written confirmation of what had been discussed over the phone or of what outcomes had been agreed. It is also of concern that in some counties, concern was expressed by carers about being on a waiting list for a carers needs assessment to be carried out. Particular issues were identified about who does the assessments for carers of disabled children which has caused significant stress for parents.

We received positive feedback from carers and key partners where clear structures to support carers exist along with a clear understanding of using 'what matters' conversations underpinned by broader links across the council and its partners. New community well-being coordinators were identified as a positive move for some local authorities. The presence of a carers champion in social work teams, education and health can be effective in raising awareness but this is inconsistent. The need for local authorities and the commissioned carers services to demonstrate flexibility and innovation in responding to what matters to carers is crucial.

Outcome: Carers are equal partners and feel supported and valued for the care they give.

Question posed: What do carers say about: how well their needs are met?

Carers report feeling that they are equal partners was a very mixed picture across Wales. Some carers reported being engaged and actively listened to as partner in the care of the cared for person, whilst others reported assessments as simply a tick box exercise. Some carers told us that they are actively involved in local groups and learn from other carers about how to access information and support, others feel they are consulted as a last resort. Some reported feeling nothing had changed following their assessment and so challenged its value.

As already reported, the availability of support for carers is varied. The better performing local authorities told us about a diverse range of flexible and creative provision including courses, counselling and direct payments to enable carers to make their own arrangements. Many local authorities had developed policies to support carers employed by the council and some counties had developed links with other employers, largely through third sector carers organisations. A few counties had also developed partnerships with job centres to support carers into employment.

A number of counties have also developed successful initiatives with health boards and notably GP practices which is often the first point of contact for carers; others have extended this to hospital wards and this area of development had often been driven by NHS involvement following the introduction of the Carers Measure.

However, other carers reported that where support is provided this is limited to provision of aids and adaptations or short breaks. In these local authorities it was difficult to evidence what was being provided to the carer in terms of their own support rather than support to the person they care for.

Young carers generally are well supported, however, there are an increasing number with complex emotional needs and the lack of child mental health services means that workers supporting young carers are dealing with some challenging and complex issues. Some local authorities have safety plans in place for young carers on who they can contact for support if needed. The issue of identifying young carers remains a concern; some young carers services have a waiting list for support and it is unclear how young carers are then supported whilst waiting to access the service. The role of education and the schools service is clearly vital, and again this is mixed across wales. Once young carers are identified the support provided appears to be strong. The development of marketing and promotion plans, web sites, engagement with the schools and youth service, accounts on Twitter and Facebook and engagement with Job Centres are all evidence of ongoing development work.

Many carers told of the benefit of having access to a short break service. There are differences in availability to such services between local authorities and between service user groups. Comments referenced the need for significant forward planning to enable carers to use short break care which meant that little help was available when short break was urgently needed. Many local authorities have reduced day care and short break services due to financial cuts but CSSIW has not been able to evidence if this has had a direct impact on carers.

Carers stated that they would welcome more information on Direct Payments especially in being able to use such payments more flexibly. Some local authorities are struggling with approaching this matter with creativity and listening to what matters to carers.

Support groups for older people seem to be universally available; however, where specialist support groups are required such as mental health and learning disabilities this is not always available in each county.

CSSIW's engagement with carers identified two types of carers where support was most limited. These were parent carers for children with complex needs and carers of adults with mental health needs.

Parents who are carers of children with complex needs, autism or behaviour that challenges told us of limited support. Diagnosis was sometimes seen as a gateway to services for children with complex needs, but parents sometimes reported their disappointment of no offer of support or services following a diagnosis. Children who had CAMHS services were not eligible for the same range of services as disabled children and this was identified as an issue that affected the level of support for the whole family.

Carers for people with mental health needs or substance misuse issues reported that even where they had received a carers assessment, it was rarely updated or reviewed and there was a lack of specialist support available that was locally accessible. Some carers reported that when they were in the midst of the 'chaos of a crisis' there was little support and they had to manage alone. Access to support was thought to be easier where a care co-ordinator was already allocated to the person with mental health needs. Carers also described periods of time when they were concerned for the safety and well-being of those they cared for and of the difficulties of accessing medical support and not being informed of issues because of the duties of confidentiality. They said that the cared for person would chose not to make use of the services available to them and this had a huge impact on the demands made on carers, they felt the strain this places on them wasn't acknowledged. Many of these carers were seen to be in a very anxious and vulnerable condition.

Outcome: The vision for support for carers recognises their economic contribution and is clear about the intended outcome.

Question posed: To what extent has the leadership of the council delivered a clear vision for supporting carers and involved its partners in this including carers themselves?

Local authorities need to quality assure and audit the work of its commissioned services more effectively, focusing more on outcomes for and voices of carers. It was apparent that local authorities do not have robust monitoring arrangements in place to determine the quality of the services they commission to provide information and support to carers. Whilst some local authorities have moved to focus on outcomes for carers rather than outputs in their monitoring arrangements, others continue to have a tick box approach to contract monitoring focused on policies and procedures, and a greater focus on the delivery of outcomes for people. Work with carers is supported through a range of models from a single carers officer, a single contacts monitoring officer or small teams of carers officers and aligned business support. Some local authorities audit the process of carers assessments taking place and being reviewed, in other local authorities the quality of assessments, inadequate timeliness of response and ongoing review was highlighted. As such there is inconsistency in oversight, monitoring of outcomes and quality assurance. This is an important area for development.

The ability and capacity of the commissioned services to deliver on the wide ranging carers agenda is a challenge and not one that is always recognised by commissioners. Whether these services can remain stable and sustainable within the current grant funding arrangements, and where historical service level agreements restrict innovation is a key issue. The importance of growing and coordinating this sector to ensure a robust and sustainable platform of service delivery was highlighted throughout CSSIW's work during the year.

As so much of the support for carers is provided through the commissioning of voluntary organisations it has resulted in a mixed picture as to local authorities' own engagement with carers through events, forums and information days and carers remarked on this absence. However we saw evidence of strong political support with many local authorities' having an elected member designated as carer champion and who were proactive in this role. Yet wider corporate recognition of their crucial role in driving, co-ordinating and delivering support for carers needs further development. The emphasis on safeguarding as being 'everybody's business' now needs to be focused on supporting carers 'being everybody's business'.

Conclusion and next steps

There exists a strong evidence base that highlights the vital economic contribution made by carers and the importance of identifying and supporting carers in this role.

CSSIW's year long engagement with carers found some very strong practice in supporting carers, but this is not consistent across Wales.

In the drive to transform services in line with the SSWBA, support for carers has slipped down the agenda and local authorities, with their partners, need to ensure that carers right to assessment and support is well understood and enacted by frontline staff.

The vital importance of timely access to information, advice and assistance was a key theme repeated by carers and local authorities need to work with partners to ensure accessible and effective provision.

It is also important that carers strategies are refreshed and coherent commissioning plans are in place that reflect the responsibilities laid down in the SSWBA. These need to be predicated on principles of co-production and what matters to carers and can demonstrate how positive outcomes for carers will be achieved.

CSSIW will continue to engage with carers as a core part of its inspection and performance review programme with local authorities and will continue the dialogue with Carers Wales to inform this work.

C09

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr

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

Ymateb gan Gofal Cymdeithasol Cymru

Response from Social Care Wales

Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr – ymateb i’r cais am dystiolaeth gan Gofal Cymdeithasol Cymru

Cyflwyniad

Dyma ymateb Gofal Cymdeithasol Cymru.

Cafodd Gofal Cymdeithasol Cymru ei sefydlu (dan Ddeddf Rheoleiddio ac Arolygu Gofal Cymdeithasol (Cymru) 2014) yn 2017 gan olygu bod proses rheoleiddio’r gweithlu gofal cymdeithasol, datblygu’r gweithlu a gwella gwasanaethau i gyd yn rhan o un sefydliad. Bydd gennym rôl ddylanwadol wrth lywio blaenoriaethau ymchwil a meithrin cysylltiadau cryf gyda rhanddeiliaid i wella gofal a chymorth. Gofal Cymdeithasol Cymru sy’n gyfrifol am ddatblygu’r gweithlu yn y sector gofal cymdeithasol a’r blynyddoedd cynnar hefyd. Ein nod yw cefnogi blaenoriaethau llesiant cenedlaethau’r dyfodol ar gyfer y sector, y cyhoedd a Llywodraeth Cymru.

Mae ein tri amcan strategol yn diffinio’r hyn a wnawn:

- darparu hyder i’r cyhoedd
- arwain a chefnogi gwelliant
- datblygu’r gweithlu

Yn ein cynllun strategol ar gyfer 2017-22, rydym yn cydnabod y gellir gwneud mwy i helpu gofalwyr di-dâl. Amcangyfrifir mai nhw sy’n darparu 96% o’r gofal yng Nghymru gan alluogi pobl agored i niwed, sâl ac anabl i gynnal eu hannibyniaeth a pharhau i fyw gartref (Gofal Cymdeithasol Cymru, 2017).

Un o’n swyddogaethau pennaf o safbwynt gofalwyr yw cefnogi’r gweithlu cyflogedig i weithio’n effeithiol gyda gofalwyr. Rydyn ni’n gwneud hyn trwy bennu safonau ar gyfer y gweithlu, dylanwadu ar y broses o gynllunio a darparu cymwysterau i weithwyr gofal cymdeithasol, rheoleiddio hyfforddiant gwaith cymdeithasol, cyhoeddi adnoddau dysgu, pennu blaenoriaethau ymchwil a chomisiynu prosiectau ymchwil penodol. Ar ben hynny, rydyn ni’n cyfrannu at wella gwasanaethau ar draws y sector gan gynnwys gwasanaethau i ofalwyr a’r rhai maen nhw’n eu helpu. Rydym yn cyfrannu at y Grŵp Cynghori’r Gweinidog i Ofalwyr a sefydlwyd yn ddiweddar.

Os oes angen rhagor o wybodaeth arnoch, cysylltwch â:

[redacted]

Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 ar ofalwyr

Ein gwaith yn paratoi'r gweithlu i roi'r Ddeddf ar waith 2015 - 2018

Fel Cyngor Gofal, gofynnwyd inni ddatblygu cynllun dysgu cenedlaethol ar gyfer y Ddeddf a chreu gwefan I gadw'r holl adnoddau am y Ddeddf. Y nod oedd cael dull cyson o ddysgu ledled Cymru ac ym mhob rhan o'r gweithlu. Roedd yn dasg anferthol: gyda 8,000 o weithwyr yn mynychu sesiynau codi ymwybyddiaeth, a chwblhau 12,000 o fodiwlau hyfforddi craidd yn 2016-17 yn unig.

Un o'r 5 modiwl craidd a ddatblygwyd gennym oedd 'Asesu a diwallu anghenion unigolion'. Er mai modiwl cyffredinol ar asesu anghenion oedd hwn, roedd yn cynnwys cyfeiriad penodol at weithio'n effeithiol â gofalwyr drwyddi draw. Yn ddiweddarach, fe wnaethom greu astudiaethau achos manwl yn canolbwyntio ar asesu a diwallu anghenion gan gynnwys pwyslais penodol ar y gofalwr a'r rhai y 'gofalir amdanynt'.

https://gofalcymdeithasol.cymru/hub/hub-resource-sub-categories/asesu-a-diwallu-anghenion

Buom ni'n gweithio mewn partneriaeth â Gofalwyr Cymru, Ymddiriedolaeth Gofalwyr Cymru a Hafal i greu adnoddau dysgu ychwanegol a manylach ar weithio gyda gofalwyr dan y Ddeddf. Fe wnaethom gomisiynu'r tri sefydliad partner hyn i gynnal dosbarthiadau arbenigol ar weithio gyda gofalwyr ac fe'u cynhaliwyd ledled Cymru.

https://gofalcymdeithasol.cymru/hub/hub-resource-sub-categories/gofalwyr-ar-ddeddf

Ar ôl gwerthuso'n gwaith, roeddem yn gwybod ein bod ni wedi creu effaith: roedd sgôr cyfartalog gweithiwr oedd â'r wybodaeth i ddarparu gwasanaethau yn unol â'r Ddeddf wedi cynyddu 40%. Roedd gwaith partneriaeth ar y cynllun hyfforddi yn cael ei ystyried yn gadarn iawn.

Ein gwaith parhaus i helpu i ddatblygu'r gweithlu a gwella gwasanaethau

Rydym yn gwybod bod gennym lawer mwy i'w wneud ac rydym yn parhau i weithio gyda phartneriaid i nodi anghenion y gweithlu mewn perthynas â'r Ddeddf a gofalwyr. Bydd y gwaith yn cyfrannu'n uniongyrchol at wella profiadau pobl sy'n defnyddio gwasanaethau gofal a chymorth yn ogystal â'u gofalwyr.

Rydym ar fin cyhoeddi modiwl e-ddysgu am ddim i godi ymwybyddiaeth o amgylchiadau gofalwyr. Gobeithio y bydd hyn yn helpu i adnabod gofalwyr pan fyddan nhw'n cysylltu â gwasanaethau (cam cyntaf hollbwysig sy'n arwain at asesiad). Datblygwyd hyn ar y cyd â'r GIG. Rydym yn cydnabod rhai o'r problemau a godwyd ym mhrosiect 'Dilyn y Ddeddf' Gofalwyr Cymru yn 2017 ynghylch asesiadau, ac wedi gweithio gyda chydweithwyr yn Llywodraeth Cymru ac awdurdodau lleol i ddatblygu fframwaith cymhwysedd sy’n helpu i ddatblygu gwybodaeth, sgiliau a chymhwysedd amrywiaeth eang o weithwyr Gwybodaeth, Cyngor a Chymorth. Mae’r fframwaith newydd hwn yn cyfeirio’n benodol at anghenion a phrofiadau gofalwyr. Bydd yn adeiladu ar ein gwaith o gefnogi gweithwyr Gwybodaeth, Cyngor a Chymorth i ddeall a gweithredu gofynion Sgyrsiau Gwell o fewn Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014.

https://gofalcymdeithasol.cymru/hub/hub-resource-sub-categories/sgyrsiau-gwell

Mae gennym brosiect penodol i gynhyrchu adnoddau dysgu i wella ymarfer asesu gyda gofalwyr – rydym yn bwriadu cyhoeddi pecyn cymorth newydd ar gyfer gweithio gyda gofalwyr erbyn diwedd y flwyddyn. Nodwyd yr angen am hyn mewn trafodaethau gyda Llywodraeth Cymru a thystiolaeth o brosiect ‘Dilyn y Ddeddf’ Gofalwyr Cymru. Bydd y pecyn cymorth yn cynnwys helpu gofalwyr i baratoi ar gyfer eu hasesiad a chael y gorau ohono, sgiliau cynnal asesiad gyda phwyslais arbennig ar sgiliau gwrando a chyfathrebu a chynllunio cymorth yn dda.

Yn 2018/19, mae ein cynllun busnes yn cynnwys blaenoriaethau datblygu gwasanaeth – gofal a chymorth yn y cartref, a dementia – dau faes lle mae cydnabod gofalwyr yn hanfodol.

Rydym yn gweithio ar welliannau cyffredinol hefyd. Er enghraifft, mae gennym raglen waith fanwl er mwyn cefnogi’r gwasanaethau cymdeithasol ar y modd maen nhw’n gweithio gyda phobl i gyflawni eu canlyniadau personol.

Yn ddiweddar, fe wnaethom gyhoeddi adolygiad cyflym o dystiolaeth o weithio’n effeithiol â gofalwyr ac rydym yn bwriadu ailadrodd y gwaith hwn gyda gofalwyr ifanc.

https://gofalcymdeithasol.cymru/gwella-gwasanaethau/gweithio-gyda-gofalwyr

Sylwadau

Mae’n amlwg bod y gweithlu angen gallu cael gafael ar adnoddau, ymchwil a chyfleoedd dysgu o’r radd flaenaf er mwyn gwireddu dyheadau’r Ddeddf a gwella ansawdd y gwasanaethau ar draws y sector gan gynnwys i ofalwyr - ac rydym yn gobeithio ein bod ni’n gwneud cyfraniad gwerthfawr yn y meysydd hyn. Yn ein holl waith, rydyn ni’n ceisio canolbwyntio ar baratoi’r gweithlu i fodloni ‘ysbryd’ y Ddeddf, a sicrhau bod gwelliannau i wasanaethau wrth wraidd ein gwaith, yn ogystal â llythyren y ddeddf. Hefyd, rydym yn gweithio gyda rheolwyr ac uwch-arweinwyr awdurdodau lleol er mwyn helpu i nodi eu hanghenion nhw o ran dysgu a gwella gwasanaethau.

Hoffem bwysleisio i’r Ymchwiliad pa mor dyngedfennol bwysig yw dysgu a datblygu parhaus wrth weithio gyda gofalwyr. Yr hyn sy’n hanfodol bwysig yw bod hyn yn berthnasol i uwch-reolwyr a’r rhai sy’n gysylltiedig â chynllunio, comisiynu a chontractio cymorth i ofalwyr yn ogystal ag ymarferwyr rheng flaen. Rhaid bod gan staff awdurdodau lleol ar bob lefel ac yn yr holl rolau amrywiol, ddealltwriaeth drylwyr o’r materion a’r problemau sy’n wynebu gofalwyr, yn ogystal â dealltwriaeth o gyfraniad aruthrol gofalwyr at ddarparu gofal a chymorth di-dâl yn eu hardaloedd. Rhaid i awdurdodau lleol allu cyflwyno gweledigaeth glir a ‘chynnig’ ymarferol wrth weithio gyda gofalwyr, gyda’r broses asesu’n gyfrwng pwysig ar gyfer ymateb i sefyllfa unigryw pob gofalwr unigol.

Fodd bynnag, nid awdurdodau lleol yn unig ddylai ysgwyddo’r cyfrifoldeb hwn. Mae’n hanfodol bod cydweithwyr mewn gwasanaethau iechyd, yn enwedig, yn gallu adnabod ac ymateb yn briodol i ofalwyr unigol. Mae gan wasanaethau iechyd gyfrifoldebau clir o dan y Ddeddf. Dylai fod yn ofynnol i bartneriaid iechyd gyfrannu at gynllun asesu a chymorth yr awdurdod lleol, lle bo’n briodol.

Polisi Llywodraeth Cymru ar ofalwyr

Yn ogystal â’r pwyntiau uchod, byddem yn annog Llywodraeth Cymru i roi ystyriaeth ofalus i’w polisi mewn perthynas â gofalwyr ifanc. Er, mewn gwirionedd, y gall fod yn angenrheidiol a phriodol i gefnogi gofalwyr ifanc yn eu rôl ofalu, mae’n bwysig deall a gweithredu polisïau sy’n helpu pobl sydd angen gofal a chymorth i gael hynny gan y gwasanaethau sydd ar gael, a dibynnu lawer llai ar blant i ddarparu gofal a chymorth sylweddol i’w teuluoedd. Efallai y bydd hyn yn gofyn am fuddsoddi mwy mewn gofal a chymorth â thâl. Fodd bynnag, byddai lleihau’r ddibyniaeth ar ofalwyr ifanc yn cyd-fynd â dyheadau Llywodraeth Cymru i gefnogi plant a phobl ifanc i ffynnu a datblygu eu llwybr bywyd eu hunain.

Rydym yn awgrymu bod angen cynnal mwy o ymchwil i archwilio i unrhyw oblygiadau anfwriadol yn sgil y Ddeddf mewn perthynas ag oedolion sy’n gofalu. Er enghraifft, yw’r pwyslais ar gyngor a gwybodaeth ac atgyfeirio at asiantaethau eraill yn arwain at awdurdodau lleol yn colli cyfleoedd i helpu gofalwyr yn y tymor hirach?

C09

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr

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

Ymateb gan Gofal Cymdeithasol Cymru

Response from Social Care Wales

Impact of the Social Services and Well-being (Wales) Act 2014 in relation to Carers – response to the call for evidence from Social Care Wales

Introduction

This response is from Social Care Wales.

Social Care Wales was established (under the Regulation and Inspection of Social Care (Wales) Act 2014) in April 2017 bringing together social care workforce regulation, workforce development and service improvement in one organisation. We will have an influential role in shaping research priorities and building strong links with stakeholders to improve care and support. Social Care Wales also has a responsibility for the development of the workforce in the social care and early years sector. Our work aims to support the priorities for the well-being of future generations for the sector, the public and Welsh Government.

Our three strategic aims below define what we do:
- providing public confidence
- leading and supporting improvement
- developing the workforce

In our strategic plan for 2017-22 we acknowledge that more can be done to support unpaid carers who it is estimated provide 96% of the care in Wales enabling vulnerable, sick and disabled people to maintain their independence and continue living at home (Social Care Wales, 2017).

One of our primary roles in relation to carers is supporting the paid workforce to work effectively with carers. We do this by setting standards for the workforce, influencing the design and delivery of qualifications for social care workers, regulating social work training, publishing learning resources, setting research priorities and commissioning some specific research projects. In addition we contribute to the improvement of services across the sector including to carers and the people they support. We are contributing to the recently established Ministerial Advisory Group for Carers.

Should you require further information please contact:

[redacted]

The impact of the Social Services and Well-being (Wales) Act on carers

Our role preparing the workforce to implement the Act 2015 - 2018

As Care Council, we were asked to develop a national learning plan for the Act and create a website to hold all resources about the Act. The aim was to have a consistent approach to learning across Wales and all parts of the workforce. The scale of the task was huge: 8,000 workers attended awareness raising sessions and 12,000 core training modules were completed in 2016-17 alone.

One of the 5 core modules we developed was 'Assessing and meeting the needs of individuals'. Whilst this was a generic module on assessments of need, the content included specific reference to working effectively with carers throughout. Later we produced detailed case studies focusing on assessing and meeting needs and these include specific focus on the carer as well as the 'cared for'.

https://socialcare.wales/hub/hub-resource-sub-categories/assessing-and-meeting-individual-needs

We worked in partnership with Carers Wales, Carers Trust Wales and Hafal to produce additional, detailed learning resources on working with carers under the Act. We commissioned these same 3 partner organisations to deliver expert classes on working with carers and these were delivered across Wales.

https://socialcare.wales/hub/hub-resource-sub-categories/carers-and-the-act

We evaluated our work and know we made an impact: the average score for a worker having the knowledge to deliver services in line with the Act increased by 40%. Partnership working on the training plan was regarded as very strong.

Our on-going work supporting workforce development and service improvement

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

We are about to publish a free e learning module to raise awareness of carers' circumstances. We hope this will help with the identification of carers when they make contact with services (a crucial first step leading to assessment). This has been developed jointly with the NHS. We recognise some of the issues raised in Carers Wales' 'Track the Act' project in 2017 around assessments and have been working with colleagues in Welsh Government and local authorities to develop a competency framework that supports the development of knowledge, skills and competence of a wide range of Information, Advice and Assistance workers. The needs and experiences of carers is specifically referenced in this emerging framework. This will build on our work to support IAA workers to understand and implement the Better Conversation requirements within the Social Services and Well-Being (wales) Act 2014.

https://socialcare.wales/hub/hub-resource-sub-categories/better-conversations

We have a specific project to produce learning resources to improve assessment practice with carers – we intend to publish a new toolkit for working with carers by the end of the year. The need for this was identified in discussion with Welsh Government and evidence from Carers Wales' 'Track the Act' project. The tool kit will include helping carers to prepare for their assessment and get the most out of it, skills in conducting the assessment with a particular emphasis on communication and listening skills and good support planning.

In 2018/19 our business plan includes the service development priorities care and support at home and dementia – two areas where a recognition of carers is essential.

We are also working on generic improvements. For example, we have a detailed programme of work to support social services with how they work with people to achieve their personal outcomes.

We recently published a rapid review of evidence for working effectively with carers and we intend to repeat this work in relation to young carers.

https://socialcare.wales/service-improvement/working-with-carers

Comment

Clearly, the workforce requires access to high quality resources, research and learning opportunities to meet the aspirations of the Act and improve the quality of services across the sector including to carers - and we hope we are making a valuable contribution in these areas. In all our work, we try to ensure a focus on preparing the workforce to meet the 'spirit' of the Act, to ensure that improvement to services is at the heart of our work, as well as the letter of the law. We also work with managers and senior leaders in local authorities to help identify their learning and service improvement needs.

We would like to stress to the Inquiry the critical importance of on-going learning and development with regards to working with carers. Crucially, this applies to senior managers and those involved in designing, commissioning and contracting support for carers as well as front line practitioners. Local authority staff at all levels, and in their full range of roles, must have a well-developed understanding of the issues faced by carers as well as an understanding of the huge contribution of carers providing unpaid care and support in their area. Local authorities must be able to articulate a clear vision and practical 'offer' for their work with carers with the assessment process acting as an important vehicle for responding to each individual carer's unique situation.

The responsibility, however, should not be with local authorities alone. It is essential, in particular, that colleagues in health services are able to recognise and respond appropriately to individual carers. Health services have clear responsibilities under the Act. Health partners should be required to contribute to the local authority assessment and support plan, where appropriate.

Welsh Government policy on carers

In addition to the points raised above, we would encourage Welsh Government to consider carefully their policy in relation to young carers. Whilst realistically it may be necessary and appropriate to support young carers in their caring role, it is important to understand and put policies in place that support people needing care and support to access that from available services, and significantly reduce a reliance on children to provide significant amounts of care and support to their families. This may well require more investment in paid care and support. However reducing the reliance on young carers would be consistent with the Welsh Government’s aspirations for supporting children and young people to thrive and develop their own life path.

We suggest that more research is necessary to explore any unintended consequences of the Act in relation to adult carers. For example, is an emphasis on information and advice and signposting to other agencies resulting in lost opportunities for local authorities to support carers in the longer term?

C10

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr

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

Ymateb gan Hafal

Response from Hafal

[redacted]

dros adferiad o afiechyd meddwl difrifol

hafal

for recovery from serious mental illness

www.hafal.org

[redacted]

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

Ideas for improvement

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. "One-size-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.

6. Contact details

[redacted]

[redacted]

C11
Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Goleg Nyrsio Brenhinol Cymru
Response from Royal College of Nursing Wales

Coleg Nyrsio Brenhinol
Cymru
Royal College of Nursing
Wales

18 September 2018

Response from the Royal College of Nursing Wales to the Health, Social Services & Sport Committee's inquiry into the Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers

The Royal College of Nursing Wales is grateful for the opportunity to respond to this consultation and would like to raise a number of points in relation to the inquiry:

Raising awareness and identification of carers

I. It is widely understood that demographic changes mean that not only are there more unpaid carers than ever before, but there has also been a significant increase in the proportion who are caring for over 20 hours a week and a rise in the number for those caring 50 hours a week or more, as demonstrated by statistics from the last census. There are currently 370,000 carers, with over 100,000 people in Wales providing over 50 hours of unpaid care per week. Figures from Social Care Wales report that there are approximately 30,000 young carers (under the age of 25) in Wales, the highest proportion of all UK countries.

II. Despite these high numbers, it is known that many carers, and the healthcare professionals that work with carers, do not always identify individuals as carers. It's important that carers are informed of their rights as carers, and that appropriate information is available to them about the support services that they can access. It is also vital that professionals and clinicians who work with carers are supported to identify carers, and have an understanding of how this should impact on care planning. Healthcare professionals working alongside carers should be fully cognisant of what the rights of carers are under the act, and be supported to signpost carers towards the information and services they need.

III. We know from the Carers Trust Wales that there are some good examples in Wales where a ward-based carers support worker has had a huge impact on supporting staff to identify and engage with carers, providing significant benefits to both. This has demonstrated that having specialist support workers for carers within hospitals can be a really effective way to support clinical staff and carers alike, and to enhance communication between carers and healthcare teams.

Assessment & support services delivered by Local Authorities

IV. According to the Carers Wales 'Track the Act' programme, whilst some local authorities have clear and workable strategies for ensuring they are meeting their statutory duties, there are significant differences between these strategies and consequently in how councils are actually delivering services. This means that some carers experience a 'post code lottery' of how and when they receive their needs assessment (if they receive one at all) and the services they subsequently receive (if any services are received at all).

V. This is an indication that not all councils are meeting their statutory duty to offer and undertake a Carer's needs assessment, and therefore not all carers are benefiting from the new rights that the Act has brought them. Welsh Government must ensure that there is appropriate monitoring and evaluation of the services available and the wider impact that the Act is having on carers.

The need for respite care

VI. The Social Services and Well-being (Wales) Act 2014 places carers on an equal legal footing as those being cared for. Local Authorities have a duty to actively promote and provide preventative service, including offering a carer's needs assessment, regardless of the type of care provided, the financial means of the carer or what the level of support needed might be. However, financial pressures on Local Authorities has meant the availability of services which can provide valuable and meaningful respite have reduced, and carers' access to respite is becoming increasingly difficult.

VII. Without proper respite, the health of carers themselves can be compromised. This not only impacts on the well-being of the carer themselves, but in turn affects their ability to promote and maintain the well-being of the individual being cared for. We know from research by Carers Wales, that the health of carers is often negatively impacted by their role as a carer. This is demonstrated by statistics that 59% of carers reported worsened physical health since they had become carers and 70% saying they had suffered mental ill health since taking on their responsibilities as a carer. The contributing factors to this are numerous and indicative of the need to ensure that carers are properly cared for, and that respite and support services are readily available.

Unpaid Carers & Nurse Education Placements

VIII. A model which the Royal College of Nursing has been advocating for some time is the innovative idea of placing nursing students in the homes of unpaid carers, thereby providing relief for carers who often receive little to no respite from their roles as carers, whilst also providing placements for nursing students. It is often acknowledged that there is a lack of variety in nurse education placements, particularly outside of hospital settings. These placements would provide valuable exposure for student nurses to a different care setting, potentially encouraging more nurses to work in the care sector.

IX. Careful account and consideration would clearly be needed around the requirements for supervision and mentoring, and there would need to be clear lines of responsibility and accountability. With the right processes and governance procedures in place however, these placements could widen access to the caring profession, whilst also assist in overcoming the issue of the lack of support and help available to those with unpaid caring duties.

Education & Employment Opportunities

X. In addition to these education opportunities for nurses, the Royal College also maintains that there should opportunities for unpaid carers to be recognised for the skills and expertise they possess thorough appropriate accreditation, providing qualifications and potential career opportunities providing nursing students with placements in the community provides a great opportunity for relieving pressures, giving unpaid carers the chance to gain qualifications. Of course these opportunities would not appeal to everybody, and there would be no obligation for carers to develop their skills if they did not wish to do so. For those that did however, not only would this give recognition to unpaid carers for the incredible job they do, it would also enable them to have a career beyond their immediate caring responsibilities in the longer term.

About the Royal College of Nursing

The RCN is the world's largest professional union of nurses, representing over 430,000 nurses, midwives, health visitors and nursing students, including over 25,000 members in Wales. The majority of RCN members work in the NHS with around a quarter working in the independent sector. The RCN works locally, nationally and internationally to promote standards of care and the interests of patients and nurses, and of nursing as a profession. The RCN is a UK-wide organisation, with its own National Boards for Wales, Scotland and Northern Ireland. The RCN is a major contributor to nursing practice, standards of care, and public policy as it affects health and nursing. The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies.

C12
Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Vision 21 – Cyfle Cymru
Response from Vision 21 – Cyfle Cymru

Dear Sir/Madam

In response to your consultation on the Social Services and Wellbeing Act 2014 I would like to add the following comments in relation " *Other changes since the Act came into force which may impact on carers, for example changes to the services provided to people who are cared for"*

I represent Vision 21, a Welsh charity that provides vocational training for adults with learning disabilities in one of 17 projects across S.E. Wales. The majority of our service users are referred by local authorities and come from six different S.E. Wales authorities. We regularly have dealings with carers (usually parents) who are trying to find the right provision. Has the Act improved things? Do they get the right information? Is it still a battle? Our experience is that it varies enormously across authorities and that in the case of some authorities it is hard to discern any real change.

Recent examples include:

(1) A student who has been withdrawn from our woodwork section and offered something that he does not want in his own authority area. The reason is not transport costs, or something nearer to home and does not seem to relate to funding. It seems to be a reluctance to fund anything outside the authority area. The carer is fighting this decision.
(2) A student who has lost his place in one project and will probably lose his place in another project. The place was previously funded through ILF and was presumably re-assessed when the grant came across to the local authority. His carer is fighting the decision and would definitely say it is a battle.
(3) A student withdrawn after 18 years when the family moved to a neighbouring authority. No consultation with the student (or with us). Again the issue seems to be about "catchment areas" not transport. The student may be coming back to us for 2 days, although at present is doing nothing and rings us in tears every day. It is stressful for the student, her carer and my staff.
(4) We have a number of students withdrawn because the local authority will no longer fund. In some cases the authority refuse to fund both a place and support.
(5) We have had other issues where LA are pressuring students to move to their projects, this is more difficult to report because the information we receive is anecdotal with no written evidence. We also have a few where the LA has removed transport funding and the place has ceased.

In my opinion some of these issues arise because individuals within authorities have not embraced the changes brought about by the Act, but also because of the financial pressures that all authorities are under. Local authorities are all seeking "free" provision and are looking to direct service users into their own provision wherever possible. In some cases this directly conflicts with the individual's right to choice and the carer's efforts to exercise that choice.

We regularly get carers ringing up for information and advice when seeking places, which suggests they are still not sure where to go. We have also seen no increase in carers using direct payments, although it is not clear whether this is a reluctance on the behalf of local authorities to give advice or on the carer to take advantage of direct payments.

I hope this helps inform the consultation. If you require any further information please do not hesitate to contact me.

Kind regards

[redacted]
Vision 21 (Cyfle Cymru)
[redacted]

C13
Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Gyngor Bwrdeistref Sirol Torfaen
Response from Torfaen County Borough Council

Consultation

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

- View the background to this consultation
- View all current consultations

Purpose of the consultation

The Health, Social Care and Sport Committee would welcome your views on the impact of the Social Services and Wellbeing (Wales) Act 2014 [Opens in a new browser window] in relation to Carers.

Terms of reference:

The Health, Social Care and Sport Committee is calling for evidence in relation to;

- The impact of the Social Services and Wellbeing (Wales) Act 2014 [Opens in a new browser window] on carers of all ages in Wales, including;
    -
    - Assessments of need;
    - Provision of support, including respite care;
    - Provision of information, advice and assistance;
    - Information collected by local authorities and Local Health Boards on carers and their needs.
- To consider broader Welsh Government policy on carers.

The inquiry will consider the following issues in relation to carers of all ages:

1. 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;
2. 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;
3. The extent to which local authorities are fulfilling their duties under the Act to provide information, advice and assistance to carers;
4. Whether local authorities and Local Health Boards have sufficient information on the number and needs of carers in their areas;
5. Other changes since the Act came into force which may impact on carers, for example changes to the services provided to people who are cared for;
6. Broader Welsh Government policy on carers and how it should be developed.

The deadline for responses is **20 September 2018**. Please send your views to: SeneddHealth@assembly.wales

Response to Questions from Torfaen County Borough Council.

1. 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;

Below is a table showing Adult Carers PI's before SSWB Act (2014/15 & 2015/16) and after the introduction of the Act (2016/17, 2017/18 & 2018/19 to date).

Questions	**2014/15**	**2015/16**	**2016/17**	**2017/18**	**Q1 2018/19**
Assessments of need;	**65**	**60**	**105**	**90**	**21**
Provision of support, including respite care;	**56**	**43**	**10***	**10***	**3***
Provision of information, advice and assistance;	**N/A**	**N/A**	**105***	**90***	**21***

It is difficult to compare the services provided to carers before and after the Act as we now record services in a different way. In many cases, services are recorded against the Cared For rather than the actual Carer, this would account for the low number of support plans. In addition we now only include commissioned services in care and support or support plans, whereas previously we were recording all services provided.

Prior to the Act, information, advice and assistance data was not recorded, we only recorded numbers of carers assessments. We now recorded advice and assistance however we still do not record contact relating to information only.

It is difficult to use the data above for any comparison as the PIs have changed and therefore we are not comparing like with like.

Work is now being undertaken to develop the new WCCIS system to record Carers information in their own right. This will include all contact with carers, carers assessments undertaken, any IAA provided and any referrals or services offered. We hope that all of this information will be available to report in future as well as the standard WG PI requirements.

2. 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;

See numbers and note for 1.

Carers requesting and receiving respite or short breaks has increased in the last 2 years. Additional funding from WG has allowed for more traditional (eg institutional) as well as more alternative forms (eg recreational groups) of respite to be made available to carers. (see appendix 2 for carer numbers and breakdown of spend per category). Funding has also been used for 3rd sector initiatives within the borough eg Age Connects Torfaen (see appendix 1 for report).

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

In Torfaen we provide IAA in a variety of formats. We have recently employed a Carers Support Worker to work directly with carers and their IAA needs. We also discharge some of our IAA duties by referring to Torfaen Carers Centre (see appendix 3 for attendance figures). Here a dedicated team of carers coordinators and volunteers are on hand to deal with all forms of IAA in relation to carers. This can be in the form of; conversations, group therapies, sessional work, activities, trips and overnight stays, training, varios forms of information and advice on a range of subjects that effect carers day to day caring duties eg carers rights and benefits.

We are also introducing a Carers Induction Course aimed primarily at new carers. This will be a 6 week course held at the carers centre and will cover all carers issues and information. We have recently started to produce and publish a quarterly Carers Newsletter to keep carers informed of national and local carers information and events as well as relevant links and contact information.

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

As previously stated in Q1, we recognise that we do not have sufficient information on carers or their needs. We are trying to rectify this by introducing new recording and reporting information areas in WCCIS specifically for carers. However we do engage with carers in a variety of formats and listen to what they say and ask what matters to them.

5. Other changes since the Act came into force which may impact on carers, for example changes to the services provided to people who are cared for;

In Torfaen we have tried to embrace not only our statutory requirements but also the whole ethos of the act. We have developed a person centered approach to care based on the “what matters” conversations. We have found that we are seeing a shift from residential institutional care to more community based care where suitable. This often results in greater reliance on family and friends of the cared for person – especially their main carer. We endeavor to provide support and assistance to the cared for person and also the carer to allow the best possible care that is suitable to all parties.

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

The message we are hearing from Carers is that they need to know that help and assistance is available from the local authority, if it is required. Too often we only hear a cry for help when a carer reaches crisis point and feels that they can't go on with their caring role. Applying the principals of the SSWB Act, especially regarding early intervention and support, will help to stop carers reaching crisis point.

Overall we don't think that the majority of carers are fully aware of their rights as a carer despite the introduction of the SSWB Act. Hopefully in time with continued promotion and awareness raising, carers rights and issues will be addressed and provided for.

Young Carers in Torfaen.

In Torfaen we have a dedicated Young Carers team who have always had a very proactive role in identifying young carers and carrying out young carer assessments. As a result, we don't feel that the SSWB Act has had a significant impact for requests for young carers assessments.

We would like to think that Torfaen is one of the leading authorities where young carers have care and support plans, as the majority of young carers services in other local authorities are with the voluntary sector and the way they assess young carers hasn't changed.

One area where we are seeing increased referrals is from schools especially when it is shown to have a positive impact on a pupil who is a young carer, other referrals often follow.

Appendix 1

Additional Information Provided by Age Connects Torfaen.

age connects torfaen.

Age Connects Torfaen is the operating title of Age Concern Torfaen

Independent • Local • Listening

Age Connects Torfaen- Information & Advice Services Statistics April 2017-March 2018

Clients who gained Carers allowance after appointments	Contacts Who have had Carers Info & Advice and welfare benefits	Carers and Family members who have attended appointments	Referrals made for carers assessment Through Social services	Carers assessments that have been turned down	Carers who were already registered and accessed social services carers assessment
7 £23,514.40	21	140	10	2: 1.client not being on correct benefit 2.client who works	15

Home Services Department, Age Connects Torfaen

The Supervisor for this service noted that only a very small proportion of referrals, approximately 5 % are referred from Social Services.

Usually, these referrals are for people that are at crisis point, with risk of carer breakdown. Referrals do not tend to come through as a preventative measure. As an organisation, it is felt that the preventative work would be far more beneficial to carers, as well as being more economically viable.

Future Plans

'Zest for Life' Young Onset Dementia Service (July 2018-July 2021)

This is a new service which is accessible by carers following evidence collated in the Young Onset Pilot Service (October 2016-October 18). A need for appropriate carer support was identified by the pilot project. Specifically, the need for a more flexible service which is responsive and tailored to the needs of the individuals, their carers and support network.

The service aims to further embed the requirements of the SSWB (Wales) Act 2014 by-

- Improving individuals' well-being and promoting outcomes.

- Transforming the way services are delivered- flexible to the needs of individuals and carers and empowering each individual to have a stronger voice, protection and more control of their lives
- Partnership working with statutory, health and third sector organisations.

We have specialist counselling sessions available to individuals, carers and other family members. This is being delivered by a trained counsellor from Torfaen and Blaenau Gwent MIND.

Carers are also able to access telephone or email support.

We will shortly be launching a drop-in group for carers and individuals on a Friday afternoon. There will be specialist information and advice, activities, respite, peer group support. Qualitative and quantitative evidence is being collated on-going.

Age Connects Torfaen Response

We have found through the implementation of the Wellbeing Wales Act that the emphasis is on prevention. However, our services are used at the point of crisis. Earlier intervention and more preventative services are needed, therefore providing the ability to support people before their needs become critical. We are often approached by professionals or carers when they have nowhere to turn, if we had been contacted earlier and services put into place, the carer and their loved one would hopefully not reach crisis point.

We adopt the principles of the Social Services and Well-being (Wales) Act by ensuring that individuals are put at the centre, giving them a stronger voice and control over services they receive.

We believe that there should be more work carried out to encourage working in partnership. Age Connects Torfaen have several well-established models of service provision established, rather than duplicating services partners could tap into the skills, knowledge and lived experiences to enhance services available for service users.

Age Connects Torfaen are constantly reacting to gaps or trends to ensure that we can manage a person’s wishes and feelings. There needs to be a greater emphasis on sharing services and ensuring that the services provided are specialised to suit the needs of the individual.

Appendix 2 – Additional Funding to Provide Respite and Short Breaks to Carers (2017/18)

The number of carers who benefitted from this additional funding and the associated costs

Local Authority: Torfaen County Borough Council

Respite Provided	Number of carers benefitting	Funding allocated to support the provision of respite care
Day Care	21	£725.02
In home respite	44	£7,414.42
Host family respite	14	£3,585.00
Institution/Overnight respite	36	£51,501.77
Total of Above	**115**	**£63,226.27**
Other: Respite Trips or Group Therapy Sessions	579	£27,121.43
Other: (Eg Transport or Room Hire)	37	£6,056.68
Overall Totals	**731**	**£96,404.38**

Appendix 3 – Torfaen Carers Centre Attendance Figures (2017/18)

TORFAEN CARERS CENTRE ATTENDANCE RECORD 2017/18

	Drop in*	Art Class	Media Class	Fun & Games	Dementia Group	Therapy Sessions	Torfaen Youth	Kinship Carers Group	Meetings	Other Carers or Visitors**	Totals	New Referrals
Totals	**650**	**51**	**25**	**43**	**748**	**289**	**55**	**24**	**92**	**135**	**2111**	**90**

* Not including attendance at group sessions.

(Advice, guidance groups,etc)**

C14
Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Gwasanaethau Gwirfoddol Morgannwg
Response from Glamorgan Voluntary Services

Glamorgan Voluntary Services

Response from Glamorgan Voluntary Services (GVS) to the National Assembly Health, Social Care and Sport Committee Inquiry on How much support is there for carers in Wales.

Introduction to GVS

Glamorgan Voluntary Services (GVS) is an independent charity and has a flourishing membership of voluntary and community organisations active in the Vale of Glamorgan. We help to improve the quality of life of people and communities by supporting volunteers, volunteering opportunities and voluntary groups.

GVS delivers an array of quality services to meet the needs of voluntary groups. We are a one stop shop for the voluntary sector. We champion best practice throughout voluntary organisations so that they excel in delivering their aims and objectives.

GVS empowers voluntary groups, providing many channels of engagement and quality services to enable them to excel at serving their communities. Our role is to provide information, advice and guidance on all aspects of volunteering for both volunteers and recruiting organisations.

The Health and Social Care Facilitator in GVS supports the third sector and statutory partners in a number of ways:

- Promoting partnership working within the sector and across sectors
- Promoting third sector organisations and services to statutory partners and vice versa
- Representing the third sector at strategic planning and partnership groups
- Engaging the sector in consultations and engagement about health and social services

1) Background

1.1 The answers in this response will include information on how the third sector provides support for carers, identified gaps, examples of good practice in the Vale and Cardiff and areas for future development.

1.2 GVS facilitates the Cardiff and Vale Carers Support and Information Network Group (CSING) which has been in existence for over 10 years. It began as a Vale group and was expanded some years ago to become a regional group. It provides an opportunity for staff who provide front line carers' services to meet, share information, find out about new services, promote what they do and identify gaps in service. CSING forwards information to the Cardiff and Vale Carers Workstream and other partnerships and planning groups as appropriate.

1.3 GVS, in its role in supporting third sector organisations, has facilitated many engagement and consultation events over recent years. In preparation for the production of the Cardiff and Vale Population Needs Assessment in 2016, we analysed the outcomes of these events, going back to 2012, in terms of themes and identified needs which related to carers and older people. This found that the same gaps were being consistently identified over the years in terms of services for carers. These were transport, access to social activities and peer support, access to information, access to advocacy, respite care especially during emergencies, financial advice including information about Lasting Power of Attorney and a simplified way of finding information about services which are available. We understand that, although this analysis was done two years ago, the gaps remain the same.

2) Answers to Inquiry

Assessment of need

2.1 GVS is aware anecdotally, from our facilitation of CSING, that carers do not always know that they are entitled to have an assessment of need or that the definition of a carer has changed. A major issue is that carers do not always identify themselves as carers and do not therefore recognise that they have rights. There is some excellent awareness raising work in terms of promotion of carers' rights via third sector organisations such as Carers Wales and Carers Trust Wales and by statutory organisations.

2.2 Carers Wales is undertaking some innovative work via their Track the Act survey for carers. This was set up to monitor and gather information on how the changes in the law have affected carers and they produce briefings on the survey results.

"I have been directed to another organisation whose support met my needs, but not by the council. I am not sure whether I have had an assessment. I have support in part. Getting respite is impossible". Track the Act respondent
(Carers Wales, Track the Act, Briefing 2, September 2017)

2.3 Some positive work was undertaken by partners in Cardiff and the Vale (Health Board, local authorities and the third sector) under the Carers Measure in terms of raising awareness amongst health and social care staff about carers and encouraging them to identify when someone is a carer and support them appropriately. To some extent this work lost momentum in the transition from the Carers Measure initiatives to the implementation of the SSWB Act. However, in Cardiff and Vale a positive outcome has been the strong partnership working between staff in the Patient Experience Team in the Cardiff and Vale University Health Board, carers leads in the local authorities and the Health and Social Care Facilitators based in GVS and C3SC and this continues.

2.4 Over the last two years the Health Board, Cardiff Council, Vale Council and GVS have been involved in a project in partnership with, and led by, the Carers Trust South East Wales (SEW). This includes engagement with carers, further work in raising awareness of carers and their need for support and assessing the feasibility of implementing a carers' service in Cardiff and the Vale.

2.5 In relation to carers' assessments, focus groups carried out with carers in Cardiff and Vale, by Carers Trust SEW, found that there appears to be general confusion. Some carers were unsure as to whether they had actually had an assessment and some considered them to be a "perfunctory exercise".

2.6 Both the Vale of Glamorgan Council and Cardiff Council have taken steps to raise awareness of the right to a carers' assessment and this is to be welcomed.

2.7 However, it is clear that there is much more to do in terms of raising awareness of carers rights and this could be further improved via a more focussed and co-ordinated approach to information and advice, by providing information sessions in community settings where carers are and possibly consider resourcing of third sector organisations so they can undertake carers' assessments.

3) Provision of support, including respite care

3.1 As stated earlier, GVS analysed the outcome of engagement and consultation events held over recent years and identified consistent gaps in services for carers. These were transport, access to social activities and peer support, access to information, access to advocacy, respite care especially during emergencies, financial advice including information about Lasting Power of Attorney and a simplified way of finding information about services which are available.

3.2 We believe, from our contact with front line staff in all sectors, that these gaps are still there and we are therefore concerned about the limited progress in addressing these, especially in the provision of respite care (emergency and short term services) and access to information.

3.3 We are aware of various third sector projects which provide respite, either directly or in an indirect way. The Gofal DIAL project in Cardiff and Vale is an excellent example of a project which provides access to interesting and social based activities for people with dementia. Their carers can also attend or utilise the opportunity for a break from their caring role.

3.4 GVS manages the Connected Carers project in partnership with the Parents' Federation and Touch Trust. Connected Carers provides opportunities for social networking and peer support for family carers for people with a life-long or life-limiting condition.

3.5 However, these projects often end up with a waiting list because they are so popular. In addition, they tend to be funded on a short term basis. This highlights some issues in terms of third sector community services. Statutory assessments often result in referrals to third sector services and there is a current emphasis on social prescribing, again often to third sector services. The third sector is ideally placed to support people in their community, but will be unable to cope with increased referrals unless there is an increase in resources.

3.6 With regard to respite for carers of people with dementia, the Welsh Government grant allocated to local authorities provides some funding, but this is for all types of respite and so is spread very thinly. The recent dementia Team around the Individual funding was welcome. We are pleased that there are some grant funding opportunities for the third sector included in the Cardiff and Vale proposals, although this will be for relatively small amounts and short term only. GVS believes that this funding could have been utilised to provide a more sustainable response to the desperate need for respite for carers of people with dementia and we hope that there will be some leeway in the Cardiff and Vale proposals to accommodate this.

3.7 Finally, a recent discussion at a CSING meeting highlighted the following areas where there could be improvement:

- Carers are fed up with consultations, want action and hands on support.
- Both Cardiff and Vale local authorities have seen an increase in assessments – there is no time to do any follow ups.

- IT systems are not compatible and third sector cannot always access statutory systems, even if they are co-located.
- Progress on the development of a Carers Centre.
- Benefits advice/form filling and help with benefit appeals for carers.
- Support for people who want to stay in the workplace.
- Resource/Capacity issues for organisations that are being signposted to.

4) Provision of Information, Advice and Assistance

4.1 Consistently, over many years, carers have expressed concern and confusion about how to find information about their rights and about services which might be able to support them. It is inevitable that any engagement and consultation with carers will find them expressing these views. It is therefore not surprising that many carers have engagement and consultation fatigue and are cynical about anything actually happening in response to their expressed needs. It is difficult to estimate the number of carers who aren't even involved in these conversations, as they will be the carers who do not identify themselves as carers or the carers who haven't yet found out where to go for help.

"You don't know where to turn, where do you find help? I approached many agencies until I found one."
(Carers Trust South East Wales, Carers services support models. Options and best practice standards for developing high-quality carers' services in Cardiff and the Vale of Glamorgan, 2018)

4.2 There have been some positive developments in ensuring a more holistic provision of information. Third sector organisations are co-located with the Community Resource Service in the Vale and Community Resource Teams in Cardiff. Age Connects Cardiff and the Vale has a Third Sector Broker co-located in the contact centre in the Vale. These services provide support and information in response to specific referrals, but cannot act as a dedicated carers' service. GVS believes that it is now time to respond to the expressed needs of carers in terms of their difficulties in accessing information.

"Carers would value a one stop shop where they could get information on support and services for them from one phone number."
(Cardiff and Vale Population Needs Assessment, 2016)

"A one stop shop is an excellent proposal and would do much to alleviate stress of the carer and also enables them to easily be kept informed and access information in a simple, one step manner."
(Vale of Glamorgan Council Adult carers' support and services consultation. Summary of responses and key findings, 2013).

"Of the 19 carers who commented (about the idea of a one stop shop for carers in Cardiff and the Vale of Glamorgan), 17 agreed with this and thought it was good idea. Two carers questioned the location and accessibility."
(Cardiff Council, Adult Carers Support and Services Consultation. Summary of Responses and Key Findings, 2013)

4.3 To this end, the project mentioned earlier in this response, which is being led by Carers Trust South East Wales, in partnership with Cardiff Council, Vale of Glamorgan Council, Cardiff and Vale University Health Board and GVS, has looked at the feasibility of establishing a 'one stop shop' carers' service in Cardiff and the Vale. After taking into account the views of carers, the proposed model would involve a dedicated phone number and email for carers to access, a co-ordinating Hub where staff will be based to deal with enquiries and a series of regular drop in sessions for carers in community settings. The service will integrate with other initiatives, such as the development of Wellbeing Hubs, and will not be a stand-alone service. As such, it is similar to the recently set up Cardiff and Vale Integrated Autism Service; ie a service which responds to the special and specific needs of an important section of our community. A proposal was put forward to the ICF Programme Board in February this year and we await confirmation as to whether funding will be available for this financial year and ongoing.

5) Considering broader Welsh Government policy on carers

5.1 There is no need to document here the vital contribution which unpaid carers make to our society. This is clearly recognised as a fact, and also documented financially in terms of how much unpaid carers save public finances by carrying out their often demanding caring role. However, our collective recognition of this does not always transfer into developing services which support carers and enable them to carry on caring. This appears to be evidenced by the fact that the same gaps in service and same needs expressed by carers keep coming up in engagement and consultation.

5.2 This Inquiry provides an opportunity for some decisive action in relation to supporting carers. GVS would welcome a Welsh Government directive as to how front line, preventative services for carers can be adequately, and sustainably, resourced in localities and regions.

If you would like further information, please contact:

[redacted]

http://www.gvs.wales/

14th September 2018

C15
Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Solva Care
Response from Solva Care

Report from [redacted]
[redacted] Web site www.solvacare.co.uk

I spoke with two people from the village who have cared for many years for relatives suffering for dementia.

MS cared for by son , S.

Suffered early onset dementia. Looked after by son (S) for 7 years (from 2010 to 2017). He has had experience as an ancillary health worker. MS had confused memory loss (Conflation of memories from different times). In the early stages she was physically fit and loved walking and singing. At this period she walked and sang with Solva Care volunteers whom she knew and trusted.

MC. cared for by wife, E.

Suffered dementia from 2006. Then complicated by strokes leading to mental confusion and loss of vision finally leading to blindness. Cared for by his wife (E. 70 – 80s). Daughter supportive but did not live near. MC was a proficient singer, reciter and dancer. He continued to enjoy singing and dancing even after the first stroke and did so at Solva Care's Friday Club until he became too confused to do so.

From what they told me the following problems emerged.

Problems

Lack of sign-posting

E was not given links to useful organisation or advocates until very late in MCs illness. She was not referred to any useful agency or advocacy till 2015 when the psychiatrist suggested a memory café. By chance at this venue M &E met an advocate who proved very supportive.

S. felt entirely on his own with nowhere official to turn

***What would help**. Medical practitioners should routinely give links to useful organisations as early as possible, even before actually needed. Carer will then know where to turn when crisis points arise.*

Lack of practical support.

E. got no support to know how to cope with M's multiple difficulties (visual problems, losing recognition of everyday items such as knife, fork, spoon, night-time wanderings. Written information was far too lengthy and complicated for E to read when under stress and tired. A Carers Assessment form was partially completed but not sent in. "Too complicated. All I needed when he came out of hospital was information on how to cope with a blind person, some pop-in visits and some respite visits."

"Where the client is part of a couple, it is assumed that the other one will be able to cope".

What would help. *Written information and guidance should be given in simple language. Perhaps official forms for assessment etc should have a simple part 1 where applicant explains situation and what support they feel would be helpful. Part 2 could then be completed if necessary (with assistance) to apply for allowances, respite care, residential care etc***Lack of co-ordination between agencies and departments***

On requests for help, agencies were very slow to act and action was usually adding M to a waiting list . Many different people were phoning E which was confusing for her and even for her daughter. Even different departments in the hospital seemed unable to coordinate. Eg. Doctor said appointment should be in 2 weeks, when letter came it said 6 weeks.

S. was told that MS could no longer be part of the group as she was "disruptive".

What would help. *Re-instate the designated social worker (or other designated person) so that the clients situation is understood at least by 1 person outside the immediate family. This could also help with dementia sufferers who might be able to set up a relationship with designated person they know and trust.*

Confusing (or lack of medical) information.

After laser treatment on eyes E was told " Give the eye drops "till they run out". Another practitioner said "Eye-drops are for life".
Staff at the laser surgery clinic were unprepared to answer questions on eye-drops because "they only did laser surgery".

Doctor said MC should not be discharged without a care package. He was discharged without any package or information.

GP prescribed unsuitable drugs that (on investigation by carer) were contraindicated for the condition

" Admission by the authorities that they did not know how to treat the condition and talking therapy would have been more useful me (carer).

What would help. *Written information and guidance routinely given in simple language with contact information and signature. More opportunity for carers to talk with experienced people.about their and their dependent's situation.*

Need for advocacy to cope with the system.

Advocacy service was not sign-posted at all. Advocate (Alzheimer's) was encountered by chance at a memory café. MC's daughter had to fight for suitable appointments and for thorough check-ups. Mother several times said " What would we do without you." Daughter's comment was "Without me Mum would probably be dead."

What would help. *Existence of the Advocacy services should be sign-posted by medical practitioners as early as possible. Carers will then have someone to turn to when critical situations arise.*

Poor administration.

Financially E had to pay for everything. SHethought that both their savings had to be taken into account when it should have been only MCs. She found this out too late.

Pembs Social Services Finance department seemed incapable of providing appropriate timely bills.

What would help*.* . The system for assessing financial aspects is inadequate putting immense burdens on families. It should be simplified and more support give to families earlier to understand their entitlements.

C16
Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Hospice UK
Response from Hospice UK

Health, social care and sport committee inquiry: Impact of the Social Services and Wellbeing Act (2014) on carers

A Hospice UK and Hospices Cymru response

September 2018

About Hospice UK

1.1 Hospice UK is the national charity for hospice care. We champion and support the work of more than 200 member organisations, which provide hospice and palliative care across the UK, so that they can deliver the highest quality of care to people with terminal or life-limiting conditions, and support their families. Our vision is hospice care for every person in need and our mission is to enable hospice care to transform the way society cares for the dying and those around them.

About Hospices Cymru

2.1 Hospices Cymru is the collective voice of Hospice UK members in Wales. This includes the 13 adult hospices and the two children's hospices in Wales. The group seeks to advance hospice care and enable better palliative and end of life care for more people in Wales.

About this response

2.3 We welcome the opportunity to respond to this consultation on the impact of the Social Services and Wellbeing Act (2014) on carers. This response draws on the experience of hospices in Wales supporting carers of people with terminal or life-limiting conditions, and those at the end of life. It also draws on the knowledge and experience of Hospice UK working at a national level and of academic research in the field. We have limited our comments to those issues affecting carers of people with terminal or life-limiting conditions.

Context: carers of dying people

3.1 There is no definitive number, or robust way of working out the number of carers of people approaching the end of life, nor a consistent approach in whether numbers are based on being in the last 12 months or 6 months of life, or by having a terminal diagnosis or life-shortening condition. Estimates vary from around 500,000 to 1 million carers of dying people in the UK.[1] At a Wales level, this is equivalent to between 24,000 and 48,000 carers. This is based on the assumption that of the 24,000 people who die each year in Wales with a palliative care need, each one will have between one and two people caring for them.

3.2 Carers of dying people face unique challenges, including: difficulties coping with the increasingly complex and demanding needs of the person being cared for; having to coordinate care and professionals on a 24/7 basis; having conversations about resuscitation, artificial feeding and stopping treatment; and dealing with loss and grief in bereavement.

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[1] See http://www.ncpc.org.uk/sites/default/files/Who_Cares_Conference_Report.pdf and https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/december-2015/hidden-costs-of-caring.pdf

3.3 For parents caring for children with life-limiting conditions, the caring journey can last several years and will impact on the person's ability to maintain employment and to sustain a family life with partners and other children.

3.4 The nature of caring for a person who is approaching the end of life means that the level of care needed will increase significantly throughout the caring journey. A recent academic study found that in the last three months of the decedent's life, carers contributed a median 69 hours 30 minutes of care-giving each week,[2] demonstrating the substantial responsibility and pressure on carers of dying people.

3.5 Following bereavement, the needs of carers enter a new phase that is as important as their needs while actively caring. Carers can experience a profound sense of isolation, loss of identity and loss of valued relationships with staff of services the cared-for person was using. As many as one in ten carers experience profound grief disorder (PGD) following the death of the person they cared for, which can have serious implications for their mental health.[3] It is therefore important to include bereavement support as part of an ongoing assessment of a carer's needs, to identify whether an early intervention from a bereavement service, including pre-bereavement support, is required.

3.6 The majority of carers of people with terminal and life-limiting conditions will come into contact with health services – hospices and NHS services – in the first instance. It is therefore vital that hospices and NHS services are able to identify and support carers, and to refer them to the local authority for statutory support, where this is appropriate.

How we're supporting carers of dying people

4.1 With this in mind, Hospice UK is supporting the implementation of the Carer Support Needs Assessment Tool (CSNAT), a person-centred, evidence-based approach to carer assessment and support in end of life care.[4] Hospice UK has supported teams from over 50 hospices to be trained in the use of CSNAT. The CSNAT tool is now used internationally and has shown that assessing carers' needs guides more appropriate support interventions; recent studies have found that carers of people at the end of life who were supported using CSNAT experienced significantly lower levels of grief, better psychological and physical health, were more likely to feel the place of death was right, and patients were more likely to die at home.[5]

4.2 In partnership with the University of Manchester, Hospice UK is researching practices at UK hospices with regards their support for carers. The first phase of this research outlined ten recommendations to hospices for providing comprehensive, person-centred assessment and support for family carers towards the end of life, including:

4.2.1 Consistent identification of carers
4.2.2 Routine identification of carers' needs
4.2.3 Training staff in carer assessment and support
4.2.4 More time available for staff to support carers

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[2] Rowland, Christine; Hanratty, Barbara; Pilling, Mark; van den Berg, Bernard; Grande, Gunn.'The contributions of family care-giving at end-of-life: a national post-bereavement census survey of cancer carers' hours of care and expenditures.' In: Palliative Medicine, Vol. 31, No. 4, 01.04.2017, p. 346-355.

[3] Marie Curie, (2015) 'The hidden costs of caring'. https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/december-2015/hidden-costs-of-caring.pdf

[4] See the CSNAT website. Available at: http://csnat.org/

[5] Røen, Ingebrigt ; Stifoss-Hanssen, Hans ; Grande, Gunn; Brenne, Anne-Tove; Kaasa, Stein ; Sand, Kari ; Knudsen, Anne Kari 'Resilience for family carers of advanced cancer patients—how can health care providers contribute? A qualitative interview study with carers.' In: Palliative Medicine, 2018.

4.2.5 Setting up a system to record carer information separate from the patient so that the carer is seen as a beneficiary in their own right.[6]

4.3 The work of this project is on-going. The next phase is a national survey of carer assessment and support within UK hospices. The purpose of the survey is to understand the current provision for carers in organisations which focus on palliative and end of life care, highlight examples of best practice and identify gaps in service delivery. Results of the survey will be published towards the end of 2018.

Hospice support for carers in Wales since the introduction of the Social Services and Wellbeing Act (2014)

Assessments of need

5.1 Carers of adults with terminal and life-limiting conditions are likely to see a health body – either a charitable hospice or an NHS service, including primary care – as their first point of contact, rather than the local authority. With this in mind, there is a responsibility on palliative care providers to identify carers and proactively support them. Carers of children with palliative care needs are likely also to be in contact with further statutory agencies to support the child to meet their social care and education needs but children's hospices will be in an expert position to advise and support families with a dying child.

5.2 For charitable hospices, there is no statutory requirement to undertake an assessment of carers' needs, though many hospices will employ qualified social workers or family liaison teams who will have expertise in this area. Each hospice will take a different approach to assessing carers' needs, dependent on hospice resource and capacity and on the local connections with the local authority, health care and other third sector providers of support for carers.

5.3 While some hospices in Wales will make an informal and proportionate assessment of a carer's needs, signposting the person to relevant third sector organisations for support or referring on to the local authority for a formal carer's assessment, other hospices have formalised their approach to assessing carers' needs and are able to intervene to support carers and families prior to the engagement of statutory local authority support.

5.3.1 Nightingale House Hospice – a case study

5.3.2 Hospices across North Wales have had access to a train the trainer course on implementing CSNAT, which has been promoted and funded by Betsi Cadwaladr University Health Board (BCUHB) across its NHS and charitable end of life services. Following this initiative, Nightingale House Hospice in Wrexham has cascaded the training on this approach to carers' needs assessment through ensuring that all members of the clinical team have CSNAT training as part of their mandatory training. This means that their day therapy unit and their family support team (those teams that support patients residing in their own homes where there is likely to be a carer(s) involved) are systematically identifying and assessing the needs of carers of dying people.

5.3.3 This initiative is in its early days, with the approach gradually being rolled out since 2017. However, initial data suggest that, of the 55 carers who were assessed using the CSNAT initial questionnaire, 80 per cent went on to have a full interview with a trained professional to thoroughly assess their support needs. Of these, around two thirds (66 per cent) received action plans to support them in their care journey. Notably, 11 per cent of people identified as carers chose not to engage with the offer of an assessment and five per cent were unable to engage in the assessment process because the person they cared for was too ill or had deteriorated

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[6] See the full report and recommendations at: Ewing G and Grande GE. 'Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change.' London: Hospice UK, 2018.

rapidly, demonstrating the particular challenges in accessing and supporting carers of dying people.

5.3.4 The support offered to those carers who were assessed as requiring action plans to enable them to maintain their caring roles ranged from referrals to coffee mornings at the hospice specifically set up for carers (including some specifically to support carers of people with designated conditions) or to 'Looking after me' wellbeing and resilience sessions; to referrals to third sector organisations offering befriending and sitting services; or, where it was deemed the person may be eligible for support, to the local authority for a carers' assessment under the Social Services and Wellbeing (Wales) Act.

5.4 Across the country, hospice employees leading on carers' needs – such as social workers and family liaison teams – report a greater awareness of statutory carers' assessments and, in some cases, report that local authority carers' teams are reaching out to hospices to improve access to carers of people with terminal or life-limiting conditions. However, there is no clear data to demonstrate whether this has translated into a greater number of carers of dying people being given a full statutory carers' assessment. Anecdotally, we hear that assessment remains informal and carers are likely to be signposted to third sector support networks as opposed to the local authority to determine their eligibility for a formal support plan under the Social Services and Wellbeing Act.

Provision of support, including respite

5.5 Hospices offer a range of support for carers, depending on the hospice's resource, capacity and set up and the local availability of dedicated carer support services. With the make up of hospice service models varying greatly across Wales – for example, either primarily as an inpatient facility or primarily as a hospice at home service (with no bedded facility) – there is no standard service offer for carers from hospices across Wales and, consequently, the offer of service varies between areas.

5.6 Common carer support services include:

5.6.1 day hospice activities, which can be for carers only or for patients and carers to attend together

5.6.2 befriending or sitting services, where a volunteer or trained professional (dependent on the patient's clinical needs) visits the patient in their own home, allowing the carer to have time to themselves

5.6.3 wellbeing activities, such as complementary therapies

5.6.4 pre-bereavement and bereavement support, which can range from informal group coffee mornings to specialist one-to-one counselling

5.6.5 specific carer support initiatives, for example art therapy groups, cooking and nutrition support

5.6.6 formal respite schemes (see below)

5.7 With regards to the provision of respite specifically, the hospice service model will have a greater impact on the service offered. For example, Shalom House in Pembrokeshire primarily serves as an inpatient respite facility, offering stays of up to five days for the people it cares for; Marie Curie in Penarth have offered a volunteer-led sitting service, which provides a block of three hours respite for carers each week; and the majority of hospices (whether bedded or not) offer day centre activities for patients, which double as respite for the carer.

5.8 While some aspects of the support for carers (such as an inpatient stay) will be partially funded through statutory sources, the vast majority of carer support provision will be funded through charitable giving and grants. All hospice services are free of charge to those using them.

Provision of information, advice and assistance

5.9 Hospice staff play a crucial role in directing carers to local authority information, advice and assistance facilities as well as in the provision of informal information, including signposting to relevant agencies.

5.10 The majority of hospices state clearly that they offer support to families and carers as well as to the patient. However, while most people are aware that hospices provide medical care, far fewer are aware of the wider services on offer.[7] This limited perception of hospice services extends to other service providers as well as the public, which has implications for local authority information, advice and assistance services and may mean that fewer carers accessing this service are informed of how their local hospice could support them as well as the cared-for person.

5.11 There is a responsibility on hospices and local authority information, advice and assistance services to promote and raise awareness of the variety of services offered by local hospices – both to people with palliative care needs and their carers.

Information collected by local authorities and health boards on carers and their needs

5.12 Of the seven published regional statutory population needs assessments under the Social Services and Wellbeing Act, only one (West Wales Region) refers in any detail to carers of people at the end of life and one other (Cardiff and the Vale Region) tangentially touches on this group of need with reference to the impact of bereavement on older people.[8]

5.13 Hospice UK strongly advocates that the needs of carers of people with terminal and life-limiting conditions are addressed in future statutory population needs assessments under the Social Services and Wellbeing Act. This should include an assessment of need, unmet need and provision of services such as:

5.13.1 Services for families with children with palliative care needs, including for siblings

5.13.2 Bereavement support, including pre-bereavement and specialist counselling

5.13.3 Respite, including inpatient facilities and sitting services.

5.14 Hospice care providers in Wales should play a part in supporting local authorities and health boards to collect the relevant data on people with terminal and life-limiting conditions, and their carers, that will inform future assessments of need.

For further information

6. Please contact [redacted], based at [redacted]

[redacted] [redacted] UK and ComRes 'Hospices survey: 7-8 August 2017' http://www.comresglobal.com/wp-content/uploads/2017/10/Hospice-UK_Public-Perceptions_Data-Tables_part-1_October-2017.pdf

[8] See the published Statutory Population Needs Assessments by each region for further detail.

C17

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr

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

Ymateb gan Gyngor Abertawe

Response from Swansea Council

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

Swansea Council's response

Western Bay (formerly ABMU) Carers Partnership Board comprises representatives from ABMU Health Board; Swansea Council is one of the three local authorities, Third Sector and Carers Service/ Centres. The Board has been working together since 2012 to increase Carer awareness, engagement and assisting carers by providing information, advice and support.

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

There had been some fluctuations in the number of carers assessment recorded within Swansea Council since the introduction of the Social Services and Wellbeing (Wales) Act 2014.

Adult Services

	Number of Carers identified in assessments of the cared for person	**Number of Carers offered an assessment**	**Number of Carers wanting an assessment**	**Number of reviews of Carers assessments undertaken**
2015	1139	1091	445	445
2016	1364	1314	522	550
2017	547	516	180	629

2018 (1st half)	678	604	232	370

Child & Family Services

	Number of Young Carer assessments undertaken
2015/16	29
2016/17	2
2017/18	17

Swansea Social Services wish to point out that numbers of completed assessments recorded decreased during 2017. This corresponded withchanges made to the assessment tool created to meet the requirements of the Act. During the pilot and implementation stages, for technical reasons linked to the development of the database it was not possible to gather the number of assessments completed through the recording system; this was also the case for assessments of young carers in this area.

This issue has been resolved with indications that there has been an increase in completed assessments.

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

Information, advice and assistance (IAA) is provided directly. The Adult Common Access Point work to provide the right response at the right time. Anyone can contact the information, advice and assistance services to have a discussion and get help. The teams will listen to whoever calls including carers and let them know what information, advice, or assistance can be provided and who can help from a range of different agencies including council services, third sector, health and the police.

Information is also available on the local authority websites this includes a range of fact sheets and leaflets., During 2017/18, 1,271 people viewed these pages. We also utilize social media, printed material and the Wales National Dewis website.

In Swansea, information, advice and assistance can be accessed via Central Children's Information, Advice and Assistance. Swansea commissions a number of services from third sector organisations for the benefit of carers including a range of respite options and a dedicated service for young carers.

Swansea Social Services commission a number of services from third sector organisations for the benefit of carers including a range of respite options and a dedicated youth club for young carers run by the local YMCA; the local Carers Centres and Carers Service, to provide a variety of services for carers of all ages including information, advice and support. In Swansea during 2016/17 there were 5,481 recorded contacts by carers to Swansea Carers centre; of those 1,111 were carers not know to the service. Two news letters are produced per year, they are distributed to approximately 4000 carers. Information, advice and assistance is provided to carers over the telephone, home visits, outreach sessions and events.

Transitional funding and Integrated Care Fund alongside other funding has been used to enable local Carers Centres and Carers Service to provide information and support services to carers within hospitals including mental health and palliative care units in the Abertawe Bro Morgannwg University Health Board area.

There were over 2000 carer contacts last year as a result of Hospital Outreach and working with Community Resource Teams.

During 2017-18 carers' information and awareness raising sessions were delivered at a number of Protected Time for Learning Sessions for staff who work in Primary Care. All areas ran awareness sessions for GP practice staff and provided signposting and information within GP surgeries including 'on screen' messages. Practices received regular information and copies of the local Carers Centres and Carers Service newsletters. This work was funded from a range of sources including Transitional funding.

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

Western Bay in partnership with local authorities and local health board undertook a population assessment, which included 'Carers who need support'. Each local authority provided a range of information to inform the regional findings.

Numerous activities have been undertaken for example:

At the Swansea 'Carers Rights' event in November 2017 carers were asked:

- What is going well?
- What are you worried about?
- What needs to happen next?

The views of carers at this event will help inform the co-production of a Swansea Carers Action Plan. This will be developed during 2018/19 and as well as addressing feedback provided by local carers will also address local and regional priorities identified via the population assessments and via the Western Bay Carers Partnership Board.

A series of Parent Carer events and workshops have been held to explore what a new parent carer forum in Swansea could look like. Parent carers have been involved throughout the whole process to create a new forum. This resulted in a tendering exercise to commission an organisation to facilitate an independent parent carer forum. The future service is expected to provide parent carers with information, advice and assistance as well as acting as a voice for their views.

The Young Carers Project in Swansea has received additional funding via the Integrated Care Fund to undertake work in schools. One of the objectives of this work is to secure a better understanding of the needs of young carers in Swansea.

Swansea Council also fulfils its statutory requirements with regards to reporting carers' information in the form of performance indicators and the annual Welsh Government carers citizen survey.

Other changes since the Act came into force which may impact on carers, for example changes to the services provided to people who are cared for

Swansea Carers Centres and Carers Service providing information, advice and assistance (IAA) to carers at hospitals in the area and work with Patient Advice and Liaison Service (PALS) and Patient Experience and Advice Service (PEAS) Teams. Collaborative working and integration is proving to have a positive impact on carers.

In Swansea, there has been a number of changes including the development of an overarching service model for adult social care to deliver requirements of the Social Services and Wellbeing (Wales) Act 2014. The Sustainable Swansea programme and the local authority's corporate priorities were agreed in June 2017. The needs of carers are considered within the model to ensure they have appropriate levels of support. This includes:

- Access to Information & advice
- Peer support
- Flexible and accessible sitting services
- respite care

Other changes that has happened in Swansea since the Act include:

- Development of new assessment tools to capture the 'What matters to me' conversation
- Introduction of charges to ensure future services are available and sustainable i.e. respite at home, day services
- Carer Champions have been established within the Adult Services Hubs
- Commencement of a review of commissioned carers services to establish best value and ensure services continue to be fit for purpose.

- A review of commissioning arrangements for carers services with a view to establishing a commissioning structure, priorities and action plan for carers services during 2018/19.

Child and Family Services in Swansea has undertaken a commissioning review of services delivered for children with a disability and their families. This made a series of recommendations which we are in the process of implementing, e.g.:

- Increase the capacity of in-house home support service
- develop an early help service for children with additional needs
- move additional resources into service areas responsible for early intervention

Support and Respite Service for Carers

Adult Services understand that respite care and short breaks have an important role in maintaining the well-being of both the carer and the person with care needs. Supporting carers helps prevent crisis, improves their physical and mental health and ensures the well-being of carers and those they care for. These principles underpin the local authority's model of care by enabling people to live as independently as possible, preventing escalation and avoidable crisis and optimising use of limited resources.

Swansea Social Services delivers a range of respite care to support carers (including young carers) through:

- Direct Payments
- Day care - a service provided outside the home without any elements of overnight stay for the carer or recipient of care
- In home respite - a (paid) care worker coming into the family home to 'sit' with the care recipient
- Host-family respite - the carer and care recipient take a break together, staying with a 'host family'
- Institutional/overnight respite - allows breaks away from the family home for the care recipient for one or more nights

Findings of Support and Respite for Carers 2017/18

Our findings and conclusion were as follows:

- The majority of current services provided for respite care are directed at the 'cared for person', this provides an opportunity for the carer to receive a break. Some carers have commented that services make assumptions that carers need a break from the people they care for but that some carers have commented that they would like support to attend events or activities with people they care for or that they may be interested in attending support groups with other carers, both with and without the people they care for. Thus it has been identified there may be gaps within the service to support the carer directly in alternative ways.
- Respite care for older people within day services has slightly decreased throughout this financial year by 3% and residential overnight respite by 7.5%, this may be due to the range of alternative types of support that are now available and the increased take up of other opportunities which has resulted from awareness raising.
- Overnight respite care at one in house service (Ty Cila) has increased by 10% during the financial year. Some remodelling of existing capacity to increase access to respite where services are at full capacity will be considered.
- In Home Respite has increased during 2017-18, delivering an additional 1460 hours. The busiest months being March, May and June.
- Respite care through our Direct Payment Service has seen a slight increase throughout the year with an average of 2 younger adults and 7 older people receiving short term respite, and an average of 15 older people and 11 younger adults receiving day care respite at any point in time throughout the year. Demand for short term direct payments for respite is greaterfor carers who look after elderly people than it is for carers who look after younger adults.

- Residential overnight respite for all Learning Disabilities and Physical Disabilities at in house and external provision has increased with a total of 438 clients receiving this service during 2017/18

- Feedback from carers indicates that the Carers Rights Event was extremely beneficial by raising awareness of services and by bringing carers in similar situations together, which provided an opportunity for mutual help and support.
- Carers Champions (a role adopted by selected Social Services Care Management Officers) continue to develop their own specialist knowledge in order to continue to provide ongoing help and support to carers and their families.
- Overall, there has been a general increase in Respite Care across the services listed above in 2017-18. The additional costs of providing additional respite care, over and beyond the grant allowance, have been met by the City and County of Swansea.

Swansea's Recommendations

Swansea Council will continue to evaluate carers' services as part of ongoing business as usual arrangements and will develop and improve options for meeting carers' needs where appropriate. The following have been highlighted as areas for potential development and will be considered for inclusion within a carers commissioning action plan to be developed in partnership with key stakeholders during 2018/19:

- Availability and affordability of transport to and from respite care, as this is a recognised barrier to many people who provide care
- Establishing carers self-support groups
- Access to training courses for carers which help to manage caring responsibilities

- Use of in-house overnight respite to increase access where certain services are at full capacity, and possible development of additional respite and short stay provision for people with complex needs
- Continue to improve networking with key stakeholders to promote carers rights and opportunities, engage support staff around carers'

rights, identify carers earlier and promote access to services so that prevention and early intervention objectives are achieved

- Continue to raise awareness of the Carers Act and assist carers to understand what is available to them
- Continue to promote awareness amongst other commissioned service providers of their duties as an employer in relation to carers and promote awareness and understanding of issues affecting carers
- Evaluation of breakdown of carer / cared for arrangements and impact on hospital admissions and other forms of more intensive managed care

In respect of Children's Services, we are currently in the process of implementing a commissioning review of child disability services. This includes the following actions:

- Re-tender of the residential overnight short break service with greater capacity to deliver day care sessions from the home
- Expansion of our in-house Home Support Service (Flexible Support Service)
- Co-production of a Parent Carer Forum
- Joint commissioning of play and leisure opportunities, including service offering respite during the day
- Pilot of a designated early help service (key worker team) to support families with a child with a disability

The City and County of Swansea will continue to strive towards promoting respite care services throughout Swansea, building ' A life for carers' as the people 'they care for' will also have a better quality of life.

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

Suggestions on how Welsh Government policy on carers maybe developed include

- co-producing policy in partnership with a wide range of carers of all ages
- recognising the challenges that come with short term funding at very short notice and consider 3 to 5 years funding which would enable more effective planning of services resulting in sustained and consistently delivered services.
- have one large grant for carers rather than a number of individual grants. One larger grant for carers would be easier to administer and monitor and would support more strategic commissioning.
- a commitment from Welsh Government to continue funding specifically for carers so that services for carers are more security and stability.
- The religious and non-religious spiritual needs of people, and the resources which support them should be given consideration on the refreshing of the 2010 Spiritual Care Standards as well as updating the supporting guidance within the 2015 Health and Care Standards on spirituality that includes carers to realign with the Act in addition to improving the health and wellbeing of the citizens of Wales
- A seamless service for young carers to adult carers. Young carers should have access to the same services as adults for support. young carers services can be time limited, adults are not.

Alzheimer's Society Cymru
Unedig Yn Erbyn Dementia
United Against Dementia

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Alzheimer's Society Cymru
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18 September 2018

Ref: Health, Social Care and Sport Committee inquiry into the Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers: Alzheimer's Society Cymru response

Dear Dr Lloyd,

I am pleased to respond on behalf of Alzheimer's Society Cymru to the Health, Social Care and Sport Committee inquiry into the Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers. Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia. Alzheimer's Society Cymru welcomes the Committee's interest in the impact of the Social Services and Wellbeing (Wales) Act 2014 on Carers. Evidence for this document was collected by a mixture of desk based research and anecdotal evidence collected from Alzheimer's Society frontline staff in the period 13 August to 10 September 2018. The evidence was collected from across Wales.

Overview

1.1 The evidence provided by staff suggests that Carer's Assessments are seen as inconsistent and tokenistic.
1.2 The well-publicised issues around funding continue to persist in Wales.
1.3 Statutory Service staff and unpaid carers are doing the best job possible in the current climate.
1.4 The sharing of information between Local Health Boards, local authorities and third sector organisations is poor and in need of improvement.
1.5 Guidance from Local Health Boards, local authorities and third sector is in need of standardisation to prevent confusion.
1.6 There are not enough services, and those services do not have enough resource.

Assessments of Need

2.1 The Adults receiving care and support in Wales Report, 2016-17 from Statistics Wales reported that 6864 carers refused an assessment. [1]
2.2 Further discussion with Statistics Wales revealed the reasons for these refusals were not reported on, or not recorded.

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[1] Adults receiving care and support in Wales, 2016-17 (Experimental statistics), Statistics Wales, 31 October 2017. First Accessed August 2018

Mae'r Gymdeithas Alzheimer yn elusen gofrestredig yng Nghymru a Lloegr (296645) ac ar Ynys Manaw (1128)
Cwmni cyfyngedig gan warant, cofrestrwyd yng Nghymru a Lloegr (2115499) ac ar Ynys Manaw (5730F)
Swyddfa gofrestredig: 43-44 Crutched Friars, London EC3N 2AE.

Alzheimer's Society is a registered charity in England and Wales (296645) and the Isle of Man (1128)
A company limited by guarantee, registered in England and Wales (2115499) and the Isle of Man (5730F)
Registered office: 43-44 Crutched Friars, London EC3N 2AE.

2.3 Anecdotal evidence from Alzheimer’s Society frontline staff revealed that most local authorities have a long waiting list, and it is often a case of “take a ticket and wait for your number to be called.”

2.4 Evidence also suggested that the assessments are being done over the te lephone as opposed to face to face, meaning that the assessor is not getting the full picture and situation of the carer being assessed.

2.5 Staff also reported that often carers are asked what they want out of an assessment and that carers often come away with a carer’s passport or carer’s card.

2.6 Reasons given by staff for this included the stigma of talking to Social Services; the fear that Social Services will remove the person being cared for if the carer cannot cope and that Social Services are seen as an extension of a figure of authority and carers are afraid to question or fight for something they need.

2.7 This has been echoed by staff across Wales who have commented that Social Services have passed the responsibility onto the carer. One example came from North Wales were staff commented that Social Services are asking carers to complete the ‘What Matters’ f orm, something that Social Services used to do themselves. Staff reported that this has led to an inconsistent service and inequitable access.

2.8 Evidence from staff also suggested that the new system has put greater expectation on carers to meet the needs of the person being cared for themselves.

2.9 However, comments from other staff indicated that Social Services have become easier to deal with and there has been an attitude change towards making things easier for the carer to be assessed and access the support needed.

2.10 Overall, staff expressed concern that whilst the new system has led to some improvements, it is patchy at best, and often feels inconsistent and tokenistic to the person being assessed.

2.11 Staff were also concerned that the Carer’s Assessments only focussed on the immediate position of the carer and not any potential needs in the future.

Provision of support, including respite care

3.1 The overarching thread that emerged from evidence given by staff and from desk research is that Social Services staff are doing all they can to support carers and the people they care for in a challenging situation.

3.2 Evidence from staff indicated that in theory everyone understands the need for the community to do what it can before statutory services step in, but in practise people generally only ask for help when they are really in need and cannot do any more.

3.3 An example was given where respite wasn’t approved for a Carer of a Person with Dementia who is prone to violent outbursts as the Council and carer were unable to fund the respite place despite the chosen facility having space and the service user wanting to go there due to past positive experiences.

3.4 An example was also given of Denbighshire cutting their respite care provision to half, with the Council outlining that the full eight weeks are only available in exceptional circumstances.

3.5 This has led to a situation where volunteer led services are attempting to fill in the gaps in the care, with befriending services asked to go in and provide respite care. Staff have said that there is an over reliance on this.

3.6 Concerns have also been raised about making sure that respite care is age appropriate. What is considered appropriate for older people living with dementia is not always appropriate for those living with early onset dementia.

3.7 Worries have also been raised on the accessibility of respite care, particularly in rural areas; with our report ‘Dementia in rural Wales: The lived experiences’ highlighting the issue, with one carer saying that: ‘They say he can go to a residential setting for respite, but that I need to take him to it and pick him up. By the time I’ve driven there and back, it’s not really giving me a break or for the purpose it’s intended.’[2]

3.8 Anecdotal evidence on taking respite together was also heard, with staff commenting that often, carers and the people they care for would like to have a holiday or break together, but are unable to do so due to a lack of options or availability of help whilst on the break.

3.9 Evidence from staff suggested that this gap is growing due to funding pressures on local authorities, with suggestions that those who can afford to pay for respite care are getting a more comprehensive service than those who cannot.

3.10 Issues were also raised with the state of respite facilities available to carers and people they care for, with staff giving examples of carers refusing to take up respite due to negative experiences in respite homes.

3.11 This has led to safeguarding issues coming to the fore in discussions around respite, with concerns that care plans are not being put in place and followed for respite care.

3.12 There were also concerns raised with the speed of response to advance requests for respite care, with an example given of a carer who had put in a request for respite for a pre-planned trip, but not hearing if respite was granted until 48 hours before the trip, adding to concerns about the person being cared for.

3.13 Finally, staff expressed bewilderment that self-neglect is not recognised as a form of abuse in Wales, and expressed a wish that this should be recognised as soon as possible.

Provision of information, advice and assistance

4.1 Staff reported that the information that exists currently is of good quality, but the people trying to either provide it out or make use of the information are being hamstrung by systems, regulations or funding.

4.2 An example of this was given whereby an assessor asked for signposting advice from the third sector as they didn’t know what services were available in their area. Whilst the information was available, joined up access to it was not, leading to this confusion.

4.3 A further example was given of trying to contact the C1V service in the Vale of Glamorgan. The caller wished to report a safeguarding issue, but was faced with a 15 minute wait and a staff member, who, whilst trying their best, were unable to understand the full issues due to a lack of information.

4.4 Evidence from staff suggested that this lack of information, and joined up access to it, has led to a much deeper questioning of the carer’s ability to provide care and the carers wider support network.

4.5 This line of questioning simply adds to their burden. People feel obliged to agree to providing support which they are not able to fulfil and get closer to crisis, despite information about helpful services existing.

4.6 Where this information exists, but is held by the third sector, staff evidenced that whilst there was a need to show a connection with the third Sector, it felt like a tick-box exercise as consultations with potentially valuable allies were going on after the majority of a plan or assessment had been finalised.

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[2] Alzheimer’s Society Cymru – Dementia in rural Wales The lived experiences - https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/dementia_in_rural_wales_the_lived_experiences.pdf - First Accessed September 2018

4.7 Finally, staff also evidenced that there have been occasions when safeguarding complaints have not been upheld as they have been told that “carers can just walk away.” This comment was echoed by staff working in various local authorities.

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

5.1 The overwhelming evidence given by staff here is that third sector organisations and Local Health Boards & local authority services are speaking different languages. Staff evidenced that this includes different policies and different structures and suggested that there is a need for some form of standardisation.

5.2 Evidence also emerged that there is a lack of signposting and that it often seems that services are talked about and offered to people on a ‘need to know basis.’

5.3 An example of this was given of a multi-disciplinary team meeting where each person at the meeting had their own agenda and were actually arguing amongst themselves to fight for their own services, as opposed to offering and producing the best services for the person in need.

5.4 A further example of this disconnect came from Rhondda Cynon Taf where people who have been diagnosed with dementia don’t know the type of dementia they have been diagnosed with. Staff commented that this lack of sharing of information leads to increased service pressures.

Broader Welsh Government Carers Policy

6.1 Evidence from staff suggested that carers are struggling to have their caring for the elderly or people living with dementia taken as seriously as childcare by employers. Staff also commented that they felt there is a need to destigmatise care for those living with dementia, with one comment suggesting that “there is more understanding of caring for a child than of caring for an elderly person.”

6.2 Comments suggested that there should be a push to enshrine carer’s rights in workplaces to attempt to combat the problem outlined above.

6.3 Staff then suggested that the definition of a dependent needed to be expanded to ensure that people living with dementia or other unseen disabilities can fit into the category to allow their carers access to the same right as those who fit into the current definition.

6.4 Evidence from staff also suggested that unpaid are carers effectively taking on a full time job with no training, and that a programme of training in skills such as manual handling, medication, finances and other useful skills should be created and rolled out nationwide.

6.5 Evidence from staff also suggested that there seems to be a system of “crisis management, not crisis prevention” meaning that local authorities and Local Health Boards were willing to let people reach crisis point before intervening rather than fix it in advance.

6.7 Comments suggested that the majority of policy on dementia focuses on the individual with dementia, rather than the team around the person. We believe that this needs to change, and the carers need to be brought more into focus in order to improve the care received by people living with dementia, both in the home, and in more formal settings such as hospitals or care homes.

6.8 Finally, concerns were raised about people with dementia who are also carers in their own right. This group of carers are often overlooked in the wider carer’s policy, and we believe that this needs to be rectified.

Recommendations

7.1 Alzheimer's Society recommends the creation of new guidelines to be rolled out nationwide to standardise and futureproof Carers Assessments.

7.2 The Welsh Government should consider issuing guidance recognising self -neglect as a form of abuse, as is the case in England.[3]

7.3 The expansion of the definition of dependent to include those living with dementia and other unseen disabilities to allow their carers to access the same help and support in the workplace.

7.4 The creation of a training programme for carers to equip them with the skills necessary to provide the best possible care for as long as possible to those they care for.

7.5 The implementation of a social care levy as outlined by Professor Holtham in order to boost the ailing finances of the social care sector in Wales.

7.6 The inclusion of people living with dementia as carers in all carer's policy and thinking going forward.

Conclusion

We welcome the Health, Social Care and Sport Committee's interest in the important topic of the impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers. Whilst the evidence outlined above may seem overly negative, we are aware that there is plenty of good practice undertaken by carers; those who work with them; those who provide information, support and advice; and those who offer services to carers.

What we have sought to achieve with this evidential submission is to outline to the committee where there are areas for improvement and to try and offer solutions to these issues. We are acutely aware of the issues that surround the funding of Health and Social Care in Wales and have aimed to provide solutions to these issues that fit into the current funding structures.

We hope that evidence contained in this document is informative and will help the committee accurately examine the impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers.

If you require any other information, please do not hesitate to contact me.

Kind regards

[redacted]

Country Director, Alzheimer's Society Cymru

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[3] https://www.scie.org.uk/safeguarding/adults/introduction/types-and-indicators-of-abuse#self-neglect

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 states[1] 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.

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[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

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[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 themselves[3]. 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 anxious[4]. 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 health[5].

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

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

[4] Carers Wales (2015): *State of Caring 2015*. 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 needs[6]. 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 by[7]. 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.

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[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:

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[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 companies[9].

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

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[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.

C20

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr

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

Ymateb gan Unigolyn

Response from an Individual

Dear Sirs.Madames,

In response to the call for comments and feedback related to carers and their charges, I have jotted down some notes that, due to time constraints i have not been able to fully flesh out in a document that directly related to the Social Services and Wellbeing (Wales) Act 2014.

However, here are some of my thoughts, which I hope will be taken on board.

'Social prescribing' has been touted as the future of healthcare and wellbeing and research supports its efficacy within the community - to some degree. However, there is no point in knowing the best way forward for future-proofing the healthcare service - especially for an ageing population - if resources (including better financial support for unpaid carers to continue to give up their own employment and risk short-term and long-term poverty) are not provided for. The social and financial risks for this group is higher than most people can possibly imagine.

Feelings are contagious. The caregiver and his/her charge feed feelings into each other - they jump from person to person, so depression and anxiety experienced by one are felt by both. Carers cannot suppress their own feelings about their life changes and new responsibilities without causing the elevation of stress hormones in their own bodies which sometimes can be so overwhelming that the coping strategies they have developed along the way fail. Immune systems are compromised, anxiety and anguish levels rise. It is hard to feel that I am surviving , let alone thriving. I often feel that my life is drifting away and getting smaller by each mundane task I undertake. Despite my best efforts to continue study and education to augment skills and training in order to earn a living again in the future, much of what I do on a daily basis has little to do with my own life goals - ones that I have worked hard to achieve all my life, and without social or financial security waiting at the end of it.

What live-in carers need is respite for themselves and actively involved, highly QUALIFIED and EXPERIENCED support workers who can suggest practical advice on how to relieve the stress of caring for an ageing parent. It is a full-time, unpaid job, is absolutely draining, especially when you don't get to 'escape' to your own home and switch off. It is a problem for many live-in carers with elderly parents, and is only going to get worse as we all become older and require support.

Thank you.

[redacted]

C21
Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Gyngor Sir Gar
Response from Carmarthenshire County Council

Carers' Assessments

Carers Assessment is still a matter of hit or miss across the divisions, across organisations and across Wales.

370,000 people in Wales are carers, giving unpaid support to loved ones who are older, disabled or seriously ill. A third are older people and 24,000 are over the age of 75. But Sarah Rochira told the assembly's health committee just 6,200 people were given an assessment and only 1,200 were offered support last year.

Older People's Commissioner Wales

The SSWBA has removed the eligibility criteria of 'regular and substantial' and introduced the notions of holism, joint assessments and proportionate assessments. Whilst the idea of joint assessment is a new concept it can also speed the process and serve the organisation as opposed to the service user and their carer. Practitioners will be doing combined assessments because the law allows them to and effectively the process ticks the box for carer and cared for. However, there is a risk (unsubstantiated as yet) that the assessment process will fall back to the situation where the cared for person's needs are prominent and the carer's secondary, with the carer not being offered a thorough assessment whilst their contribution is expected and assumed.

This paper justifies the logic of separate assessment as a basic principle of best practice that doesn't allow for misconceptions or shortcutting the process and offers solid reasoning why carers' assessment must follow comprehensive service user assessment and **come before any care planning can take place**. It is targeted at the assessment of adults and their carers as there is no legislative responsibility for one adult to care for another whereas disabled children remain the responsibility of their parents until adulthood – a fundamental difference.

1. Assessing service users

   Assessment is the process of gathering facts and information about an individual's capacity to function, their strengths and their weaknesses. However, custom and practice seems to have diluted the process which has become an examination of what we need to do to keep the person at home with their family and as independent from services as possible to reduce the burden of cost (it is acknowledged that many people don't have family or carers). This has effectively reduced the carer's role to one that is expected, assumed and rarely officially recognised as a partner provider.

   Blind assessment has been a concept for many years and featured in the guidance to the Unified Assessment Process in the early 2000's. Essentially this is about assessing the cared for person in isolation. Isolation from their family and carer(s) determines that a person’s total needs are assessed without any consideration of the contribution of their informal support.

Roper, Logan and Tierney developed a model of nursing based on holistic assessment of the individual and their ability to self-care. This paper proposes that a similar approach is fostered across social care teams where service users have their total functioning capacity assessed and their deficits identified.

2. Areas for assessment

Roper’s model looks at the following:

- maintaining a safe environment
- communication
- breathing
- eating and drinking
- elimination
- washing and dressing
- controlling temperature
- mobilization
- working and playing
- sleeping
- sexuality
- death

These are termed: Activities of Daily Living and according to the model, there are five factors that influence the activities of living. The incorporation of these factors makes it a holistic model. If they aren't considered, the resulting assessment is incomplete and flawed. The factors are used to determine the individual patient's relative independence in regards to the activities of daily living.

They are: biological, psychological, sociocultural, environmental, and politicoeconomic. The biological factor addresses the impact of the overall health, of current injury and illness, and the scope of the patient's anatomy and physiology. The psychological factor addresses the impact of emotion, cognition, spiritual beliefs, and the ability to understand. According to Roper, this is about "knowing, thinking, hoping, feeling and believing."

The sociocultural factor is the impact of society and culture as experienced by the individual patient. This includes expectations and values based on class and status, and culture within the sociocultural factor relates to the beliefs, expectations, and values held by the individual patient for him or herself, as well as by others pertaining to independence in and ability to carry out the activities of daily living.

The environmental factor in Roper's theory of nursing makes it a "green" model. The theory takes into consideration the impact of the environment on the activities of daily living, but also examines the impact of the activities of daily living on the environment. The politicoeconomic factor is the impact of the government, politics, and economy on the activities of daily living. This factor addresses issues such as funding, government policies and programs, war or conflict, availability to benefits, political reforms, interest rates, and availability of public and private funding, among others. Significant others (Carers) must be invited to contribute to the process as they have expertise, experience and knowledge of the cared for person.

Underpinning practice with a model such as Roper's will shape practice and help guide practitioners through a comprehensive process that will stand scrutiny. In addition the model will serve as a framework for understanding what is important to individuals – a key element of the SSWBA.

When the service user has been carer blind assessed and their strengths and deficits understood, this proposal suggests that the family and carers are invited to declare how much of the person's deficits they are prepared to meet, for example;

Eating and Drinking:

Mr Jones has had a stroke. His cognition is fine but has suffered left side paralysis. His assessment showed that he cannot fend for himself. He cannot mobilise to get to the shops, cannot, therefore, buy provisions and cannot prepare food and drinks. Internet connectivity is poor so on-line shopping is not available and neither Mr or Mrs Jones are IT literate. The assessment has shown that Mr Jones is totally dependent in this 'activity of daily living'.

During her separate carer's assessment Mrs Jones has declared that she has always shopped and prepared his meals – his only contribution being that he would drive her to the shops and carry the bags – they live rurally at least five miles from any shops and Mrs Jones doesn't drive. Public transport is non-existent. Mrs Jones states that she is more than willing to continue with everything she has done for her husband but fears she won't be able to get to the shops and carry everything. Their daughter, also present, says that she is willing to drive her mum and help with the shopping every week and that her brother will also help out. Mrs Jones is relieved and says that as long as she is fit and well she will happily continue to ensure Mr Jones has adequate food and drink.

Mrs Jones must be offered to sign this care plan as the person who has agreed to deliver.

The care plan describes how this deficit will be addressed and who will be responsible for delivery – in this case Mrs Jones and her children. As the main provider of this service delivery Mrs Jones must be offered opportunity to sign the care plan and be involved at every review that follows. This practice promotes inclusion and recognition of the carer and their contribution. In turn, the carer feels integral and recognised and retains a degree of control (e.g. ability to declare issues during reviews).

Extrapolating this example across each Activity of Daily Living ensures that the individual requiring care and support benefits from a comprehensive and inclusive assessment that is followed by an assessment of their carer's ability, capacity and willingness to contribute. The carer is offered opportunity to declare the amount of support they can offer, taking into account their own circumstances, e.g. work, education, leisure, other caring commitments, their own health and well-being and their aspirations. When the carers circumstances are fully understood they are offered opportunity to state exactly how much they are prepared or not prepared to contribute (including breaks from caring) and this is recorded on the care plan as stated above. The care plan can then be fulfilled with commissioned support to address the AoDL where a deficit remains and is deemed essential.

What is beneficial about this model is the fact that it can be applied to all adult service user assessments and offers a framework that once embedded in practice will become a statute that practitioners can model practice on. It will eradicate the poor practice of assumptions and expectations and elevate carers as partners in the provision of care whilst themselves being assessed and allowed to state how much and how often they contribute. Partnerships between statutory agencies, commissioned providers and carers will form the basis of community care where everyone understands their role and commitment.

Key questions to identify levels of risk to the sustainability of the caring role (these are not exhaustive) may include:

- how long has the carer been caring?
- how much help does the carer get?
- how often does the carer get a full night's sleep?
- how much physical impact does the caring role have?
- how much emotional impact does the caring role have?
- does the carer understand the nature of the cared for person's condition?
- how much time does the carer have when they feel 'off duty'?
- how appropriate is the role for someone of the carer's age or in that particular relationship to the cared for person?
- how appropriate is the role for someone of the carer's culture, religion, gender?
- how many other roles (parent, employee, carer for someone

else) impact on the carer?

- how does the caring role impact on the carer’s other relationships and community networks?
- how sustainable does the carer’s role appear?
- does the cared for person want the carer to continue in this role?
- how far does the carer gain any sense of satisfaction/reward from caring?

[redacted]

Impact of the SSWB Act on Carers

Response to the Health, Social Care and Sports Committee Consultation

This response has been produced by the Centre for Innovative Ageing (CIA) Swansea University. We are pleased to offer this response and would be very happy to provide further evidence both written and oral to support the Committee's Inquiry. Our response has been compiled in the following way: Paragraphs 1 – 4 highlights the current work within the CIA that we believe is relevant to the aims of the Inquiry and that we would be very pleased to elaborate on further. What follows are we specific responses offered in relation to the issues raised within the consultation pertaining to: 1) information and data 2) other changes since the Act came into force and 3) broader Welsh Government policy on carers.

Introduction

This response has been compiled by [redacted] a PhD candidate at the Centre for Innovative Ageing the 3 year funded PhD has been awarded by the Wales School for Social Care Research. The overall aim of the PhD we believe is of particular interest to the Committee's current inquiry in relation to carers and the Social Services and Well-being Act. The PhD aims to contribute to a theorisation of the concept of well-being in relation to older family carers of people living with dementia, in order to support care policy and practice development that can deliver sustainable well-being outcomes for older family carers of people living with dementia in Wales.

The PhD research is of particular importance because recent evidence highlights that older family carers of people living with dementia are at particular risk of poor health and well-being outcomes. In comparison with the general carer population, carers of people with dementia are particularly vulnerable to high levels of psychological distress and stress, and levels of self-efficacy, subjective wellbeing and physical health are significantly lower in dementia care givers than in other caregivers (Brodaty & Donkin, 2009). The needs of this particular group of carers are growing, and the number of unpaid carers over the age of 65 is increasing more rapidly than the general carer's population; whilst the total number of carers has risen by 11% since 2001, the number of older carers rose by 35% (ONS 2011). In the UK, two thirds of people living with dementia are living at home and most are supported by unpaid family carers and caring for a person with dementia is associated with longer caring hours when compared with people cared for with other conditions. Welsh based data demonstrates the clear need to examine the experiences and challenges of carers of people living with dementia. The National Survey for Wales 2016-2017 'Volunteering and Caring Report' highlights that people who were caring for others were more likely than those who were not to have a limiting long-term illness, and were more likely to be in material deprivation. This relationship was strongest for those who spent more time caring and for those that provided more hours in a week, the proportion who were in material deprivation increased (Welsh Government, 2017 p. 11). Despite the increased risk of poorer health income and well-being outcomes, carers of people with dementia have been shown to be less likely to use services compared to the general carer population (Philp et al., 1995; Toseland, McCallion, Gerber, & Banks, 2002) Toseland et al (2002) found that enabling variables (which included such things as; knowledge of and barriers to service use, transportation, location) explained more variance in carers of people with dementia service use, than either need or predisposing variables (Toseland et al., 2002, p. 1261). Developing evidence based policy that supports service delivery for this particular group of carers is needed to tackle a growing number of the older population in Wales who are experiencing poor health and well-being outcomes.

- We recommend that in addition to gathering evidence on the level of take up of carers assessments in the broad carer population, that Welsh Government consider undertaking specific work that seeks to identify the barriers and obstacles that could be encountered when accessing services by family care givers of people living with dementia.

Sustainable Care: Connecting People and Systems

The PhD is formally connected to The Sustainable Care programme. The Programme is a multi-disciplinary ESRC-funded programme (2017-2021) exploring how care arrangements, can be made sustainable and deliver wellbeing outcomes. It aims to support policy and practice actors and scholars to conceptualise sustainability in care as an issue of rights, values, ethics and justice, as well as of resource distribution. Led by Professor Sue Yeandle, Sheffield University, the project brings together academics from eight universities, and is working with an extended network of international academic partners in fifteen other countries. The programme takes a future-oriented and internationally comparative look at current approaches to the care needs of adults living at home with chronic health problems or disabilities, examining these in the context of care systems, care work and care relationships. The PhD hosted within the CIA is connected to this programme through its' UK international network of PhD candidates, and as a named researcher on the work specifically in relation to work package 2 comparing care systems across the nations of the UK. We would welcome the opportunity to discuss further this substantial programme of work.

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

We are aware of significant data gaps in relation to carers and there is an absence of accessible and comprehensive data more broadly. Lack of coordination and large data gaps were identified across the 4 nations in a recent expert round table event ran by the Sustainable Care programme. Some of the key issues identified included the lack of a coordinated data strategy for social care and carers across the whole of the UK.

- A key recommendation from the expert roundtable is the establishment of a UK coordinating body for adult social care, this body would coordinate and summarise data trends for policy and research use.

The Centre for Innovative Ageing would be very happy to discuss the development of improving data collection on carers and through its close links with the Sustainable Care Programme is best placed to connect into work that is happening at the national and international level.

2) Other changes since the Act came into force which may impact on carers, for example changes to the services provided to people who are cared for;

Given the increase in population ageing, accompanied by increases in limiting lifelong condition such as dementia, and UK Government programme of austerity based social care reform older carer's needs are growing. There is now irrevocable evidence of the negative impact that caring for someone with dementia can have on individual health well-being and material circumstance. Sustainable systems of support are needed to alleviate these negative impacts and protect carers from old age exclusion and limited life chances.

It is not clear from the current literature how family carers of a person living with dementia in Wales are balancing increasing care demands with less welfare support, and no work to date has attempted to critically engage with the context of austerity driven care reform within the well-being in care paradigm in Wales. Notable exceptions to knowledge gaps do exist in Wales (Seddon et al, 2010; Shuie, 2015) but these studies do not provide a focus on the particular experiences of older family carers of people living with dementia, nor do they relate current systems to the promotion of older carer's well-being, or to the broader socio-political landscape in Wales and the UK.

3) Broader Welsh Government policy on carers

The Welsh Government approach to preventative social care services that promote individual well-being is welcome, however, well-being outcomes set for carers are based on measures of entitlements and rights. These measures do not adequately provide a clearer picture of the experiences of carers lives, particularly those carers who are particularly vulnerable to poor health and well-being outcomes such as older family carers of people living with dementia. The CIA has been recently commissioned by the Older People's Commissioner in Wales to carry out secondary data analysis of current well-being outcomes in relation to older people.

- We suggest that alternative methods of data collection in relation to carers are considered including the use of mixed method and qualitative research data to help build a deeper understanding of carer's lives.

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Appendix 1

'Well-being for older family cares of people living with Dementia – The Case of Wales'

[redacted], Centre for Innovative Ageing.

Supervisory team: [redacted].

A 3 year funded PhD programme (2017-2020) awarded by the Wales School for Social Care Research

This research is located at the interface between social care systems in Wales and the older family carer of persons living with dementia. The worldwide phenomenon of population ageing is a global success story; however, population ageing can bring challenges to nations particularly in relation to how families and Governments can reconcile the increasing need for long term social care for older living with long term health conditions.

Research aims and objectives

The overall aim of the PhD is to contribute to a theorisation of the concept of well-being in relation to older family carers of people living with dementia, in order to support care policy and practice development that can deliver sustainable well-being outcomes for older family carers of people living with dementia in Wales. In order to achieve this aim, the following objectives have been identified:

1. To advance understanding of the concept of well-being in care systems in relation to older family carers of people living with dementia in Wales, taking into account individual life course caring history, place based resources, policy influences (e.g. austerity), and social-cultural constructions of care.
2. Identify features and conditions of social care system that could contribute to well-being outcomes for family carers of people living with dementia.
3. Consider the implications of findings from objective 1 and 2 on well-being within social care policy making in Wales.

Research questions

The research will investigate the extent to which specific well-being legislation has generated positive well-being outcomes for family carers of people living with dementia. The research questions are as follows:

1. What is the state of knowledge in relation to well-being and older family carers of people living with dementia in Wales?
2. How do stakeholders (social care providers, policy makers, and carers) perceive of and experience well-being support systems in Wales?
3. What features of the care systems in Wales enhance well-being outcomes for older family carers of people living with dementia?

The research will be qualitative and conducted in three stages. Stage 1 will comprise of an in-depth literature review to inform the development of a theoretical framework and conceptualisation of well-being in relation to family carers of people living with dementia in Wales. During stage 2, primary evidence will be gathered through the use of participatory visual methods, written and audio diaries, in-depth interview and direct observation to elicit information to explore the views and experiences of older carers of people with dementia of social care services as well as practitioners and policy makers. Participants will choose which method they would like to use or a combination of methods to capture their views and experiences of interacting or their experiences of working within care support services over a one month period. Three focus groups will be held in phase 2 to explore themes identified by stakeholders and to identify common and divergent beliefs and experiences of well-being in care systems in Wales. During phase 3, the results from phase one and two will be analysed to develop a set of features that could enhance well-being for family carers within the socio-political context of Wales. These features will be tested with carers to arrive at a sustainable social care model for older family carers of people living with dementia in Wales.

For further information contact [redacted] [redacted]

C23
Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Ymddiriedolaeth Gofalwyr Cymru
Response from Carers Trust Wales

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

Contents

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 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

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 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 2015**[1] 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 England[2] and Scotland[3] 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

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[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(c)

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 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 or friends 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]

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[4] https://www.carersuk.org/files/section/5763/track-the-act-briefing-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.

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[5] http://static.carers.org/files/in-poor-health-carers-uk-report-1674.pdf

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 2012[6].

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 caring[7]. 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 Act[8]. 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 Fora 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.

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[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.

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 organisations 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 has been made in 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 caring[11]. 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 2015[12], far exceeding the £1.7bn spent across Wales on social care during 2016-17[13]. 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 carers[14]. 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 responsibilities[15].

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

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[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-resources/carers-support.aspx

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 £7.88[17].

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 co-resident carer when it comes to preventing or delaying residential care admissions[18].

One study found that problems associated with the carer contributed to readmission in 62% of cases[19].

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 Wales[20].

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 week[21]
- 65% of older carers (aged 60–94) have long-term health problems or a disability themselves[22]
- 68.8% of older carers say that being a carer has an adverse effect on their mental health[23]
- One third of older carers say they have cancelled treatment or an operation for themselves because of their caring responsibilities[24]

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[17] Department of Health (2014) Impact Assessment (Carers) **http://www.legislation.gov.uk/ukia/2014/407/pdfs/ukia_20140407_en.pdf**

[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-and-people-they-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 year[26]
- Young adult carers are more likely than the national average not to be in education, employment or training (NEET) between 16 and 19[27]
- A quarter of young carers say they are bullied at school because of their caring role[28]
- Carers provide 96% of care in the communities of Wales[29]
- Unpaid carers contribute £8.1 billion to the Welsh economy each year[30]

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 acknowledged[31] 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.

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[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 level[32]. 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 depression[33].

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 for[34]. 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 Nottingham[35] 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 anxiety[36].

- Young carers are 1.5 times more likely than their peers to have a special educational need or a disability[37]
- “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]

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[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 activities[40]. 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 incident[41].

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 health[42]. 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 activity[43]:

- 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

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[39] Caerphilly County Council. 2016. **Available online** [Accessed 8 February 2018].
[40] 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 responsibilities[45]

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 lives[46].

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

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[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 2011[49] 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 caring[50]. 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 evidence[51], 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

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[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 Change[52] 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 cases[53]. 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 Rocky[54], 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 authorities[55]. 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.

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[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: Denbighshire

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

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[56] **https://socialcare.wales/cms_assets/file-uploads/Carers-Report.pdf**

short breaks were urgently needed, something that many of our Network Partners have identified as a priority.

Ymateb gan Gomisiynydd Pobl Hŷn Cymru

i’r

Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon Cynulliad Cenedlaethol Cymru: Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â gofalwyr

Medi 2018

For more information regarding this response please contact:

Older People’s Commissioner for Wales
[redacted]

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.

Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon Cynulliad Cenedlaethol Cymru: Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â gofalwyr

Ymateb Comisiynydd Pobl Hŷn Cymru (‘y Comisiynydd’)

Cynnwys

- **Crynodeb**
- **Cyflwyniad**
  - Gofalwyr hŷn yng Nghymru
  - Dyletswyddau cyfreithiol
  - Grŵp Cynghori’r Gweinidog ar Ofalwyr
- **Asesiadau gofalwyr**
  - Dyletswydd gyfreithiol i asesu
  - Dull ‘yr hyn sy’n bwysig’
  - Cael asesiad
  - Adnabod gofalwyr
  - Asesiadau a chynlluniau cymorth
- **Cymorth i ofalwyr a seibiant**
  - Gwybodaeth, cyngor a chymorth
  - Gwasanaethau seibiant
    - Seibiant a Chynllun Gweithredu Cymru ar gyfer Dementia
    - Gofal Iechyd Parhaus
    - Taliadau Uniongyrchol
  - Eiriolaeth
    - Sicrhau Lleisiau i Bobl Hŷn
    - Yr angen am eiriolaeth nawr ac yn y dyfodol
- **Polisi Llywodraeth Cymru’n ehangach**
  - Iechyd
    - Mesur Strategaethau Iechyd a Gofalwyr (Cymru) 2010
    - Gwasanaethau meddygon teulu
    - Cynllun Gweithredu Cymru ar gyfer Dementia
  - Gofalu a cham-drin domestig
  - Gofalu ac arian
  - Gofalu a thai
  - Gofalu a thechnoleg

Crynodeb

- Mae’r Ddeddf yn rhoi hawl gyfartal i ofalwyr i gael asesiad – ond mae pryder nad oes digon o bobl yn manteisio ar yr asesiadau, nad oes digon o asesiadau’n arwain at roi cymorth ac nad ydym yn gwybod pam mae pobl yn gwrthod asesiadau. Mae diffyg data deallus sy’n golygu nad oes modd gwerthuso’r ystadegau hyn mewn modd ystyrlon. Mae angen i Lywodraeth Cymru, Awdurdodau Lleol a Byrddau Iechyd gasglu gwybodaeth fwy manwl am asesiadau, gan gynnwys y rhesymau pam y mae pobl yn eu gwrthod a’r math o gymorth sydd ar gael.

- Mae cymorth i ofalwyr yn aml yn cael ei ystyried ar sail dehongliad cyfyngedig o seibiant yn unig. Mae safbwyntiau ar ofal seibiant a’r opsiynau eraill sydd ar gael yn rhwystro gofalwyr rhag gallu cael seibiant hyblyg a phriodol sy’n cyfrannu at eu canlyniadau llesiant.

- Dylai Taliadau Uniongyrchol gael eu cynnig yn eang fel ffordd o gael seibiant, y mae pobl yn cael eu hannog i’w harchwilio a’u grymuso i’w defnyddio. Mae’n rhaid i Awdurdodau Lleol ddod i ddeall taliadau uniongyrchol yn well a defnyddio mwy arnynt, sicrhau bod cymorth ar gael i ofalwyr, ac annog pobl i ddefnyddio taliadau uniongyrchol mewn modd hyblyg ac ystyrlon ar gyfer cyfarpar a seibiant.

- Yn sgil diddymu Mesur Strategaethau ar gyfer Gofalwyr (Cymru), mae angen i wasanaethau iechyd barhau i ganolbwyntio ar adnabod a bodloni anghenion gofalwyr. Mae mwy o lawer o ofalwyr yn ymdrin â gwasanaethau iechyd na gwasanaethau gofal cymdeithasol yn rhan o’u rôl ofalu. Er hynny, gall gwasanaethau iechyd, megis gwasanaethau meddygon teulu, fod yn anhyblyg o ran anghenion penodol gofalwyr. Mae’n hanfodol bod y gwasanaethau iechyd yn ymwybodol o ofalwyr, yn eu hadnabod ac yn ymateb iddynt er mwyn cynorthwyo gofalwyr i barhau i ofalu ac i ofalu am eu lles eu hunain.

- Mae angen gwneud mwy i sicrhau bod anghenion gofalwyr am eiriolaeth annibynnol yn cael ystyriaeth briodol ac yn cael eu bodloni o dan y Ddeddf. Byddai mentrau ymwybyddiaeth wedi'u targedu, megis gwybodaeth mewn meddygfeydd a llyfrgelloedd, yn sicrhau bod y bobl fwyaf agored i niwed yn cael gwybod am eiriolaeth annibynnol, p'un a ydynt mewn cysylltiad â gwasanaethau statudol neu'n eu gweld eu hunain fel gofalwyr ai peidio.

- Mae'n rhaid cydnabod anghenion cymorth a chanlyniadau lles gofalwyr fel unigolion yn eu rhinwedd eu hunain, yn ogystal â chydnabod eu rôl ofalu a'r cyfraniad sylweddol mae hyn yn ei wneud i wasanaethau iechyd a gofal cymdeithasol.

Cyflwyniad

Gofalwyr hŷn yng Nghymru

Ledled Cymru, amcangyfrifir bod 370,000 o ofalwyr yn darparu gofal a chymorth di-dâl i anwyliaid[1]. Mae mwy na hanner y gofalwyr rhwng 40 a 64 mlwydd oed ac mae eu chwarter yn 65 neu'n hŷn[2]. Gofalwyr sy'n darparu mwyafrif helaeth y gofal i bobl mewn cymunedau ledled Cymru, ac mae 96% o'r gofal mewn cymunedau'n cael ei ddarparu gan deulu a ffrindiau[3].

Mae'n debygol fod cyfran y gofalwyr hŷn yn uwch na'r amcangyfrifon hyn ac mae'n debygol o godi eto, ac felly hefyd nifer y bobl hŷn sy'n cael gofal a chymorth di-dâl gan un o'u hanwyliaid. Er enghraifft, daw'r data ar gyfer nifer y gofalwyr o Gyfrifiad 2011. Yn ystod y saith mlynedd ers hynny, mae demograffeg Cymru wedi esblygu, mae cyfran y bobl hŷn o gymharu â chyfran y bobl iau yng Nghymru'n uwch nag yng ngweddill y DU, mae dementia wedi dod yn fwyfwy cyffredin ac erbyn hyn mae'n un o brif achosion marwolaethau ymhlith pobl hŷn[4].

Yn ogystal, nid yw llawer o bobl hŷn yn eu hystyried eu hunain yn ofalwyr ac nid ydynt yn arddel hynny. Er enghraifft, fe gymerodd hi dros flwyddyn i 55% o ofalwyr gydnabod eu rôl ofalu, a chymerodd dros 5 mlynedd i 24% ystyried eu hunain yn ofalwyr[5].

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[1] ONS, Cyfrifiad 2011

[2] Social Market Foundation, Caring for Carers, 2018

[3] Datganiad, Huw Irranca-Davies AC, y Gweinidog dros Blant, Pobl Hŷn a Gofal Cymdeithasol, 14 Mehefin 2018

[4] ONS, Deaths registered in England and Wales, 2017

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

Er bod amcangyfrif nifer y bobl hŷn a allai fod yn ofalwyr ledled Cymru’n fan cychwyn er mwyn deall lefel a graddfa’r cymorth di-dâl a ddarperir i anwyliaid – nid yw ystadegau ar eu pen eu hunain yn treiddio’n ddyfnach i bwy yw’r gofalwyr hŷn hyn.

Mae’n bwysig cofio nad grŵp unffurf yw gofalwyr. Mae perthnasoedd gofalu’n amrywiol iawn, ac nid perthynas rhwng dau unigolyn a geir o reidrwydd. Gall gofalwyr fod yn gofalu am un unigolyn neu am sawl unigolyn ar draws a rhwng y cenedlaethau, a gallant fod yn rhan o rwydwaith gofalu ehangach.

Nid dim ond derbyn gofal y mae pobl hŷn. Mae llawer o bobl hŷn yn ofalwyr eu hunain, yn darparu cymorth i frawd neu chwaer, gŵr neu wraig, cymar (neu gyn gymar), plant, rhieni a ffrindiau. Weithiau bydd pobl hŷn hefyd yn rhoi cymorth i fwy nag un o’u hanwyliaid. Er enghraifft, mae swyddfa’r Comisiynydd wedi rhoi cymorth i fenyw oedd yn gofalu am ei mab anabl yn ogystal â’i gŵr.

Yn ogystal â’r amrywiaeth o berthnasoedd a rhwydweithiau gofalu, mae amrywiaeth ymhlith y gofalwyr eu hunain hefyd. Gall pobl a chanddynt un neu fwy o nodweddion gwarchodedig gael profiad amrywiol o ofalu. Er enghraifft, mewn rhai diwylliannau mae disgwyl i’r teulu gymryd cyfrifoldeb am bobl hŷn, a gall mythau ynghylch diwylliannau pobl dduon ac Asiaidd a lleiafrifoedd ethnig lywio meddylfryd gweithwyr proffesiynol sy’n gweithio ym maes iechyd a gofal cymdeithasol[6] [7]. Yn ogystal, gall rhagdybiaethau heteronormadol orfodi pobl hŷn a gofalwyr LHDTC i guddio’u rhywioldeb wrth ymwneud â gweithwyr proffesiynol iechyd a gofal cymdeithasol[8].

Mae Adran 6 (2) y Ddeddf yn amlinellu bod yn rhaid i rywun sy’n arfer swyddogaethau o dan y Ddeddf ystyried barn, dymuniadau, teimladau, nodweddion, diwylliant a daliadau’r unigolyn. Mae’r Ddeddf hefyd yn cynnwys dyletswydd i roi ystyriaeth ddyledus i Egwyddorion y Cenhedloedd Unedig ar gyfer Pobl Hŷn. Felly, mae’n hollbwysig meithrin dealltwriaeth ddofn o bwy yw gofalwyr er mwyn cyflawni’r dyletswyddau cyffredinol hyn yn y Ddeddf.

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[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

Mae gofalwyr yn gwneud cyfraniad sylweddol i'n heconomi ac i'n cymdeithas. Amcangyfrifir bod cyfraniad economaidd gofalwyr ledled y DU yn arbed £91 biliwn bob blwyddyn mewn costau gofal posib, sy'n werth economaidd o £139 biliwn y flwyddyn. Yng Nghymru amcangyfrifir bod gofalwyr hŷn di-dâl yn arbed £1.88 biliwn i economi Cymru mewn costau gofalu. Rhagwelir y bydd hyn yn codi i £2.44 biliwn erbyn 2030. Mae amcangyfrifon eraill yn awgrymu y gallai gofalwyr yng Nghymru fod yn cyfrannu cyfanswm o £8.15 biliwn y flwyddyn[9]. Ni ellir gorbwysleisio'r risgiau i'r system yn ehangach, ac i'r gymdeithas gyfan, os na chefnogir llesiant gofalwyr.

Yn y bôn, fodd bynnag, mae eisiau ac mae angen cymorth ar ofalwyr hŷn er mwyn iddynt allu parhau i ofalu ac i'w cynorthwyo i gyflawni eu hamcanion a'u nodau llesiant eu hunain fel dinasyddion yn eu rhinwedd eu hunain o dan y Ddeddf.

Dyletswyddau cyfreithiol

Mae'n gadarnhaol fod Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 (y Ddeddf) wedi gosod gofalwyr yn gydradd â'u hanwyliaid drwy'r Ddeddf. Er enghraifft, mae gan ofalwyr hawl gyfreithiol i gael asesiad, a hawl gyfreithiol i gael cymorth ag anghenion cymwys gan awdurdod lleol ar ôl cael asesiad, mae'r diffiniad o ofalwr wedi'i ehangu ac mae'n rhaid i awdurdodau lleol sicrhau eu bod yn cynnig gwasanaethau gwybodaeth, cyngor a chymorth sy'n cael eu hysbysebu'n glir er mwyn i ofalwyr gael y wybodaeth iawn ar yr adeg iawn[10].

Mae dyletswyddau yn y ddeddfwriaeth sy'n cyfeirio'n uniongyrchol at ofalwyr, ond mae llawer o ddyletswyddau eraill hefyd sy'n effeithio ar ofalwyr ac yn eu diogelu fel unigolion yn eu rhinwedd eu hunain. Er enghraifft, dylai egwyddorion cyffredinol y Ddeddf ddylanwadu ar bob cyswllt â gofalwyr o ran eu hanghenion cymorth. Mae'n rhaid i Awdurdod Lleol ystyried barn, dymuniadau a theimladau'r unigolyn a darparu cymorth priodol er mwyn i'r unigolyn allu cymryd rhan, ar sail rhagdybiaeth mai'r unigolyn yw'r person gorau i benderfynu beth sydd orau iddo[11]. Mae'n rhaid i bawb sy'n arfer dyletswyddau o dan y Ddeddf

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[9] Prifysgol Bangor, Byw yn iach yn hirach: y ddadl economaidd dros fuddsoddi ym maes iechyd a lles pobl hŷn yng Nghymru, 2018

[10] Gofalwyr Cymru, Dilyn y Ddeddf, Papur Briffio 2, 2017

[11] Adran 6 Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014

hefyd roi ystyriaeth ddyledus i Egwyddorion y Cenhedloedd Unedig ar gyfer Pobl Hŷn[12].

Er hynny, diddymwyd Mesur Strategaethau ar gyfer Gofalwyr (Cymru) 2010 a deddfwriaeth arall ar gyfer gofalwyr pan gyflwynwyd y Ddeddf, ac mae rhywfaint o’r darpariaethau wedi eu trosglwyddo i’r Ddeddf. Gwrthwynebwyd hynny’n gryf gan fudiadau gofalwyr ar y pryd, oherwydd bod rhai o’r darpariaethau wedi’u glastwreiddio. Trafodir hyn ymhellach yn yr ymateb.

Ddwy flynedd ar ôl gweithredu’r Ddeddf, mae angen troi’r sylw oddi wrth ei chynnwys a thuag at ei heffaith. Nid yw’n glir eto a yw’r Ddeddf yn cyflawni ei bwriad pellgyrhaeddol ac a yw’r effaith ar ofalwyr wedi bod yn un cadarnhaol. At ei gilydd, ymddengys fod lle i bryderu am ddiffyg gwybodaeth a data cadarn i’n cynorthwyo i lunio casgliadau ynghylch a yw dyletswyddau’r ddeddf yn cael eu cyflawni.

Llywodraeth Cymru, Grŵp Cynghori’r Gweinidog ar Ofalwyr a’r Egwyddorion Cenedlaethol

Yn 2017, sefydlodd Llywodraeth Cymru dair egwyddor genedlaethol i lywio gwaith i wella bywydau gofalwyr a chyhoeddodd y byddai cyllid o £1 miliwn yn mynd law yn llaw a hynny[13]. Sefydlwyd Grŵp Cynghori’r Gweinidog, a chlustnodwyd £95,000 yn 2018/19 i ariannu prosiectau i fwrw ymlaen â dull cenedlaethol o gyflawni yn unol â’r blaenoriaethau. Cyn hynny, roedd Strategaeth Gofalwyr 2013-2016 yn cael ei dilyn.

Nid yw blaenoriaethau cenedlaethol mor sylweddol â strategaeth genedlaethol – ac nid yw’r egwyddorion hyn chwaith yn cynnwys camau gweithredu penodol. Nid yw’n glir a yw’r blaenoriaethau ynddynt eu hunain yn ymrwymiad digon cryf i sicrhau bod anghenion gofalwyr yn cael eu bodloni. Er enghraifft, mae’r blaenoriaethau i gyd yn gysylltiedig â dyletswyddau y mae’r Ddeddf eisoes yn darparu ar eu cyfer ac mae’n anodd gweld ar hyn o bryd sut y maent yn hyrwyddo ymhellach hawliau gofalwyr ac ymwybyddiaeth gofalwyr ledled Cymru.

Yn ogystal, bydd llwyddiant y blaenoriaethau cenedlaethol o ran gwella cymorth a chydnabyddiaeth i ofalwyr yn dibynnu ar effeithiolrwydd Grŵp

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[12] Adran 7(1) Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014

[13] Llywodraeth Cymru, Datganiad Ysgrifenedig, Gwlad sy’n Cefnogi Gofalwyr, 24 Tachwedd 2017

Cynghori'r Gweinidog wrth lunio sylfaen i gynllun gweithredu clir i Gymru.

Siom oedd nodi bod y cyllid a oedd yn gysylltiedig â chymorth i ofalwyr eisoes wedi'i ddyrannu a'r amcanion wedi'u gosod cyn i Grŵp Cynghori'r Gweinidog gwrdd, gyda chyllid penodol wedi'i glustnodi i gymorth i ofalwyr ifanc, canolfan gyflogaeth a seibiant[14]. Nid yw cyllid i sicrhau ansawdd bywyd a chanlyniadau i ofalwyr hŷn yn cael ei enwi'n benodol ond mae ymhlyg yn y gyllideb £1m i godi ymwybyddiaeth gofalwyr ar draws meddygfeydd teulu yng Nghymru ac i wella'r cymorth i ofalwyr o safbwynt rhyddhau pobl o'r ysbyty. Mae'n hollbwysig bod yr arian hwn yn cael ei ddefnyddio'r ddarbodus er budd gofalwyr hŷn yng Nghymru. Er enghraifft, byddai cysondeb o ran datblygu a defnyddio cofrestrau meddygon teulu neu brosesau rhyddhau mwy hwylus yn cyfrannu at sicrhau bod anghenion a dymuniadau gofalwyr yn cael eu cydnabod ac yr ymatebir iddynt.

Asesiadau Gofalwyr

Dyletswydd gyfreithiol i asesu

Mae'r Ddeddf yn gosod nifer o ddyletswyddau ar Awdurdodau Lleol ynghylch asesu anghenion gofalwyr am gymorth. Yn eu plith mae hawl i gael asesiad, gallu i gyfuno neu wahanu asesiadau a chynlluniau gofal a chymorth, dyletswydd i asesu parodrwydd a gallu gofalwyr i ddarparu gofal, a dyletswydd i ystyried sut y byddai anghenion pobl ag anghenion gofal a chymorth yn cael eu bodloni pe na bai ganddynt ofalwr[15].

Gall gofalwyr wrthod cael asesiad o'u hanghenion o dan y Ddeddf os mynnant, ond nid yw'r ffaith bod gofalwr wedi gwrthod asesiad yn y gorffennol yn golygu na chaiff ofyn am asesiad eto yn y dyfodol. Yn ogystal, nid oes llai o ddyletswydd ar yr Awdurdod Lleol i asesu os gwrthodwyd yr asesiad. Er enghraifft, gall Awdurdod Lleol asesu gofalwr os yw o'r farn nad oes gan y gofalwr alluedd perthnasol, a chaiff person awdurdodedig wneud penderfyniad ar ran y gofalwr. Os nad oes person awdurdodedig, gall Awdurdod Lleol asesu a fyddai er budd pennaf y gofalwr[16].

Sgyrsiau 'yr hyn sy'n bwysig'

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[14] Llywodraeth Cymru, Grŵp Cynghori'r Gweinidog ar Ofalwyr, Cylch Gorchwyl

[15] Adran 24, 28, 29 Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014

[16] Adran 25 Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014

Pan fydd pobl hŷn yn cysylltu â'r Awdurdod Lleol i ofyn am gymorth, gwybodaeth neu gyngor, dylai'r drafodaeth fod yn seiliedig ar 'yr hyn sy'n bwysig'. Dylai'r pwyslais fod ar 'yr hyn sy'n bwysig' i'r unigolion dan sylw, ar ddysgu amdanynt, eu cryfderau a'u hanghenion cymorth, gan ragdybio mai nhw sy'n gwybod orau beth sydd orau iddynt o ran eu llesiant[17].

Wedi i'r unigolyn gysylltu â'r gwasanaethau cymdeithasol, dylai'r sgwrs honno osod cywair a chyfeiriad y cymorth sydd ar gael i'r unigolyn a'r modd y gwireddir ei hawliau. Mae'r dull hwn yn allweddol er mwyn sicrhau bod pobl hŷn yn cael eu cydnabod fel gofalwyr (ganddyn nhw eu hunain a'r gwasanaethau cyhoeddus), a bod eu hanghenion hwythau'n cael eu cydnabod ac y darperir ar eu cyfer drwy gynnal asesiad a llunio chynllun priodol yn sgil hynny.

Cael asesiad

Felly, dylai asesiad o'u hanghenion fod ar gael i ofalwyr o dan y Ddeddf, a dylid ei gynnal ar sail 'yr hyn sy'n bwysig'. Mae sicrhau bod asesiad ar gael, ac ansawdd y ffordd y cynhelir yr asesiad, yn hanfodol er mwyn cydnabod canlyniadau, llesiant ac anghenion cymorth gofalwyr yn eu rhinwedd eu hunain.

Er hynny, mae cyfraddau asesiadau gofalwyr gryn dipyn yn is na'r amcangyfrif o 370,000 o ofalwyr yng Nghymru. Er enghraifft:

- Yn 2016/17, cynhaliwyd 6,207 o asesiadau gofalwyr yn ystod y flwyddyn.
- Arweiniodd 1,823 o'r asesiadau hyn at lunio cynllun cymorth
- Gwrthododd 6,864 o ofalwyr asesiad[18].

Roedd y gofalwyr a dderbyniodd neu a wrthododd asesiad yn cyfrif am lai na 4% o'r amcangyfrif o nifer y gofalwyr yng Nghymru a dim ond 29% o'r rhai a aseswyd a gafodd gynllun cymorth.

Yn ôl adroddiad 'State of Caring' Gofalwyr Cymru, o blith y 370,000 o bobl sy'n darparu gofal di-dâl yng Nghymru, mae'n destun pryder fod

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[17] Adran 6(3)(a) Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014

[18] Stats Cymru, Oedolion a aseswyd yn ôl awdurdod lleol a mesur, 2016/17

dros eu hanner (66%) yn dweud nad oeddent wedi cael cynnig asesiad neu nad oeddent wedi gofyn am un[19].

Mae angen holi cwestiynau difrifol felly er mwyn mynd at wraidd y ffigurau hyn. Pam mae cyn lleied o ofalwyr yn cael asesiadau, pam mae cyn lleied o asesiadau'n arwain at gynlluniau cymorth ac a oes mathau eraill o gymorth ar gael yn eu lle?

Mae swyddfa'r Comisiynydd wedi rhoi cymorth i ofalwr hŷn a ddywedodd ei bod o'r farn nad yw gofalwyr hŷn yn cael yr un ystyriaeth â gofalwyr eraill, a'u bod yn aros yn hwy i gael asesiad.

Mae amrywiadau lleol a rhanbarthol ledled Cymru o ran yr asesiadau sydd ar gael i ofalwyr. Er enghraifft, mae adroddiad 'Dilyn y Ddeddf' Gofalwyr Cymru'n nodi bod loteri cod post ar waith ar hyn o bryd lle mae gofalwyr mewn rhai ardaloedd yn cael asesiad, ac eraill ddim yn cael asesiad.[20] Yn ogystal, mae adborth gan ofalwyr i'r Comisiynydd yn dangos bod ymarfer yn amrywio o fewn Awdurdodau Lleol hyd yn oed a hefyd rhwng gweithwyr cymdeithasol yn yr un tîm.

Mae nifer o resymau posib dros yr ystadegau ynghylch asesiadau gofalwyr. Er enghraifft, efallai fod gofalwyr yn cael eu cyfeirio at wasanaethau cymunedol neu ataliol nad ydynt yn cael eu cofnodi mewn cynllun cymorth ffurfiol, neu fod unigolion yn dewis gwrthod asesiad am eu bod yn teimlo bod eu gallu i ofalu'n cael ei asesu, neu efallai nad ydynt yn eu hystyried eu hunain yn ofalwyr neu nad yw'r gwasanaethau iechyd a chymdeithasol yn cydnabod eu bod yn ofalwyr er mwyn gallu cael asesiad.

Mae'r data a ryddhawyd gan Stats Cymru ynghylch asesiadau gofalwyr yn arbrofol, ac mae rhywfaint o amrywiadau o ran cofnodi rhwng yr Awdurdodau Lleol. Mae'n destun pryder nad yw'r data sy'n cael ei gofnodi ar hyn o bryd yn adlewyrchu profiad gofalwyr o ran cael asesiadau. Er enghraifft, nid yw'r data a gofnodir yn cynnwys:

- Cymorth cymunedol/ataliol nad yw wedi'i gynnwys mewn cynllun cymorth
- Y rheswm dros wrthod asesiad
- A yw canlyniadau gofalwyr yn cael eu bodloni drwy gynlluniau cymorth

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[19] Gofalwyr Cymru, State of Caring 2017, 2017

[20] Gofalwyr Cymru, Dilyn y Ddeddf, Papur Briffio 2, 2017

- Adborth gan ofalwyr ar y broses asesu

Adnabod gofalwyr – perthnasedd i asesiadau

Yn gyffredinol, mae ‘Dilyn y Ddeddf’ Gofalwyr Cymru’n amlygu amrywiadau ledled Cymru o ran y dull strategol a chyflenwi gwasanaethau i adnabod a bodloni anghenion gofalwyr[21].

Mae’n hanfodol bod pobl yn cydnabod eu bod yn ofalwyr, neu fod y gwasanaethau cymdeithasol yn cydnabod eu bod yn ofalwyr [neu drwy atgyfeiriad gan y gwasanaethau iechyd] er mwyn cael asesiad. Mae llawer o bobl hŷn yng Nghymru nad ydynt efallai’n eu hystyried eu hunain yn ofalwyr neu sy’n gofalu am gryn dipyn o amser cyn cydnabod eu rôl. Er enghraifft, yng Nghymru fe gymerodd hi dros flwyddyn i 55% o ofalwyr gydnabod eu rôl ofalu, a chymerodd dros 5 mlynedd i 24% ystyried eu hunain yn ofalwyr[22].

Mae’r ddyletswydd i asesu gofalwyr o dan a24 y Ddeddf yn dod i rym “pan fo’n ymddangos i awdurdod lleol y gall fod ar ofalwr anghenion am gymorth” – ac nid yw’n ddyletswydd ragweithiol ar y gweithiwr cymdeithasol i chwilio am unigolion sy’n ofalwyr neu beidio a’u hadnabod, ac y mae efallai angen cymorth arnynt neu beidio (pan fo hynny wedi’i nodi mewn asesiad).

Mae’n bosib felly na fydd pobl hŷn yn cysylltu â’r Awdurdod Lleol i ofyn am gymorth fel gofalwyr, gan nad ydynt yn cydnabod eu bod yn ofalwyr. Os nad yw unigolion yn datgan drostynt eu hunain eu bod yn ofalwyr, mae rôl y gwasanaethau cymdeithasol o ran adnabod gofalwyr a chyfleu’r berthynas hon i unigolyn yn dod yn fwyfwy pwysig. Er enghraifft, rhoddodd swyddfa’r Comisiynydd gymorth i ddyn hŷn nad oedd yn cael ei ystyried yn ofalwr dros ei wraig, ac na allai, o’r herwydd, arfer ei hawl i gael asesiad gan nad oedd ei wraig wedi ei rhyddhau o’r ysbyty eto a’i bod yn cael gofal fel claf mewnol.

Mae’n bwysig hyfforddi staff iechyd a gofal cymdeithasol felly er mwyn sicrhau bod unigolion yn cael eu trin yn gyson â’r Ddeddf. Mae Gofal Cymdeithasol Cymru’n datblygu cyfres o ddeunyddiau dysgu i weithwyr gofal cymdeithasol a staff cysylltiedig ar gefnogi gofalwyr, ac asesiadau gofalwyr. Mae’r adnoddau hyn wrthi'n cael eu datblygu, ond gallai’r ffordd y cânt eu cyflwyno a’u rhoi ar waith fod yn hanfodol i wella

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[21] Gofalwyr Cymru, Dilyn y Ddeddf, Papur Briffio 2, 2017

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

ymwybyddiaeth ac adnabod gofalwyr ymhlith staff gofal cymdeithasol, a sicrhau bod mwy o asesiadau ar gael i ofalwyr hŷn.

Mae Asesiadau Poblogaeth (AP), fel y'u nodir yn a14 y Ddeddf, yn chwarae rhan hanfodol yng ngallu'r Awdurdodau Lleol i ddeall anghenion gofal a chymorth y bobl sy'n byw yn eu hardal, gan gynnwys gofalwyr, a'r gwasanaethau sydd eu hangen i fodloni'r anghenion hynny[23]. Mae hynny'n gam tuag at wella ymwybyddiaeth ac adnabod gofalwyr, a fydd yn ei dro'n golygu bod mwy o asesiadau a chymorth ar gael.

Er hynny, er mwyn i ganfyddiadau'r AP fod yn fwy na phroses academaidd, bydd angen i Awdurdodau Lleol ddadansoddi eu canfyddiadau'n feirniadol yn erbyn realiti asesiadau gofalwyr. Er enghraifft, a yw'r asesiadau gofalwyr a gwblhawyd yn eu hardal yn gyson ac yn unol â'r disgwyl o ran nifer y gofalwyr a gafodd eu hadnabod yn eu AP?

Asesiadau a chynlluniau cymorth

Ledled Cymru yn 2016/17, darparwyd 1,823 o gynlluniau cymorth yn sgil 6,207 o asesiadau gofalwyr[24]. Dim ond 29% o'r rhai a aseswyd a dderbyniodd gynllun cymorth.

Gallai nifer y cynlluniau gofal yn sgil asesiadau fod yn isel oherwydd bod cymorth weithiau'n cael ei gyfuno ag asesiad o anghenion a chynllun y sawl sydd ag anghenion gofal a chymorth, efallai mai cymorth anffurfiol yn y gymuned neu wasanaethau ataliol a geir, nad ydynt wedi'u nodi yn y cynllun, neu efallai nad yw'r meini prawf cymhwyso'n ddigon clir neu efallai eu bod yn cael eu rhoi ar waith yn wahanol ledled Cymru[25].

Mae Rheoliadau Gofal a Chymorth (Asesu) Cymru 2015 yn nodi bod yn rhaid i'r ALl gadw cofnod ysgrifenedig o asesiadau[26] a rhoi copi o'r cofnod ysgrifenedig o'r asesiad i'r unigolyn dan sylw[27].

Er hynny, mae pobl hŷn wedi cysylltu â'r Comisiynydd i ddweud nad yw'r gwaith papur sy'n egluro cynlluniau cymorth a'r broses o wneud penderfyniadau fel arall bob amser yn gywir, nac yn cael ei roi mewn da

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[23] a14 Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014

[24] Stats Cymru, Oedolion a aseswyd yn ôl awdurdod lleol a mesur, 2016/17

[25] Gofalwyr Cymru, Dilyn y Ddeddf, Papur Briffio 1, 2016

[26] Rheoliad 5(1) Rheoliadau Gofal a Chymorth (Asesu) (Cymru) 2015

[27] Rheoliad 6 Rheoliadau Gofal a Chymorth (Asesu) (Cymru) 2015

bryd, neu nad yw'n cael ei roi i ofalwyr. Er enghraifft, rhoddodd swyddfa'r Comisiynydd gymorth i unigolyn yr aseswyd nad oedd ganddo unrhyw anghenion fel gofalwr, ond na chafodd gopi o'r asesiad am bum mis ar ôl gofyn amdano. Ar ôl i'r copi ddod i law, gwelwyd bod rhywfaint o wybodaeth anghywir yn yr asesiad a chynhaliwyd asesiad newydd lle y nodwyd bod ganddo anghenion cymorth.

Cymorth i ofalwyr a seibiant

Mae adroddiad 'State of Caring' 2017 Gofalwyr Cymru'n nodi nad yw 1 o bob 5 gofalwr sy'n gofalu am 50 awr neu fwy yr wythnos yn derbyn nac yn prynu dim cymorth ymarferol i'w helpu[28]. Er hynny, mae cydnabyddiaeth a chymorth priodol yn hanfodol er mwyn cynnal a gwella lles gofalwyr, eu helpu i barhau i ofalu a'u helpu i fyw bywyd y tu hwnt i'w rôl ofalu.

Mae dyletswydd yn y Ddeddf i ddarparu gwasanaethau ataliol, ac mae hyn yn cynnwys gwasanaethau cymorth i ofalwyr[29]. Mae cymorth priodol a gwasanaethau ataliol yn hanfodol er mwyn cyflawni canlyniadau i ofalwyr, a phrofwyd bod gwasanaethau ataliol a chymorth i ofalwyr a phobl sy'n byw gyda dementia yn cynnig budd cadarnhaol ar y buddsoddiad[30].

Er hynny, canfu Gofal Cymdeithasol Cymru fod adnabod a chydnabod gofalwyr ganddynt hwy eu hunain a gweithwyr proffesiynol, a'r wybodaeth, y cyngor a'r cymorth am hawliau a gwasanaethau sydd ar gael i ofalwyr yn themâu allweddol sy'n effeithio ar allu pobl i gael gwasanaethau ataliol[31]. Yn ogystal, nid yw'r gwasanaethau a'r cymorth bob amser yn cael eu cynllunio a'u darparu yn y ffordd fwyaf priodol i'r rhai sydd mewn angen. Er enghraifft, canfu adroddiad y Comisiynydd 'Ailystyried Seibiant' fod angen ailystyried mewn modd sylfaenol iawn y ffordd y mae gwasanaethau seibiant i ofalwyr yn cael eu cynllunio a'u darparu – a bod angen i ofalwyr a phobl sy'n byw gyda dementia gael eu cynnwys wrth gynllunio gwasanaethau cymorth seibiant, a chyfrannu at hynny[32].

Gwybodaeth, cyngor a chymorth

Mae'r Ddeddf yn gosod dyletswydd ar Awdurdodau Lleol i ddarparu gwybodaeth, cyngor a chymorth (GCC) i ddinasyddion, sy'n cynnwys

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[28] Gofalwyr Cymru, State of Caring 2017, 2017

[29] a15 Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014

[30] Prifysgol Bangor, Byw yn iach yn hirach: y ddadl economaidd dros fuddsoddi ym maes iechyd a lles pobl hŷn yng Nghymru, 2018

[31] Gofal Cymdeithasol Cymru, Cymorth ataliol ar gyfer gofalwyr sy'n oedolion yng Nghymru: adolygiad cyflym, 2018

[32] Comisiynydd Pobl Hŷn Cymru, Ailystyried Seibiant ar gyfer pobl a effeithir gan ddementia, 2018

gofalwyr[33]. Mae darparu gwybodaeth, cyngor a chymorth yn hanfodol er mwyn i ofalwyr gael gwybod am wasanaethau cymorth ac ataliol ac er mwyn iddynt allu eu defnyddio. Er hynny, bydd gwasanaethau GCC Awdurdodau Lleol ledled Cymru'n amrywio o ran strwythur a dull gweithredu a gallant amrywio o linell ffôn i ganolbwynt cymunedol.

Pa fath bynnag o ddarpariaeth GCC a gynigir, wrth gysylltu â gwasanaeth GCC yng Nghymru nid oes dyletswydd yn y Ddeddf i gasglu data ynglŷn â sut y mae gofalwyr yn defnyddio'r gwasanaeth. Canfu 'Dilyn y Ddeddf' Gofalwyr Cymru mai dim ond 16% o ofalwyr oedd wedi cael gwybodaeth gan eu Hawdurdod Lleol yn ystod y chwe mis wedi i'r Ddeddf ddod i rym i'w cynorthwyo yn eu rôl ofalu. Cynyddodd hynny i 46% yn y chwe mis wedi hynny a dywedodd 78% o ofalwyr fod y wybodaeth a gawsant naill ai'n ddefnyddiol neu'n ddefnyddiol iawn[34].

Er hynny, er bod hyn yn rhoi rhyw syniad i ni ynglŷn â'r sefyllfa, nid data cenedlaethol, swyddogol mohono. Byddai gwella'r data'n fodd o ddeall anghenion gofalwyr yn well ac yn helpu i nodi bylchau yn y cymorth a'r gwasanaethau GCC, er enghraifft a yw unigolion eu hunain yn datgan eu bod yn ofalwyr neu a ydynt wedi'u hadnabod gan staff GCC, y math o gymorth y gofynnwyd amdano, a gafodd unigolion eu hatgyfeirio i gael asesiad, neu'r rhesymau dros wrthod asesiad gofalwyr.

Nid oes modd ar hyn o bryd diffinio pa mor llwyddiannus yw gwasanaethau GCC o ran cyfeirio gofalwyr yn effeithiol at wasanaethau cymorth. Er gwaethaf hynny, mae sefydliadau'r trydydd sector wedi codi pryderon â'r Comisiynydd fod unigolion sy'n defnyddio gwasanaethau GCC wedi'u cyfeirio'n ôl i'r gymuned lle y gallai asesiad pellach fod wedi bod yn fwy priodol.

Gwasanaethau seibiant

Mae seibiant yn cael ei weld yn aml fel y math mwyaf cyffredin o gymorth i ofalwyr. Er hynny, mae'n aml yn cael ei weld fel noson i ffwrdd neu ddiwrnod mewn cartref gofal yn unig, i'r unigolyn ag anghenion gofal a chymorth.

Canfu adroddiad y Comisiynydd 'Ailystyried Seibiant'[35] na ddylid cyfyngu seibiant i'r dewis cyfyngedig hwn nad yw bob amser yn bodloni

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[33] a17 Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014

[34] Gofalwyr Cymru, Dilyn y Ddeddf, Papur Briffio 2, 2017

[35] Comisiynydd Pobl Hŷn Cymru, Ailystyried Seibiant ar gyfer pobl a effeithir gan ddementia, 2018

anghenion gofalwyr, neu’r rhai sy’n byw gyda dementia. Er bod yr adroddiad yn canolbwyntio’n benodol ar bobl sy’n byw gyda dementia a’u gofalwyr, mae llawer o’r prif negeseuon yr un mor berthnasol i bobl eraill y mae angen seibiant arnynt.

Mae angen cyfleoedd ar bobl i gymryd seibiant gyda’i gilydd ac ar wahân, gartref ac oddi cartref yn unol â’u barn, eu dymuniadau a’u teimladau. Mae’n amlwg fod angen mathau mwy creadigol o seibiant, ar y cyd ag ystod o sectorau, o letygarwch, i’r amgylchedd, chwaraeon, y celfyddydau a hamdden – megis cynllun ‘respitality’ yn yr Alban.

Er hynny, nid yw’r systemau sydd ar waith ar hyn o bryd i fonitro, mesur a gwerthuso lefelau o ‘seibiant’ yn addas at y diben, ac maent yn seiliedig ar ddiffiniad cul ac unochrog o seibiant (e.e. mae dangosydd perfformiad Llywodraeth Cymru ar gyfer seibiant yn ymwneud ag aros dros nos yn unig). Yn ogystal, nid yw gwybodaeth am opsiynau seibiant ar gael yn ddigon hwylus, nac yn cael ei darparu ar yr adeg iawn ac ar y ffurf iawn, ac nid oes digon o gymorth i wneud synnwyr o’r opsiynau sydd ar gael. Mae’n bosib na fydd staff y gwasanaethau cymdeithasol yn gwbl ymwybodol o’r opsiynau eu hunain.

Canfu’r adroddiad hefyd nad yw systemau iechyd a gofal cymdeithasol yn ddigon ymatebol i bobl sydd â mwy nag un rôl ofalu. Er enghraifft, mae swyddfa’r Comisiynydd wedi rhoi cymorth i fenyw sy’n gofalu am ei gŵr a’i mab. Er ei bod yn cael cymorth seibiant ysbeidiol gan weithwyr gofal cymdeithasol sy’n mynd â’i mab allan, nid yw’n cael dim amser iddi hi ei hun gan ei bod yn dal i ofalu am ei gŵr.

Yn yr adroddiad cynigiodd y Comisiynydd fap newydd o ganlyniadau seibiant, yn seiliedig ar y canlyniadau y dywedodd gofalwyr a phobl sy’n byw gyda dementia eu bod eisiau eu cyflawni. Mae hyn yn cyd-fynd â’r Fframwaith Canlyniadau Cenedlaethol a allai fod yn offeryn defnyddiol i ymarferwyr, rheoleiddwyr, y rhai sy’n llunio polisïau, darparwyr a phobl sy’n defnyddio gwasanaethau, i hybu gwaith i ddatblygu dewisiadau seibiant amgen mwy ystyrlon a mesur eu heffaith.

Mae hefyd wedi’i groesawu gan Rwydwaith Dysgu a Gwybodaeth y Swyddogion Gofalu, mudiadau gofalwyr a gweithwyr proffesiynol sydd wedi’i ddisgrifio fel testun trafod defnyddiol er mwyn gwneud y Fframwaith Canlyniadau Cenedlaethol yn ystyrlon ac yn gyraeddadwy o ran canlyniadau personol.

Seibiant a’r Cynllun Gweithredu ar gyfer Dementia

Cyhoeddodd Llywodraeth Cymru Gynllun Gweithredu Cymru ar gyfer Dementia 2018-2022[36] (y Cynllun) ym mis Chwefror 2018. Bydd £10m y flwyddyn yn ychwanegol ar gael i helpu i roi camau gweithredu allweddol y Cynllun ar waith. Bydd cynnydd o ran rhoi’r cynllun ar waith yn cael ei oruchwylio gan Grŵp Sicrwydd Cyflenwi a Gweithredu ar Ddementia[37], a chyhoeddir cofnodion y grŵp er mwyn sicrhau tryloywder[38].

Mae’r Cynllun yn cydnabod bod angen cynnig gwahanol opsiynau o ran gofal seibiant sy’n berthnasol i wahanol grwpiau oedran, mae’n cynnwys ymrwymiad i sicrhau bod dull newydd ‘timau sy’n canolbwyntio ar yr unigolyn’ yn galluogi teuluoedd a gofalwyr i gael gofal seibiant sy’n bodloni anghenion y gofalwr yn ogystal ag anghenion y sawl sy’n byw gyda dementia, ac yn ymrwymo i ddysgu o adroddiad Ailystyried Seibiant. Bydd cynnydd yn erbyn y cynllun hwn yn ‘gyfrwng allweddol i ddangos llwyddiannau a’r meysydd sydd angen eu gwella a amlinellwyd yn Safonau Iechyd a Gofal Cymru’[39].

Gofalwyr a Gofal Iechyd Parhaus

Gall Bwrdd Iechyd ddarparu cyllid Gofal Iechyd Parhaus os aseswyd bod anghenion yr unigolyn yn anghenion iechyd yn anad dim. Er hynny, wedi i’r cyllid a’r pecyn gofal hwn gael eu rhoi ar waith, mae’n bosib y bydd gofalwr yn dal i fod yn bresennol, a dylid ei gydnabod a’i gefnogi.

Awdurdodau Lleol sy’n gyfrifol am asesu anghenion cymorth gofalwyr, sy’n cynnwys gofalwyr unigolion sy’n derbyn arian Gofal Iechyd Parhaus[40]. Er hynny, pan fo gofalwyr yn cefnogi unigolyn sy’n derbyn arian Gofal Iechyd Parhaus, mae’r Comisiynydd yn ymwybodol y gall yn ymarferol fod diffyg eglurder neu weithredu ynghylch pa gorff cyhoeddus sy’n gyfrifol am gefnogi’r gofalwr.

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[36] Llywodraeth Cymru, Cynllun Gweithredu Cymru ar gyfer Dementia, 2018

[37] Mae’r grŵp hwn bellach wedi’i ailenwi’n Grŵp Goruchwylio Gweithrediad ac Effaith ym maes Dementia. Bydd aelodau’r grŵp hwn yn cynnwys pobl sy’n byw gyda dementia a’u gofalwyr a’u teuluoedd.

[38] Llywodraeth Cymru, Dementia, 2018

[39] Comisiynydd Pobl Hŷn Cymru, Ailystyried Seibiant ar gyfer pobl a effeithir gan ddementia, 2018

[40] a24 (1)(a) Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014

Rhoddodd swyddfa’r Comisiynydd gymorth i ddyn hŷn pan wnaed penderfyniad budd pennaf i symud ei wraig i gartref gofal. Mynegodd y dyn awydd i ofalu amdani yn eu cartref eu hunain, ond er mwyn gwneud hynny dywedodd y Bwrdd Iechyd fod angen iddo ddarparu cynllun gofal yn dangos sut yr oedd yn bwriadu gofalu am ei wraig. Ni chynigiwyd cymorth iddo i lunio’r cynllun hwnnw ac nid oedd cymorth ar gael yn hwylus iddo, ac mewn cyfarfod budd pennaf arall penderfynwyd nad oedd wedi rhoi digon o sicrwydd y gallai fodloni anghenion ei wraig, er gwaetha’r ffaith iddo fod yn aelod allweddol o dîm gofal ei wraig pan oedd hi’n cael triniaeth yn yr ysbyty.

Yn ogystal, rhoddodd swyddfa’r Comisiynydd gymorth i unigolyn a wrthwynebodd benderfyniad i gael gwared ar gymorth 1 ag 1 i aelod o’r teulu a oedd yn cael arian Gofal Iechyd Parhaus. Wedi i’r Comisiynydd ymyrryd, gofynnodd y Bwrdd Iechyd i’r gofalwr am ei sylwadau ar lenyddiaeth newydd i gleifion i atal anghydfodau o’r fath rhag codi eto. Roedd y gofalwr o’r farn ei bod wedi cyfrannu at wneud gwahaniaeth i ofalwyr eraill a bod y Bwrdd Iechyd wedi cymryd ei hadborth o ddifrif.

O ran seibiant, mae cyllid ar gael ar gyfer hyn pan fo arian Gofal Iechyd Parhaus yn cael ei ddarparu ond mae pobl hŷn wedi dweud ei bod yn anodd cael gafael arno a bod yn rhaid iddynt godi cwestiynau neu gwyno i’r Bwrdd Iechyd er mwyn ei gael.[41]

Taliadau uniongyrchol

Dylai Taliadau Uniongyrchol gael eu cynnig yn eang fel ffordd o gael seibiant, y mae pobl yn cael eu hannog i’w harchwilio a’u grymuso i’w defnyddio. Mae’n rhaid i Awdurdodau Lleol ddod i ddeall taliadau uniongyrchol yn well a defnyddio mwy arnynt, sicrhau bod y cymorth angenrheidiol ar gael i ofalwyr i’w defnyddio, ac annog pobl i’w defnyddio ar gyfer cyfarpar a seibiant.

Canfu adroddiad ‘Ailystyried Seibiant’[42] y gall taliadau uniongyrchol fod yn gyfrwng pwysig er mwyn sicrhau hyblygrwydd, dewis a rheolaeth wrth roi cymorth i ofalwyr hŷn. Er enghraifft, roedd nifer fach o bobl wedi defnyddio taliadau uniongyrchol i drefnu cymorth seibiant gyda chanlyniadau cadarnhaol. Yn eu plith roedd talu am seibiant dros nos yn eu dewis le, naill ai ar eu pen eu hunain neu fel teulu (naill ai mewn

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[41] Comisiynydd Pobl Hŷn Cymru, Ailystyried Seibiant ar gyfer pobl a effeithir gan ddementia, 2018

[42] Comisiynydd Pobl Hŷn Cymru, Ailystyried Seibiant ar gyfer pobl a effeithir gan ddementia, 2018

cartref gofal neu yn y sector lletygarwch), neu dalu am ‘gyfaill’ am ychydig oriau neu ddyddiau’r wythnos, i helpu i roi cymorth i’r person sy’n byw gyda dementia i wneud yr hyn roedd eisiau ei wneud, gartref neu yn rhywle arall.

Er hynny, ychydig iawn o bobl sy’n manteisio ar yr opsiwn hwn, yn enwedig pobl hŷn a gofalwyr[43]. Canfu adroddiad ‘Ailystyried Seibiant’ fod y rhan fwyaf o bobl hŷn sy’n byw gyda dementia a gofalwyr yn anghyfarwydd â’r ffordd hon o gael cymorth, gan nodi nad oedd eu gweithiwr cymdeithasol wedi dweud wrthynt am daliadau uniongyrchol.

“Taliadau uniongyrchol – rydych chi’n gorfod brwydro i’w cael nhw.” Gofalwr

“Rwy i wedi clywed y Cyngor yn dweud na fyddan nhw’n talu taliadau uniongyrchol i ofalwyr nawr ac mae hynny’n anghyfreithlon.” Gofalwr

Dywedodd rhai gofalwyr a oedd wedi ceisio defnyddio taliadau uniongyrchol ar gyfer seibiant nad oedd yn brofiad cadarnhaol, naill ai am nad oeddent yn teimlo iddynt gael digon o gymorth i drin a thrafod y taliadau, neu am nad oedd y swm o arian a ddarparwyd gan y Gwasanaethau Cymdeithasol yn ddigon i dalu’r costau neu am nad oeddent yn gallu dod o hyd i rywun a oedd yn darparu’r gwasanaeth.

Mae gan ofalwyr hawl i geisio cymorth iddyn nhw’u hunain ar ffurf taliad uniongyrchol. Er enghraifft, roedd gofalwr wedi defnyddio’r taliad i dalu rhywun i dorri’r glaswellt, rhywbeth a oedd yn anodd iddo am resymau iechyd. Roedd hynny’n cyflawni canlyniadau, sef cael seibiant a’i gynnal yn ei rôl ofalu:

“Helpu gyda rhai o’r pethau ro’n i’n teimlo ei bod yn anodd i mi eu gwneud – pethau a allai wneud hynny’n haws.” Gofalwr

Eiriolaeth i ofalwyr

“Roedd yr eiriolaeth wedi fy helpu i wybod fy hawliau.” – Gofalwr a defnyddiwr gwasanaeth eiriolaeth[44]

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[43] 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

[44] Comisiynydd Pobl Hŷn Cymru, Sicrhau Lleisiau i Bobl Hŷn: Mynediad Pobl Hŷn at Eiriolaeth Annibynnol, 2018

Mae'n rhaid cynnal hawliau gofalwyr i gael eiriolaeth, lle y bo hynny'n briodol, er mwyn sicrhau y gallant gael y gwasanaethau a'r cymorth sydd eu hangen arnynt i barhau yn eu rôl – ac mae hefyd yn rhan hanfodol o roi'r Ddeddf ar waith yn llwyddiannus.

Er hynny, canfu adroddiad y Comisiynydd, 'Sicrhau Lleisiau i Bobl Hŷn: Mynediad Pobl Hŷn at Eiriolaeth Annibynnol yng Nghymru'[45] fod nifer sylweddol o bobl hŷn yn methu â chael eiriolaeth annibynnol, yn fwy cyffredinol ac o dan ddyletswyddau deddfwriaethol.

"Dy'ch chi ddim yn gwybod beth dy'ch chi ddim yn ei wybod." – Person hŷn sy'n byw gyda dementia[46]

Mae'n awgrymu bod angen gwneud mwy i sicrhau bod anghenion gofalwyr o ran eiriolaeth annibynnol yn cael ystyriaeth briodol ac yn cael eu bodloni o dan y Ddeddf. Byddai mentrau ymwybyddiaeth wedi'u targedu, megis gwybodaeth mewn meddygfeydd a llyfrgelloedd, yn sicrhau bod y bobl fwyaf agored i niwed yn cael gwybod am eiriolaeth annibynnol, p'un a ydynt mewn cysylltiad â gwasanaethau statudol neu'n eu hystyried eu hunain yn ofalwyr ai peidio.

I lawer o ofalwyr, efallai y bydd aelod o'r teulu, ffrind neu rywun maen nhw'n rhoi gofal a chymorth iddynt yn gallu darparu eiriolaeth anffurfiol er mwyn iddynt allu cymryd rhan a sicrhau bod eu barn a'u dymuniadau'n cael eu clywed wrth wneud penderfyniadau. Er hynny, nid yw'n glir ar hyn o bryd faint o ofalwyr sydd wedi cael cymorth gan eiriolwr anffurfiol i'w helpu â'u cyswllt â'r gwasanaethau cymdeithasol. Yn yr un modd, nid yw'n glir faint o ofalwyr sydd wedi cael cynnig Eiriolaeth Broffesiynol Annibynnol (IPA) statudol yn unol â'r Ddeddf na faint o ofalwyr sydd wedi derbyn y cynnig hwnnw.

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[45] Comisiynydd Pobl Hŷn Cymru, Sicrhau Lleisiau i Bobl Hŷn: Mynediad Pobl Hŷn at Eiriolaeth Annibynnol, 2018

[46] Comisiynydd Pobl Hŷn Cymru, Sicrhau Lleisiau i Bobl Hŷn: Mynediad Pobl Hŷn at Eiriolaeth Annibynnol, 2018

Mae data cenedlaethol[47] yn dangos bod 762 o bobl wedi cael gwasanaeth ‘eiriolaeth’ yn ystod 2016-17 yn rhan o’u gofal a chymorth ond nid oes rhagor o ddata ar gael i gadarnhau’r math o eiriolaeth a ddarparwyd na chanran y gofalwyr a gafodd gymorth eiriolaeth. Yn ogystal, er bod yr Adroddiad Blynyddol ar y Fframwaith Canlyniadau Cenedlaethol yn dangos bod 71% o ofalwyr sy’n cael cymorth yn cytuno eu bod wedi’u cynnwys yn unrhyw benderfyniadau am sut roedd eu gofal neu gymorth yn cael ei ddarparu[48], nid yw’n cynnwys rhagor o fanylion am y rheswm pam nad oedd bron i 30% o ofalwyr yn teimlo’u bod yn rhan o’r penderfyniadau amdanynt ac a oedd eu hangen am eiriolaeth, statudol neu fel arall, yn ffactor yn hynny.

Mae’r diffyg data i ddangos a yw angen gofalwyr am eiriolaeth wedi’i ystyried yn destun pryder. Roedd gofalwyr yn unfryd eu hawydd i wasanaethau eiriolaeth annibynnol arbenigol fod ar gael iddynt i sicrhau eu bod yn gwybod beth yw eu hawliau, a hawliau’r bobl maent yn gofalu amdanynt, ac er mwyn iddynt gael mwy o wybodaeth a theimlo’n fwy abl i barhau i ddarparu gofal a chymorth.

Mae’r diffyg data a gesglir ynghylch cynnig eiriolaeth yn ystod y broses asesu’n golygu nad yw’n glir a allai eiriolaeth annibynnol, neu’r ffaith nad oes gan ofalwyr lais effeithiol yn ystod y broses ac nad ydynt yn gwybod beth yw eu hawliau, fod yn ffactor o ran y nifer fach o Gynlluniau Cymorth sy’n deillio o asesiadau gofalwyr.

Canfu’r adroddiad hefyd wendidau posib yn lefel yr hyfforddiant i staff sy’n gweithio mewn gwasanaethau statudol ar y gofynion cyfreithiol o ran eiriolaeth, a bod hynny yn ei dro’n arwain at ddiffyg dealltwriaeth ymhlith gweithwyr proffesiynol o hawliau pobl i gael eiriolaeth annibynnol a allai fod yn rhwystr i ofalwyr o ran cael eiriolaeth.

O dan Ddeddf Galluedd Meddyliol 2005, gall y rhai sy’n gweithredu fel eiriolwyr anffurfiol i rywun sydd heb alluedd, megis gofalwr di-dâl, aelod

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

[48] Llywodraeth Cymru, Mesur llesiant cenedlaethol:Adroddiad ar y fframwaith canlyniadau cenedlaethol ar gyfer pobl sydd angen gofal a chymorth ac ar gyfer gofalwyr sydd angen cymorth, 2016–17, 2017

o’r teulu neu ffrind, gael cymorth gan IMCA[49] i’w helpu i gyflawni swyddogaeth eiriolwr anffurfiol. Nid oes llawer o wybodaeth ar gael ynghylch i ba raddau y cynigir yr hawl hon i eiriolwyr anffurfiol, a’r defnydd a wneir o IMCA ar lefel genedlaethol. Mae hyn yn destun pryder oherwydd gallai peidio â rhoi cymorth IMCA i eiriolwyr anffurfiol er mwyn iddynt allu cyflawni eu rôl yn effeithiol danseilio llais y rhai y maent yn eirioli drostynt.

Er enghraifft, rhoddodd swyddfa’r Comisiynydd gymorth i deulu a oedd yn anghytuno â phenderfyniad budd pennaf a wnaed ynghylch aelod o’r teulu. Ni ystyriwyd atgyfeiriad IMCA gan fod gan yr unigolyn eisoes gymorth teuluol. Er hynny, dyma’r math o sefyllfa lle y gellid bod wedi defnyddio IMCA i sicrhau bod budd pennaf y person hŷn yn cael ei warchod.

Mae’r niferoedd isel sy’n manteisio ar gymorth IMCA 39D ymhlith aelodau o’r teulu neu ffrindiau sy’n gweithredu fel eiriolwyr anffurfiol yn destun pryder. Mae’n codi amheuon ynghylch i ba raddau y mae gweithwyr proffesiynol yn rhoi gwybod yn briodol i’r rhai sy’n cyflawni rôl eirioli anffurfiol, llawer ohonynt yn ofalwyr, am yr hawl hon. Er bod adroddiad monitro diweddaraf Trefniadau Diogelu rhag Colli Rhyddid[50] yn dangos bod cyfran uwch o heriau’n cael eu cyflwyno i awdurdodiadau Trefniadau Diogelu rhag Colli Rhyddid pan fo IMCA yn bresennol, mae’n nodi bod defnydd o IMCA yn y broses Trefniadau Diogelu rhag Colli Rhyddid wedi bod yn gymharol sefydlog ers 2015/16. Mae’r adroddiad yn dangos, o’r 363 o achosion lle y penodwyd IMCA (o gyfanswm o 13,627 o geisiadau Trefniadau Diogelu rhag Colli Rhyddid a wnaed yn 2016/17[51]), mai dim ond 94 o’r rhain oedd yn IMCA “39D”. Ac ystyried y rhan bwysig mae IMCA’n ei chwarae (gan gynnwys IMCA 39D) er mwyn sicrhau bod llais yr unigolyn yn cael ei glywed pan wneir penderfyniadau budd pennaf, mae’n hollbwysig sicrhau bod hawliau pobl i IMCA (gan gynnwys hawl eiriolwyr anffurfiol i IMCA 39D) yn cael eu hyrwyddo’n fwy cyson.

Yr angen nawr ac yn y dyfodol am eiriolaeth annibynnol

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[49] Mae Deddf Galluedd Meddyliol 2005 yn nodi, pan fo gan unigolyn gynrychiolydd di-dâl, fod yn rhaid cyfarwyddo IMCA 39D os gofynna’r unigolyn neu ei gynrychiolydd di-dâl amdano neu os yw’r corff goruchwylio o’r farn y byddai’r unigolyn neu ei gynrychiolydd yn elwa ar gymorth IMCA 39D

[50] AGGCC & AIC, Trefniadau Diogelu rhag Colli Rhyddid: Adroddiad Monitro Blynyddol ar gyfer Gofal Cymdeithasol ac Iechyd 2016-17

[51] AGGCC & AIC, Trefniadau Diogelu rhag Colli Rhyddid: Adroddiad Monitro Blynyddol ar gyfer Gofal Cymdeithasol ac Iechyd 2016-17

Mae'n destun pryder nad yw'r Asesiadau Poblogaeth (AP) ar hyn o bryd o dan y Ddeddf yn nodi eiriolaeth annibynnol mewn unrhyw fanylder, er gwaetha'r gofyniad i wneud hynny. Er bod AP yn nodi sawl gwahanol grŵp yn yr adroddiadau gan gynnwys pobl ag anabledd dysgu, pobl â chyflwr iechyd meddwl, pobl hŷn a gofalwyr – pob un o bosib ac arnynt angen eiriolwyr annibynnol â sgiliau gwahanol – nid oes awgrym pa wahanol fathau o wasanaethau eiriolaeth annibynnol y gallai fod eu hangen i fodloni'r angen hwn.

Fe ddylai fod yn ddigon posib dadansoddi data ar grwpiau penodol o bobl i amcangyfrif y galw am eiriolaeth annibynnol; byddai cynnydd yn nifer y bobl sy'n byw gyda dementia, er enghraifft, yn awgrymu bod angen cynnydd cymesur yn nifer yr eiriolwyr annibynnol sy'n gallu gweithio yn y maes hwnnw. Mae'n destun pryder nad yw'r cysylltiad hwn wedi'i wneud yn yr un o'r adroddiadau AP.

Dyma golli cyfle go iawn ac mae'n codi pryderon am effeithiolrwydd AP fel offeryn i 'sicrhau bod gwasanaethau'n cael eu cynllunio a'u datblygu mewn ffordd effeithlon ac effeithiol gan bartneriaid yn y sector cyhoeddus er mwyn hyrwyddo llesiant pobl ag anghenion gofal a chymorth'[52].

Polisi Llywodraeth Cymru'n ehangach

Iechyd

Gall gofalu gael effaith negyddol ar iechyd corfforol a meddyliol gofalwyr. Yn ôl adroddiad 'State of Caring' Gofalwyr Cymru:

Gall gofalwyr ei chael yn anodd dod o hyd i amser i ofalu am eu lles eu hunain wrth ofalu:

- Dywedodd dros hanner y gofalwyr yng Nghymru (53%) hefyd eu bod yn gwneud llai o ymarfer corff oherwydd eu bod yn gofalu a dywedodd 47% eu bod wedi'i chael yn anodd sicrhau diet cytbwys.

Mae gofalwyr yn fwy tebygol o fod â chyflyrau iechyd corfforol neu feddyliol ac maent yn aml yn esgeuluso'r cyflyrau hynny:

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[52] Paragraff 79, Cod Ymarfer Rhan 2 (Swyddogaethau Cyffredinol), Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014

- Dywedodd 6 o bob 10 gofalwr (59%) fod eu hiechyd corfforol yn waeth oherwydd eu bod yn gofalu a dywedodd 70% o ofalwyr yng Nghymru eu bod yn dioddef problemau iechyd meddwl.

Mae gofalwyr yn fwy tebygol o brofi straen, gorbryder ac iechyd meddwl gwaeth:

- Dywedodd hanner (50%) y gofalwyr yng Nghymru fod eu hiechyd meddwl wedi gwaethygu oherwydd eu bod yn gofalu, dywedodd 8 o bob 10 o bobl (78%) eu bod yn teimlo dan fwy o straen oherwydd eu rôl ofalu, a dywedodd 7 o bob 10 (67%) fod gofalu wedi gwneud iddynt deimlo'n fwy pryderus[53].

Yn ogystal â'u hanghenion iechyd eu hunain, mae mwy o lawer o ofalwyr yn ymdrin â gwasanaethau iechyd na gwasanaethau gofal cymdeithasol yn rhan o'u rôl ofalu[54]. O'r herwydd, mae'n hanfodol bod y gwasanaethau iechyd yn ymwybodol o ofalwyr, yn eu hadnabod ac yn ymateb iddynt er mwyn cynorthwyo gofalwyr i barhau i ofalu ac i ofalu am eu lles eu hunain.

Mesur Strategaethau Iechyd a Gofalwyr (Cymru) 2010

Diddymwyd Mesur Strategaethau ar gyfer Gofalwyr (Cymru) 2010 (y Mesur) a deddfwriaeth arall ar gyfer gofalwyr pan gyflwynwyd y Ddeddf, oherwydd bod bwriad i drosglwyddo'i ddarpariaethau i'r Ddeddf. Gwrthwynebwyd hynny'n gryf gan fudiadau gofalwyr ar y pryd.

Cododd Cynghrair Cynhalwyr Cymru bryderon fod diddymu'r Mesur, a chyflwyno Deddf Llesiant Cenedlaethau'r Dyfodol (Cymru) 2015 wedi glastwreiddio swyddogaeth y Byrddau Iechyd wrth gydgynllunio gwasanaethau i ofalwyr, a bod canllawiau manwl a oedd yn sail i'r Mesur wedi eu colli[55].

O dan y Mesur, dynodwyd y byddai'r Byrddau Iechyd yn asiantaethau arweiniol wrth ddatblygu strategaethau gofalwyr lleol, y bwriedid iddynt sicrhau bod gofalwyr yn cael eu hadnabod a bod gwybodaeth yn cael ei darparu i ofalwyr mewn modd systematig[56]. Mae hyn bellach wedi'i gynnwys mewn gofyniad mwy cyffredinol i Fyrddau Gwasanaethau

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[53] Gofalwyr Cymru, State of Caring 2017, 2017

[54] Cynghrair Cynhalwyr Cymru, Assembly Member Briefing for the Stage 3 Debate of the Wellbeing of Future Generations (Wales) Bill, 2015

[55] Cynghrair Cynhalwyr Cymru, Assembly Member Briefing for the Stage 3 Debate of the Wellbeing of Future Generations (Wales) Bill, 2015

[56] Mesur Strategaethau ar gyfer Gofalwyr (Cymru) 2010; Mesur Strategaethau ar gyfer Gofalwyr (Cymru) 2010 Canllawiau ar gyfer Byrddau Iechyd Lleol ac Awdurdodau Lleol, Rhagfyr 2011

Cyhoeddus gwblhau asesiadau llesiant a chyhoeddi cynllun llesiant lleol[57].

Er nad ydym yn gwybod eto beth fydd effaith y newidiadau deddfwriaethol hyn, mae'r fframwaith cyfreithiol ar gyfer adnabod gofalwyr a darparu gwybodaeth iddynt a oedd yn bodoli o'r blaen drwy'r Mesur wedi'i ddirwyn i ben. Mae'r newid hwnnw wedi'i weld hefyd drwy ddirwyn i ben swyddogaethau strategol cysylltiedig[58].

Er gwaethaf hyn, ceir enghreifftiau o arfer da mewn perthynas â gofalwyr ar draws Byrddau Iechyd, megis cynlluniau i annog a chymell arferion i geisio sicrhau bod mwy o wybodaeth a chymorth ar gael i ofalwyr megis y cynllun 'Buddsoddwyr mewn Gofalwyr' i feddygfeydd ledled Bwrdd Iechyd Prifysgol Hywel Dda[59]. Yn ogystal, mae rôl Hyrwyddwr Gofalwyr mewn gwasanaethau meddygon teulu wedi'i rhoi ar waith yn dda mewn rhai practisau, ond amrywiol fu llwyddiant ac effaith y rôl hon[60]. Er hynny, mae dyfodol y cynlluniau a'r camau gweithredu hyn ar draws pob Bwrdd Iechyd yn awr yn ddibynnol ar ewyllys pob mudiad yn erbyn y gofynion a nodir yn y Mesur.

Gwasanaethau Meddygon Teulu

Cyhoeddodd y Comisiynydd adroddiad ar wasanaethau meddygon teulu yn 2017[61], ac roedd bron i 17% o'r rhai a ymatebodd i'r holiadur yn eu hystyried eu hunain yn ofalwyr, a chodwyd nifer o faterion ynghylch gofalwyr.

Canfu'r adroddiad y gall systemau iechyd fod yn anhyblyg a pheidio ag ymateb i anghenion unigol pobl – er enghraifft wrth drefnu apwyntiad a'r diffyg cydnabyddiaeth i'r anawsterau y gall gofalwyr eu hwynebu wrth gyrraedd apwyntiadau ar fyr rybudd. Soniodd gofalwyr am heriau trefnu ymweliad cartref, a'r rhwystredigaeth a ddaw yn sgil gorfod esbonio'u sefyllfa dro ar ôl tro wrth geisio trefnu hyn.

"Anodd i ofalwyr fynd i apwyntiadau ar yr un diwrnod oherwydd eu bod yn methu cael rhywun i gymryd eu lle neu helpu mor gyflym â hynny -

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[57] a37 Deddf Llesiant Cenedlaethau'r Dyfodol (Cymru) 2015

[58] Tystiolaeth a gasglwyd gan Rwydwaith Dysgu a Gwybodaeth Swyddogion Gofalwyr ar gyfer adroddiad Ailystyried Seibiant Comisiynydd Pobl Hŷn Cymru

[59] Bwrdd Iechyd Prifysgol Hywel Dda, Buddsoddwyr mewn Gofalwyr

[60] Comisiynydd Pobl Hŷn Cymru, Gwasanaethau Meddygon Teulu yng Nghymru, 2017

[61] Comisiynydd Pobl Hŷn Cymru, Gwasanaethau Meddygon Teulu yng Nghymru, 2017

efallai na fydd gwasanaeth car gwirfoddol hyd yn oed ar gael mor fyr rybudd.” Ymgysylltu

“Y broblem fwyaf yw mynd heibio i’r derbynnydd. Mae angen ymweliadau â’r cartref arnom oherwydd dydy fy ngwraig ddim yn gallu gadael y tŷ, a fi yw ei gofalwr. Mae fel holiad bob tro - llwyth o gwestiynau peryglus y mae’n rhaid eu hateb. Dylai fod nodyn ar eich ffeil os oes angen ymweliadau â’r cartref arnoch chi. Yn lle hynny, mae’n frwydr bob tro.” Ymgysylltu

At ei gilydd, roedd yr adborth gan bobl hŷn fel petai’n dangos newid cadarnhaol o ran croesawu a chydnabod presenoldeb a rôl gofalwyr, ac roedd enghreifftiau o arfer da megis rhoi nodiadau yn y system (gyda chaniatâd) yn effeithiol i adnabod unigolion sy’n ofalwyr, sy’n byw gyda dementia, neu sydd ag anghenion cyfathrebu penodol.

“Dydy dod â gofalwr ddim yn broblem. Maen nhw’n siarad â’r ddau ohonon ni. Rydyn ni’n cael ein derbyn fel cwpl - does neb yn cael ei adael allan.” Ymgysylltu

Er hynny, roedd nifer fach o bobl hŷn yn teimlo bod gweithwyr iechyd proffesiynol yn siarad â’r gofalwr neu’r gweithiwr cymorth yn hytrach nag yn uniongyrchol â nhw, ac nad oeddent yn ddigon ymatebol wrth gofnodi statws unigolyn fel gofalwr.

“Rydw i’n credu bod angen i fy meddygfa wneud mwy i ddiwallu anghenion Gofalwyr (di-dâl). Rydw i wedi cyflwyno ffurflen gofrestru Gofalwr, ond mae hi’n anodd gweld oes unrhyw beth wedi cael ei roi ar waith. Rydw i wedi gofyn am atgyfeiriad i fy Ngwasanaethau Cymdeithasol lleol (i gael gwybodaeth am Ofalwyr) ond dydw i ddim wedi cael dim byd. Dydw i ddim wedi cael dim gohebiaeth am Ofalwyr gan fy Meddygfa (e.e. gwahoddiad i glinig ffliw).” Holiadur ar-lein

Cynllun Gweithredu Cymru ar gyfer Dementia 2018-2022

Mae Cynllun Gweithredu ar gyfer Dementia Llywodraeth Cymru’n cydnabod y rhan hanfodol y mae gofalwyr yn ei chwarae wrth gefnogi pobl sy’n byw gyda dementia. Mae hefyd yn cydnabod yr hawl i gael asesiad gofalwr a’r angen am ddarpariaeth seibiant hyblyg, ac mae’n cyflwyno egwyddorion Ymgyrch John er mwyn i ofalwyr gael aros gyda’r bobl maen nhw’n eu cefnogi mewn ysbytai[62].

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[62] Llywodraeth Cymru, Cynllun Gweithredu Cymru ar gyfer Dementia, 2018

Mae’n hollbwysig cynnwys gofalwyr wrth gynllunio gofal cleifion mewnol i bobl sy’n byw gyda dementia er mwyn cael canlyniadau gwell ar ôl eu derbyn i’r ysbyty. Ar hyn o bryd mae prosesau ysbytai’n golygu nad yw gofalwyr yn gallu cymryd rhan mewn ffordd ystyrlon wrth gefnogi eu hanwyliaid sydd â dementia. Felly, bydd angen cynnwys gofalwyr wrth roi’r strategaeth ar waith – nid dim ond fel unigolyn sy’n cadw cwmni i rywun yn yr ysbyty, ond fel partner allweddol wrth gynllunio a darparu gofal.

Nid ydym yn gwybod eto sut y bydd Llywodraeth Cymru’n gofyn i Fyrddau Iechyd adrodd ar weithredu Ymgyrch John ledled Cymru; er hynny, mae’n rhaid i unrhyw ddull gweithredu rhanbarthol sicrhau nad yw hawliau gofalwyr i aros gyda’u hanwyliaid yn cael eu glastwreiddio neu’n dibynnu ar hap a damwain.

Cam-drin domestig a gofalu

Mae risg uwch[63] i bobl sy’n byw gyda dementia gael eu cam-drin gan aelod o’r teulu sy’n gofalu amdanynt, ac yn yr un modd mae risg hefyd y bydd gofalwyr yn cael eu cam-drin gan y rhai y maent yn gofalu amdanynt. Mae canfyddiadau’n dangos bod cysylltiad agos rhwng profi trawma, iechyd gwael, lefelau isel o gymorth cymdeithasol, a byw ar eich pen eich hun, a phrofi rheolaeth drwy orfodaeth gan rywun agos atoch yn ystod eich bywyd. Mae’r rhain i gyd yn ffactorau risg sy’n gysylltiedig â risg uwch o gam-drin corfforol i bobl dros 60 oed[64]. Mae’n hanfodol felly fod gweithwyr proffesiynol iechyd a gofal cymdeithasol yn gallu adnabod risgiau i ofalwyr ac i’r sawl sy’n cael gofal mewn sefyllfa lle y gallai rhywun gael ei gam-drin.

Er hynny, gall ystyriaethau staffio gyfyngu ar gyfleoedd i weithwyr cymdeithasol i ddatblygu perthynas gadarnhaol sy’n seiliedig ar ymddiriedaeth â phobl hŷn. Ceir tystiolaeth yng Nghymru fod asiantaethau statudol yn troi at reoli achosion dros y ffôn[65]. Gall hyn fod yn rhwystr rhag datblygu ethos ‘sy’n canolbwyntio ar yr unigolyn’ o ran diogelu oedolion a llesteirio ymdrechion i bersonoli gofal i oedolion yn gyffredinol[66].

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[63] National 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

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

[65] Comisiynydd Pobl Hŷn Cymru, Cael cymorth a chyfiawnder, 2015

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

Mae angen i Awdurdodau Lleol a Byrddau Iechyd fynd ati i hybu ymwybyddiaeth o broblem gudd cam-drin domestig y mae pobl hŷn yn ei brofi, a chydnabod mai ymateb cymunedol wedi'i gydlynu yw'r strategaeth fwyaf priodol er mwyn ymdrin â chymhlethdod cam-drin domestig, a chymryd camau i roi hynny ar waith[67].

Gofalu ac arian

Gall bod yn ofalwr gael effaith negyddol ar sefyllfa ariannol pobl. Bydd costau cadw tŷ weithiau'n uwch i ofalwyr, ynghyd â chostau cludiant (yn enwedig mewn ardaloedd gwledig), ac efallai na fydd trefniadau gweithio hyblyg ar gael iddynt, neu efallai eu bod yn llai abl i weithio oherwydd eu rôl ofalu[68]. Mae'n bosib y bydd gofalwyr hŷn eisiau dal ati i weithio, ond bod hynny'n anodd iddynt oherwydd eu rôl ofalu – neu efallai na fydd gofalwyr hŷn yn cael y cymorth ariannol y mae ganddynt hawl iddo.

Yn ôl yr Ymddiriedolaeth Gofalwyr, ledled y DU:

- 67% yw'r gyfradd gyflogaeth ymhlith gofalwyr; mae dros hanner y rhai nad ydynt yn gweithio'n dweud eu bod eisiau gwneud hynny. Mae un o bob pump gofalwr yn rhoi'r gorau i swydd er mwyn gofalu.
- Mewn arolwg, roedd 53% o ofalwyr wedi benthyca arian oherwydd eu rôl ofalu.
- Mae 60% wedi defnyddio eu cynilion i gyd i dalu costau gofalu.
- Roedd 35% o ofalwyr wedi colli cyfle i gael budd-daliadau'r wladwriaeth am nad oeddent yn sylweddoli bod ganddynt hawl i'w hawlio. Roedd 9% wedi colli cyfle i gael Lwfans Gofalwr am 3–5 mlynedd, 10% am 5–10 mlynedd ac 14% am dros 10 mlynedd, am nad oeddent yn sylweddoli bod ganddynt hawl iddo[69].

Mae'r Lwfans Gweini ar gael i bobl 65 a hŷn sydd ag anabledd sy'n golygu bod angen gofal neu oruchwyliaeth arnynt bob dydd. Mae'n cael ei hawlio gan 100,000 o bobl yng Nghymru, sef 17% o bobl dros 65 (ar gost o £400m). Mae pryderon nad yw'r Lwfans Gweini'n cyrraedd y rhai y mae ei angen arnynt, ac efallai nad yw pobl hŷn yn eu gweld eu hunain fel pobl sy'n hawlio budd-daliadau. Er enghraifft, nid oes cyfatebiaeth rhwng cyfran y bobl hŷn sy'n derbyn Lwfans Gweini a'r bobl hŷn sy'n cael gofal dibreswyl ledled ardaloedd awdurdodau lleol Cymru[70]. Gallai

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

[68] Carers UK, The Cost of Caring, 2013

[69] Carers Trust, Key facts about carers, cyrchwyd Medi 2018

[70] Sefydliad Bevan, Future of Attendance Allowance in Wales, 2016

codi ymwybyddiaeth o fudd-daliadau megis y Lwfans Gweini fod yn gam tuag at wella sefyllfa ariannol gofalwyr.

Gofalu a thai

Rydym yn gwybod bod ansawdd tai a pha mor briodol ydynt yn ffactor allweddol i iechyd a lles unigolion. Gall cartrefi twym sy’n defnyddio ynni’n effeithlon olygu costau is ac atal problemau sy’n gysylltiedig ag amodau byw oer, llaith. Yn ogystal, gall sicrhau bod eu cartrefi’n hygyrch a gwneud addasiadau priodol wella ansawdd bywyd pobl ag anghenion gofal a chymorth, ynghyd â’u gofalwyr, yn aruthrol.

Ymhlith y materion yn ymwneud â thai y mae gofalwyr yn eu hwynebu mae peidio â chael blaenoriaeth ar gyfer tai neu ddiffyg cydnabyddiaeth bod angen ystafell wely ar wahân arnynt, diffyg cydnabyddiaeth o hawliau etifeddu neu denantiaeth os nad yw’r gofalwyr wedi’u henwi yn y gweithredoedd neu’r denantiaeth, a heriau parhaus o ran cael addasiadau neu gartref wedi’i addasu[71].

Wrth fwrw ymlaen ag argymhellion y Grŵp Arbenigol ar Ddarparu Tai i Boblogaeth sy’n Heneiddio[72] a pholisïau tai eraill, mae angen i Lywodraeth Cymru fod yn ymwybodol o’r materion penodol y mae gofalwyr yn eu hwynebu, ac ymateb iddynt.

Gofalu a thechnoleg

Pe dymunid hynny, gallai technoleg gynorthwyol helpu gofalwyr a phobl ag anghenion gofal a chymorth fel ei gilydd i fyw bywydau mwy annibynnol gartref, ac allan yn eu cymuned. Gwelwyd cynnydd yn y mathau o dechnoleg sydd ar gael dros y blynyddoedd diwethaf, sy’n mynd y tu hwnt i’r systemau larwm cymunedol traddodiadol. Heddiw rydym yn defnyddio mwy o offer electronig na’r un gymdeithas o’r blaen, o oleuadau a reolir o bell i dechnolegau sy’n defnyddio’r llais e.e Alexa. Mae’r rhain yn cynnig cyfle i bobl i fyw’n annibynnol gan ddefnyddio amryw o ddyfeisiau o gwmpas y cartref e.e. rheoli apwyntiadau.

Mae’r Adolygiad Seneddol o Iechyd a Gofal Cymdeithasol yn argymell bod Llywodraeth Cymru ac iechyd a gofal cymdeithasol yn “Defnyddio arloesedd a chyflymu datblygiadau mewn technoleg a seilwaith”[73].

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

[72] Llywodraeth Cymru, Grŵp Arbenigol ar Ddarparu Tai i Boblogaeth sy’n Heneiddio, 2017

[73] Adolygiad Seneddol o Iechyd a Gofal Cymdeithasol, Chwyldro o’r Tu Mewn: Trawsnewid Iechyd a Gofal yng Nghymru, 2018

Mae angen gwybodaeth, cyngor ac arweiniad da ar ofalwyr hŷn ynglŷn â'r dechnoleg gynorthwyol sydd ar gael a sut y gall eu helpu i barhau i fyw'n annibynnol. Mae hyn yn aml yn cael ei ddarparu gan Therapyddion Galwedigaethol a Ffisiotherapyddion, ond fe ddylai cyngor mwy cyffredinol fod ar gael drwy Weithwyr Cymdeithasol a Gwasanaethau Gwybodaeth a Chynghori i ategu nodau ataliol y Ddeddf.

Er hynny, mae cynhwysiant digidol, ac ansawdd gwasanaethau band eang ledled Cymru'n rhwystro llawer o bobl rhag mabwysiadu technolegau o'r fath. Yn ogystal, dylai technolegau bob amser gael eu gweld fel modd o gynorthwyo yn hytrach na'u bod yn disodli'r ymwneud a'r cyswllt go iawn rhwng pobl sy'n hanfodol i'n llesiant.

Older People's Commissioner for Wales
Comisiynydd Pobl Hŷn Cymru

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
[redacted]

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

- 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 well-being 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 one[1]. More than half of carers are aged 40 to 64 and a quarter of carers are aged 65 or over[2]. Carers provide the vast majority of care to people in communities across Wales, with 96% of care in communities being given by family and friends[3].

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 people[4].

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 carer[5].

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.

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[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

[4] ONS, 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 professionals[8].

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

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[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 year[9]. 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 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 time[10].

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 them[11]. As highlighted above, a person exercising duties under the Act must also have due regard to the United Nations Principles for Older Persons[12].

However, the Carers Strategies (Wales) Measure 2010 and other pre-existing 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.

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[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 this[13]. 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 respite[14]. 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,

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[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 carer[15].

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 interest[16].

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-being[17].

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

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[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 assessment[18].

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 assessment[19].

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.

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[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 carers[21].

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,

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[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 carer[22].

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 needs[23]. 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

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[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' assessments[24]; 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 Wales[25].

The Care and Support (Assessment) Wales Regulations 2015 state that a Local Authority must produce a written record of an assessment[26] and a copy of the written record of assessment must be given to the person[27].

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

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[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 them[28]. 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 carers[29]. 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 investment[30].

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 services[31]. 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 services[32].

Information, advice and assistance

The Act places a duty on Local Authorities to provide information, advice and assistance (IAA) to citizens, including carers[33]. 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

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[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 useful[34].

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' report[35] 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.

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[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 2018-2022[36] (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

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[36] Welsh Government, Dementia Action Plan for Wales, 2018

Assurance and Implementation Group[37], the minutes of which will be published for transparency[38].

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 funding[40]. 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.

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[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 carers[43]. 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

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[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] 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

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 User[44]

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 Wales[45]’ found that a

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[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 dementia[46]

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 data[47] 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 provided[48], it does not contain any further detail on the reasons why almost 30% of carers

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[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 IMCA[49] 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 Safeguards[50] 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 2016/17[51]), 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.

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[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 anxious[53].

In addition to their own health needs, far more carers deal with health services than with social care as part of their caring role[54]. 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 well-being.

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 lost[55].

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 carers[56]. 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 plan[57].

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 roles[58].

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 Board[59]. 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 role[60]. 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 2017[61], 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

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[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 hospitals[62].

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 risk[63] of people living with dementia experiencing abuse from a family carer. Similarly, carers are also at risk of being

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[62] Welsh Government, Dementia Action Plan for Wales, 2018

[63] National 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

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 60[64]. 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 telephone[65], 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 general[66].

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 abuse[67].

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 role[68]. 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] 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,

[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 it[69].

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 areas[70]. 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 home[71].

In taking forward the recommendations of the Expert Group on Housing an Ageing Population[72] and further housing policy, the Welsh

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[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

C25
Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Gyngor Sir Ceredigion
Response from Ceredigion County Council

Cyngor Sir CEREDIGION County Council

[redacted]

Swyddog Arweiniol Corfforaethol : Gwasanaethau Oedolion
Corporate Lead Officer : Adult Services

[redacted]

Dyddiad
Date 20/09/2018

Gofynnwch am
Please ask for [redacted]

Llinell uniongyrchol
Direct line [redacted]

Fy nghyf
My ref

Eich cyf
Your ref

Ebost
Email [redacted]

FAO Health Social Services and Sport Committee,

Re: Consultation on the impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers

Ceredigion County Council welcomes the opportunity to provide a response to the Health, Social Services and Sport Committee in relation to Carers of all ages with regard to the issues below.

1. *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;*
2. *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;*
3. *The extent to which local authorities are fulfilling their duties under the Act to provide information, advice and assistance to carers;*
4. *Whether local authorities and Local Health Boards have sufficient information on the number and needs of carers in their areas;*
5. *Other changes since the Act came into force which may impact on carers, for example changes to the services provided to people who are cared for;*
6. *Broader Welsh Government policy on carers and how it should be developed*.

Within this submission, we have incorporated a joint Ceredigion response to the Inquiry. The response encompasses a partnership approach, offering the perspectives of the Local Authority Ceredigion County Council, our partners Hywel Dda University Health Board Ceredigion County Team (HDUHB) and the Ceredigion Association of Voluntary Organisations (CAVO), and as a result, the submission has been extended accordingly to allow for the inclusion of the combined viewpoints.

Prif Weithredwr / Chief Executive :
Cyfarwyddwyr Corfforaethol / Corporate Directors : [redacted]

Cyngor Sir CEREDIGION County Council

[redacted]

Cyfarwyddwr Statudol y Gwasanaethau Cymdeithasol / Statutory Director of Social Services
Swyddog Arweiniol Corfforaethol : Gwasanaethau Oedolion / Corporate Lead Officer : Adult Services

[redacted]

Health, Social Service and Sport Committee:
Inquiry on Carers

Ceredigion County Council has a longstanding ethos where “Carers are everyone’s business”. The vision is to provide Carers with the support they need, and to work consistently to achieve our vision of a carer friendly community that supports Carers to have a life alongside caring. The activity and initiatives embedded, and in development, demonstrate how the ethos of the Social Services and Wellbeing Act (SSWBA) drives the conversations and effective facilitation with and for Carers. We continue to develop and support our professional workforce to be “Carer Aware and Young Carer Aware” and to help develop more “Carer friendly” practices and in turn value those in our workforce who are Carers.

Ceredigion County Council is a partner in the West Wales Regional Partnership Board (RPB) and in addition to the strategic and operational activities within Ceredigion as a county, we work closely with our neighbouring local authorities, Hywel Dda University Health Board and third sector colleagues in the delivery of services to meet the needs of Carers highlighted within the published Population Needs Assessment. Within the RPB Area Plan in which Carers are a priority, the RPB benefits from a long established West Wales Carers Development Group which was initially established to drive forward the Carers Strategies (Wales) Measure 2010 and has continued to evolve to provide a catalyst for collaborative and integrated partnership working.

1. *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;*

1.1 Porth Gofal is a partnership between the Council, HDUHB, and the third sector; providing a referral pathway for Health and Social Care services. Building on the expertise developed within our Single Point of Access, our Prevention Support Officers work alongside a Senior Social Worker for Adults and Adult Safeguarding, a Social Care Worker for Children and Families, senior clinical nurses, occupational therapists, physiotherapists and third sector facilitators. Where Carers contact Ceredigion Social Care for a Carers needs assessment, the Triage service determines the most appropriate professional to undertake the assessment. The team around Porth Gofal is responsive to identify Carers and undertake the Carers needs assessments or refer requests on to the Long Term teams if already involved with them. In addition, Porth Gofal and Social Services assessment teams consistently offer proportionate assessment (Carers needs

Rydym yn croesawu gohebiaeth yn Gymraeg a Saesneg. Cewch ateb Cymraeg i bob gohebiaeth Gymraeg ac ateb Saesneg i bob gohebiaeth Saesneg. Ni fydd gohebu yn Gymraeg yn arwain at oedi.
We welcome correspondence in Welsh and English. Correspondence received in Welsh will be answered in Welsh and correspondence in English will be answered in English. Corresponding in Welsh will not involve any delay.

Prif Weithredwr / Chief Executive :
Cyfarwyddwyr Corfforaethol / Corporate Directors : [redacted]

assessments) to people identified as Carers when they appear to need support (as required under current legislation. A Carer support plan is completed for those who have eligible needs resulting in a service being provided. Additional support in the form of specialist advice is available to professionals from the Ceredigion County Council Carers Unit where required.

1.2 Following the CSSIW Key Lines of Enquiry Carers Focus October 2016 and January 2017, CSSIW noted that Carers confirmed that they have been offered assessments and that generally their views are listened to, that they had received a copy of their assessment, and the assessment had resulted in additional services. In all cases, regardless of whether Carers are assessed as having eligible needs or not, Carers are provided with information and signposted to other organisations that may be able to help them in their caring role. As was anticipated, since the implementation of the Social Services & Wellbeing Act, there has been a reduction in the number of formal Carers needs assessments. The reasons for this are manifold. Whilst Carers that appear to require support are offered a Carers needs assessment, the formal annual offer of a Carers needs assessment is not a requirement of SSWBA to directly re-engage Carers with a formal social care intervention. In addition, the number of Carers needs assessments in 2015/16 increased significantly from the previous years because of the introduction of a Carer self-evaluation system. This self-evaluation system was withdrawn with SSWBA implementation as it more appropriate to mainstream Carers within the same assessment system as individuals in need of care and support. Whilst withdrawal of this system aligned with a reduction in Carers needs assessments, it established a return to a face to face assessment for all those undertaken.

Time period	1st April 2013 – 31st March 2014	1st April 2014 to 31st March 2015	1st April 2015 to 31st March 2016	1st April 2016 to 31st March 2017	1st April 2017 to 31st March 2018
Number of adult Carers that had Carers needs assessment	234	144	442	138	193
Average number of adult Carer needs assessments completed per year		273		166	

1.3 Carer's needs are addressed proportionately, a focus on the what matters conversation and aligned with the Signs of Safety approach adopted in Ceredigion as a through age holistic model, aimed at helping social workers to focus on prevention and early intervention throughout our systems and processes. The model has a strong emphasis on building partnerships and collaboration, not only with the family, but also with other professionals, extended family and peer relationships. There is a strong focus on promoting information with partners; some Carers needs have been met at an earlier stage of intervention with third sector organisations and will have not engaged with social care as a result and not progressed to having a formal Carers needs assessment. For example, Social Care's Porth Gofal (Care Gateway) provides information and advice to Carers to help meet their needs, without necessitating formal assessment if that is the appropriate option for the Carer.

1.4 Young Carers under the age of 18 who are identified by Social Services assessment teams or who contact Social Services for support, are referred to the Council's commissioned provider, Action for Children Young Carers Service and for those in transition and over 18-25 years their Young Adult Carers Service, for help and support. The Young Carers and Young Adult Carers Service has delegated responsibility under a formal Protocol Agreement for carrying out age appropriate Carers needs assessment. Where they identify a need for support requiring multi-disciplinary input or social care interventions, they refer via Ceredigion Social Care's Porth Gofal Plant for coordinated professional support.

Time Period	1st April 2013 – 31st March 2014	1st April 2014 to 31st March 2015	1st April 2015 to 31st March 2016	1st April 2016 to 31st March 2017	1st April 2017 to 31st March 2018
Number of young Carers that had Carers needs assessment	71	45	6	107	73
Average number of young Carer needs assessments completed per year	41			90	

2. *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;*

2.1 The allocation of the Welsh Government Respite for Carers Grant and its transfer into Revenue Support grant from 2018/19 has provided us with the opportunity to test a wider range of innovative approaches to respite, supporting pilots and testing new models: a) short breaks - the Supported Sleepover/Day break, a partnership initiative with third sector and statutory agencies. The project supports children with complex needs to have a 'supported sleepover or day break' at an adapted bungalow in the county and /or other locations in the community for supported activities, to enable the Parent Carer to have a much needed break and or time with other family members, the adapted bungalow has a sensory garden, established with the support of a further 3rd sector community group. b) Carers wellbeing alongside caring, - the responsive "Time for Me, Time to Do" Carers flexible respite fund enabling individual Carers and Carers Groups, to apply for a discretionary grant to support them to pursue an activity, take a break, access therapeutic support, explore personal development opportunities c) Carers Contingency, providing the Porth Gofal Team with access to immediate additional funding to respond to a triaged Carer issue, to enable a more immediate response, whilst allowing agencies to jointly prepare for an ongoing support need. d) Respitality/Social tourism/Carer discounts model mapping – exploring the extent to which these models can offer a range of additional breaks for Carers and those for whom they care. e) Young Adult Carers - service implementation to support 16-25 year olds through transitions from school to college, university, work.

2.2 There is case study collated evidence that social care staff are being more flexible in terms of finding solutions to meet Carers needs, i.e. direct payment support where such service requests would have been less responsive prior to Social Services and Wellbeing Act. Through the good practice taken forward by our social care teams in carrying out Carers needs assessments and the links between the Council's Carers Unit and those teams, there have been a number of successes regarding outcomes for Carers. For example:

- Sourcing a range of benevolent funds: staff are supported to seek and source solutions in the community, i.e. a social worker worked with the Council's Carers Unit to make a successful application to a benevolent fund linked to self-employment to receive grant aid to help a Carer with household finances during a period of intense Carer ill health and subsequent treatment.
- Direct Payments: Carer awarded a weekly direct payment to enable them to finance transport to take the person they care for to and from a work placement. The continuation of the work placement was important for Carers own emotional wellbeing. The Carer was providing extensive practical and emotional support to the cared for person on a daily basis and whilst they wanted to continue in the caring role, they were struggling with the financial pressures of providing the transport.

2.3 The number of Carers receiving support after they have had an assessment has not changed significantly. During the period 1st April 2016 to 31st March 2017, Social Services provided support/ services to **47** adult Carers following a Carers needs assessment. During the period 1st April 2017 to 31st March 2018, Social Services provided support/ services to **55** Carers following a Carers needs assessment. The difference is the increased flexibility of support considered and the ways that support is encouraged.

2.4 We are currently implementing a pilot Carer Quality Assurance Framework developed to focus our attention on what needs to be in place to ensure that when Carers come in to contact with the Council, their experience meets or exceeds their expectations. The Framework itself defines quality in terms of Carer outcomes, states how it will be measured and determines how it will be improved. The framework encompasses casefile audits of Carers that have had Carers assessments, case file audits of Carers that have declined a Carers assessment but have received information or guidance and internal audits of procedures that assessment teams work to. A casefile audit tool and associated guidance notes are being developed for use alongside the framework. A set of reports have been developed by the Business Information Team to compliment the framework. When fully in operation in the latter part of 2018/19, an annual quality assurance programme will be piloted ensuring that all required areas are covered across the year. The Carers Unit will maintain a record of emerging issues and concerns identified as part of internal audit and case file audit process. Team members, team managers and service managers will be notified of these emerging issues and concerns as required. Corrective actions will be implemented, changes to procedures actioned and subsequent training carried out as required.

2.5 Other support provided to Carers falls outside of a Carers needs assessment. For instance, during the period 1st April 2017 to 31st March 2018, **70** Carers were in receipt of the Council's Carers Emergency Card service. Carers do not need to have had a Carers needs assessment to receive this service. The service provides the Carer with a credit-sized card to carry with them at all times. It is used as an instant source of identification in case the Carer suffers an accident or sudden illness. Social Services hold the pre-prepared plan that specifies nominated emergency contacts so that in the event of an emergency, help can be coordinated, through the nominated emergency contacts, for the person being cared for.

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

3.1 Members of staff within the Council's Carers Unit, Porth Gofal and Porth y Gymuned have completed a Level 4 qualification in Information Advice and Guidance.

3.2 We have implemented a corporate approach to embedding DEWIS aligned with the third sector Infoengine as our core digital repository for community information and Carers Support is fundamental within it. The corporate Contact Centre CLIC officers have all completed Carer Aware and Young Carer Aware training. The Carers Unit Service and the Carers Information Service have transferred from Social Care to Customer Contact, under the corporate transformation programme, in order to embed Carers within the corporate infrastructure. This will ensure that Carers are recognised and identified more swiftly at the first point of contact with the authority. The Carers Unit acts as a conduit to improve understanding, enhance recognition and embed into practice and service delivery, the commitment from all sectors, and all services, to support Carers as core activity.

3.3 Carers may request and are provided with information, advice and assistance via a number of routes:

- During the period 1st April 2016 – 31st March 2017, **349** Carers were in contact with the Information, Advice and Assistance service run by Social Service's Porth Gofal. During the period 1st April 2017 – 31st March 2018, **285** Carers were in contact with the same service. The number of Carers accessing the service has most likely reduced because of the increased focus on prevention, early intervention and signposting alongside enhanced connections between services, meaning that more Carers are accessing information they need within the community thereby reducing the need to contact Social Services.

- Connectors working within the Council's Porth y Gymuned (Community Gateway) service, have an important role in identifying unknown Carers within our communities. Through using the Signs of Wellbeing principals and having the What Matters conversation with individuals on a 1:1 basis, Connectors are able to ensure that appropriate information and advice is offered where they identify Carers during their visits. They have an opportunity to link Carers to community groups and third sector services as well as raise the level of understanding relating to the support available from the Carers Unit and how to register with the Carers Information Service. Importantly, the team are also able to highlight the option of having a Carers needs assessment and to ensure an appropriate level of information is provided. This service will help to address the needs of Carers and others in the community before they are at the threshold of requiring Social Services support via Porth Gofal, the Carers Information Service run by the Council's Carers Unit, Social Services assessment teams or via the Family Information Service. There is a good staff awareness of services locally and nationally and periodic speed networking events are held. The third sector commissioned Carers' service providers are members of a wider Ceredigion Carers Alliance network with a wide range of other third sector providers which is a conduit to ensure professionals are well connected.

- The Council's Carers Information Service is a core service of the Carers Unit. It is enhanced through a joint partnership agreement with the Hywel Dda University Health Board. This enables the joint extension of the information service to health professionals, to ensure they are provided with access to resources which offer support to Carers.

- There are a number of joint initiatives across the Health Board, the local authority and CVCs to maximise service impact. Integrated Care Funding has been used to fund the Third Sector Integration Facilitators whose role is to work across the sectors to raise awareness of professionals of third sector services which may support patients / clients / Carers. The Third Sector Integration Facilitators regularly support events organised by the Carers Unit.

- The Ceredigion Third Sector Core Community Resource Team is a collaborative working partnership between key Third Sector partners in Ceredigion which provides blended, timely and appropriate support to address the causes of issues faced by those who are frail and elderly. During initial discussions with the client, the team identify whether there are any unpaid Carers supporting the individual or whether the client is a Carer themself, to ensure that they are signposted to services and can access appropriate support. The Third Sector Community Resource Team is facilitated by CAVO funded through WG Integrated Care Fund (ICF). British Red Cross Home from Hospital Team facilitates referrals for a rapid intervention, with partners, Care and Repair and Age Cymru Ceredigion. They are actively identifying Carers and providing a further route to IAA. The CAVO Caring Communities Fund is a Small Grant Scheme under ICF to enable smaller groups to apply for seed funding to test community ideas. Carers are a priority group to develop new initiatives.

- All ICF funded schemes in Ceredigion are expected to report in their work with a person with care needs, where they identify a Carer, that they have been provided with signposting to IAA and report any outcomes the Carer derives from the support provided to the individual with care needs.

3.4 The Carers Unit has a well-developed communications plan which sets out the engagement plan for the year and includes several large public events. Feedback is sought from Carers and partners as to the effectiveness of these events. The Carers Unit also publishes a Carers Information Service Magazine three times a year that receives universal praise from Carers and partners, and serves as a single source of information and directory of support. As evidenced during the CSSIW Key Lines of Enquiry Carers Focus Inspection, this is welcomed by Carers. Social media platforms, such as Facebook and Twitter are being increasingly utilised to communicate information to Carers alongside paper publications.

3.5 Raising awareness of the needs of Carers and recognising adults and young people with a caring role, continues to be developed and promoted throughout the county on an ongoing basis. One example of this is the Hywel Dda Regional Partnership (Ceredigion, Carmarthenshire and Pembrokeshire local authorities, Hywel Dda Health Board and third sector partners) Investors in

Carers (IiC) Quality Assurance scheme, an initiative initially developed by Ceredigion in 2006. Originally developed for GP surgeries, the scheme has 3 levels: bronze, silver and gold to provide recognition of the setting/service's commitment to Carers. The scheme offers a range of benefits including:

- A tool for improving the lives of Carers and providing a catalyst for change
- Helps to promote opportunities to support Carers in ways which matter to them
- It provides a framework to foster and maintain engagement with carers and partner organisations
- It is an evidence based scheme and provides a benchmark for continuous improvement

3.6 IiC is being increasingly utilised across sectors: i.e. health, social care, education, community and the third sector. Coleg Ceredigion was the first college in the region to achieve the Bronze Award and Ysgol Penglais the first Secondary School in Ceredigion. GP Practices submitted 101 referrals to Porth Gofal in 2017/18. 51 requested a Carers needs assessment and 82 requested to join the Carers Information Service. 1942 Carers were registered with their GP as a Carer in Ceredigion as of 31st March 2018. There has also been a significant adoption of the IiC scheme across the Health Board Mental Health teams, as IiC is considered a supporting element of their Quality Assurance programme.

3.7 Developing Carers Resilience and Wellbeing is a critical component of our approach. The Council's Carers Unit has been working with partners on the ground breaking international first 'Carers Resilience and Wellbeing Programme' designed by Dr Dee Gray. The report and evaluation from phase 1 of the pilot programme demonstrated that the mental wellbeing of Carers that attended the programme was significantly improved, their isolation was reduced, and the skills they learnt that that contribute towards enduring a demanding role were adopted and continue to be used 18 months on. Phase 2 feasibility explored the programme adaptation for Adult Carers in Employment (ACE) and for Young Carers in education (YCE), and considered whether a Train the Trainer model was viable. Phase 3 is currently underway to develop a Train the Trainer module with 11 Council Employees sponsored to become Trainers to deliver the programme to Carers in the Council's Workforce, 8 of which are current Carers. Concurrently, 6 Teaching staff of Penglais Secondary School with 6 Young Carers will also develop a schools programme. The delivery programme will be rolled out in 2019. The funding for Phase 2 & 3 has come from successful county bids within the WG Integrated Care Fund (ICF).

3.8 Ceredigion County Council led the innovative development of the original Wales "Carer Aware and Young Carer Aware" E Learning programme, licensed from a previously successful version outside of Wales. This was subsequently redeveloped as a West Wales partnership through the Carers Measure. Within the Council, this was mandatory for social care staff, with almost 750 staff completing the course up to March 2018. Access was also available to Health and voluntary sector. The e-learning course was a practical, engaging online training resource and feedback from over 95% of the learners stated that after completing the course, they felt confident to engage with Carers and provide Information, Advice and Assistance. Analysis of participants identified 21% were current Carers and 46% were previously. Approximately 70% anticipated becoming Carers in the future. The e learning was fully adapted to incorporate the SSWBA and provided a fundamental building block to the workforce understanding of the Act in support of Carers. In 2017, Social Care Wales commissioned a Wales wide e-learning course, and our regional licensed course was decommissioned. The replacement due early 2018 is expected to launch in the latter part of 2018.

3.9 Under the Social Care Training programme, we are piloting wellbeing programmes for Carers and, with Carers. The first of these is supporting Carers of those with Dementia to access structured social gatherings together with the person they care for, supported by agencies to deliver information, knowledge and signposting in a natural environment as part of community occasion. Further work with Carers is ongoing to identify additional topics. Carers are also part of a “training” session with County Councillors this autumn, illustrating the impact of dementia on Carers’ lives.

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

4.1 The Council’s Carers Unit provides a bridge between partners in understanding the range of Carers issues, ensuring these are embedded in a “what matters” focused approach. The broad understanding of the numbers of Carers is part of partnership efforts to develop. The challenge lies in the myriad of reporting systems and identification/duplication of known individuals across multiple agencies. WCCIS will support that much more effectively when Health are working within the same IT system and we can extract data that cross references between health and social care. WCCIS is a critical tool in achieving that outcome.

4.2 Effective Commissioning of third sector services and domiciliary care service is key to the transformation agenda and the success of the prevention and early intervention agenda and is fundamental to the support for Carers. The Social Services Commissioning team has been reviewing all third sector contracts as part of a corporate wide review of commissioned services. We are also working closely with health colleagues on joint reviews of shared contracts. One of the themes has been around Carer Awareness and outcomes in current services for Carers. The review highlighted the lack of a Carer-focus in many general commissioned services. The focus is on ensuring the future tendering process reflects current and anticipated Carer requirements, mainstreaming Carers identification as everyone’s business. All future contracts for general services will include performance indicators to proactively identify Carers, to evidence signposting and to demonstrate the benefit derived by any Carers, from their service to the service user. Further, all contract awards will require services to undertake Carer Aware training and to demonstrate working towards achieving IiC to the appropriate level for their service area. This monitoring information will support ongoing profiling of our communities and support the next population needs assessment. Business Intelligence is a hugely important tool in developing processes which enable us to analyse the available information that can help us to better target Carers and support the communities in which they live, and at an earlier point in their caring journey. Methodologies for collating and sharing information between third sector partners, is also a critical component to address the future needs of the Carer population and we continue to support CAVO in their work to encourage more collaborative approaches between Third Sector organisations.

4.3 The Ceredigion Population Needs Assessment provided significant information through direct Carer engagement. It evidenced prevalence data from work undertaken throughout the region and with partners across Wales. The 2011 Census identified 8,603 Carers across Ceredigion and across the region circa 47,000. Local data is also collected by the Council and third sector organisations on an ongoing basis on the number of Carers referred and registered with services. The number of Carers known to the Council will always reflect a lower “known” Carer figure in comparison to the overall self-reported Census data. Whilst we strive to identify as many Carers as possible at as early stage in their caring journey, it is important to remember that not all Carers want or need support all of the time. It is generally accepted that there is a turnover of approximately 30%, of Carers start caring and cease caring during the course of the year. A percentage of these will not want to engage with services because they are managing with the caring role or have sought and accessed support outside of statutory services. Conversely, not all Carers are aware of the support available to them or what benefits they are eligible to. In part, they do not recognise themselves in the term ‘a Carer’. Strengthening and supporting the work of the Health Board at hospital admission and predominantly at the point of discharge/transfer of care is essential in increasing the robustness of data and analysis of the needs of Carers. More Carers are seen as a first point of contact in a health setting than in social care, so the process and systems for collating and reporting need embedded throughout health services to support Carers, which will support Health and Social Care to reduce the risk of Carer breakdown. A stronger focus on supporting Primary Care to identify, record and report on Carers as a priority group would provide a robust health profile associated with the impact of caring, physical and emotional and assist to improve public health in the context of Carers health as evidenced in the Carers UK State of Caring Report 2018.

5. *Other changes since the Act came into force which may impact on carers, for example changes to the services provided to people who are cared for;*

5.1 With changes in any service, there can be unintended consequences to the outcomes for Carers. Ensuring an understanding of the impact both positive and negative on Carers through robust Carer Impact Assessments is a new concept and not generally recognised in equality terms. There has in the context of stakeholder engagement for the Transforming Clinical Services with Hywel Dda been a great deal of effort and intent to ensure that the Carers viewpoint has been included at all stages of the consultation.

5.2 Within Social Services, it is acknowledged that currently some of our day community services may not be meeting the changing needs of Carers, in particular, when we consider Carers maintaining their employment or needing emergency health care appointments for example. A key intent over the next 12 -18 month period will be to talk in detail with service users and Carers, listen to what their needs are and transform services to allow greater flexibility to the services we commission and deliver. This could mean access to 7 day service, hours that are more flexible e.g. a supper club and respite that is timely and accessible. But key will be to ensure that we have services that are meeting the needs of the service users and their Carers.

5.3 At times, assessment teams have found it a challenge to evidence that a Carer has eligible needs within the Act; it can be difficult for staff to prove that a Carer cannot meet their own needs and needs cannot be met by community. This is an evolving area of experience, and the need for robust evidence shown by a practitioner can result in delay for Carers because service requests are referred back, where there is insufficient evidence, which is equally understandable in ensuring resources are appropriately discharged. It is crucial to have ongoing high quality and innovative training opportunities for staff to develop and grow in line with this process. The value in maintaining the Social Care Wales programmes for developing staff in relation to Carers under the Act will be fundamental to changing the long term culture and expertise of our workforce, particularly in relation to working with Carers outcomes. Given the growing demographics of caring and the increasing health conditions in those living with complex needs, the impact on Carers lives cannot be underestimated. We are still evolving the practice of staff within the new models, expanding the understanding of the community in supporting and meeting Carer needs, as well as supporting our Carers and communities to adapt to the changes. We are broadening our perspective in acknowledging and supporting Carer's needs that may not be met with a traditional Social Services "service" such as day care etc, but that their personal outcomes may be met with financial support to attend an art class or to purchase art equipment, or exploring funding for holistic therapy to achieve resilience and independence, which enables them to manage the expectations of their caring role with wellbeing and reduce their need for more formal interventions. Equally where the need for interventions is identified, we need to have flexible and responsive support for Carers before they reach crisis point. Work will continue to ensure outcomes can be evidenced as value for money as well as meeting wellbeing and resilience, but we have made considerable progress.

5.4 With the impact of budgetary pressures, and the reconfiguration of services, third sector organisations have reported that the services that they provide to Carers and people in need of care and support are stretched resulting in increased waiting lists and delays in service provision. This obviously adds to pressures on Carers, who often try to bridge the gap with resultant impact on their own wellbeing. With the increased focus on early intervention, signposting and enhancing connections through services such as Porth y Gymuned, this has the potential to further increase the demand on our third sector providers and a reliance on short term funding solutions.

5.5 In a rural county, access to close to home services, geographical based community groups and activities close to local communities remains a challenge. Many Carers live in very rural and remote communities where lack of transport, access to transport services, infrequency, inaccessibility and reliability of transport services, together with financial hardship and time restraints and long travel times, can make it difficult to access services, groups and activities which would support the Carer and enable them to sustain both their caring role and a life alongside caring.

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

6.1 In November 2017, the Minister for Children, Older People and Social Care announced 3 national priorities to improve the lives of Carers: These need embedded across all strategies within all areas of government policy:

- **Supporting life alongside caring**- All carers must have reasonable breaks from their caring role to enable them to maintain their capacity to care, and to have a life beyond caring;
- **Identifying and recognising carers** -Fundamental to the success of delivering improved outcomes for carers is the need to improve carer's recognition of their role and to ensure they can access the necessary support; and
- **Providing information, advice and assistance -** It is important that carers receive the appropriate information and advice where and when they need it.

6.2 Carers are the epitome of a cross cutting citizen, the foundation on which all else relies. They support individuals across the spectrum. Their lives are impacted from across the spectrum. There is rarely a policy, strategy or funding stream, consultation, or service change that does not encompass an impact on some part of a Carers life, from transport, to public conveniences, refuse collections, to employment and employers, education, health and social care, leisure, tourism, environment and many more. Carers are in all communities, across all ages, across all sectors and would benefit from wider consideration under equality and diversity and impact assessment processes as a special category.

6.3 Whilst there are a number of national priorities for Carers, there is no formal Carers Strategy for Wales. This raises two opposing viewpoints that a) Carers are not seen as a national focus of attention that warrants a dedicated strategic policy, or alternatively b) Carers should be embedded in ALL WG strategies and explicitly referenced as a requirement to identify and report within that arena to mainstream, rather than a standalone strategy that risks short term attention from a narrow sector viewpoint.

6.4 Being mainstream within all strategies provides for long term sustainability of focus, however with the growing number of references to Carers across numerous initiatives from different sections of government (which is itself a positive), it is increasingly challenging to implement a whole system approach to deliver the cultural change required to embed Carers as core business for all sectors, without a central focus from which to connect the different requirements across all areas of policy. There is an inherent risk that the requirements fail to connect in similar language, monitoring and reporting terms. Validating the range of strategies and policies to have the same core Carer principles would assist sector specific activity to evidence a whole system implementation for Carers.

6.5 The Minister for Children, Older People and Social Care has also recently established a Ministerial Advisory Group for Carers to provide a cross sector response to the challenges faced by Carers and provide a national forum to target and monitor improvements within the three national priority areas. It is crucial that this membership can develop inclusivity from all geographical areas and partners across Wales; using Welsh Government offices as a technological hub would help ensure those at a distance successfully engage.

C26

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr

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

Ymateb gan Gymdeithas Clefyd Motor Niwron

Response from Motor Neurone Disease Association

mnda
motor neurone disease
association
cymdeithas
clefyd motor niwron

Impact of the Social Services and Well-Being (Wales) Act 2014 in relation to carers in Wales

The MND Association welcomes the opportunity to respond to Welsh Government's request for written evidence into the inquiry on the impact of the Social Services and Well-Being (Wales) Act 2014 in relation to carers. People affected by MND have fed directly into the inquiry via a focus group – here we enclose some additional information from the results of our *Improving MND Care Survey 2017* as well as some general points about MND itself and the impact on carers, their care and support.

MND is a rapidly progressing disease of the brain and nervous system. MND kills a third of people within a year and more than half within two years of diagnosis – there is no cure. As the condition rapidly progresses, the severity of the needs associated with MND means that caring for a person living with the condition can be extremely intense, exhausting and demanding. Well over half of carers of those with MND devote more time to their caring responsibilities than they would in the average full-time job. Therefore, speedy assessments and support for carers of those with MND is all the more important in this context.

Carer's Assessments

In our recent *Improving MND Care survey* we found, that, only 30% of our respondents who are carers in Wales have had an assessment of their needs or are in the process of having one (this matches similar statistics to our respondents in England where the legislation has been in place for longer)[1]. Many carers do not know about their rights under the SSWB Act and our survey suggests that more needs to be done to promote this right.

Additionally, recent research by Carers UK found that 39% of people caring for someone at the end of life waited 6 months or more for their assessment[2]. Timely access to an assessment is critical for carers of those with a rapidly progressing condition like MND.

Policy recommendation: The right to an assessment of support for carers is promoted more widely, particularly at the point of diagnosis. Carers of people with progressive and terminal illnesses like MND must be fast-tracked for assessments.

Respite care and provision of support

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[1] MND Association (2018) Improving MND Care Survey

[2] Carers UK (2016) State of Caring 2016

Over half of carers (52% of our respondents in Wales) spend 50 hours plus caring for people with MND[3]. Provision of support such as respite or short breaks can be a lifeline for maintaining the health and well-being of the person providing care.

Only two fifths of our respondents had taken any planned breaks even for as short as two hours and many have to rely on family and friends to enable them to do so[4].

Respite care is oftentimes not offered, not available or prohibitive to carers because of their finances:

> *[I need] financial support for helping to pay for carers for respite or a regular help to take the emotional and financial pressure off the families.*
>
> *MND Association Carers Survey 2015 respondents*[5]

Sometimes people are unwilling to take respite for concerns about the quality and expertise of care agencies and providers. MND is a particularly complex disease and any provision of respite care must be delivered by high quality services with the right expertise. Additionally, we need to see the development of availability of respite at hospices where, at present, it is very limited.

We welcomed the Welsh Government's 3 million investment into respite care to local authorities as part of the Ministerial Advisory Group for Carers, Annual Plan 2018-2019. We await the interim reporting on this and the impact it could potentially have on respite care for carers of those with progressive conditions like MND, and in areas of provision where there are limited respite facilities; e.g. hospices. We further recommend that an assessment of how the funding was spent identifies the support for those caring for people with complex diseases like MND in order to identify gaps, and plan for future provision in Wales.

Policy recommendation: Welsh Government should seek an evaluation of the impact of the 3 million funding on respite provision in Wales. This evaluation should specifically identify quality and quantity of respite provision and support for carers of those with complex conditions.

To consider broader Welsh Government policy on carers

The Ministerial Advisory Group on Carers has a dedicated action plan for 2018/19 - including dedicated funds for respite provision (as mentioned above), awareness raising in primary care as well as funds for third sector provision. **We suggest that an evaluation and detailed analysis and progress towards this action plan and funding will help to identity gaps in current support and plan for support for carers post 2019.**

Additionally, whilst we recognise that benefits for carers are not within the scope of the inquiry, Carer's Allowance simply does not provide enough financial support for carers. In Scotland, Carer's Allowance is going up by £8.50 per week to the same level as Jobseeker's Allowance and we support the current campaign by Carers UK to raise the amount in other parts of the UK to the same amount.

Policy recommendation: We would like to see Carer's Allowance increased to at least the value of Jobseekers Allowance and introduce a taper that facilitates carers who

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[3] MND Association (2018) Improving MND Care Survey

[4] Ibid

[5] MND Association (July 2015) Experiences and views of carers of people living with MND

need to transition out of work as their caring role increases and move back into work gradually after bereavement.

About MND and the Association

i. Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.
ii. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, talk, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Some people with MND may also experience changes in thinking and behaviour, and 10-15% will experience a rare form of dementia.
iii. MND kills a third of people within a year and more than half within two years of diagnosis, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.
iv. A person's lifetime risk of developing MND is up to 1 in 300. It can affect any adult, but is more common in older people: it is most commonly diagnosed between the ages of 50 and 65. There are about 5,000 people living with MND in the UK, approximately 250 of them in Wales.
v. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer-led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

For more information, please contact [redacted], Policy and Public Affairs Manager (Wales) at MND Association: [redacted] or [redacted].

Inquiry response
September 2018

carers WALES
making life better for carers

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 setting[i]. 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[ii] 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 "T*he 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?"*

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, 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.

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[i] Carers Strategies (Wales) Measure 2010
[ii] https://gov.wales/docs/statistics/2017/171031-adults-receiving-care-support-2016-17-en.pdf

C28
Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr
Inquiry into Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers
Ymateb gan Gymdeithas Llywodraeth Leol Cymru a Chymdeithas Cyfarwyddwyr Gwasanaethau Cymdeithasol Cymru
Response from Welsh Local Government Association & Association of Directors of Social Services Cymru

WLGA AND ADSS CYMRU EVIDENCE TO THE HEALTH, SOCIAL CARE & SPORT COMMITTEE’S INQUIRY INTO THE IMPACT OF THE SOCIAL SERVICES AND WELLBEING (WALES) ACT 2014 IN RELATION TO CARERS

CLILC • WLGA

ADSS Cymru
Leading Social Services in Wales
Yn arwain Gwasanaethau Cymdeithasol yng Nghymru

SEPTEMBER 2018

About Us

1. The Welsh Local Government Association (WLGA) represents the 22 local authorities in Wales, and the three national park authorities and the three fire and rescue authorities are associate members.

2. The WLGA is a politically led cross-party organisation, with the leaders from all local authorities determining policy through the Executive Board and the wider WLGA Council. The WLGA also appoints senior members as Spokespersons and Deputy Spokespersons to provide a national lead on policy matters on behalf of local government.

3. The WLGA works closely with and is often advised by professional advisors and professional associations from local government, however, the WLGA is the representative body for local government and provides the collective, political voice of local government in Wales.

4. As the national leadership organisation for social services in Wales, the role of the Association of Directors of Social Services (ADSS Cymru) is to represent the collective, authoritative voice of Directors of Social Services, Heads of Adult Services, Children’s Services and Business Services, together with professionals who support vulnerable children and adults, their families and communities, on a range of national and regional issues of social care policy, practice and resourcing.

The important role of carers

5. According to Carers Wales, there are 370,000 people caring, unpaid, for a family member or friend, and 3 in 5 of us will be carers in our lifetime. This is the highest proportionate figure of all UK countries, with 103,594 people in Wales providing over 50 hours of unpaid care per week. It is estimated that the care provided by unpaid carers in Wales is worth an estimated £8.1 billion a year. The number of carers continues to rise and it is estimated that by 2037 there will be over half a million carers in Wales - a 40% rise. Many do not define themselves as 'carers', but a family member, friend or neighbour – however the act of caring, the time it involves, the physical and emotional expenditure, the impact on working life and social networks can significantly affect the carer's health and wellbeing, financial security and ability to meet their own life-time's goals.

6. The demographic changes being seen across the UK will also have an impact on unpaid carers. An ageing population with improved life expectancy for people with long term conditions or complex disabilities means the need for more high level care provided for longer. We are likely to see more older people in a caring role, with the number of carers over 85 predicted to double in the next 20 years. Increasing hours of care often results in the general health of carers deteriorating incrementally. Unpaid carers who provide high levels of care for sick, or disabled relatives and friends, are more than twice as likely to suffer from poor health compared to people without caring responsibilities. Caring responsibilities can have an adverse impact on the physical and mental health, education and employment potential of those who care, which can result in significantly poorer health and quality of life outcomes. These in turn can affect a carer's effectiveness and lead to the admission of the cared for person to hospital or residential care, placing further pressure on our already over-stretched system.

7. Supporting and improving the wellbeing and rights of unpaid carers is important for councils who fully recognise the vital role and the significant contribution carers make to people with social care needs, and the wider health and care economy. Without these vital informal carers, the safety net of care and support they provide to thousands of people every day would collapse.

8. As a society, we need to do more to ensure the role of a carer is seen as a positive, rather than a stigma, and we are keen to work with Welsh Government, carers and carers organisations to make sure that carers are fully supported and signposted to services to avoid them and families reaching crisis point and care breakdown. It is fundamentally important for society as a whole that carers have the support they need to maintain their own wellbeing and to be able to lead fulfilling lives; to maintain social relationships; undertake education and training; maintain employment; and be active community members.

Local government funding

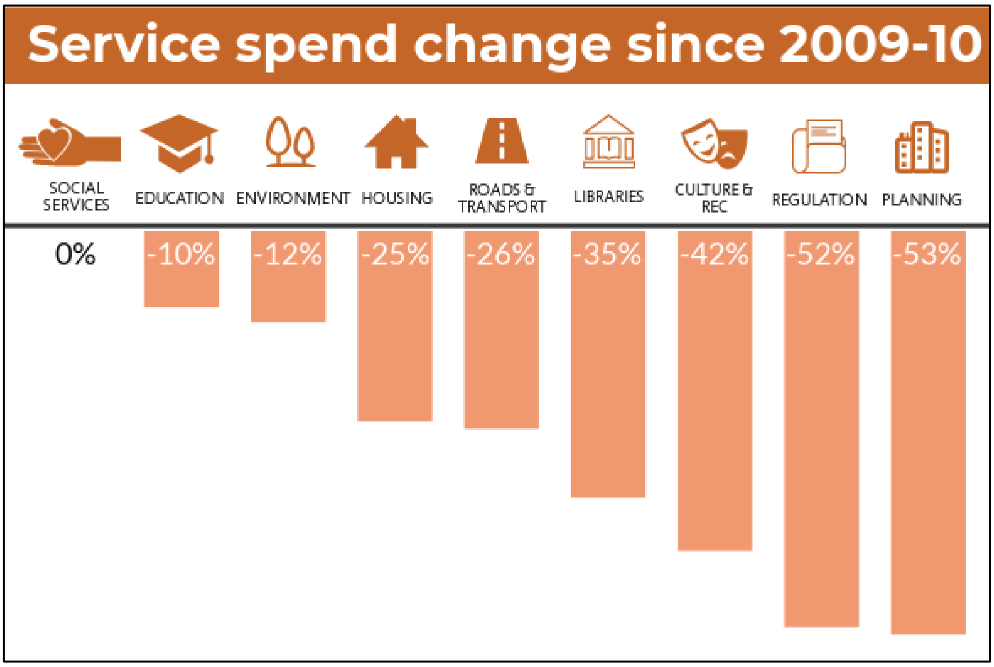
9. Councils' ability to provide this well-being support is however undermined by the continued cuts to council budgets. If we are to achieve our aspirations for all carers - who are needed in increasing numbers to address the rise in those needing care - and fulfil the ambition and intent

of the Social Services and Wellbeing (Wales) Act, Welsh Government needs to ensure that local authorities are adequately funded to meet the requirements that are being placed upon them.

10. Local government provides more than 700 local services, a significant proportion of which help improve wellbeing and tackle the social determinants of health. This includes housing, employment, welfare, leisure and transport and these help support the health and wellbeing of carers.

11. However, over the last 8 years Council's core grant funding has reduced by 22% after adjusting for inflation. If you take schools funding out, core funding has fallen by 35%. Figure 1 below shows how this reduction in funding has impacted on individual local government service areas.

Figure 1 – Service Spend Change



12. The statutory services of social services and education have been protected as far as possible by local government. This has meant that other non-statutory preventative community based services, such as leisure, parks, adult education, housing, transport and community facilities, all of which support carer's wellbeing and health, have faced the brunt of cuts to local authority budgets out of necessity. The report by Wales Public Services 2025, 'Austerity and Local Government in Wales: an analysis of income and spending priorities, 2009-10 to 2016-17', highlighted the significant impact that eight years of austerity have had on local public services. Cuts in the smaller but vital services have been deep, with question marks over their future sustainability if a further period of cuts were to continue.

13. Local government has kept the worst consequences of austerity at bay in recent years but its impact is now catching up with councils, threatening services that improve our lives and our communities, including services vital to supporting carers. We know that the cumulative financial

pressures will continue to mount for local government over the next four years. Just to stand still on providing current services, local government would need a revenue increase of £264m (5% of net spend) in 2019-20 and 4% the year after. During this period unavoidable workforce costs will increasingly drive inflationary pressures and in 2021-22 and the year after, the overall inflationary pressures will run at around 3% in each year. Despite the best efforts of local government against the scale of the reduction outlined, these efforts can only go so far. Without a more fundamental review of how we fund services there is little wriggle room for further cuts. The current model is not sustainable, annual incremental budgeting just stores up problems for the future.

14. Further information on the financial pressures facing local authorities in Wales can be found in the WLGA's publication 'Fair and Sustainable Funding for Essential Local Services'[1]

15. In our evidence to the Health, Social Care and Sport Committee's scrutiny of the Welsh Government's draft budget we were clear that the local government funding position has serious consequences for wellbeing. It constrains social care which, in turn, constrains the voluntary sector and care providers. This all points to the need to urgently reform our current arrangements and take on the complex task of developing a long term sustainable funding framework for social care.

16. It is therefore welcomed that the new long-term plan for health and social care, *A Healthier Wales*, identifies the need to achieve a sustainable funding model for health and social care, recognising that health and social care currently consume a growing proportion of the Welsh Government's budget, at the expense of other public service areas, which also have a great influence on the health and wellbeing of the people of Wales. There is a desperate need for this work to lead to the provision of an additional source of funding for local government as part of an overall settlement that provides sustainable funding for all the vital services that councils deliver. All funding options to tackle the social care crisis must be on the table given the scale of the current crisis.

17. The recent announcement of additional consequential funding coming into Wales as a result of the UK Government's decision to provide an extra £20bn a year by 2023 to the NHS in England also provides Welsh Government with an opportunity to look at providing much needed additional funding to local government which would enable Welsh councils to plan with some surety over the next three years and provide local authorities flexibility to best meet local demand and needs, focussed on improving outcomes for their citizens and communities. Recent funding made available for social services from Welsh Government has only been for specific pieces of work and to support new initiatives rather than to be able to meet increasing demand and current pressures.

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[1] Available at: https://www.wlga.wales/SharedFiles/Download.aspx?pageid=62&mid=665&fileid=1754

How councils support carers

18. Both the WLGA and ADSS Cymru welcomed the principles of the Social Services and Wellbeing (Wales) Act, but we need to recognise the increasing expectations that are being placed on local authorities at a time of reducing resources. Working alongside Welsh Government, we have played (and continue to play) a key role in supporting the implementation of the legislation. The Social Services and Wellbeing (Wales) Act sets out important legislative changes for carers, crucially giving them the same recognition and parity of esteem with those they support. Local authorities have a duty to offer assessments and support plans for carers, developed with them as equal partners, and with the goal of enabling carers to live the life they want to achieve.

19. These responsibilities that are specific to carers sit alongside other general provisions within the legislation, which are also relevant to carers. These include, for instance:

    - A duty to provide an information and advice service
    - A duty to ensure the provision of preventative services.

20. Under the Act all regions are also required to develop and publish Regional Population Needs Assessments, which provide an assessment of the care and support needs of their area, with carers being one of the core themes of the assessments. These assessments have now been completed and regions have also recently published their Population Area plans, another requirement of the Act. All identify the important and vital role that unpaid carers undertake and are committed to improving access to suitable breaks and respite that meet the varied, often complex needs of the people they care for. Regions recognise it is vital that all carers, young and old, need to have a break from their caring role, with a need for suitable and flexible respite opportunities to help support people to remain in their caring role. However, we also need to acknowledge the impact that funding cuts have placed on local authorities and their capacity to be able to continue to offer services such as these. Many regions are mapping or exploring more flexible options that meet specialist needs, such as autism or dementia. It is acknowledged that planning for carers services needs to consider the potential future needs of older carers and find ways of supporting older carers to plan ahead. Some regions have also highlighted concerns over the sustainability of carers services, which in many cases is provided through third sector support which is often reliant on short term grant funding.

21. The assessments identify that there are dedicated services for young carers linked to schools with additional one to one support and access to emotional support. There are examples of using social media to support young carers and involving young carers in service development. Respite and access to leisure opportunities are also available. A Team Around the Carer approach is also being utilised in one area. This supports the recent Care Inspectorate Wales (CIW) thematic review, ‘In Support of Carers’, which found that, “young carers generally are well supported”, but warned that there are an increasing number with complex emotional needs and the lack of child mental

health services means that workers supporting young carers are dealing with some challenging and complex issues.

22. A recent report by the Social Care Institute for Excellence (SCIE), 'Preventative support for adult carers in Wales' identified a number of examples in Wales of services that support carers, including:

Services to support better identification and recognition of carers

Blaenau Gwent ran a Carers Engagement Project based within GP surgeries and run by the third sector on behalf of the local authority. The project employed carers support workers to raise awareness of carer support, to offer signposting and referral services, facilitate access to assessments and respite, and provide broader support and counselling

Rhondda Cynon Taf Council employs carers' champions, volunteer members of council staff who act as the main contacts for carer information in the service department in which they work. The network of champions encourage other staff to complete carer awareness training and gather carer information to cascade internally and to carers.

Services providing information, advice and advocacy

The Welfare Benefits Service in Swansea is funded by Swansea Council to support carers, and prevent them from having to access higher tier and more expensive services. It offers benefits checks to maximise carer income, support with filling in forms and making claims, support with appeals and access to grants for carer support. Carers using the benefits service are also encouraged to make use of the full range of Swansea carers' centre services, which includes a local authority funded counselling service.

Dewis Cymru is a key information hub for carers looking for information or advice about their wellbeing. Funded and managed by Local Authorities across Wales so that information can be kept up to date and relevant. It acts as a signposting service for up to 6,000 local and national services across Wales.

Shared Lives Wales

There are 12 Shared Lives schemes in Wales, which is the first of the four UK nations to have Shared Lives services across almost every local authority area. Almost half (46 per cent) the people using Shared Lives in Wales in 2015 to 2016 enjoyed flexible, personalised short breaks and day support in a Shared Lives carers' home. Short breaks are an effective and affordable alternative to traditional respite care, particularly for families supporting people with dementia.

Caerphilly County Borough Council has addressed the emergency needs of carers through a range of measures, including advice on dealing with emergencies and an emergency card scheme together with a carers' time out service enabling carers to access time to attend their own appointments and health treatments.

23. SCIE has also published a series of practice examples which evidence the types of models of support available to carers in Wales (further details can be found in Appendix 1), with examples including:
    - Programmes of support being designed to support emotional wellbeing and improve outcomes in relation to isolation, stress and identity. This includes access to free training, workshops, social events and support networks.
    - Introduction of carers' emergency cards - a credit card sized piece of plastic that denotes that the carrier is a carer and provides a number to contact in case of emergencies (24 hours per day). Ringing this number enables contingency support to be arranged.
    - Carers Support Services which help carers in managing their health and wellbeing needs, providing support and advice
    - Introduction of a dedicated carer's coordinator roles to oversee future developments and implementation of the Social Services and Well-being (Wales) Act 2014.
    - Carers Champions whose role is to act as a liaison point between carers and services. They provide advice and information to carers; lead on carer issues at a service level and cascade information to their colleagues about what carers need.

24. Whilst much work is ongoing the SCIE report, 'Preventative support for adult carers in Wales' identifies that considerable challenges remain in providing consistent support and better outcomes for carers across the UK. They found that the most effective services in both England and Wales have been developed in response to local priorities, shaped by a strong carer voice at local level, and supported by proactive partnership working between health, social care and the voluntary sector. They aim to provide person-centred, holistic support tailored to specific needs. One of the key messages of the research is that caring is more than a health and social care issue, and to develop caring communities, carers' rights need to be embedded within broader health, social and employment policies.

25. One of the overarching challenges is identification, both encouraging people to self-identify as a carer but also with health and care professionals identifying carers, so that carers are able to access the information and support that is available. When carers do not conceptualise or identify themselves as carers but see the support they provide as a natural part of their relationship with the cared-for person they may be reluctant to come forward and fail to access benefits or support services, which could improve their quality of life. According to a poll published by Carers UK on Carers Rights Day, "the public is unable to recognise friends and family that care" with 51 per cent of those polled underestimating the number of carers in their own family, friendship network or workplace. Carers UK's 'Missing Out' report noted that in Wales 55 per cent of carers took more than a year to recognise their caring role, while 24 per cent took more than five years to identify as a carer. Early intervention, identifying carers before they reach crisis point, is crucial, as is

identifying priorities and outcomes for carers on an individual basis once they have come forward to provide the right level and type of support. This has shown to be particularly true in relation to older carers (aged 80 years old or above) looking after a spouse or partner, BME carers, LGBT+ carers, and carers of people with dementia or mental health issues where there may be perceived to be an element of stigma and a wish to keep things private.

26. The challenge around identification and awareness is also evident from the recent figures which show that more than half of those offered a carers assessment refuse it, pointing to the need to increase our awareness raising efforts as part of an on-going process.

27. Issues of identification are compounded by those of accessibility. For example, carers living in remote or rural communities in Wales will have specific needs where social isolation, poverty, deprivation, lack of transport and long distances to travel to access health and care services mean that rural carers face additional challenges in accessing services. For example, if there are significant transport times this has an impact of the availability and length of time of respite care.

28. In Wales we need to have an overarching ambition to make being identified as a 'carer' a positive, with the support of our communities, so that more people can ask for support - and not just monetary help – to look after their own health, and ultimately benefit the whole of society, with a focus on encouraging people to self-identify as carers as a route to unlocking support from the community, public sector and businesses. This could include making it clearer that supporting the carer is supporting the one who is cared for, and that being a carer does not detract from being a husband, wife, sibling, daughter, son, friend, etc.

29. There is a need for practical recommendations on how to support carers who don't self-identify. The NHS and GPs are crucial in helping to identify carers, but there may also be more community-based or voluntary services adept at identifying and supporting carers. There may also be particular groups that are more difficult to identify. Working with other sectors, for instance faith groups, may open other avenues for engaging with these groups.

30. In our evidence to the Parliamentary Review we highlighted the importance of the workforce, and in particular the need to ensure that unpaid carers are recognised, valued and included as part of the workforce planning to ensure carers receive appropriate training and support for the roles they undertake. It is positive to see 'A Healthier Wales' identify the need to recognise and support the vital role played by the informal workforce of unpaid carers and the need for greater parity of esteem not just between health and care professionals, but with carers as well. The new long-term workforce strategy provides an opportunity to ensure that the workforce we have in Wales, including carers, feel valued and supported and are enabled to access relevant education, training and support opportunities.

31. There is also a need to recognise that the ability of councils to deliver any new ambitions is reliant on additional investment from Welsh Government. With a case for investment, whilst

acknowledging that upfront investment to save money later requires that additional investment money to be available in the first place. There is a clear case here around the early intervention and prevention agendas for carers.

Appendix 1 – Types of models of support available to carers

Carers Resilience and Wellbeing Programme - Ceredigion County Council Carers Unit

Since autumn 2016, Ceredigion County Council Carers Unit have been working to deliver and evaluate a programme of support for local carers designed to support emotional wellbeing and improve outcomes in relation to isolation, stress and identity. The ultimate goal is to enable carers to become more resilient so that they are better able to cope with their caring responsibilities and prevent crises from occurring. The programme was originally designed as a means of supporting the wellbeing of frontline care staff and to reduce the risks associated with the high levels of stress and burnout that can be a feature in the sector. However, recognition of the role that family and friends play ‘on the frontline’ when caring for a loved one suggested that the programme might have wider applications. In response to a commission from the Mid Wales Collaborative and Hywel Dda University Health Board the programme was adapted for carers.

The programme encourages carers to develop a ‘situational awareness’ of their own resilience (and regularly consider at what level this is), and motivates them to improve this by taking part in activities that can improve their wellbeing. Underpinning this is a theoretical model drawing on a range of approaches from the fields of psychology, neuroscience and pedagogy.

The first phase of the project ran for seven months and was designed as a pilot service in order to determine whether the programme could be adapted for use with carers and to measure the impact of the programme on carers’ outcomes (in particular those aligned with the Social Services and Well-being (Wales) Act 2014).

Carers Support Service - Vale of Glamorgan

Carers support in the Vale of Glamorgan is being reviewed, with Cardiff Council, as part of their joint response to the Social Services and Well-being (Wales) Act 2014. This is part of the regional partnerships’ work stream dedicated to carers. As the work stream is relatively new, the first objective is to conduct scoping work and map support for carers that is already in existence. This information is then fed in to a long-term strategy.

In terms of support for individual carers, a key piece of work has been the introduction of the carers’ emergency card. This is a credit card sized piece of plastic that denotes that the carrier is a carer and provides a number to contact in case of emergencies (24 hours per day). Ringing this number enables contingency support to be arranged. The service is run jointly with Cardiff Council using existing record management systems and out of hours arrangements, and provides carers with reassurance that the person that they look after will be cared for if anything should happen to them.

The service also provides help with carers in managing their health and wellbeing needs. For those with relatively low level needs, the service enables them to experience a range of alternative therapies such as massages and holistic treatments. These provide an immediate relief from stress but during the course of the treatment, the carer is also given practical tools that they can take away that will help them to take care of themselves, e.g. in relation to their sleep patterns, diets, and nutrition. The key is to help them to recognise the importance of looking after themselves. Where a carers needs appear to be more acute the service encourages them to seek medical advice.

The council also commissions Care and Repair, a tailored service designed to help carers with small maintenance problems such as fixing a broken lock or a broken tap. Services are commissioned on a local basis, using outcomes based contracts. These are monitored using a Results Based Accountability system (on a quarterly basis). This has demonstrated good results in terms of the number of carers supported and the added value provided by the service, for example by identifying other issues and risks (e.g. fuel poverty) that can be addressed either directly support or by signposting to other services.

Carers Project - Monmouthshire County Council and the Gwent Association of Voluntary Organisations (GAVO)

Monmouthshire Carers Project is an initiative run by Monmouthshire County Council and the Gwent Association of Voluntary Organisations (GAVO). The Monmouthshire Carers Project is the umbrella under which commissioned providers, the Monmouthshire Carers Strategy Group and carers work collaboratively in providing information, advice, events, training and support for each other, the third sector, social care, health and other organisations.

The programme provides free access and support for carers (via self-referral) including free training, social events, Carers Week events, Carers Rights Day (respite and transport can be provided so the carer can attend these events), the Carers Handbook, emergency and future planning booklet, carers emergency card and most importantly opportunities for carers to talk and be listened to. The goal is to be as responsive as possible and to ensure that services are designed with input from carers.

The initiative also places an emphasis on the role of GP surgeries in supporting carers with the Investment in Carers scheme (developed in collaboration with Hwyel Dda Health Board). The Investors in Carers scheme is a framework of good practice which GP practices can utilise to develop their carer awareness and ways of working to support carers on their patient register.

Another key strand to the project is the young carers strategy, which was developed in collaboration with a group of young carers and highlights the importance of working with providers to provide preventative support.

Carers Support Service - Caerphilly County Borough Council

Caerphilly County Borough Council carers support service is an inclusive support network that seeks to improve carer outcomes and promote the caring agenda. The service has been a long standing service, however it was significantly development through the introduction of a dedicated carer's coordinator role to oversee future developments and implementation of the Social Services and Well-being (Wales) Act 2014. This post was established in September 2016 and has resulted in the service being able to provide a wide range of support. This includes the organisation of frequent social events as well as activities during Carers' Week and Carers' Rights Day. The service also provides information through newsletters and mailing lists (both in print and electronically) and staff manage an online carer support group (using a closed Facebook page). The service has also worked in partnership with neighbouring local authorities and health board to establish the carers grant scheme. They have relaunched the carer's emergency card and the 'time out' respite service.

Team members also work hard to promote the importance of carers' assessments and ensure that all carers receive an assessment if they wish to do so. However the service is an inclusive one and will ensure carers have access to all necessary information and support groups even if they do not wish to have a carers assessment. The first task for staff was to identify what was important to carers and what barriers there were to achieving this by asking 'what matters to you?' The intention in asking this question is to ensure that the focus is upon the carer as an individual and not purely on their role as a carer. The assessment remains focused on identifying potential solutions rather than simply listing problems (a cultural shift in assessment practice). This approach has seen many benefits to carers, including carers being supported to access small breaks, education opportunities, and support to carers to meet their own personal outcomes and continue in their caring role.

Since its inception, the carers coordinator role has ensured the objectives of the service have expanded to become more strategic in outlook are underpinned by a recognition that to be effective the service must be responsive to the needs of the local carer population. This was in part informed by consultation on a carers rights day held in November 2016, where the emphasis on outcome focused, person-centred support that recognised the needs of the individual was identified.

Consequently, there is a significant focus on engagement with local carers to provide a clearer understanding of their needs, and to determine which aspects of support are working well and which are not. By doing so it is hoped that a more sustainable and responsive service can be provided which will prevent crises and reduce the need for intensive intervention, thereby meeting the requirements of the Social Services and Well-being (Wales) Act 2014. Over the next two years a range of consultation events are planned to inform the development of the service strategy, including an event specifically for young carers.

The service is funded by the council, the integrated care fund and is staffed by a small team of four. A range of other organisations are also involved; for example the carers grant scheme is overseen by the Carers Trust and services for young carers are contracted to Barnardo's.

Carers Support Service - Rhondda Cynon Taf County Borough Council

Rhondda Cynon Taf (RCT) Borough Council's carers support project provides support and advice to individuals living in the area who care for a family member, friend or neighbour who is ill, frail, has a disability, suffering with a mental illness or substance misuse problem. The service has been running for twenty years and takes an early intervention and prevention approach to support aiming to meet low level needs of carers in order to prevent crises. The geographic profile of the area can make it difficult to co-ordinate support as the borough is relatively large and the towns often lie some distance from each other. As a result, the service has to be a little more creative in the way it works, with events being held in places such as local job and leisure centres.

The service is run by six members of staff working both full and part time. Referrals can be made from health and social care practitioners as well from the third sector professionals and from self-referrals. Support is provided through a range of projects. In addition to one to one assistance and signposting to carer's assessments and direct payments; the service also produces a carer's newsletter, an in house counselling and peer support service, advice regarding legal problems and facilitates access to local authority services. The service also regularly runs outreach services and coffee mornings as a means of informal support as well as working with the Past Carers group to support individuals whose caring roles have come to an end.

The Project has strong links with RCT leisure services and offer discounted access to carers to council run leisure facilities in RCT. A key piece of work that has proven very popular amongst local carers is the Carers Emergency card. This is a credit card sized card that carers carry with them and is used as source of identification in case they have an accident or are suddenly taken ill. By ringing the support line number on the card (staffed 24 hours per day and 365 days per year) help can be arranged for both the carer and the person whom they look after.

The Project provides a range of workshops, events and training to carers across RCT. These include anything from first aid, manual handling, stress busting and healthy eating, to family fun days, relaxed inclusive cinema screenings and the more social craft workshops and team building opportunities. All of this is provided to carers free of charge. The service also provides targeted support, with staff focusing on carer populations with more unique needs, for example, young adults (helping with work, education, etc.) and parent carers of children with additional needs (working closely with the Disabled Children Team). Staff also work with the Alzheimer's Society to run the Carers Information and Support Programme (CRISP) which provides support to carers of people with dementia and empowers them to address their own wellbeing needs.

In addition to working with individual carers, the service also aims to help services to understand the needs of carers through the Carers Champion role. The role of a champion is to act as a liaison point between carers and services (their employer). They provide advice and information to carers; lead on carer issues at a service level and cascade information to their colleagues about what carers need. There are currently champions working in a range of settings such as day centres, children's services, colleges and schools, community teams, home care services, housing teams, job centres, leisure centres, social care teams, and welfare rights teams.

C29

Ymchwiliad i Effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2014 mewn perthynas â Gofalwyr

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

Ymateb gan Together for short lives

Response from Together for short lives

25 September 2018

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

A written submission to the National Assembly for Wales Health, Social Care and Sport Committee from Together for Short Lives

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1. We are the UK's leading charity for the 49,000 babies, children and young people in the UK living with life-limiting conditions and life-threatening conditions, and their families. Together with our members, we speak out for children and young people who are expected to have short lives. We are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.

2. We are a membership organisation and represent professionals and organisations spanning the statutory, voluntary and private sector who provide palliative care to babies, children and young people. These include children's hospices in Wales.

3. There are an estimated 1,000 children in Wales with life-limiting or life-threatening conditions.

4. We believe that the Social Services and Wellbeing (Wales) Act 2014 has potential to make sure that children in Wales with life-limiting conditions receive the social care assessments, plans and services they need. However, our members have identified a number of challenges with the way in which the act is being implemented.

The way in which assessments are carried out

5. Since the introduction of the legislation, some members have reported that the children and families they work with have experienced increasing difficulty in accessing a social care assessment. This can mean that children and families do not receive the care and support they need - or receive it too late. This increases their risk of needing to access acute, unplanned and expensive NHS care.

6. We ask the committee to recommend that the Welsh Government does more to hold local authorities to account to make sure that assessments are carried out when families need them.

The way in which the NHS and local authorities work with voluntary sector children's palliative care services

7. Voluntary sector providers, including children's hospices, bring social value to communities. When local NHS organisations and local authorities remunerate these charities for the children's palliative care they provide, the funding is matched and exceeded by charitable donations which also contribute to running services. Local volunteers also help to provide children's palliative care which are part-funded from statutory sources, further adding value.

8. Despite this, our members feel that too many local health boards and local authorities are failing to recognise the role that the voluntary sector children's palliative care providers can play. Our voluntary sector members are not receiving equitable and sustainable funding from local health boards and local authorities for the palliative care they provide.

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

10. We believe that this is caused, in part, by local authorities and local health boards not being clear about their responsibilities to work together to plan, fund and deliver children's palliative care services. This is particularly in terms of short breaks for respite for children with life-limiting conditions and their families, which are both a health and social care service. We ask the committee to recommend that the Welsh Government produces statutory guidance to clarify these responsibilities, and to hold local authorities and local health boards to account to make sure that they work together to jointly plan and fund children's palliative care services.

Transition to adulthood

11. For young people with life-limiting conditions, making the transition from children's to adult palliative care services is often described as like falling off a cliff edge. Medical advances mean there is now a growing number of young adults in Wales aged between 18 and 40 with life-limiting conditions. However, the transition these young people have to undergo from the comprehensive care offered by children's palliative care to unfamiliar adults' services can be daunting and is often not joined up. There are also too few palliative care services which meet the needs and wishes of young people in ways which are appropriate to their age and developmental stage, particularly in terms of the way in which short breaks are provided.

12. Young people with life-limiting conditions have specific needs which differ from both younger children and older adults. However, there is a lack of age and developmentally-appropriate palliative care services which can meet this growing demand. Young people with life-limiting conditions must forge relationships with new agencies and professionals, and for many young people, this transition coincides with a rapid decline of their condition.

13. It's also hard for these young people to get the support they need beyond their health needs, to do all the other things that all teenagers want to do: going out, living independently, exploring their sexuality, having relationships or entering the world of work and further education. Young people face too many barriers and obstacles, making it impossible for them to get on with enjoying adulthood. They need help now; they don't have the luxury of time on their hands.

14. Together for Short Lives is concerned that there is currently no statutory duty on local health boards and local authorities to work together to assess the future care and support needs of young people who are likely to need health and/or social care as adults. While we acknowledge that the Social Services and Wellbeing (Wales) Act applies to both children and adults, we ask that the committee to recommend that more is done to make sure that assessments, plans and services join up when a young person undergoes the transition to adulthood. This could include a new statutory right to a transition plan for young people which sets out the education, health and care they will need during this period.

For more information, please contact:

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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.

<u>Provision of Information and Advice</u>

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.

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