National Assembly for Wales
**Health, Social Care and Sport Committee**

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

# Roundtable event - summary of discussion

## Health Social Care and Sport Committee

### Carers inquiry round table event 17 October 2018

### Summary of the discussions

**Main points** raised by people attending the event included:

- There is little awareness amongst carers of the SSWB Act and of carers' rights under it – this needs addressing;
- Better information and awareness of carers' rights under the SSWB Act is also needed across all public services with which carers have contact – good signposting is needed;
- Carers should be identified and supported at first contact with services;
- Social services staff aren't always knowledgeable and aware of the issues carers face and sometimes discourage requests for assessment;
- There is need for flexible, person centred services for carers;
- More frequent reviews of the needs of individual carers are needed;
- Resources used to support carers saves money in the long run;
- Caring is exhausting and having to find and access support is exhausting too: carers don't have the strength and energy to do both.

## 1. Awareness of the Act

Carers reported that they had had **little awareness** of the *Social Services and Well-being (Wales) Act 2014* prior to contacting carers' charities. Some reported that they had only discovered the existence of the Act, and its provisions for carers, as a result of their own research, or from other carers.

Health services in particular had not provided information on carers' services. There was a feeling that the Act, and carers' rights aren't promoted and that **understanding of the Act amongst professionals is often poor.**

Some carer support workers commented that **initial optimism** about the difference the Act would make had subsided. There were now some concerns, in particular that the support given to carers was **dependent on individual social workers** and that the NHS needs to play a bigger role.

Carers need **more help to understand their entitlements** and how to obtain them. However, the Act can be a good tool for achieving this. Community based services are the first point of contact for most carers so carers are dependent on the availability of this service to make them aware of their rights.

## 2. Seeking help from social services

Experiences suggested that some staff were **disinterested or discouraging.** Conversely, other staff were helpful. Experiences of seeking an assessment highlighted the **barriers** which discourage people – e.g. questioning why an assessment is needed or having to make several attempts to obtain one – this was the experience of several of the carers.

There is a lack of clarity regarding the **definition of a carers assessment** by social services. Some participants had had an assessment but had not received services, having not met the **eligibility criteria.**

Some people are **reluctant to approach social services** – there is a stigma about it and some expressed a fear of appearing to fail to care for their children. It was felt that carers' assessments should be undertaken by an **independent organisation.** This would also help to ensure that assessments are undertaken separately from the cared for person, and without being driven by resource considerations. Carers should be able to choose where the assessment takes place – some people prefer to be assessed without the cared for person present.

Carers said they are sometimes **not listened to and feel disempowered.**

There was a view amongst some participants that public services, including social services, are **driven by processes and targets** and that the do not put the user at the centre. However, people had experienced both good and bad services.

**Funding is inconsistent.** There is no point in legislation without the resources to implement it.

Services respond **where they have duties** but less well where there is no duty.

Once a carers' assessment has been done, it is important to **follow it up** periodically to check on how things are progressing. Sometimes there is no point of contact in social services to follow things up.

There are issues around **financial support for carers**, including the lack of an earnings disregard (unlike the cared for person), and ineligibility for **Carers Allowance** for full time students.

**Data collection by local authorities is poor.** e.g. data is not collected on the help carers need or receive.

"It's like trying to wade through quicksand every day"

"Having to fight for services is exhausting"

## 3. Information and support

In general, carers felt that there is a **lack of information** on carers' services in the places where it would be most useful and accessible such as GP surgeries. Information on how to obtain an assessment should be easily available. Suitable places include libraries, hospitals, post office, food banks, community boards in supermarkets, social media. Some carers had had to find the information themselves.

**Third sector organisations** had often been the best source of information and advice but this had often been accessed much later in the process, when carers had discovered voluntary sector services.

In some cases information and support was only forthcoming when the carer had **reached a crisis** and had received statutory services. There is a need for **follow up information and advice**; it's not enough to provide it only at the point of diagnosis, people can't take it all in.

One person said that information is provided for people with physical illnesses about what to expect and how to manage their condition and its treatment, but **not for mental health conditions.**

"People need signposting – a roadmap and guidance on how to deal with services."

"Finding help as a carer is a matter of luck."

Experiences of **respite care** were mixed - respite care may be scarce, unsuitable or unreliable, particularly in rural areas, and at weekends, but some had found it helpful, even if it had taken some effort to obtain. One person caring for two children waited nine years for coordinated respite care. Others commented that they had to organise and coordinate their respite care or fit in with respite services rather than having them tailored to their needs. **Greater flexibility is needed.**

There was praise for the support provided by **third sector organisations** – most participating carers had accessed support from them, including from Ty Hapus and Crossroads Care in the Vale, MND Association, Credu Cymru, Hafal, Bi-Polar UK, Marie Curie, Alzheimer's Society and St John Ambulance.

There was praise also for the support provided by **carers' centres** – one person said it had offered support at a point when she was considering ending her life. There was a view that carers centres can **save public money** and some people commented on the uncertain funding arrangements. Not supporting carers costs more money in the long term – their health deteriorates and they become more dependent on the NHS, unable to work etc. It's a public health issue. Some carers' centres offer counselling but more services are needed and funding for the service is limited.

There was general agreement that **caring is exhausting** (some people care for more than one person) and that having to search for, and to fight for, services and support is exhausting too: carers don't have the strength and energy to do both.

## 4. Suggestions for improving support and information.

- Several people suggested that an **annual review for carers** is needed to take account of changing circumstances. There was a suggestion that this could be done through GP surgeries and would include both their physical and emotional health needs.
- a **point of contact in every hospital** to represent carers and offer signposting before the carers, or those who have been identified as likely to become carers, leave.
- **Post care support** for carers when the cared for person dies or moves into permanent residential care.
- **Direction/signposting/guidance to carers services** is needed at the point of diagnosis. All relevant services should be able to offer it – GPs, social services, libraries, supermarkets, social media, advice services etc.
- Carer support should be provided by the most appropriate organisation, whether it's the statutory, third sector etc. there should be a **"team around the carer".**
- **Prompt follow up** is needed and carers' assessments need updating in response to the changing needs of both the carer and the cared for person. **Respite care and mental health support** in particular are needed.
- A **carers passport** – evidence that you are a carer, to enable access to services with ease and to provide details around the cared for person's treatment and medications to date, to avoid repeated explanations.
- Carers need the right to **represent the cared for person** in communications with support services.
- The demands on carers should be taken into account within **waiting times for medical attention.**

- Better **data collection** is needed
- More uniformity of services between local authorities, LHBs and across Wales.
- Improve **communication** around the Act
- Distribute the **Carers Light self help guide**, for example to GP surgeries.
- Share **good practice.**
- Raise **awareness and recognition of carers.**
- We need **directives from Welsh Government**, instead of suggestions.

# Recommendations from each table

## Table 1

1. Person centred services are needed – people shouldn't just have to fit in with what is available, flexibility is important.
2. A separate department is needed to deal with carers assessments.
3. Ongoing monitoring and review of each carer's needs are required.

Other points: carers should have the right to represent the cared for person; they shouldn't be assessed in the presence of the cared for person; there is no recognition of the double caring role.

## Table 2

1. Direction/signposting/guidance to carers services is needed at the point of diagnosis. All relevant services should be able to offer it – GPs, social services, advice services etc. Communication is essential – to ensure both service providers, and carers themselves, know about carers services.
2. Carer support should be provided by the most appropriate organisation, whether it's the statutory, third sector etc. there should be a "team around the carer".
3. Prompt follow up is needed and carers' assessments need updating in response to the changing needs of both the carer and the cared for person. Respite care and mental health support in particular are needed.
   People have to battle alone to get support.

## Table 3

1. Carers should be identified as soon as they are in contact with services (the assessment should start there).
2. There has been a diminution of support since the demise of the Carers Measure.
3. There needs to be a guide to carers' rights – information on what help they could get.
4. A carer of a child remains a carer, even when the child becomes an adult. They then need to have a say/be involved/know what's going on. (kinship carers are often excluded too).
5. There are too many blanket policies – personalised support is needed.
6. Reviews are infrequent – better monitoring is needed.

There are examples of good practice which the Committee should investigate – e.g. in BCUHB (triangle of care), ABMU and Hywel Dda. Needs to be disseminated.

## Table 4

1. Good communication/information is needed – e.g. on what carers are entitled to.
2. There should be outreach workers in hospitals who can provide advice and information.
3. There should be an annual review of each carer's needs.
4. Additional resources are needed to support carers – it saves money in the long run.