

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

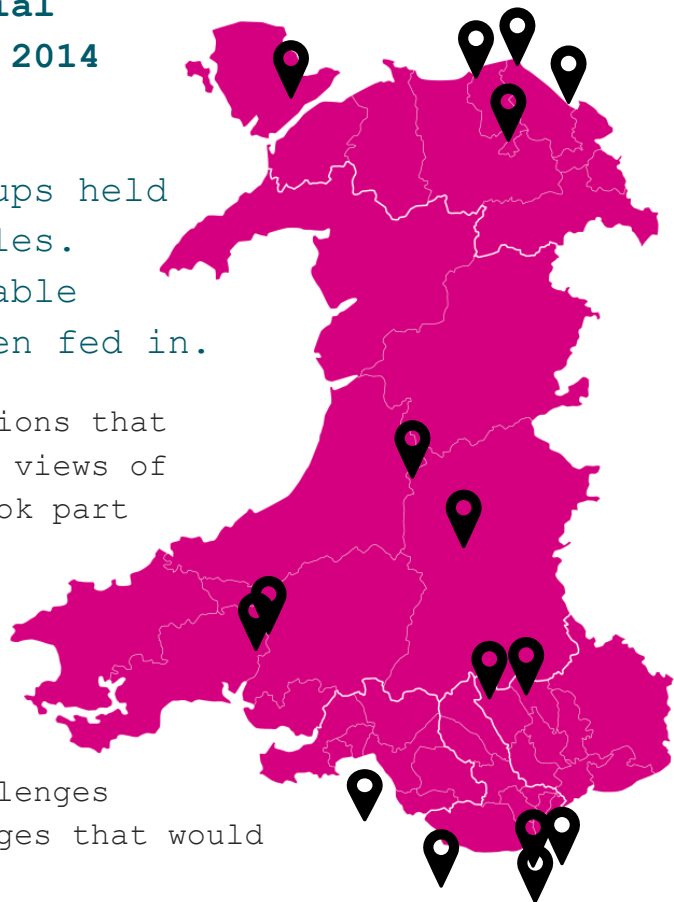
Background

This report summarises the findings of focus groups held as part of the **Health, Social Care and Sport Committee's** inquiry into the **Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to Carers.**

Findings are based on **14** focus groups held in a number of locations across Wales. Input from individuals who were unable to attend focus groups has also been fed in.

Sessions were arranged through organisations that support both adult and young carers. The views of the **136 carers and support staff** that took part have been summarised into key themes. Notes from individual sessions can be made available on request.

Participants discussed their awareness of the Act, the current services and support available to them, the main challenges they experience and their ideas for changes that would make a difference to them.



The purpose of these findings is to help the Committee determine the impact the Social Services and Well-being (Wales) Act 2014 on carers in Wales and will be a base for discussions with representatives from these groups at a roundtable event with the Committee on the 17th October.

Summary of Key Themes:

1. Awareness of the Social Services and Well-being (Wales) Act 2014

Lack of awareness

The majority of participants, including the young carers who participated, were unaware of the Act and its impact on them as carers.

Where there was an awareness, this had come either from an advocate or through their own research.

"Nobody has ever told me about my rights under the Act." *Participant from Caerphilly Mental Health Carers group*

"I only found out about the Act because of this focus group." *Participant from Bridgend Carers Centre*

Open to interpretation

Of those who were aware, many felt the Act itself was very positive in terms of the rights it gave carers. However, none were seeing the impact of the Act and felt that although legislation now protected carers, the resources to implement those services were not there.

Participants said the Act was open to interpretation which led to inconsistent support, and a lack of understanding from those supporting carers across different sectors.

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

"The Act is fantastic, but it isn't being implemented. I don't feel valued and I'm being taken for granted." *Participant from Credu Carers Llandinam*

No difference

As a result, many who were unaware of the Act were surprised to hear of legislation which was supposed to help them, and those who were aware of it, felt no difference had been made.

"There has been no impact from the Act - it has made no difference."

Participant from Credu Carers Llandrindod Wells

"The Act is not working. We are all at the brink. We are not coping."

Participant from Hafal West Wales Carers group

2. Carers needs assessments and outcomes

Inconsistencies

On average, around half of participants had received a carers needs assessment. However, the circumstances were very varied.

Some were unaware they were being assessed and had no understanding of what should happen next.

Others were being assessed in front of those they care for and didn't feel they could be as honest as they would like.

Some participants had requested assessments, only to be told there was a 3-6 month waiting list. Others had been told the cost of the assessments in an attempt to dissuade them from requesting one formally.

Participants felt that the quality of assessments were very dependent on the form being used as the new form is based on outcomes and what the carer wants. They also felt it was very dependent on the social worker and their understanding of carers and their rights.

Although three participants (from different sessions) were happy with the support they had received, very few participants had been offered an assessment, had it carried out appropriately and then seen a difference to the support they were able to access.

"If people don't know they're having an assessment, they don't know what to ask for, or what they're entitled to."

Participant from Stroke Association Carers group

"I had an assessment eventually. There were delaying tactics and it took tears and a booked holiday to get the respite recommended."

Participant from Credu Carers Llandinam

"The social worker told me an assessment wouldn't make a difference to me." *Participant from Credu Carers Llandrindod Wells*

Social Services

Some participants said recommendations for support had been made during their assessment but there was no resource available to put them in place.

Others felt that social services know how much they have to work with and will offer support accordingly, rather than based on the need of the carer. It will then take a lot of time and energy to push for anything additional, even if they're entitled to it.

As a result, many participants felt assessments should be delivered by a third party. This could also avoid the carer worrying they are being judged on their ability to care, especially in the case of parent carers, who are often reluctant to have an assessment in case there are repercussions.

Some carers were being offered assessments by third sector organisations as opposed to social services. Many felt this was better as they were impartial and could make recommendations based on need. However, this did not always lead to the right support being offered and support staff from the third sector said they were often not kept updated on the progress of the recommendations made.

"Nothing happens after an assessment now - but how could it without the money?" *Participant from Carers Wales Committee*

"I was told not to bother as the LA can't do anything about it." *Participant from Credu Carers Llandrindod Wells*

"It massively depends on who is delivering the assessment. The LA are more focused on what they can offer, the carers centres are far more holistic and recommend support that is available." *Participant from Carers Trust frontline staff group*

Change in assessments

Many participants had been carers for a long time and had received assessments both before the Act and afterwards. Some didn't like the new system and felt the assessments were less valuable now.

A number of participants felt the 'What matters'¹ conversations put more responsibility on the carer to raise issues and ask for help, rather than being offered support that was relevant to their situation.

What's the point?

Of those who hadn't received an assessment, some were unaware they were entitled to one and therefore hadn't requested one.

Others had lost faith in the system and didn't want to go through the process if nothing would be implemented afterwards.

A number of support workers who participated, felt the assessments raised expectations when, because of a lack of resource, very little support could then be offered.

"Many carers ignore social services and sort it out themselves. Social services is a last resort when you are desperate and need something."

Participant from Carers Trust frontline staff group

"I've washed my hands of them." *Participant from Caerphilly Mental Health Carers group*

Young carers

Of the young carers and the young adult carers we spoke to, none could identify an assessment being carried out. Many did not think social services offered them any support.

"One person said they were in a meeting for a whole year."

Participant from Swansea Young Adult Carers group

3.Support and information currently available for carers

Lack of information

Many of the participants felt there was a lack of information available for carers on the support that was available to them.

¹ Carers assessments are now regularly called 'What matters conversations' in an attempt to make the process less formal and more focused on outcomes.

Some said they had stumbled on information by accident, others had done their own research in order to find out what they were entitled to.

There were also inconsistencies in the information and support offered to participants. Some members of the same group had received different levels of information from the same authority and many felt that the help offered depended heavily on individual social workers.

"There isn't enough help out there, where should I go for help?"

Participant from Credu Carers Llandrindod Wells

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

"I only found things out through my own research. You stumble across people or information." *Participant from Credu Carers Llandinam*

"I only know about support through word of mouth" *Participant from Stroke Association Carers group*

"I wasn't aware of the support that was available. It took 10 years to find out about respite." *Participant from Motor Neurone Disease Association Carers*

Third sector

The majority of the participants received most of their support from third sector organisations.²

Many felt they could not have coped without the support offered by these organisations, either in the form of information about what they are entitled to, or through support groups and counselling.

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

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

² Please note the majority of the focus group sessions were arranged through support groups offered by third sector organisations.

"The third sector is keeping us alive." *Participant from Hafal West Wales Carers group*

"The third sector is very important in supporting carers and helping them to understand the stigma of social services is outdated."

Participant from Carers Trust frontline staff group

Fight for support

A common theme to emerge from the sessions was the feeling of having to fight for information and support.

Many participants said they felt exhausted by their caring responsibilities, only to have to work hard to find information on what they are entitled to and then fight to access that support.

There were also inconsistencies in the support offered to carers of different conditions. Carers of certain conditions, such as mental health, were particularly distressed with the lack of support and felt they were passed between different departments, which presented additional barriers to accessing support.

"Carers who are tired emotionally and physically, haven't got round to finding the support." *Participant from Carers Trust frontline staff group*

"Every step of the way there is a wall." *Participant from Credu Carers Llandinam*

"They say there is support but there's so many barriers." *Participant from Hafal West Wales Carers group*

"Only because I'm the sort of person who will go and ask that I got my support." *Participant from Bridgend Carers Centre*

"Where do you think people get the energy to find the support?" *Participant from Hafal West Wales Carers group*

4. Support that could make a difference

More information, advice and advocacy

Based on the discussions around the lack of support, every group said that better signposting and more information about support would make a difference to them.

For many, they had fallen into a caring role, and hadn't identified with being a 'carer' straight away. Many felt this had made it difficult to access support, or recognise they needed support, until they were in desperate need of it.

"People don't recognise the word carer, we need to use language people understand." *Participant from Carers Wales Committee*

"Half of us don't want to be carers - we want to be husbands and wives." *Participant from Motor Neurone Disease Association Carers*

Joined up services and better education

Support workers who participated felt that the Act had diluted what the Carers Measure had set in place and that more work was needed with the Health Boards. They felt the Act was so focused on the LA's responsibilities, the health service had 'taken its foot off the pedal'.

Carer participants also felt the system was too complicated and wanted 'one person' they could contact for information about support, along with a clear and consistent process for assessments.

Participants also wanted those who work with carers to be better educated about carers rights and the available support services. Hospital staff for example were at times the first to come into contact with carers and yet weren't able to offer the relevant information or signposting.

"I'm shocked at how little people know sometimes. There needs to be joined up working and signposting." *Participant from Credu Carers Llandinam*

Respite

Respite was raised in every session as one of the most important resources available to carers. Without regular and appropriate respite, carers felt they couldn't cope with their caring responsibilities and felt their health was suffering as a result.

The majority of groups felt they had to fight for respite and many said they were not offered appropriate services. One participant said she had to book a holiday before she was able to secure a place for her mother, and then it wasn't appropriate for her needs so she was forced to cancel the time away.

Participants who lived in rural areas found this a particular problem.

"I need respite, just a few days off and to feel comfortable leaving them. I don't give myself me time." *Participant from Caerphilly Mental Health Carers group*

"More accessible respite should be seen as a right, rather than having to fight for it." *Participant from Credu Carers Llandinam*

"You don't address your own health issues - you put yourself second." *Participant from Carers Wales Committee*

"I dare not go and sort out my issues - what will happen to him if I am ill?" *Participant from Carers Wales Committee*

"I have my own needs and medical issues which have been made worse." *Participant from Credu Carers Llandinam*

Recognition

Every group wanted to see more recognition for the work carers do.

The majority felt strongly they were supporting the care system and saving local authorities money, and yet most felt undervalued and treated with little respect.

"All we'd like is for them to recognise the work we do." *Participant from Credu Carers Llandrindod Wells*

"We're saving local authorities a huge amount of money. Without carers, we'd be in big trouble." *Participant from Bridgend Carers Centre*

"We're not treated fairly and we're not treated with respect. How much money do we save the country?" *Participant from Motor Neurone Disease Association Carers*

"We're forgotten about." *Participant from Stroke Association Carers group*

Young Carers and Young Adult Carers

Support staff who participated felt that more support was needed to ensure the good health, mentally and physically, of carers. This was of particular concern relating to young carers where mental health problems were common as a result of their increased responsibilities.

In particular, young carers felt that there was a lack of recognition from their schools and GPs in relation to how much care they are responsible for. This was also raised as a concern separately by support staff.

Those support staff also felt more support was needed for young adult carers (17+) who are transitioning between children and adult services. There was a frustration at the lack of definition from WG for this bracket and a call for a different type of service.

"Their needs are very complex - looking after you parents, your siblings and juggling education or work. Young carers need support workers not just information."

"WG transition age change muddied the water here and made it difficult for the older young carers to find a place. Barnardo's is not comfortable for them."

"There is a definite gap here. We have made progress with young carers but young adult carers are falling behind."

All comments from Carers Trust frontline staff group

Older carers

There was a concern amongst many of the groups in relation to their caring responsibilities and what happens when they are no longer around. Many participants were caring for partners or children and worried who would look after them should anything happen to them as the primary carer.

Many wanted reassurance about options available and arrangements put in place in advance for peace of mind.

"If I go first, he won't survive. What will happen to him?"

Participant from Caerphilly Mental Health Carers group

5. Additional Comments

Isolating

Every group talked about the effects of caring on them as individuals. Many found it a very lonely experience, regardless of the condition they were affected by.

This further emphasised the need for better support and recognition of caring roles.

Support groups were helpful for some, who found it comforting to meet people in similar situations and to share information.

"It can be very isolating. I couldn't leave the house so I didn't know about the support that was available." *Participant from Bridgend Carers Centre*

"I was quite a normal person before I was a carer." *Participant from Credu Carers Llandinam*

"As a carer, you lose a sense of yourself." *Participant from Credu Carers Llandinam*

"You have to shelve your own dreams." *Participant from Bridgend Carers Centre*

"After you finish caring, you're lost, your whole life changes." *Participant from Bridgend Carers Centre*

"You lose your identity. You're now the carer. You need a balance so you get what you need too." *Participant from Bridgend Carers Centre*

"Once you fall into being a carer, there's nowhere to go." *Participant from Credu Carers Llandinam*

Stigma of Social Services

Many participants felt there was a stigma attached to social services which discouraged many to ask for help when it was needed.

As previously mentioned, parent carers particularly felt they couldn't be honest about how they were coping with their responsibilities in the fear of repercussions. Young carers were also said to associate social services with negative experiences and there was a fear of letting them know they were struggling to cope.

Some groups took this further and expressed feeling bullied by professional services, feeling unable to complain without restrictions being imposed, and having to fight for every small step.

The majority agreed that carers are concerned about challenging the professionals in case what has been offered is withdrawn.

"No complaints are made as they are fearful of the repercussions. Most will only speak up once the person they were caring for has passed away." *Participant from Carers Trust frontline staff group*

Conclusion

A small number of carers who participated in the focus groups felt they had received the appropriate level of support and were happy that their caring responsibilities were being recognised. However, these participants acknowledged this wasn't universal and felt it had been dependent on individual social workers or their own research and requests.

Participants were also affected by different conditions which brought about different challenges. For example, participants caring for individuals with mental ill-health found it difficult to focus on their own needs as carers as the strength of feeling and frustration at the lack of adequate support and care being offered to those they are caring for was so strong.

However, the majority of participants agreed that although the Act appeared to support carers needs, in reality this was not being implemented to the full extent intended.

Appendix

Format

Participants were asked the following questions:

- Are you aware of the Social Services and Well-being (Wales) Act 2014?
- Have you had a carers need assessment? If yes, what was the outcome? If no, why not?
- What support are you currently receiving? Who do you get this support from? Do you know where to go for support/information?
- What else would help you?
- Do you have any additional comments?

Participants discussed the questions as a group and post it notes were used to collect answers and quotes.

Focus Group Participants:

- Gwynedd and Mon Young Carers - Action for Children
- Carers Trust support workers
- Carers Trust Taith Ni
- Credu Cymru
- Crossroads Care in the Vale
- Motor Neurone Disease Association Carers
- Carers Wales Committee

- Carers Wales - Parkinsons Carers group
- Stroke Association Carers
- Macmillan Cancer Care and Bridgend Carers Centre
- Flintshire Young Carers - Barnardos
- North Wales Carers Trust - Crossroads Care Services
- Hafal West Wales Carers
- Caerphilly Mental Health Carers
- Swansea Carers - young adult carers
- Carmarthenshire Young Carers