

# THE WELL-BEING OF YOUNG PEOPLE

## YOUNG ADULT CARERS



WALES AUDIT OFFICE  
SWYDDFA ARCHWILIO CYMRU

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This report has been prepared  
for presentation to the National  
Assembly under the Government  
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# ABOUT THIS REPORT

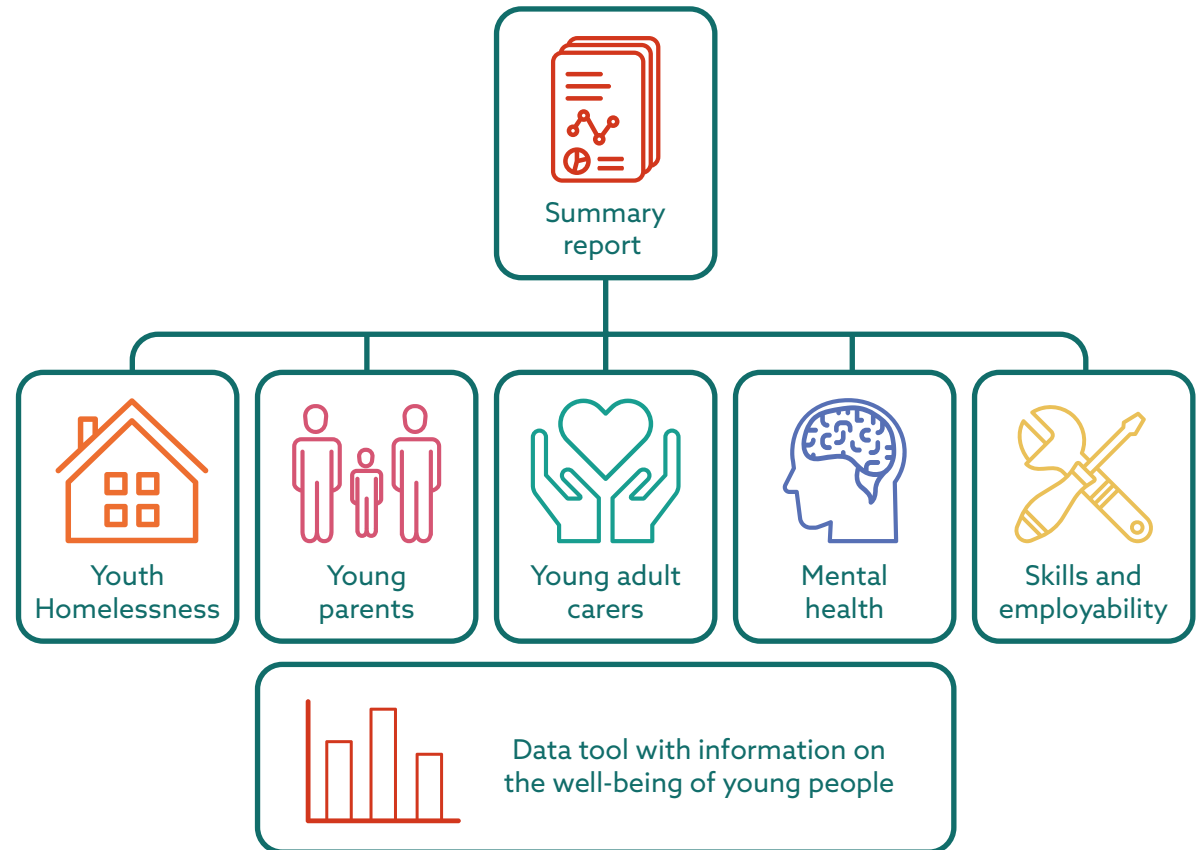
About our wider work on the well-being of young people

## Joint-working

We have been working with other organisations to examine a common theme of 'Youth'. The education inspectorate Estyn published its report on **youth support services** in July 2018. Healthcare Inspectorate Wales published its **review of healthcare services for young people** in March 2019. Care Inspectorate Wales published its **report on care experienced by children and young people** in June 2019.

## Our work

We looked at the Welsh Government's work to support the well-being of young people in Wales. Well-being is a broad concept, so we have focussed our work on five topics: youth homelessness; young adult carers; young parents; mental health; and skills and employability. We are publishing seven products based on our work, including this report. The diagram provides a link to each product.



## About this report on young adult carers

In this report we refer to young adult carers as 16-to-24 year olds<sup>1</sup> looking after someone without being paid. There are lots of reasons people need care. They might be ill, have a disability, mental health problem or an addiction and find it difficult to cope on their own. We looked at young adult carers because caring can have a major impact on a young person's physical, emotional and mental well-being. The Welsh Government wants to improve the well-being of all carers but recognises that young adult carers can have specific needs.

This report is not a comprehensive audit of services for young adult carers. Our focus is what the Welsh Government does to support organisations helping young adult carers. We give our observations based on interviews with Welsh Government officials and organisations working with young people. We also reviewed Welsh Government strategies, plans, research evidence and statistics. The diagram provides an overview of this report and you can use it to move to the different sections that explain what we found.

### FOOTNOTES

- 1 Some organisations use different age groups to describe young adult carers.



### A picture of young adult carers

6% of 16-to-24 year olds in Wales were carers in 2011.



### How much is being spent?

It is not entirely clear how much is being spent on carers of all ages including young adult carers.



### Who else is involved

Councils and health boards must work with other organisations to identify and support young adult carers.



### What is the Welsh Government trying to achieve

There are three national priorities for carers of all ages. The Social Services and Well-being (Wales) Act 2014 says how organisations should help carers.

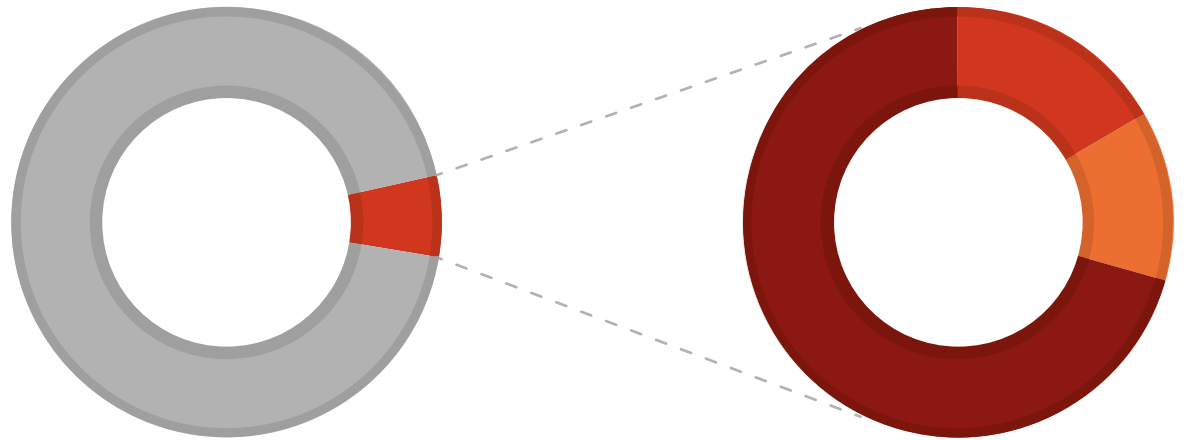


### Opportunities for improvement in the Welsh Government's approach

It could base its plans on better evidence. It could also be clearer on what help young adult carers can get and its own role in making sure they get it.

# A PICTURE OF YOUNG ADULT CARERS

16-24 year olds providing unpaid care in 2011<sup>2</sup>



- Not providing care  
94% or 331,060 people
- Providing unpaid care  
6% or 21,113 people

- Providing 1 to 19 hours  
4% or 14,936 people
- Providing 20 to 49 hours  
1% or 3,527 people
- Providing 50 or more hours  
1% or 2,650 people



More young women were providing unpaid care than young men in 2011 (11,506 women compared to 9,607 men). [Click here to see an interactive version of the chart.](#) [Our data tool](#) gives more information on young adult carers

Source: Provision of Unpaid Care, Census 2011

## FOOTNOTES

- 2 Data in this report may differ slightly from our data tool which includes live data updates.

**Research for the Carers Trust** shows that young adult carers in the UK:

### School, college or university



- Are likely to miss school, be bullied and get lower grades, although 26% said using specialist young adult carer services improved their grades and attendance.
- Are four times more likely to drop out of college or university.
- Many had not told anyone in school, college or university they were a carer. Many who did tell someone they were a carer felt they did not get the educational help they needed.

### Work



- Are likely to not be in education, employment or training (NEET).
- Miss an average of 17 work days per year.
- Many prioritised caring over work choices including choosing a job close to home and to fit around caring responsibilities.

### Health



- 65% said they had a disability or health difficulty. 45% said they had a mental health problem including anxiety, depression and eating disorders.
- 72% said that using specialist young adult carer services increased their confidence and 60% said it made them feel they have friends.

### Information



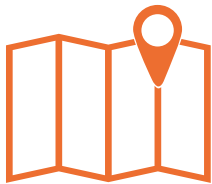
- Have insufficient information about the resources and guidance available to them
- Many did not feel they had the information and advice they needed to plan for the future. This included good careers advice and advice on fitting work around caring.

Organisations working with young adult carers told us relationships can become strained when a young person is caring for a parent and trying to exert their independence as they grow into an adult. The National Assembly's Health, Social Care and Sport Committee is doing an **inquiry of the impact of the Social Services and Well-being** (Wales) Act 2014 on being a carer. In January 2019, young people from the Carers Trust Wales Youth Council told the Committee what it is like to be a carer. They described guilt, isolation, bullying, lack of recognition and inconsistency of support.

# WHAT IS THE WELSH GOVERNMENT TRYING TO ACHIEVE



The **Social Services and Well-being (Wales) Act 2014** (the SSWB Act) changed the way that Welsh Ministers, councils and health boards help people who need care, or carers who need help themselves. The SSWB Act aims to help people who need care or support to achieve well-being and involve them in decisions about their own care. The Welsh Government explains what it means by well-being in its **Well-being Statement**.



The SSWB Act says that councils and health boards must work together with their partners in new partnerships called Regional Partnership Boards. They must find out about people who need care and support in their local area and put this information in a local population needs assessment.



The SSWB Act puts a legal duty on councils and health boards to work with their partners to do **individual assessments** saying what outcomes people who need care and support want to achieve and what help they need to do it. They must also do assessments for carers of all ages.

**The Welsh Government lists three national priorities for carers of all ages on its website:**

- Supporting life alongside caring
- Identifying and recognising carers
- Providing information, advice and assistance

The Welsh Government does not have specific priorities for young adult carers but recognises they have specific needs, and funds some third-sector organisations to support carers of all ages<sup>3</sup>. The Welsh Government has set up a **Ministerial Advisory Group on Carers** to support work on its national priorities.



The **Welsh Government's Extending Entitlement Guidance 2002** sets out what support all young people are entitled to under the Learning and Skills Act 2000. **The Welsh Government commissioned a review of its guidance** in 2018 but has not decided whether to update it.

## ■ FOOTNOTES

- 3 Including funding for Children in Wales and Carers Trust Wales to provide information for carers and increase awareness of carers' rights.

# WHO ELSE IS INVOLVED?

Who else is involved in supporting young adult carers?



Councils and health boards have a legal duty to help young adult carers. Some councils support young adult carers themselves and others pay third-sector organisations to do it for them.



**Social Care Wales** is responsible for regulating and developing the social care workforce, and leading improvement in the sector. The Welsh Government sets strategic objectives for Social Care Wales in an annual remit letter.



Teachers, GPs and other people who meet young adult carers can help identify them and help them find organisations who can help them.



Various third-sector organisations support young adult carers.



# HOW MUCH IS BEING SPENT?

The Welsh Government does not know how much public services are spending to help carers of all ages. The section below shows some of the money being used to help young adult carers<sup>4</sup>:



## Local social services budgets

Councils decide how much of their social services budget to spend on helping young adult carers and do not give information to the Welsh Government on how much they spend.

## Welsh Government funding for respite care

Since 2017-18, the Welsh Government has given £3 million a year for councils to pay for extra respite care to give carers a break<sup>5</sup>.

## Families First money

The Welsh Government has given money to councils to deliver its **Families First programme**. Some councils have used it to pay for support for young adult carers, but the Welsh Government does not collect information on how much they are spending on young adult carers. From 2019-20, money for Families First will be combined with money for six other programmes including childcare and play, in a new Children and Communities Grant.

## ■ FOOTNOTES

4 Figures have been rounded to the nearest decimal point.

5 In 2018-19 the funding became part of the Revenue Support Grant to councils. Councils use the Grant to pay for many different services and may spend more or less than £3 million on respite care.

## Other Welsh Government funding

Other Welsh Government funding in 2018-19 included:

- £1 million to health boards, councils and their partners to improve awareness of the needs of carers of all ages
- £210,000 to Carers Wales to support carers of all ages
- £206,600 to Carers Trust Wales to support carers of all ages
- £10,000 to the All Wales Forum for Parents and Carers
- £95,000 to third-sector organisations for projects to support carers including:
  - £45,000 to Carers Wales to help employers create a carer-friendly workplace
  - £36,000 to **Carers Trust Wales** to develop young carers' ID cards
  - £14,000 to Children in Wales to support the **Young Carers Network**

## Integrated Care Fund

As part of the £50 million **Integrated Care Fund** revenue budget, in 2018-19 the Welsh Government gave £15 million to partnerships across Wales to support children with complex needs, carers and people with learning disabilities. Partnerships must follow the Welsh Government's guidance for the fund. Partnerships decide how much money to spend on carers. Partnerships publish investment plans showing how they will spend the money. The Welsh Government is working with partnerships to find out how much money they spent on carers of all ages.

# OPPORTUNITIES FOR IMPROVEMENT

## | Opportunities for improvement in the Welsh Government's approach

### Identifying young adult carers and understanding their needs



Councils, health boards and their partners must assess carers' needs in their area but the information available and the quality of assessments varies across Wales. Census 2011 data is out of date and organisations do not know who and where young adult carers are. Many are limited to information on carers who have been referred to their services. Some young people do not realise they are a carer which makes it even harder to find them. The Welsh Government does not yet have a comprehensive picture of who and where young adult carers are because local data is limited.

Young adult carers are not always identified by schools, GPs and other professionals. The Welsh Government is working with organisations to encourage professionals to identify and share information about carers.

Some young adult carers discuss issues of concern through the Young Carers Network. A group of young carers also shares their views with Welsh Ministers annually<sup>6</sup>. The Carers Ministerial Advisory Group is a way for organisations supporting carers to share their views with the Welsh Government. But still there are gaps in the collective understanding of young adult carers' needs, what matters to them and how they experience public services. The Carers Ministerial Advisory Group plans to work more closely with young carers to understand their needs including a new engagement and accountability group.

The Welsh Government will launch a new Performance and Improvement Framework in 2020. Under the Framework, councils will collect more information on young carers. The new Performance and Improvement Framework will be launched in April 2020.

The Welsh Government will also collect stories from young carers (aged under 25) and young people who experience care and support as part of its Measure the Mountain work. Measuring the Mountain will publish its final report at the end of 2020.

### | FOOTNOTES

- <sup>6</sup> The group includes young carers and young adult carers from projects across Wales. The young people act as representatives for the Young Carers Network.

## Understanding what services exist and gaps

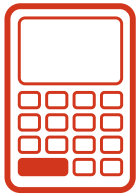


Young adult carers can have complex needs. They need help with their responsibilities as a carer, such as getting prescriptions or medical advice. They also need help in other parts of their life that is tailored to their needs as a carer. Help could include training or work placements that fit round caring, or help with their emotional well-being that recognises the additional pressure they may be under. The Welsh Government recognises that carers of all ages have lives beyond caring. It has a national priority to support life alongside caring.

The SSWB Act says that people with an eligible care or support need, including young adult carers, should get some help. Local population needs assessments done by councils, health boards and their partners are supposed to inform the design of local services. Without better information in the assessments, it is difficult for local partners to design services to meet local needs and the Welsh Government cannot know whether there is enough support across Wales to meet everybody's needs.

Help for young adult carers varies across Wales. Some organisations told us that they do not have enough money or staff to provide the help young people need.

## Understanding Costs



Some organisations are concerned about a lack of public sector investment in services for carers. Carers Wales evaluation<sup>7</sup> of the impact of the SSWB Act on carers '**Track the Act**' said that short-term Welsh Government funding makes it difficult for councils to plan services for carers of all ages.

The Welsh Government has commissioned an independent evaluation of the SSWB Act by the University of South Wales. The evaluation will include information on the financial implications of the Act. With better information on how well local services are meeting carers' needs, the Welsh Government can start to understand how much it will cost to do the things the SSWB Act promises or whether the public sector can afford it. The contract for the evaluation will take place over the next three years.

The Welsh Government and wider public sector also need to understand the costs of being a carer to individuals. Costs vary from one carer to another but some are paying for additional support and struggling financially<sup>8</sup>.

### ■ FOOTNOTES

7 Based on an annual online survey.

8 Carers Allowance is the responsibility of the UK Government under the Department for Work and Pensions.

## Joining up policy making



The Welsh Government's main way of joining up its approach to social care is through the SSWB Act. The SSWB Act sets out some of the ways organisations must work together. Helping public services support carers in a joined-up way goes beyond the requirements of the Act. But many young adult carers are not getting tailored support to meet their needs across different areas of their life. Carers Trust Wales said a lack of joined-up thinking across public services means some carers (of all ages) are having to choose between their needs rather than having them all met. Its evidence to the Committee inquiry said that Welsh Government funding arrangements are one of the barriers to joining up support for carers.

The Welsh Government wants the SSWB Act to focus councils and health boards on working with people to identify and meet their support needs. The SSWB Act set criteria to say which needs are eligible for support<sup>9</sup>. It does not specify the level and type of support young adult carers should expect in each part of their lives because needs and the best way of meeting them will vary from person to person. But some organisations are not used to working in this way. They told us that without clearer requirements, they did not always know who to join up with or what support to provide.

Beyond the SSWB Act, public services can better support young adult carers by tailoring and joining up services they already provide. The Welsh Government communicates its message on supporting carers in various ways. It has also made links across its own departments and with public sector partners to join up its approach. The Welsh Government has asked the Carers Ministerial Advisory Group to look at how support for carers can be more strategically driven, by the Welsh Government and wider public services. The work will include making links across relevant policy areas. But the Welsh Government has more work to do to translate links into a joined-up service that meets young adult carers' needs. Specific examples include mental health and skills and employability support.

### ■ FOOTNOTES

- 9 Some needs are not eligible for support under the SSWB Act. Individual carers' needs assessments are intended to focus on what matters to the individual, and on preventing problems occurring or getting worse. Some individual needs may not need to be met by statutory services.

## Working out who does what



The SSWB Act does not say who is responsible for helping young adult carers at each stage and in each part of their lives. Organisations working with young adult carers are struggling to get other organisations and council departments (except social services) to accept they have a role in helping young adult carers.

Many young adult carers do not know where to get information about services in their area. The [Dewis Cymru website](#) has information about local services. Councils pay for the website and the Welsh Government paid some of the set-up costs. We heard that young people are not using the website. Some do not know where to go for help because they do not know who is responsible for giving it.

Organisations also told us that most young adult carers are not aware of their rights to an individual carer's needs assessment under the SSWB Act. Track the Act and responses to the National Assembly's Health, Social Care and Sport Committee inquiry raise similar concerns. The Welsh Government is planning a communication campaign to raise awareness of carers' rights under the SSWB Act.

## Learning from and improving delivery on the ground



The Welsh Government plans to improve the information it has about whether young adult carers are getting the help they need through its new Performance and Improvement Framework and Measure the Mountain work.

Track the Act said it is difficult to see how some services for carers meet the needs of the people who need help the most. It recommended ways for the Welsh Government and councils to improve the information they have on carers of all ages. By April 2020, the Welsh Government hopes to have a way of measuring whether young carers and young adult carers are getting the help they need.

Track the Act said the SSWB Act has not had much impact on carers so far. It said that the Welsh Government should understand the barriers in the system which are preventing the SSWB Act improving support for carers. The Welsh Government told us it is too soon to understand the impact of the SSWB Act on carers. It will use information from its Performance and Improvement Framework, Measure the Mountain and the independent evaluation to understand impact in the future.

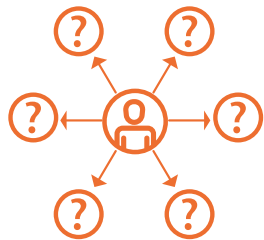
The Welsh Government asked Estyn to review the provision made for young carers<sup>10</sup> in maintained secondary schools, pupil referral units and further education colleges across Wales. **Estyn published its report in May 2019.**

### ■ FOOTNOTES

<sup>10</sup> Including young adult carers in maintained secondary schools, pupil referral units and further education colleges.



## Providing leadership



Through the SSWB Act, the Welsh Government is asking councils, health boards and their partners to work in a very different way. But there are problems with the way public services work together, which means some young adult carers are not getting the help they need.

Individual carer's needs assessments are an essential part of the SSWB Act and meeting young adult carers' needs. But some councils are not doing the assessments. The Track the Act evaluation found that some carers had not had a needs assessment or were unaware if they had<sup>11</sup>. Feedback from 14 focus groups for the Committee inquiry showed that some carers had not been offered assessments. Some had to wait three to six months and others felt actively discouraged from having an assessment. Carers Wales called the lack of assessment and support a 'woeful' and 'systematic failure to provide a service'. Third-sector organisations are worried that without the assessments, young adult carers will not get the help they need and their problems might reach crisis point.

It is difficult to know how many people are not getting assessments because there is limited information about the number of carers in Wales. Some people do not want to be defined as a carer and some refuse an assessment<sup>12</sup>. Councils collect information on the number of carers' assessments they do each year and how many result in a support plan. They do not collect information on why carers refuse assessments. Track the Act recommended that councils collect information on the number of carers' needs assessments and services provided per head of the population per month.

The Welsh Government does not currently know whether councils are complying with the SSWB Act or whether council committees are holding their councils to account for compliance and the quality of their support for carers. It plans to use its new Performance and Improvement Framework to better understand council performance. It could also think about other ways to work with councils to make sure carers are assessed and get the support they need.

### ■ FOOTNOTES

- 11 Carers need to ask their local council for an assessment, so it is possible that some of the carers responding to the evaluation had not asked for an assessment.
- 12 The Welsh Government will ask councils to record the reasons carers refuse an assessment in its new performance and improvement framework.

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