



National Assembly for **Wales**

# Health, Social Care and Sport Committee

## Inquiry on carers and the Social Services and Wellbeing (Wales) Act 2014

### Notes from informal evidence session with young carers

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The Committee met with young carers on 31 January 2019 to hear first-hand about their experiences of caring, the challenges they face and their views about the support they receive and what they would find helpful.

This paper provides a summary of the informal discussions.

## Background

### Terms of reference for the inquiry

1. To assess the impact of the *Social Services and Wellbeing (Wales) Act 2014* 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.
2. To consider broader Welsh Government policy on carers.

### Consultation

The Committee undertook a written consultation on the impact of the *Social Services and Wellbeing (Wales) Act 2014* in relation to carers in summer 2018. The consultation closed on 20 September 2018 and received 30 responses. In addition, some witnesses to the inquiry have submitted supplementary written evidence.

### Focus groups of carers and support staff

During the 2018 summer recess the Assembly Outreach Team undertook a series of focus groups with carers of all ages, and with a wide range of experiences which included caring for people with dementia, mental ill health, cancer and stroke.

### Roundtable event with carers

The Committee held a roundtable event on 17 October 2018 for carers and carer support workers.

## **The event**

Young carers from across Wales were invited to the Assembly to meet and speak with Committee Members in an informal setting. The event coincided with Young Carers' Awareness day. In a separate session, three young carers gave formal evidence to the Committee.

Support for the event was provided by Carers Trust Wales.

The aim of the session was to understand the experiences and views of the young carers, specifically :

- Direct experience of being a young carer
- How being a young carer affects their lives and their families' lives
- How much support is provided by third sector organisations and at school

Following an ice breaker the young carers were asked to work together on a flipchart to identify what they felt were the strengths and qualities they have as carers, to provide a context for discussing their day-to-day experiences and the challenges they face. The second part of the session comprised a discussion about support: support the young carers provide to other people; support the young carers receive from other people; additional support they would like to receive.

### **Areas for discussion:**

- Support provided by young carers
- Support provided to young carers
- Additional support which would be helpful

## 1. Support provided by young carers

Each group discussed their experiences of caring – i.e. what young carers do. They identified the following:

- Domestic chores (cooking, cleaning, laundry etc.)
- Shopping
- Taking responsibility for and looking after other children (siblings), including preparing meals, personal care, help with homework, getting ready for and accompanying to school. Attending school parents' evening.
- Caring for, supporting and 'being there' for the family. Making people happy when they feel down.
- Personal care for the cared for person, including feeding. The cared for person may be a child (sibling) or adult (e.g. parent).
- Using Makaton<sup>1</sup> to communicate with the cared for person.
- Operating equipment, including wheelchair.
- Handling seizures.
- Watching/supervising/spending the night with the cared for person.
- Provide emotional support for the cared for person. Helping a person to cope with panic attacks. "I stay up most nights so she can sleep".
- Accompanying the cared for person to hospital, meetings and appointments.
- Providing company for the cared for person.
- Help with organising the household/cared for person, including scheduling/timekeeping.
- Looking after pets.
- Collecting and organising medication.
- Giving treatment, including injections, pumps/tablets/drinks.
- "Missing days at school when Mum is suicidal".
- Sacrificing social life/emotional support
- Involvement with clubs/voluntary organisations connected with cared for person.
- Love.

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<sup>1</sup> Makaton is a form of sign language for people with limited speech.

## 2. Support provided to young carers

The groups discussed what support young carers receive, and from whom. A variety of sources of support was identified by all groups but not everyone had the same experience of accessing their support – for some it was positive and helpful, for others it was unhelpful or non-existent, and the comments reflect this.

- **Support services for young carers:** Carers Trust Wales support services. Young carers' groups. Support from outreach worker.
- **School** – there was a lot of discussion about this.

School support is variable. Support depends on individual staff members – support is often from individuals rather than the school as a whole. One dedicated teacher is needed – sometimes a particular teacher to whom the young carer can relate is helpful. But not all young carers are aware of the support available.

The Schools Award Programme has improved support in Caldicott School. There are lunchtime clubs in Swansea school.

The register sometimes includes a note on young carer(s) in the class but teachers don't always look at it. They are not always aware of carer support policies.

Lack of support/ difficulties at school: some teachers are sympathetic and helpful, others are 'not on the same page' and don't understand, e.g. things like depression. Lack of school support can add to young carers' problems. At GCSE stage schools are target driven and unsupportive, e.g. refusing extensions to assignment deadlines. Other children can be nasty/undermining and bullies bring down self-esteem. Schools should raise awareness of carers' issues.

There is a lack of information in schools on young carers (e.g. the only information is a leaflet on the school notice board).

There is less support at college.

Friends can help but young carers don't always feel able to tell them. Caring for someone with a mental disability is harder to talk about.

- **Health and social care professionals**

There was much less discussion about support from health and social care professionals, possibly reflecting the young carers' lack of experience of receiving this kind of support. Comments included:

There is no support from healthcare professional or social workers. GPs are sometimes unsympathetic. Young carers sometimes underplay their caring role to GPs.

Other young carers had received support from District Nurses, doctors, therapists, support workers and professionals attending to care for person. Some had found counsellors and support groups helpful, others had benefitted from mindfulness and therapy. Other sources of help included a support charity (Ty Gobaith), youth groups.

Things aren't improving quickly enough.

- **Family, friends, other young carers**

Young carers identified the following sources of help: friends, other young carers, family, pets.

### **3. Additional support which would be helpful**

The groups discussed what further support is needed.

- Raise awareness of the work of young carers and its impact on them. All groups emphasised the importance of this issue.
- Raise awareness in the Assembly.
- Better support at school and better awareness amongst teachers of the needs of young carers.
- More young carers' support groups and more resources for them. Transport to carers' groups. Discounted travel.
- Social services carers' assessments. Four out of seven young carers had received an assessment. Two didn't know they existed.
- Training in manual handling
- Greater acknowledgement of the knowledge and skills young carers have. Sometimes health professionals 'take over'. Young carers should be able to collect prescriptions.
- ID cards for all young carers.
- More and appropriate/suitable/helpful respite.
- Social media – mixed benefits – provides contact with other young carers groups/organisations, friends, but there is also a risk of bullying.
- A voice.